

Standards of Psychosocial Care for Parents of Children With Cancer

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Parents and caregivers of children with cancer are both resilient and deeply affected by the child's cancer. A systematic review of published research since 1995 identified 138 studies of moderate quality indicating that parent distress increases around diagnosis, then returns to normal levels. Post-traumatic symptoms are common. Distress may be impairing for vulnerable parents and may impact a

child's coping and adjustment. Moderate quality evidence and expert consensus informed a strong recommendation for parents and caregivers to receive early and ongoing assessment of their mental health needs with access to appropriate interventions facilitated to optimize parent, child, and family well being. *Pediatr Blood Cancer* 2015;62:S632–S683. © 2015 Wiley Periodicals, Inc.

Key words: anxiety; childhood cancer; depression; distress; intervention; mental health; parents; pediatric oncology; psychosocial

INTRODUCTION

Parents are profoundly affected by a child's cancer diagnosis. Many parents are resilient and well functioning; for them pediatric cancer is an extreme stressor which causes transient, marked distress, slowly returning to a new, changed "normal" that includes the reality of the illness. For parents already struggling to cope or with pre-existing mental health problems, a child's diagnosis of cancer can be overwhelming. A parent's emotional issues may disrupt the ill child's cancer treatment, impact parenting and support for the ill child and well siblings, and threaten family functioning and stability over time.[1–4]

Consistent with growing literature on the interconnectedness of parent and child mental health,[5–7] family centered psychosocial care has been long considered essential in pediatric oncology.[8–10] This paper reviews the literature for evidence of a need for parent mental health support, to determine which parent-directed supports should be considered "essential" for pediatric oncology centers to provide, when they should be offered, and what barriers exist to providing this care within diverse healthcare settings. The evidence on psychological impact of childhood cancer on parents of children with cancer (PCC) as well as literature on the development of parent-specific interventions will be reviewed.

METHODS

This review was performed as part of the collaborative Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) which was created to develop evidence- and consensus-based standards for psychosocial care in pediatric oncology. PSCPCC consists of a group of pediatric oncology psychosocial professionals in collaboration with a larger interdisciplinary group of experts. For a full description of the methods used to develop each standard, please refer to Wiener et al.[11]

After review of published search strategies,[12] and iterative refinement of the strategy, the final search (Supplemental Table SI) was carried out (March 2015) in PubMed, OVID, and PsycINFO databases. Studies were identified which contained four main concepts: (i) psychosocial adjustment; (ii) parents/caregivers; (iii) pediatric/child; and (iv) cancer. Papers were limited to the English language and restricted by publication date range March 1995–2015, resulting in 4,580 citations. Through title, abstract and full text review, they were narrowed by the authors to 138 citations with these inclusion criteria: (1) subjects are parents of pediatric cancer patients, ages 0–18 years old, on

Psychosocial Standard of Care

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treatment (not in survivorship or bereavement) and (2) studies report parent outcomes measuring distress, coping or psychopathology (Supplemental Fig. S1). The three authors received extensive training in GRADE methodology[13,14] as part of the PSCPCC; each author reviewed a selection of the citations for inclusion in the final review. Regular discussion was used for clarification and consistency of the application of both inclusion criteria and assignment of study rigor. High-quality qualitative research on this subject was identified, but given the large number of articles, qualitative studies were excluded except where they added new or clarifying data. International studies were included if judged to be culturally relevant to the United States health system. A detailed summary of each study's results and study rigor is in Supplemental Table SII. This standard was developed using the GRADE methodology[13,14] for both qualitative and quantitative research. The evidence was reviewed throughout its development by several national professional committees

Abbreviations: PCC, parents of children with cancer; PTSD, post-traumatic stress disorder; PTSS, post-traumatic stress symptoms; PSST, problem solving skills training; RCT, randomized controlled trial

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including experts from multiple disciplines in psycho-oncology and pediatric oncology.

RESULTS

This body of literature is based on empirically supported theoretical frameworks that initially stemmed from developmental literature and have been refined to account for the unique experiences and needs of children with cancer and their families. Three main themes were identified as interwoven in the literature: (i) adjustment trajectories of parents of children with cancer (PCC); (ii) identification of psychopathology in PCC (primarily anxiety, depression and posttraumatic stress symptoms [PTSS]); and (iii) development of psychological interventions for PCC. The 138 articles included 102 observational studies (92 quantitative cohort, case control, or cross-sectional descriptive designs, 10 qualitative); 14 systematic reviews; 18 intervention studies (mostly pilot, randomized controlled trial (RCT) studies) and four critical analysis/expert commentary articles. The evidence consistently indicates that attention to parental mental health in pediatric oncology populations is imperative.

Trajectories of Parental Adjustment and Patterns of Risk for Psychopathology

The first two themes discovered in the literature are found throughout all 138 articles included here. PCC must engage internal and external resources to effectively cope with the tremendous stress of their child's diagnosis and treatment. A typical pattern of adjustment is one of elevations in distress around the time of diagnosis, with decreases over time to normal functioning, 3–6 months post-diagnosis,[3,15–22] but a cluster analysis showed there may be more than one trajectory of distress.[23] Most PCC and families adjust well, and report growth, increased closeness, and good family functioning. Potential resiliency factors include higher socio-economic status[24,25] higher levels of social support[26–30] and higher family cohesion and functioning.[31] Parent attributes such as optimism[32,33] and use of problem-solving coping strategies (defined as “sets about solving problems purposefully”, compared to “emotion-focused coping” and other described coping styles)[26,34–36] have also been associated with decreased parental distress.

Parental distress has a negative impact on parental quality of life, mental and physical health factors, family functioning, [3,37–39] and marital distress.[40] Parental psychosocial functioning at 6 months post-diagnosis has been found to predict long-term psychosocial outcomes,[2] with a significant number of PCC (27% of PCC vs. 15% in control group of parents without children with cancer) still reporting elevated distress up to 5 years post-diagnosis.[15] Although most data on parental adjustment is based on mothers, both parents have been shown to exhibit significant distress.[41–45] Gender differences in parent adjustment and coping should be considered in intervention development.[19,34,46–48]

Measurement of the impact of parent distress on child adjustment and distress has been methodologically challenging. Previously, parent reporting bias (distressed parents report more child distress) seemed to explain much of the link between these two outcomes.[18,20,23,31] However, a recent longitudinal study

showed a lagged, downstream relationship between maternal distress and child internalizing symptoms, one that may not be completely explained by methodology.[49] Furthermore, adolescents' self-reports of distress have been found to correlate with higher parent distress.[50] More research, using controlled, longitudinal designs and multiple reporters, is needed to delineate this relationship.

Data reflecting elevations in distress are based primarily on self-report questionnaires compared to either measure norms or control groups comprised of parents of healthy children[3,51–54] or parents of children with other acute or chronic conditions.[1] Data from these studies indicate that a subset of PCC is at risk for marked or prolonged distress or psychopathology. Rates of reported depression, anxiety, and PTSD vary amongst samples and methodologies with one paper reporting no clinically significant elevations on standardized measures,[51] and others reporting rates up to 43%.[29,42,52,55–59] Others, using questionnaires based on diagnostic criteria, have shown that 11% of mothers and 9% of fathers have PTSD.[55] Virtue et al.[60] reported 27% of mothers of children undergoing stem cell transplant met criteria for specific depressive or anxiety disorder diagnosis.

Post-traumatic stress symptoms (PTSS) and PTSD have received significant attention. Models of pediatric medical traumatic stress have informed this research and show that a pediatric cancer diagnosis and subsequent events can be potentially traumatic.[9] PCC have more PTSS than ill children themselves—nearly all PCC report at least one PTSS symptom in the first 2–4 weeks after diagnosis and, in one study, 51% of mothers and 40% of fathers met criteria for acute stress disorder (ASD) in the first 2 weeks.[61] Beyond the first month, studies have varied with some groups finding PTSD/PTSS rates similar to those of the general population of adults (without children with cancer), reinforcing the findings that in general PCCs as a group are resilient.[62] Assessment of subclinical levels of PTSS and associations with other outcomes may be most applicable as a framework to inform research and intervention.[63]

Several potential factors have emerged as indicators of risk for parental maladjustment. Socioeconomic factors like lower household income,[55,56] lower level of education, lack of employment,[55,64] pediatric disease factors such as relapse, treatment severity/risk,[65,66] or poorer child's functional impairment or physical symptoms[67] prior traumatic life events and prior parent psychiatric treatment have all been associated with parental caregiving burden and distress and poorer adjustment in different studies.[68]

Interventions

Psychological interventions to reduce distress and improve adjustment in PCCs are emerging. Most are family systems informed cognitive and behavioral therapies that are delivered individually. Twenty-one articles focused on interventions were identified (Supplemental Table SII), of which three were reviews; [69–71] the other 18 described various aspects of development of ten distinct intervention programs.[10,49,72–86] Unifying this group of studies are strong theoretical frameworks based in social ecological psychology, resiliency and illness-specific coping models, as well as overall good tolerability and feasibility. Problem solving skills training (PSST), which has now been implemented with over 800 mothers, was efficacious in improving problem

solving skills and reducing negative affect in mothers of children newly diagnosed with cancer.[78–81,87] It may be most effective for young, single mothers, but is effective for all groups, with lasting benefits beyond the timing of the intervention.[78] In addition, Fedele et al.[49,72] showed parent and child benefits after a 12-session intervention targeting mothers’ coping with illness uncertainty, which supports the parent-targeted intervention model. Critiques of the literature overall, have cited methodological problems with small populations of generally psychologically healthy parents, difficulties with recruitment when families are stressed, inclusion of mostly mothers, timing of interventions and lack of appropriate controls.[71,88] Future studies should focus on dissemination, and further refining interventions to target patients at risk for poor adjustment.

DISCUSSION

Based on this review a recommendation was developed and circulated to colleagues in pediatric oncology, as well as discussed at a “think tank” of pediatric psycho-oncology professionals from various clinical settings.[11] Structured feedback (received through rating forms) and unstructured comments from the Standards Committee supported the recommendation but helped refine the language, resulting in a final standard that was applicable in a wide range of pediatric oncology centers. We strongly recommend the following standards of psychosocial care for PCC:

Parents and caregivers of children with cancer should have early and ongoing assessment of their mental health needs. Access to appropriate interventions for parents and caregivers should be facilitated to optimize parent, child, and family well being. Table I details a summary of the results and the basis of the recommendation based on GRADE criteria. Family centered care should include standard systematic screening for psychosocial risk,[89] including

assessment of parent mental health and coping.[9,90] Assessment of children referred for distress or psychiatric disturbance should also include assessment of parent functioning.

Evidence-based interventions for families facing childhood cancer are not yet routinely available, given the recent and developing nature of this literature, lags in dissemination, and site-specific resource limitations.[91] Appropriate interventions for PCC are those provided by mental health providers who are knowledgeable about childhood illness and its effects on the family. Providers should be familiar with established theoretical frameworks (e.g., pediatric medical traumatic stress, models of resiliency and family systems theory),[92] aware of the normal trajectory of resilience so they do not miss persistent distress or psychopathology in PCC,[93] prepared to address cancer-specific parenting concerns, parental traumatic symptoms, difficulties coping with illness uncertainty, need for support for problem solving, and stress management.

Practical barriers and recommended responses to parent treatment, discussed in Supplemental Table SIII, should be systematically and individually assessed. Importantly, the parents who are most impaired will struggle to overcome these common obstacles to referral-based mental health care and it is important to partner with them to prioritize and facilitate their own mental health care even during a child’s active cancer treatment.

Several gaps are identified as targets for research. Specific risk factors for parent maladjustment such as need for stem cell transplant, presence of hereditary cancer risk, and prior child loss will likely require tailored interventions. The impact of co-existing parent mental illness (e.g., major depression, bipolar disorder, substance abuse) on parent and child adjustment in cancer and suitability of these PCC for participation in emerging evidence-based treatments for PCCs is not well understood. Finally, research is urgently needed to guide best practice for the delivery of

TABLE I. Summary of Results (GRADE)[9,10]

| Standard | Evidence summary | Methodology ¹ | Quality of evidence ² | Strength of recommendation ³ |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Parents and caregivers of children with cancer should have early and ongoing assessment of their mental health needs. Access to appropriate interventions for parents and caregivers should be facilitated to optimize parent, child, and family well being | Most parents experience a trajectory of significant transient distress, but ultimately good coping and resiliency Subset of at-risk parents, 25–30%, will have increased or prolonged distress or psychopathology Parent distress to due childhood cancer has a broad and deep impact on parent, child and family functioning over the long term (at least 5 years) | Mixed-methods, qualitative quantitative studies, and literature reviews Majority cross-sectional survey and in-depth interviews Randomized controlled trials and pilot intervention trials Replication of findings evident Think tank/expert consensus | Moderate quality given consistent findings from lower to moderate level evidence studies. | Strong recommendation based on moderately well documented impact of parent mental health on child mental health and family functioning; consistent replication of findings in moderate quality studies on levels of parent distress and wish for support; flexibility and tolerability (low risk) of the recommended intervention to fit individual parent and family values, address their needs, and overcome barriers to care and limited resources |

¹Types of studies: for example, RCT, cross-sectional, longitudinal; consensus; systematic review article; ²Quality of evidence: high, moderate, low, or very low (based on GRADE criteria); ³Strength of recommendation: strong or weak (based on GRADE quality criteria).

integrated medical and mental healthcare that is accessible and effective.[94]

A significant body of literature now supports a family systems approach to pediatric cancer care with special attention to the mental health needs of PCC. Pediatric oncology and psychoncology clinicians must address the barriers unique to each setting and case to achieve this essential integrated, flexible, expert care for PCC.

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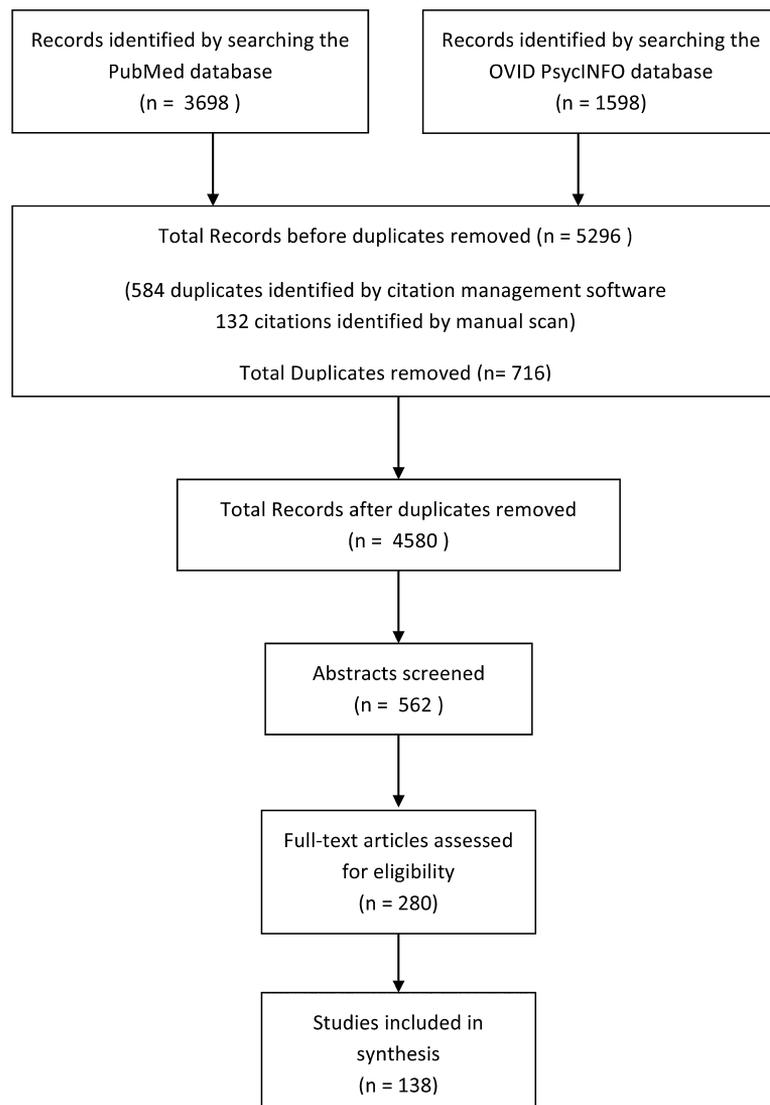
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SUPPLEMENTARY INFORMATION



SUPPLEMENTAL FIGURE 1: Flow Diagram of Literature Review for Psychosocial Standard of Care for Parents of Children with Cancer.

SUPPLEMENTAL TABLE I: Detailed Search Strategy for Psychosocial Standard of Care for Parents of Children with Cancer

| Database Name | Search Strategy | Number of Results |
|------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|
| PubMed (3/18/15) | ((psychiatr* OR psychopharm* OR intervention OR cognitive behav* OR problem solving) OR (psychological AND (stress OR resilience OR adaptation OR adjustment OR support OR trauma)) OR (psychosocial) OR (cope OR coping) OR (distress OR distressed) OR (depression OR depressive) OR (anxiety) OR (emotion OR emotional)) AND (parent* OR caregiver* OR mother* OR father* OR maternal OR paternal) AND (infan* OR newborn* OR new-born* OR perinat* OR neonat* OR baby OR baby* OR babies OR toddler* OR minors OR minors* OR boy OR boys OR boyhood OR girl* OR kid OR kids OR child OR child* OR children* OR schoolchild* OR schoolchild OR school child[tiab] OR school child*[tiab] OR adolescen* OR juvenil* OR youth* OR teen* OR under*age* OR pubescen* OR pediatrics[mh] OR pediatric* OR paediatric* OR peadiatric* OR school[tiab] OR school*[tiab]) AND (cancer OR cancers OR oncology OR oncolog* OR neoplasms OR neoplas* OR carcinoma OR carcinom* OR tumor OR tumour OR malignan* OR hemato oncological OR hemato oncological OR hemato-oncological OR hematologic neoplasms OR hematolo* OR bone marrow transplantation OR bone marrow transplant* OR lymphoma OR leukemia OR leukemi* OR leukaemi* OR lymphoma OR lymphom* OR hodgkin OR hodgkin* OR t-cell OR b-cell OR non-hodgkin OR sarcoma OR sarcom* OR sarcoma, ewing's OR Ewing* OR osteosarcoma OR osteosarcom* OR wilms tumor OR wilms* OR nephroblastom* OR neuroblastoma OR neuroblastom* OR rhabdomyosarcoma OR rhabdomyosarcom* OR teratoma OR teratom* OR hepatoma OR hepatom* OR hepatoblastoma OR hepatoblastom* OR pnet OR medulloblastoma OR medulloblastom* OR PNET* OR neuroectodermal tumors, primitive OR retinoblastoma OR retinoblastom* OR meningioma OR meningiom* OR glioma OR gliom* OR (pediatric oncology OR paediatric oncology) OR (childhood cancer OR childhood tumor OR childhood tumors) OR (brain tumor OR brain tumour* OR brain neoplasms OR central nervous system neoplasm OR central nervous system neoplasms OR central nervous system tumor OR central nervous system tumour* OR brain cancer* OR brain neoplasm* OR intracranial neoplasm*) OR (leukemia, lymphocytic, acute[mh])) AND ((“1995/03/01“[PDAT]: “2015/03/01“[PDAT]) AND English[lang]) | 3698 |
| PsycINFO (3/19/15) | ((psychiatr\$ OR psychopharm\$ OR intervention OR cognitive behav\$ OR problem solving) OR (psychological AND (stress OR resilience OR adaptation OR adjustment OR support OR trauma)) OR (psychosocial) OR (cope OR coping) OR (distress OR distressed) OR (depression OR depressive) OR (anxiety) OR (emotion OR emotional)) AND (parent\$ OR caregiver\$ OR mother\$ OR father\$ OR maternal OR paternal) AND (infan\$ OR newborn\$ OR new-born\$ OR perinat\$ OR neonat\$ OR baby OR baby\$ OR babies OR toddler\$ OR minors OR minors\$ OR boy OR boys OR boyhood OR girl\$ OR kid OR kids OR child OR child\$ OR children\$ OR schoolchild\$ OR schoolchild OR school child OR school child\$ OR adolescen\$ OR juvenil\$ OR youth\$ OR teen\$ OR underage\$ OR under-age\$ OR pubescen\$ OR pediatrics OR pediatric\$ OR paediatric\$ OR peadiatric\$ OR school OR school\$) AND (cancer OR cancers OR oncology OR oncolog* OR neoplasms OR neoplas\$ OR carcinoma OR carcinom\$ OR tumor OR tumour OR malignan\$ OR hematooncological OR hemato oncological OR hemato-oncological OR hematologic neoplasms OR hematolo\$ OR bone marrow transplantation OR bone marrow transplant\$ OR lymphoma OR leukemia OR leukemi\$ OR leukaemi\$ OR lymphoma OR lymphom\$ OR hodgkin OR Hodgkin\$ OR t-cell OR b-cell OR non-hodgkin OR sarcoma OR sarcom\$ OR sarcoma, ewing's OR Ewing\$ OR osteosarcoma OR osteosarcom\$ OR wilms tumor OR wilms\$ OR nephroblastom\$ OR neuroblastoma OR neuroblastom\$ OR rhabdomyosarcoma OR rhabdomyosarcom\$ OR teratoma OR teratom\$ OR hepatoma OR hepatom\$ OR hepatoblastoma OR hepatoblastom\$ OR pnet OR medulloblastoma OR medulloblastom\$ OR PNET\$ OR neuroectodermal tumors, primitive OR retinoblastoma OR retinoblastom\$ OR meningioma OR meningiom\$ OR glioma OR gliom\$ OR pediatric oncology OR paediatric oncology OR childhood cancer OR childhood tumor OR childhood tumors OR brain tumor OR brain tumour\$ OR brain neoplasms OR central nervous system neoplasm OR central nervous system neoplasms OR central nervous system tumor OR central nervous system tumour\$ OR brain cancer\$ OR brain neoplasm\$ OR intracranial neoplasm\$ OR leukemia, lymphocytic, acute,) limit 5 to (english language and yr=“1995 - 2015“) | 1598 |
| Total citations | | 5296 |

SUPPLEMENTAL TABLE II. Psychosocial Care Standard for Parents in Pediatric Oncology, Literature Review, organized by study type

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|
| Cohort, descriptive and observational studies (4 or 6) | | | | | |
| Alderfer (2009)* Family psychosocial risk, distress, and service utilization in pediatric cancer: predictive validity of the Psychosocial Assessment Tool [1] | Longitudinal design. Parents of pediatric cancer patients completed questionnaires within two weeks of new diagnosis (T1) and approximately four months later (T2). Study examined utility of a screening tool (PAT2.0) measuring psychosocial risk in families. | 132 mothers and 72 fathers of 141 children newly diagnosed with cancer participated at T1. 97 mothers and 39 fathers provided data at T1 and T2. | <ul style="list-style-type: none"> On the PAT2.0 screening measure, Family Problems increased from T1 to T2 according for family and father scores. Fathers also reported significant increases in Traumatic Stress Symptoms and decreases in Social Support from T1 to T2. At T2, mother reported PTSS scores varied by psychosocial risk screening classification with higher scores in families with greater identified risk. The same pattern was identified for parenting stress. | <ul style="list-style-type: none"> 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 | 4 |
| Allen (1997)* Anxiety and depression in adolescent cancer: findings in patients and parents at the time of diagnosis [2] | Cross-sectional design. Self-report questionnaires administered. | Forty-two adolescents newly diagnosed with cancer and mothers ($n = 34$) and fathers ($n = 27$) from their families. Control sample of adolescents ($n = 173$) in the United Kingdom. | <ul style="list-style-type: none"> Mothers had higher state anxiety scores than fathers and there were no differences in trait anxiety scores. Sixty percent of mothers and 40% of fathers had state anxiety scores more than one SD above the reported mean. Mothers of cancer patients had significantly higher state anxiety scores than fathers ($t = 4.52$) State anxiety and depression scores were positively correlated for mothers and fathers. Thirty percent of mothers and 38% of fathers reported mild to moderate depression while 19% of parents reported moderate to severe depression. More than half the families had at least one parent with high levels of anxiety. | <ul style="list-style-type: none"> 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 | 6 |
| Barrera (2004)* Predictors and mediators of psychological adjustment in mothers of children newly diagnosed with cancer [3] | Cross-sectional design. Mothers completed measures of depression (BDI), anxiety (STAI) and a global measure of mental health (SCL-90-R) in addition to other measures. | 69 mothers of children diagnosed with cancer (MCC) in the past 3 months and 22 mothers of children experiencing a significant acute illness (MCA) in Canada | <ul style="list-style-type: none"> MCC reported greater depression, use of emotion-focused coping, and social support than MCA. 22% of the MCC had depression scores in the clinical range compared to 5% of the MCA. Within the MCC group, concurrent family stress and strains mediated the relationship between children's behavior and mothers' depression symptoms. Mothers' anxiety and general mental health were directly influenced by the child's behavior. Within the MCC group, emotion-focused coping influenced mothers' depression, anxiety, and general mental health through its impact on concurrent stress and strains. This same finding was identified for the MCA group for depression only (not anxiety or general mental health). | <ul style="list-style-type: none"> 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 | 6 |

(Continued)

SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
|---------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|
| Barreira (2012) ^a Differences in mothers' and fathers' health-related quality of life after pediatric SCT: a longitudinal study [4] | Longitudinal design. Participants completed a self-report questionnaire of HRQOL (MOS SF-36) prior child's SCT and again 1 and 2 years post SCT. | At pre-SCT, 49 mothers and 35 fathers participated. A 1 year post SCT there were 26 mothers and 20 fathers and at 2 years post SCT there were 31 mothers and 19 fathers in Canada | <ul style="list-style-type: none"> • Prior to SCT, psychosocial HRQOL was poorer for both mothers and fathers than normative values. For mothers, psychosocial HRQOL improved from pre-SCT to 2 years post and mothers of children with less behavioral problems before SCT were more likely to report psychosocial HRQOL 2 years post SCT. Fathers of children who had radiation were less likely to report improved psychosocial HRQOL at 2 years post SCT. • Pre-SCT factors predicting poorer maternal psychosocial HRQOL at 2 years included child's poor health and child's gender (female). • Pre-SCT factors predicting poorer paternal psychosocial HRQOL at 2 years included child receiving radiation. | <ul style="list-style-type: none"> • 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 | 4 |
| Barreira (2012) ^a Differences in mothers' and fathers' psychological distress after pediatric SCT: a longitudinal study [5] | Participants completed self-report questionnaires prior child's SCT and again 1 and 2 years post SCT. Scores were compared with a historical cohort of mothers of children newly diagnosed with cancer. | At pre-SCT, 69 mothers and 42 fathers participated. At 1 year post SCT there were 49 mothers and 35 fathers and at 2 years post SCT there were 49 mothers and 31 fathers in Canada. | <ul style="list-style-type: none"> • At pre-SCT, 29% of mothers and 19% of fathers scored in the mild range of depression. Mothers' depression scores were similar to comparison mothers' but fathers' scores were significantly lower. • Mothers' and fathers' anxiety scores did not significantly differ but both scores were higher than the anxiety scores reported in the comparison sample. | <ul style="list-style-type: none"> • 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 | 4 |
| Benaroya-Milshstein (2004) ^a Neuroimmunological function in parents of children suffering from cancer [6] | Cross-sectional study examining parental depression and immune functioning of parents in Israel. | Parents ($n = 32$, 72% female) of children with cancer in Israel. | <ul style="list-style-type: none"> • The sample was divided into two groups for analyses: group 1 "depressed" parents ($n = 7$) were those with a BDI score > 14 and group 2 non-depressed parents ($n = 24$) with a BDI score < 14. Group status did not differ based on the parent's age, gender, or economic status, or the child's diagnosis or time from diagnosis. • Seventy-two percent of parents reported their child's cancer to be the worst trauma they ever had experienced. • Groups did not statistically differ with regard to percentage of PTSD diagnoses (43% in depressed group and 32% in non-depressed group), number of PTSD symptoms score, or severity of PTSD symptoms score. • Depressed parents reported experiencing more stressful events in the hematology-oncology ward, a greater degree of dysfunction, and lower quality of life than non-depressed parents. | <ul style="list-style-type: none"> • 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 | 6 |

(Continued)

SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
|-------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|
| Bennett Murphy (2008)* Fathers of children with cancer: involvement, coping, and adjustment [7] | Cross-sectional design. Participants completed questionnaires regarding parent and child adjustment. | Mothers ($n = 20$) and fathers ($n = 20$) of children with cancer and fathers ($n = 20$) of healthy children | <ul style="list-style-type: none"> There were no significant group differences in parent adjustment as measured by the BSI and all parents fell in the normal range of functioning. Mothers and fathers of children with cancer were more distressed if their children were more distressed but there was no association for fathers of healthy children. Mothers of children with cancer who used more problem-focused coping, and less emotion-focused coping, reported less depression, anxiety, and distress however these associations were not found for fathers of children with cancer. Fathers of children with cancer spent more hours at work and more hours caring for children than did control fathers Child adjustment was significantly correlated to mothers' coping behavior, but not to fathers' coping behavior The longer a child had lived with cancer, the more the father began to utilize emotion-focused strategies Fathers of children with cancer who spent more hours working were more likely to use avoidant coping strategies than emotion-focused strategies | <ul style="list-style-type: none"> Sufficient sample size; Blinding or data collection appropriate to study method Appropriate analysis; Evidence derived from high quality case control or cohort studies | 6 |
| Bjork (2005)* Striving to survive: families' lived experiences when a child is diagnosed with cancer [8] | A descriptive inductive design with a hermeneutic phenomenological approach. | Interviews were conducted with 17 families and included 17 mothers, 12 fathers, and 5 patients in Sweden. | <ul style="list-style-type: none"> Parents felt the situation was unreal and wanted to escape but could not. Parents felt an immediate threat of death. Parents felt a new outlook and altered priorities. Parents felt "emotionally locked in since their thoughts stayed with the child." Families strove to feel hopeful. Parents felt powerless, particularly when their children "begged for help from painful or unpleasant situations." Parents sometimes found it difficult to understand information. Some parents felt the spousal relationship had changed – that they lived together but not as husband and wife. | <ul style="list-style-type: none"> 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 | 6 |
| Boman (2013)* Impact of prior traumatic life events on parental early stage reactions following a child's cancer [9] | Participants completed self-reported questionnaire of earlier TLEs (prior to child's diagnosis) and PTSS as part of a larger study. | Mothers ($n = 97$) and fathers ($n = 72$) of 102 children newly diagnosed with cancer in Sweden. | <ul style="list-style-type: none"> Mothers reported significantly higher levels of intrusion, hyperarousal, and total PTSS scores than fathers. There were no differences between mothers and fathers for traumatic life events or symptoms of avoidance. Traumatic life events were positively correlated with symptoms of hyperarousal and intrusion. | <ul style="list-style-type: none"> 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; | 6 |

(Continued)

SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
|----------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|
| Bonner (2007)* Brief report; psychosocial functioning of fathers as primary caregivers of pediatric oncology patients [10] | Cross-sectional design. Participants completed self-report questionnaires as part of a larger study. | Fathers ($n = 23$) who identified themselves as the primary medical caregiver of children with cancer. Fathers were matched on demographic variables with mothers who served as a comparison group. | <ul style="list-style-type: none"> There were no significant differences between fathers' and mothers' reported psychological distress. However 11 fathers and 8 mothers obtained clinically meaningful global symptom index scores. Eleven mothers and 9 fathers had clinically meaningful levels of anxiety, 8 fathers and 5 mothers reported clinically meaningful levels of somatization symptoms, 13 fathers and 6 mothers fell above the cut-off for clinically meaningful levels of depression. The majority of mothers and fathers fell within the "high" symptom category for PTSS and there were no differences between mothers and fathers. Unmarried parents reported more guilt, anxiety, somatization, global symptom severity, and greater internalized subjective burden. | <ul style="list-style-type: none"> 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 | 6 |
| Canning (1995)* Factors predicting distress among caregivers to children with chronic medical conditions [11] | Cross-sectional design exploring predictors of caregiver distress. | Caregivers ($n = 116$) of children with cancer ($n = 51$), cystic fibrosis ($n = 21$), IBD ($n = 11$) or diabetes ($n = 33$). | <ul style="list-style-type: none"> Caregivers' distress was significantly higher than community sample. Nineteen percent of caregivers had levels of distress meeting clinical cut-offs. Distress did not vary among the 4 illness groups. Caregiver distress was higher for those with lower family income and a female child. Caregiver reports of burden, but not physician reports, were positively associated with parental distress ($r = .40$) | <ul style="list-style-type: none"> 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 | 6 |
| Cardella (2004)* The Relationship Between Religious Coping and Psychological Distress in Parents of Children with Cancer [12] | Cross-sectional design. Self-report questionnaires administered via email to assess coping and psychological distress (BSI). | Mothers ($n = 113$) and fathers ($n = 53$) of children with cancer or in remission for <1 year | <ul style="list-style-type: none"> Lower household income predicted greater psychological distress ($p < .01$). Mothers reported significantly more distress ($p < 0.5$) than fathers. Parents reported a higher degree of distress than the normative group. Religious coping strategies were positively correlated with parents' psychological distress Parents who child was undergoing treatment or was in remission reported significantly more collaborative coping than did those whose child was at the end of care ($p < 0.5$) | <ul style="list-style-type: none"> 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 | 6 |
| Cernvall (2012)* The factor structure of traumatic stress in parents of children with cancer: a longitudinal analysis [13] | Data regarding the factor structure of PTSD collected during longitudinal study investigating disease and care-related responses of parents of children with cancer. Data collected at three time points. | At T1 (2 weeks post diagnosis), 249 parents of children in Sweden participated. There were 234 at T2 (2 months post diagnosis) and 203 at T3 (4 months post diagnosis). | <ul style="list-style-type: none"> At T1, 43% of mothers and 21% of fathers scored above the suggested clinical cut-off for PTSD. At T2, 33% of mothers and 19% of fathers were above the cut-off and at T3, 28% of mothers and 7% of fathers were above the cut-off. At all time points, mothers had higher (poorer functioning) PTSS full scale and subscale scores (Reexperiencing, Dysphoria, and Hyperarousal) than fathers. Most scores declined for both mothers and fathers over time. | <ul style="list-style-type: none"> 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 | 4 |

(Continued)

SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|
| Clawson (2013)* Concordance of parent proxy report and child self-report of posttraumatic stress in children with cancer and healthy children: influence of parental posttraumatic stress [14] | Cross-sectional design. Self-report data collected within larger study examining adjustment (included parent and child PTSS) for children with cancer and parents. | Children with cancer and their parents ($n = 249$) were enrolled and 199 provided complete data. Control group ($n = 297$) were sent questionnaire packets and 108 returned complete data. | <ul style="list-style-type: none"> Parental PTSS correlated with child-reported PTSS and parent-reported child PTSS within the cancer group. Parental PTSS correlated with only parent-reported child PTSS in the control group. After controlling for ethnicity and SES, parental distress accounted for 31% of the variance in parent-reported child PTSS in the cancer group. As parental PTSS increased, parent-child correlations in child PTSS increased within the cancer group. | <ul style="list-style-type: none"> 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; | 6 |
| Colletti (2008)* The relationship of parental overprotection, perceived vulnerability, and parenting stress to behavioral, emotional, and social adjustment in children with cancer [15] | Cross sectional study. Data collected via self-report questionnaires. | Parents of 62 children (85.5% mothers) on treatment for cancer. | <ul style="list-style-type: none"> Increased parenting stress predicted parent-reported child social, emotional, and behavioral adjustment. Higher levels of parent reported perceived vulnerability predicted greater emotional problems. Parental overprotection did not predict any of these outcomes. | <ul style="list-style-type: none"> 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 | 6 |
| Compas (2015)* Mothers and Fathers Coping With Their Children's Cancer: Individual and Interpersonal Processes [16] | Cross sectional design. | Mothers ($n = 317$) and fathers ($n = 166$) of children within 2 months of cancer diagnosis (89%) or relapse. The participants comprised 151 couples. | <ul style="list-style-type: none"> Mothers' mean depression scores fell in the "mild range", while fathers' fell in the "minimal range." Twenty-nine percent of mothers and 13% of fathers reported moderate-to-severe depressive symptoms. Lower depressive symptoms were associated with greater primary and secondary control coping. Analyses examining interpersonal processes suggest that mothers' and fathers' coping are associated with their partners' coping and depressive symptoms. Parents of children with cancer were more likely to report clinically relevant depressive symptoms (5 times more likely) and negative financial life events than parents of health children. Among all parents, those who reported clinically relevant depressive symptoms were more likely to report negative financial life events, lower social support, and lower income. Within the cancer group, negative financial life events were associated with 5 times the likelihood of reporting clinically relevant depressive symptoms while higher social support was associated with lower likelihood of reporting clinically relevant depressive symptoms. | <ul style="list-style-type: none"> 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 | 6 |
| Creswell (2014)* Parental depressive symptoms and childhood cancer: the importance of financial difficulties [17] | Cross sectional design. | Participants ($N = 215$) were parents of children with cancer ($n = 75$) and parents of healthy children ($n = 140$) | <ul style="list-style-type: none"> Parents of children with cancer were more likely to report clinically relevant depressive symptoms (5 times more likely) and negative financial life events than parents of health children. Among all parents, those who reported clinically relevant depressive symptoms were more likely to report negative financial life events, lower social support, and lower income. Within the cancer group, negative financial life events were associated with 5 times the likelihood of reporting clinically relevant depressive symptoms while higher social support was associated with lower likelihood of reporting clinically relevant depressive symptoms. | <ul style="list-style-type: none"> 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 | 6 |
| Dahlquist (1996)* Parents of children with cancer: a longitudinal study of emotional distress, coping style, and marital adjustment two and twenty months after diagnosis [18] | Longitudinal design, self-report questionnaires administered 2 months post diagnosis (T1) and 20 months into treatment (T2). | Mother-father dyads ($n = 42$) | <ul style="list-style-type: none"> At T1, mothers scored higher than fathers on anxiety but scores did not significantly differ at T2. At T2, parental report of anxiety did not differ from questionnaire norms. At T2, clinically elevated scores were found for state anxiety (2% of mothers and 5% of fathers), trait anxiety (5% of mothers and 7% of fathers), depression (7% of mothers and 7% of fathers), and marital distress (19% of mothers and 24% of fathers). Mothers' state and trait anxiety significantly declined between T1 and T2. There were not changes for fathers' anxiety or parental depression scores. | <ul style="list-style-type: none"> 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 | 4 |

(Continued)

SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Dockety (2000)* Impact of childhood cancer on the mental health of parents [19] | Data obtained from national case-control study of the causes of childhood cancers. | Women ($n = 236$) and men ($n = 197$) who cared for children with cancer (cases) and women ($n = 274$) and men ($n = 243$) of randomly selected children (controls). Data were collected in New Zealand. | <ul style="list-style-type: none"> • Fathers of cases cancer had more threatening life events (excluding the child's cancer diagnosis) than fathers of controls. • Mothers of cases reported lower satisfaction with social support than mothers of controls (finding was statistically significant though mean values were similar) and also a lower number of supporters. There were small differences for fathers of cases than controls but those findings were not statistically significant. • Mothers and fathers of cases had poorer scores on a measure developed to identify non-psychotic psychiatric disorders and also had poorer mood ratings than mothers and fathers of controls. Authors reported that the adjusted differences in the mean scores were small on these measures. • Mothers of cases reported poorer social life ratings and fathers of cases reported poor coping abilities than their control counterparts. • Within the subgroup of mothers of children with cancer, poorer scores on a measure of non-psychiatric disorders and health, social life, mood, and coping were associated with lower social support. These scores were also associated with the mother not having paid employment and/or neither parent in paid work. • Within the subgroup of fathers of children with cancer poorer scores on a measure of non-psychiatric disorders and health, social life, mood, and coping were associated with lower social support. Poorer mood and coping were associated with the father having no paid job. • Mothers of children who were "ill or on treatment" had poorer social life and mood ratings than mothers of children who were "well or in remission." Mothers of deceased children had better social life ratings and poorer mood ratings than mothers of children living with cancer. Fathers of deceased children had poorer scores on a measure of non-psychiatric disorders, mood ratings and coping abilities than fathers of living children with cancer. | <ul style="list-style-type: none"> • 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 | 6 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Doğın (2007)* Trajectories of adjustment in mothers of children with newly diagnosed cancer: a natural history investigation [20] | Longitudinal study. Data obtained from RCT investigating intervention designed to reduce negative affectivity. | Mothers of children diagnosed with cancer in the past 2–16 weeks. Mothers ($n = 212$) enrolled in the usual care condition were assessed following the child's diagnosis (T1) and again 3 (T2) and 6 (T3) months later. T1 data were also used from the mothers ($n = 217$) in the intervention condition. | <ul style="list-style-type: none"> • Scores in negative affectivity (mood disturbance and depression scores) significantly decreased from T1 to T2 and from T2 to T3. There were also declines in PTSS from T1 to T3, with the greatest declines on the Intrusion and Hyperarousal subscales between T1 and T2. • Mood disturbance scores over time were predicted by neuroticism and social problem solving scores. • Three subgroups of mothers with distinct adjustment levels were identified: 1) low-stable distress, 2) moderate-stable distress, 3) high-declining distress. Mothers with low-stable distress were less neurotic, better problem solvers, more agreeable and extraverted, better educated, non-Israeli, and non-Hispanic/Spanish speaking. Mothers with moderate-stable distress were more neurotic, poorer problem solvers, less agreeable and extraverted, single, Israeli, and Hispanic/Spanish speaking. Those in the high-declining distress group were generally similar to those in the moderate-stable distress group. | <ul style="list-style-type: none"> • 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 | 4 |
| DuHamel (2004)* Cognitive processing among mothers of children undergoing bone marrow/stem cell transplantation [21] | Longitudinal study of maternal distress and coping after pediatric BMT/SCT. Data were collected after the child was admitted to the hospital for transplant (T1) and 3 months post-transplant (T2). | 91 mothers of children undergoing HSCT. | <ul style="list-style-type: none"> • At T1, Caucasian mothers reported significantly higher levels of intrusions than mothers in other racial/ethnic groups. Caucasian women were more likely to report higher annual household income and were older than other racial/ethnic groups. • Mothers' fears played a role in distress during and after the child's transplantation. Intrusions served as a mediator between mothers' fears and distress. The child's transplantation risk was associated with mothers' distress. | <ul style="list-style-type: none"> • 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 | 4 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| DuHamel (2007)* Optimism and life events as predictors of fear appraisals in mothers of children undergoing hematopoietic stem cell transplantation [22] | Longitudinal study of maternal distress and coping after pediatric BMT/SCT. Data were collected after the child was admitted to the hospital for transplant (T1), 3 months post-transplant (T2), and 6 months post-transplant (T3). | 140 mothers of children undergoing HSCT | <ul style="list-style-type: none"> There was no association between life trauma and mothers' report of fear. Mothers with higher optimism reported less fear at T1, T2, and T3. Mothers reporting more negative life events in the 6 months prior to the child's HSCT reported greater fear. | <ul style="list-style-type: none"> 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 | 4 |
| Dunn (2012)* Posttraumatic stress symptoms in parents of children with cancer within six months of diagnosis [23] | Cross-sectional design. Self-report questionnaires of PTSS, depression, and anxiety | Mothers (n = 190) and fathers (n = 93) of children diagnosed (first diagnosis or relapse) with cancer in the past 6 months | <ul style="list-style-type: none"> 11% of mothers and 9% of fathers met modified diagnostic criteria for PTSD, while 41% of mothers and 30% of fathers had total symptom scores greater than or equal to the questionnaire cut-off scores for PTSS. Mothers with elevated PTSS had significantly higher levels of reported depression and anxiety than mothers without elevated PTSS. Fathers with elevated PTSS had significantly higher levels of reported depression and anxiety than fathers without elevated PTSS. Mean scores for mothers' depressive symptoms fell in the 'mildly depressed' range while mean scores for fathers' depressive symptoms fell in the 'minimally depressed' range. Mean scores for mothers and fathers anxiety symptoms fell in the 'mild anxiety range'. Fathers' level of education was negatively associated with avoidance, hyperarousal, depressive symptoms, and anxiety symptoms. | <ul style="list-style-type: none"> 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 | 6 |
| Elkin (2007)* Religiosity and coping in mothers of children diagnosed with cancer: an exploratory analysis [24] | Cross-sectional study | Mothers and their children with cancer (n = 27) | <ul style="list-style-type: none"> Fifteen percent of mothers (n = 4) reported a prior diagnosis of depression. Mean depression scores fell in the minimal to mild depression range. Four mothers reported being "severely depressed," 3 being "moderately depressed," 1 being "mildly depressed," and 19 being "minimally depressed." Overall 30% reported elevated levels of depression. | <ul style="list-style-type: none"> 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 | 6 |

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| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Fotiadou (2008)* Optimism and psychological well-being among parents of children with cancer: an exploratory study [25] | Cross-sectional study | Parents of children with cancer ($n = 100$) and parents of healthy children ($n = 117$) in the United Kingdom. | <ul style="list-style-type: none"> • Within the group of parents with cancer there were no significant differences between men and women on levels of pessimism in relation to depression, life satisfaction and coping, seeking social support, and family stability. Men had higher optimism and lower anxiety scores than women. • Parents of children with cancer reported lower optimism and satisfaction with life, greater anxiety and depressed mood, and were lower in seeking social support relative to the parents of comparison children. • Among women, 68% of those caring for a child with cancer were at risk for clinically significant anxiety symptoms relative to 24% in the comparison group. Twenty-seven percent of women caring for a child with cancer were at risk for clinically significant symptoms of depression while there were 6% in the comparison group. • Among men, 37% of those caring for a child with cancer were at risk for clinically significant anxiety symptoms relative to 20% in the comparison group. Seventeen percent of men caring for a child with cancer were at risk for clinically significant symptoms of depression while there were 6% in the comparison group. • Among caregivers of children with cancer, greater optimism was negatively associated with anxiety and depression and positively associated with subjective health perception and satisfaction with life. Among caregivers of healthy children, greater optimism was negatively associated with anxiety, depression, and parental health problems and positively associated with satisfaction with life, subjective health perception, and social support as a coping strategy. | <ul style="list-style-type: none"> • 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 | 6 |
| Frank (2001)* Predictors of affective responses of mothers and fathers of children with cancer [26] | Cross-sectional study | Mothers ($n = 77$) and fathers ($n = 48$) of children with cancer receiving treatment. | <ul style="list-style-type: none"> • Mean scores for depression and anxiety were in the average range. Using the 90th percentile of the normative sample as clinically elevated, 14% of mothers and 9% of fathers met criteria for poor affective responses for depression; 5% of mothers and 18% of fathers met criteria for poor affective responses for anxiety (state); 2% of mothers and 9% of fathers met criteria for poor affective responses for anxiety (trait). | <ul style="list-style-type: none"> • 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 | 6 |

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| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Graziano (2015) Comparison of psychological functioning in children and their mothers living through a life-threatening and nonlife-threatening chronic disease: A pilot study [27] | Cross-sectional design. Self-report questionnaires to assess distress in mothers and their children living with cancer to mothers and children living with JRA. | Children ($n = 15$) 2–11 years old diagnosed with malignant solid tumor 2–6 months before recruitment and currently receiving chemo and their mothers in Italy ($n = 15$). Two control groups: hospitalized patients with JRA ($n = 15$) and their mothers ($n = 15$); and healthy children ($n = 15$) and their mothers ($n = 15$). | <ul style="list-style-type: none"> Levels in depression, anxiety, and somatic complaints were significantly higher in mothers of children with cancer than in control groups (JRA and healthy) The group with mothers of cancer patients reported higher levels of parental distress than did the JRA group Mothers of cancer patients reported significantly higher symptom levels of trauma (intrusive experiences, defensive avoidance, dissociation, and tension reduction behavior) than both mothers of healthy children and those with JRA With respect to the State Anxiety scale, significant differences were found in mothers of children with cancer than in the healthy control group ($p < 0.01$) Mean depression, PTSD, and anxiety scores fell in the nonclinical range. Less than 1% scored in the clinical range for depression, 15% scored in the clinical range for PTSD, and 7% scored in the clinical range for anxiety. | <ul style="list-style-type: none"> Blinding or data collection appropriate to study method Appropriate analysis; Evidence derived from high quality case control or cohort studies; Reporting comprehensive, clearly described | 6 |
| Greening (2007)* Brief report: pediatric cancer, parental coping style, and risk for depressive, posttraumatic stress, and anxiety symptoms [28] | Cross-sectional design. Self-report questionnaires of depression, PTSD, anxiety, and coping skills | Parents ($n = 150$) of children diagnosed with cancer (first diagnosis). | <ul style="list-style-type: none"> Parents who reported using emotional regulation strategies (i.e. negative self-blame/-affect) reported higher levels of depression, PTSD and anxiety than those using the method of coping (i.e. social support v. emotional expression) Parents' anxiety symptoms increased as a function of using active coping strategies Coping strategies were found to account for 31–48% of the variance in parents' psychological symptoms | <ul style="list-style-type: none"> 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 | 6 |
| Grootenhuis (1996) Secondary control strategies used by PCC [29] | Cross-sectional interview survey to determine primary and secondary control strategies used by parents of children with cancer | 163 parents ($n = 84$ mothers and $n = 79$ fathers) of 84 children with cancer with different survival perspectives, remission vs. relapse. | <ul style="list-style-type: none"> Part of larger cohort study of relapse vs. remission families (kids and parents) Primary control measures were invaluable Mothers relied more on interpretative and illusory control than fathers. Parents of children in remission relied more on predictive and vicarious control. Parents with a lower educational level tended to rely more on all control strategies with the exception of interpretative control. Developed survey/interview for assessment of control strategies, but acknowledged it needs further development | <ul style="list-style-type: none"> Research question clearly stated; Study context clearly described; Sampling strategy appropriate for research question; Method of data collection clearly described; Role of researcher clearly described | 4 |
| Grootenhuis (1997) Parents' emotional reactions related to different prospects for the survival of their children with cancer [30] | One-time point cross-sectional interview survey to determine primary and secondary control strategies used by parents of children with cancer | 163 parents ($n = 84$ mothers and $n = 79$ fathers) of 84 children with cancer with different survival perspectives, remission vs. relapse | <ul style="list-style-type: none"> Parents of relapsed children reported more feelings of helplessness and uncertainty than parents of children whose cancer was in remission. Mothers of children with a relapse also reported more depression and anxiety. The problems of fathers of children who had relapsed were revealed only with the use of an illness-related questionnaire. Time since diagnosis did not change the emotional reactions of any of the parents. The authors conclude that the parents of children whose cancer has relapsed should be carefully monitored. | <ul style="list-style-type: none"> Reporting comprehensive, clearly described; Sufficient sample size; Appropriate analysis; Evidence derived from high quality case control or cohort studies | 4 |

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| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Grootenhuis (1997) Predictors of parent emotional adjustment to childhood cancer [31] | Same as [28] | Same as [28] | <ul style="list-style-type: none"> Lack of positive expectations about the course of the illness was most strongly related to negative emotions for mothers and fathers. Secondary control strategies contribute significantly to the emotional adjustment of PCC Mothers feelings of helplessness and uncertainty were associated with poorer prognoses (relapsed cancer). Fathers reported uncertainty only if child was depressed. | <ul style="list-style-type: none"> Reporting comprehensive, clearly described; Sufficient sample size; Appropriate analysis; Evidence derived from high quality case control or cohort studies | 4 |
| Gudmundsdottir (2011) Psychological resilience and long-term distress in Swedish and Icelandic parents' adjustment to childhood cancer [32] | Cross sectional survey study, paper and pencil surveys, validated illness specific measures SOC and PDQQ, GHQ. | 398 parents; 190 PCC, and 208 controls. Swedish and Icelandic. | <ul style="list-style-type: none"> Resiliency model is useful for understanding PCC and long term distress SOC predicted lower distress, (and had a stronger effect in mothers) but may also be affected by stressful situations. Control for time since diagnosis but not on/off treatment | <ul style="list-style-type: none"> Sufficient sample size; Research question clearly stated; Study context clearly described; Sampling strategy appropriate for research question; Method of data collection clearly described; Role of researcher clearly described | 4 |
| Gudmundsdottir (2013) Psychological outcomes in Swedish and Icelandic parents following a child's cancer-in the light of site-related differences [33] | Re-analysis of same data to determine study site differences Iceland vs. Sweden | Same as [32] | <ul style="list-style-type: none"> While both groups of PCCs had more distress than controls, Icelandic parents had more distress than Swedish parents. Possible effects of smaller cancer center, less psychosocial services and less supports overall were hypothesized. | <ul style="list-style-type: none"> Sufficient sample size; Research question clearly stated; Study context clearly described; Sampling strategy appropriate for research question; Method of data collection clearly described; Role of researcher clearly described | 4 |
| Harper (2012) Longitudinal study of parent caregiving self-efficacy and parent stress reactions with pediatric cancer treatment procedures [34] | On the day of each of three procedures parents rated their self-efficacy for six caregiving goals. Parents also self-reported their negative affect in response to each procedure. Three months after the last procedure, parents reported their level of post-traumatic stress symptoms (PTSS). | Participants were 75 pediatric cancer patients and PCC dyads, (80% mothers, patient mean age 6.6 years) Participants were in ongoing larger study | <ul style="list-style-type: none"> Parents' self-efficacy for keeping their child calm before and during procedures were significantly negatively associated with parents' state anxiety immediately before procedures. Self-efficacy for keeping the child calm during procedures was also significantly and negatively correlated with parents' self-reported distress during them. Parents' self-efficacy for keeping child calm before procedures reduced PTSS at 3 months follow up. Other types of caregiving self-efficacy were not correlated. | <ul style="list-style-type: none"> Sufficient sample size; Blinding or data collection appropriate to study method Evidence derived from high quality case control or cohort studies; Reporting comprehensive, clearly described | 4 |
| Harper (2014) Posttraumatic Stress Symptoms in Parents of Pediatric Cancer Patients: A Mediation Analysis [35] | Same as [33] | Same as [33], 101 participants, only 2 procedures were included (80% mothers). | <ul style="list-style-type: none"> Trait anxiety was positively associated with state anxiety immediately before procedures and negative mood after procedures. Depression was positively associated with state anxiety immediately before procedures and negative mood and distress after procedures. Both trait anxiety and depression were positively associated with posttraumatic stress symptoms at 3-months follow-up. Parent state anxiety, negative mood, and distress partially mediated the effects of trait anxiety and/or depression on posttraumatic stress symptoms. | <ul style="list-style-type: none"> Sufficient sample size; Blinding or data collection appropriate to study method Evidence derived from high quality case control or cohort studies; Reporting comprehensive, clearly described | 4 |

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| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Haverman (2013) Development and validation of the Distress Thermometer for Parents (DT-P) against the Hospital Anxiety and Depression Scale (HADS) and the Parenting Stress Index. Cross-sectional survey study, recruitment through children's hospitals. | Development and validation of the Distress Thermometer for Parents (DT-P) against the Hospital Anxiety and Depression Scale (HADS) and the Parenting Stress Index. Cross-sectional survey study, recruitment through children's hospitals. | 706 parents of children with chronic illness, 10% oncology | <ul style="list-style-type: none"> The DT-P consists of a thermometer score from 0 (no distress) to 10 (extreme distress) and a problem list (practical, social, emotional, physical, cognitive, and parenting domains). A cutoff-score of 4 correctly identified 86% of "clinical HADS cases" (sensitivity) and 67% of "nonclinical HADS cases" (specificity). Lack of diversity in sample may have skewed results. | <ul style="list-style-type: none"> Sufficient sample size; Blinding or data collection appropriate to study method Reporting comprehensive, clearly described | 4 |
| Hinds (2009) "Trying to be a good parent" as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children [37] | Qualitative analysis of recorded interviews with parents answering two open-ended questions about 1) the definition of a good parent and 2) about how clinicians could help them fulfill this role. Semantic content analysis by trained rater panel. | 62 PCC who had made one of three decisions (enrollment on phase I study, do not resuscitate status, or terminal care) for 58 patients | <ul style="list-style-type: none"> Rater panel inter-rater reliability was excellent. Among the aspects of the definition qualitatively identified were making informed, unselfish decisions in the child's best interest, remaining at the child's side, showing the child that he is cherished, teaching the child to make good decisions, advocating for the child with the staff, and promoting the child's health. Identified 15 clinician strategies that help parents be a part of making these decisions on behalf of a child with advanced cancer. | <ul style="list-style-type: none"> 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 | 6 |
| Hocking (2013) Parent perspectives on family-based psychosocial interventions in pediatric cancer: a mixed-methods approach [38] | Mixed methods: qualitative focus groups and quantitative survey Retrospective data (parents' reflections of what they needed during their child's treatment.) | 25 PCC, 2-5 years after the diagnosis, not relapsed. | <ul style="list-style-type: none"> Qualitative themes suggested that interventions should be flexible and tailored to the needs of parents and families based on diagnosis, distress level, and time since diagnosis. Such considerations complicate the ability to simultaneously conduct "pure" RCTs to test the intervention's efficacy and effectiveness, enhance participation in intervention research, and address the needs of all families. Additionally, these three themes provide context regarding traumatic stress responses (e.g., "survival mode") of parents of children with newly diagnosed cancer that can inform everyday care and interactions with these families | <ul style="list-style-type: none"> Sufficient sample size; Blinding and data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 6 |
| Hoelstra-Weebbers (1998) Gender differences in psychological adaptation and coping in parents of pediatric cancer patients [39] | Survey study of parents of children newly diagnosed with cancer at diagnosis, 6 months later, and 12 months later. Assessed social support, psychological functioning and distress. | PCC (n=124) recruited at diagnosis, 62 mothers and 62 fathers | <ul style="list-style-type: none"> Distress for all parents declined over time and were the same between mothers and fathers. Fathers used problem-focused coping and less palliative reaction pattern at 12 months than mothers. Mothers used more social-support seeking at all time points. A tendency for similarity in the use of the coping styles within couples was found. Discrepancies in coping in couples were positively related to distress in fathers at diagnosis. Discrepant coping styles among couples affected father's distress at diagnosis (increased) and increased mothers' distress at 12 months. | <ul style="list-style-type: none"> Sufficient sample size; Blinding and data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 6 |

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| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Hoekstra-Weebers (1999) Risk Factors for Psychological Maladjustment of Parents of Children With Cancer [40] | Survey study of parents of children newly diagnosed with cancer in the Netherlands. Questionnaires were given at diagnosis (T1) and one year later (T2). They assessed demographics, illness-related variables, other life events, personality, coping styles, and social support. | PCC (n=128) recruited at diagnosis, including 66 mothers and 62 fathers, all married except one widow. | <ul style="list-style-type: none"> Strongest predictor of distress for both mothers and fathers was trait anxiety, a personality characteristic. Fathers who seek more support at diagnosis as a coping style and who were dissatisfied with support were also more at risk for distress. Assertive behaviors were found to be a protective factor for mothers over time. | <ul style="list-style-type: none"> Sufficient sample size; Blinding and data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 6 |
| Hoekstra-Weebers (2001) Psychological adaptation and social support of pediatric cancer patients: a prospective longitudinal study [41] | Survey study of parents of children newly diagnosed with cancer. Investigated the link between social support at different time points (diagnosis, 6 months later, and 12 months later) and psychological functioning and distress for PCC. | PCC (n=128) recruited at diagnosis, 66 mothers and 62 fathers. | <ul style="list-style-type: none"> Everyone received more support at diagnosis than at 6 or 12 months. Mothers receive more support than fathers at diagnosis but not beyond that. Mothers and fathers fared differently when looking at relationship of support and distress. Mothers' distress does not vary with changes in support. Fathers' distress was worse with increased negative support and fathers' dissatisfaction with support. At diagnosis, parents' coping styles were similar to the norm population except more frequent use of support seeking. Changes in parents' coping behavior over time in response to demands of the cancer stressor were present but small. Gender differences were found in the ways mothers and fathers use social support seeking. Implications are discussed. | <ul style="list-style-type: none"> Sufficient sample size; Blinding and data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 6 |
| Hoekstra-Weebers (2012) Coping and its effect on psychological distress of parents of pediatric cancer patients: a longitudinal prospective study [42] | Part of a prospective longitudinal five year study examining adjustment of parents of children with cancer. This study reports coping styles of parents. Assessments were mailed questionnaires of various self-report measures at shortly after diagnosis, 6 and 12 months, and 5 years later. | 115 parents of children with cancer in the Netherlands | <ul style="list-style-type: none"> Parents in the "complicated cancer category" reported significantly higher disease-related fear (mean of 2.13), anxiety (mean of 2.41), depression (mean of 2.13), late effects-related uncertainty (mean of 3.34), and poorer self-esteem (mean of 1.82) compared with parents of children with ALL (mean of 1.89, 2.20, 1.91, and 1.70, respectively) Parents of children with bone (mean of 3.09) or CNS tumors (mean of 2.99) reported more general uncertainty than parents of children with AML (2.65) or ALL (2.86) | <ul style="list-style-type: none"> Sufficient sample size; Blinding and data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |
| *Hoven (2008) The influence of pediatric cancer diagnosis and illness complication factors on parental distress [43] | A multidimensional questionnaire assessed symptoms of distress to investigate how primary diagnosis and risk for diagnosis-related complication factors influence parental distress after a child's cancer diagnosis. | Parents in Sweden (n = 144) of children with central nervous system tumors, acute myeloid leukemia, and bone tumors; parents (177) of children with acute lymphoblastic leukemia (ALL). Age of children ranged from birth to 20 years (mean of 7 years, 4 months). | <ul style="list-style-type: none"> Lone mothers (SD = 11.71) reported significantly more depressive symptoms on the BDI-II than married/partnered mothers (SD = 8.91) While scores on the SPS-R did not significantly differ in either group, lone mothers did have a lower mean score than married/partnered women, suggesting they may use more negative and fewer positive problem-solving strategies. Mothers who used more positive problem-solving skills reported better mood and less PTSS | <ul style="list-style-type: none"> Blinding or data collection appropriate to study method Appropriate analysis; Evidence derived from high quality case control or cohort studies; Reporting comprehensive, clearly described | 4 |
| Lobst (2009) Brief report: problem solving and maternal distress at the time of a child's diagnosis of cancer in two-parent versus lone-parent households [44] | Self-report questionnaires assessing negative affectivity and problem-solving skills in mothers in relation to their child's cancer diagnosis. Lone and married/partnered mothers were compared. | Mothers (n = 87 lone, 377 married/partnered) of children diagnosed with cancer 2-16 weeks before recruitment | <ul style="list-style-type: none"> Mothers who used more positive problem-solving skills reported better mood and less PTSS | <ul style="list-style-type: none"> Blinding or data collection appropriate to study method Appropriate analysis; Evidence derived from high quality case control or cohort studies; Reporting comprehensive, clearly described | 4 |

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| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Jobe-Shields (2009) Parental depression and family environment predict distress in children before stem cell transplantation [45] | Self-report questionnaires assessing how parental symptoms of depression and family environment contribute to the severity of distress in children undergoing stem cell or bone marrow transplants. Children completed questionnaires measuring illness-related distress, while parents completed measures studying depressive symptoms and family environment (cohesion, expressiveness, and conflict). | Children (n = 146) with cancer, ages 6-18, scheduled to undergo a stem cell or bone marrow transplant and anticipated a hospital stay of ≥ 3 weeks, and their parents (n = 146) | <ul style="list-style-type: none"> Parental depressive symptoms, family cohesion, and family expressiveness were significant predictors of child distress; when parental depressive symptomatology was high, child distress was high. Family cohesion ($p = 0.2$) and family expressiveness (0.3) were positively correlated with high levels of parental depression There was a statistically significant relation between family cohesion and child distress when parental depressive symptomatology was low Severity of child distress was significantly correlated with family expressiveness: children with more expressive families reported less illness-related distress Child age was significantly correlated with severity of parental depressive symptoms, with parents of younger children reporting greater depressive symptoms | <ul style="list-style-type: none"> Sufficient sample size; 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 | 4 |
| Jurbergs (2009) Symptoms of posttraumatic stress in parents of children with cancer: are they elevated relative to parents of healthy children? [46] | A cross-sectional study with self-report questionnaires examining PTSS in parents of children with cancer in relation to time since diagnosis, treatment status, and relapse history, and compared to parents of healthy controls. Group 1: parents of children from 1-6 mo. since diagnosis. Group 2: parents of children from 6-18 mo. since diagnosis. Group 3: 18 mo.-5 years since diagnosis. Group 4: parents of survivors or ≥ 5 yrs since diagnosis. | Parents (n = 199) of children (ages 7-18 and ≥ 1 mo. since diagnosis) with cancer and parents (n = 108) of healthy children | <ul style="list-style-type: none"> Parents in the cancer group who children were off treatment reported significantly lower levels of PTSS than did controls Parents of children on active treatment reported similar levels of PTSS as control parents Parents of long-term survivors (at least 5 years) reported significantly lower levels of PTSS (mean of 13.10) than all other groups—one-six months post diagnosis, 6-18 months since diagnosis, 18 months - 5 years since diagnosis, and controls—(mean of 22.23, 25.04, 23.17, and 23.86, respectively). Parents of children who experienced a relapse reported significantly higher levels of PTSS (mean of 31.28) compared to those with children off treatment and no relapse, children on treatment and no relapse, and controls (mean of 16.23, 24.05 and 23.59, respectively). | <ul style="list-style-type: none"> 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 | 4 |
| Kazak (1997)* Brief Report: Parenting Stress and Quality of Life During Treatment for Childhood Leukemia Predicts Child and Parent Adjustment after Treatment Ends[110] | Data were collected from two separate studies. Children and parents were recruited in the initial study while on treatment and then were invited to participate in a separate study about children off treatment. During the on treatment study, parents completed measures of parenting stress (PSI) and patient QOL. During the off treatment study parents completed measures of post-traumatic stress reactions and state-trait anxiety (STAI-C). | 29 children treated for leukemia and their parents. Data were collected from two separate studies. | <ul style="list-style-type: none"> Fathers, but not mothers, reported higher level post-traumatic stress symptoms than the normative sample. Parenting stress total scores were positively associated with state anxiety for mothers and fathers. Parenting stress was also positively correlated with the PSI "Reaction Index" for fathers. For both mothers and fathers, the Parental Distress subscale of the PSI was most strongly correlated with the Reaction Index on the PSI and with state anxiety. The Parent-Child Dysfunctional interaction subscale of the PSI was positively correlated with state anxiety for mothers. | <ul style="list-style-type: none"> 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 | 6 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Kazak (2005) Posttraumatic Stress Symptoms During Treatment in Parents of Children With Cancer [47] | Parents were surveyed with PTSD-RI at a single time point. Data from a sample of parents of cancer survivors was used as comparison referent sample. | 119 mothers and 52 fathers from 125 families of children on treatment for a pediatric cancer, at least one month after diagnosis | <ul style="list-style-type: none"> 68% of mothers and 57% of fathers reported PTSS within the moderate-to-severe range on the PTSD-RI. It may be difficult to determine single traumatic event as re-traumatization may continue to occur and individuals experience different events as traumatic, even events which staff may experience as "routine." | <ul style="list-style-type: none"> Sufficient sample size; Binding and data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 6 |
| Landolt (2003) Incidence and associations of parental and child posttraumatic stress symptoms in pediatric patients [48] | Diagnostic interviews were done 5-6 weeks after an accident or a new diagnosis of cancer or diabetes mellitus type 1 using the Child PTSD Reaction Index. Parents were assessed with the survey Posttraumatic Diagnostic Scale at one time point. | 209 children (aged 6.5-14.5 years), 180 mothers and 175 fathers from Switzerland. | <ul style="list-style-type: none"> 16% fathers and 24% mothers met full DSM-IV criteria for current PTSD. Children had PTS symptoms in the mild range. Children were more traumatized by accidents, parents more traumatized by child's cancer diagnoses. Functional status of child predicted PTSS. | <ul style="list-style-type: none"> Sufficient sample size; Data collection - limitation stated that children were interviewed however parents were surveyed. Parents may have filled out each other's surveys. Appropriate analysis; Reporting comprehensive, clearly described | 6 |
| Landolt (2012) The mutual prospective influence of child and parental post-traumatic stress symptoms in pediatric patients [49] | Observational cohort study assessing children and parents 5-6 weeks and 1 year after an accident or a new diagnosis of cancer or diabetes mellitus type 1 in the child. Assessments were done as described above in Landolt (2003). | 287 children (aged 6.5-16 years) and mothers (n = 239) and fathers (n = 221) | <ul style="list-style-type: none"> 29% mothers and 18% fathers met criteria at T1, which decreased to 14% mothers and 7% fathers at T2. Initially high PTSS in parents was related to poor recovery from PTSS in child. | <ul style="list-style-type: none"> Sufficient sample size; Data collection - limitation stated that children were interviewed however parents were surveyed. Appropriate analysis; Reporting comprehensive, clearly described | 4 |
| *Lavee (2005) Correlates of change in marital relationships under stress: The case of childhood cancer [50] | This study examined the factors associated with positive and negative change in the marital relationship among parents of children with cancer. While the researcher was self-reported, a participant's homes to answer any questions. | Israeli couples (n = 35) whose child was receiving active cancer treatment. | <ul style="list-style-type: none"> There was a significant correlation ($r = .81$) between spouses' perceptions of change occurring in the relationship. Change in couples' relationships were associated with mothers' social support and fathers' sense of coherence, as well with the duration of their child's illness. Change in relationships was also associated with fathers' psychological distress, but not with mothers. Fathers' distress was significantly related to the distress of their spouse, while mothers' distress was not. Instead, mothers' distress was positively associated with worry. Contrary to couples who reported negative changes, parents who reported positive changes in their marriage were more likely to have a child who had been ill for a shorter period of time, a mother with stronger social support, and a father with a higher sense of coherence. This was true for over 86% of the couples who experienced a positive change in their relationship. | <ul style="list-style-type: none"> 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 | 4 |

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| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Litzelman (2011) Quality of life among parents of children with cancer or brain tumors: the impact of child characteristics and parental psychosocial factors [51] | A case-only sample was drawn from a longitudinal study of parents of children with or without cancer or a brain tumor. In-person interviews were performed using surveys to examine the impact of child clinical characteristics and QoL on parents of children with cancer or brain tumor, and how parental psychosocial factors play a role. | Children with cancer or brain tumor (n = 75) and their parent. Children were an average of 10.1 years old. | <ul style="list-style-type: none"> Child impairment was associated with worse parental scores of QoL (3.8 points lower), and worse mental health (5.4 points lower). Parents also had significantly worse mental health if their child was on active treatment (4.4 points lower) Higher parental education and poor sleep quality were associated with worse QoL (4.8 points lower and 7.9 points lower, respectively) Parents with a spouse or partner generally reported better QoL. Symptoms of stress and perceived stress significantly mediated the relationship between child impairment and parental QoL (z = -2.5 and -2.9, respectively). | <ul style="list-style-type: none"> Research question clearly stated; Qualitative approach clearly justified; Study context clearly described; Sampling strategy appropriate for research question; Method of data collection clearly described | 6 |
| Manne (1995)* Predictors of depressive symptomatology among parents of newly diagnosed children with cancer [52] | Longitudinal design. Data were collected at time of recruitment (T1) and three months later (T2). Additional data were collected at 1 month and three months after recruitment. | 59 parents of children diagnosed with non-CNS cancer in the last month who were identified as the parent primarily responsible for provided home medical care and accompanying child to clinic visits. The majority (n = 55) were mothers. | <ul style="list-style-type: none"> At T1, parental depression score (BDI) mean scores were in the mildly depressed range. 42% of parents had scores in the nondepressed range, 34% had scores in the mildly depressed range, 15% had scores in the moderately depressed range, and 9% had scores in the severely depressed range. At T2, mean depression scores were in the mildly depressed range. 49% of parents scored in the nondepressed range, 32% scored in the mildly depressed range, 12% scored in the moderately depressed range, and 7% scored in the severely depressed range. There were no significant differences between mothers and fathers. At T1, parents of male patients reported greater depressive symptoms than parents of female patients. There were no significant differences in depression between married and unmarried parents. At T1, parents with higher levels of depression symptoms reported less family cohesion. Depressive symptoms were not related to disease parameters. At T2, parental depressive symptoms were positively correlated with child functional impairment and child behavior problems, and negatively correlated with family cohesion, spousal assistance with caring for the child, family routines. Regression analyses revealed the child functional impairment accounted for a marginally significant amount of the variance in T2 depressive symptoms while caregiving assistance from the spouse accounted for 9% and child behavior problems accounted for 20% of the variance. Family cohesion did not account for variance in depressive symptoms. When T1 depressive symptoms were added to the regression, the contribution of child behavior problems decreased to 6%, "suggesting that the effects of child behavior problems are in part confounded with parent prior depressive symptoms." Parents who reported moderate to severe depression at T1 and continued to report this level of depressive symptoms at T2 had lower family cohesion and children with greater behavioral problems than parents who reported mild to nondepressed levels of depression at T1 or T2 or parents whose levels of depressive symptoms changed from mild to moderate or moderate to mild levels. | <ul style="list-style-type: none"> 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 | 4 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Manne (1996)* Depressive symptoms among parents of newly diagnosed children with cancer: A 6-month follow-up study [53] | Longitudinal design. Parents were assessed at time the of study recruitment (T1), three months later (T2) and six months later (T3). | 55 children newly diagnosed with cancer and their parents (51 mothers and 4 fathers). | <ul style="list-style-type: none"> • At T3, the percentage of parents with more severe depressive symptoms was higher in comparison with community samples. • T3 depressive symptoms did not vary by child cancer diagnosis (sarcoma, lymphoma, or leukemia). There were no significant differences between mothers or fathers. Depressive symptoms were not associated with marital status, parental age, parental education, or income level. • Depressive symptom scores at T1 and T2 were significantly correlated with T3 depressive symptom scores. The change in depressive symptoms over the 6 month period was not statistically significant ($p = .09$). • At T3, six parents scores were in a higher category (nondepressed, mildly depressed, moderately depressed, or severely depressed) than at T1. • T3 depressive symptom scores were positively correlated with treatment severity and child functioning impairment at T3. • Less spousal assistance was associated with higher levels of depression at all time points. • Parents whose depressive symptoms persisted over the 6 month period had children with greater behavior problems and received less caregiving assistance than parents whose depressive symptoms remained low or declined over the 6 month period. | <ul style="list-style-type: none"> • 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 | 4 |

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| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| <p>Manne (2001)* Anxiety and depression in mothers of children undergoing bone marrow transplant: symptom prevalence and use of the Beck depression and Beck anxiety inventories as screening instruments [54]</p> | <p>Data taken from larger longitudinal study. Semi-structured clinical interviews and paper and pencil measures of depression (BDI) and anxiety (BAD) were administered.</p> | <p>115 mothers of children undergoing HSCT were assessed from 1 week prior to 10 days after transplant. Measures were administered within the week prior for 86% of parents. A subset ($n = 64$) of mothers were chosen the semi-structured interview based on criteria of a BDI or BAI score greater than 14. The interview was also administered to 20% of sample who were randomly selected.</p> | <ul style="list-style-type: none"> For anxiety, 38% of mothers fell in the mild to moderate range, 10% of mothers fell in the moderate to severe range, and 8% fell in the severe range. For depression, 42% of mothers fell in the mild to moderate range, 13% fell in the moderate to severe range, and 2% fell in the severe range. Among the mothers administered the semi-structured clinical interview, 36% ($n = 23$) received at least one of three diagnoses (MDD, GAD, or PD). 25% received a diagnosis of MDD, 17% received a diagnosis of GAD, and 9% received a diagnosis of PD. Of the 23 mothers, 5 had both MDD and GAD, 2 had both MDD and PD, 1 had GAD and PD, and 1 had MDD, GAD, and PD. The scores on the BAI and BDI were positively correlated ($r = .72$). Examination of the predictive accuracy of the BAI and BDI revealed that the BDI had better screening utility for depression than the BAI had for anxiety disorders. When exploring predictor of BDI/BAI scores, Caucasians were more likely to report greater anxiety and depression and mothers with annual family income of less than \$30,000 were more likely to report symptoms of anxiety. When exploring diagnoses on the semi-structured interview, mothers of female patients who were not currently married and had a history of prior psychiatric care were more likely to receive a diagnosis. Mothers with a prior psychiatric history were more than 4 times more likely to receive a diagnosis and mothers of girls were more than 5 times more likely to receive a diagnosis. | <ul style="list-style-type: none"> 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 | 6 |
| <p>Manne (2002)* Predictors of PTSD in mothers of children undergoing bone marrow transplantation: the role of cognitive and social processes[55]</p> | <p>Data taken from larger, longitudinal study. Questionnaires were completed prior to the HSCT (T1), 3 months post HSCT (T2), and 6 months post HSCT (T3). General distress, fear network, perceived supportive and unsupportive responses in social network were assessed at all three time points. T3 also included a paper and pencil measure of PTSD and a PTSD structured interview for those mothers who received a cut-off score of 35 on the paper and pencil measure. The interview was also administered to 20% of sample who were randomly selected.</p> | <p>90 mothers of children undergoing HSCT. A subset ($n = 40$) were administered the diagnostic interview.</p> | <ul style="list-style-type: none"> 17.5% of mothers administered the diagnostic interview were diagnosed with current PTSD. Partial PTSD was evident in 15% of the mothers administered the interview. One the paper and pencil measure, only 3 (3.3%) of mothers met criteria for PTSD. Depression, anxiety, general distress, and perceived family criticism declined over time. Regression analyses revealed that paper and pencil PTSD questionnaire scores were predicted by T1 fear network, distress, and negative responses from friends and family, together accounting for 48.4% of the variance in scores. Scores were also predicted by T2 distress and concurrent (T3) distress. Regression analyses revealed that PTSD diagnoses based on the interview were predicted by T3 distress but none of the T1 or T2 variables. | <ul style="list-style-type: none"> 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 | 4 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Manne (2003)* Coping and the Course of Mother's Depressive Symptoms During and After Pediatric Bone Marrow Transplantation [56] | Data taken from larger longitudinal study. Questionnaires were completed prior to the HSCT (T1), 3 months post HSCT (T2), and 6 months post HSCT (T3). Measures assess anxiety (BAI), depression (BDI), and perceived partner criticism and avoidance. | 148 mothers of children undergoing HSCT. | <ul style="list-style-type: none"> At T1, 32% scored in the mild to moderate range for anxiety, 13.6% scored in the moderate to severe range, and 7.5% scored in the severe range. At T2, 20.3% scored in the mild to moderate range, 4.2% scored in the moderate to severe range, and 6% scored in the severe range. At T3, 17.3% scored in the mild to moderate range, 13.3% scored in the moderate to severe range, and 2.0% scored in the severe range. Anxiety declined over time, though for some mothers the decline was more pronounced than others. Mothers who were initially more anxious had greater declines in anxiety than those who were less anxious. Mothers with higher income were less anxious at all time points and income accounted for 28% of the differences among mothers in rates of declines in anxiety over time. Child transfer to the ICU was positively associated with mothers' anxiety. Perceived partner criticism did not predict anxiety over time, but perceived partner avoidance did. Greater perceived avoidance was associated with less anxiety. At T1, 41.2% of mothers scored in the mild to moderate range of depression, 12.0% scored in the moderate to severe range, and 3.3% scored in the severe range. At T2, 26.0% scored in the mild to moderate range and 11.3% scored in the moderate to severe range. At T3, 25.0% scored in the mild to moderate range, 7.2% scored in the moderate to severe range, and 1.0% scored in the severe range. Mothers with higher initial levels of depression over demonstrated a greater decline in depression over time than mothers with lower levels initially. Family income was negatively related to T2 and T3 depression scores. More hospitalizations post discharge for HSCT was associated with higher depression scores. Perceived partner criticism was positively associated with maternal depressive symptoms over the three time points. | <ul style="list-style-type: none"> 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 | 4 |
| Manne (2003) Perceived Partner Critical and Avoidant Behaviors as Predictors of Anxious and Depressive Symptoms Among Mothers of Children Undergoing Hemopoietic Stem Cell Transplantation [57] | Part of a larger longitudinal study of mothers whose children were undergoing HSCT. Mothers were surveyed at 3 timepoints, T1 = in hospital but prior to SCT infusion, T2 = 3 mos post-transplant, T3 = 6 mos post-transplant for anxiety, depression and perceived partner unsupportive responses (critical and avoidant behaviors.) | 148 mothers of children undergoing HSCT at six pediatric HSCT centers. | <ul style="list-style-type: none"> Perceived partner criticism predicted maternal depressive symptoms during child HSCT, but not maternal anxiety. Perceived partner avoidance actually was associated with reduced anxiety, and possible reasons for this are discussed. Child medical factors associated with maternal depression and anxiety included ICU transfer and number of hospitalizations in 6 mos after transplant. | <ul style="list-style-type: none"> Sufficient sample size; Blinding and data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |

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| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Matthews (2015) Sleep in mother and child dyads during treatment for pediatric acute lymphoblastic leukemia [58] | A comparative, descriptive study comparing the sleep of children with ALL to healthy controls to measure the effect on maternal sleep. Mothers completed self-report questionnaires, and recorded perceptions of maternal and child sleep-wake patterns in a sleep diary for a period of one week. | Dyads of mothers and children with ALL in maintenance and 10 (<i>n</i> = 26), and matched controls (<i>n</i> = 26). | <ul style="list-style-type: none"> Mothers of children with ALL reported greater insomnia compared to control mothers There were significant differences between sleep latency in children with ALL and controls. Children with ALL took longer to fall asleep, with an average bedtime of 9:30pm (SD = 61 minutes), and 8:42pm (SD = 38 minutes). There was a weak correlation between total sleep time of mothers and children in both groups (<i>r</i> = 0.28). Although results were not significant, it took mothers of children with ALL less time to fall asleep than control mothers. | <ul style="list-style-type: none"> Research question clearly stated; Study context clearly described; Sampling strategy appropriate for research question; Method of data collection clearly described; Role of researcher clearly described | 4 |
| McCarthy (2009) Measuring psychosocial risk in families caring for a child with cancer: The psychosocial assessment tool (PAT2.0) [59] | An assessment of the external validity of the PAT2.0, a screening measure for assessing psychosocial risk in families with a child with cancer. Parents' PAT2.0 scores were examined, as well as the change in psychosocial risk over time, and the correlation between treatment intensity and psychosocial risk. The PAT2.0 was completed at diagnosis (T1) and 6–8 months later (T2). | Parents (<i>n</i> = 143) of children recently diagnosed with cancer. | <ul style="list-style-type: none"> For the majority of parents (70%), psychosocial risk did not change over time. At T1, over two-thirds (66.8%) of parents fell into the Universal (low-risk) group, less than one-fourth (23.6%) in the Targeted (intermediate risk) group, and 9.5% into the Clinical (high-risk) group). The PAT2.0 risk categories remained relatively stable over time, with 60.7% in the Universal group, 31.0% in Targeted, and 8.3% in Clinical at T2. Mothers' PAT2.0 scores were significantly higher at T2 (SD = 0.70) than at T1 (SD = 0.61). Fathers' PAT2.0 scores were also significantly higher at T2 (SD = 0.54) than at T1 (SD = 0.44). | <ul style="list-style-type: none"> Sufficient sample size; Research question clearly stated; 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 | 4 |
| McCarthy (2012) Predictors of acute and posttraumatic stress symptoms in parents following their child's cancer diagnosis [60] | Longitudinal study examining acute and posttraumatic stress symptoms and predictors of traumatic stress symptoms in parents of children with a recent cancer diagnosis. Questionnaires were completed at diagnosis (T1) and 6–8 months later (T2). | Mothers (<i>n</i> = 135) and fathers (<i>n</i> = 85) of children ages 0–18 with a new diagnosis of cancer. | <ul style="list-style-type: none"> At T1, nearly two-thirds (63%) of mothers and 60% of fathers met the criteria for acute stress disorder (ASD). At T2, less than one-fourth (21%) of mothers and 16% of fathers met the criteria for PTSD Risk factors for ASD symptoms were gender, presence of psychosocial risk factors, trait anxiety, family functioning, and CNS tumor diagnosis. Predictors of PTSD symptoms were younger maternal age, severity of ASD symptoms, trait anxiety at T1, and child's QoL at T2. | <ul style="list-style-type: none"> Sufficient sample size; Research question clearly stated; 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 | 4 |
| * McGrath (2004) Fathers' perspectives on the treatment for pediatric hematology: Extending the findings [61] | An article from Queensland, Australia reporting data from qualitative open-ended interviews during the end of induction remission treatment (T1) of a longitudinal study looking at the experience of pediatric ALL treatment from the child, parent, and well sibling's perspective. The findings of the article focus on interviews with the parents of the ALL children. Mothers shared their perspectives on the fathers' coping tendencies. | Mothers (<i>n</i> = 13) and fathers (<i>n</i> = 6) of children (<i>n</i> = 13), ages 18 months to 8 years, diagnosed with ALL. | <ul style="list-style-type: none"> Several fathers found it difficult to share their emotions, especially when crying. They shared strategies they used to avoid crying in public, such as changing the subject, leaving the room, or putting on a "brave face" Fathers typically responded to shock by withdrawing from the situation. Examples included spending more time at the office, going to the movies, or emotionally shutting down. When it came to shock, fathers also tended to feel intense anger, usually stemming from fear of the child's death, a sense of powerlessness, and worrying about the future. Fathers typically reported feeling the need to maintain a positive attitude for the rest of the family Fathers indicated using blocking or avoidance strategies when dealing with a dynamic tension | <ul style="list-style-type: none"> Research question clearly stated; Study context clearly described; Method of data collection clearly described; Role of researcher clearly described | 6 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| McGrath (2008) "It is very hard:" Treatment for childhood lymphoma from the parents' perspective [62] | Findings taken from the first time point (T1) of a five-year longitudinal study examining the experiences and psychosocial issues of families associated with the treatment of pediatric ALL and associated hematological disorders. Qualitative open-ended interviews took place at three time points with child patients, their parents, and well siblings. Lymphoma families were interviewed at three time points during treatment: two months from the beginning of treatment (T1); end of treatment (T2); and one-year post treatment (T3). | Six two-parent families with children (age 2–13 years) currently undergoing treatment for lymphoma. One child had no siblings, four had 1 sibling, and one had 2 siblings. Siblings ranged in age from 0–16 years. Three of the fathers participated in the interviews. | <ul style="list-style-type: none"> Parents often spoke about their distress related to the intense and continuous nature of treatment, including: toxicity of chemotherapy; stress associated with invasive blood samples; stress associated with injecting medications and lumbar punctures. Families with pediatric lymphoma were likely to report feeling isolated from other families with hematological malignancy due to the lack of available information and support services. Due to the high curative success rate, parents reported feeling as though their angst was not warranted Parents were often concerned about their children's serious emotional reactions, including withdrawal, aggression, depression, negative self-image, and loss of the previous self | <ul style="list-style-type: none"> Research question clearly stated; Qualitative approach clearly justified; Study context clearly described; Sampling strategy appropriate for research question; Method of data collection clearly described; Analysis appropriate for research question | 4 |
| Merueta (2007) Parents' illness perceptions, maladaptive behaviors, and their influence on the emotional distress of the child [63] | This study explored the relationship between factors influencing distress experienced by children with cancer. Parents' maladaptive behaviors were also examined in relation to their children's distress. Children and their parents were assessed individually by undergraduates using instruments such as the EDP (Emotional Distress Profile), Illness Perception Questionnaire (IPQ), and Cancer Behavior Inventory (CBI). | Children ($n=25$), ages 9 to 16, with acute lymphoblastic leukemia (ALL) diagnosed within the past one month to five years. Parents ($n=25$, 88% female) ranged between 26 and 48 years of age. | <ul style="list-style-type: none"> There was a strong correlation between parents' perceived severity of their child's cancer and their own maladaptive behaviors. Parents' perception of the illness and maladaptive behavior suppressed effects on their children's distress. | <ul style="list-style-type: none"> Research question clearly stated; Qualitative approach clearly justified; Study context clearly described; Sampling strategy appropriate for research question; Method of data collection clearly described; Analysis appropriate for research question | 4 |
| Moore (1997) Adjustment responses of children and their mothers to cancer: Self-care and anxiety [64] | A descriptive multivariate study exploring adjustment responses in children with cancer and their mothers. Children completed the Children's Self-Care Performance and Children's State-Trait Anxiety Inventory. Mothers completed the Dependent Care Agent Performance Questionnaire, the State-Trait Anxiety Inventory, and a demographic survey. | Children ($n=74$) with cancer, ages 9–18, and their mothers. | <ul style="list-style-type: none"> Children not undergoing cancer treatment, as well as their mothers, had better adjustment responses than those receiving treatment. There was a significant correlation between adjustment responses in children and their mothers. Over one-fourth (26%) of children's adjustment responses were influenced by their mothers' responses, and over one-third (35% of mothers' responses were influenced by their children's responses. Children's self-care practices and state and trait anxiety were significantly dependent on basic conditioning factors (16.9% and 5.3%, respectively). Similarly, mothers' dependent-care and state anxiety were significantly correlated with basic conditioning factors (9.2% and 9.3%, respectively). | <ul style="list-style-type: none"> Sufficient sample size; Research question clearly stated; Qualitative approach clearly justified; Study context clearly described; Sampling strategy appropriate for research question; Method of data collection clearly described; Analysis appropriate for research question | 6 |

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| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Muscara (2015) Early psychological reactions in parents of children with a life threatening illness within a pediatric hospital setting [65] | Cross-sectional data was used from a prospective, longitudinal study to investigate A.) the rates and patterns of early and clinically significant psychological reactions in parents with acutely ill children, and B.) whether parent distress is linked to medical diagnosis or illness type. Self-report questionnaires were used to measure symptoms of acute traumatic stress, depression, anxiety, and general stress. | Mothers (n = 134) and fathers (n = 60) of children with cancer (n = 145) ages 0-18 years old who had been admitted to cardiology, oncology, or PICU (length of stay ≥48 hours) due to a life-threatening illness within the previous four weeks | <ul style="list-style-type: none"> • About half of parents of children with chronic illnesses (49–54%) who reported levels of traumatic stress symptoms were reflected an ASD diagnosis • 15–27% of parents reported clinically significant levels of depression and anxiety • One-fourth to almost one-third (25–31%) of parents reported symptoms of general stress • 12–24% of parents scored above a clinical cut-off score (according to DSM-IV criteria) indicating a high risk for developing PTSD • Levels of depression, anxiety, and general stress did not differ significantly across the different illness groups | <ul style="list-style-type: none"> • 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 | 4 |
| Neil-Urban (2002) Father-to-father support: Fathers of children with cancer share their experience [66] | A group phenomenologic approach with two focus groups was conducted with fathers of children with cancer. Guided by an open-ended questionnaire, they spoke about their experiences regarding their children's diagnoses (such as its effects on family roles, its emotional impact (i.e. meaning making and other coping strategies), and experiences with health care providers). The group interview lasted approximately 2.5 hours and was audiotaped and later transcribed/coded for primary themes. | Fathers (n = 7), as well as one grandfather and two stepfathers (total n = 10), of children with cancer who were currently receiving or had received cancer treatment within the past 4 months. One focus group included three fathers, one stepfather, and one grandfather. The second group consisted of four fathers and one stepfather. | <ul style="list-style-type: none"> • Discussion themes included the following: 1.) impact on the provider role; 2.) the emotional impact: "I cry privately;" 3.) "it's the fight of our lives;" 4.) tag-team parenting; 5.) hypervigilance; 6.) "that place is scary;" what happens next—coping and moving on. • It was common for fathers to discuss their attempt to remain in control despite feeling vulnerable • Many fathers described their romantic relationships as being "on hold" • There was a common need to understand why childhood cancer "happened to" their family | <ul style="list-style-type: none"> • 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 | 6 |
| Nelson (1997) Coping and support effects on mothers' stress responses to their child's hematopoietic stem cell transplantation [67] | A prospective repeated measures study used self-report questionnaires to examine mothers' emotional and physical responses during the first 30 days of their children's hospitalization for a HSCCT. Data was collected on the day of the child's admission (T1), on the second (T2), after transplant protocol is completed, 10th (T3), approximate time when stem cells show evidence of engraftment) and 20th (T4, when preparing for discharge) days. Six variables were studied: emotional responses of anxiety and depressive symptomatology, physical responses of somatic complaints and sleep behavior changes, and resources of cognitive coping and social support. | Mothers (n = 50, ages 21–52 years) of children with cancer ages 6 months – 21 years who were to undergo HSCT. All mothers could read and write in English, had legal custody of the child and lived with the child prior to hospitalization. | <ul style="list-style-type: none"> • Anxiety levels for 26 mothers (52%) at T1, 24 mothers (48%) at T2, 25 mothers (50%) at T3 and 25 mothers (50%) were above the group mean • There was a significant decline in anxiety mean scores in a linear trend from T1 to T4 • Two-thirds (66%) of mothers reported significant depressive symptomatology at T1, almost half (44%) at T2, half (50%) at T3 > half (52%) at T4. • There was a significant decline in depression mean scores in a linear trend from T1 to T4 • Almost half (42%) of mothers reported significant somatic complaints at T1, 40% at T2, 46% at T3, and 44% at T4 • Anxiety mean scores were similar to scores for mothers whose children were admitted to PICU and those whose pre-term infants in neonatal intensive care units • Social support significantly explained differences in depressive symptomatology scores at T1 and T3 | <ul style="list-style-type: none"> • 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 | 4 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Neu (2014) Anxiety, Depression, Stress, and Cortisol Levels in Mothers of Children Undergoing Maintenance Therapy for Childhood Acute Lymphoblastic Leukemia [68] | Comparison of physiologic and emotional stress of mothers of children on treatment for ALL and community sample. Measured anxiety and depressive symptoms, overall stress and cortisol levels (salivary cortisol.) | 26 mothers of children with standard risk-ALL who were on maintenance therapy and 26 mothers from community matched to child's age and gender | <ul style="list-style-type: none"> Mothers of children with ALL had higher depressive symptoms than controls, but not anxiety. No differences were found in cortisol levels – reasons for this may have included sample collection issues. Sample size was not large enough to determine influence of other variables like mothers' age, education, work status or length of time in treatment. | <ul style="list-style-type: none"> Sufficient sample size; Blinding and data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |
| Nicholas (2009) Experiences and resistance strategies utilized by fathers of children with cancer [69] | In-person qualitative semi-structured interviews used a grounded theory approach to examine the experiences of fathers of children with cancer. Interviews ranged from one to four hours, were taped and later transcribed. | Fathers ($n = 16$, ages 20 to 60 years) of children (ages 1 to 17 years) who were being actively treated for cancer. All fathers were biological except one adoptive and one step-father. | <ul style="list-style-type: none"> Fathers identified four main themes of devastation centered around realities of childhood cancer: emotional experiences, uncertainty leading to role confusion, isolated suffering, and the role as a family provider in peril Fathers defined their paternal roles as providing family support, providing resources, as well as maintaining family stabilization Resistance strategies included 1) Family integration and stabilization; 2) Healthy lifestyle and attitude; 3) Support seeking; and 4) Hope and spirituality. Many fathers described physical symptoms, including stress and anxiety, dry throat, decreased sleep, and interrupted appetite Most fathers assumed the responsibility for ensuring that their partner did not have to carry the burden of employment/finances Fathers expressed a general sense of responsibility to be "strong" for their spouse and suppress their own emotions | <ul style="list-style-type: none"> 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 | 6 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Norberg (2005) Coping strategies in parents of children with cancer [70] | Analysis of self-report questionnaires examining coping strategies, anxiety, and depression in parents of children with cancer over three time points: 1–8 weeks (T1), 18–30 months (T2) and 60–120 months (T3) post-diagnosis. The Utrecht Coping List was used to compare seven coping strategies utilized by parents of children with cancer and parents of healthy children. The relationship between coping strategies and anxiety/depression was also examined. | Mothers ($n = 224$) and fathers ($n = 171$) of children (mean age 10 years, 4 months) with on-going or successfully completed treatment for cancer, and parents ($n = 184$, with 58% mothers and 42% fathers) of children (mean age 9 years, 4 months) with no serious or chronic diseases. | <ul style="list-style-type: none"> Parents whose child had cancer consistently reported higher levels of anxiety (0.69 SD above the mean) and depression (0.60 SD above the mean), compared to the reference group (0.43 and 0.41, respectively). Mothers reported higher levels of anxiety and depression than did fathers in both groups More frequent use of active problem focusing was correlated with lower anxiety (correlation of -0.27) and depression (correlation of -0.31) levels in across groups In both cancer and reference groups, more frequent use of passive reactions was positively correlated with higher levels of anxiety (0.56 and 0.55, respectively). They were also correlated with higher levels of depression (0.56 and 0.38, respectively). In all parent groups across all time points, more frequent use of active problem focusing and less frequent use of passive reaction pattern was associated with lower levels of emotional distress in both groups across all different time points Avoidance behavior was positively correlated to anxiety (correlation of 0.44) and depression (0.43) at T3, but only to anxiety at T2 (correlation of 0.33). Avoidance behavior was related to neither at T1. | <ul style="list-style-type: none"> Blinding or 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 | 4 |
| Norberg (2008) Parent distress in childhood cancer: A comparative evaluation of posttraumatic stress symptoms, depression and anxiety[71] | Survey study to compare rates of PTSS related to the child's illness and generic distress (anxiety and depression) in parents of children with cancer compared with recruited community sample. Data on specific PTSS in a cohort of sexual assault victims with PTSD were also used as a reference sample, to compare "severity" of PTSD symptoms. | Swedish parents of children with all types of cancer, (266 mothers, 208 fathers) 190 families had both parents participate, 47% had a child in active treatment, 53% in survivorship. 176 parents from community were included in a reference group (which was 57% mothers, 43% fathers.) | <ul style="list-style-type: none"> Rates of elevated stress and distress (anxiety and depression) varied over time from diagnosis. Parents of recently diagnosed children had more cancer-related intrusive thoughts than those of long-term survivors. Heightened anxiety and depression was most prominent in mothers and fathers up to 2.5 years after diagnosis. In a subset of parents (12%) intrusive thoughts, avoidance and numbing remained problematic up to five years later and matched or exceeded symptom levels of patients with PTSD from sexual assault. Conclusions were that parents of both gender may need continuous support throughout and beyond the cancer experience (not only at diagnosis). Vulnerability to trauma and resilience in the face of distress should be assessed. | <ul style="list-style-type: none"> Sufficient sample size; Blinding or data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 6 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| *Norberg (a.k.a Lindahl Norberg) (2011) Early avoidance of disease-related and treatment-related distress predicts post-traumatic stress in parents of children with cancer [72] | Data was collected from a longitudinal study in Sweden exploring the occurrence and development of PTSD among parents of children with cancer. The study examined whether parents' avoidance of cancer-related distress increased their risk of PTSS or PTSD. The study has seven time points (T1-T7), but only T1-T4 and T6 are included in this paper. Time points were one week (T1), two months (T2), and four months (T3) after diagnosis; one week after the end of treatment/six months after bone marrow, stem cell or organ transplant (T4); and one year after the end of treatment/ eighteen months after transplant/one year after the child's death (T6). | Parents (n = 220) of children, ages 0-18, diagnosed with cancer for the first time and scheduled to receive chemotherapy and/or radiation. | <ul style="list-style-type: none"> The association between PTS and symptoms of avoidance increased over time. The mean avoidance index for mothers was 3.81 at T1, 3.46 at T2, 3.53 at T3, and 3.30 at T4. Measured at the same time points, fathers' mean avoidance indexes were 3.38, 3.02, 2.86 and 2.87, respectively. At T6, one-fifth (20%) of mothers and 13% of fathers had scores indicative of PTSD. At T6, over half (53%) of mothers who had become bereaved and one-third (33%) of bereaved fathers scored as potential cases of PTSD. | <ul style="list-style-type: none"> Sufficient sample size; 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 | 4 |
| *Norberg (2012) Objective and subjective factors as predictors of post-traumatic stress symptoms in parents of children with cancer—a longitudinal study [73] | A longitudinal study with self-report questionnaires studied the predictive power of objective and subjective cancer-related factors for PTSS among parents of children with cancer. Assessments were given at six time points: one week (T1), two months (T2), four months (T3), and four months and one week (T4) after diagnosis; three months (T5); and one year (T6) after end of successful treatment or death of the child. A T7-assessment will be administered after 5 years of successful treatment or death. | Parents (n = 224) of children treated for cancer in Sweden. Children (ages 0-18) were diagnosed with cancer for the first time and scheduled for chemo-and/or radiation. | <ul style="list-style-type: none"> Immigrants and unemployed parents reported higher levels of PTSS Higher levels of PTSS were positively correlated with a child's poorer prognosis, more intense treatment/death of the child, and parents' perceptions of the child's psychological and physical symptoms, and total number of symptoms. Death of a child was a strong predictor of parental PTSS | <ul style="list-style-type: none"> 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 | 6 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Noll (1995) Comparing parental distress for families with children who have cancer and matched comparison families without children with cancer [74] | Two blind studies compared parental perceptions of distress and family functioning for parents of children with cancer and parents without an ill child. <i>Study 1</i> : Demographic questionnaire, Brief Symptom Inventory (BSI), Family Environment Scale (FES) – Family Relationship Index (FRI). <i>Study 2</i> : Demographic questionnaire, FES, SCL-90-R, the extensive version of the BSI, and the Norbeck Social Support Interview (NSSI). | Study 1: Parents ($n = 25$) of children with cancer who had an average time since diagnosis of 52.4 months. Study 2: Parents ($n = 42$) of children with cancer. Children were ages 8-15, receiving chemotherapy and in remission. | <ul style="list-style-type: none"> • <i>Study 1</i>: • Mothers of children without an ill child reported higher levels of distress (40%) than did mothers of children with cancer (32%). These results were nonsignificant. • Over-three-fourths (77%) of comparison fathers were in the clinical range for distress, while just over half (55%) of fathers of children with cancer met criteria. Again, these results were nonsignificant. • <i>Study 2</i>: • Mothers of children with cancer reported higher levels of distress (48%) than did comparison mothers (26%). • Comparison fathers reported significantly higher scores on the Controlling scale of the FES than did fathers of children with cancer. • All other comparisons were nonsignificant. • Parental stress was linked to child anxiety (correlation of 0.15) and PTS (correlation of 0.19) in the cancer group • Girls reported significantly higher levels of anxiety than boys in both groups • For children whose mother was the participating parent, children reported higher depressive symptoms ($SD = 5.45$) and anxiety symptoms ($SD = 12.00$) than children whose fathers participated ($SD = 4.18$, and $SD = 10.56$, respectively)—not clear which group • Children with a history of relapse reported significantly lower levels of anxiety ($SD = 7.56$) than those without relapse ($SD = 12.18$) • 51% of mothers and 40% of fathers met diagnostic criteria for ASD. • The majority of the sample reported at least one subclinical symptom of acute stress (SAS). • General anxiety, but not family functioning, was a strong predictor of SAS in both mothers and fathers • Parents demonstrate modest, but significant elevations in distress from admission through week +3. • Elevations in parental distress largely resolved by 4-6 months post-SCT. • Higher parental distress was significantly related to lower socioeconomic status (SES). • Moderate correlations were observed between measures of parent and child distress, and level of child distress at the time of admission for SCT was predictive of parental distress trajectories across the acute phase of SCT. | <ul style="list-style-type: none"> • 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 | 4 |
| Okado (2014) Association between parent and child distress and the moderating effects of life events in families with and without a history of pediatric cancer [75] | Self-report measures were used to examine the associations between parental and child distress, and the moderating effect of child exposure to life events, in families with and without a history of pediatric cancer. Parents and children reported on their own symptoms, and children also reported on life events. | Children with cancer and their parents ($n = 255$) and healthy comparison dyads ($n = 142$). Children were between 8 and 17 years of age. | <ul style="list-style-type: none"> • Sufficient sample size; • Blinding or data collection appropriate to study method • Appropriate analysis; • Evidence derived from high quality case control or cohort studies | 6 | |
| Patino-Fernandez (2008) Acute stress in parents of children newly diagnosed with cancer [76] | Cross-sectional survey | 129 mothers and 72 fathers of 138 children newly diagnosed with cancer | <ul style="list-style-type: none"> • Sufficient sample size; • Data collection appropriate to study method • Appropriate analysis; • Reporting comprehensive, clearly described; • Issues with follow-up or missing data clearly described | 4 | |
| Phipps (2004) Patterns of distress in parents of children undergoing stem cell transplantation [77] | Prospective, longitudinal cohort study | 151 parents of children undergoing bone marrow or stem cell transplantation (SCT) | <ul style="list-style-type: none"> • Sufficient sample size; • Data collection appropriate to study method • Appropriate analysis; • Reporting comprehensive, clearly described; • Issues with follow-up or missing data clearly described | 4 | |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Phipps (2005) Psychosocial predictors of distress in parents of children undergoing stem cell or bone marrow transplantation [78] | Prospective, longitudinal cohort study | 151 parents of children undergoing bone marrow or stem cell transplantation (SCT) | <ul style="list-style-type: none"> After correcting for demographic and medical factors, significant predictors of parental distress trajectories included: prior parent and patient illness-related distress, premorbid child internalizing behavior problems, family environment, and parental avoidant coping behaviors. Subgroups of parents at higher risk for increased distress during the acute phase of transplant are identified and may benefit from additional intervention. | <ul style="list-style-type: none"> Sufficient sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |
| Poder (2008) Posttraumatic stress disorder among parents of children on cancer treatment: a longitudinal study [79] | Prospective cohort study | 107 mothers, 107 fathers | <ul style="list-style-type: none"> 33% score as potential cases of acute stress disorder (ASD) at 1 week, 28% as potential cases of PTSD at 2 months and 22% at 4 months. Mothers had higher rates than fathers. Half of the parents who score as potential cases of ASD a week after the child's diagnosis score as potential cases of PTSD four months later. | <ul style="list-style-type: none"> Sufficient sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |
| Pollock (2013) Correlates of physiological and psychological stress among parents of childhood cancer and brain tumor survivors [80] | Cross-sectional case control study | 73 case parent-child dyads (children with cancer or a brain tumor) and 133 healthy comparison dyads | <ul style="list-style-type: none"> Parents of children with cancer exhibited higher levels of physiological symptoms of stress than parents of healthy children. Poor sleep quality and greater social stress were significant correlates of increased levels of stress in parents of children with cancer. | <ul style="list-style-type: none"> Sufficient sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |
| Robinson (2007) Parent and family factors associated with child adjustment to pediatric cancer [81] | Cross-sectional case control study | 94 mothers, 67 fathers of 95 children with cancer and 97 mothers, 77 fathers of 98 comparison peers | <ul style="list-style-type: none"> Significant associations were found between parent and child distress. Family environment, child age and gender, cancer diagnosis, and treatment severity were found to be moderators of fathers' distress on children. Family environment also partially mediated father and child distress. | <ul style="list-style-type: none"> Sufficient sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |
| Rodrigue (1996) Mothers of children evaluated for transplantation: stress, coping resources, and perceptions of family functioning [82] | Cross-sectional survey study | 36 mothers of children awaiting solid organ or bone marrow transplantation | <ul style="list-style-type: none"> 20% of mothers reported clinically elevated stress responses which were higher for mothers of children evaluated for solid organ transplantation vs. bone marrow transplantation. Coping strategies characterized by maintenance of personal and family stability were strongly associated with lower levels of parenting stress There was a strong association between lower socioeconomic status and higher parenting stress | <ul style="list-style-type: none"> Small sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 6 |

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| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Rodriguez (2013) Mother-child communication and maternal depressive symptoms in families of children with cancer: integrating macro and micro levels of analysis [83] | Cross-sectional survey and video-recorded communication and coding | 94 dyads (children with cancer and their mothers) | <ul style="list-style-type: none"> Macro-level indicators (positive and negative communication) were associated with certain micro-level indicators of communication (topic maintenance, reflections, reframes, and imperatives). Higher depressive symptoms predicted lower positive communication and higher negative communication. Maternal reflections and imperatives predicted positive communication, and topic maintenance and reframes predicted negative communication, beyond child age, family income, and depressive symptoms | <ul style="list-style-type: none"> Sufficient sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described Qualitative approach clearly justified; Study context clearly described; Sampling strategy appropriate for research question; | 6 |
| Rosenberg (2013) Psychological distress in parents of children with advanced cancer [84] | Cross-sectional survey embedded in randomized clinical trial | 86 parents: Survey About Caring for Children With Cancer. 81 parents: Kessler-6 Psychological Distress Scale | <ul style="list-style-type: none"> More than 50% of parents reported high Psychological Distress (PD) and 16% met criteria for serious PD (compared with US prevalence of 2%-3%). Parent perceptions of prognosis, goals of therapy, child symptoms/suffering, and financial hardship were associated with PD. Psychological Distress Scale scores were higher among parents who believed their child was suffering highly and who reported great economic hardship. Conversely, PD was significantly lower among parents whose prognostic understanding was aligned with concrete goals of care | <ul style="list-style-type: none"> 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 |
| Sahler (1997)* Sibling Adaptation to Childhood Cancer Collaborative Study: the association of sibling adaptation with maternal well-being, physical health, and resource use [85] | Cross-sectional survey study | 170 siblings and mothers of children with cancer | <ul style="list-style-type: none"> Mothers of children with cancer reported significantly lower levels of well-being than matched controls. Mothers of siblings in the Dysfunctional sibling group reported the lowest levels of well-being and were more likely to have sought professional services than mothers of children in the Resilient sibling group and were least likely to have found social support helpful. | <ul style="list-style-type: none"> 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 |
| Sawyer (1998) Influence of parental and family adjustment on the later psychological adjustment of children treated for cancer [86] | Prospective longitudinal cohort study | 38 children (aged 2 to 5 years) with cancer and their parents and families | <ul style="list-style-type: none"> Maternal adjustment during the period after the children's cancer was diagnosed had a significant relationship with children's psychological adjustment 2 years after diagnosis. The adjustment of fathers and family adjustment appeared to have a more limited impact on the later psychological adjustment of the children. | <ul style="list-style-type: none"> Small sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |
| Shapiro (1998) The importance of family functioning to caregiver adaptation in mothers of child cancer patients: testing a social ecological model [87] | Cross-sectional survey study | 29 mothers of children with cancer | <ul style="list-style-type: none"> Family functioning was positively related to both caregiver adaptation and doctor-parent relationship and burden were significantly more likely to report respectively improved spousal relationships and improved spousal communication. Mothers reporting more positive doctor-parent relationships also described themselves as having improved relationships with spouse and child, and improved spousal communication. Maternal well-being and doctor-parent relationship were not directly related. | <ul style="list-style-type: none"> Small sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described Self-selected cohort of families participating in support event Depression measure was only standardized measures, others designed for his study Appropriate analysis; Reporting comprehensive, clearly described | 6 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Sharan (1999) Psychiatric disorders among parents of children suffering from acute lymphoblastic leukemia [88] | Cross-sectional survey study | 30 parents of children with cancer in India | <ul style="list-style-type: none"> Fifty percent (n = 15) of the parents had psychiatric disorders, namely neurotic depression (n = 11, 36.7%) and adjustment disorder with depressed mood (n = 4, 13.3%). These disorders were of mild to moderate severity. Psychiatric morbidity was associated with women and unemployment. A score of 14 on the Hamilton Depression Rating Scale provided a reliable cutoff for selection of subjects for referral. | <ul style="list-style-type: none"> Small sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described | 6 |
| Sharghi (2006) Depression in mothers of children with thalassemia or blood malignancies: a study from Iran [89] | Cross-sectional survey study | 294 mothers of children with thalassemia, blood malignancies, and a control group from the general hospital clinic without either condition | <ul style="list-style-type: none"> Mothers of ill children in both groups were had significantly higher BDI depression scores than the control group. | <ul style="list-style-type: none"> Sufficient sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described | 6 |
| Sloper (1996) Needs and responses of parents following the diagnosis of childhood cancer [90] | Cross-sectional survey and interview study | 98 parents of children with cancer | <ul style="list-style-type: none"> Negative effects on parental employment, finance and family relationships and lack of emotional support were associated with higher levels of distress. Parental concerns regarding delay in diagnosis and unmet needs for counselling were noted. | <ul style="list-style-type: none"> 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 |
| Sloper (2000) Predictors of distress in parents of children with cancer: a prospective study [91] | Prospective longitudinal cohort study | 68 mothers and 58 fathers of children with cancer | <ul style="list-style-type: none"> 51% of mothers and around 40% of fathers had high levels of distress at both time points, with little change over time. For mothers, their appraisal of the strain of the illness, and their own ability to deal with it, and family cohesion were predictive of distress, both concurrently and prospectively. For fathers, risk factors of employment problems (Time 1) and the number of child's hospital admissions (Time 2), appraisal and family cohesion were predictive of distress | <ul style="list-style-type: none"> Sufficient sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |
| Smith (2005) Stress and weight gain in parents of cancer patients [92] | Longitudinal case-control study | 49 parents of healthy children and 49 parents of children with cancer | <ul style="list-style-type: none"> Parents of cancer patients were more likely to gain weight, and experienced significantly greater weight gain over the 3 months than parents of healthy children. The magnitude of weight gain was related to the degree of psychological distress that the parents experienced. Parents of cancer patients reported lower levels of physical activity and lower caloric intake than parents of healthy children, with the most marked differences between groups occurring in the area of physical activity | <ul style="list-style-type: none"> Sufficient sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Steele (2004) Patterns of maternal distress among children with cancer and their association with child emotional and somatic distress [93] | Prospective longitudinal cohort study | 65 mothers of children with cancer | <ul style="list-style-type: none"> Cluster analyses revealed four distinct patterns of maternal distress: high, moderate, declining, and low. The high maternal distress group reported higher child emotional distress at all three points but higher child somatic distress only at the final assessment. Maternal distress group was unrelated to nurse-reported child distress, possibly related to common method variance. | <ul style="list-style-type: none"> Sufficient sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |
| Steele (2003) Changes in maternal distress and child-rearing strategies across treatment for pediatric cancer [94] | Prospective longitudinal cohort study | 65 mothers of children with cancer | <ul style="list-style-type: none"> Maternal affective distress decreased over the time course of the study. Perceived stress also decreased, while caregiver burden remained relatively stable. Parental consistency fluctuated over the study period, while other parenting strategies (i.e., control, nurturance, and responsiveness) remained stable. High levels of cortisol were associated with higher levels of posttraumatic stress symptoms Mothers who exhibited higher cortisol levels at the time of their child's diagnosis showed statistically significant declines in symptomatology from diagnosis to 12 months postdiagnosis compared to mothers who exhibited lower cortisol levels at diagnosis | <ul style="list-style-type: none"> Sufficient sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |
| Stoppelbein (2010) Brief report: Role of cortisol in posttraumatic stress symptoms among mothers of children diagnosed with cancer [95] | Prospective longitudinal cohort study | 27 mothers of children with newly-diagnosed cancer | <ul style="list-style-type: none"> Internal consistency reliability for the PIP was high (Cronbach alpha range: 80–.96). PIP scores were significantly correlated with a measure of state anxiety and also with parenting stress, demonstrating construct validity. After controlling for demographic variables and general parenting stress, PIP scores showed strong independent associations with state anxiety. | <ul style="list-style-type: none"> Small sample size; but longitudinal data Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described | 4 |
| Streissand (2001) Childhood illness-related parenting stress: the pediatric inventory for parents [96] | Cross-sectional psychometric survey study | 105 mothers, 21 fathers of children with cancer | <ul style="list-style-type: none"> In early time period (45 days and 3 months), a GVHD grade ≥ 2, intermediate or poor organ toxicity, and systemic infection were associated with decreases in mean parental emotional functioning In the later time period (6 and 12 months), systemic infection was associated with a decreased parental emotional functioning scores. GVHD was not significantly associated. | <ul style="list-style-type: none"> 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 |
| Terrin (2013) Parental emotional functioning declines with occurrence of clinical complications in pediatric hematopoietic stem cell transplant [97] | Prospective longitudinal cohort study | 165 patients and parents of children undergoing pediatric hematopoietic stem cell transplant | <ul style="list-style-type: none"> Couple connectedness, family routine re-organization, parental communication around the child's illness and trust in the medical care significantly increased from T1 to T4 | <ul style="list-style-type: none"> Sufficient sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |
| Tremolada (2012) Post-traumatic stress symptoms in mothers of children with leukemia undergoing the first 12 months of therapy: predictive models [98] | Prospective longitudinal cohort study | 94 mothers of children with leukemia in Italy | | <ul style="list-style-type: none"> Sufficient sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Virtue (2014) Psychological distress and psychiatric diagnoses among primary caregivers of children undergoing hematopoietic stem cell transplant: an examination of prevalence, correlates, and racial/ethnic differences [99] | Cross-sectional survey study | 215 caregivers of children preparing to undergo hematopoietic stem cell transplant | <ul style="list-style-type: none"> Posttraumatic stress symptoms were reported by 54% of caregivers during the time preparing for the child's HSCT. Twenty-seven percent of caregivers met diagnostic criteria for at least one of the psychiatric diagnoses during this time. Few factors were associated with distress or psychiatric diagnosis, except the child scheduled for allogeneic transplant, being married and prior psychological/psychiatric care. Sociodemographic factors accounted for racial/ethnic group differences, except that Hispanic/Latino caregivers reported higher BDI scores than non-Hispanic white caregivers | <ul style="list-style-type: none"> Sufficient sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |
| Wijnberg-Williams (2006) Psychological adjustment of parents of pediatric cancer patients revisited: five years later [100] | Prospective longitudinal cohort study | 115 parents of children with cancer | <ul style="list-style-type: none"> Levels of reported distress, psychoneurotic symptoms and state anxiety significantly decreased across time to normal levels at T4 except on the GHQ. A significantly higher percentage of parents (27%) than in the norm group (15%) showed clinically elevated scores on the GHQ. Mothers had higher scores than fathers only on state anxiety. Parents of relapsed children reported higher anxiety levels than parents of surviving and deceased children. Psychological functioning at T1 was significantly related to functioning at T4. | <ul style="list-style-type: none"> Sufficient sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 4 |
| Witt (2010) Stress-mediated quality of life outcomes in parents of childhood cancer and brain tumor survivors: a case-control study [101] | Cross-sectional survey study | 74 parent-child dyads diagnosed with cancer or a brain tumor and 129 healthy control dyads | <ul style="list-style-type: none"> Parents of children with cancer or a brain tumor had significantly worse health-related quality of life, including worse overall mental health. Overall physical health was no different between cases and controls. Worse health-related quality of life is completely mediated by perceived stress in these parents. | <ul style="list-style-type: none"> 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 |
| Yeh (2002) Gender differences of parental distress in children with cancer [102] | Cross-sectional survey study | 164 mother-father dyads of children with cancer in Taiwan | <ul style="list-style-type: none"> Mothers averaged significantly higher levels than fathers for all forms of distress. Mothers and fathers whose children had been diagnosed within the previous 2 months reported higher levels of depression, anxiety, and global stress than those in the other groups. Both mothers and fathers whose children had been diagnosed within the past 2 months reported greater marital dissatisfaction than parents whose children were in the other treatment groups. | <ul style="list-style-type: none"> 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 |

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| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| <p>Review articles (1 or 5)</p> <p>Beattie (2011)* The experience of caregivers of hematological cancer patients undergoing a hematopoietic stem cell transplant: a comprehensive literature review [103]</p> | <p>Literature review</p> | <p>Review included 16 quantitative articles and 3 qualitative articles.</p> | <ul style="list-style-type: none"> • Five studies demonstrated that caregivers of children undergoing HSCT reported elevated levels of distress compared with normative samples. Distress is highest prior to the transplant and decreases over time. • Prevalence of distress was not widely cited among the articles reviewed, however the few studies that did report on this revealed "significant rates" of distress. • Three studies revealed that predictors of distress were being a female caregiver, higher levels of subjective burden, and greater patient symptom distress though most studies examining distress have not identified psychosocial predictors of distress. • Caring for a child undergoing HSCT is demanding with caregivers putting the needs of their child before their own. | <ul style="list-style-type: none"> • Right types of papers included; • Important, relevant studies included; • Reasonable to combine results in this way; • Important outcomes considered | <p>5</p> |
| <p>Bougea (2011)* A systematic review of randomized controlled interventions for parents' distress in pediatric leukemia [104]</p> | <p>Systematic review of RCTs</p> | <p>Seven studies were selected based on inclusion/exclusion criteria.</p> | <ul style="list-style-type: none"> • There has been an increase in the use of RCTs to address parental distress; however the authors indicated that "methodological quality of most the trials that we reviewed was not optimal." • Many of the interventions reviewed appeared to demonstrate some effectiveness in reducing distress. | <ul style="list-style-type: none"> • 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 | <p>1</p> |
| <p>Clarke (2009)* Gender differences in the psychosocial experience of parents of children with cancer: a review of the literature [105]</p> | <p>Literature review</p> | <p>Thirty papers were selected and were based on data from 25 separate research studies.</p> | <ul style="list-style-type: none"> • Studies included in the review were cross-sectional ($n = 18$), longitudinal ($n = 6$), and retrospective ($n = 1$). • Gender differences in the studies reviewed were primarily assessed by analyzing mothers' and fathers' data separately and comparing group means. Eight studies employed paired tests to compare mothers and fathers of the same children. • Twenty studies assessed parents' psychological distress defined as "upsetting or aversive feelings or affect experienced by an individual." • Several studies using published measures reported that mothers experienced greater symptoms of depression, anxiety, hopelessness, psychosomatic symptoms, and poorer general well-being than fathers. Longitudinal studies suggested that mother experienced greater distress than fathers during the early stages of the child's illness by not after 18-20 months suggesting that gender differences may diminish over time. Other studies, primarily those that were cross-sectional, involving parents later in the illness trajectory or involving parents at heterogeneous illness phases found that mothers and fathers did not significantly differ on measures including depression, anxiety, somatization, post-traumatic stress, and general well-being and functioning though both mothers and fathers had elevated scores compared to normative data. One study found that fathers had greater distress than mothers. • In general, mothers were more likely to use more "engaged and emotion-focused coping strategies such as social support seeking and information seeking" while fathers used more problem-focused strategies. | <ul style="list-style-type: none"> • Right types of papers included; • Important, relevant studies included; • Reasonable to combine results in this way; • Important outcomes considered | <p>5</p> |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Gibbins (2012) ^a A systematic review of qualitative studies exploring the experience of parents whose child is diagnosed and treated for cancer [106] | Systematic review of qualitative studies | Twenty-eight studies met criteria for inclusion. Studies were from the United States (<i>n</i> = 6), Canada (<i>n</i> = 5), Australia (<i>n</i> = 5), China (<i>n</i> = 3), Taiwan (<i>n</i> = 2), the Netherlands (<i>n</i> = 2), and one each from Ireland, Turkey, England, South Africa, and Finland. Participants were a total of 784 parents of children with cancer. | <ul style="list-style-type: none"> Eight themes emerged including: confronting the reality, attempts to gain control and the need for information, continuously adjusting and different coping styles, negative impact, positive outcome support, gender differences, and cultural differences. Parents reported initially feeling shocked, scared, frightened, in despair, upset, overwhelmed, and a sense of helplessness. Parents felt guilty. Uncertainty and lack of control caused anxiety. Parents later found acceptance, but acceptance "came at a cost, as parents experienced intense feelings of despair and fear." Parents employed old and new coping strategies such as sharing experiences with other parents, using humor, expressing emotional distress, focusing directly on the child (at the expense of their own health), relaxation exercises, yoga, listening to music, eating comfort food, relying on faith/spiritual beliefs/religious practices. Parents reported mostly negative changes as a result of the child's illness. They reported feeling more vulnerable and emotionally/physically/mentally strained. They reported feeling prone to burn out and overwhelmed and feel they did not have the emotional resources to support their child. Other negative changes including financial concerns, marital strain, grieving the loss of a healthy child. Positive changes including personal growth, feeling proud of surviving the experience, improvements in parenting skills, observing increased maturity in their child, strengthened relationships with the child and with others in the family. Identified many conflicting studies on parent coping/adjustment Identified issues in literature including: heterogeneous patient populations (illness variables); lack of inclusion of fathers and analysis of father/mother data separately; use of instruments measuring psychopathology only; use of instruments not specific to illness; variable definitions of coping/adjustment; small sample sizes (most had <50 patients); Called for prospective, longitudinal data: inclusion of diverse populations; inclusion of both standardized and illness specific measures; standard definition of coping. | <ul style="list-style-type: none"> 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 |
| Grootenhuis (1997) Adjustment and coping by parents of children with cancer: a review of the literature [107] | Literature review searched by Medline, Clinical Psychology and Psychological Abstracts; Keywords: cancer, children, parents, coping, adjustment, anxiety, depression. English only, 1980-1997. | 83 studies included | <ul style="list-style-type: none"> Identified many conflicting studies on parent coping/adjustment Identified issues in literature including: heterogeneous patient populations (illness variables); lack of inclusion of fathers and analysis of father/mother data separately; use of instruments measuring psychopathology only; use of instruments not specific to illness; variable definitions of coping/adjustment; small sample sizes (most had <50 patients); Called for prospective, longitudinal data: inclusion of diverse populations; inclusion of both standardized and illness specific measures; standard definition of coping. | <ul style="list-style-type: none"> 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 II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Jones (2010) Fathers of children with cancer: A descriptive synthesis of the literature [108] | A systematic review of 53 research studies (published between 1980 and 2007) on fathers of children diagnosed with cancer in order to identify the stressors resulting from their child's diagnosis, and identify gender-related differences for studies comparing fathers and mothers of children with cancer | N/A | <ul style="list-style-type: none"> Employment concerns and the frequency of hospitalizations proved to be significant stressors for fathers across several studies. Fathers tend to experience conflict when it comes to balancing work and hospital commitments Consistent across studies, fathers report that health care providers tend to address mothers as the primary caregivers, which lead fathers to feel less informed Fathers experience stress when their ability to support their family financially is compromised due to medical bills or less work hours Some fathers report experiencing a positive transformation as a result of their child's cancer Perceived support appears to have a greater effect on psychosocial functioning in mothers than in father of children with cancer Fathers tend to report that family relationships were strengthened during the cancer process Many studies suggest that fathers typically ask existential questions surrounding "why me, why my child" in relation to meaning-making of the cancer experience Many fathers report having difficulty expressing feelings, and that they need to be "strong" to allow other family members to rely on them for support | <ul style="list-style-type: none"> Right types of papers included; Important, relevant studies included; Important outcomes considered | 1 |
| Jones (2012) The challenge of quality care for family caregivers in pediatric cancer care [109] | An article reviewing research studies focusing on the needs and potential interventions for parental caregivers of children with cancer | N/A | <ul style="list-style-type: none"> A significant majority of parents experience PTSS Families report that caring for a child with cancer disrupts identity and family structure, and can cause negative outcomes for mothers, fathers and siblings Families who demonstrate optimism, resilience, and positive outlook report increased life satisfaction, depression When a child is facing the end of life, most parents prefer to be informed but to make decisions with the help of their health care providers | <ul style="list-style-type: none"> Right types of papers included; Important, relevant studies included; Important outcomes considered | 5 |
| Law (2014) Systematic review and meta-analysis of parent and family-based interventions for children and adolescents with chronic medical conditions[111] | A systematic review and meta-analysis looking to evaluate the efficacy of parent-and family-based therapy for children and adolescents with chronic and medical conditions on family and child outcomes. This review also aimed to explore the effects of these interventions on mental health, behavior, and family functioning in parents and families of children with chronic medical illnesses. | 37 studies were included: 18 used CBT, 9 used Problem-solving therapy (PST), and 10 used Systemic Therapy (ST). | <ul style="list-style-type: none"> PST was the only family-based intervention that had an effect on behavior and mental health in parents. While small, there was a significant effect on parent behavior ($z = 2.64$) and mental health ($z = 3.44$) posttreatment. | <ul style="list-style-type: none"> 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 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Muglia (2014) Effectiveness of psychological interventions intended to promote adjustment of children with cancer and their parents: an overview [112] | A review of 14 articles (published between 1998 and 2010) designed to assess interventions intended to support psychological adjustment of children with cancer and their parents. | 14 articles involving a total of 509 children ages 6 months—20 years (mean: 12 years); 958 parents or caregivers (mean: 38 years) | <ul style="list-style-type: none"> Over three-fourths (77.7%) of the interventions with parents focused on reducing stress and emotional distress caused by cancer diagnosis or children's hospitalization. Treatments included teaching the following coping skills: problem solving, communication skills, stress inoculation, writing about the experience and cognitive restructuring. Cognitive restructuring was the most used technique with children (3 studies), followed by social skills training (2 studies), teaching coping strategies/self-care and relaxation (2 studies), interactive music therapy (1 study) and cognitive rehabilitation (1 study). Over one-third (37.5%) of the interventions were found to be effective, since they produced significant changes in all outcome measures Over one third (again, 37.5%) had partial or mixed effects, meaning they produced changes in some measures but not others Most children's interventions (62.5%) produced mixed results Almost half (44.44%) of the parent interventions produced positive effects compared to control groups One-third (33.33%) of parent interventions (n = 6) were successful at achieving treatment objectives | <ul style="list-style-type: none"> Right types of papers included; Important, relevant studies included; Important outcomes considered | 5 |
| Pai (2007) A meta-analytic review of the influence of pediatric cancer on parent and family functioning [113] | Meta-analytic review using fixed effects, weighted least squares methods; analyzed quantitative studies with control groups | 29 studies, mean N = 68 cancer subjects per study. | <ul style="list-style-type: none"> Mothers and fathers of children newly diagnosed with cancer reported significantly greater distress than comparison samples. Mothers reported greater distress than fathers up to 12 months post-diagnosis. Mothers of children with cancer reported higher levels of family conflict than mothers of healthy children | <ul style="list-style-type: none"> 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 Sufficient sample size; Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 1 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Rabineau (2008) Parenting stress in pediatric oncology populations [114] | Literature Review | n/a | <ul style="list-style-type: none"> Although parenting stress symptoms are transitory, the impact of stress symptoms on parent and child functioning is worthy of therapeutic attention. Factors associated with increased risk of parental posttraumatic stress symptoms include poor social support, adverse experience with invasive procedures, negative parental beliefs about the child's illness and/or associated treatment, and trait anxiety. | <ul style="list-style-type: none"> Inclusion criteria not described Important, relevant studies included; Reasonable to combine results in this way; Important outcomes considered | 5 |
| Vrijmoet-Wiersma (2008) Assessment of parental psychological stress in pediatric cancer: A review [115] | Literature Review | 67 studies included for review | <ul style="list-style-type: none"> The conceptualization of parental stress and timing of assessment varies considerably between the studies, which makes comparison difficult. Most emotional stress reactions are seen around the time of diagnosis, with mothers reporting more symptoms than fathers. Parents seem relatively resilient, although a subset of parents reports continuing stress even up to 5 years or more post-diagnosis. | <ul style="list-style-type: none"> 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 |
| Vrijmoet-Wiersma (2009) Parental stress before, during, and after pediatric stem cell transplantation: a review article [116] | Literature Review | 18 studies included for review | <ul style="list-style-type: none"> Highest levels of parental stress are reported in the period preceding SCT and during the acute phase. Stress levels decrease steadily after discharge in most parents. However, in a subgroup of parents, stress levels still remain elevated post-SCT. Parents most at risk in the longer term display highest levels of stress during the acute phase of the SCT. | <ul style="list-style-type: none"> 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 |
| Intervention articles (2 or 3) | | | | | |
| Askins (2009)* Report from a multi-institutional randomized clinical trial examining computer-assisted problem-solving skills training for English- and Spanish-speaking mothers of children with newly diagnosed cancer [117] | Longitudinal assessment of parents participating in study evaluating feasibility and efficacy of handheld PDA for maternal PSST (part of larger RCT). Data were collected at T1 (prior to randomization), T2 (immediately after completion of PSST), and T3 (three months after completion of PSST). | 197 mothers of children newly diagnosed with cancer participating in PSST intervention. 104 were in the PSST only arm and 93 in PSST + PDA arm. | <ul style="list-style-type: none"> Parents in PSST and PSST + PDA groups showed improvement in problem-solving skills and mood as well as reduction in depressive symptoms and PTSS from T1 to T2 and T1 to T3. | <ul style="list-style-type: none"> 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 | 2 |
| Barreira (2014)* Does the use of the revised psychosocial assessment tool (PATrev) result in improved quality of life and reduced psychosocial risk in Canadian families with a child newly diagnosed with cancer? [118] | Pilot RCT to assess the psychosocial benefit providing the summary of family psychosocial risk to the medical team. Parental anxiety was among the other variable assessed. Data were collected at T1 (2-4 weeks post diagnosis) and T2 (6 months later) | 67 parents (63% mothers) of children who were 2-4 weeks from diagnosis of cancer in Canada. | <ul style="list-style-type: none"> Parental anxiety at T1 and T2 was significantly higher than the mean scores of the normative sample. Parents whose medical team received psychosocial risk information had a clinically significant reduction in anxiety while parents whose medical team did not receive the information did not have this reduction. | <ul style="list-style-type: none"> 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 | 2 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| *Burke (2014) Adapting acceptance and commitment therapy for parents of children with life-threatening illness: pilot study [119] | Pilot study of a therapeutic intervention with self-report questionnaires administered at three time points to assess changes in levels of distress | Eight parents of children with cancer and 3 parents of children with life saving cardiac surgery in Australia. | <ul style="list-style-type: none"> Data collected prior to the intervention revealed levels of PTSS above the clinical cut-off and uncertainty related to child's illness above the normative mean. Levels of reported guilt, worry, unresolved sorrow, and anger were close to one SD above the mean. Parents reported their emotional resources were within the range of the mean of the normative group. Postassessments revealed significant reduction in PTSS and impact of the illness. Parental perception of emotional resources improved. Results continued to improve and were maintained at follow-up. | <ul style="list-style-type: none"> 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 | 3 |
| Cernvall (2015)* Internet-based guided self-help for parents of children on cancer treatment: a randomized controlled trial [120] | RCT investigating internet-based guided self-help intervention for Swedish speaking parents of children with cancer. | 58 parents of children with cancer in Sweden were randomized. 26% of parents approached enrolled in the study and there was a 58% attrition rate. | <ul style="list-style-type: none"> At the intervention postassessment, there were significant reductions in PTSS. 12 participants in the intervention group had clinically significant reductions while 4 participants in the wait-list control group had clinically significant reductions. At postassessment, there was also a significant reduction in depressive and anxiety symptoms in the intervention group but minimal reduction in wait-list control group. | <ul style="list-style-type: none"> 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 | 2 |
| Dahlquist (2005)* When distraction fails: parental anxiety and children's responses to distraction during cancer procedures [121] | Examined the effect of parental baseline anxiety on children's response to a distraction intervention | The mothers ($n = 25$) and fathers ($n = 4$) of children with cancer undergoing treatment. | <ul style="list-style-type: none"> The parents of children who were deemed to be intervention "failures" had significantly higher state anxiety scores than parents of other children. Regression analyses examining child age, months since diagnosis, parent state anxiety, parent pretherapy anxiety ratings, and the child's baseline observed distress demonstrated that parent state anxiety contributed the most to predicting the child's failure of the intervention. | <ul style="list-style-type: none"> 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 | 3 |
| Fedele (2013) Impact of a Parent-Based Interdisciplinary Intervention for Mothers on Adjustment in Children Newly Diagnosed With Cancer [122] | Subanalysis of data from parent intervention trial analyzing downstream child outcomes. Randomized, controlled pilot trial to determine feasibility and acceptability of an intervention for mothers of children newly diagnosed with cancer. Control group received treatment as usual. Intervention group received a CBT-based interdisciplinary intervention by psychology and nursing to target problem solving skills, maladaptive cognitions, communication skills and social support. An overarching theme was managing illness uncertainty. | Participants were 52 mothers of children who were newly diagnosed with cancer (28 males, 24 females), 27 in intervention group and 25 in the control group. | <ul style="list-style-type: none"> Maternal distress predicts later child internalizing symptoms (not the other way around.) Effect size was 0.41 (moderate.) The intervention resulted in reduced child internalizing symptoms, with a small-medium effect size of -0.28. This change in child internalizing symptoms was mediated more by maternal "unobserved" (unmeasured) factors than by maternal distress. Potential mediators for this observed effect of the intervention are improved parenting, communication patterns or problem solving skills. Externalizing symptoms were also improved in the intervention group but are less common and not as clearly mediated by maternal distress. | <ul style="list-style-type: none"> Sufficient sample size; Blinding and data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 2 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Hall (1995) Intrusive thoughts as determinants of distress in parents of children with cancer [123] | Subset of parents in a longitudinal study of distress in Parents of children with illness. Conducted Stroop tests, IES, distress and physiological measurements of parents in groups with either high or low intrusive thoughts | 17 PCCs and 10 control parents of healthy children. | <ul style="list-style-type: none"> • Cancer related Stroop test performance was not affected by distress or intrusive thoughts (maybe parents were well accustomed to the task) • Physiological stress was not demonstrated (maybe parents were habituated to distressing thoughts about cancer.) • Distress and intrusive thoughts were correlated. • PTSD was not present in this small sample (maybe why Stroop task not affected.) | <ul style="list-style-type: none"> • Research question clearly stated; • Study context clearly described | 3 |
| Hoekstra-Weebers (1998) Brief report: An intervention program for parents of pediatric cancer patients: A randomized controlled trial [124] | Randomized, controlled, longitudinal intervention study. Psychoeducational/ cognitive behavioral intervention with the aims of reducing psychological distress in parents of children with cancer, regulating the intensity of emotions and helping to elicit support. Measures were Goldberg Health Questionnaire, Symptom Checklist, State trait anxiety inventory, Social support L-D and a self-made intensity of emotions scale, (all well-established for the Dutch population and norm group data are available.) | 120 PCC randomized, 81 completers evaluated. Included 40 Fathers, 41 mothers. | <ul style="list-style-type: none"> • All parents improved over time in both groups. • Evaluation of the intervention was positive but no differences between groups were found. • Clinical-case level distress was present in 88% of fathers and 90% of mothers at study enrollment, and still 39% and 41% respectively at completion of study. • Most children were in remission at close of study. | <ul style="list-style-type: none"> • Sufficient sample size; • Blinding and data collection appropriate to study method • Appropriate analysis; • Reporting comprehensive, clearly described; • Issues with follow-up or missing data clearly described | 2 |
| Kazak (2005)* Feasibility and preliminary outcomes from a pilot study of a brief psychological intervention for families of children newly diagnosed with cancer [125] | Randomized Clinical Trial (RCT) of a three session intervention for caregivers of children newly diagnosed with cancer. This paper described feasibility of the intervention and preliminary data. Data were collected prior to the intervention (T1) and 2 month after the final session (T2). Parents were randomized to the intervention arm or control arm. The intervention was the Surviving Cancer Competently Intervention Program (SCCIP-ND) | 38 caregivers (20 female and 18 male) from 19 families participated. Nine families were randomized to the intervention and ten families were randomized to the control group. The intervention required a primary caregiver to participate. | <ul style="list-style-type: none"> • Caregivers viewed the program positively and that the timing and format of the intervention were acceptable. • Participation rate in the study was 40%. • State anxiety scores were elevated for caregivers at T1 and did not differ between the groups. These scores were 1 standard deviation above the measure normative values. • Primary caregivers in the SCCIP-ND condition demonstrated declines in mean state anxiety scores from T1 to T2. There was no change for primary caregivers in the control group. State anxiety scores decreased between T1 and T2 for partner caregivers in both groups but the slope of the decline was steeper for the SCCIP-ND group than the control group. • Primary and partner caregivers in the SCCIP-ND arm showed declines in PTSS between T1 and T2, while primary and partner caregivers in the control condition show an increase between T1 and T2. | <ul style="list-style-type: none"> • 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 | 2 |

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SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Lindwall (2014) Adjustment in parents of children undergoing stem cell transplantation [126] | This study examined an intervention to increase positive adjustment of parents of patients undergoing SCT. Patient-parent dyads were randomly assigned to one of three study arms: 1. Child-Targeted Intervention (a pediatric intervention with massage and humor therapy), 2. Child and Parent Intervention (pediatric intervention with massage and humor therapy as well as parental intervention with massage and relaxation/imagery), or 3. Standard care (no intervention). The interventions were designed to promote positive emotions and decrease emotional distress. | Children with cancer—ages 6–18—receiving pediatric stem cell transplantation (SCT) or bone marrow transplantation and their parents (171 patient-parent dyads). | <ul style="list-style-type: none"> Parental distress decreased significantly from week 0 to week +6, with a rate of about 1.7 each week. Across all groups, symptoms of depression and PTSD decreased significantly from baseline (M = 28.3, SD 16.1) to week +24 (M = 20.2, SD = 15.0) Parent adjustment improved over time across all study arms. Depression scores decreased significantly between baseline (M = 18.2, SD = 10.8) and week +24 (M = 12.8, SD = 11.6) Across all groups, parental reports of benefit finding changed significantly between baseline (M = 65.0, SD = 11.5) to week +24 (M = 68.9, SD = 11.7) | <ul style="list-style-type: none"> Sufficient sample size; 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 | 2 |
| Marsland (2013) A pilot trial of a stress management intervention for primary caregivers of children newly diagnosed with cancer: Preliminary evidence that perceived social support moderates the psychosocial benefit of intervention [127] | Controlled pilot study exploring the acceptability and feasibility of a stress management intervention for caregivers of children with a recent cancer diagnosis. The “Connections to Coping” intervention included six face-to-face sessions, six between-session phone calls, and web-based support. The study examined whether caregivers with lower levels of perceived social support at baseline experienced a greater benefit than those who reported higher perceived support. Questionnaires measuring social support, depression, anxiety, and perceived stress were completed pre-intervention (T1; mean = 24 days post-diagnosis) and post-intervention (T2; mean = 165 days post-diagnosis). | Caregivers (n = 45) of children 7–17 years with a recent diagnosis of non-CNS cancer that required chemotherapy, and had a life expectancy of greater than 4 months. The sample included 42 mothers, 2 fathers, and 1 grandmother; all randomized to the intervention (n = 30) or the control group (n = 15). | <ul style="list-style-type: none"> The acceptability and feasibility of the intervention produced positive results, as evidenced by high enrollment, retention, and satisfaction data There was a significant decrease in anxiety from T1 to T2 across all participants. However, there were no significant differences in levels of distress from T1 to T2 Distress levels did not differ significantly between the intervention group and control group Caregivers in the intervention group with lower levels of support reported greater levels of distress at T1 and greater intervention-related decreases in depression, anxiety and stress. Caregivers reporting greater social support experienced little benefit from the intervention. | <ul style="list-style-type: none"> Sufficient sample size; Research question clearly stated; 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 | 3 |

(Continued)

SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Mullins (2012) A Clinic-Based Interdisciplinary Intervention for Mothers of Children Newly Diagnosed With Cancer: A Pilot Study [128] | Randomized, controlled pilot trial to determine feasibility and acceptability of an intervention for mothers of children newly diagnosed with cancer. Control group received treatment as usual. Intervention group received a CBT-based interdisciplinary intervention by psychology and nursing to target problem solving skills, maladaptive cognitions, communication skills and social support. An overarching theme was managing illness uncertainty. | Participants were 52 mothers of children who were newly diagnosed with cancer (28 males, 24 females). 27 in the intervention group and 25 in the control group. | <ul style="list-style-type: none"> Feasibility was high, based on acceptability and intervention completion. Mothers ranked the intervention as “highly beneficial” to parents of children with cancer. The study did show trends in decreasing PTSS, psychological distress and caregiver burden for the intervention group. Clinic-based intervention (in context of child’s cancer treatment visits) was accessible and convenient for parents. | <ul style="list-style-type: none"> Sufficient sample size; Blinding and data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described; Issues with follow-up or missing data clearly described | 2 |
| Sahler (2002) Problem-solving skills training for mothers of newly diagnosed cancer: a randomized trial [129] | Randomized Clinical Trial | 92 mothers of children with cancer | <ul style="list-style-type: none"> After 8-week intervention, mothers in the PSST Group had significantly enhanced problem-solving skills and significantly decreased negative affectivity compared with controls. Changes in self-reports of problem-solving behaviors accounted for 40% of the difference in mood scores between the two groups. PSST had the greatest impact on improving constructive problem solving, whereas improvement in mood was most influenced by decreases in dysfunctional problem solving. | <ul style="list-style-type: none"> 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 | 2 |
| Sahler (2005) Using problem-solving skills training to reduce negative affectivity in mothers of children with newly diagnosed cancer: report of a multisite randomized trial [130] | Randomized Clinical Trial | 430 English- and Spanish-speaking mothers of recently diagnosed children with cancer | <ul style="list-style-type: none"> Compared with Usual Psychosocial Care mothers, PSST intervention mothers reported significantly enhanced problem-solving skills and significantly decreased negative affectivity. Effects were largest immediately after PSST, and differences in problem-solving skills and distress levels persisted to the 3-month follow-up. Spanish-speaking mothers and young, single mothers profited most from PSST. | <ul style="list-style-type: none"> 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 | 2 |
| Sahler (2013) Specificity of problem-solving skills training in mothers of children newly diagnosed with cancer: results of a multisite randomized clinical trial [131] | Randomized Clinical Trial | 309 English- or Spanish-speaking mothers of children newly diagnosed (2–16 weeks) with cancer | <ul style="list-style-type: none"> No significant between-group differences at baseline (T1). Except for level of problem-solving skill, which was directly taught in the PSST intervention arm, outcome measures improved equally in both groups immediately postintervention (T2). At 3-month follow-up (T3), mothers in the PSST intervention group continued to show significant improvements in mood, anxiety, and post-traumatic stress; mothers in the Non-Specific support group showed no further significant gains. | <ul style="list-style-type: none"> 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 | 2 |

(Continued)

SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Sample | Findings | Study Rigor | Level of evidence |
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| Stehl (2009) Conducting a randomized clinical trial of an psychological intervention for parents/caregivers of children with cancer shortly after diagnosis [132] | Randomized Clinical Trial | 81 families of children with newly diagnosed cancer | <ul style="list-style-type: none"> Difficulties enrolling participants included a high percentage of newly diagnosed families failing to meet inclusion criteria (40%) and an unexpectedly low participation rate (23%). Movement through the protocol was generally completed in a timely manner and those completing the intervention provided positive feedback. Outcome data showed no significant differences between the arms of the RCT. | <ul style="list-style-type: none"> 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 | 2 |
| Streisand (2000) Brief report: parents of children undergoing bone marrow transplantation: documenting stress and piloting a psychological intervention program [133] | Prospective longitudinal cohort study, randomized intervention trial | 22 mothers of children undergoing BMT | <ul style="list-style-type: none"> Repeated measures ANOVAs detected significant changes in stress over time, with most stress reported preadmission. Mothers in the intervention condition reported using more stress management techniques than mothers in the standard care condition, though the majority of analyses revealed no significant differences in stress between groups. | <ul style="list-style-type: none"> Small sample size; Data collection appropriate to study method Appropriate analysis; Reporting comprehensive, clearly described | 4/2 |
| Warner (2011) Treating persistent distress and anxiety in parents of children with cancer: an initial feasibility trial [134] | Open trial | 5 parents of children 1 month post-diagnosis | <ul style="list-style-type: none"> Parents had decreased distress, state anxiety, and depressive symptoms, and feelings of burden associated with their children's cancer. | <ul style="list-style-type: none"> Small sample size; Data collection appropriate to study method Appropriate analysis; reporting comprehensive, clearly described | 3 |
| Study | Design | | Findings | | Level of evidence |
| Expert Opinion Articles (7) | | | | | |
| Last (1998) Emotions, coping and the need for support in families of children with cancer: a model for psychosocial care [135] | This article reviews current understanding of emotional responses and coping strategies of children with cancer and their parents. Secondly, the authors discuss the process of coping with childhood cancer, and present a conceptual framework based on a model developed by Rothbaum (1982). | <ul style="list-style-type: none"> The authors use the Rothbaum model, which includes primary coping strategies (things that can be changed by the individual) and secondary coping strategies (ways the individual can change to adjust to unchanging environment) to consider the predicament of patients and families facing childhood cancer. Multiple cases are presented within this framework and possible interventions discussed. Emphasis is placed on uncontrollability and uncertainty of the patient's experience. This framework is presented as one model and the authors warn against reliance on one approach or framework for intervention development when in reality coping is multidimensional and complex. | <ul style="list-style-type: none"> Researcher have questioned "whether childhood illness and medical injury is a viable framework for studying PTSD and PTSS." These issues have been examined in the literature through documentation of prevalence of PTSD and comparison of those rates previously found in the same population, comparing rates of PTSD to norms from the general population, and comparing rates to a recruited healthy control sample. Rates in the literature vary by methodology and sample with rates for children facing acute injury or chronic health conditions ranging from 5% to 30%. Studies comparing children in these populations to other populations reveal lower levels of PTSD, higher levels of PTSD, or no differences in PTSD. Rates found in samples of parents also vary but, in general, are higher than rates found in children. The author suggests adopting a "broad, cross-situational perspective" to the study of PTSD in pediatric medical populations which may lead to identifying characteristics of the illness/injury, cognitive/psychological/biological characteristics of the child and parents, and characteristics of the family's social context that may serve as risk or protective factors. The author suggests that a "broad, cross-situational perspective" to the study of PTSD may increase understanding of sub-clinical PTSS, and the links between sub-clinical PTSS/PTSD to other psychological problems or medical late effects. | 7 | |
| Manne (2009)* Commentary: Adopting to a Broad Perspective on Posttraumatic Stress Disorders, Childhood Medical Illness and Injury [136] | Commentary | | | | 7 |

(Continued)

SUPPLEMENTAL TABLE II. (Continued)

| Study | Design | Findings | Level of evidence |
|--------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|
| Mullins (2015) Models of Resilience: Developing Psychosocial Interventions for Parents of Children with Chronic Health Conditions [137] | Critical analysis of three models of resiliency applied to the field of intervention development for parents of children with chronic illness, using pediatric cancer literature to illustrate one example. Models reviewed include Wallander and Vami's Disability-Stress-Coping Model, Thompson and Gustafson's Transactional Stress and Coping Model, and Kazak's Social Ecological Model. | <ul style="list-style-type: none"> All models share framework of Bronfenbrenner's ecological systems theory. Substantial research has supported the reciprocal nature of the parent-child adjustment relationship. Particularly, parent adjustment predicts child adjustment. Presentation of the Parent Uncertainty Management Intervention model by Pai and Mullins. Discussion of the trials of the intervention in Mullins 2012 and Fedele 2013. Conclude that interventions should 1) target parents 2) target cognitive appraisal mechanisms demonstrated to be predictive of adjustment outcomes (e.g. illness uncertainty), 3) provide interdisciplinary team to support families in context of medical systems and treatment regimens. Interventions should be accessible to parents to reduce burden of seeking care, (e.g. at child's treatment center). | 7 |
| Vami (1999) Maternal problem-solving therapy in pediatric cancer [138] | Expert description of CBT intervention for parents | <ul style="list-style-type: none"> The authors discuss the challenges and effects of maternal adjustment throughout the various stages of the child's illness, review the characteristics of adult learners, describe a maternal problem-solving therapy program, and provide an overview of the structured educational process, followed by a detailed discussion of a six-step maternal problem-solving therapy intervention. | 7 |

Abbreviations: ALL = acute lymphoblastic leukemia, AML = acute myeloid leukemia, ANOVA = analysis of variance, ASD = acute stress disorder, BAI = Beck Anxiety Inventory, BDI = Beck Depression Inventory, BMT = bone marrow transplant, BSI = Brief Symptom Inventory, CNS = central nervous system, DSM-IV = Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, DT-P = Distress Thermometer for Parents, FES = Family Environment Scale, FRI = Family Relationship Index, GAD = generalized anxiety disorder, GHQ = General Health Questionnaire, GvHD = Graft versus Host Disease, HADS = Hospital Anxiety and Depression Inventory, HRQOL = health related quality of life, HSCT = hematopoietic stem cell transplant, IBD = Inflammatory Bowel Disease, ICU = Intensive Care Unit, IES = Impact of Events Scale, JRA = juvenile rheumatoid arthritis, MCA = mother of children with significant acute illness, MCC = mothers of children with cancer, MDD = major depressive disorder, MOS SF-36 = Medical Outcomes Survey Short Form 36, NSSI = Norbeck Social Support Interview, PAT2.0 = Psychosocial Assessment Tool, PCC = parents of children with cancer, PD = panic disorder or psychological distress, PDA = personal digital assistant, PSST = Problem-Solving Skills Training, PICU = Pediatric Intensive Care Unit, PIP = Pediatric Inventory for Parents, PSI, Parenting Stress Index, PSST = Problem Solving Skills Training, PST = Problem Solving Therapy, PTSD = posttraumatic stress disorder, PTSD-RI = Post-Traumatic Stress Disorder-Reaction Index, PTSS = posttraumatic stress symptoms, QOL = quality of life, RCT = randomized controlled trial, SAS = symptoms of acute stress, SCCIP = Surviving Cancer Competently Intervention Program, SCT = stem cell transplant, SD = standard deviation, SES = socioeconomic status, SOC = sense of coherence, SPSI-R = Social Problem Solving Inventory-Revised, STAI = State-Trait Anxiety Inventory, SCL-90-R = Symptom Checklist-90-Revised, ST = Systemic Therapy, T1 = time 1, T2 = time 2, T3 = time 3, T4 = time 4, T5 = time 5, T6 = time 6, T7 = time 7, TLE = traumatic life events* only data relevant to this standard were reported.

Key: Levels of evidence

- 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.

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SUPPLEMENTAL TABLE III. Barriers and Responses to Barriers to Mental Healthcare (MH) for Parents of Children with Cancer (PCC)

| Levels of Barriers | Parent and Family | Pediatric Oncology | Adult Psychiatric Systems |
|----------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>Barriers</i> [1] | <ul style="list-style-type: none"> Emotionally overwhelmed or unwilling to leave the bedside of their ill child. Parent needed at bedside for care/comfort of sick child Feel guilty caring for self, or normal defense mechanism to put self last when child is sick Bias about using mental health services Pre-existing or distress-related impairment of problem-solving skills, further limiting parent's ability to follow through with community-based mental health referrals. Time limitations for parents with multiple responsibilities (e.g. work, ill child's care, well child care) Lack of access to transportation | <ul style="list-style-type: none"> Inadequate funding for staff (e.g., too few providers, not enough dedicated time to address the clinical need) Training needs of staff (e.g. little experience with adult/parent individual treatment, unfamiliar with parent literature) Pediatric institutions unwilling to accept parents as "adult patients" Billing and documentation of parent treatment in context of child cancer care (e.g. PSST) | <ul style="list-style-type: none"> Limitations in mental health insurance coverage and "out of network" benefits Insurance requiring approval and appeals to approve out of state/network mental health care Lack of appropriate providers who speak multiple languages Inflexible and overburdened community mental health systems (e.g. policies which discharge adult patients who miss appointments, inability to schedule according to child's clinic schedule, make last minute or urgent appointments as needed when medical crises for child occur, wait-lists) Lack of training and awareness of PCCs' experiences, needs, evidence-based interventions, and parenting guidance among community mental health providers |
| <i>Suggested Responses to Barriers</i> | <ul style="list-style-type: none"> Psychoeducation about normal trajectories of distress, resilience, and impact on child Problem solving skills training, modeling prioritizing parent mental healthcare Targeted practical support around overcoming barriers to accessing additional parent mental healthcare (e.g. helping with scheduling, paperwork, insurance issues) Provision of respite care for the sick and well children Transportation assistance for parents | <ul style="list-style-type: none"> Integrated bedside or on-site MH services for parents in Peds Oncology Educational and training opportunities for staff regarding effective interventions for parents Outreach, education and advocacy to accessible psychiatric/psychotherapy practices or clinics to create referral mechanism and practice policies consistent with pediatric medical home and family-centered care [2, 3] Direct and ongoing communication between pediatric psycho-oncology providers (e.g., social workers, psychologists, psychiatrists) with community providers who are not familiar with pediatric oncology psychosocial frameworks (e.g. child cancer prognoses and treatments, parental adjustment trajectories, medical traumatic stress models) [4] Parents report openness to technology (e.g., web or telephone based) supported interventions to improve engagement, and online versions of existing interventions and other innovations are being tested.[5] | |

Abbreviations: PSST = Problem solving skills training

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