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Psychosocial Assessment as a Standard of Care in Pediatric Cancer

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This paper presents the evidence for a standard of care for psychosocial assessment in pediatric cancer. An interdisciplinary group of investigators utilized EBSCO, PubMed, PsycINFO, Ovid, and Google Scholar search databases, focusing on five areas: youth/family psychosocial adjustment, family resources, family/social support, previous history/premorbid functioning, and family structure/function. Descriptive quantitative studies, systematic reviews, and meta-analyses (n = 149) were reviewed and evaluated using grading of recommendations, assessment development, and evaluation (GRADE) criteria. There is high quality evidence to support a strong recommendation for multifaceted, systematic assessments of psychosocial health care needs of youth with cancer and their families as a standard of care in pediatric oncology. Pediatr Blood Cancer 2015;62:S426–S459. © 2015 Wiley Periodicals, Inc.

Key words: pediatric oncology; psychosocial assessment; screening; standards of care

INTRODUCTION

The significant psychosocial impact of a diagnosis of childhood cancer on the child and family over the course of treatment and beyond is well established and widely understood. Despite this, psychosocial care for children with cancer and their families is not provided in a systematic or consistent manner across and even within pediatric cancer programs. In a study of Children's Oncology Group institutions, about half of families were offered psychosocial services within the first 30 days after diagnosis. Only 9% of institutions used empirically supported psychosocial evaluations and less than 11% implemented empirically based treatments.[1]

Assessment of the psychosocial needs of the child and family is the first action necessary to determine subsequent steps for delivering treatments addressing psychosocial needs for youth (the terms "youth" and "children and adolescents" are used interchangeably in this paper) with cancer and their families throughout the treatment trajectory. A large literature, dating back to the 1970s, provides support for the importance of recognizing psychosocial concerns both during and after cancer treatment. The psychosocial impact of pediatric cancer on the child, mothers and fathers, siblings, and extended family has garnered the most attention in the research literature.[2] This literature is broad but consistent themes run through it. Most work has argued for the consideration of children in the context of broader systems (e.g., families, schools, healthcare settings, communities, cultures). Outcomes include both psychosocial risks for patients and family members (e.g., anxiety, depression, adjustment problems, posttraumatic stress symptoms, lack of financial resources, poverty, family problems, social isolation) and resiliencies (e.g., coping, well-being).

Support for the importance of assessment or brief screening in pediatric cancer has been articulated by a number of prominent groups and organizations, including the Institute of Medicine,[3] the American Cancer Society,[4] the National Comprehensive Cancer Network,[5] and the Association of Pediatric Oncology Social Workers.[6] Screening, usually for depression or distress, has become more common in adult oncology. The Commission on Cancer guidelines[7] require distress screening, particularly at times of highest distress (i.e., at diagnosis, family meeting with oncologist to discuss treatment, transitions off treatment) and applies to pediatric as well as adult cancer programs. This paper refers to both screening and assessment, with the latter generally involving a more comprehensive and lengthier approach than screening, which is very brief. Assessment may be thought of as the follow-up step to screening, in order to identify specific areas for treatment.

Psychosocial Standard of Care

Youth with cancer and their family members should routinely receive systematic assessments of their psychosocial health care needs.

Abbreviations: DT, distress thermometer; GRADE, grading of recommendations, assessment development and evaluation; PAT, psychosocial assessment tool; PSCPCC, psychosocial standards of care project for childhood cancer; SES, socioeconomic status

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This review was performed as part of the collaborative Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC). For a full description of the methods used to develop each standard, refer to Wiener, Kazak, Noll, Patenaude, and Kupst in this Special Issue.[8] This paper provides a review of the relevant literature with the goal of identifying and summarizing the evidence for the systematic assessment of children with cancer and their families, reflecting the breadth of factors necessary to assure comprehensive care.

METHODS

This review was conducted by an interdisciplinary team from the PSCPCC. The sub-group of the PSCPCC that conducted the reviews for this standard included pediatric psychologists (n = 7), social workers (n = 1), psychiatrists (n = 1), counselors (n = 3), all with experience in pediatric cancer. One parent of a child with cancer also participated. In addition to broad representation across the United States, we included representation from the Netherlands to provide an international perspective.

Given the breadth of this standard, the study team identified distinct areas embedded in the broader content of the standard during its first meeting.[8] The group subdivided accordingly into five groups, each with 2–3 members: 1) *Youth and family psychosocial adjustment* (e.g., depression, anxiety, posttraumatic stress); 2) *Family resources* (e.g., financial, socioeconomic status [SES], language issues, barriers to care); 3) *Family and social support* (e.g., extended family, friends, community resources); 4) *Previous history/premorbid functioning* (e.g., prior stressors, behavioral, and educational problems); and 5) *Family structure and function* (e.g., family dynamics, beliefs, cultural factors).

Each group conducted the initial literature search independently for their subgroup in the spring of 2013. In March 2015, the search was monitored across groups by team members (SD, JC) under the supervision of the senior authors (AK, MJK), including updating the search to capture literature from a broader range of January 1, 1995 through March 31, 2015. The literature search utilized five databases: EBSCO, PubMed, PsycINFO, Ovid, and Google Scholar. Literature search terms included: "ped* cancer" OR "pediatric cancer" OR "childhood cancer" OR "child* cancer" OR "cancer*" AND "PAT" OR "psychosocial assessment tool" OR "ongoing assessment" OR "assessment" or "child adjustment" OR "parent adjustment" OR "family adjustment" OR "adjustment" OR "child understanding" OR "family understanding" OR "understanding" OR "PedsQL" OR "distress thermometer" OR "quality of life" OR "QOL" OR "language barrier" OR "outcome barriers" OR "barriers" OR "barriers to care" OR "psychosocial" OR "SES barrier" OR "SES" OR "healthcare disparities" OR "family resources" OR "barriers to treatment" OR "treatment barriers" "outcome barriers" OR "cancer support" OR "family support" OR "support" OR "child support" OR "peer*" OR "peer support" OR "friend" OR "commun*" OR "community" OR "church" OR "faith" OR "spirit*" OR "pre-morbid" OR "family history" OR "illness history" OR "ill* history" OR "prior loss" OR "behavioral" OR "behavior*" OR "education*" OR "previous history" OR "function*" OR "before diagnosis" OR "family" OR "family functioning" OR "functioning" OR "family structure" OR "cultural factors" OR "culture" OR "family dynamics" OR "dynamics" OR "family belief*" OR "belief." The reference sections of identified studies were hand-searched for additional studies. All studies were reviewed to assure that they included families of children 0–18 years of age. All studies were evaluated for their quality using grading of recommendations, assessment development, and evaluation (GRADE).[9]

RESULTS

A large number (n = 149) of studies/reviews was identified in the literature search. Because of the size and breadth of the literature, the original five areas of psychosocial assessment were considered separately initially (and reported separately in this section) and then combined for the Summary of Evidence Table (Table I). Supplemental Table I includes all of the 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.[9]

Youth and Family Psychosocial Adjustment

There is strong and highly consistent research evidence that children and parents experience increased distress, poorer quality of life, and difficulties in psychosocial functioning immediately and in the months after the diagnosis of cancer.[10] These papers (n = 29) come from mostly quantitative descriptive studies, conducted at single institutions, with some mixed methods research. These findings are strongly supported by systematic reviews (n = 3), randomized clinical trials (n = 1), longitudinal studies (n = 6), and consensus statements (n = 3).

Family Resources

Cancer care is impacted by family resources, including socioeconomic status (SES), parental education, and income. Families at socioeconomic risk experience more difficulties with respect to access to care and barriers to treatment throughout the course of care.[11–13] There are health care disparities and barriers as well with respect to language.[14] The research in this area provides rigorous and critically important justification for the importance of identifying families that are at risk for poorer outcomes related to pre-existing socioeconomic considerations (n = 38). Most studies are quantitative (n = 25) although there is also evidence from qualitative (n = 5) and mixed methods studies (n = 4). Additional support comes from longitudinal (n = 3) studies, retrospective chart reviews with large samples (n = 6), and systematic and narrative reviews (n = 5).

Family and Social Support

Perceived support from family members and others is related to psychosocial functioning and reduced distress across the course of treatment. Similar to the other areas of psychosocial assessment, the literature (n = 17 studies and reviews) consists primarily of cross sectional studies, including qualitative (n = 6) and quantitative (n = 5, plus two longitudinal) studies. Systematic (n = 4) and narrative (n = 3) reviews provide additional support. This literature documents the association of child and parent social support with other psychosocial outcomes and provides justification for helping families remain connected with important support systems during and after treatment.[15–17] The overall evidence is robust; the literature is highly consistent albeit smaller in size than the other areas.

TABLE I. Summary of Evidence—Assessing Psychosocial Needs in Children and Adolescents With Cancer and Their Families

Standard	Evidence summary[1]	Methodology[2]	Quality of evidence[3]	Strength of recommendation[4]
Youth with cancer and their family members should routinely receive systematic assessments of their psychosocial health care needs	The diagnosis and treatment of childhood cancer has a significant impact on the emotional and behavioral functioning of children and their families, including increased distress and lower quality of life. Many well-designed studies have determined risk and protective factors that affect psychosocial outcomes. Pre-cancer stresses and psychosocial functioning are related to psychosocial functioning in children with cancer and their parents. There is some evidence that psychosocial functioning early in treatment is predictive of later functioning during and after treatment. Family factors play an important role in adaptation to childhood cancer. Family resources (SES, education, income) as well as disparities and barriers based on race/ethnicity and language are related to access to care, burden of care, adherence, relapse, and survival. Family cohesion, resources, perceived family, and social support can be protective factors in psychosocial outcomes. There is some evidence that cultural factors are related to access, utilization, communication, and adherence to treatment. These findings strongly indicate the need for early and continued screening and monitoring of factors related to psychosocial functioning of children with cancer and their families. Reliable and valid screening instruments have been developed for this population, as well as use of standard psychological measures	149 studies and reviews Systematic reviews (16), two meta-analyses, 9 narrative reviews, and 3 consensus studies have indicated consistent results. Most studies were quantitative, with qualitative and mixed method cross-sectional descriptive studies. Longitudinal (22) and comparison group (17) studies, two RCTS (one pilot) reviewed. In addition, six retrospective record surveys were conducted with large scale cohorts	High quality evidence based on the results of meta-analysis, systematic reviews, and a large number of well-designed lower level studies	Strong recommendation based on the quality of evidence as well as the balance between desirable (early screening and continued monitoring of risk and protective factors) and undesirable (lowered psychosocial functioning going undetected and untreated) effects

[1]Based on summary of evidence table for that standard; [2]Types of studies: e.g., RCT, cross-sectional, longitudinal; consensus; systematic review articles. Quality of evidence; [3]High = A, moderate = B, low, and very low = C (based on GRADE criteria) strength of recommendation; [4]Strong = 1, weak = 2 (based on GRADE quality criteria).

Previous History/Premorbid Functioning

Stressors and experiences that predate the diagnosis of cancer in a child are associated with functioning after diagnosis. This finding is well supported by the literature (n = 20 studies and reviews), with quantitative (n = 18), one systematic review, and one narrative review. Most studies are descriptive with five cohort/comparison group studies, some are longitudinal (n = 5), and there is one pilot randomized clinical trial. The strongest evidence comes from the longitudinal studies of Kupst[18] and from studies of families entering stem cell transplantation because a true "pre" evaluation can be conducted.[19,20]

Family Structure and Function

There is a substantive and cogent body of evidence to support the roles of both family structure and functioning in relation to psychosocial outcomes in pediatric cancer (n = 45 studies and reviews). Most were quantitative studies, with four qualitative and two mixed methods studies (six case comparison studies and six longitudinal studies); one meta-analysis and seven systematic reviews provided additional support. With respect to family structure, being a lone parent is associated with increased risk.[21,22] Family cohesion, resources, and perceived social support from family and community can be protective factors in psychosocial outcomes across family members, findings that are supported in narrative reviews.[23,24] There is some evidence that cultural factors are related to access, utilization, communication, and adherence to treatment.[25]

DISCUSSION

The evidence for understandable levels of psychosocial distress of patients and families is strong and highly consistent across multiple areas related to child and family functioning during childhood cancer treatment. The evidence all points in the expected

directions, demonstrating that cancer is an extreme stressor for children and families and one that is often associated with distress and decreases in overall quality of life. Family structure and beliefs of the family, as well as the family's natural ability to cope and function, are similarly associated with adaptive adjustment to cancer and its treatment. The social support system for the child and family is critically important. Similar to other literatures, social isolation and poverty are risk factors for ongoing and escalating distress. In addition, a prior history of child or family dysfunction, the presence of pre-existing problems, or the presence of other stressors are also associated with less optimal psychosocial outcomes. Finally and notably, the socioeconomic status of the family, the extent to which the family experiences cancer as a financial hardship[26] and other factors associated with health disparities in pediatric cancer are all well documented and critical factors related to overall adjustment and wellbeing.

Although the data presented in this paper and in the accompanying supplemental table show the consistency of findings across study designs and methodologies, this succinct report summarizing a large body of literature precludes a detailed discussion of many of the nuances of work in this field. One of the significant strengths of this literature is its inclusion of the family voice in psychosocial assessment and care delivery. Many of the studies reviewed conceptualize the care of children with cancer from a family systems or socioecological perspective and accordingly include data from multiple members of the family (e.g., mothers, fathers, siblings). We also know, for example, that distress is elevated at diagnosis but that it tends to return to baseline levels after 3–6 months for most, but across multiple studies and reviews 10–30% of families have long-term sequelae.[27–29] Indeed, although many families cope remarkably well with cancer and its treatments, identifying those families who will continue to experience difficulties is a paramount concern, and entirely consistent with recent efforts to mandate screening in cancer programs. The research summarized in this report provides additional strong support for this effort and for the implementation of a standard of care associated with psychosocial assessment: *Youth with cancer and their family members should routinely receive systematic assessments of their psychosocial health care needs.*

Implementation of this standard can facilitate the early identification of risks and resiliencies for families and the delivery of evidence-based treatments to assist all members of the family across the continuum of cancer treatment. How can this be accomplished? Fortunately the literature in the field has shifted more recently in the direction of developing models to guide psychosocial screening and assessment and toward the validation of instruments to assure that screening can be accomplished in an evidence-based practical manner.[30] Kazak et al. conducted a systematic review,[31] which identified the psychosocial assessment tool (PAT)[29,32] and the distress thermometer (DT)[33] as two evidence-based screening approaches used in pediatric cancer.

The conceptual model underlying the PAT is the Pediatric Preventative Psychosocial Health Model[34] a three-tier model, based on a public health approach, identifying families at universal, targeted, and clinical levels of risk. These levels are determined by examining risk across multiple domains (e.g., family resources, family problems, social support, child and sibling problems, etc). Intervention approaches depend both on level of risk and also specifically identified risk areas. The PAT is a parent-report screener that takes 5–10 min to complete and is available in web-based and electronic health record forms. PAT is used currently in 50 sites in the United States and has been adapted/translated for use in a number of other countries,[29] with published reports from Canada [35] and Australia.[36] The PAT is also used in survivorship, with scores associated with survivors requiring psychological consultations.[37]

The DT is a brief screening instrument which provides a rating of distress on a 1–10 scale. The DT was used in a prospective study using multiple respondents (children, parents, and staff), highlighting the importance of each perspective in a thorough understanding of distress.[38,39]

The well-documented evidence for psychosocial risk and the availability of valid instruments for screening can minimize some of the barriers to systematic screening and assessment. This is necessary in order to implement this psychosocial standard and advance pediatric cancer care. Concerns about the time necessary for screening can be addressed by use of the brief PAT or DT. Screening that is family-centered, integrated into the health record, and that quickly flags patients and families at risk is an essential first step in accessing psychosocial care quickly and efficiently by addressing staffing concerns (e.g., who will conduct the screening). It is also important to consider the timing and frequency of screening and assessment. The evidence shows that although distress usually diminishes over the first year after a pediatric cancer diagnosis,[40–42] many disease, treatment, patient, and family factors may contribute to ongoing or even escalating distress over time,[43] including demographic and socioeconomic factors that indicate the importance of delivering early evidence-based interventions.[44]

Although the evidence is strong, it is not without its limitations. There are few randomized clinical trials in this field and a reliance on mostly single institution studies, based in the United States. It is important that screening be viewed as the first step in a process of psychosocial care delivery and that pediatric cancer centers provide adequate levels of appropriate staff to implement interventions pertinent to the identified needs, while at the same time conducting further research to identify optimal evidence-based interventions to promote adaptive functioning and quality of life in youth with cancer and their families.

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SUPPLEMENTARY INFORMATION

SUPPLEMENTAL TABLE I. Psychosocial Assessment as a Standard of Care in Pediatric Cancer

Abbreviations listed at end of table

Group I. Child and Family Understanding and psychosocial adjustment, monitored continuously over the course of the illness

Study	Design	Sample	Findings	Study rigor	Level of evidence
Barakat et al., 2014 [1]	Child, care giver proxy, and parent- self report; cross-sectional study of HRQoL in survivors of childhood brain tumors	n = 186 mothers & 126 childhood cancer survivors (14-39 years old)	• Adolescent and young adult survivors of childhood brain tumors are at risk for poor HRQoL • Both the objective and subjective experience of childhood cancer are central to understanding functional outcomes and general adaptation post-treatment • To enhance physical and emotional HRQoL, findings from the study underscore the importance of coordinated, multidisciplinary follow-up care for the survivors and their families to address treatment late effects and support family management • Critical area for clinical research: focus attention on enhancing HRQoL measurements	Sufficient sample size; data collection appropriate to study method; appropriate analysis; evidence derived from high quality case control or cohort studies; reporting comprehensive, clearly described	**6**
Barrera, Hancock, Rokeach, Atenafu et al., 2014[2]	Pilot RCT across 2 time points: T1 (2-4 weeks after diagnosis) and T2 (6 months later) assessing the benefits of the Psychosocial Assessment Tool (PAT) as a screening tool	n = 67 caregivers: experimental group (n = 33); control group (n = 34)	• PAT systematically assesses the psychosocial risk of children diagnosed with cancer and their families • The pilot study investigated the benefits of providing a PAT summary to the medical team treating the newly diagnosed child (experimental group) compared to the control group • By using the PAT as a screener and providing the child's treating team with a summary of information, at time 2 there was a significant reduction in psychosocial difficulties and lower levels of risk for future problems (compared to the control group) • Providing psychosocial risk information to the treatment team also was associated with lower levels of parental perception of family's psychosocial difficulties and improvement in child's QoL	Blinding or data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	**2**
Barrera, Hancock, Rokeach, Cataudella et al., 2014[3]	2 Phase assessment of cultural adaptation and validity/ reliability of a Canadian adaptation of the PAT (PATrev)	Phase 1 n = 7 parents and 6 pediatric oncology healthcare experts; phase 2 n = 67 parents of children diagnosed with cancer	• Uses a Canadian adaptation of the PAT (PATrev) • PATrev: strong interrater reliability (0.77), test-retest reliability (0.75) and internal consistency (0.85) • Moderate to strong validity comparing to PedsQL total (-0.49); PedsQL Anxiety (-0.47); BASC-2 internalizing (0.64), behavioral (0.63) and adaptive scores (-0.56) • Discriminative validity confirmed with BASC-2 scores: (0.70-0.74) • The PAT is a reliable and valid psychosocial screening tool and provides unique evidence regarding early psychosocial risk in the family; highlights the importance of systematically screening pediatric cancer families for psychosocial risk	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	**6**
Engelen et al., 2012 [4]	Parent and self report; Longitudinal intervention study with a sequential cohort design to study the effect of the use of PRO's in clinical practice of pediatric oncology	n = 94 patients in the intervention group (feedback of PROs), age 0-18 years; n = 99 patients in the control group (no feedback of PROs), age 0-18 years	• The use of PRO's, profile of HRQoL of the patient, increased discussion of emotional functioning and identification of emotional problems • PRO's are a helpful tool for systematic monitoring of HRQoL of children treated for cancer, without lengthening the duration of the consultation	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis evidence derived from high quality case control or cohort studies; reporting clearly described; issues with follow-up or missing data clearly described	**3**

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SUPPLEMENTAL TABLE I. (*Continued*)

Group I. Child and Family Understanding and psychosocial adjustment, monitored continuously over the course of the illness

Study	Design	Sample	Findings	Study rigor	Level of evidence
Feeny et al., 1999 [5]	Framework for measures of HRQoL	N/A	• Critical need for the development of valid and useful measures of HRQoL for children with cancer • HRQoL – concerned with the opportunities that a person's health status affords, the constraints that it places and the value that the person places on his/her health status • Purposes of measures: screening, describing health status, assisting in management of individual patients and also the formulation of clinical policy	No information on how studies were acquired; Important outcomes considered	7
Felder-Puig et al., 2006[6]	5 year longitudinal prospective study examining HRQoL in pediatric patients receiving SCT	n = 68 German speaking patients (4 – 18 years) and their parents receiving SCT. Physicians completed the HUI2/3	• This study showed that the PedsQL is an adequate tool to use in assessing HRQL across time. Reviewing the 7 time points [Pre-SCT (4-6 weeks, 7 days); Post SCT (10 days, 28 days, 100 days, 180 days and 360 days)], there was a distinct decline in HRQoL at 10 days following SCT with a steady improvement for most participants at 360 days after SCT • 3 variables associated with decreased HRQoL at 360 days post SCT were poor emotional functioning, high worry, and reduced communication indicating areas of intervention • Assessing inter-observer agreement, patients generally rated their HRQoL higher than their parents and physician report fell between the two, indicating that the use of adult proxy report may not be most accurate	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis; issues with follow-up or missing data clearly described	6
Gilleland, 2013[7]	Parental completion of the PAT 2.0 at a child survivorship appointment	n = 79 caregivers of childhood cancer survivors	• Internal consistency of the PAT 2.0 in a survivorship population was strong ($\alpha = 0.92$) • Psychology was consulted to see 53% of participant families and these families had significantly higher PAT 2.0 total scores than families without psychology consults • PAT scores were consistent with Pediatric Psychosocial Preventative Health Model • PAT demonstrated strong psychometric properties among survivors of pediatric cancer	Blinding or data collection appropriate to study method; appropriate analysis; reporting clearly described	6
Grootenhuis et al., 1997[8]	Narrative Review of adjustment and coping of parents of children with cancer	N/A	• Parental adjustment to their child's cancer diagnosis varies greatly depending on the individual and the context, thus it is important for ongoing assessment • Studies found that directly after diagnosis parents experience increased emotional distress and this increased psychological distress is still evident after 1 year, thus pointing to the important of monitoring this over the course of the child's illness • Parents of children with cancer are in an unusual situation; existing instruments may not assess their specific problems • Essential to investigate not only standardized instruments but also illness related questionnaires	Right types of papers included; Important, relevant studies included; Appropriately assessed for quality of studies; Reasonable to combine results in this way; Important outcomes considered	7
Haverman et al., 2013[9]	Parent-report study to assess the validity of a Distress Thermometer for Parents (DT-P) for parents of chronically ill children	n = 706 parents of chronically ill children	• DT-P was validated with the Hospital Anxiety and Depression Scale (HADS) and the Parenting Stress Index (PSI) and indicates it is a good measure for assessing parental distress • Mean score was 3.7 (SD 3.0) with strong relations between scores in the areas of practical, physical, emotional, and cognitive problems on the DT-P with anxiety, depression, and total score on the HADS ($0.55 \leq r \leq 0.72$). • Domain scores on the DT also showed moderate to strong relations to the PSI ($0.38 \leq r \leq 0.63$) • Similar to previous studies, a cut-off score of 4 was found to provide good sensitivity (86% of clinical HADS cases) and specificity (67% of non-clinical HADS cases)	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis	6

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SUPPLEMENTAL TABLE I. (*Continued*)

Group I. Child and Family Understanding and psychosocial adjustment, monitored continuously over the course of the illness

Study	Design	Sample	Findings	Study rigor	Level of evidence
Johnston, 2013[10]	Data obtained from AAML1031 (a phase 3 COG multi-center trial experimental, randomized study) to assess reasons for non-completion of HRQoL measures. Reasons were assessed by three pediatric oncologists	n = 196 enrolled patients with AML (ages 2 – 18) and their parents. A study coordinator contacted the sites with these patients to assess reasons for delinquent HRQoL data	• Assessing reasons for non-completion included the patient being too ill, passive or active refusal by the participant, developmental delay, logistical challenges (forms lost, uncertainty of whether forms were given, inability to gather completed forms, and parents not being around), and lack of knowledge of the study process • Suggested strategies to increase adherence was broaden the time frame for completion, decrease the number of assessments to lessen the burden on families, provide guidance to assessors for how to approach families, allow responses to be given verbally with the assessor reading the questions for the patient, and have a dedicated staff to collect responses	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis; issues with follow-up or missing data clearly described	6
Kazak & Barakat, 1997[11]	Parent and self-report; Data from 2 studies (on and off tx studies). Eligible families that participated in the in tx study were sent letters to participate in the off treatment study	n = 29 children and their parents	• Level of adjustment of families at diagnosis and during treatment for childhood cancer is indicative of later adjustment • Higher levels of parenting stress for mothers and fathers during treatment were associated with higher anxiety after treatment • Parents may receive less support and have fewer psychological resources provided during the treatment of their child • Parents' perceptions of child QoL were related to adjustment for mothers • Parental perceptions of child's overall adjustment are potent predictors of long-term family adjustment	Blinding or data collection appropriate to study method; appropriate analysis	6
Kazak et al., 2011 [12]	Feasibility study: Parental completion of the PAT versus Psychosocial care as usual	n = 99 parents of children newly diagnosed with cancer (PAT group n = 52 parents; Psychosocial care as usual group n = 47)	• Using an evidence based psychosocial screener is feasible in a pediatric oncology clinic • Greater documentation of psychosocial risks occurs when using the PAT vs. assessment as usual	Blinding or data collection appropriate to study method; appropriate analysis; reporting clearly described	3
Kazak et al., 2012 [13]	Systematic Review of papers published since 1990 to identify models to guide screening of pediatric oncology patients and approaches for psychosocial risk during treatment	n = 63 articles included	• Three models for screening pediatric oncology patients were identified: 1) the Pediatric Preventative Psychosocial Health Model (the basis for the PAT), using a public health framework assessing levels of risk and matched treatments, 2) the Family APGAR approach focusing on dimensions of family functioning, and 3) the HEADDS framework which has a focus on teens • Two empirical approaches found to screen for psychosocial concerns were the DT and PAT. Findings indicate that the DT has small to medium size correlations with ratings of depression and QoL, which indicates that it may be useful as a general distress screener in pediatric cancer. The PAT was found to have excellent sensitivity and specificity and that families screened using the PAT received more psycho-social services as needed • Screening is an invaluable aspect to pediatric oncology care and helps to provide resources where they are most needed	Right types of articles included, appropriately assessed the quality of the studies, reasonable to combine results, important outcomes considered	1
Macartney et al., 2014[14]	Systematic Review of HRQoL instruments	n = 16 articles included	• HRQoL assessment instruments used: PedsQL, Health Utilities index, PedsQL Cancer Module, Child Health Questionnaire, TNO-ZAL Questionnaire for Children's Health-Related Quality of life • Study highlighted the importance of ongoing assessment of HRQoL	Right types of papers included; Important, relevant studies included; Appropriately assessed for quality of studies; Reasonable to combine results in this way; Important outcomes considered	5

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SUPPLEMENTAL TABLE I. (*Continued*)

Group I. Child and Family Understanding and psychosocial adjustment, monitored continuously over the course of the illness

Study	Design	Sample	Findings	Study rigor	Level of evidence
Maurice-Stam et al., 2008[15]	Parent and self-report; 5 year longitudinal study (6 time points) on emotional functioning and coping of parents of children with cancer after end of successful treatment	n = 122 mothers and 109 fathers from 130 families and 130 childhood cancer survivors (age 1-18 years old)	• Initial elevated levels of distress, disease-related feelings of uncertainty and helplessness returned to normal levels during the first two years after treatment • Disease-related coping strategies and generic coping styles were associated with emotional functioning of parents. Especially, being more optimistic about the further course of the disease (predictive coping) was correlated with lower levels of psychological distress, and stronger passive reaction pattern was associated with higher psychological distress • Though in general the parents showed adequate emotional resilience, support should not stop when treatment ends. It can help parents to get back to normal life • Aftercare should especially be directed at parents at risk for emotional problems. Parents in need of help maybe identified on the basis of their coping abilities	Sufficient sample size (except T6); blinding or data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described; issues with follow-up or missing data clearly described	6
Maurice-Stam et al., 2009[16]	Self-report; 4 year longitudinal (5 time points) study on HRQoL, anxiety and coping of children after end of successful treatment	n = 49 non-CNS patients (ages 8-16 years)	• From one year after treatment survivors did no longer differ from the norm. • Disease-related coping strategies were associated with HRQoL and anxiety to a limited extent • As a group, survivors regained good HRQoL and normal levels of anxiety from one year after end of treatment • Monitoring and screening are necessary to be able to trace survivors with worse emotional functioning	Sufficient sample size (except T5); blinding or data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described; issues with follow-up or missing data clearly described	6
Maurice-Stam et al., 2011[17]	Self-report; Cross-sectional study on benefit and burden of childhood cancer and the relation with emotional well-being	n = 77 survivors of childhood cancer (ages 8-18 years old)	• Levels of benefit finding were on average twice the level of disease-related burden • Benefit did not correlate with emotional well-being. Burden was associated with HRQoL (-), Anxiety (+) and Posttraumatic stress symptoms (+) • As benefit finding and disease-related burden appeared to be distinct constructs, both should be considered when examining children's adjustment to potentially traumatic experiences • The Benefit and Burden scale for Children may useful as monitoring and screening instrument	Blinding or data collection appropriate to study method; appropriate analysis; reporting clearly described	6
McCarthy 2009[18]	Parental completion of the PAT 2.0 2 time points (at diagnosis and 6-8 months later)	n = 143 parents of children newly diagnosed with cancer	• Majority of families stratified to Universal Category (lowest risk) and one third elevated psychosocial risk • Supported external validity of the PAT 2.0 as a psychosocial screener	Loss of data at T2; Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis; reporting clearly described	6
Pai et al., 2008[19]	Study of the PAT 2.0 to assess psychometric properties	n = 204 caregivers (132 female, 72 male) of 141 children newly diagnosed with cancer	• Demonstrated internal consistency and reliability of the PAT 2.0 • Total score on the PAT 2.0 was associated with parent acute distress, child behavior problems and family conflict for both mothers and fathers	Sufficient sample size; blinding or data collection appropriate to study method	6
Parsons et al., 2012 [20]	Analysis of a longitudinal data set from a study of EPO and HRQoL collected at 4 time points during the first 16 weeks of cancer treatment Patient self-report; parent proxy-report	n = 222 patients diagnosed with cancer (13-18 years) and a parent	• Internal consistency varied by domain of the PedsQL. Parent and child reliability was lowest for social functioning and highest for physical functioning • Patients generally indicated higher functioning than their parents reported with the largest differences occurring in the area of emotional functioning, however differences tended to decrease over time • Findings indicate that parent proxy report can be used as reasonable estimates of child report. Some differences between parent and child report were attributed to domains with less internal consistency. Differences were also thought to occur as some believe children answer questions based on what is occurring in the moment or a recent event versus parents basing responses on multiple events	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis; issues with follow-up or missing data clearly described	6

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SUPPLEMENTAL TABLE I. (*Continued*)

Group I. Child and Family Understanding and psychosocial adjustment, monitored continuously over the course of the illness

Study	Design	Sample	Findings	Study rigor	Level of evidence
Patel et al., 2011 [21]	Prospective multi-informant (self-report, caregiver, psycho-social staff, and medical staff) study to assess feasibility and utility of the distress thermometer with pediatric oncology patients	n = 91 English and Spanish speaking oncology patients and their parents	• Distress thermometer was an inexpensive, quick to administer, and easy to score instrument to assess distress in pediatric oncology patients • Concurrent validity of the distress thermometer was supported by modest significant correlations with the CDI, $r(57)=0.37$, $p<0.01$ and the Emotional Wellbeing subscale of the PedsQL, $r(53)=-0.44$, $p<0.05$ • Caregiver rating of the patient distress on the distress thermometer correlated significantly with the PedsQL-Parent Proxy Report of the child's Emotional Wellbeing, $r(65)=0.48$, $p<0.01$ • There was significant agreement with the patient's self-report of distress and the caregiver's and psycho-social team's report of patient distress, however there was low agreement with the medical team's ratings of patient distress • Predictors of higher patient self-reported distress were older age, less time since diagnosis, and being scheduled to have a bone marrow transplant within a month of baseline assessment	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis; issues with follow-up or missing data clearly described	6
Patel et al., 2014 [22]	Self-report and caregiver report to assess for change in distress of pediatric oncology patients at end of life	Patients and their caregivers (n = 75), including patients who died (n = 14) and survived (n = 61)	• The distress thermometer was found to be sensitive to changing patient distress nearing the end of life • Patient self-report of distress increased over time for those who later died compared to those who survived. Though distress ratings were not evidenced as high overall (4.07/10), they did increase across time (from 2.36/10) and may have been higher if it have been possible gather more data closer to deterioration of health • Caregiver ratings of their own distress remained high across time • There was no change on the CDI across time for patients who died, however findings could be due to the smaller sample size as 6/14 were able to complete the CDI. This finding appears due to the higher amount of energy it takes to complete a longer assessment instrument versus the single distress rating of the distress thermometer	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis; issues with follow-up or missing data clearly described	6
Richardson et al., 1999[23]	Evidence based clinical practice guidelines for attending to emerging medical and psychosocial needs of young adult survivors of cancer	N/A	• Childhood cancer survivors must receive the best long-term follow-up care available • Given that this population is at risk for significant psychosocial effects, there is a stressed importance of long-term follow-up assessment including screening for risk factors and ongoing collection of patient data	Right types of papers included; Important, relevant studies included;, Reasonable to combine results in this way; Important outcomes considered	1
Ruccione et al., 2013[24]	Prospective longitudinal study examining patient-reported psychosocial outcomes (through a structured interview) during the first 5 years of cancer survivorship	n = 94 cancer survivors (11 – 21 years old)	• 18% of participants' PedsQL psychosocial functioning summary scores were less than or equal to 1 SD below the mean • Treatment duration was negatively related to psychosocial functioning • Strong negative correlations found between psychosocial functioning and symptoms of pain, fatigue, posttraumatic stress, and depression • The window between treatment completion and survivorship has been neglected, however may be at time when interventions may be useful in minimizing the adverse psychosocial effects of the cancer experience and improving long-term HRQoL	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis	6

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SUPPLEMENTAL TABLE I. (*Continued*)

Group I. Child and Family Understanding and psychosocial adjustment, monitored continuously over the course of the illness

Study	Design	Sample	Findings	Study rigor	Level of evidence
Salmon et al., 2014 [25]	Selective review of research and policy literature on screening for psychological distress in cancer	N/A	• Cancer has profound psychological impact even years after treatment has ended • Routine screening of psychological effects of cancer is recommended throughout the course of treatment (at key points from diagnosis to end of treatment or recurrence) • Aim of screening should be to reduce distress in pediatric cancer population by assuring that patients receive the psychological help they need • Emphasizes screening to be conducted throughout trajectory of cancer given that a single assessment may be misleading about need of psychological treatment	Unsystematic Review; Right types of papers included; Important, relevant studies included;, Reasonable to combine results in this way; Important outcomes considered	7
Seid et al., 1999[26]	Self-report and parent report, validation study of the Pediatric Cancer Quality of Life Inventory (PCQL)	n = 291 patients (8-18 years) and their parents	• Measurement of pediatric cancer patients' HRQoL is becoming an essential component in evaluating the health outcomes • The Pediatric Cancer Quality of Life inventory (PCQL) – internal consistency (0.83) and reliability (0.86) • Demonstrated internal consistency reliability and validity for both patient-report and parent-report forms • PCQL can be a useful and feasible measure to use in pediatric cancer populations	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis (need to assess test-retest reliability)	6
Varni et al., 2002 [27]	Self-report and parent proxy report to determine measurement properties for the PedsQL 4.0 Generic Core Scales, PedsQL Multidimensional Fatigue Scale, and 3.0 PedsQL Cancer Module	n = 339 pediatric oncology patients (2-18 years) and a proxy parent; n = 989 comparison healthy families	• PedsQL is the only empirically validated assessment of health-related quality of life that has a specific cancer module • The PedsQL was found to be a reliable instrument with acceptable internal consistency reliability for the PedsQL 4.0 Generic Core Total Score ($\alpha = 0.88$ for the child; $\alpha = 0.93$ for parent report), Multidimensional Fatigue Total Scale score ($\alpha = 0.89$ child; $\alpha = 0.92$ parent), most Cancer Module Scales ($\alpha = 0.72$ child; $\alpha = 0.87$ parent). Validity was demonstrated and the PedsQL was able to distinguish healthy children from those with cancer and in the cancer group, those out of treatment	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis	6
Varni et al., 1998 [28]	Self- report and parent report validation study of the Pediatric Cancer Quality of Life inventory (PCQL) given to patients at various stages of treatment	n = 291 patients (8-18 years old) and their parents	• Importance of measuring both patient and parent report of patient related symptoms and problems in pediatric cancer health-related quality of life assessment • Need to be aware of differing perspectives of multiple informants in determining HRQoL • PCQL is a symptom or problem-focused questionnaire • The use of the PCQL can help with screening, identifying, and treating children's symptoms and problems • Allows for a more easily implemented patient/treatment match • Should be administered to all children with cancer at regular intervals depending on stage of treatment or follow-up	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis (need to assess test-retest reliability)	6
Verberne et al., 2012[29]	Self-report and parent report; Cross-sectional study on sleep disorders and the psychosocial consequences in children after treatment for a CNS tumor	n = 31 CNS tumor patients, (ages 5-17 years) and 78 non-CNS, (ages 4-17 years)	• Increased insomnolence was found in CNS tumor patients compared to norm data and compared to non-CNS tumor patients • Excessive somnolence in CNS tumor patients was related to increased fatigue and worse daily functioning • The issue of sleep should be directed systematically in follow-up programs for CNS tumor patients • Pediatric psychologists can help oncologists identifying sleep problems and present possible interventions if these sleep disorders have an impact on daily functioning	Blinding or data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	6

(*Continued*)

SUPPLEMENTAL TABLE I. (*Continued*)

Group II. Family Resources: Financial, SES status, language issues, barriers to care, safety of environment

Study	Design	Sample	Findings	Study Rigor	Level of evidence
Aung et al., 2012[30]	Cross-sectional self-report questionnaires to assess financial burden, familial/ social impact, personal strain and coping in families	n = 79 caregivers of children > 6 months post-diagnosis of all types of cancer in Singapore	• Burden of childhood cancer in Singapore comparable to US and Italy • Being of Malay/Indian origin was associated with higher overall family burden • 61% of families receiving financial aid • Caregivers who were unemployment or asked to quit their job experienced increased financial, social, and personal burden	Lack of control for treatment phase, blinding or data collection appropriate to study method; appropriate analysis; reporting comprehensive	6
Austin et al., 2015[31]	Retrospective record survey of health disparities in children with cancer	n = 4603 children with cancer (age ≤ 18 years)	• Hispanic or non-Hispanic Blacks were most likely to have advanced-stage cancer • Patients with lowest SES had the worst 1 and 5 year survival • Compared to non-Hispanic Whites, non-Hispanic Blacks had significantly worse overall survival • Racial/ethnic differences play an important role in both disease presentation and overall survival • Socioeconomic factors contribute to differences in survival observed between different racial and ethnic groups	Sufficient sample size; appropriate analysis	6
Barakat et al., 2012[32]	Retrospective medical record study examining risk factors for inadequate follow-up care	n = 173 children with cancer (0-18 years)	• Prediction of lower attendance to follow-up appointments were: gender (male), race (non-white), use of public insurance, having a brain tumor, longer time off from treatment, and greater distance from the hospital • Targeted programs are needed for educational and supportive interventions for at risk families	Sufficient sample size; appropriate analysis	6
Bhatia, 2011 [33]	Narrative Review of disparities in cancer outcomes in children	N/A	• Low SES, limited cancer knowledge, disease biology, genetic predispositions and low quality of treatment influence disparities • Poorer outcomes were found in non-white Hispanics and African Americans- likely due to a combination of differences in disease biology, pharmacogenetic differences, SES factors and sociocultural factors that influence access to care and adherence to therapy	No description of how studies were chosen (selection bias); Reasonable to combine results in this way; Important outcomes considered	7
Bona et al., 2014[34]	Parent-report, cross-sectional survey examining perceived financial hardship and economic impact	n = 71 caregivers of children with progressive, recurrent, or nonresponsive cancer	• 94% parental work disruptions across all income levels • 42% reported 1 parent had to quit job; 27% described child's illness as a great economic hardship. Income losses because of work disruptions were substantial for all families • Families at or below 200% of Federal Poverty Level were significantly impacted • 50% of the poorest families lost more than 40% of annual income relative to 5% of wealthiest families • Secondary to income losses, 15% of non-poor families fell from above to below 200% of Federal Poverty Level	Poor families and ethnic minorities underrepresented in sample; imprecision in reporting of outcomes; sufficient sample size; blinding or data collection appropriate to study method	6
Cohn et al., 2003[35]	Parent-report, cross-sectional retrospective survey examining type of out-of-pocket expenses and impact on family lifestyle	n = 100 caregivers of children diagnosed with cancer in Australia	• 80% families reported out-of-pocket expenses in travel, accommodation, phone costs, and changes in employment. This impacted social lifestyle • Families vulnerable to financial burden resided furthest from treatment center, or child's treatment length was longer	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis	6
Creswell et al., 2014 [36]	Parent-report, case comparison of parents of cancer patients vs. parents of healthy children	n = 215 children ages 2 - 18 (75 cancer patients; 140 healthy comparisons)	• Compared to the parents of healthy children, parents of children diagnosed with cancer reported significantly more clinically relevant depressive symptoms and negative financial life events • Depressive symptoms were associated with negative financial life events, lower average income and lower social support • Financial difficulties are an important contributor to the development of poor mental health among parents of pediatric cancer patients	Data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	4

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SUPPLEMENTAL TABLE I. (*Continued*)

Group II. Family Resources: Financial, SES status, language issues, barriers to care, safety of environment

Study	Design	Sample	Findings	Study Rigor	Level of evidence
Dockerty et al., 2003 [37]	Parent-report, epidemiological based cross-sectional survey of economic effects of childhood cancer	n = 237 parents of children newly diagnosed with cancer	• Majority of caregivers reported economic hardship during first month of treatment related to lost income and increased treatment related expenses. • Hardship related to length of time in hospital but not to distance travelled	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis	6
Eiser & Upton, 2006[38]	Parent-report, cross-sectional survey assessing financial impact of cancer on families	n = 145 caregivers of children ranging from 3-months to 3-years post diagnosis in UK	• Expenditure post-diagnosis greater than pre-cancer • Treatment associated with increased costs and decreased earned income. Suggests changes to allow early release of benefits to help parents recoup losses	Selective sampling; Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis	6
Fluchel et al., 2014[39]	Parent-report, cross-sectional survey analyzing geography and burden of care	n = 354 caregivers of pediatric cancer patients	• As a direct result of child's cancer diagnosis: 1/3 of caregivers reported changing jobs; Rural caregivers had substantially greater out-of-pocket travel expenses; Rural patients missed more days of school, leading to an increased risk of repeating a grade; Some rural caregivers moved residences to be closer to treatment center; Rural caregivers missed more days of work • Rural caregivers reported a significantly greater perceived financial burden; The social and financial burden associated with providing care for a child with cancer is increased when families live farther away from the treatment center	Data collection appropriate to study method; appropriate analysis; reporting clearly described	6
Gage, 2010 [40]	Parent-report, qualitative study (case studies and interviews) of impact of SES on cancer	n = 21 parents of children with cancer	• Three major domains of SES: financial, education, occupation • Financial domain: Importance of finances to foster opportunities; lack of finances presented barriers to treatment • Education influenced ability to communicate with HCP and to understand Tx spell out treatment options • Occupational themes: flexibility of work schedule, benefits (paid leave), working from home, flex time, and access to health insurance	Methodologically weak; selective sampling; research question clearly stated; qualitative approach clearly justified; study context clearly described; method of data collection clearly described; method of data analysis clearly described	6
Gage-Bouchard et al., 2013 [41]	Analysis of data obtained from a large mixed-methods study of parents and children with cancer; Parent-report, qualitative interview and questionnaires analyzing socio-demographic characteristics, environment and caregiver coping	n = 60 Caregivers of pediatric cancer patients	• Educational attainment and caregiver gender influence caregiver coping styles following a cancer diagnosis • If lower educational attainment, less use of active coping • Men more likely to use substance abuse coping, particularly if they did not receive a bachelor's degree • Educational attainment rather than financial resources drive the association between SES and coping • Programs should address educational gaps and teach caregivers planning and active coping skills • Family coping style and the family environment influence adaptation to serious pediatric illness	Data collection appropriate to study method; appropriate analysis; reporting clearly described	6
Giammona et al., 2002 [42]	Narrative Review of the psychological effect of childhood cancer on the family	N/A	• Quality of physician caregiver communication has effect on the family's perception of prognosis and their ability to cope • Inadequate education or language barriers might be of particular concern – address these issues during the prediagnostic and diagnostic phases to allow for good communication, appropriate support and better psychological adjustment	No description of studies picked for review; relevant studies included; important outcomes considered	7
Gupta et al., 2014[43]	Systematic review of SES and impact on survival rates in families of children with cancer	n = 36 Studies included in review	• Lower SES was uniformly associated with inferior survival • Majority of associations between SES and survival were statistically significant ○ 73.1% found low SES to be associated with worse survival ○ Uninsured status was significantly associated with worse survival rates • Given the findings, interventions should be designed to mediate socioeconomic effects • Targeting the effect of low SES will allow for future improvements in childhood cancer survival	Right types of papers included; Important, relevant studies included; Appropriately assessed for quality of studies; Reasonable to combine results in this way; Important outcomes considered	5

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SUPPLEMENTAL TABLE I. (*Continued*)

Group II. Family Resources: Financial, SES status, language issues, barriers to care, safety of environment

Study	Design	Sample	Findings	Study Rigor	Level of evidence
Heath et al., 2006[44]	Parent-report, cross-sectional survey assessing psychosocial impact and economic burden	n = 56 caregivers of children newly diagnosed	• 74% families reported moderate-to-great economic hardship • Economic hardship associated with single parent, decreased family income, and increased distance from hospital • Highest impact of cancer on families was in caregivers perceived cancer burden • Perceived hardship led to increased emotional stress and restricted normal activities	Selective reporting; blinding or data collection appropriate to study method	6
Karlson et al., 2013[45]	Parent-report, longitudinal study (4 time points), completing the PAT, assessing demographic and SES variables associated with risk for patient and family problems	n = 163 caregivers from low-income and rural pediatric oncology population	• Pediatric oncology patients with caregivers of lower educational attainment and financial difficulties are a significantly greater risk for psychosocial problems • Younger age was significantly associated with PAT psychosocial risk • Financial difficulties were related to greater psychosocial risk across all PAT subscales • Other areas associated with PAT risk were lower caregiver education, having Medicaid insurance, relationship status (divorce), fewer adults in the home, and more children in the home • Emphasis should be on early assessment and prevention in low-income and rural pediatric medical populations	Sufficient sample size; data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described; issues with follow-up or missing data clearly described	6
Lahteenmaki et al., 2004 [46]	Parent-report of childhood cancer and its' impact on family income, longitudinal study with 2 time-points: 3-months post diagnosis and 12-months post	n = 21 caregivers of children newly diagnosed with cancer, and n = 46 control group matched on mothers education level	• Perceived loss of family income high during first few months post diagnosis • Families of children with cancer reported increased loss of income and treatment related expenditures compared to control families	Loss to follow-up in cancer group; blinding or data collection appropriate to study method; appropriate analysis	6
Lau et al., 2014[47]	Parent-report, prospective cohort study at 3 time points (~1 month after dx; ~6 months after dx; and ~12 months after dx) of family life events in the first year of childhood cancer	n = 159 parents of children with ALL	• Economic burden due to pediatric cancer is substantial during the first year of therapy: Parents decline work / educational opportunities, decreased work hours, lose employment; Associated with lower income and less than college education in the mother ○ Relocated residences ○ In general, families of all economic socioeconomic backgrounds were vulnerable to economic stresses • Burden on relationship: after diagnosis, 13% of parents were divorced or separated by 12 months after diagnosis; 22% decided not to have any additional children as a result of diagnosis • Understanding the impact on the entire family is essential as a family's adaptation impacts a child's adjustment to cancer	Sufficient sample size; data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	6
Meeske et al., 2013[48]	Parent measures assessing mental health disparities in Hispanic and non-Hispanic childhood cancer survivors	n = 139 parents of child survivors of cancer (79 Hispanic, 60 non-Hispanic)	• Hispanic parents experienced more depressive symptoms and more PTSS (compared to non-Hispanic parents) • Parental depression and PTSS were associated with lower child psychosocial QoL • Assessments and education need to be conducted in parent's preferred language and parent's literacy must be evaluated	Selective sampling; sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis	6
Miller et al., 2005[49]	Parent-report (semi-structured interview) and observational coding of informed consent process analyzing the clinician-parent communication process	n = 127 parents of child leukemia patients	• Ethnic minorities and families from lower SES were found to have lower levels of understanding of clinical procedures and higher parent anxiety • Individual differences in parents (such as race and SES) may influence beliefs about rules that should govern communication between HCP and parents	Selective sampling; lack of standardized measure for parent anxiety; sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis	6

(*Continued*)

SUPPLEMENTAL TABLE I. (*Continued*)

Group II. Family Resources: Financial, SES status, language issues, barriers to care, safety of environment

Study	Design	Sample	Findings	Study Rigor	Level of evidence
Mostert et al., 2008[50]	Parent-report, cross-sectional semi-structured interviews on influence of SES	n = 51 caregivers of children receiving treatment for leukemia	• Family income decreased 69% since start of treatment • 29% of fathers and 8% mothers lost their jobs. Unemployment related to cancer diagnosis • Treatment costs resulted in financial difficulties for 78% of families, 65% incurred significant debt forcing parents to either postpone or withdraw from parts of child's medical treatment	Selective reporting; blinding or data collection appropriate to study method	6
Mullins et al., 2014[51]	Narrative Review of parent and family interventions with clinical practice guidelines	N/A	• Barriers to care: ○ Parent/Caregiver (stress, emotional functioning, health care beliefs, education/cognitive functioning) ○ Family (Caregiver support, relationship satisfaction, conflict/stress, family cohesion and organization) ○ Child (Emotional/behavioral functioning, age/developmental level, health status, health beliefs) ○ Pragmatic/Utilitarian resources (SES, insurance status, transportation, work/school flexibility) ○ Medical (Hours of operation, lengthy waitlists, childcare availability, communication between providers) • Measures should be created to assess each potential barrier within the family • Barriers can significantly impact the implementation of family interventions	Reasonable to combine results in this way; Important outcomes considered; Right types of papers included; Important, relevant studies included	7
Njoku et al., 2013[52]	Retrospective record survey of socioeconomic variation in survival from childhood cancer	n = 1007 children diagnosed with cancer (0-14 years)	• Compared to those with highest SES, those in the middle class were at a 68% increased risk and those in the lowest class at an 86% increased risk for death • This is true regardless of the fact that all classes have access to health care in England	Limited validated measures for SES; Sufficient sample size; data collection appropriate to study method; appropriate analysis; reporting clearly described	6
Panganiban-Corales et al., 2011 [53]	Parent-report, cross-sectional study examining family resources, functioning and caregiver strain	n = 90 caregivers of children with cancer	• 80% of caregivers reported having inadequate economic resources • 45.6% of parents were predisposed to caregiver strain or experiencing caregiver strain prior to child's diagnosis • Physicians should regularly assess family function, family resources and strain experienced by caregivers	Convenience sampling; limited validated Filipino psychosocial tools; sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis; reporting clearly described	6
Patel et al., 2013[54]	Parent-report, cross-sectional study examining neurocognitive and behavioral outcomes in Latino childhood cancer survivors	n = 73 parents of childhood cancer survivors	• Age at diagnosis predicted dysfunction in attention, learning and impulse control • Children of parents who were less acculturated were at greater risk for peer-relational and executive functioning problems • Children with higher neurocognitive and behavioral dysfunction exhibited lower quality of life	Lack of control group; blinding or data collection appropriate to study method; appropriate analysis	6
Patterson et al., 2004 [55]	Parent-report, qualitative study (Focus Groups) on the impact of cancer on the family	n = 45 parents of children with cancer	• Domains of strains due to diagnosis: Cancer-related strains (treatment effects), Child strains (emotions, self-consciousness, loss of a normal life, worry about expense of treatment), Family strains, Community strains (avoidance by friends, lack of support), and Health-care system strains • Major stressors and barriers to care during treatment: conflict with or lack of financial support from former spouses, changes in family roles	Non-representative sample; research question clearly stated; qualitative approach clearly justified; study context clearly described; method of data collection clearly described; method of data analysis clearly described; analysis appropriate for research question	6

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SUPPLEMENTAL TABLE I. (*Continued*)

Group II. Family Resources: Financial, SES status, language issues, barriers to care, safety of environment

Study	Design	Sample	Findings	Study Rigor	Level of evidence
Petridou et al., 2015[56]	Meta-analysis examining socioeconomic disparities in survival from childhood leukemia	n = 29 studies included	• Substantial and growing disparities in survival from childhood leukemia in lower SES families ○ Survival gap (between high and low SES) was considerably highest in the United States than elsewhere in the world • Increase in death rates related to: ○ Lower SES areas of residence ○ Lower-level parental occupation • Lower SES associated with: poor adherence, abandonment of treatment, inadequate health insurance, and restricted access to quality health care/clinical trials • Findings indicate a need for improvement in health systems and policies ○ Raising awareness of the demanding needs of individuals from lower SES backgrounds is important ○ Special attention should be paid by the health care team regarding the treatment of lower SES children in finding ways that they can also benefit from the therapeutic advancements in childhood cancer	Right types of papers included; Important, relevant studies included; Appropriately assessed for quality of studies; Reasonable to combine results in this way; Important outcomes considered	1
Rosenberg-Yunger et al., 2013 [57]	Parent-report and social worker report; Cross-sectional, qualitative study on caregiver strains	n = 29 single caregivers; 2 social workers were also interviewed for the perspective of a health care provider	• Despite access to resources including charitable organizations single caregivers report unmet needs • Reported need for more social-emotional, practical and financial support to assist them with caregiving for a child with cancer	Research question clearly stated; study context clearly described; method of data collection clearly described; method of data analysis clearly described; analysis appropriate for research question	6
Ryan et al., 2013[58]	Parent-report, cross-sectional study assessing SES level	n = 73 parents of children with cancer	• Parents of lower social status and less income and education reported more parenting capacity difficulties • Families with lowest annual income (<$20,000) reported more overprotection and higher parenting stress • Families with low incomes (<$20,000 and $21,000-$39,000) reported increased externalizing and internalizing problems compared to families with higher annual incomes (>$60,000) • Parents with high school education or less reported more parental overprotection, perceptions of child vulnerability and parenting stress	Sufficient sample size; data collection appropriate to study method; appropriate analysis; reporting clearly described	6
Selove et al., 2012[59]	Healthcare provider report, Cross-sectional survey on psychosocial services provided to families of children with cancer	n = 290 informants from COG institutions; informants were identified by site PIs as pediatric oncology staff "likely to know most about psychosocial services provided to patients"	• Greater than 50% of families were offered psychosocial services at participating institutions • Barriers to treatment: inadequate funding for staff, families' time constraints, transportation difficulties, lack of insurance reimbursement, and language difficulties • Use of evidenced based practices infrequent (11% of sites) • Efforts must be made to close the research practice/gap & standardized assessment must be increased	Use of non-validated survey; sufficient sample size; data collection appropriate to study method; appropriate analysis; reporting clearly described	6
Shaw et al. 2013[60]	Self-report and parent-report; Qualitative study, semi-structured interviews within a focus group format assessing feasibility and acceptability of culturally targeted intervention	n = 12 cancer patients & 4 caregivers	• Unfamiliarity with English negatively impacts care received • Mandarin, Cantonese, and Arabic patients reported desiring face to face contact with HCP in their native language and supported continued telephone access to HCP fluent in their native language as care progressed • Language and cultural understanding of care providers must be considered	Convenience sampling; methodologically weak; research question clearly stated; study context clearly described; role of the researcher clearly described	6

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SUPPLEMENTAL TABLE I. (*Continued*)

Group II. Family Resources: Financial, SES status, language issues, barriers to care, safety of environment

Study	Design	Sample	Findings	Study Rigor	Level of evidence
Simon et al., 2003[61]	Parent-report and observational coding of informed consent process analyzing the clinician-parent communication process during informed consent	n = 108 parents of children with cancer	• Minority patients (spoke little to no English), misunderstood the concept of RCTs and their rights more frequently than majority patients • Differences due to language barriers, social status and prevailing cultural norms	Convenience sample; appropriate analysis; reporting clearly described; data collection appropriate to study method	6
Son et al., 2011[62]	Retrospective record survey of inequalities in cancer mortality according to parental SES	n = 1,102 children with cancer	• Lower parental education and parental unemployment or employment in manual labor were associated with higher likelihood of cancer mortality	Weak methodology; could not control for confounding variables; Sufficient sample size; reporting clearly described	6
Syse et al., 2012[63]	Retrospective record survey examining mortality after cancer based on social or economic resources of parents	n = 6,280 children with cancer (age $\leq$ 20 years)	• Children whose parents were less educated had a 15% higher mortality rate in the decade following diagnosis • Survival after childhood cancer depends, in part, on the family's resources	Mortality rate was from any cause (not just cancer); sufficient sample size; appropriate analysis	6
Tsimicalis et al., 2011 [64]	Systematic literature review of costs incurred by families of children diagnosed with cancer	n = 13 studies critically appraised using Pediatric Quality Appraisal Questionnaire	• Families incur significant variable costs throughout cancer treatment; magnitude of costs uncertain • Strategies for enhancing quality of childhood cancer cost of illness presented and implications for clinical practice discussed	Right papers included; important relevant studies included; appropriately assessed for quality of studies; reasonable to combine studies; important outcomes considered	1
Tsimicalis et al., 2013 [65]	Parent-report, prospective mixed method cost-of illness design analyzing out-of-pocket expenses due to child's illness	n = 99 families	• 75% of costs are attributed to travel (56%) and food (18%) • Parents described facing significant out-of-pocket expenses to ensure their children had access to cancer treatment, to cope with clinical treatment side effects and maintain the household • Clinicians should assess family costs, develop and evaluate guidelines to lessen burden; offer referrals as needed	Sufficient sample size; appropriate analysis; reporting comprehensive, clearly described; issues with follow-up or missing data clearly described	6
Viana et al., 1998[66]	Prospective case study examining low SES as a predictor of relapse	n = 167 patients with ALL (age $\leq$ 15 years at diagnosis)	• Socioeconomic and cultural background of the child with leukemia impact the results of treatment • SES indicators of poverty (including: poor housing conditions, low per capita income and energy consumption) were significantly associated with greater risk for relapse • Low SES is a significant predictor of relapse	Data collection appropriate to study method; appropriate analysis	6
Warner et al., 2014[67]	Parent-report, cross-sectional survey of financial burden of pediatric cancer for patients and their families	n = 254 caregivers of pediatric cancer patients	• As a result of child's cancer diagnosis, approximately 1/3 of caregivers quit or changed their job • Caregivers living in a rural residence reported higher financial burdens • Caregivers' perceived financial burden from cancer differs over time since diagnosis ○ After 1 year from diagnosis, families may be increasingly vulnerable to financial stress and burden • Findings demonstrate need to medical and social support teams on an ongoing basis, even after the end of primary therapy	Sufficient sample size; appropriate analysis; reporting comprehensive, clearly described	6

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SUPPLEMENTAL TABLE I. (*Continued*)

Group III. Child and family social support- adequate support, extended family, child's friends, community resources like church

Study	Design	Sample	Findings	Study rigor	Level of evidence
Abrams et al., 2007 [68]	Literature review examining the psychosocial impact upon adolescents diagnosed with cancer	N/A	• Surveys the literature on adolescents with cancer concerning autonomy, informed consent and assent, initial responses to the diagnosis of cancer, quality of life and the experience of the adolescent with cancer, psychological adjustment, support systems, body image issues, sexuality, education, hope, treatment compliance, and survivorship issues • The psychosocial complexities facing an adolescent with cancer are monumental, disrupting the normal path toward autonomy and independence, attitudes toward body image and sexuality, peer relations, and psychological identity • Risk factors that increase the likelihood of psychosocial difficulty in adolescents include difficulties in parental coping, social or emotional problems prior to diagnosis, and a depressive attributional style	Right types of papers included; Important, relevant studies included; Reasonable to combine results in this way; Important outcomes considered	7
Barakat et al., 1997[69]	Child and parent-report of PTSS, Cross-sectional; questionnaires (mailed); comparison group; parents included with both groups	n = 309 Cancer survivors (6-20 years) (309 mothers, 213 fathers); n = 219 healthy children (211 mothers, 114 fathers)	• Poorer social support and family resources were related to more PTSS in parents • Social support and family functioning are essential to long-term adjustment • Need to target families' sense of support from the health care team and extended families / communities • Poorer social support and family resources were related to more PTSS in parents • Social support and family functioning are essential to long-term adjustment • Need to target families' sense of support from the health care team and extended families / communities	Sufficient sample size; Issues with missing data clearly described; Data collection appropriate to method; appropriate analysis	6
Barnes et al., 2014[70]	Narrative review examining ways to promote healthy development of children with cancer	n = 10 studies included	• Increased social support (and parent support) increases likelihood of appropriate development in adolescent survivors • Interventions should include peer support components to ensure normal developmental markers (autonomy in adolescents)	Relevant studies included; reasonable to combine results in this way	7
Charlebois & Bouchard, 2007[71]	Grandparent report; qualitative, semi-structured interviews with individuals and couples assessing the experience of grandparents with grandchildren diagnosed with cancer	n = 8 grandparents of children with cancer	• Having a grandchild with cancer is an extremely difficult experience for grandparents • Themes generated from interviews suggested grandparents described this event as "one of the worst experiences of their lives" • Grandparents report experiencing pain for themselves, their children and their grandchildren	Research question clearly stated; qualitative approach clearly justified; study context clearly described sampling strategy appropriate for research question; method of data analysis clearly described; analysis appropriate for research question	6
Decker, 2007 [72]	Systematic literature review and critical analysis of studies of social support for adolescents with cancer	n = 17 studies included	• Parents, especially mothers, are reported to be the major source of support. • Adolescents are generally satisfied with family support, but support from friends, while important, is described as less satisfactory • Methodological concerns include small samples and lack of consistency in the instruments used to assess social support	Right types of papers included; Important, relevant studies included; Appropriately assessed for quality of studies; Reasonable to combine results in this way; Important outcomes considered	5
Kazak et al., 1997[73]	Parent and self-report; cross-sectional; questionnaires (mailed) assessing PTSS, social support and family functioning	n = 130 child leukemia survivors (8-19 years) and parents; comparison group n = 155 and parents	• No significant differences in survivor and comparison groups • Higher levels of perceived support was indicative (both groups) in a reduction/fewer PTSS • Social support instrumental in parental responses and adaptation • Higher parental support was associated with increased avoidance symptoms (needs further exploration)	Missing data clearly described; Data collection appropriate; Reporting comprehensive; appropriate analysis	6

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SUPPLEMENTAL TABLE I. (*Continued*)

Group III. Child and family social support- adequate support, extended family, child's friends, community resources like church

Study	Design	Sample	Findings	Study rigor	Level of evidence
Kyngas et al., 2001[74]	Self-report; cross-sectional; Semi-structured interviews	n = 14, adolescents (16 – 22 years) with cancer for 2+ months	• Respondents reported using emotion-focused, appraisal-focused and problem-focused coping strategies • The major coping strategies were social support, belief in recovery, and getting back to normal life as soon as possible • The family was the most important source of emotional support • Major resources included discussions with family members, friends and health care providers, belief in one's own resources to cope, belief in God, willingness to fight against the disease.	Research question clearly stated; Qualitative approach clearly justified; Sampling strategy appropriate for question; Method of data collection clearly described	6
La Greca et al., 2002 [75]	Literature review examining the role of peers as a source of support, peer influence on treatment adherence, and peer impact on health-promoting and health-risk behaviors	N/A	• Young people with chronic conditions do not have more problems in their peer relations than other youth, although children with medical conditions that are stigmatizing or involve the central nervous system may encounter peer difficulties • Social support from friends and classmates facilitates adaptation and may help with lifestyle aspects of treatment regimens • Affiliation with certain peer-groups (e.g., "brains" or "jocks") who are linked to health-promoting behaviors may prove beneficial to youngsters' disease management and health	Important, relevant studies included; Important outcomes considered	7
Laing et al., 2014[76]	Family Interviews; Qualitative study assessing the experience among families attending a cancer camp	n = 9 families (19 participants total, including children with cancer under the age of 20, siblings, and parents)	• Social supports increase a sense of community and belonging among families • Nurses (medical team) in position to foster support systems through understanding current supports and increasing support connections	Research question clearly stated; method of data collection clearly described; method analysis clearly described	6
Manne et al., 2000[77]	Parent-report mail questionnaire regarding coping style, past traumas, perceived social support and perceived social constraints are associated with stress in mothers of pediatric cancer survivors	n = 72 mothers of children who had successfully completed cancer treatment	• Greater time since treatment was completed was associated with a significantly lower desire to talk with others about the child's cancer but not with less actual talking • Mothers who perceived more constraints in talking about their thoughts and feelings reported more traumatic stress symptoms • Higher levels of social support were associated with lower traumatic stress symptoms • Mothers with a higher monitoring coping style did not report greater PTSD symptomatology • Parents with more life-time traumatic events did not report greater PTSD symptomatology	Sufficient sample size; data collection appropriate to study method; appropriate analysis; evidence derived from high quality case control or cohort studies; reporting comprehensive, clearly described; issues with follow-up or missing data clearly described	6
McGrath, 2001[78]	Parent-report; longitudinal, qualitative study (interviews) identifying support issues for parents of children with cancer	n = 12 parents	• The need for support was reported as intense, and offers of support tend to lessen over time • Among the sources of support noted were partners, family, friends, employers, hospital staff, and other parents in the same situation • Community resources appeared to be lacking, underused, or both	Research question clearly stated; qualitative approach clearly justified; study context clearly described; sampling strategy appropriate for research question; method of data collection clearly described; method of data analysis clearly described; analysis appropriate for research question	6

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SUPPLEMENTAL TABLE I. (*Continued*)

Group III. Child and family social support- adequate support, extended family, child's friends, community resources like church

Study	Design	Sample	Findings	Study rigor	Level of evidence
Mertens et al., 2014 [79]	Child and sibling report; cross-sectional study, mailed questionnaires; Ancillary study to the CCCS assessing health and well-being of cancer survivors	n = 307 cancer survivors (ages 15-19) and 97 siblings	• Previous studies showed decrease in functioning in CNS survivors, current study (Teen Health Survey) higher functioning in social problem solving and less at-risk behaviors – possibly due to increase peer and family supports • Increasing social support of survivors should be a primary aim of psychosocial professionals, specifically with families in lower SES	Sufficient sample size (limitations: lack generalizability- majority lower SES patients, CCSS data from survivors Dx 1970-1986); appropriate analysis; reporting comprehensive	6
Neil-Urban & Jones, 2002[80]	Two focus groups with fathers; qualitative interviews to explore the emotional experience and coping strategies of having a child diagnosed with cancer	n = 10 fathers of children in treatment or recently treated for cancer	• Findings clustered around the themes of 1) effect upon their role as providers, 2) emotional impact, 3) impact on relationships with their wives/parenting, 4) hypervigilance/distrust, 5) overcoming fear of negative outcome, 6) coping/moving on • Participants were forthcoming with their feelings and also generous about supporting one another	Research question clearly stated; qualitative approach clearly justified; study context described; sampling strategy appropriate for research question; method of data collection clearly described; analysis appropriate for research question	6
Ritchie, 2001 [81]	Self-report, descriptive correlation study examining relationships among the stages of adolescence, gender, self-esteem and hopefulness	n = 45 adolescents with cancer	• Perceived level of self-esteem and hopefulness did not significantly differ between boys and girls overall; between early, middle and late adolescents; or between boys and girls within each stage of adolescence • A stepwise multiple regression analysis showed self-esteem and the early stage of adolescence accounted for 27.3% of the variance in hopefulness scores • Self-esteem was the most significant predictor explaining 20.7% of the variance	Sufficient sample size; data collection appropriate to study method; appropriate analysis	6
Rosenberg et al., 2014 [82]	Parent-report; cross-sectional, surveys mailed to parents reporting on levels of social support	n = 96 parents (1 per family)	• Parents of children with cancer reported more social support than United States and Washington state population norms • Lower social supports reported were associated with higher levels of distress and lower levels of family overall functioning	Data collection appropriate (but with limitations to show directional associations); issues with missing data clearly described	6
Wilkins et al., 2005[83]	Systematic review of qualitative studies that look at the childhood cancer experience from the sibling perspective	n = 27 articles included	• Three themes: 1) profound life changes experienced by siblings, 2) intense feelings of sadness, loneliness, rejection, anxiety, anger, jealousy and guilt, and 3) unmet needs • Siblings reported the need for honest communication, adequate information about cancer, involvement in the care of the sick child, and support to maintain their own interests and activities	Right types of papers included; Important, relevant studies included; Appropriately assessed for quality of studies; Reasonable to combine results in this way; Important outcomes considered	5
Woodgate, 2006[84]	Self-report; longitudinal qualitative study of adolescents involving open-ended individual interviews, focus groups and participant observation to analyze sources of social support	n = 15 adolescents in remission from cancer (ages 4 – 18 years)	• Relationships with families, health care team and special friends were main supportive relationships in adolescents' lives • The act of others "being there" (for comfort, encouragement, etc.) was seen as the key element of a supportive relationship • Although the three key supportive relationships were essential in helping adolescents get through cancer, these relationships were at times a source of stress	Research question clearly stated; qualitative approach clearly justified; sampling strategy appropriate for research question; method of data collection clearly described; method data analysis clearly described; analysis appropriate research question	6

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SUPPLEMENTAL TABLE I. (*Continued*)

Group IV. Previous history/premorbid functioning: prior illness history, prior loss, behavioral, educational

Study	Design	Sample	Findings	Study rigor	Level of evidence
Armstrong & Horn, 1995 [85]	Narrative review of educational issues in childhood cancer	N/A	• Children diagnosed with and treated for cancer tended to have increased absences from school • Short and long-term academic performance problems tended to occur in this population • Assessment and intervention may be needed to increase school completion rates and academic achievement • Children should be assessed prior to school re-entry and after treatment	Unsystematic review; Right type of papers included; Relevant studies included; reasonable to combine results in this way	5
Barrera & Atenafu, 2008[86]	Parent-report, cross-sectional; and child (and sibling) cognitive, educational, & visual motor tests	n = 46 survivors of SCT (3 – 16 years) and 33 siblings (3 – 20 years)	• Siblings had significantly more internalizing problems that survivors did • The education and cognitive abilities of the cancer survivors were similar to those of their siblings' at 2 years post-HSCT	Issues with missing data clearly described; Data collection appropriate to method; Reporting comprehensive; appropriate analysis	6
Barrera et al., 2000[87]	Parent-report; longitudinal (pre and post SCT); measures and semi-structured interview, examining QoL and adjustment after SCT	n = 26 mothers	• Children's levels of internalizing and externalizing behavior stayed consistent at pre-SCT and post-SCT • Significant changes seen at 6-months post-SCT compared to pre-SCT QoL in role restrictions and physical discomfort • Overall depressive symptoms in mothers stable across time • Maternal anxiety ratings did not reach the clinical cutoff score for an anxiety diagnosis, but overall they were significantly higher at pre-SCT compared to post-SCT	Issues with missing data clearly described; Data collection appropriate to method; Reporting comprehensive; appropriate analysis	6
Campbell et al., 2009 [88]	Parent and self- report; cross-sectional, matched control; assessing executive function, coping and behavior in cancer survivors	n = 30 children / adolescents (10-20 years) and 30 matched control. 1 caregiver per child	• ALL group showed decrease in executive function (working memory and cognitive flexibility) • Impairment in executive function related to developmental impairments in academics and emotional regulation • History of special education in ALL group associated with six times greater chance of mood disturbance • ALL group showed less ability to use adaptive coping skills and showed more behavioral issues than matched controls	Issues with missing data clearly described; Data collection appropriate to method; Reporting comprehensive; appropriate analysis	4
Cherven et al., 2014[89]	Child and parent report; Longitudinal, questionnaires, assessing knowledge and risk perception of late effects of childhood cancer	n = 65 participants (28 adolescent survivors (age $\geq$ 16) and 37 parents); n = 50 at follow up (20 survivors and 30 parents)	• It is difficult to know if the school difficulties upon returning to school after treatment were impacted by cancer treatment trajectory or would have occurred without diagnosis/treatment • Important to pay attention to possible school difficulties in all cancer survivors and not just those with neurocognitive deficits	Issues with follow-up and missing data clearly described	6
Currier et al., 2009[90]	Child and parent report; Cross-sectional, non-experimental; questionnaires examining stressful life events and PTSS	n = 121 children diagnosed with malignant disease and 1 caregiver	• Children whose parent endorsed moderate to severe PTSS more likely to report PTSS • Accumulation of stressful life events associated with more severe traumatic responses in coping with cancer • Positive association between number of endorsed stressful life events and child traumatic response to cancer Dx and Tx • Cancer appeared to be contributing stressful life event that caused vulnerability to future stressful events	Issues with missing data clearly described; Data collection appropriate to method; Reporting comprehensive; appropriate analysis	6
Hagan et al., 2008[91]	Best clinical guidelines for health supervision of infants, children and adolescents	N/A	• To understand and promote healthier outcomes in children and families developmentally appropriate assessment of risk factors should occur in specific domains: behavioral, developmental, school, social, and environmental growth and development	No report of studies used	7

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SUPPLEMENTAL TABLE I. (*Continued*)

Group IV. Previous history/premorbid functioning: prior illness history, prior loss, behavioral, educational

Study	Design	Sample	Findings	Study rigor	Level of evidence
Jobe-Shields et al., 2009 [92]	Child and parent report; Cross-sectional, questionnaires examining depression and family environment and their impact on child distress	n = 146 children undergoing SCT and one parent	• Family history of anxiety or depression associated with worse psychosocial and QoL outcomes during and after SCT • Positive adjustment in children with cancer related to family cohesion and expressiveness • Family conflict associated with child internalizing and externalizing behavior • When parent depressive sx are low, quality of family environment is a protective factor that buffers children from exhibiting sx of distress; however when parental depressive sx are high, the family environment is no longer a protective factor	Data collection appropriate to method; Reporting comprehensive; appropriate analysis	6
Kupst et al., 2002[93]	Clinician administered testing for children and parent-report questionnaire/ interview; Prospective longitudinal; non-experimental study examining cognitive and psychosocial functioning of HSCT patients	n = 153 (at pre), 153 (at 1 year post HSCT), and 74 (at 2 year post) children/ adolescents undergoing HSCT and their parents	• Pre-HSCT functioning was strongest predictor of cognitive and psychosocial functioning • Possible resiliency factors: pre-HSCT behavioral and social functioning; higher socioeconomic status; older age of child	Issues with missing data clearly described; Data collection appropriate to method; Reporting comprehensive; appropriate analysis	4
Lahteenmaki et al., 2002 [94]	Self-report (with healthy child and sibling control); Cross-sectional; non-experimental study assessing childhood cancer patients in school	n = 43 children with cancer; healthy control n = 103; sibling control n = 28	• Cancer survivors' perception of peer relationships was related to long-term psychosocial adjustment • Significant differences in patients compared to healthy and sibling control were: being bullied at school, needing extra tutoring, doing worse in school compared to the prior term • Worrying about being misunderstood and about classmate interaction associated with avoidance to returning to school, with bullying the primary factor in difficulties re-entering school • Poor self-esteem associated with social isolation and loss of friendships	Issues with missing data clearly described; Data collection appropriate to method; Reporting comprehensive; appropriate analysis	4
Mitby et al., 2003[95]	Self-report; Retrospective long-term follow up cohort study; questionnaires examining use of special education services and attainment of cancer survivors	n = 12,430 cancer survivors (and 3,410 siblings) from the CCSS	• Cancer survivors used significantly more special education services compared to siblings • Survivors who received CRT were 7 times more likely than survivors not on CRT to need services • Absenteeism from school due to cancer treatment was a significant factor for determining child's placement in special education services • Dx before age 11, Dx with CNS tumor, kidney tumor, and non-Hodgkin lymphoma increased need for services and lower test scores	Data collection appropriate to method; Reporting comprehensive; appropriate analysis	6
Neu et al., 2014[96]	Parent-report, Cross-sectional matched-control study; non-experimental study of anxiety, depression and stress in mothers	n = 26 per condition (mothers of children with cancer and healthy control)	• Depression levels in mothers of children with cancer were sig higher than control group • Mothers with children with cancer continued to experienced emotional distress months after initial diagnosis • Screening should occur upon diagnosis for mothers focusing on anxiety, depression, and stress	Lack of longitudinal data to see if symptoms increase, decrease or maintain; Reporting comprehensive	4
Okado et al., 2014[97]	Child and parent report; Cross-sectional, non-experimental study analyzing the association between child and parent distress	n = 255 children with cancer and parents; healthy comparison parent and child dyads n = 142	• Previous stressful life experiences were related to increased symptoms of depression, anxiety and PTSS in both groups of children • Parental distress associated with child psychopathology, but not only related to the diagnosis (not discussed if present prior to diagnosis)	Sufficient sample size; appropriate analysis; reporting comprehensive	4

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SUPPLEMENTAL TABLE I. (*Continued*)

Group IV. Previous history/premorbid functioning: prior illness history, prior loss, behavioral, educational

Study	Design	Sample	Findings	Study rigor	Level of evidence
Phipps et al., 2005[98]	Parent-report, longitudinal, questionnaires, study assessing psychosocial predictors of distress in parents	n = 151 parents of children undergoing SCT	• Parental distress prior to SCT was positively correlated to parental distress post SCT • Parent distress prior to and during SCT correlated with child internalizing problems throughout SCT • Parent use of avoidant coping strategies correlated with parental distress pre and post SCT • Higher parent distress during SCT if child had pre-transplant history of internalizing behavior	Issues with missing data clearly described; Data collection appropriate to method; Reporting comprehensive	6
Phipps et al., 2006[99]	Parent and self-report; Cross-sectional; non-experimental study of the adaptive style and PTSS in children with cancer and their parents	n = 162 Children with cancer (7 – 17 years) and parents	• Parent PTSS has been shown to be direct correlate of child self-reported PTSS • General emotional distress and cancer fears correlate with parental PTSS • Significantly higher levels of PTSS in newly diagnosed patients compared to survivors • Parent anxiety associated with higher distress in child • Parents with less anxiety and repressive adaptive styles tended to be less aware of child symptoms	Issues with missing data clearly described; Data collection appropriate to method; Reporting comprehensive; appropriate analysis	6
Rynard et al., 1998[100]	Parent and teacher report; Cross-sectional; non-experimental; questionnaires on school support program for children with cancer	n = 67 teachers; n = 55 parents	• Teachers and parent reports indicated no significant issues with student readjusting to school post treatment • Absenteeism was at a rate of approximately one third of school days for children diagnosed with cancer • Parents perceived significantly greater behavioral and emotional adjustment concerns than teachers for same child • No discussion of prior school or behavioral history compared to current	Issues with missing data clearly described; Data collection appropriate to method; Reporting comprehensive; appropriate analysis	6
Streisand et al., 2000 [101]	RCT; pilot intervention trial for parents of children undergoing SCT	n = 22 parents of children from pre-admission to 3 weeks post SCT (Intervention N = 11); (Standard care N = 11)	• Both groups of mothers reported increased levels of stress at pre-admission • Intervention group mothers reported using intervention techniques significantly more than Standard care group ○ Results not significant between Intervention and Standard Care on reported levels of stress (possibly due to limited sample size)	Issues with missing data clearly described; Data collection appropriate to method; appropriate analysis	2
Stuber et al., 1997[102]	Parent and self-report; Cross-sectional; questionnaires assessing predictors of PTSS in cancer survivors	n = 186 pediatric cancer survivors (8 – 20 years) and parents n = 246	• Significant predictors of persistent PTSS include: survivors retrospective appraisal of life threat at time of treatment, and the degree to which the treatment was experienced as "hard" or "scary"; child's level of anxiety; history of other stressful experiences; time since termination of tx (negative association); female gender; and family/social support • Predictors of PTSS are primarily subjective factors	Issues with missing data clearly described; Reporting comprehensive; appropriate analysis	6
Vrijmoet-Wiersma et al., 2009 [103]	Parent (self and proxy) and self-report; Prospective, pre- (2 wks prior) post (>2 months post); questionnaires; study assessing HRQoL	n = 21 children undergoing SCT and their parents, n = 31	• Parents of children in the SCT group showed higher levels of stress post-SCT (when compared to normative data for specified measures); levels did not differ when comparing pre-SCT and norm group • Self-reports and proxy-reports both showed children who underwent SCT had significantly lower HRQoL post-SCT • Proxy rated HRQoL correlated positively with parental perception of child "demandingness" ○ Parent rating of child HRQoL post-SCT was negatively correlated to parental Sx of PTSS, depression, and anxiety	Issues with missing data clearly described; Data collection appropriate to method; Reporting comprehensive; appropriate analysis	6
Zebrack et al., 2004[104]	Child and sibling report; Retrospective follow-up to prior study; evaluating and comparing psychological outcomes of long-term survivors of cancer and their siblings	n = 1101 brain cancer survivors (age ≥ 18 years) and 2817 siblings from the CCSS	• Depression and distress were significantly higher in survivors of brain cancer than in siblings • Higher level of depression was associated with respondents who had lower academic attainment • Current medical problems were positively associated with an increase in anxiety and somatization	Issues with missing data clearly described; Reporting comprehensive; appropriate analysis	6

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SUPPLEMENTAL TABLE I. (*Continued*)

Group V. Family structure and function: family dynamic, belief system, cultural factors

Study	Design	Sample	Findings	Study rigor	Level of evidence
Alderfer et al., 2009[105]	Parent-report, Cross-sectional study; questionnaires assessing family functioning and PTSD	n = 308 married and 75 single parents of youth with chronic health conditions (144 with cancer)	• Adolescents with PTSD were over 5 times as likely to be from a poorly functioning family then those in a well functioning one • 8% of children with cancer were diagnosed with PTSD	Sufficient sample size; data collection appropriate to study method; appropriate analysis	6
Alderfer et al., 2010[106]	Systematic review of psychosocial impact of childhood cancer on siblings	n = 65 quantitative, qualitative and mixed methods studies included	• Siblings of children with cancer do not experience elevated mean rates of psychiatric disorders, but a significant subset experiences PTSS, negative emotional reactions, and poor QoL • In general, distress is higher closer to diagnosis • Qualitative studies: themes of loss of attention and status, but also positive outcomes, e.g. increased maturity and empathy	Important, relevant studies included; appropriately assessed for quality of studies; reasonable to combine results in this way; important outcomes considered	5
Best et al., 2001[107]	Parent-report, follow up study, questionnaire to evaluate the association between anxiety during treatment and posttraumatic stress symptoms post-treatment	n = 113 parents of children treated for childhood leukemia	• Anxiety during treatment was found to be a significant predictor of later PTSS for mothers, but not fathers • Anxiety, self-efficacy, posttraumatic growth, and length of time since treatment ended were associated with parental avoidance • Parents reported relatively high self-efficacy generally, but lower self-efficacy for items related to follow-up care, such as ability to cope with medical late effects and/or relapse	Sufficient sample size; data collection appropriate to study method; appropriate analysis; issues with follow-up or missing data clearly described	6
Bjork et al., 2011[108]	Parent, child and sibling report; qualitative study examining families' lived experience after completing cancer treatment	n = 10 families consisting of 10 mothers, 8 fathers, 4 patients and 2 siblings	• An essential theme emerged, "returning to a changed ordinary life – incorporating a trying and contradictory experience' ○ Families felt relieved that treatment was over, but still experienced strains in their daily lives ○ Families felt changed, particularly the parents ○ Importance of closeness with family members for recovery ○ Previously sick children felt a loss of concern from parents, where as siblings experienced increased attention ○ Parents described returning to "ordinary life" as uncharted territory • Findings stress the importance of offering families a structured follow-up to help with the transitional into daily life after treatment	Research question clearly stated; study context clearly described; sampling strategy appropriate for research question; method of data collection clearly described; method of data analysis clearly described	6
Bonner et al., 2007[109]	Parent-report; cross-sectional; questionnaires assessing the functioning of fathers as primary caregivers of pediatric cancer patients	n = 27 fathers identified as the primary caregivers compared to 23 mothers matching on demographic variables	• No differences between groups on self-report measures of distress or illness-related parenting stress • However, the majority of the parents were above normative means for measures of psychological distress, with a significantly greater proportion of fathers endorsing elevated levels of depression on the BSI • Stresses the importance of including fathers in pediatric psycho-oncology research and to conceptualize pediatric cancer as a "family disease"	Blinding or data collection appropriate to study method; appropriate analysis; reporting clearly described	6
Brown et al., 2008[110]	Narrative review/ commentary of research pertaining to single-parent families of children with chronic illnesses	N/A	• Most studies focus on stresses of parenting a child with a chronic illness, however few studies have examined single parents of children and adolescents with chronic illnesses and related stressors from being the single caregiver • There is a dearth of research and a critical need to conduct research with single-parent families of children with cancer • Significant gaps include: standardized definition of "lone" or "single" parent, measurement (how to quantify and measure "lone" parent), demographics, and psychosocial adaptation of the single parent	Important, relevant studies included; appropriately assessed for quality of studies; reasonable to combine results this way; important outcomes considered	7
Da Silva et al., 2010 [111]	Systematic integrative review of the impact of childhood cancer on parents' relationships	n = 14 articles included	• Four themes emerged: changes in the parents' relationships during the trajectory of the child's illness; difficulty in communication between couples; gender differences in parental stress and coping; and role changes • Changes in parents' relationships, communication, stress and roles were both positive and negative	Important, relevant studies included; reasonable to combine results in this way; important outcomes considered	5

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SUPPLEMENTAL TABLE I. (*Continued*)

Group V. Family structure and function: family dynamic, belief system, cultural factors

Study	Design	Sample	Findings	Study rigor	Level of evidence
Drotar, 1997 [112]	Systematic review of parent and family functioning and psychological adjustment of children with chronic health conditions	n = 57 studies included	• Supportive relationships among family members predicted fewer behavioral symptoms and more competent psychological functioning in the children with chronic illness • More adaptive family relationships and parental psych adjustment were associated with psychological adjustment in children with chronic health conditions	Right types of studies included; important, relevant studies included; appropriately assessed for quality of studies; reasonable to combine results in this way; important outcomes considered	**5**
Goldbeck, 1998[113]	Parent-report, cross-sectional pilot study using mailed questionnaires to assess coping	n = 44 parents of children with cancer	• Most parents reported coping well but those in the low coping group had lower family cohesion, high depressive symptoms • Parent and child coping significantly correlated	Sufficient sample size; data collection appropriate to study method; appropriate analysis	**6**
Gray et al., 2014[114]	Systematic review of cultural factors impacting families of children with cancer	n = 72 studies included	• Cultural factors affected illness representations, reactions to diagnosis, coping strategies, and end of life issues • Potential cultural barriers to effective treatment: stigma related to illness, conceptualization of the illness, illness attributions, disclosure of the illness, use of complementary and alternative medicine, coping, different types of support, end of life beliefs • Lack of culturally specific practices and treatments in pediatric cancer • Importance of ongoing clear communication between family and medical team	Right types of paper included; Important, relevant studies included; Appropriately assessed for quality of studies; Reasonable to combine results in this way; Important outcomes considered	**5**
Hildenbrand et al., 2014 [115]	Parent and self-report; Mixed Methods study; questionnaires and semi-structured interviews to assess coping and coping assistance	n = 15 children with cancer (6 – 12 years) and their parents (n = 17)	• Mixed methods studies provide complementary and unique ways to understanding coping among families of a child who has cancer • Using mixed methods approaches to assess coping allows for a richer understanding of the families experiences, which in turn can better inform clinical practice • Coping with pediatric cancer and its treatment is a dynamic, multifaceted process that requires multiple methods of information to accurately assess and understand families' experiences	Mixed methods; Blinding or data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	**6**
Hocking et al., 2011 [116]	Narrative review of neurocognitive, family functioning and QoL among adult survivors of childhood cancer	N/A	• Theoretical model of survivorship suggests that family functioning and survivor neurocognitive functioning interact to affect survivor and family outcomes • The review highlights the influence of age at cancer diagnosis, family functioning, and family adaptation to the illness on survivor QoL and family outcomes • There is an need to assess the impact of child cancer on parental relationships • Importance of attempting to identify parents at risk for relationship issues that could prevent the most optimal care for the child with cancer	Reasonable to combine results in this way; important outcomes considered	**7**
Houtzager et al., 1999 [117]	Narrative Review of adjustment of siblings to childhood cancer	n = 35 studies included	• Childhood cancer affects the entire family system • Emotional needs of siblings are often not adequately met • Childhood cancer can affect many aspects of siblings' lives: emotional and socio-behavioral adjustment, social competence, school-related issues, health • Variables related to adjustment in siblings: ○ Previous functioning, siblings' perception of the experience, coping resources, social support and ventilation of feelings, communication between parents and siblings, denial, sociodemographic factors family variables (parental coping, family functioning, parental distress, family life-events and pre-existing problems) • There is a lack of standardized assessment of coping for siblings	Unsystematic review; Right types of papers included; Important, relevant studies included; Appropriately assessed for quality of studies; Reasonable to combine results in this way; Important outcomes considered	**7**

(*Continued*)

SUPPLEMENTAL TABLE I. (*Continued*)

Group V. Family structure and function: family dynamic, belief system, cultural factors

Study	Design	Sample	Findings	Study rigor	Level of evidence
Houtzager et al., 2004 [118]	Sibling report; longitudinal study; questionnaires assessing how coping and family functioning predict the psychological adaptation in siblings of childhood cancer patients	n = 83 siblings (ages 7 – 19 years) of children with cancer	• Assessed at 1, 6, 12 and 24 months after diagnosis • Sibling adjustment problems were associated with high family adaptation and cohesion, older age, and female gender • Siblings of pediatric cancer patients are most affected by the illness in the first months • Siblings psychosocial functioning was impaired at 1 month but improved over time	Blinding or data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described; issues with follow-up or missing data clearly described	6
Houtzager et al., 2005 [119]	Sibling report; cross-sectional, questionnaires; study assessing siblings adjustment to childhood cancer	n = 83 siblings of children Dx'd with cancer (8-17 years)	• Compared to questionnaire reference groups, siblings had lower quality of life (26-56% siblings) during the first two months after diagnosis	Sufficient sample size; appropriate analysis	6
Hullman et al., 2010 [120]	Parent-report, cross-sectional, questionnaires examining the relation between parental overprotection and HRQoL	n = 89 parents of children with cancer	• Parental overprotection and perceived child vulnerability are both found to be significantly related to child health-related quality of life and perceived child vulnerability mediated the relationship between overprotective parenting behaviors and the child's health-related quality of life	Sufficient sample size; appropriate analysis	6
Kazak et al., 2004[121]	Parent-report, cross-sectional, validation study of the FIBI in parents of children with cancer	n = 125 families (119 mothers, 56 fathers)	• Identification of parental beliefs is essential, given that they may be important in predicting/mediating outcomes in parents of children with cancer • The FIBI consists of five factors derived from maternal data: treatment related suffering ($\alpha = .83$), death and devastation ($\alpha = .80$), caregiver competence ($\alpha = .72$), connection ($\alpha = .74$), and finding meaning. ($\alpha = .74$) • Correlations with validation measures supported the structure • Paternal data showed similar patterns • The FIBI is psychometrically sound for identifying parental cancer-related beliefs • May be helpful in developing and evaluating interventions to reduce parental distress related to childhood cancer and to enhance family functioning	Sufficient sample size; data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	6
Kazak et al., 2010[122]	Child-report and HCP report; cross-sectional; questionnaires assessing psychological outcomes and health beliefs in cancer survivors	n = 167 cancer survivors and 170 healthy controls	• Cancer survivors had less positive and adaptive health beliefs compared to healthy controls • Age was significantly related to psychological distress and health beliefs in that, adolescent children with the diagnosis of cancer had greater psychological distress and fewer positive health beliefs than those diagnosed with cancer earlier • Treatment intensity (rated by HCP) was related to greater anxiety and fewer positive health beliefs	Sufficient sample size; Blinding or data collection appropriate to study method; appropriate analysis	6
Kelly & Ganong, 2011a[123]	Secondary qualitative analysis of parent-report data on the diagnosis of childhood cancer in step-families	n = 13 parents of 6 stepfamilies	• Stepfamily's coparental relationships changed, which shifted family boundaries and created instability • The shifts in family boundaries lead to ambiguities in coparental relationships and roles • Stepparents reported uncertainty and confusion about their place in the entire process • However, stepparents reported that their needs were largely unmet, given that they had little direct access to the clinical team	Research question clearly stated; study context clearly described; sampling strategy appropriate for research question; method of data collection clearly described; method of data analysis clearly described	6
Kelly & Ganong, 2011b[124]	Parent-report; qualitative examination of tx decision making in single-parent and repartnered family structures	n = 15 custodial parents, nonresidential parents and stepparents who had made a major tx decision for their children with cancer	• "Moving to place" was the central psychosocial process by which parents negotiated involved in tx decision making ○ Based on parent position in the family, pre-diagnosis family dynamics, and time since diagnosis they were moved toward or away from involvement • These family settings caused additional stressors, which affected the decision making process • It is important to include diverse families to understand their unique parental decision making experiences in regards to the child's treatment	Research question clearly stated; study context clearly described; sampling strategy appropriate for research question; method of data collection clearly described	6

(*Continued*)

SUPPLEMENTAL TABLE I. (*Continued*)

Group V. Family structure and function: family dynamic, belief system, cultural factors

Study	Design	Sample	Findings	Study rigor	Level of evidence
Klassen et al., 2011[125]	Systematic review of quality of life in childhood cancer	n = 58 publications included	• Parental health and well-being, anxiety, depression and distress related to QoL of child with cancer	Right types of studies included; important, relevant studies included; appropriately assessed for quality of studies; reasonable to combine results in this way; important outcomes considered	**5**
Kobayashi et al., 2015 [126]	Parent and sibling report; cross-sectional, mixed methods study examining interrelations between siblings and parents in families living with children with cancer	n = 14 families in quantitative study and 4 families in qualitative	• Strong correlation between parental family functioning and siblings HRQoL • Importance of interventions directed to individual family members and the family as a whole • Identified three family-unit stages during the time period of diagnosis of the child: 1) role changes and relocation of family members and subsystems; 2) managing to maintain stability of family unit; and 3) reuniting of family members and subsystems into a unit • Important to evaluate and provide appropriate support to the entire family as individuals and as a unit	Mixed methods; blinding or data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	**6**
Kupst et al., 1995[127]	Parent and child report; follow-up study 10 years posttreatment; questionnaires and a semi-structured interview assessing family coping after treatment	n = 28 former patients (ages 14 – 30 years) and their parents (23 mothers and 12 fathers)	• Long-term survivors and their parents continued to be well-adjusted to life posttreatment • Coping and perceived adjustment in long-term survivors were positively related to SES and mothers coping and negatively related to academic problems • The key is to determine which children and families are at risk for poor adjustment over time • Early risk factors for poor family coping are low SES, poor parental coping and adjustment, concurrent stresses, poor family/social support, poor communication, and young age at diagnosis	Blinding or data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	**6**
Labay & Walco, 2004[128]	Sibling report; cross-sectional; questionnaires assessing empathy and adjustment in siblings	n = 29 siblings from 20 families of children with cancer (7 – 16 years)	• Empathy in siblings correlated with adjustment • Older siblings tended to be lower in adjustment than younger siblings in rel. to child with cancer • Family size negatively related to adjustment	Appropriate analysis	**6**
Lavee & May-Den, 2003[129]	Parent-report; cross-sectional; questionnaires assessing marital relationships	n = mothers and fathers of 35 children (ages 2-16 years) treated for cancer	• Having a child with cancer strengthened some aspects of the relationship (communication and trust), while others weakened (sexuality) • Slight decrease in relationship satisfaction within 1 year of dx • Deterioration was reported in the marital relationship after more than 4 years of illness	Data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	**6**
Long & Marsland, 2011[130]	Systematic review of family adjustment to childhood cancer	n = 28 quantitative studies, 42 qualitative studies, and 1 mixed method study included	• Family risk or protective factors can precede (e.g. anxiety, depression) and/or result from (PTSS) the child's diagnosis • Body of literature suggests that family relationships are often strengthened as result of cancer experience • Longitudinal studies – family supportiveness and cohesion predict lower distress	Right types of studies included; important, relevant studies included; appropriately assessed for quality of studies; reasonable to combine results in this way; important outcomes considered	**5**

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SUPPLEMENTAL TABLE I. (*Continued*)

Group V. Family structure and function: family dynamic, belief system, cultural factors

Study	Design	Sample	Findings	Study rigor	Level of evidence
Long et al., 2013[131]	Sibling and parent-proxy report; cross-sectional study; measures assessing sibling adjustment to childhood cancer	n = 209 siblings of children with cancer (ages 8-18 years old) and their parents (186 mothers, 70 fathers)	• Greater sibling distress was associated with increased sibling-reported problems with family functioning and parental psychological control, and lower parental acceptance • Strongest effects were found for family functioning problems • Elevated levels of distress in siblings were found to be predicted by family risk factors, both alone and in combination • Findings support a contextual model of sibling adjustment to childhood cancer • Findings also support screening and intervening with families that endorse multiple risk factors	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	6
Long et al., 2015[132]	Sibling report; cross-sectional; qualitative study of the siblings' experience of a brother's or sister's cancer diagnosis	n = 30 healthy siblings of children with cancer (10 – 17 years)	• Themes of siblings' experience of pediatric cancer: knowing something is seriously wrong, figuring out the meaning of cancer, adapting to changes in personal and family life, and handling emotional reactions to cancer • Siblings go through a process in which they realize the seriousness of the illness and that it disrupts day-to-day routines, predictability and emotional security within the family. They come to take an active role in stabilizing their own emotional reactions and contribute to the family's ability to function effectively • Context around the cancer experience is an important influence on siblings' adjustment • Stresses the importance of the family as a whole and the interplay between siblings and their family members, peers, and the health care system • Siblings are partners in the day-to-day cancer management and should be recognized as an important part of family-centered care	Research question clearly stated; qualitative approach clearly justified; study context clearly described; role of the researcher clearly described; sampling strategy appropriate for research question; method of data analysis clearly described; analysis appropriate for research question	6
Mullins et al., 2011[133]	Parent-report; Retrospective comparison of single and married parents of children with chronic conditions	n = 383 mothers of children with chronic conditions, (94 with cancer)	• Single mothers had higher levels of perceived vulnerability and parenting stress but not overprotection in comparison with married parents • Differences are associated with income – low income accounts for the higher level of risk associated with single parent status	Sufficient sample size; appropriate analysis	6
Noll et al., 1995[134]	2 studies; parent-report; cross-sectional, questionnaires comparing parental distress in families of children with cancer and health families	Study 1 n = 25 families of children with cancer and 25 healthy comparison families; Study 2 n = 42 families of children with cancer and 42 healthy comparison	• Study 1 findings: no significant differences between the two groups of families on matter or father distress or family functioning • Study 2 findings: Significant differences in social support between mothers of a child with cancer and comparison mothers, but not for fathers • Findings emphasize the importance of family support	Data collection appropriate to study method	6
Ozono et al., 2010[135]	Parent and child report; cross-sectional; assessing family functioning of families of cancer survivors	n = 88 adolescent cancer survivors 87 mothers, 72 fathers	• Family functioning is a predictor of psychological distress among childhood cancer survivors and their family members • Found 3 clusters based on cohesiveness, expressiveness, and conflict – supportive, conflictual, and moderate. Conflictual group had higher levels of posttraumatic stress symptoms	Sufficient sample size; appropriate analysis	6
Pai et al., 2006[136]	Meta-analysis of the effect of psychological interventions in pediatric oncology on outcomes of psychological distress and adjustment	n = 29 studies included	• Mothers of children with cancer had significantly greater distress than mothers of healthy children or fathers of children with cancer • Fathers of children with cancer had significantly more distress than fathers of healthy children • Mothers of children with cancer perceived more family conflict than mothers of healthy children • Parental distress tended to decrease over time	Right types of studies included; 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*)

Group V. Family structure and function: family dynamic, belief system, cultural factors

Study	Design	Sample	Findings	Study rigor	Level of evidence
Robinson et al., 2007 [137]	Parent and child-report; cross-sectional; questionnaires assessing parent and family factors associated with child adjustment to pediatric cancer	n = 95 children with cancer and their parents (94 mothers, 67 fathers) and 98 comparison peers (97 mothers, 77 fathers)	• Significant positive associations were found between parent and child distress • Variables of family environment, child age and gender, cancer diagnosis, and tx severity were found to moderate the impact of fathers' distress on children • Family environment also partially mediated father and child distress	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	6
Sieminska & Greszta, 2008[138]	Parent-report; cross-sectional, semi-structured questionnaire assessing changes within the family system in families of children with cancer	n = 116 parents of 58 families of children with cancer	• When faced with a child with cancer, almost half of the families showed increased coherence and stronger marital ties. However, over time, marital quality and spousal support were found to decline • 25% of the families developed stronger religious faith • Family functioning was influenced by the illness duration in that the most well-balanced families were families in which the cancer lasted the longest	Sufficient sample size; blinding or data collection appropriate to study method	6
Sloper 2000b[139]	Parent-report; prospective study at 6 months and 18 months post –diagnosis; semistructured interview & questionnaires assessing predictors of distress in parents	n = 68 mothers and 58 fathers	• Family cohesion predictive of level of distress • Mothers: appraisal of stress and ability to deal with it related to distress • Fathers: employment issues at diagnosis, number of admissions, appraisal of distress, and cohesion related to distress	Sufficient sample size; appropriate analysis	6
Sloper 2000a[140]	Sibling report; longitudinal study; semi-structured interviews assessing the experiences and needs of siblings	n = 94 siblings of children with cancer	• Siblings feel not adequately informed about their siblings illness, and as a result felt excluded from the family unity and caused higher levels of anxiety • Need to focus on effective communication between all parties involved • HCPs should draw parents' attention to siblings' likely reactions and needs to ensure support is available	Sampling and research methodology flawed	6
Spinetta et al., 1999[141]	Clinical practice guidelines for treatment of siblings of children with cancer	N/A	• Address feelings of isolation • Need to communicate with and listen to siblings • Concerns vary based on the phase of the treatment the child is in (make sure to assess the child at all phases to better understand what is going on with them) • Involve siblings from the very beginning and keep them informed in an age related manner • Continue to emphasize the positive/optimistic side of treatment • Encourage parents to bring siblings to the hospital	No report on studies used; Important outcomes considered	7
Steele et al., 2003[142]	Parent-report; longitudinal; questionnaires given at 3 time points assessing patterns of maternal distress	n = 65 mothers of children with cancer during first 6 months of dx and tx	• Perceived stress and maternal affective distress decreased over time • Caregiver burden remained high and relatively stable throughout course of treatment, indicating the need for interventions to bolster parental coping resources	Data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	6
Streisand et al., 2003 [143]	Parent-report; cross-sectional; questionnaires examining parenting stress and family functioning in parents of children with cancer	n = 116 parents of children (21 years and younger) in active tx for cancer	• Parenting stress was significantly correlated with family functioning such that increased parenting stress is associated with poorer family functioning outcomes ○ Parents that experience more frequent stressors are also more likely to experience less behavioral control within their families • Importance of assessing parenting stress and family functioning when working with children being treated for cancer	Sufficient sample size; blinding or data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	6

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SUPPLEMENTAL TABLE I. (*Continued*)

Group V. Family structure and function: family dynamic, belief system, cultural factors

Study	Design	Sample	Findings	Study rigor	Level of evidence
Svavarsdottir, 2005[144]	Parent-report; longitudinal (3 time points), descriptive study; questionnaires assessing parents caring for a child with cancer	n = parents of 26 children with cancer (age = under 18 years old)	• Most time-consuming and difficult caregiving activity for both mothers and fathers was providing emotional support to the patient and other children in the family • Mothers also reported difficulty with managing behavior problems and planning family activities (reported to be time-consuming) • Fathers reported difficulty managing work and organizing care for the child at the same time, and to give their partner emotional support	Data collection appropriate to study method; appropriate analysis	**6**
Svavarsdottir et al., 2013 [145]	Parent-report; quasi-experimental intervention study, measures given pre and post intervention; assessing perceived family support and family functioning	n = 19 parent caregivers (10 primary, 9 partner) of children in active cancer treatment	• After completing the intervention, primary caregivers perceived significantly higher family support, expressive family functioning, and emotional communication • Partner caregivers reported significantly lower verbal communication after the intervention compared to before • Brief, beneficial family interventions such as the one in this study, can be brief, easy to provide and beneficial for families of children and adolescents in active cancer treatment • Knowing that primary caregivers experienced support and information may result in more effective evidence-based family care	Blinding or data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	**3**
Trill & Kovalcik, 1997[146]	Opinion paper; describes cross-cultural issues relevant in medical and psychological care of children with cancer	N/A	• Culturally defined health beliefs and practices may explain behaviors such as nonadherence to prescribed therapies, the degree and quality of parents' involvement in patient care, and the family's relationship with health-care staff • Assumptions about the meaning of culture in a particular patient or family should therefore be avoided • Cultural and religious variability in people's preference for disclosing cancer information t their children	No report on studies used; Important outcomes considered	**7**
Varni et al., 1996[147]	Self-report; prospective design with questionnaires given at Time 1 (within 1 month of Dx); Time 2 (6 months post dx); Time 3 (9 months post dx); study assessing family functioning predictors of adjustment in children with cancer	n = 62 children with cancer (5 – 13 years)	• Family functioning was correlated with psychological and social adjustment ○ Higher cohesion and expressiveness were associated with lower psychological distress and higher social competence ○ Family functioning was more predictive of concurrent child adjustment than prospective child adjustment ○ Current family functioning is more important for children with newly diagnoses cancer at 6 and 9 months post dx than predicting family functioning from time of the cancer Dx • Findings suggest the importance of measuring multiple domains of family functioning for potential differential influence on psychological and social adjustment • Aspects of the family psychosocial environment (including commitment, help, support, and the open expression of feelings) facilitate child adjustment to newly-diagnosed cancer and biomedical treatment	Blinding or data collection appropriate to study method; appropriate analysis; reporting comprehensive, clearly described	**6**
Vrijmoet-Wiersma et al., 2008 [148]	Systematic review of parental stress reactions after the diagnosis of childhood cancer	n = 67 studies covering phases of treatment and survival	• Family functioning predictive of post-traumatic stress • Family relationships and coping protective factors • Anxiety tended to decrease over time except in cases of relapse • Mixed results for depression • Variability in conceptualization, definitions	Right types of studies included; important, relevant studies included; appropriately assessed for quality of studies; reasonable to combine results in this way; important outcomes considered	**5**

(*Continued*)

SUPPLEMENTAL TABLE I. (*Continued*)

Group V. Family structure and function: family dynamic, belief system, cultural factors

Study	Design	Sample	Findings	Study rigor	Level of evidence
Yi, 2009[149]	Narrative review on using the family systems theory to understand cultural influences on the survivorship of families affected by childhood cancer	N/A	• Emphasizes the use of family systems theory to examine the factors that make some family members able to cope well with the cancer diagnosis, while others do not • Three central constructs important in family dynamics: ○ Family cohesion, flexibility and communication • Cultural differences to consider: ○ Collectivist cultures in which "we" precedes "I" may neglect/ignore those that deviate from the norm (those that are sick), thus leading to potential isolation from the society ○ Gender and birth order of siblings of children with cancer have different meanings in different cultures ○ In cultures where the illness is more stigmatized, communication about the illness is less accepted ○ In some cultures cancer is extremely stigmatized and survivors are blamed, or there are negative traditional/religious beliefs about cancer • Importance of considering cultural values and norms in understanding family dynamics	Important, relevant studies included; reasonable to combine results in this way; important outcomes considered	7

Note: **Search terms used**: "ped* cancer" OR "pediatric cancer" OR "childhood cancer" OR "child* cancer" OR "cancer*" AND "PAT" OR "Psychosocial Assessment Tool" OR "ongoing assessment" OR "assessment" or "child adjustment" OR "parent adjustment" OR "family adjustment" OR "adjustment" OR "child understanding" OR "family understanding" OR "Understanding" OR "PedsQL" OR "Distress thermometer" OR "Quality of Life" OR "QOL" OR "language barrier" OR "Outcome barriers" OR "barriers" OR "barriers to care" OR "psychosocial" OR "SES barrier" OR "SES" OR "healthcare disparities" OR "family resources" OR "barriers to treatment" OR "treatment barriers" "outcome barriers" OR "cancer support" OR "family support" OR "support" OR "child support" OR "peer*" OR "peer support" OR "friend" OR "commun*" OR "community" OR "church" OR "faith" OR "spirit*" OR "pre-morbid" OR "family history" OR "illness history" OR "ill* history" OR "prior loss" OR "behavioral" OR "behavior*" OR "education*" OR "previous history" OR "function*" OR "before diagnosis" OR "family" OR "family functioning" OR "functioning" OR "family structure" OR "cultural factors" OR "culture" OR "family dynamics" OR "dynamics" OR "family belief*" OR "belief"

Literature Review: The Literature was searched using EBSCO databases, PubMed, Ovid, PsycInfo, and Google Scholar (1995 through March 2015). **Study Rigor** - in this column,please describe the methodological rigor of the study. Based upon the type of study (i.e., qualitative, quantitative, and review) please select from the list of descriptors all that apply. ***Qualitative (select all that apply)***

- research question clearly stated;
- qualitative approach clearly justified;
- study context clearly described;
- role of the researcher clearly described;
- sampling strategy appropriate for research question;
- method of data collection clearly described;
- method of data analysis clearly described;
- analysis appropriate for research question

Quantitative (select all that apply)

- sufficient sample size;
- blinding or data collection appropriate to study method
- appropriate analysis;
- evidence derived from high quality case control or cohort studies;
- reporting comprehensive, clearly described;
- issues with follow-up or missing data clearly described

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Review (select all that apply)

- Right types of papers included;
- Important, relevant studies included;
- Appropriately assessed for quality of studies;
- Reasonable to combine results in this way;
- Important outcomes considered

Levels of evidence - Equates to the type of study (e.g., RCT, Qualitative, etc.) that you are reviewing and the level of evidence that the study produces.Please refer to the document*"Types of studies and level of evidence" for a mapping of how level of evidence equates to a type of study performed*. **I**n the last column place a corresponding number (1-7) to the type of study reviewed. **1** = Systematic review or meta-analysis of controlled studies, or evidence-based clinical practice guidelines; **2** = Individual experimental studies (RCT); **3** = Quasi-experimental studies (no randomized); **4** = Non-experimental studies (Case-control, cohort); **5** = Systematic reviews of descriptive or qualitative study; **6** = Individual descriptive or qualitative study; **7** = Opinions of respected authorities and expert committees.

Abbreviations: HRQoL – health related quality of life; PRO- Patient reported outcome; AML – Acute Myeloid Leukemia; PCQL- Pediatric Cancer Quality of Life; QoL – Quality of life; CNS – Central Nervous System; PAT – Psychosocial Assessment Tool; EPO - intravenous epoetin alfa; SES – Socioeconomic status; ALL – Acute lymphoblastic leukemia; HCP – healthcare provider; RCT- Randomized controlled trial; PTSS – posttraumatic stress symptoms; COG – Children's Oncology Group; Sig-significant; SCT – stem cell transplantation; Pos-positive; Tx-treatment; CRT-cranial radiation therapy; CCSS – childhood cancer survivor study; PTSD – posttraumatic stress disorder; Dx – diagnosis; FIBI – The Family Illness Beliefs Inventory

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