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Bereavement Follow-Up After the Death of a Child as a Standard of Care in Pediatric Oncology

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After a child's death to cancer, families commonly want continued connection with the healthcare team that cared for their child, yet bereavement follow-up is often sporadic. A comprehensive literature search found that many bereaved parents experience poor psychological outcomes during bereavement and that parents want follow-up and benefit from continued connection with their child's healthcare providers. Evidence suggests that the standard of care should consist of at least one meaningful contact between the healthcare team and bereaved parents to identify those at risk for negative psychosocial sequelae and to provide resources for bereavement support. Pediatr Blood Cancer 2015;62:S834–S869. © 2015 Wiley Periodicals, Inc.

Key words: bereaved parents; bereavement; cancer; death of a child; palliative care; pediatric oncology

INTRODUCTION

The loss of a child is considered by many to be the most devastating type of bereavement.[1] Intense and persistent grief reactions are common and may be debilitating for some bereaved family members.[2–4] Protracted grief reactions, such as prolonged grief disorder, are associated with poor psychological and physical health outcomes, including mortality.[5–8] Grief reactions may be compounded by secondary losses, such as the loss of support from the child's medical team, whom the family has come to trust and rely on for comfort and information.[9] An abrupt end to contact soon after the child's death is experienced by some parents as abandonment.[10,11] This loss may be mitigated by providing continuity of care through bereavement to the families from pediatric cancer care facilities.[12] Unfortunately, however, resources, such as dedicated staff and time, are often limited, and thus, families commonly return to their communities without a sustained connection to the medical team.

Bereavement follow-up through telephone calls, emails, and/or mailed cards or letters is considered to be part of good medical care,[13] and the need to provide bereavement care has been increasingly recognized.[14,15] The American Academy of Pediatrics and the Institute of Medicine each call for care to continue through bereavement.[16,17] Many providers make efforts to support bereaved families, but efforts are highly inconsistent, in part, because there are no existing guidelines advising staff on best practices for bereavement follow-up. Several reports have described the obligation that hospitals have to provide some level of bereavement follow-up to the patient's family.[18–21] A recent article suggests that pediatric palliative care physicians have an ethical duty of "nonabandonment" to care for the families of children with life-threatening conditions through their illness and bereavement.[22] Moreover, the child's primary medical team can be an important source of transitional support for bereaved parents and other family members.[17] The objective of this review was to assess and appraise the literature on bereavement outcomes, follow-up, and needs to determine an evidence-based standard for routine assessment of bereavement needs of parents whose children died from cancer.

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Psychosocial Standard of Care

A member of the healthcare team should contact the family after a child's death to assess family needs, to identify those at risk for negative psychosocial sequelae, to continue care, and to provide resources for bereavement support.

METHODS

This review was performed as part of the collaborative *Standards for Psychosocial Care of Children with Cancer and Their Families* effort. For a full description of the methods used to develop each standard, refer to Wiener, Kazak, Noll, Patenaude, and Kupst.[23] A comprehensive electronic literature search for articles in PubMed, PsycINFO, CINAHL, EMBASE, SCOPUS, and Web of Science was performed by a medical librarian at Memorial Sloan Kettering Cancer Center. This was an expansion of an initial preliminary literature search conducted in early 2014.

Abbreviations: PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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Recommendations were generated based on the search findings. The search strategy, recommendations, and potential barriers to implementation of the recommendations were sent for external blinded review. The reviewers were identified through the Standards of Pediatric Psychosocial Oncology Care workgroup.[23] The returned comments noted the need for future evaluative research. Reviewers indicated that there was evidence that parents find bereavement contact helpful, and although more research needs to be done, there is sufficient evidence to indicate that some bereavement contact should be part of good psychosocial care. Reviewers offered recommendations for future research directions. We responded to these reviews by expanding the literature search.

The searches of the English-language literature published from March 1, 1995 to March 1, 2015 combined pediatric cancer terms with bereavement and follow-up-related terms and MeSH headings. See Supplemental Table I for a description of the search terms. Studies were eligible for inclusion if they focused on bereaved parents', siblings', or grandparents' experiences after the loss of a child ages 0–18 at the time of cancer diagnosis and at least one of the following areas: bereavement support programs or interventions for parents; parents, clinicians, or siblings reporting need for follow-up; bereavement outcomes after the death of a child; outcomes associated with bereavement aftercare; predictors of negative bereavement outcomes; and end-of-life care factors associated with bereavement outcomes or need for aftercare. Articles were excluded if they were biomedical in nature and if they focused exclusively on the following topics: diseases other than cancer; psychosocial factors associated with active cancer treatment or survivorship rather than bereavement; experiences of the child with cancer; or bereaved parents of adult children.

Supplemental Figure 1 depicts the review process according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.[24] For the full-text review phase, the articles were randomly assigned to six authors (W.L., C.S., K.R., G.C., L.D., and L.W.) to code for exclusion and to extract pre-determined information from each eligible article for the qualitative synthesis. The authors had regular discussions to assure consistent rating of study rigor and to reach consensus about the inclusion and exclusion of all articles.

RESULTS

See Table I for a summary of the evidence extracted from the literature and Supplemental Table II for complete results from the literature review. The review of the evidence demonstrated that bereaved parents experience poor psychological outcomes in bereavement, following up with and supporting bereaved parents is perceived to be helpful, and bereaved families want and need services.

Bereavement Outcomes and Associated Factors

Several studies have demonstrated the psychological challenges parents bereaved by cancer face,[25] with increased rates of depression and anxiety,[26] grief,[27] existential distress, challenges to their sense of identity and meaning-making,[28–30] guilt,[31] and posttraumatic stress disorder.[32] These symptoms commonly persist over time.[26,27] Approximately 10–25% of parents bereaved by cancer experience debilitating levels of grief.[27,33–35] Furthermore, studies have shown that bereaved parents' grief typically persists and often even intensifies after the first year.[34,36] Poorer outcomes have been reported among mothers,[36,37] regardless of cultural background;[38] among parents dissatisfied with their child's medical care;[31] and among those whose children had anxiety or sleep disturbances,[39] a stem cell transplant,[30,40,41] or uncontrolled pain or a difficult death.[31,42]

Families bereaved by cancer also often struggle with isolation due to fear of burdening their support network with their persistent pain

TABLE I. Summary of Evidence Table

Standard	Evidence summary[1]	Methodology[2]	Quality of evidence[3]	Strength of recommendation[4]
A member of the healthcare team should contact the family after a child's death to assess family needs, to identify those at risk for negative psychosocial sequelae, to continue care, and to provide resources for bereavement support	• Many bereaved parents, siblings, and grandparents experience long-lasting negative outcomes, with a subset debilitated by their distress • Parents have generally indicated their wish for and appreciation of follow-up by the healthcare team after the death of their child • Professional support can assist with grief, particularly among those with more severe, debilitating symptoms	• Quantitative, qualitative, and literature reviews • Majority were cross-sectional surveys and in-depth interviews • Limited randomized controlled trials • Replication of some findings evident	Moderate quality; findings from lower level evidence studies were consistent	Strong recommendation given risk–benefit ratio, including significant health impact on bereaved family members and positive outcomes with contact made after the death of the child

[1]Based on summary of evidence table for that standard; [2]Types of studies: for example, randomized controlled trial, cross-sectional, longitudinal; consensus; systematic review articles; [3]Quality of evidence: High, moderate, low, and very low (based on Grading of Recommendations, Assessment, Development and Evaluation [GRADE] criteria [109]); [4]Strength of recommendation: Strong or weak (based on GRADE quality criteria).

[43] and experience decreased social support over time.[29,44] Other family members also struggle after the loss, including some siblings [45–48] (see Gerhardt, Lehmann, Long, and Alderfer[49] in this issue) and grandparents.[50] Being reminded of, speaking about, and feeling connected to the deceased child are frequently described as helpful[51–56] and are associated with better outcomes.[57]

Bereavement Follow-Up Efforts and Formal Interventions

Despite families' risk for poor outcomes, few bereavement follow-up programs and formal interventions to support them have been rigorously evaluated. A systematic review of studies on hospital-based bereavement programs concluded that such programs help families feel cared for, reduce their sense of isolation, and improve their coping.[58] Importantly, in qualitative studies, parents have not reported negative effects of follow-up, and most have expressed appreciation.[59–62] Additionally, staff who engage in bereavement follow-up have also reported that they, too, experience benefits from reaching out to families.[59,63–66]

Without an existing standard of care, however, follow-up attempts by a given medical team are inconsistent,[11,62,67] and some families are never contacted. A variety of practices are used when there is follow-up, including making phone calls; sending cards; attending funerals; providing information and resources; connecting parents with other bereaved parents; acknowledging birthdays, holidays, and anniversaries; visiting the family; holding family meetings; and organizing memorial services.[63,68–71] Qualitative studies have found that phone calls and family meetings after the child's death are beneficial, helping parents feel like their child is remembered, facilitating meaning-making, responding to unanswered questions about their child's care, reassuring them they did everything they could, and providing a sense of closure.[11,64–66,72–76] Of note, some follow-up efforts have been perceived as inadequate,[77] suggesting the importance of training staff. In addition, involving bereaved parents in developing and administering bereavement education programs and interventions has been shown to have great value for them,[28,78] further giving meaning to their child's life.[79]

Need for Bereavement Follow-Up and Mental Health Services

One of the most consistent findings in the literature is that most parents want and appreciate continued connection with the medical team[11,66,80–83] and expect follow-up after their child underwent such intense treatment.[70,77] Parents often value ongoing contact with a provider who knew their child and may appreciate providers connecting them with other bereaved parents.[83–85]

Research has shown that some parents would like, in addition to follow-up, bereavement mental health support,[34,86,87] sometimes well beyond the first year of bereavement.[26,27,34] However, parents, especially minorities, often face barriers in accessing such support.[34,88] For example, although parents often appreciate services from the institution at which their child was treated,[11,44,89] studies have shown that it is emotionally difficult for parents to physically return to the place of treatment,[11,70] which may be, in part, why home visits are desirable.[87] Parents are also frequently concerned about the well-being of their surviving children and want formalized bereaved sibling support.[75,83,87,88,90] Evidence suggests that there are benefits to grief interventions focusing on the entire family.[85,91]

There is a need for effective, evidence-based bereavement mental health services. Although randomized controlled trials are limited, descriptive data suggest that bereavement mental health services can be beneficial,[3] particularly for those with more severe symptoms or prolonged grief disorder.[8,28,58,92] Unfortunately, existing services appear underused,[93] and some are perceived as unhelpful.[2,34,94] Healthcare providers are in a position to link families with bereavement services and should, thus, provide referrals when making contact. There is also a need for screening to identify those in greatest need.[14,15,95] Existing bereavement needs assessments have been described as insufficient,[96] but efforts to develop a more valid, reliable screening tool are underway.[97] Once identified, family members may benefit from interventions designed to prevent or reduce debilitating prolonged grief symptoms.[28,92,98]

DISCUSSION

This review demonstrated that families who lose a child to cancer are at risk for poor bereavement outcomes and desire continued connection to their child's healthcare team.[9,99] Bereaved families often feel abandoned when contact is lacking, creating a secondary loss in addition to the excruciating loss of their child.[70,83,99,100] Contact with staff is commonly wanted by parents and may prove very helpful to families as they transition back to their communities,[80,100] wherein support frequently wanes over time.[36,44]

The IOM has emphasized that bereavement care is a public health priority and should be a part of comprehensive emotional and spiritual care for grieving family members.[17,101] Data suggest that what healthcare providers do around the time of a child's death has a lasting impact on families[102,103] and can be important in processing their own grief.[59,63–66,104] Review of the current available literature provides compelling evidence for the benefit of having a member of the healthcare team contact the bereaved family by phone at least one time after a child's death in order to assess the family's needs, to let them know they and their child have not been forgotten, to identify families who are at risk for negative bereavement outcomes, and to link families to resources for bereavement support in their community.[105,106]

Although the literature included rich evidence on the need for bereavement care and recognized bereavement services, many of the studies reviewed, which were mostly descriptive, cross-sectional, and lacking control groups, had substantial methodological and conceptual weaknesses. Additional limitations included healthy selection biases, underrepresentation of fathers, and lack of racial and ethnic diversity.[34] Future studies should address these limitations, using prospective, longitudinal, and randomized controlled designs with more representative, diverse samples. Specifically, a randomized controlled trial examining the effects of the healthcare team following up with families at least one time and exploring the impact of continued follow-up is warranted. In addition, studies should address the important logistical and emotional barriers that may impede follow-up and the development of bereavement programs [68] through evaluation of continuing education[59,107,108] and organizational structure.[65] Research to strengthen the evidence base on bereavement interventions is also needed.

CONCLUSION

Consistency of findings from 94 studies utilizing different study designs and methodologies supports the importance of healthcare providers initiating contact with families after the death of a child to cancer. The data suggest that the standard of care should consist of at least one meaningful contact, such as a call, email, or letter, between the healthcare team and bereaved parents following the death of a child to cancer. Efforts to remember the child through, for example, invitations to memorial services or the sending of special occasion cards, are often greatly appreciated.[11,70] Bereavement support from the psychosocial team, including psychoeducation, risk assessment, and referrals to the community when appropriate, should also be offered to all grieving family members.[22,44–47] Although moderate evidence was found, an overall strong recommendation for this standard is given due to minimal risk to families and the consistent evidence of potential long-term benefits.

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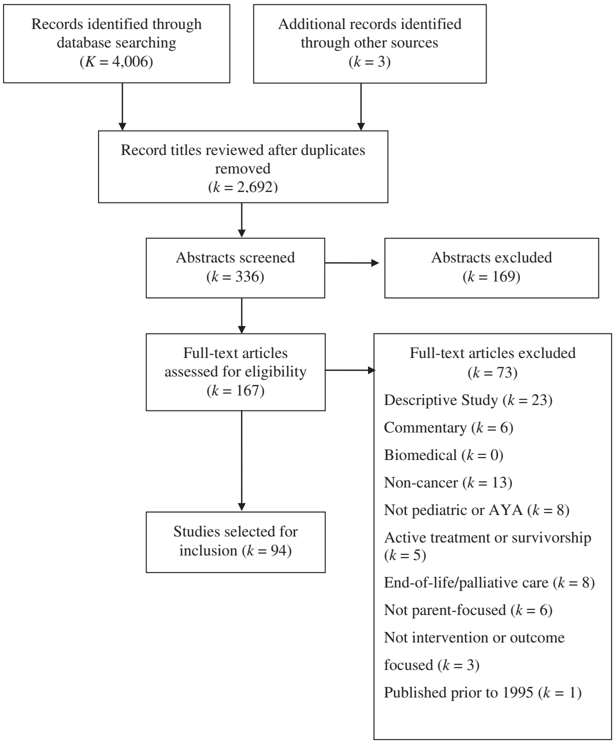
SUPPLEMENTARY INFORMATION



Supplemental Fig. 1. PRISMA flow chart.

SUPPLEMENTAL TABLE I. Search Terms

MEDLINE Search Strategy

1. (die OR dies OR grief OR griev* OR bereave* OR condolence* OR funeral OR autopsy)
2. (parent* OR caregiver* OR mother* OR father* OR maternal OR paternal)
3. (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])
4. (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*)
5. 1 and 2 and 3 and 4
6. (pediatric oncology OR paediatric oncology)
7. (childhood cancer OR childhood tumor OR childhood tumors)
8. (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*)
9. (leukemia, lymphocytic, acute[mh])
10. 5 or 6 or 7 or 8 or 9
11. 5 and 10
12. limit 11 to English language
13. limit 12 to yr = "1995 - Current"

SUPPLEMENTAL TABLE II. Literature Review Results

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Bereavement Outcomes and Associated Factors					
Alam, Barrera, D'Agostino, Nicholas, & Schneiderman (2012) [1]	• Mostly in-person, semi-structured interviews with bereaved parents 6 and 18 months after their loss • Qualitative • Longitudinal	• Bereaved parents who lost a child treated in a hematology/ oncology unit at a hospital (n = 31 parents from 20 families) • Canada	• Mothers had more intense grief than fathers that lessened over time • Parents reported diversity in the relationship with their spouses over time, with both patterns of improvement and increased strain	Strengths • 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 Limitations • Limited participation of fathers • Limited cultural diversity of sample	**6**
Barrera, D'Agostino, Schneiderman, Tallett, Spencer, & Jovcevska (2007) [2]	• Cross-sectional • Mixed methods study • Two standardized questionnaires measuring depression and grief • Face-to-face interview exploring patterns of parental bereavement	• Bereaved parents (n = 20) of children who had died following a diagnosis of cancer (n = 9), congenital heart disease (n = 3), meningitis or drowning (n = 3) • Canada	• Three bereavement patterns were identified: 65% of parents presented uncomplicated *Integrated grief,* five mothers (25%) were *Consumed by grief,* and one mother and one father expressed *Minimal grief* (10%) (within *minimal* defined as inhibition and avoidance of expression of emotional pain) • Parental gender, symptoms of depression and pre-death relationship between parents and their deceased child differentially related to these patterns • Having surviving children, social support and being active appeared to help to integrate grief into daily life	Strengths • Research question clearly stated • Qualitative approach clearly justified • Study context clearly described • Method of data collection clearly described • Method of data analysis clearly described • Analysis appropriate for research question Limitations • Insufficient sample size	**6**
Barrera, O'Connor, D'Agostino, Spencer, Nicholas, Jovcevska, Tallet, & Schneiderman (2009) [3]	• Cross-sectional • Qualitative • Individual, semi-structured interviews exploring parental bereavement and adjustment after childhood cancer death	• Bereaved parents who lost a child to cancer (n = 31; n = 18 mothers, n = 13 fathers) • Canada	• 90% of parents spoke of the importance of maintaining a relationship with their deceased child in their adjustment • Some parents did not want to burden members of their social network with requests for help or with their intense emotions, which ultimately led to isolation from social support, often having become disconnected from support while their child was ill • At 6 months post-loss, nearly all parents were able to report some resolution of their shattered view of life	Strengths • 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	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Barrera, Alam, D'Agostino, Nicholas, & Schneiderman (2010) [4]	• Longitudinal • Qualitative • Individual, semi-structured interviews exploring parental and sibling bereavement and adjustment after childhood cancer death	• Bereaved parents who lost a child to cancer (n = 31; n = 19 mothers, n = 12 fathers) • Canada	• Themes included: 1) Expression of grief (older siblings: intense grief; younger siblings: delayed grief) 2) Siblings coping (resuming daily routine for both groups, talking with friends and counselling for older siblings) 3) Bond with deceased sibling (younger siblings: pretend-play, using their belongings; older siblings: building legacy)	Strengths • Research question clearly stated • Qualitative approach clearly justified • Study context clearly described • Method of data analysis clearly described Limitations • Symposium abstract – not able to fully assess rigor	**6**
Birenbaum, Stewart, & Phillips (1996) [5]	• Longitudinal • Descriptive • Questionnaire and interview administered at terminal phase and 2 weeks, 4 months and 1 year after death	• Parents of children dying from cancer (n = 80; n = 47 mothers, n = 33 fathers) • USA	• Health of bereaved parents did not differ significantly from a normative group of adults on symptom scales • Mothers demonstrated lower levels of social health compared with the normal sample • Results on the four health scales did not differ from the normative sample	Strengths • Sufficient sample size • Data collection appropriate to study method • Appropriate analysis Limitations • Selective reporting	**4**
Davies (1987) [6]	• Interviews with family members • Qualitative	• Families who lost a child to cancer 2-36 months prior (n = 34) • USA • Canada	• Discrepant meanings within the family may vary and may influence bereavement outcomes	Strengths • Research question clearly stated • Qualitative approach clearly justified • Study context clearly described • Interviews coded; high inter-coder reliability (91-100%) Limitations • Interviews not audio recorded	**6**
Davies, Deveau, deVeber, Howell, Martinson, Papadatou, Pask, & Stevens (1998) [7]	• Cross-sectional • Semi-structured interviews • SCL-90	• Mothers from 5 different countries who lost a child to cancer up to 6 months ago (n = 21) • Canada, • Norway • Greece • Hong Kong • USA	• No culturally related differences were found among mothers • Mothers described similar challenges in coping with bereavement	Strengths • Interviews coded by pairs of coders, second pair checked coding Limitations • Interview guide translated into 5 languages may have resulted in dif-ferent interpretations of questions	**6**
Domingue (2010) [8]	• Cross-sectional, correlational study • Used standardized questionnaires • Used multiple regression	• Couples bereaved by cancer (n = 86 individuals from 32 couples) • USA	• Retrospective attachment was associated with grief • Discrepancies in attachment styles in couples was moderated by time since the death • Social support was associated with psychological distress, marital satisfaction, and some aspects of grief • Retrospective insecure attachment was associated with grief oscillation	Strengths • Sufficient sample size • Data collection appropriate to study method Limitations • Reporting not comprehensively, clearly described • Issues with missing data not clearly described • Incorrect analysis, did not account for correlated data within couples • No matched control/comparison group	**4**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Drew, Goodenough, Maurice, Foreman, & Willis (2005) [9]	● Cross-sectional ● Case-matched design	● Bereaved parents (n = 56; 28 whose children received stem cell transplant (SCT), 28 whose children who did not receive SCT) ● Australia	● SCT group showed higher levels of depression, anxiety, and stress ● For those who died in hospital, SCT group has greater traumatic grief levels	Strengths ● 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 Limitations ● Cross-sectional ● Retrospective ● Single institution sampling ● Variability in death being due to STC	**3**
Dussel, Bona, Heath, Hilden, Weeks, & Wolfe (2011) [10]	● Cross-sectional survey	● Bereaved parents who lost a child to cancer (n = 230) ● USA ● Australia	● Families reported a great deal of financial hardship ● Poverty and income loss associated with financial hardship	Strengths ● Reporting from three tertiary-care pediatric sites ● Large sample size Limitations ● Retrospective reporting ● Cross-sectional design does not allow for comparisons of financial difficulties across disease trajectory ● Out of pocket costs not measured	**4**
Eilegard & Kreicbergs (2010) [11]	● Cross-sectional ● Self-report questionnaires ● Matched control design	● Bereaved parents who lost a child to cancer (n = 449) and matched controls with a living child (n = 457) ● Sweden	● Bereaved parents were significantly more likely to be married to or to be living with their child's other parent than matched controls	Strengths ● Sufficient sample size ● Data collection appropriate to study method ● Appropriate analysis Limitations ● No data collected about when parents got married	**4**
Eilertsen, Eilegard, Steineck, Nyberg, & Kreicbergs (2013) [12]	● Longitudinal ● Individual descriptive ● Study specific questionnaire which included the Hospital Anxiety and Depression Scale measuring sibling anxiety and Social Support Questionnaire assessing satisfaction with social support	● Siblings bereaved by cancer (n = 174; including n = 73 men, n = 101 women of 240 eligible) ● Sweden	● Siblings had a higher risk of anxiety if social support needs (support from family) were unsatisfied within the last month before their sibling's death ● Siblings who did not perceive their parents and neighbors cared for them after their brother's or sister's death demonstrated higher risk for anxiety	Strengths ● Sufficient sample size ● Study completed as planned ● Appropriate analysis ● No significant losses to follow up or missing data Limitations ● Lack of blinding ● Selective reporting	**6**
Foster, Gilmer, Davies, Barrera, Fairclough, Vannatta, & Gerhardt (2009) [13]	● Mixed methods ● Questionnaires ● Semi-structured interviews	● Families of children who died from cancer (n = 36 mothers, n = 27 fathers, and n = 40 siblings from 40 families) ● USA ● Canada	● Legacies included bereaved individuals remembering children's qualities, children's concern for family members while alive, and beliefs about afterlife	Strengths ● 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 Limitations ● Lack of diverse sample ● Retrospective reporting	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Foster, Gilmer, Davies, Dietrich, Barrera, Fairclough, Vannatta, & Gerhardt (2011) [14]	● Mixed methods ● Questionnaires ● Semi-structured interviews	● Mothers (n = 36), fathers (n = 24), and siblings (n = 39), bereaved by cancer	● Over half of participants reported comforted effects from reminders of the deceased child	Strengths ● 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 Limitations ● Lack of diverse sample	**6**
Foster, Gilmer, Vannatta, Barrera, Davies, Dietrich, Fairclough, & Gerhardt (2012) [15]	● Cross-sectional study investigating losing a sibling to cancer from the perspectives of parents and siblings ● Home interviews	● Parents (n = 36 mothers and n = 24 fathers) and siblings (n = 39) from families who had lost a child to cancer ● USA	● Parents and siblings reported changes in siblings (school, personality, goals) and changes in relationships (family, peers) ● 21% of all participants (both parents and siblings) reported no changes in the sibling related to the death	Strengths ● 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 Limitations ● Role of researcher could have been described in more depth, including potential biases	**6**
Gerhardt, Fairclough, Grossenbacher, Barrera, Gilmer, Foster, Compas, Davies, Hogan,& Vannatta (2012) [16]	● Cross-sectional ● Questionnaires administered to bereaved siblings, their classmates, their teachers, and matched control participants	● Bereaved siblings aged 8-17 (n = 105) ● Matched nonbereaved comparison classmates (3 per bereaved sibling, n = 311) ● USA	● Bereaved boys were perceived as more sensitive-isolated and victimized than their peers ● Bereaved siblings in elementary grades had lower peer acceptance, fewer best friend nominations, and were rated by peers as less prosocial and more sensitive-isolated	Strengths ● Sufficient sample size ● Data collection appropriate to study method ● Appropriate analysis ● Evidence derived from high quality case control study ● Reporting comprehensive, clearly described Limitations ● Issues with any missing data not described ● Power for detecting interactions was limited ● Sample selection bias and potential lack of generalizeability ● Cross-sectional study, so unable to determine causal relationships	
Gerrish, Neimeyer, & Bailey (2014) [17]	● In-person, semi-structured interviews with bereaved mothers, who also filled out questionnaires and provided data with the biographical grid method ● Mixed methods	● Bereaved mothers who lost a child to cancer (n = 13) ● Australia ● USA	● All mothers exhibited both adaptive and complicated grief responses, although the proportion of adaptive to complicated grief responses varied ● Important features of adaptive vs. complicated grief include changes in or reinforcement of world assumptions, ongoing relationships with the deceased child and the social world, and management of loss- and restoration-oriented coping	Strengths ● Research question clearly stated ● Qualitative approach clearly justified ● Study context clearly described ● Method of data collection clearly described ● Method of data analysis clearly described ● Analysis appropriate for research question ● Interpretation of quantitative data described Limitations ● Limited description of participating mothers ● Role of researcher in interviews unclear ● Most specific quantitative analyses and results were not included ● Unclear when results are from qualitative or quantitative data ● Small, purposeful sample	**4**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Gilmer, Foster, Vannatta, Barrera, Davies, Dietrich, Fairclough, Grolmman, & Gerhardt (2012) [18]	• In-person, semi-structured interviews with bereaved mothers, fathers, and siblings • Qualitative	• Bereaved mothers and fathers who lost a child to cancer at hospitals (n = 60 parents; n = 36 mothers, n = 24 fathers, and n = 39 siblings from 40 families) • USA • Canada	• Parents frequently experience a variety of changes in their personal lives, which include changes in emotions, perspectives and priorities, physical state, work habits, coping behaviors, spiritual beliefs, and feeling that something is missing	Strengths • 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 Limitations • Lack of racial and ethnic diversity in parents	**6**
Gilrane-McGarry & O'Grady (2011) [19]	• Grandparents who lost a grandchild to a range of causes were interviewed about their relationship with the child, their roles in the child's life, emotional response to the death, contact with health professionals and family dynamics	• Grandparents (n = 13 grandmothers, n = 4 grandfathers) of a child who died at least 6 months ago were interviewed • Ireland	• Three main themes about grandparents' experiences included: cumulative pain, factors helping to resolve pain, factors stopping the pain from resolving • Cumulative pain in this study referred to pain from prior loss, loss of grandchild, pain witnessing son/daughter's suffering, and grief	Strengths • 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 Limitations • Sampling strategy not specific with respect to cause of death and distribution of gender unequal • Distribution of gender unequal	**6**
Gilrane-McGarry & O'Grady (2012) [20]	• The purpose of the study was to describe the experiences of bereaved grandparents (part 2 of a two-part study) • Grandparents who lost a grandchild to natural causes were interviewed about their relationship with the child, their roles in the child's life, emotional response to the death, contact with health professionals and family dynamics	• Grandparents (n = 13 grandmothers, n = 4 grandfathers) of a child who died at least 6 months ago were interviewed • Ireland	• Grandparents expressed a desire to have their relationship with the deceased grandchild acknowledged, acknowledgement of the deceased child, acknowledgement of the relationship with the daughter or son, and support/care for self, and spiritual beliefs	Strengths • 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 Limitations • Sampling strategy not specific with respect to cause of death • Distribution of gender unequal	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Jalmsell, Kreicbergs, Onelov, Steineck, & Henter (2010) [21]	● Cross-sectional ● Descriptive study ● Self-report questionnaire of bereaved parents assessing symptoms affecting their child's well-being during their last month of life, and their own current psychological well-being	● Bereaved parents who lost a child to cancer (n = 449; n = 191 fathers, n = 251 mothers) ● Sweden	● Parents whose children were anxious during their illness reported depression, anxiety, decreased psychological well-being, and decreased quality of life more frequently than parents of children without anxiety ● Parents of children with disturbed sleep also had increased risk of depression, anxiety, decreased psychological well-being, and decreased quality of life ● The risk of anxiety was higher in parents who were further out from their loss ● The risk of depression was higher in parents closer in time to the death of their child	Strengths ● Sufficient sample size ● No selective reporting ● Appropriate analysis ● Study completed as planned ● No significant losses to follow-up or missing data Limitations ● Lack of blinding	**6**
Jalmsell, Onelov, Steineck, Henter, & Kreicbergs (2011) [22]	● Cross-sectional ● Non-experimental case control study ● Self-report questionnaire investigating physical and psychological well-being	● Bereaved parents who lost a child to cancer (n = 97 whose child had undergone a hematopoietic stem cell transplant [HSCT], n = 336 whose child had not undergone an HSCT) ● Sweden	● Bereaved parents whose children underwent HSCT had an increased risk of long-term anxiety, poor psychological well-being, low quality of life, and poor physical health ● Risks of these consequences were compounded in cases of multiple HSCT	Strengths ● Sufficient sample size ● Data collection appropriate to study method ● Evidence derived from high quality case control study ● No selective reporting ● Appropriate analysis ● Study completed as planned ● No significant losses to follow-up or missing data Limitations ● Discrepancy between data from instruments used	**4**
Kim, Lucette, & Loscalzo (2013) [23]	● Systematic review	● Bereaved family members (mixed) ● Countries of studies included not specified	● Greater psychological distress and poorer QOL in bereaved samples ● Around 6 months post-loss is when symptoms, loss of meaning, and use of services peak ● Larger comparative studies needed ● Specific bereavement guidelines are lacking	Strengths ● Important, relevant studies included ● Appropriately assessed for quality of studies ● Reasonable to combine results in this way ● Important outcomes considered Limitations ● Most studies reviewed were descriptive	**5**
Kreicbergs, Valdimarsgottir, Onelov, Henter, & Steineck (2004) [24]	● Cross-sectional ● Matched control ● Bereaved and non-bereaved parents completed questionnaires	● Bereaved parents who lost a child to cancer (n = 449) and non-bereaved parents (n = 457) ● Sweden	● Increased risk of anxiety and depression among bereaved parents, compared with non-bereaved ● Risk is higher 4-6 years after bereavement than 7-9 years	Strengths ● Sufficient sample size ● Evidence derived from high quality case control or cohort studies ● Reporting comprehensive, clearly described Limitations ● Uneven attrition rates across time since loss, with fewer responses from parents who are further out from their loss ● Parental age and marital status are potential confounding variables	**4**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Kreicbergs, Valdimarsdottir, Onelov, Bjork, Steineck, & Henter (2005) [25]	• Parents who lost a child to cancer were recruited through a population registry • Parents were mailed a questionnaire that had been developed using bereaved parent input	• Parents of a child who died of cancer between 4 and 9 years prior to the time of the study (n = 449; n = 191 fathers, n = 251 mothers, n = 7 unreported gender) • Sweden	• The two most significantly impactful factors on long-term distress were parents' perceptions that the child experienced unrelieved pain and a difficult moment of death	Strengths • Sufficient sample size • Appropriate analysis • Data collection appropriate to study method • Reporting comprehensive, clearly described Limitations • Cross-sectional • Evidence not derived from high quality case control or cohort studies	**6**
Lannen, Wolfe, Prigerson, Onelov, & Kreicbergs (2008) [26]	• Cross-sectional • Population-based cohort survey study	• Parents bereaved of children ages 25 or younger who died of cancer 4 to 9 years prior (n = 449) • Sweden	• 26% of parents reported they had not worked through their grief 4 to 9 years post-loss • Parents reporting unresolved grief had higher levels of anxiety and depression and poorer quality of life than those who worked through their grief • Fathers reporting unresolved grief reported more sleep difficulties and deteriorating physical and mental health in the past five years than those who worked through their grief • Mothers reporting unresolved grief reported more doctors visits and taking sick leave and were more likely to report deteriorating physical/mental health than those who had worked through their grief	Strengths • Sufficient sample size • Data collection appropriate to study method • Appropriate analysis • Reporting comprehensive, clearly described • Missing data described Limitations • Self-reported health • Single item assessment of unresolved grief • Did not account for correlated data between mothers and fathers of the same child • Homogeneous population • No matched control/comparison group	**4**
Lichtenthal, Currier, Neimeyer, & Keesee (2010) [27]	• Mixed methods • Cross-sectional • Written responses to open-ended questions • Self-report questionnaires	• Bereaved parents (n = 156) who lost a child to a variety of causes including miscarriage, stillbirth, natural expected (i. e., cancer), natural sudden, accident, suicide, homicide • USA	• The parents who could not make sense of their loss or identify benefits related to their loss experience had more maladaptive grief symptoms • 45% of parents could not make sense of their loss • 21% of parents could not identify benefits related to their loss	Strengths • Blinding or data collection appropriate to study method • Appropriate analysis • Evidence derived from high quality case control or cohort studies • Reporting comprehensive, clearly described Limitations • Sample not diverse (primarily Caucasian and female)	**4**
Lichtenthal, Wiener, Sweeney, Roberts, & Farberov (2012) [28]	• Cross-sectional • Questionnaires	• Bereaved mothers (n = 48) and bereaved fathers (n = 27) • USA	• Minorities showed significantly higher levels of PGD • Fewer minority parents sought mental health services	Strengths • Reporting comprehensive, clearly described Limitations • Sample not diverse	**4**
Lichtenthal, Neimeyer, Currier, Roberts, & Jordan (2013) [29]	• Cross-sectional • Written responses to open-ended questions • Self-report questionnaires	• Parents bereaved by violent and non-violent causes (n = 155) • USA	• There was overlap in sense-making strategies across violent vs. non-violent causes of death	Strengths • Blinding or data collection appropriate to study method • Appropriate analysis • Evidence derived from high quality case control or cohort studies • Reporting comprehensive, clearly described Limitations • Sample not diverse (primarily Caucasian mothers) • Small sample size in some cause of death categories	**4**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Lichtenthal & Breitbart (2015) [30]	• Review of literature	• Studies examining parents bereaved by cancer • Countries of studies included not specified	• Parents bereaved by cancer experience meaning-related challenges • Meaning-Centered Grief Therapy targets these issues	Strengths • Important, relevant studies included • Important outcomes considered Limitations • Did not comment on quality of studies included • Did not specify search strategy • Not a systematic review	**5**
Ljungman, Hoven, Ljungman, Cernvall, & Essen (2014) [31]	• Longitudinal • Self-report questionnaire	• Parents of children with cancer from diagnosis (n = 259) up to 5 years after end of treatment or a child's death • Sweden	• After a child's death, 19% of mothers and 8% of fathers reported levels indicative of at least partial posttraumatic stress disorder (PTSD) • Bereaved parents reported a high level of PTSSPTSD • For bereaved mothers, the prevalence of PTSD decreased with time and post-loss was equal to the prevalence among mothers of survivors	Strengths • Data collection appropriate to study method • Appropriate analysis Limitations • Poster abstract - Selective reporting	**6**
Lyngstad (2013) [32]	• Marriage and bereavement data from the Norwegian administrative register • Analyzed for the years 1970-2003 using a discrete time-hazard statistical model and matched control design	• Marriages in the Norwegian register that ended in divorce (n = 120,417) • Couples who lost a child younger than 20 years old (n = 4170) • Cause of death was not reported • Norway	• Higher divorce rate observed in bereaved parents as compared to non-bereaved parents • The divorce rate in bereaved parents increased over time • Authors emphasized that this difference in divorce rate is likely due to a number of confounding relationship and circumstantial factors	Strengths • Sufficient sample size • Appropriate analysis Limitations • Reporting not comprehensive as cause of death and other potential influences on the findings were not recorded and the data was limited by what was contained in the population registry	**4**
McCarthy, Clarke, Ting, Conroy, Anderson, & Heath (2010) [33]	• Cross-sectional • Descriptive • Standardized self-report questionnaire measuring prolonged grief disorder and depression • Structured interviews designed to elicit perceptions of their child's end-of-life care and burden of illness	• Bereaved parents who lost a child to cancer (n = 58) • Australia	• 10% of parents fulfilled criteria for a diagnosis of prolonged grief disorder • 41% of parents met diagnostic criteria for grief-related separation distress • 22% of parents reported clinically significant depressive symptoms • Time since death and parental perception of the oncologist's care predicted parental grief symptoms but not depressive symptoms • Perceptions of the child's quality of life during the last month, preparedness for the child's death, and economic hardship also predicted grief and depression outcomes	Strengths • Data collection appropriate to study method • Appropriate analysis • Reporting comprehensive, clearly described Limitations • Retrospective study which relies on parents' ability to accurately recall the circumstances surrounding their child's death • Small sample size limited the generalizeability of the findings	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
McClowry, Davies, May, Kulenkamp, & Martinson (1995) [34]	● Longitudinal study following families from 1 month post-loss onward ● Grounded theory was utilized to analyze sections of qualitative interviews with the parents that focused on experiences of an "empty space" or ongoing sense of loss following the child's death	● 150 interviews with family members were analyzed (n = 46 mothers, n = 33 fathers, and n = 71 siblings) ● USA	● The authors suggest families fall into three possible grieving patterns: "getting over it," "filling the emptiness," and "keeping the connection" ● Families who did not "get over it" or "fill the emptiness" continued to experience "empty space" for 7-9 years	Strengths ● Study context clearly described ● Sampling strategy appropriate for research question ● Method of data collection clearly described ● Qualitative approach clearly justified Limitations ● Research question was somewhat unclear and complicated ● Unclear why grounded theory was selected as the analysis method versus theoretical thematic analysis ● Role of the researchers was not clearly described	**6**
Middleton, Raphael, Burnett, & Martinek (1998) [35]	● Longitudinal design ● Questionnaire administered at 4 time points over 13 months	● Bereaved spouses (n = 44), bereaved adult children (n = 40), and bereaved parents (n = 36) who lost family members to cancer, accidents, heart disease, or other illnesses ● Australia	● Intensity of grief for parents who lost a child was higher than for widow/ers, who had more intense grief than adult children losing a parent	Strengths ● 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 Limitations ● High drop-out rates (8 spouses, 9 adult children, 7 parents)	**3**
O'Connor & Barrera (2014) [36]	● Longitudinal ● Qualitative ● Prospective Semi-structured interviews exploring self identify with parents at 6, 12, and 18 months following the death of a child to cancer	● Parents who lost a child to cancer (n = 26; n = 16 mothers; n = 10 fathers) ● Canada	● A subset of parents experienced identity disintegration (unable to positively reframe, limited personal growth and purpose, negative perceptions of social support, difficulty with permanence of death, inability to envision their own future, lack of fulfillment in life, difficulty parenting surviving children, self-destructive thoughts and behaviors) ● Patterns were stable from 6 to 12 months with a shift toward identify disintegration observed at 18 months ● Waning social support between the 12- and 18-month marks, as well as social expectations regarding how long it should take bereaved parents to "recover," were repeatedly discussed by parents in the mixed reintegration–disintegration group	Strengths ● Research question clearly stated ● Qualitative approach clearly justified ● Study context clearly described ● Method of data collection clearly described ● Method of data analysis clearly described Limitations ● Challenges with maintaining sample diversity at the 18-month interviews, when fathers and minority-group parents were more likely to drop out	**6**

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SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Saiki-Craighill (2001) [37]	● Interviews conducted before and after participation in a support group held for approximately 2 years ● Support group discussions were also used as sources of data	● Mothers who lost a child to cancer and who were attending a support group ran by the author (n = 24) ● Japan	● The chronological experiences of the mothers were presented as themes, including initial numbness, grieving period, post-traumatic growth, and narrative reconstruction	Strengths ● Qualitative approach clearly justified ● Study context clearly described ● Sampling strategy appropriate for research question Limitations ● While the role of the researcher was clearly described, her potential biases could have been defined more clearly given she was the interviewer and conducted the analyses without consensus coding ● Analysis was appropriate for research question, but the generalizeability of the findings is somewhat over-stated	**6**
Saiki-Craighill (2002) [38]	● Open-ended interviews focusing on mothers' experiences during and after their child's death	● Japanese mothers who lost a child to cancer (n = 57)	● Themes resulting from the qualitative analysis included: factors regulating the mothers' role as caregiver (e.g., lack of support), becoming tougher (e.g., maintaining emotional stability), changing perceptions of life and death (e.g., becoming connected with the deceased child), and changing values	Strengths ● 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 Limitations ● While the role of the researcher was clearly described, her potential biases could have been defined more clearly given she was the interviewer and conducted the analyses without consensus coding ● Analysis appropriate for research question but the study lacked quality assurance checks	**6**
Schwartz, Manring, Misiti, Eversole, Barrera, Compas, Fairclough, Foster, Gilmer, Vannatta, & Gerhardt (2013) [39]	● Cross-sectional ● Case control study	● Families bereaved by cancer with a surviving child (n = 88) and matched comparison families (n = 73) ● USA	● Mothers' internalizing problems were associated with their children's internalizing problems; this pattern was not observed in fathers ● Findings similar between bereaved parents and controls	Strengths ● Data collection appropriate to study method ● Appropriate analysis ● Reporting clearly described Limitations ● Poster abstract - Selective reporting	**4**
Sirkia, Saarinen-Pihkala, & Hovi (2000) [40]	● Cross-sectional ● Retrospective ● Descriptive ● Structured interviews	● Parents of children who died of cancer while in terminal care (n = 60) and parents of children who died of cancer while on active therapy (n = 26) ● Finland	● Minimal differences between families who lost a child after terminal care and those whose child died during active anticancer therapy ● Mothers reported it took a longer time to come to terms with their loss than fathers and returned to work later ● Parents of children over the age of 12 years reported it took longer to come to terms with their loss than parents of children under age 12	Strengths ● Data collection appropriate to study method ● Appropriate analysis ● Reporting clearly described ● Issues with follow-up clearly described Limitations ● Insufficient sample size limited the generalizeability of the findings	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Sormanti & August (1997) [41]	• Qualitative • Open-ended questionnaire	• Bereaved parents who lost a child to cancer (n = 43)	• All parents noted at least one way they remained connected to their child • The majority of parents reported spiritual experiences related to their child	Strengths • Research question clearly stated • Qualitative approach clearly justified • Study context clearly described • Sampling strategy appropriate for research question • Method of data collection not clearly described • Analysis appropriate for research question Limitations • Role of the researcher not clearly described • Method of data analysis not clearly described • Low response rate	**5**
Surkan, Kreicbergs, Valdimarsdottir, Nyberg, Onelov, Dickman, & Steineck (2006) [42]	• Cohort study • Used mailed anonymous questionnaire	• Bereaved parents who lost a child to cancer (n = 449) • Sweden	• 19% of parents reported experiencing guilt weekly or daily in the year after their child died • Higher levels of guilt were found in parents who reported the staff did not take the initiative to offer supportive counseling and in those who did not access psychological support • Guilt among non-depressed parents was associated with dissatisfaction with their child's care; feeling that something went wrong in handling the child's death; feeling uncertain that the child would get immediate help; feeling that the medical staff was incompetent; feeling that their child did not have access to dietary advice, pain relief, or psychological support; feeling they could not get information in a dignified way or that they did not get answers from the medical team; and not knowing that their child would die in the week before his/her death	Strengths • Sufficient sample size • High response rate • Use of anonymous questionnaire • Data collection appropriate to study method • Appropriate analysis • Evidence derived from high quality cohort study • Reporting comprehensive, clearly described Limitations • Only face validity of questionnaire was evaluated, no other psychometrics assessed • Use of single item to assess guilt • Retrospective reporting about psychological state in year after child died • No matched control or comparison group • Did not account for correlated data between mothers and fathers of the same child • Did not correct for conduct of multiple statistical tests	**4**
Thompson, Miller, Barrera, Davies, Foster, Gilmer, Hogan, Vannatta, & Gerhardt (2011) [43]	• In-person, semi-structured interviews with bereaved family members • Qualitative	• Bereaved parents and siblings who lost a child to cancer (n = 99 family members, including mothers [n = 36], fathers [n = 24], and siblings [n = 39], from 40 families) • USA • Canada	• Reliance on social support, including support within the family, community, and professional counseling soon after the death • Importance of "talking about it" to others soon after the death • Advice to never forget the child who died and maintain a continued bond with the child	Strengths • 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 Limitations • No information about parents who refused participation	6

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Vega, Rivera, & González (2014) [44]	- Qualitative phenomenological study - Open-ended interviews - Analyzed using Streubert's method	- Parents bereaved by cancer 2 to 6 years post-loss (n = 8) - Chile	- Finding meaning in the child's life and death and helping other bereaved parents also played an important part in adaptation	Strengths - 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 Limitations - Convenience sample recruited from foundation - Sample restricted to those not depressed	**6**
Wiener, Aikin, Gibbons, & Hirschfeld (1996) [45]	- Cross-sectional - Descriptive study - Used questionnaire measuring distress (standardized tool) and questions exploring how parents grieve	- Parents whose child had died from HIV (n = 48) or cancer (n = 8) - USA	- The majority of parents were comforted by evocative experiences, which helped them feel connected to their child	Strengths - Study context clearly described - Sampling strategy appropriate for research question - Sufficient sample size Limitations - Method of data analysis unclear - Role of the researcher not stated	**6**
Woodgate (2006) [46]	- Qualitative - Interviews focused on parents' lives before, during, and after their child's death - Phenomenological qualitative analysis	- Parents who lost a child (n = 17 mothers, n = 11 fathers) - The cause of the child's death varied with 5 of the 18 children dying of cancer - Canada	- Parents had experienced a sense of closure and did not want closure because of their desire to continue the bond with their child - Highlighted that health professionals should be aware that parents may not see closure as a treatment goal	Strengths - Research question clearly stated - Qualitative approach clearly justified - Study context clearly described - Sampling strategy appropriate for research question - Analysis appropriate for research question Limitations - Method of data analysis clearly described but there was a lack of consensus coding as a quality check - While the role of the researcher clearly described in that the author conducted the interviews and analysis, it was not made clear what the author's biases might be; this is especially important given the lack of consensus coding	**6**
Wu, Bonanno, DuHamel, Redd, Rini, Austin, Nereo, Ostroff, Parsons, Martini, Williams, Mee, Sexson, & Manne (2008) [47]	- Longitudinal - Descriptive - Prospective face to face or telephone administered questionnaire exploring the association of meaning making with psychological adjustment to distress among mothers of children who had undergone Hematopoietic Stem Cell Transplant (HSCT)	- Mothers whose child with cancer had undergone HSCT (n = 35) - USA	- 37% of mothers whose child had an HSCT scored in the mild to moderate range of distress symptoms postloss, 17% in the moderate to severe range, and 6% in the severe range - Searching for meaning from their child's illness at the time of HSCT was associated with postloss distress - Finding meaning in their child's illness during the HSCT predicted less postloss distress	Strengths - Data collection appropriate to study method - Appropriate analysis - Reporting comprehensive, clearly described - Issues with follow-up or missing data clearly described Limitations - Small sample size - Large number of participants refused to participate in the study	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Bereavement Outreach Efforts and Formal Interventions					
Adams, Green, Towe, & Huett (2013) [48]	• Qualitative • Used in-depth interviews • Content analysis	• Bereaved parents who participated as educators in a pediatric palliative care education program (n = 9) • Health care professionals (n = 11) • USA	• For families, a sense of purpose emerged from participation, giving additional meaning to their child's lives, helping to assure that their child will not being forgotten, helping other families and staff understand families better and giving back to the hospital for the care they received • Recommendation to choose parents who can balance being a parent and educator, share without being overwhelmed, and can consider other perspectives	Strengths • Qualitative approach justified • Methods (data collection, role of researcher, training, analyses) well described • Study completed as planned Limitations • Having parents present may have limited health care professionals, openness and frankness	**6**
Aho, Astedt-Kurki, Tarkka, & Kaunonen (2010) [49]	• Phases of "action research" include baseline study on fathers grief and social support, survey of existing bereavement support system in Finnish university hospitals, a systematic literature review, and collaboration with experts	• University hospitals (n = 25) • Systematic literature review (20 studies met inclusion criteria) • Finland	• Addressed the steps needed in developing a bereavement program • Combination data suggests that a follow-up bereavement program should focus on the whole family • A wide variation in the bereavement follow-up provided to bereaved parents was found • Fathers experienced a lack of support after leaving the hospital • Support provided mainly about memorial services • Recommendations provided on how to implement a bereavement support intervention within nursing practice	Strengths • Important, relevant studies included • Appropriately assessed quality of studies • Reasonable to combine results in this way • Important outcomes that led to the developed intervention considered Limitations • In the study of current bereavement programs, limited information provided to assess rigor • Research with experts: Limited information provided to assess rigor	**6**
Aho, Tarkka, Astedt-Kurki, Sorvari, & Kaunonen (2011) [50]	• Comparison of self-report data from bereaved fathers receiving a bereavement intervention with a control group of bereaved fathers who did not receive the intervention • Intervention included support, peer contact, and health care personnel contact • Quantitative	• Bereaved fathers who lost a child at a hospital in (n = 103 fathers, 62 of whom received the intervention and 41 of whom were selected as controls) • Finland	• Fathers receiving the intervention felt that they received more support from health care personnel and peer supporters • Fathers generally reported that this support was helpful • Fathers in the intervention group reported more personal growth around their grief, although there were few other differences in grief	Strengths • Sufficient sample size • Blinding or data collection appropriate to study method • Appropriate analysis Limitations • Limited to descriptive analysis • No information provided about recruitment • No specific information about services received in the control group • Control group and intervention group were from different hospitals, and there were differences between these two groups at baseline	**4**

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SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Baker, Windham, Hinds, Gattuso, Mandrell, Gajjar, West, Hammarback, & Broniscer (2013) [51]	• Cross-sectional • Prospective multicenter mixed methods study • Decisional regret survey • Structured telephone interview • Explored parents' perceptions about participating in autopsy-related research	• Bereaved parents who lost a child to cancer (n = 33) • USA	• 30.3% of parents had been in contact with bereavement resources • 15.2% reported were not in contact with bereavement resources and express a need for bereavement follow-up, suggesting a total of 45.5% had a wish for bereavement support	Strengths • 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 Limitations • Generalizeability of findings limited due to study inclusion criteria	**6**
Eggly, Meert, Berger, Zimmerman, Anand, Newth, Harrison, Carcillo, Dean, Willson, & Nicholson (2011) [52]	• In-depth interviews with parents whose child died in the pediatric intensive care unit (PICU) about their desire to meet their child's physician post-loss, location, and who they would like to be present • Interviews were also conducted with PICU physicians • A thematic analysis was conducted to develop the framework for follow-up	• Qualitative interviews conducted with parents whose child died in the PICU (n = 56) and PICU physicians (n = 70) • USA	• A follow-up framework was developed that included invitations, meeting preparation (family preferences, attendees, discussion topics, inviting hospital staff, reviewing patient history), and conducting the meeting • Follow-up instructions for after the meeting were provided for parents and physicians	Strengths • The framework was developed based on interviews with two stakeholder groups • Analysis appropriate for research question Limitations • Thematic analysis was briefly described as analysis method but details about coders etc. were not provided	**6**
Eggly, Meert, Berger, Zimmerman, Anand, Newth, Harrison, Carcillo, Dean, Willson, & Nicholson (2013) [53]	• Qualitative interviews with physicians who conducted follow-up meetings with bereaved parents about use of the word, "closure"	• Critical care physicians (n = 67) • Analysis focused on the interviews of 38 physicians who mentioned the word closure in their interview • USA	• Closure was described as being facilitated by gaining an understanding of the causes of death, reconnecting in relationships • Physicians' feedback indicated follow-up meetings can be important for closure in bereaved parents	Strengths • Qualitative approach clearly justified • Study context clearly described • Sampling strategy appropriate for research question • Method of data analysis clearly described analysis appropriate for research question Limitations • While the role of the researcher was described, potential biases could have been defined more clearly	**6**
Eggly, Manning, Slatcher, Berg, Wessel, Newth, Shanley, Harrison, Dalton, Dean, Doctor, Jenkins, & Meert (2015) [54]	• Qualitative interviews with parents were interviewed about their impressions of a bereavement follow-up meeting with physicians • Linguistic Inquiry and Word Count (LIWC) was used to analyze the results looking at positive and negative emotion words	• Pediatric intensive care unit (PICU) physicians (n = 23) and parents (n = 53) whose child died in the PICU participated • Parents were Spanish and English speaking • 74% of children died from chronic conditions • USA	• Parents used more positive emotion words than negative as the meeting progressed, which the authors suggested showed that the meetings were helpful to parents	Strengths • Research question clearly stated • Sampling strategy appropriate for research question • Method of data analysis clearly described Limitations • Insufficient sample size • While LIWC as an analytic approach can be useful, it was not clear why this approach was used rather than a thematic analysis • Role of researcher not clearly stated	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Granek, Barrera, Scheinemann, & Bartels (2015) [55]	• Cross-sectional • Qualitative study • Interviews • Grounded theory method of data collection	• Pediatric oncologists (n = 21) • Canada	• Pediatric oncologists engaged in follow-up practices in a number of ways including: making phone calls (n = 13); sending condolence cards or emails ('always' n = 10); attending funerals ('some of the time' n = 13); visitations (n = 5); short-term/long-term meetings with parents (n = 14); and participation in hospital memorials (n = 5) • Primary nurse or social worker made the follow-up phone call on behalf of the team if the oncologist was unable • Barriers to not engaging in follow-up practices included logistical (e.g., time constraints) and emotional	<u>Strengths</u> • 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 <u>Limitations</u> • Method of data collection not clearly described • Small sample size, not generalizeable results	**6**
Hechler, Blankenburg, Friedrichsdorf, Garske, Hubner, Menke, Wamsler, Wolfe, & Zernikow (2008) [56]	• Semi-structured interviews done in person or by phone	• Parents who lost a child to cancer (n = 48) • Germany	• 41 parents said the medical team contacted them after the death • The majority of parents were contacted by multiple members of the medical team • 15% of parents were not contacted by anyone	<u>Strengths</u> • 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 <u>Limitations</u> • Low response rate • Sample lacked generalizeability • Parental attitudes towards the different centers involved may have influenced their participation	**6**
Heiney, Ruffin, & Goon-Johnson (1995) [57]	• One 7-session group of parents was studied • Participants completed pre- and post-test questionnaires measuring emotional status, family adjustment, social adjustment, utility of and satisfaction with the group • Co-therapists provided qualitative data in a group process log	• Parents who lost a child to cancer (n = 5 parents) • 12 parents began the group but only 5 completed • USA	• Parents described a decrease in depression and mistrustfulness post-intervention • No changes were found in family and social adjustment	<u>Strengths</u> • Descriptive analyses appropriate given the small sample size • Reporting comprehensive, clearly described <u>Limitations</u> • Insufficient sample size • Evidence not derived from high quality case control or cohort studies	**3**
Jankovic (1999) [58]	• Descriptive report of meetings with parents after the death of their child from leukemia	• Bereaved couples were approached after the death of their child (n = 74)	• Parents needed to talk to the physician who cared for their child • Physicians should routinely be available to parents shortly after a child's death	<u>Strengths</u> • Descriptive analyses appropriate given the small sample size • Reporting comprehensive, clearly described <u>Limitations</u> • Descriptive findings • No systematic qualitative analysis	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Liisa, Marja-Terttu, Paivi, & Marja (2011) [59]	• Open-ended questionnaire and subsequent clarifying interviews with health care professionals • Qualitative	• Health care professionals who participated in providing a bereavement follow-up intervention (n = 29 providers) • Finland	• Providers had positive impressions of the intervention and its viability • Health professionals perceived supporting grieving families as important and rewarding • Found parents were willing to receive support • Resources for providers were considered important • Implementation difficult because of scarce resources but made easier by co-worker support • Continuous education about bereavement follow-up care is vital, and inter-organizational cooperation is important and feasible	Strengths • Research question clearly stated • Qualitative approach clearly justified • Study context clearly described • Role of the researcher clearly described • Method of data collection clearly described • Method of data analysis clearly described • Analysis appropriate for research question Limitations • Sample composed entirely of female staff members • No systematic recruitment of staff members, all participants volunteered	6
MacDonald, Liben, Carnevale, Rennick, Wolf, Meloche, & Cohen (2005) [60]	• Cross-sectional • Qualitative study • Semi-structured interviews and field observations in family homes regarding the experience of the death of their child	• Bereaved parents (n = 12) who lost a child in the pediatric intensive care unit (PICU) • Canada	• Parents placed great importance on the hospital's memorial service and on staff member's presence at the service • Parents found it difficult to return to the hospital after the child's death, however all attended the memorial service and found some closure in the return • Parents appreciated receiving cards and valued staff members' efforts to telephone/visit and attend the funeral • Parents expressed disappointment when staff members did not engage in these activities	Strengths • Adequate sample size • Qualitative approach clearly justified • Sampling strategy appropriate for research question • Method of data collection clearly described • Role of the researcher clearly described • Method of data analysis clearly described • Study completed as planned • No selective reporting Limitations • Lack of blinding	**6**
Meert, Eggly, Pollack, Anand, Zimmerman, Carcillo, Newth, Dean, Willson, & Nicholson (2007) [61]	• Cross-sectional • Qualitative study • Audio recorded telephone interviews with parents of children who died in the pediatric intensive care unit	• Bereaved parents (n = 56) who lost a child in the pediatric intensive care unit (PICU) to a variety of causes • USA	• 63% of parents had spoken with one or more hospital workers since their child's death • 25 parents (45%) had spoken with a nurse or ancillary health provider, and 12 (48%) of these had planned professional contacts for psychosocial support • 13% of parents had a scheduled meeting with a physician to discuss their child's death • 59% wanted to meet with their child's intensive care physician • 82% were willing to return to the hospital to meet • Parents wished to discuss the chronology of events leading to PICU admission and death, cause of death, treatment, autopsy, genetic risk, medical documents, withdrawal of life support, ways to help others, bereavement support, and what to tell family • Parents described the meeting as a way of seeking reassurance and the opportunity to voice complaints and express gratitude	Strengths • Research question clearly stated • Qualitative approach clearly justified • Study context clearly described • Method of data collection clearly described • Method of data analysis clearly described • Analysis appropriate for research question Limitations • Issues with large number of parents who could not be contacted and the predominance of mothers among participants	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Meert, Schim, & Briller (2011) [62]	• Cross-sectional • Qualitative • Semi-structured audio recorded telephone interviews of critical care physicians regarding follow up meetings with parents after a child's death in the pediatric intensive care unit (PICU)	• Critical care physicians (n = 70) • USA	• Twenty-three (33%) physicians reported never participating in a follow-up meeting with bereaved parents; 22 (31%) participated in one to five meetings, and 25 (36%) participated in more than five meetings • Of those with prior experience, 44 (94%) met with parents at the hospital and 40 (85%) met within 3 months of the death • Meeting content included discussing autopsy, parent questions, hospital course, cause of death, genetic risk, bereavement services, and legal or administrative issues; providing emotional support; and receiving parent feedback • Forty (85%) physicians perceived the meetings to be beneficial to families, and 35 (74%) to physicians • Physicians suggested that a systematic hospital process for meeting initiation and planning would allow follow-up meetings to be more easily integrated into clinical practice (e.g., having a designated social worker to contact parents, assess parents' preferences, schedule time and place)	Strengths • Research question clearly stated • Qualitative approach clearly justified • Study context clearly described • Method of data collection clearly described • Method of data analysis clearly described • Analysis appropriate for research question Limitations • Small sample size	**6**
Meert, Eggly, Berg, Wessel, Newth, Shanley, Harrison, Dalton, Clark, Dean, Doctor, & Nicholson (2014) [63]	• Cross-sectional • Qualitative (video recorded follow-up meetings between bereaved parents and critical care physician) • Post-meeting survey	• Parents bereaved by a range of causes, including cancer (n = 54; n = 33 mothers, n = 21 fathers), parents' support persons (n = 17), critical care physicians (n = 23), and other health professionals (n = 47) • USA	• 46 of parents (92%) agreed or strongly agreed the meeting was helpful for them • 33 of critical care physicians (92%) agreed or strongly agreed that the meeting was beneficial to parents and 31 (89%) indicated it was beneficial to them • Aspects of the meeting parents perceived most helpful included the opportunity to gain information, receive emotional support, and provide feedback in an honest and non-threatening style of communication • Least helpful aspects were the need for additional information that was not available or communicated clearly and the desire for different support staff at the meeting • Aspects of the meeting physicians described as most helpful included having a system for inviting parents and arranging the meeting and having a structure to guide the meeting • Least useful aspects described by physicians was the need for more structure to the meeting for inexperienced physicians • Physicians benefited by reconnecting with parents, gaining a deeper understanding of parents' perspectives and achieving a sense of closure	Strengths • 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 Limitations • Low parent participation rate limits the generalizeability of findings	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Meert, Eggly, Kavanaugh, Berg, Wessel, Newth, Shanley, Harrison, Dalton, Dean, Doctor, Jenkins, & Park (2015) [64]	• Video recorded parent-physician bereavement meetings	• Parents of 35 deceased children who died from a range of causes, including cancer (n = 53)	• Sense-making, benefit finding, continuing bonds, and identity reconstruction were observed in bereavement meetings • Parent-physician meanings facilitate meaning-making in parents	Strengths • 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 Limitations • Self-selection of participants • Inability to distinguish between meaning-making efforts and meaning made	**6**
Nikkola, Kaunonen, & Aho (2013) [65]	• Self-report data from bereaved mothers receiving a bereavement intervention • Intervention included support, peer contact, and health care personnel contact • Quantitative	• Bereaved mothers who lost a child at a hospital who received a bereavement intervention (n = 86) • Finland	• Mothers felt that the support they received was useful and helped them in coping with their loss • Most mothers felt that they received helpful support from health professionals and peers with this intervention	Strengths • Sufficient sample size • Data collection appropriate to study method • Appropriate analysis Limitations • Limited to descriptive analysis • No information provided about recruitment	**4**
Welch, Mannix, Boergers, Jelalian, Barbosa, Fuijii-Rios, & Forman (2012) [66]	• Cross-sectional • Qualitative • Questionnaire assessing parental interest in and preferences for a pediatric oncology home visit following a child's death from cancer	• Bereaved parents (n = 31) who lost a child to cancer • USA	• 84% of participants agreed that a home-based bereavement program is desirable • 64% thought that they would have personally benefited from such a program • 22% expressed some perceived psychological risk from the proposed program 'may feel like you're dragging out the bereavement process' • 29.3% expressed some unmet need related to their family's bereavement 'you don't have the support you had while your child is sick'	Strengths • Research question clearly stated • Qualitative approach clearly justified • Study context clearly described • Method of data collection clearly described • Method of data analysis clearly described Limitations • Small sample size • Only 30% of eligible families participated • Lack of detailed demographic data	**6**
Wilkinson, Croy, King, & Barnes (2007) [67]	• Qualitative interviews • Purposive sampling	• A purposive sample of parents whose family had and had not used hospice bereavement services (n = 25) • United Kingdom	• Parents whose surviving child participated in bereavement services expressed it had been generally helpful for the family, assisting bereaved children at home and school and reducing their sense of isolation • Families who had refused support services had done so generally because they felt they did not need professional support	Strengths • Research question clearly stated • Qualitative approach clearly justified • Study context clearly described • Sampling strategy appropriate for research question • Method of data collection clearly described Limitations • Method of analysis was not described in detail beyond identifying thematic analysis • Role of the researcher was not clearly described	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Need for Bereavement Follow-up and Services					
Belletrutti, Nicholas, Barrera, Beaune, & Blumberg (2014) [68]	• Cross-sectional • Qualitative • Interviews • Focus groups	• Fathers of children with cancer (n = 15), and fathers bereaved by cancer (n = 6) • Canada	• Fathers described a need for support (clinical and community based) and potential benefits of engaging in support (e.g., giving and receiving tangible supports) • Fathers described use of technology and peer-based activities as a means of support	<u>Strengths</u> • Research question clearly stated • Study context clearly described • Method of data collection clearly described <u>Limitations</u> • Poster abstract – not able to fully assess rigor	**6**
Brooten, Youngblut, Seagrave, Caicedo, Hawthorne, Hidalgo, & Roche (2013) [69]	• Qualitative data were collected at 7 and 13 months post-death using semi-structured audio-recorded interviews	• Bereaved parents (n = 63) who had lost a child in the neonatal intensive care unit (NICU) or pediatric intensive care unit (PICU) from 4 hospitals • USA	• Compassionate, sensitive, caring staff and understandable explanations helped parents the most • Competent nursing staff, perception that providers did everything to help the child, and parents involvement in care and decisions were all found as helpful • After the child's death, staff that cried and/or prayed with the parents, went to the child's funeral, and telephoned the parents were perceived as caring, sensitive, and compassionate	<u>Strengths</u> • Research question clearly stated • Qualitative approach clearly justified and described • Role of the research team, method of data collection, and data analysis clearly described <u>Limitations</u> • Limited information to evaluate the sampling strategy • Study limitations not addressed	**6**
Butler, Hall, Willetts, & Copnell (2015) [70]	• Integrative review, critique, and synthesis of current research studies that examined parental perceptions of healthcare provider actions during and after the death of a child	• 15 research studies • Countries of studies not specified	• 10 studies made some mention of follow-up care or contact between parents and hospital staff, including actions such as phone calls or cards from staff, funeral attendance, nurse-run bereavement follow-up services that were well received • Lack of follow-up care or a card or phone call was noted as unhelpful in several studies. Lack; lack of follow-up often left families feeling isolated or abandoned • Very few studies addressed the frequency of ongoing contact between hospital staff and parents	<u>Strengths</u> • Appropriate and relevant types of papers included • Studies appropriately assessed for quality • Critical Appraisal Skills Programme (CASP) methodology for literature appraisal reasonable • Interpretation and analyses well documented • Important outcomes considered <u>Limitations</u> • Majority of studies reviewed were undertaken in either the United States or Canada: limited diversity noted	**1**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Clerici, Ferrair, Massimino, Luksch, Cefalo, Terenziani, Casanova, Spreafico, Polastri, Meazza, Podda, & Fossati-Belani (2006) [71]	● Retrospectively identified parents who spontaneously contacted medical staff ● Families contacted by telephone and administered a semi-structured interview to assess bereavement process and needs ● Literature review	● Parents who lost a child to cancer (n = 17) contacted ● Italy	● Half of the families who lost their child during the study period contacted the hospital ● Families mostly wanted to say hello and express thanks, some wanted to make offers and provide gifts, others wanted medical explanation, many spoke of a need to connect with people familiar with 'how they fought their child's disease for months', and to connect with other patients; no contact was made to complain ● Most calls well received; some expressed disappointment by the lack of the call until then ● Having a physician on the phone helped reduce guilty feelings of not having done enough ● Parents reported feeling more serene and grateful by the end of the call ● During the call, 'dysfunctional coping mechanisms' were identified and staff offered follow-up interventions ● Physicians appreciated being in touch with families, helping to support them, and would have otherwise avoided the pain ● Findings highlighted the strong need, primarily of the families but also of the hospital team to restore contact, to review the cancer treatment experience, provide explanation and to assess the psychological needs of parents who have lost their child to cancer	Strengths ● Research question clearly stated ● Qualitative approach clearly justified ● Study context clearly described Limitations ● No qualitative analyses used ● Calls were not recorded ● No analytic measures to review the literature described	**6**
Contro, Larson, Scofield, Sourkes, & Cohen (2002) [72]	● In-person, structured or semi-structured interviews with bereaved parents ● Qualitative	● Bereaved family members, mostly parents, of children who died, (28 due to cancer) (n = 68 family members, including 59 parents and 44 children ● USA	● Bereavement follow-up was inconsistently offered, but when it was, it was appreciated	Strengths ● 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 Limitations ● High rate of refusal and unreachable, no description of these families	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Contro & Sourkes (2012) [73]	• In-person, semi-structured interviews with staff members at a children's hospital from multiple different disciplines • Qualitative	• Interdisciplinary staff members (n = 60) participating in bereavement care at a children's hospital • USA	• Bereavement care can depend on the relationship between staff and families • Logistical factors (time, space, geography) play a role in offering bereavement services • Importance of culture and languages of families • Importance of continuity of care in bereavement follow-up • Importance of needs of siblings and other family members • Importance of staff communication cooperation and care coordination • Staff suffering in offering these services • Need for education, mentoring, and staff support	<u>Strengths</u> • Research question clearly stated • Qualitative approach clearly justified • Study context clearly described • Role of the researcher clearly described • Method of data collection clearly described • Method of data analysis clearly described • Analysis appropriate for research question <u>Limitations</u> • Sampling strategy may not be appropriate for research question, with services nominating staff members for interviews • Interviews potentially conducted by colleagues	**6**
Copnel (2005) [74]	• Literature review of research findings on neonatal intensive care unit (NICU) deaths and suggests future directions for research to improve care	• 62 articles addressing modes of death; decision-making; managing the dying process; nurses, clinicians, and parent perceptions; and bereavement follow up	• Highlighted major gaps in research, most reports (2005) were descriptive • Support for bereaved parents seen as increasingly the responsibility of the hospital staff, reviewing nurse-managed bereavement programs • Programs had similar components – written information at the time of death, cards, letters, telephone calls for 1-2 years after the child's death, remembrance services, referral to other services as required; several programs included a bereavement counselor • Bereavement care at time of death was reviewed by nursing staff as beneficial to families and helped their own grief and increased their confidence in caring for parents, which, in turn, increased the parents' confidence in them • Nurses less comfortable with reaching out to parents after death and the need for more education on bereavement • Limited data on parent perceptions of bereavement outreach • The papers reviewed were generally positive with families wanting more contact with their child's physician • One study showed beneficial effect on the grieving process	<u>Strengths</u> • Appropriate types of papers included • Important, relevant studies included • Well written, described study limitations • Appropriate recommendations provided <u>Limitations</u> • Methodology not described	**5**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
D'Agostino, Berlin-Romalis, Jovcecska, & Barrera (2008) [75]	● In-person, structured, or semi-structured focus group with bereaved parents ● Qualitative	● Bereaved parents of children who lost a child to cancer at a hospital (n = 7 parents of 6 children) ● Canada	● Importance of flexible and continuous bereavement services from the hospital ● Helpful to talk to other parents with similar experiences ● Helpful to maintain contact with staff	Strengths ● Research question clearly stated ● Qualitative approach clearly justified ● Study context clearly described ● Role of the researcher clearly described ● Method of data collection clearly described ● Method of data analysis clearly described ● Analysis appropriate for research question Limitations ● Small, convenience sample of parents participating in a single focus group	**6**
Darbyshire, Cleghorn, Downes, Elford, Gannoni, McCullagh, & Shute (2013) [76]	● In-person, unstructured, or semi-structured interviews with bereaved parents about a bereavement support program ● Qualitative ● Additional, preliminary study involved interviews with bereaved parents prior to the bereavement program, although these were not described in detail	● Bereaved parents who lost a child to cancer and who participated in a support program offered in the first year of bereavement (n = 6 parents from 5 families) ● Additional participants in a preliminary study included bereaved parents from the same hospital prior to the implementation of the bereavement program (n = 7 pairs of parents, not described in detail) ● Australia	● Program offered in the first year of bereavement described as supportive ● Appreciated ongoing contact with nurses who knew them ● Telephone contact preferred because of painful memories associated with returning to the hospital ● Calls are important in creating meaning and memory around the child ● Preliminary study found that prior to this program, support was offered erratically and that more contact would have been appreciated	Strengths ● Research question clearly stated ● Study context clearly described ● Role of the researcher clearly described ● Method of data collection clearly described ● Method of data analysis clearly described ● Analysis appropriate for research question Limitations ● Small sample with limited description of parents or children ● Very few participating fathers ● Lack of quantitative data evaluating this program ● Method not clearly described for preliminary study	**6**
Davies (2005) [77]	● In-person, unstructured or semi-structured interviews with bereaved mothers ● Qualitative	● Bereaved mothers who lost a child to a life-limiting condition in the last three years (n = 10 parents, 5 of whom had access to a children's hospice, 5 of whom did not) ● United Kingdom	● Mothers' need for time, space, and privacy with their dying child and their child's body after death ● Mothers' memories of these events have an impact during bereavement	Strengths ● 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 Limitations ● Small sample size, especially when divided up into mothers who had access to hospice care and mothers who did not	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
deCinque, Monterosso, Dadd, Sidhu, MacPherson, & Aoun (2006) [78]	• In-person, unstructured interviews with bereaved parents • Qualitative	• Bereaved parents who lost a child to cancer (n = 9 parents of 6 children) • Australia	• Parents experience intense grief, even far out from the loss • Need for supportive contact from hospital staff following the child's death • Need for contact with other bereaved parents • Need for formal grief support for siblings	Strengths • 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 Limitations • High refusal rate among contacted parents	**6**
Dent, Condon, Blair, & Fleming (1996) [79]	• 2-year qualitative, retrospective study carried out in 11 health districts • Postal questionnaires developed by the study team	• Bereaved parents who lost children to accident or illness (n = 42) returned questionnaires (58% response rate) • United Kingdom	• More than half the parents were not offered follow-up care at the hospital to talk of the death with a pediatrician • Of those that were, 88% thought the meeting was helpful • Only 13% of families received formal support from their general practitioners and 12% from health visitors • Those who had been helped by their general practitioner and/or health visitor commented how helpful this had been • Only 36% made contact with a local support group • A further 18% said they would have liked to • 55% reported they had experienced a serious strain in their relationship with their partner • Two-thirds of parents turned to other bereaved parents • Three-quarters of families spoke of difficulties with their surviving children • Only 27% of these families received advice from health professionals about the needs of grieving siblings and only two of the children were receiving professional support • Two-thirds of the parents thought the health professionals could have been more helpful in dealing with bereaved siblings • Many parents advocated the need for professionals to conduct home visits and to make regular contact	Strengths • Research question clearly stated • Qualitative approach justified • Sampling strategy appropriate for the research question • Challenges well described Limitations • Data analyses appear purely descriptive, not well described • Number of families that could be included was small in comparison to those that were identified	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. *(Continued)*

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Donovan, Wakefield, Russell, & Cohn (2015) [80]	• Systematic review of descriptive and qualitative studies of hospital based bereavement services following the death of a child	• Qualitative (n = 14); quantitative (n = 6); mixed method (n = 10) studies • International review	• Qualitatively, parents, grandparents, and siblings who accessed hospital based bereavement care reported feeling cared for and supported by staff, a reduction in sense of isolation, and improved coping and personal growth • Quantitatively, little or no change in grief, adjustment, or coping generally was found for parents, grandparents, and siblings who accessed hospital based bereavement care • Bereavement services had most effect for those with more complex mourning • Bereaved family members and health care professionals recommended bereavement services be theoretically driven and evidence based, offer continuity of care prior to and follow the death of a child, and provide a range of interventions for the whole family and flexibility in service delivery	Strengths • Important, relevant studies included • Appropriately assessed for quality of studies • Reasonable to combine results in this way • Important outcomes considered Limitations • Dearth of rigorous quantitative and qualitative studies and difficult to draw conclusions that are truly representative and based on sound methodology • Lack of demographic diversity	**5**
Flahault,Seigneur, Laurence, Pacquement, & Montel (2015) [81]	• In-person, semi-structured interviews • Qualitative	• Bereaved parents of adolescents/young adults with cancer (n = 21) • France	• Prominent themes included the importance of psychological care during the terminal phase of the child's illness and after child's death, the need to be listened to and understood by the medical team, and the need for information from the medical team • Found discrepancy between emphasis on the importance of psychological support and the proportion of parents who actually consulted a mental health provider or participated in bereavement groups	Strengths • 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 Limitations • Lack of diversity in sample (almost all Caucasian) • Inter-rater reliability for coding not reported	**6**
Foster, Thompson, Miller, Barrera, Davies, Fairclough, Gilmer, Vannata, & Gerhardt (2010) [82]	• This was a qualitative study exploring bereaved parents' and siblings' advice to other families after losing a child to cancer • Semi-structured interviews were conducted with the parents and siblings at their homes	• Parents (n = 36 mothers and n = 24 fathers) and siblings (n = 39) were interviewed 3-12 months post-loss • USA	• Advice included noting the individual nature of grief, addressing different time periods of the illness experience, seeking social support, continuing bonds, and seeking religion • Advice for the future included seeking acceptance and living for the moment	Strengths • Research question clearly stated • Qualitative approach clearly justified • Sampling strategy appropriate for research question Limitations • Method of data analysis not clearly described • Role of researcher not clearly described	**6**

(Continued)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Fujii, Watanabe, & Okada (2003) [83]	• Retrospective medical record review • Semi-structured interview	• Medical records of children who died from cancer (n = 28) and sets of bereaved parents (n = 8 sets) • Japan	• Some parents wanted to maintain a relationship with medical staff following their child's death • 2 sets of parents were pleased with visits by medical staff after child's death	Strengths • Qualitative approach clearly justified • Method of data collection clearly described Limitations • Coding strategy/ analysis not described	**6**
Goldstein & Rimer (2013) [84]	• Mostly in-person, semi-structured interviews with bereaved parents • Qualitative	• Bereaved parents who lost a child to a medical illness in the year 2005 (n = 16)	• Some primary care providers attend funerals, extend sympathy, or prescribe medication to parents • Few primary care providers ask about sibling coping, which is disappointing to parents • Few primary care providers checked in throughout bereavement	Strengths • Research question clearly stated • Qualitative approach clearly justified • Study context clearly described • Method of data collection clearly described • Method of data analysis clearly described • Analysis appropriate for research question Limitations • Limited description of participating parents • Details of recruitment unclear • Role of researcher in interviews unclear	**6**
Kreicbergs, Lannen, Onelov, & Wolfe (2007) [85]	• The purpose of this study was to examine pediatric end-of-life interventions' impact on parental grief and possible influence of social support on grief 4-9 years post-loss • Parents who lost a child to cancer were recruited through a population registry • Parents were mailed a questionnaire that had been developed using bereaved parent input and asked about the child's medical care and parents' mental health • Parents were specifically asked if they felt they had "worked through their grief"	• Parents of a child who died of cancer between 4 and 9 years prior to the time of the study (n = 449) • Fathers (n = 191), mothers (n = 251), 7 unreported gender • Sweden	• Analyses demonstrated social support was beneficial for parents who expressed a desire to communicate about their grief • Parents who had access to professional support were also more likely to report having worked through their grief • Social support outside of professional settings was also beneficial	Strengths • Sufficient sample size • Appropriate analysis • Data collection appropriate to study method • Reporting comprehensive, clearly described Limitations • Cross-sectional • The questionnaire item on "working through grief" may have been interpreted in different ways by participants • Evidence not derived from high quality case control or cohort studies	**6**
Laakso & Paunonen-Ilmonen (2001) [86]	• Mailed surveys and in-person, semi-structured interviews with bereaved mothers who lost a child, typically to an illness; only qualitative results were discussed	• Bereaved mothers who lost a child under the age of 7 years in a hospital (n = 91 mothers for the survey, 50 for the interview; about three-quarters of mothers lost a child to illness) • Finland	• Feelings of grief had physical, psychological, and social manifestations and were highly individualized • Mothers expected contact from health care personnel even after the child's death	Strengths • Research question clearly stated • Qualitative approach clearly justified • Study context clearly described • Method of data collection clearly described • Method of data analysis clearly described • Analysis appropriate for research question Limitations • Limited description of participating parents • No use of quantitative data despite the survey • Role of researcher in interviews unclear	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Laakso & Paunonen-Ilmonen (2002) [87]	• Mailed surveys and in-person, semi-structured interviews with bereaved mothers who lost a child, typically to an illness • Mixed methods	• Bereaved mothers who lost a child under the age of seven in a Finnish hospital district (n = 91 mothers for the survey, 50 for the interview, and about three-quarters of mothers lost a child to illness) • Finland	• Spouses, children, grandparents, next of kin, friends, and colleagues are the main sources of support for bereaved mothers • Support groups with other parents can be helpful or anxiety-inducing • Public health nurses' contact after the death was considered to be a positive gesture and included sending flowers or postcards or making a phone call or visit • Mothers wanted communication, advice on practical matters, information on crisis groups, and a genuine interest in their grief from professional practitioners	Strengths • Research question clearly stated • Qualitative approach clearly justified • Study context clearly described • Method of data collection clearly described • Method of data analysis clearly described • Analysis appropriate for research question • Sufficient sample size • Appropriate quantitative analysis mentioned (although not reported) • Issues with non-response clearly described Limitations • Limited description of participating parents • Role of researcher in interviews unclear • Most specific quantitative analyses and results were not included • Unclear when results are from qualitative or quantitative data	**4**
Lichtenthal, Nilsson, Kissane, Breitbart, Kacel, Jones, & Prigerson (2011) [88]	• Diagnostic interviews and questionnaires	• Bereaved caregivers (n = 86)	• Majority of caregivers with prolonged grief disorder did not access mental health services	Strengths • Research question clearly stated • Study context clearly described • Method of data collection clearly described • Method of data analysis clearly described • Analysis appropriate for research question Limitations • Participants who declined were more distressed than those participating- may underestimate underutilization • Retrospective reporting • Cross-sectional design	**3**
Lichtenthal, Roberts, Bohn, & Farberov (2011) [89]	• Cross-sectional • Questionnaires	• Bereaved mothers (n = 19) and bereaved fathers (n = 13)	• Majority of parents accessed at least one service • Parents with higher levels of grief are under-utilizing services	Strengths: • Reporting comprehensive, clearly described • Research question clearly stated Limitations • Retrospective reporting • Cross-sectional design	**4**
Meert, Eggly, Berger, Zimmerman, Anand, Newth, Harrison, Carcillo, Dean, Willson, & Nicholson (2011) [90]	• Systematic review of descriptive and qualitative studies to identify instruments useful for assessing the needs of parents bereaved in the pediatric intensive care unit (PICU)	• Articles from 357 abstracts that described 31 instruments (n = 96 articles) • USA	• 15 instruments were selected based on their: 1) use with parents/and or the bereaved; 2) use in PICU, neonatal intensive care, or pediatric wards; 3) measurement of family needs or related constructs; and 4) published psychometrics • Validity and reliability were not established for parents bereaved in the PICU • No tools addressed the full range of needs for parents bereaved in the PICU	Strengths • Important, relevant studies included • Appropriately assessed for quality of studies • Reasonable to combine results in this way • Important outcomes considered Limitations • Self-selection of participants • Inability to distinguish between meaning-making attempts and meanings made	**5**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
Lichtenthal, Corner, Sweeney, Wiener, Roberts, Baser, Li, Kissane, Breitbart, & Prigerson (2015)[91]	● Cross-sectional ● Multi-site ● Self-report questionnaire assessing mental health service use and barriers, prolonged grief, depression, anxiety, attachment styles, and sense of meaning	● Bereaved parents who lost a child to cancer (n = 120) ● USA	● 41% of parents between 6 months and 6 years bereaved were using mental health services ● Talk therapy was the most commonly used service (included psychotropic medication and/or a support group) ● 40% of parents who wanted bereavement support reported not receiving services ● Barriers to service use included 'too painful to speak about the loss (64%) and 'too difficult to find help' (60%) ● Nearly half of parents 1 year after loss were currently using services, with 58% using services in the second year ● Minority parents expressed greater unmet needs than non-minority parents	Strengths ● Sufficient sample size ● Appropriate analysis ● Study completed as planned ● Missing data reported clearly ● Limitations clearly noted in the manuscript Limitations ● Reduced power due to large number of predictors in multivariable models ● Selection bias noted due to exclusion of potentially more distressed parents ● Limited representation from minority groups	**6**
Schwab (1995-96) [92]	● Parents were interviewed using a questionnaire over the phone about why they did or did not participate in a support group	● Bereaved parents who participated in a support group offered by the author (n = 43) and bereaved parents who did not participate in the group (n = 42) ● Over half of the parents experienced the death of their child due to illness (76%)	● Parents reported a number of reasons for not joining a support group, with the most common reason being they already had sufficient social support ● Reasons for joining a support group were to connect with other bereaved parents	Strengths ● Appropriate analysis ● Reporting comprehensive Limitations ● Sample size insufficient to conduct strong group comparisons ● Evidence was derived from a highly variable sample and findings may be strengthened if parents experienced the same cause of death of their child ● Parents were not randomly assigned to be in the support group or not	**3**
Steele, Kaal, Thompson, Barrera, Compas, Davies, Fairclough, Foster, Gilmer, Hogan, Vannatta, & Gerhardt (2013) [93]	● In-person, semi-structured interviews with bereaved family members ● Qualitative	● Bereaved parents and siblings who lost a child to cancer (n = 99 family members, including mothers [n = 36], fathers [n = 24], and siblings [n = 39], from 40 families) ● USA ● Canada	● Bereaved family members expressed a desire for continuity of care and to remain connected with hospital staff after the death of their child or sibling	Strengths ● 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 Limitations ● No information about parents who refused participation	**6**

(*Continued*)

SUPPLEMENTAL TABLE II. (*Continued*)

Study	Design	Sample	Findings*	Study Rigor	Level of evidence
van der Geest, Darlington, Streng, Michiels, Pieters, & van den Heuvel-Eibrink (2014) [94]	• Questionnaire about grief experiences and perceptions of interactions with health care professionals administered to bereaved parents • Quantitative	• Bereaved parents who lost a child to cancer (n = 89 parents from 57 families) • Netherlands	• Parents highly rated the frequency of consultations with health care professionals after their child's death • Higher levels of continuity of care and communication with hospital staff were associated lower levels of long-term grief, although this includes care and communication prior to the death	Strengths • Sufficient sample size • Data collection appropriate to study method • Evidence derived from high quality case control or cohort studies • Reporting comprehensive, clearly described Limitations • Analyses do not appear to account for participating couples • No information about parents who refused participation and a high refusal rate • Cross-sectional study that includes retrospective reporting of continuity of care and communication with hospital staff	**4**

***Note**. Only findings relevant to the bereavement follow-up standard are presented. **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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