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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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Abstract

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 health care providers. Evidence suggests that the standard of care should consist of at least one meaningful contact between the health care team and bereaved parents to identify those at risk for negative psychosocial sequelae and to provide resources for bereavement support.

Keywords

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

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

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Conflict of Interest

There are no conflicts of interest to disclose.

Supplemental Table I. Search Terms

Supplementary Table II. Literature Review Results

Supplementary Figure 1. PRISMA Flow Chart

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 paper 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.

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, please 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. 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 to 18 at 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 6 authors (WGL, CS, KR, GC, LD, and LW) 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% to 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 [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. Though 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]. Health care 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 health care team [9,99]. They 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] where support frequently wanes over time [36,44].

The IOM has emphasized that bereavement care is a public health priority and should be part of comprehensive emotional and spiritual care for grieving family members [17,101]. Data suggest that what health care 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 health care 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 health care 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 health care 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 health care 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]. While 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.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

PRISMA Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Box 1

A member of the health care 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.

Table 1

Summary of Evidence Table

Standard	Evidence Summary ¹	Methodology ²	Quality of Evidence ³	Strength of Recommendation ⁴
A member of the health care team should contact the family to assess parents', siblings', and grandparents' needs to identify families who are at risk for negative physical, psychological, and social sequelae, to let them know they have not been forgotten, and to provide resources for bereavement support.	<ul style="list-style-type: none"> 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 health care team after the death of their child. Professional support can assist with grief, particularly among those with more severe, debilitating symptoms. 	<ul style="list-style-type: none"> Quantitative, qualitative, and literature reviews. Majority 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: e.g. RCT, cross-sectional, longitudinal; consensus; systematic review articles

³ Quality of Evidence: High, Moderate, Low & 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)