

Original Article

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Personalized and yet standardized: An informed approach to the integration of bereavement care in pediatric oncology settings

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Abstract

Objective. The death of a child has been associated with adverse parental outcomes, including a heightened risk for psychological distress, poor physical health, loss of employment income, and diminished psychosocial well-being. Psychosocial standards of care for centers serving pediatric cancer patients recommend maintaining at least one meaningful contact between the healthcare team and bereaved parents to identify families at risk for negative psychosocial sequelae and to provide resources for bereavement support. This study assessed how this standard is being implemented in current healthcare and palliative care practices, as well as barriers to its implementation.

Method. Experts in the field of pediatric palliative care and oncology created a survey that was posted with review and permission on four listservs. The survey inquired about pediatric palliative and bereavement program characteristics, as well as challenges and barriers to implementation of the published standards of care.

Result. The majority of participants ($N=100$) self-reported as palliative care physicians (51%), followed by oncologists (19%). Although 59% of staff reported that their center often or always deliver bereavement care after a child's death, approximately two-thirds reported having no policy for the oncology team to routinely assess bereavement needs. Inconsistent types of bereavement services and varying duration of care was common. Twenty-eight percent of participants indicated that their center has no systematic contact with bereaved families after the child's death. Among centers where contacts are made, the person who calls the bereaved parent is unknown to the family in 30% of cases. Few centers (5%) use a bereavement screening or assessment tool.

Significance of results. Lack of routine assessment of bereavement needs, inconsistent duration of bereavement care, and tremendous variability in bereavement services suggest more work is needed to promote standardized, policy-driven bereavement care. The data shed light on multiple areas and opportunities for improvement.

Introduction

Despite significant advances in the treatment of childhood cancer, there are more than 100,000 childhood cancer deaths worldwide each year (Sullivan et al., 2013). In the United States alone, nearly 2,000 children die of cancer annually (Cancer in Children and Adolescents, 2014). Intense and persistent grief reactions following the loss of a child are common. Not surprisingly, child loss has been associated with adverse parental outcomes, including a heightened risk for psychological distress, poor physical health and diminished psychosocial well-being (Lichtenthal et al., 2015; Rosenberg et al., 2012) each of which has implications for service provision.

An abrupt end to a relationship with the child's medical team whom the family has come to trust and rely on for support, comfort, and guidance can compound this sense of loss. However, although 96% of pediatric oncologists believe bereavement support is a part of good clinical care, bereavement aftercare is sporadic (Jensen et al., 2017). For example, although 82% of pediatric oncologists report that they at times engage in some sort of bereavement activity such as writing condolence cards or attending memorial services, fewer than one-half participate in any of these activities consistently (Jensen et al., 2017). Oncologists have reported that personal grief reactions (Granek et al., 2013) and logistic- and time-related

barriers are responsible for their lack of provision of consistent bereavement care (Chau et al., 2009; Granek et al., 2015; Kutner, 2009).

The importance of reliable bereavement care and the value of follow-up contact from the child's healthcare team was addressed in the first set of evidence-based Standards for the Psychosocial Care of Children with Cancer published in December 2015, supported by the Mattie Miracle Cancer Foundation (www.mattie-miracle.com). This included 15 standards created following an extensive and rigorous review of the literature. A full description of the methods used to develop the standards is available (Wiener et al., 2015). The 14th Standard focused on bereavement care (Lichtenthal et al., 2015) and recommended maintaining 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 (Fig. 1). Additionally, provision of bereavement care is now required for Palliative Care Certification by the Joint Commission (Croney & Clark, 2015). For programs that provide care for pediatric patients, the Joint Commission requires age and developmentally appropriate methods be used by staff to address the loss, grief, and bereavement needs of dying and grieving children.

The standards provide a starting point for cancer centers to identify essential elements of comprehensive psychosocial care. To implement these standards widely, it is critical to understand cancer centers' current practices. This study examined current practices and barriers facing centers as they implement bereavement care as stated within the Psychosocial Standards of Care.

Methods

A survey was created by the authors (LW, AR, MW) based on extensive clinical experience, a review of the literature, and the published Standards of Care addressing palliative care and bereavement needs. It was designed according to the Tailored Method of Survey Design (Dillman, 2009). Questions focused on programmatic structure and services to investigate the way infrastructure impacts implementation of care delivery and to identify barriers to bereavement care implementation. The survey was independently reviewed and piloted for usability, technical functionality, clarity of items, and length by experts in survey research methods, palliative and bereavement care (two psychosocial specialists, a nurse, two pediatric oncologists, a social worker, and seven pediatric palliative care providers) with revisions incorporated before distribution. The final survey included two sections, one based on a standard recommending integration of palliative care concepts regardless of disease outcome and the second on the inclusion of bereavement care. The survey questions inquired about pediatric palliative and bereavement program characteristics, as well as challenges and barriers to implementation of the published standards of care. Likert-type scales, force-choice responses, and open-ended text responses were used

along with adaptive questions using branching and skip logic. Participant name and institution name were not obtained to maintain anonymity. The study was approved by the Office of Human Subject Research at the National Institutes of Health.

An announcement of the survey was posted with review and permission on three nationally focused listservs: The American Academy of Pediatrics Section on Hospice and Palliative Medicine listserv (AAP SOHPM); the American Society of Pediatric Hematology and Oncology Palliative Care Working Group listserv (ASPHO WG); and the American Academy of Hospice and Palliative Medicine Pediatric Palliative Care Special Interest Group listserv (AAHPM SIG). For inclusion of a global perspective, the Société Internationale D'Oncologie Pédiatrique Palliative Care Special Interest Group listserv was included as a fourth distribution approach. Potential participants were instructed to have one response per institution. If potential participants did not have the time or knowledge to complete the survey, they were asked to forward the survey link to a provider who was knowledgeable about bereavement care services at their center. Survey responses were collected and maintained in an encrypted version of SurveyMonkey. A link to the survey was sent in an introductory email inviting listserv participants to complete the survey with three reminder emails sent in two week intervals.

Analyses

Survey responses were exported into Microsoft Excel and then imported into SPSS (version 24; IBM SPSS Statistics). Data from the closed-ended items (size of program, type of services provided, composition of staff that provides services, and challenges) were analyzed descriptively. Chi-square analyses were used to determine associations using frequency data. Statistical significance was determined using $p < 0.05$ and analyses used two-tailed significance.

Results

One hundred and forty-two participants responded to the survey. Data were received from members of all four listservs. Six of the 142 participants received the survey from other sources (0.04%) (i.e., direct referrals). One hundred and thirteen of 142 (80%) respondents worked in United States facilities. One hundred participants provided complete responses to the bereavement questions. We only report results from these 100 participants representing 34 US states (60 cities), the District of Columbia, and 13 countries. The majority of participants self-reported as palliative care physicians (51%), followed by oncologists (19%). The remainder of participants were advanced practice providers, nurses, psychologists, social workers, or child life specialists. Characteristics of the survey respondents and participating programs are provided in Table 1.

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.

Fig. 1. Psychosocial standard of care: bereavement.

Table 1. Characteristics of participants and participating programs

	<i>n</i> (%)
Participant discipline*	
Palliative care physician	51 (51)
Oncologist	19 (19)
Nurse practitioner/physician assistant 14 (14) Nurse	7 (7)
Social Worker	5 (5)
Child life specialist	2 (2)
Psychologist	2 (2)
Geographic location (US) [†]	
Midwestern	35 (35)
Southern	21 (21)
Western	16 (16)
Northeastern	11 (11)
Geographic location (international)	
Asia	5 (5)
South America	4 (4)
Canada	2 (2)
Africa	1 (1)
Europe	1 (1)
Other	4 (4)
Program size (patients in 2016)	
1–50	16 (16)
51–100	29 (29)
101–150	19 (19)
>150	36 (36)
Work setting*	
Inpatient	90 (90)
Outpatient clinic	72 (72)
Hospice	28 (28)
Other	19 (19)
Survey access (listserv)	
AAP Section of Hospice and Palliative Care	53 (53)
SIOP PODC Palliative Care Working Group	13 (13)
AAHPM Palliative Care Special Interest Group	12 (12)
Pediatric Palliative Care Network	9 (9)
Referred by a local pediatric palliative care team	4 (4)
ASPHO	3 (3)
Other	6 (6)

AAP, American Academy of Pediatrics; AAHPM, American Academy of Hospice and Palliative Medicine; ASPHO, American Society of Pediatric Hematology and Oncology; PODC, Pediatric Oncology in Developing Countries; SIOP, Société Internationale D'Oncologie Pédiatrique.
*Not mutually exclusive.

[†]The following states had one or more programs represented in the study: Washington, New York, Minnesota, California, Utah, Texas, Ohio, Iowa, Illinois, Pennsylvania, Florida, Michigan, Nebraska, Missouri, Tennessee, Alabama, Georgia, and Washington, D.C.

Bereavement assessment

Approximately two-thirds (65%) of participants reported having no policy for the oncology team to routinely assess bereavement needs at their respective centers. Just over one-third (35%) of respondents reported that someone from the oncology team “always” or “often” routinely assesses the bereavement needs of families who lost a child to cancer. According to 55% of respondents, someone from the palliative care team does the same. Only 5% reported using a formal bereavement assessment tool to assess bereavement needs. The size of the center (either more or less than 100 pediatric oncology patients per year) was not significantly associated with having a bereavement policy in place ($p = 0.085$).

Bereavement care

When asked whether staff delivers bereavement care after a child's death, 59% of participants reported this care is “always” or “often” provided. This care is primarily in the form of sending a card (80%) or making a phone call to the family from a healthcare (72%) or bereavement team member (28%). Other services include sending literature about child or adult grief (61% and 56%, respectively) and holding an annual memorial service (8%; Table 2). Forty-one percent of participants expressed that these bereavement services are inconsistent, or in their facility.

The Standard recommends that the healthcare team makes at least one meaningful contact to bereaved families to assess family needs. Twenty-eight percent of participants indicated that this does not systematically occur at their center. For the majority of participants (70%), the staff person who contacts the bereaved parent personally knew the family before the child's death. This staff person is most often the social worker (76%) but this varies greatly (Table 3). Length of bereavement care was also variable, with contact with the family continuing for a few months after death to several years. Participants often described continued contact with the family as “not consistent” and the type and length of services provider dependent (Table 4).

Larger programs (more than 100 pediatric oncology patients per year) were associated with a higher likelihood of the staff contact person having known the family ($p = 0.036$). A significant

Table 2. Forms of bereavement services systematically offered*

	<i>n</i> (%) <i>N</i> = 100
Cards	80 (80)
Phone call from a healthcare team member	72 (72)
Literature: child grief	61 (61)
Attend service/funeral	59 (59)
Referral to a support group	57 (57)
Literature: adult grief	56 (56)
Referral to a counselor/therapist	55 (55)
Anniversary cards	50 (50)
Counseling in person	31 (31)
Phone call from a bereavement coordinator	28 (28)
Invitation to a memorial service	8 (8)

*Not mutually exclusive.

Table 3. Discipline of the staff member who contacts family members after the death of a child*

	<i>n</i> (%)
Social worker	76 (76)
Physician	44 (44)
Nurse	43 (43)
Nurse practitioner/physician assistant	38 (38)
Chaplain/pastoral care provider	32 (32)
Psychologist	25 (25)
Bereavement counselor	20 (20)
Other	10 (10)

*Not mutually exclusive.

association was found between facilities with a dedicated pediatric palliative care program (not just a sub-division of an adult program with pediatric coverage or pediatric providers) and longer duration of bereavement care ($p = 0.042$). Fifty-six percent of centers with dedicated a pediatric palliative care program reported providing bereavement care for at least 1 year, whereas the same practice occurred in 4.9% of centers with no pediatric-specific palliative care program. Program size was not associated with the duration of bereavement care ($p = 0.525$).

Challenges and barriers

Challenges and barriers impeding consistent bereavement care support were identified through participants' open-ended text responses, provided spontaneously at the end of the survey. Participants described institutional concerns, specifically palliative and bereavement care not being integrated into the hospital infrastructure. There were also programmatic concerns raised (demand exceeding resources in their facility, inadequate staff, funding needed for a bereavement program and staff positions, lack of specific criteria that trigger the need for a palliative care assessment), and inadequate time to provide bereavement services.

Discussion

A recommendation for a standardized approach to bereavement follow-up care in families whose child dies from cancer has been publically available for 18 months (Wiener et al., 2015). To our knowledge, this is the first study to assess how this

Table 4. Duration of contact between bereavement care programs and family

	<i>n</i> (%)
At time of death only	12 (12)
First month after death	5 (5)
2–6 months after death	6 (6)
7–12 months after death	11 (11)
1–2 years after death	37 (37)
>2 years after death	11 (11)
Varies according to parent need, staffing, etc	18 (18)

standard is being implemented in routine healthcare and palliative care practices, and, importantly, to identify barriers to its implementation.

There is evidence that many bereaved parents experience poor psychological health following their child's death and would benefit from continued contact with a member of their child's medical team (Contro et al., 2002; Lichtenthal et al., 2015), yet, in a recent survey, only 60% of pediatric oncologists knew about the substantial psychosocial challenges that parents experience during bereavement (Jensen et al., 2017). Our findings from representatives of pediatric palliative care and oncology services further demonstrate that there is a considerable gap between the recommendations provided in the bereavement standard and the bereavement care that is actually being provided in many pediatric cancer programs. Although it was encouraging to learn that many centers provide bereavement care, it was concerning to discover that these bereavement services are not consistently implemented across all facilities.

These data shed light on how care is provided as well as opportunities for improvement. First, several sites do not meet the basic tenet of the standard: to have a member of the healthcare team provide at least one meaningful contact to bereaved parents to identify those at risk for negative psychosocial sequelae and to provide resources for bereavement support. Bereaved families often feel abandoned when contact is lacking (Heller & Solomon, 2005), creating a secondary loss in addition to the excruciating loss of their child (D'Agostino et al., 2008; deCinque et al., 2006; deJong-Berg & Kane, 2006; Lichtenthal et al., 2015; Macdonald et al., 2005), reinforcing the importance of consistent implementation of this Standard.

The standard also recommends that families are contacted by a member of the healthcare team who knew the child and family. We found that many parents are contacted by a staff member not known to the family, which can potentially exacerbate grief, particularly when the family was hoping for follow-up from someone from their child's team. Thus, programs optimally should work toward having the call to assess bereavement needs be made by someone familiar to the family.

Because there are data to support that pediatric oncologists often do not have sufficient time or feel equipped to engage in bereavement outreach (Jensen et al., 2017), strong team work is important to help meet the needs of bereaved families. Although they primarily appear to be made by social workers, respondents reported phone calls to bereaved parents being made from those working in various disciplines. Therefore, training for bereavement outreach that reviews communication skills and education about bereavement risk factors and resources should cut across disciplines. Recent data (Kearney, 2017) on a 1-day communication training program with pediatric nurse practitioners using novel custom role play scenarios based on pediatric nurse practitioners' clinical experiences, was shown to be highly effective.

Second, there was tremendous variation in the type of services provided. Many participants reported that bereavement care consisted of sending a card after the child's death, whereas others described sending cards in addition to or instead of making phone calls to assess bereavement needs. There is no definitive data on when families should be contacted after the death of their child. One study, examining mental health needs of parents who lost a child to cancer, provides some insight. Bereaved families preferred to be approached about psychosocial support services within the first 3 months of a child's death (40.3%) and to

begin services in that timeframe as well (62.2%) (Lichtenthal et al., 2011). Given that grieving parents often express a need for mental health services between 2 and 4 years after a child's death, efforts to extend bereavement care through at least the first 2 years is ideal (Lichtenthal et al., 2015). Some programs provided bereavement services during the first year after the death of the child, whereas others extended bereavement care for several years. Barriers to consistent implementation of bereavement services included lack of institutional support, time, staff, and funding resources. Similar barriers were recently reported by pediatric oncologists (Jensen et al., 2017); therefore, a standardized but personalized approach (such as a list of possible ways to connect with parents after the loss of their child) that can be tailored to the size, type and staffing of the program can help ensure more consistent implementation of bereavement assessment and support to families.

Third, only approximately one-third of participants indicated that their facility's oncology team has a policy on how to support families after the death of a child. There was no association between program size (number of patients) and presence of a bereavement policy, indicating that even larger facilities, presumably with more resources, also have barriers to implementing bereavement standards. "Bereavement care" may be an ambiguous term when there is a lack of institutional guidelines detailing how to support families after the death of a pediatric cancer patient. Having a standard operating procedure can help facilitate communication and provide consistency in services provided (e.g., when and who contacts a family after the death of a child, bereavement interventions for staff to choose from that families find meaningful), increase productivity and facilitate cross training (e.g., staff members interested and comfortable providing bereavement care). Moreover, training across disciplines can provide an opportunity for staff members to coach and support one another in this emotionally challenging work.

Fourth, in addition to the availability of institutional guidelines, the data also illustrate that most centers do not use a bereavement screening or assessment tool. Use of a standard assessment tool would provide a systematic way to assess risk and facilitate more effective identification of family members in need of psychosocial support both before and after a cancer loss (Roberts et al., 2017). The use of a such a tool can also be part of a bereavement policy, although individual programs would need to determine how such records would be integrated into a deceased patient's medical record for ongoing tracking of care.

Overall, we found lack of routine assessment of bereavement needs, inconsistent duration of bereavement care, and tremendous variability in bereavement services provided. Thus, programs are not yet implementing a "standard"; rather, bereavement care is highly inconsistent. The result is that families in most need of support may not receive it. Insufficient policies, tools, and available staff may be primarily responsible. The development of institutional policies that allow for a personalized approach to bereavement interventions based on family need and center resources are needed. User-friendly checklists to assure that bereavement care is provided to all families can be very useful.

Several study limitations exist. These include an overrepresentation of respondents who work in US facilities and overrepresentation of physicians versus other members of the palliative care team. The survey was distributed online specifically to members of various pediatric palliative care communities. These are persons interested in and working in programs where pediatric palliative care services are provided and therefore may over-represent bereavement services being provided in pediatric oncology

centers. Had we asked all participants to address barriers to bereavement care in the survey, we might have gained a more specific and complete understanding of challenges programs face. Participants were requested to provide one respondent per site; however, this could not be guaranteed because of anonymity. Moreover, we could not feasibly calculate response rate because of overlapping membership on palliative care listservs. Finally, we did not ask whether respondents were aware of the publication of the standards or if centers have changed their bereavement practices since the publication of the standards and so our understanding of the standards' impact is limited. Future research should explore this.

There is more work to be done to promote standardized, policy-driven bereavement care. Fortunately, evidence shows that providers with training in a variety of disciplines are involved in bereavement outreach. Facilities should recognize the diversity of team members involved and encourage teamwork in providing families with the best possible interdisciplinary bereavement care. We recommend an institutional commitment to the training of specific staff for bereavement screening and interventions, protection of personnel time for this important work, and extension of bereavement resources for programs caring for these families. New and creative approaches to bereavement care should also be considered. Parents who have lost a child to cancer have unique and valuable insights of the grief experience. Recent reports of communication training using bereaved parent educators has been found to be feasible and effective as well as beneficial for both the trainees as well as bereaved parent educators (Snaman et al., 2016). Bereaved parent educators can also help healthcare providers identify key components intrinsic to the development, implementation, and maintenance of a bereavement policy and program (Snaman et al., 2017). A formal bereavement assessment tool to evaluate family needs is another necessary future focus. Improved screening and assessment processes will identify those families at risk for poor bereavement outcomes earlier on in the trajectory and will assist with protecting and supporting families as they grieve the loss of their child (Roberts et al., 2017).

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