

# When a child dies: pediatric oncologists' follow-up practices with families after the death of their child

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## Abstract

**Objectives:** Follow-up practices with bereaved families are considered a part of good medical care, yet little is known about pediatric oncologists' protocol with families when their patients die. The objective of this study was to examine follow-up practices employed by pediatric oncologists after patient death using an in-depth qualitative analysis.

**Methods:** The Grounded Theory method of data collection and analysis was used.

Twenty-one pediatric oncologists at two Canadian pediatric hospitals were interviewed about their follow-up practices with bereaved families after patients died. Line-by-line coding was used to establish codes and themes, and constant comparison was used to establish relationships among emerging codes and themes.

**Results:** Pediatric oncologists actively engage in follow-up practices that include making phone calls, sending an email or condolence card, attending funerals or visitations, having long-term and short-term meetings with parents, and attending hospital or departmental memorials for the deceased child. Attending funerals or visitations was less frequent and varied widely across pediatric oncologists. Reasons for not participating in bereavement follow-up practices included logistical, emotional, and practical considerations.

**Conclusions:** While the majority of pediatric oncologists at two Canadian centers engage in some follow-up practices with bereaved families, these practices are complex and challenging because of the emotional nature of these interactions. Medical institutions should provide both structured time for this follow-up work with families, as well as medical education and financial and emotional support to pediatric oncologists who continue caring for these families long after their child has died.

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## Introduction

Bereavement follow up for families (e.g., making a telephone call, meeting with families, and sending a condolence card) who have had a family member die of cancer is considered to be part of good medical care [1] but has received little research attention in the oncology context. The few research studies that have examined oncologists' follow-up practices with bereaved family members have focused on the adult care context [2–4]. In one study that looked at Israeli adult oncologists, the majority of participants rarely attended bereavement rituals that involved direct contact with families including funerals and visitations, 28% occasionally participated in rituals involving direct contact, 45% had some form of indirect contact such as sending a condolence letter, and 34% of the physicians reported 'frequently' making a phone call [2].

In a Canadian study examining palliative care and oncology physicians who treat adults, only one-third of medical professionals reported usually, or always making a phone call to families, sending a condolence card, or attending a funeral following a patient's death; another one-third of them reported never or rarely participating in any bereavement rituals at all [3].

Finally, in a Canadian qualitative study, Granek and colleagues [4] found that adult oncologists had no standard protocol on how to deal with patient deaths in terms of follow up with families. Oncologists turned to a number of *ad hoc* strategies in dealing with families including phone calls, sending cards, meeting with the family, and/or attending funerals. These practices were found to be rare and did not follow any systematic guidelines [4].

While the recognition of the physician's responsibility to support parents after the death of a child is not new in

the literature [5,6], in the pediatric oncology context, there has been limited research that has looked at bereavement follow-up care. In response to families reporting feeling 'abandoned' or 'forgotten' after the child's death, one pediatric oncology unit in Australia instituted a nurse-led telephone intervention program for bereaved parents and found that families benefited from the program [7]. In another study, a survey of nine tertiary pediatric oncology units in Australia and New Zealand found that the majority provided some kind of bereavement services that were led mostly by mental health professionals or spiritual care workers (e.g., social workers, psychologists, and chaplains). Only one of the nine centers provided anniversary cards or contact with the bereaved families, four of the nine offered remembrance ceremonies, and two of the nine offered supportive contact (phone or face to face) [8].

The only publication that has looked at bereavement follow up in the pediatric oncology context is an anecdotal essay written by Stein and colleagues in Israel [9]. They noted, 'every family is visited, even if they live far from our facility. These home visits are part of an integrated program that we provide for bereaved families that includes a condolence letter by a department chair' (p. 3705).

To our knowledge, there are no empirical studies examining what pediatric oncologists do in terms of follow up with families after their patients die. We note that bereavement protocol refers to follow-up practices (i.e., making a phone call and attending a funeral) and not to bereavement services provided by hospitals such as mental health counseling or support groups nor to individual coping strategies that oncologists might use to cope with patient deaths (i.e., hobbies, exercise, and social support). As part of a larger study examining pediatric oncologists' experiences of patient death [10], the purpose of this analysis was to examine follow-up practices employed by pediatric oncologists after their patients died using an in-depth qualitative analysis.

## Methods

### Participants and recruitment

Pediatric oncologists from two participating hospitals in Ontario, Canada, were emailed information about the study by the co-investigators at each center and asked to respond to the email if they were interested in study participation. Only colleagues who have had a patient die in their care were eligible. Twenty-one of 34 pediatric oncologists contacted agreed to participate. They were at different stages of their career trajectory (e.g., trainees, junior oncologists with 10 years of experience or less, and senior oncologists with 10 years or more of experience) and varied in gender and ethnicities.

### Procedure

Research ethics board approvals at each participating pediatric oncology center were obtained prior to study opening. All interviews were conducted by L.G. using a semi-structured interview guide. Interviews were recorded and transcribed verbatim with all identifiable information removed from the transcripts.

### Data analysis

The Grounded Theory method of data collection and data analysis was used in this study [11]. Data collection and analysis took place concurrently, which allowed the researchers to revise the interview guide regularly to gather data to refine emerging codes. Analysis involved line-by-line coding, and was inductive, with codes and categories emerging from participants' narratives. Data collection stopped when the team determined that we had reached saturation and that no new codes were created. NVivo 9 computer software was used to organize the data.

## Results

Pediatric oncologists were found to have a substantial amount of contact with families after a child died in their care. In Table 1, we outline our findings that report on the types of contact pediatric oncologists had with families and supporting quotations that illustrate the complexities involved with follow-up care in this context. There were some established practices identified at the two hospital sites, which are described in more detail in the succeeding texts. Consistent with those practices, pediatric oncologists reported almost always having some form of contact with the child's family after the death, and in addition, the family would be contacted by the treating team's primary nurse or social worker. Contact with families involved sending a condolence card or an email, making a phone call, attending funerals, attending visitations, having short-term and long-term meetings with parents, and attending memorials. Each is explained in more detail in the succeeding texts.

### Sending a condolence card or an email

Pediatric oncologists described a range of practices when it came to sending cards or emails to families after patients died. Nearly half ( $n=10$ ) reported always, or sometimes sending cards ( $n=10$ ), while the other half ( $n=11$ ) reported that they never sent cards because of apprehension about the families reactions to such outreach or because they relied on the nurse or social worker to send a card out on behalf of the healthcare team. One of the subprograms in pediatric oncology had a policy of sending a card and flowers to the family at the first anniversary of the

**Table 1.** Pediatric oncologists' follow-up practices when patients die

Category	Sub-theme	Quotations
Follow-up practices when patients die	Condolence card or email	I personally do condolence cards on behalf of our team. We normally try to do this a little bit later, not immediately and then really leave it open there - feel free to contact us.
	Phone call	I have been following up with phone calls to families, sort of a year later, but some families find that very difficult, so now I wait for families.... I leave it open with families to come back in contact anytime if they want to discuss their child's care or what happened, or even if they just want to chat.
	Funeral	I had a lot of people who passed away, and then it takes.. you go everywhere in your sort of neighbourhood to a funeral. You are away for 4 or 5 hours, it's emotional, draining, but the work in the hospital does not go away. So at a certain point, I thought this is just not in balance with what I can do. And then I started to work harder during the weekend instead, it was a conflict with my own family and kids, so I have decided I do what I can, when the patient is in the hospital and that's it.  For me [attending funerals], I think it's part of my grief process. I grieve for a child as well... I know I'm not the parents, I'm only the treating physician, but you still develop a relationship. And it's normally a really nice opportunity. You see the parents again, they maybe have a question or not, you see all these beautiful pictures of a child you have most likely never met like this. I mean, most of the times we are seeing the kids, they are really sick already, and you see all of this and you can see their, and together with some of my other child, they are always really happy to introduce you to some of the extended family and for me it's a nice way, to round the journey out a little bit for this child.  I think sometimes people go for the family because you have that feeling of, you know, we have one patient that's been treated here for 10 or 11 years, and you think of what a big part... our team and the people that have looked after their son has played in that child's life. And so by not showing up at that funeral, you know, my question would be if you're the physician that had sort of taken the lead on that patient for 11 years, and you didn't go to that funeral, how would that family feel?
	Visitations	We normally try at least like one of the team goes to the visitation and I'm doing this just to show it to the family but also helps me in my grief process.  Whereas if I can go to the viewing I find I've sometimes chatted with them for 45 minutes. And get to meet the rest of the family, and all sorts of other people, and you see the pictures. I walk out of there and I think "Okay, it's you know, it's...you fill up the loop." I think it's a bit of both closure for me and for the family.
	Short-term and long-term meetings with parents	You develop a relationship with the family, and I think by the nature of what childhood cancer is, the family's entire life becomes the hospital and everything around it. There's some families who even after the child dies find themselves repeatedly drawn back to the hospital, some in a sort of attempt to actually contribute to the culture. And many a child dies and there's no longer a reason for you to be here, and I think for some families it's incredibly difficult... So I've had families who at least in the beginning come back quite frequently.  There are some who will, out of the blue, give you a call. ...Gosh, we haven't seen her in a couple of years. Feels good! Yeah, you know, I give them a hug, I say "hi"... Ask how they're doing, find out what's going on, whether they've had another baby... life goes on and they want us to know that life goes on. They have this hole there but they're getting along and they kind of, I think, it's partly they do this to tell us that they're okay.
	Hospital/departmental memorials	For a lot of people I think the child died, and let's move on, and I mean, I don't want to judge on this either, that's how everyone has to have their, their own grief thing...but I think, and have learned from a lot of feedback from the parents, it's so important that we don't forget their children. And I think with this, it's a small gesture. It's not a lot of work and things like this but this like yearly memorial for a lot of families it is so important.

death, while another subprogram sent the family a card on behalf of the whole healthcare team immediately after the child had died. Pediatric oncologists also described a range of time points in which they might choose to send a card or an email that included immediately after the child had died, a few months after the death, at the first anniversary, and in some cases, 2 years later.

Part of the explanations about refraining from sending a card included the logistics and time involved in obtaining cards, writing them, and seeking out mailing information. Explanations for sending cards included as a gesture of care and as an opportunity to invite the family back for a meeting when they were ready and/or to keep the lines of communication open between families and the healthcare

team. It was stressed that healthcare workers were often like 'a second family' to the parents and that pediatric oncologists felt that the outreach was a way to show the family they are not abandoned even if their child had died. In those instances, families and physicians seem to derive comfort from the opportunity to exchange memories and reassure each other's diligence in the care of the child.

#### Making a phone call

Some pediatric oncologists ( $n=13$ ) followed up with a phone call to the bereaved family after the patient had died. Fellows were the least likely to follow up with a phone call. If the oncologist themselves were unable to call, the

primary nurse or the social worker on the healthcare team would make the phone call on behalf of the team. As with the practice of sending a card, pediatric oncologists described the phone call as both a gesture of care and concern about the family and as a way to invite the family to come back if they wished to talk further about the child's treatment and/or death. A few oncologists ( $n=2$ ) noted that they do not make phone calls themselves because they found the practice emotionally difficult for them or because they felt it was more appropriate to allow the families to initiate contact themselves.

### Funerals

Attending funerals of patients who had died was found to be an *ad hoc* practice among pediatric oncologists. By funerals, we mean the culturally specific ritual surrounding the burial of the child often taking place in a funeral home and/or a cemetery. Some oncologists ( $n=13$ ) attended funerals at least some of the time, while others did not ( $n=8$ ). In group practices, if one oncologist could not attend, often someone from the healthcare team attended as a representative of the group. Reasons for attending funerals included a need for personal closure, a desire to want to be there for the family and/or feeling close to the family and wanting to support them, and having a chance to see the patient's impact on their communities and in their extended social contexts (instead of only as the sick child they cared for when ill).

Reasons for not attending funerals included time constraints, especially when in a practice with a high number of patient deaths (i.e., brain tumors), a sense of equity or being unable to attend all funerals and therefore, choosing to attend none, logistical reasons including the funeral being held far away or being held on short notice so that attendance was not feasible because of work obligations/duties, the emotional drain of attending such events and a subsequent sense of needing to keep a distance in order to continue their work, and a lack of interaction with families at the funerals and therefore concluding it would not be helpful for the families to attend.

### Visitation

A few pediatric oncologists ( $n=5$ ) reported attending visitations, Shivas (Jewish practice of the 7-day mourning period that follows a funeral in which friends, family, and community members visit with the family in their home), wakes (a ceremony normally held prior to the funeral where people visit the deceased and their loved ones in their home), or other family and community gatherings after a patient died. Visitations are a common custom, usually taking place at funeral homes and which often include an open casket viewing as well as an opportunity to view pictures and slide shows of the child. The visitations provide the opportunity to express sympathy

and interact with the parents and family members in a way that is less accessible than at a funeral and are often scheduled in the evenings so that the pediatric oncologist could attend after the work day was over.

### Short-term and long-term meetings with parents

The majority of pediatric oncologists ( $n=14$ ) invited families in for a meeting after their child had died or made themselves available to parents who asked for, or initiated a visit. As with the other protocol practices, fellows were the least likely to follow up with families in this way. Pediatric oncologists reported this follow-up visit with families as being very common among bereaved families in order to talk about what had happened, to ask any lingering questions they may still have, to hear that everything possible was carried out for their child, and/or to begin the process of slowly disconnecting from the healthcare team that were a major part of their lives for so long and who they may have felt close to. Pediatric oncologists described on-going contact with these families for months, years, and in some cases even decades after a child had died.

### Hospital memorial

A hospital or departmental memorial is part of the yearly ritual to commemorate children who had died that year. Pediatric oncologists ( $n=5$ ) reported attending these memorials in instances where one of the children they cared for had died and when they knew that the families would be present.

### Discussion

To our knowledge, our study is the first to empirically examine what pediatric oncologists do in terms of follow-up practices with bereaved families when patients die. We found that the majority of pediatric oncologists actively engage in follow-up practices that includes making phone calls, sending an email or condolence card, attending funerals or visitations, having long-term and short-term meetings with parents, and attending memorials. Attending funerals or visitations as a practice was less frequent and varied widely across pediatric oncologists. While the range of practices is interesting in of themselves, the in-depth interviews provided a particularly complex picture of the meaning behind these acts and the challenges inherent in this emotionally difficult work. For example, the rich qualitative data revealed some of the intricate processes by which decisions about follow-up practices are made including whether to attend a funeral or a visitation and the emotional, logistical, and practical considerations that go into making these decisions.

One of the most striking findings in this study is its stark contrast from the adult oncology setting. The majority of

studies indicate that adult oncologists rarely participate in bereavement follow-up care [2–4]. One reason for this difference may be that pediatric oncologists experience fewer patient deaths on average than adult oncologists and that childhood cancer has a long trajectory, is family focused, and thus requires an intensive amount of time and care on the part of the healthcare workers. Given children's dependency on parents, they are always accompanied by their parents and/or extended family members who may also develop a close relationship with the healthcare team over time. This combination of fewer deaths, longer treatment protocols and emotion intensive relationships with patients and their families, suggests a higher likelihood of emotional bonding. Thus, not surprisingly, pediatric oncologists will retain contact with the family after the child has died as was evident in our research.

Another significant difference between the adult and pediatric oncology settings is that parents are frequently invited to come back for a meeting with the oncologist and often retain long-term contact, sometimes even for decades after a child has died. In this sense, the pediatric oncologist's work includes the aftercare of the family in a way that is not as salient in the adult context. While this does not necessarily prolong the pediatric oncologists' grief over the patient's death [10], it puts them in touch with their own sad feelings surrounding the child's death for a much longer time than is the case in the adult oncology context [4,12].

Some of our research is corroborated by other studies in the field. While no other research has looked at pediatric oncologists' bereavement follow-up practices, one survey of 204 members of the American Academy of Pediatrics Section of Critical Care found that 79% of the respondents contacted families at least sometimes after a child had died. As reflected in our own research, some of these critical care physicians met with the family, called them, and/or sent a note after a child had died, however, unlike in our own research, and as the authors themselves note in their paper, critical care doctors generally do not have long-term relationships with children and families they treat; thus, the emotional impact of patient deaths in their practices may be different than it is for pediatric oncologists [13].

There are clinical implications to our research. The evidence suggests that parents can be disappointed with the way medical professionals deal with them after their child's death [14,15] and that these interactions can have a long-lasting impact on the parent's bereavement process [9,16,17]. Research that has looked at bereaved families' perspectives have found that respondents desired physicians who could convey empathy and compassion for both the family and the deceased child and wanted follow-up care from the physician including a phone call or a note from the doctor [15]. Despite the sensitive nature of this period for families and despite the frequency of these occurrences in pediatric oncology, very little medical

education is provided to pediatric oncologists on how to conduct follow-up care for bereaved families. In 2001, a survey of pediatric oncologists found that the vast majority of oncologists (90%) reported that they learned about end-of-life care for children and their families through a 'trial and error' process [18]. In response to these concerns, there has been a recent plea in the United States for institutionalized framework for conducting follow-up meetings with parents after a child's death that includes inviting families to follow-up meetings, tips on effective communication in these meetings, and follow up for both physicians and parents [19]. Our own study joins this call for a more structured framework around follow-up care and suggests that while pediatric oncologists are doing an excellent job at follow up with the bereaved families, they may need some institutional assistance and support in maintaining this stellar and holistic care for the families in the short and long term, recognizing that bereavement follow up is part of best practice care. This might include changing the hospital vision and mission of providing family-centered care and develop standard follow-up protocols that include structured time in the work week to write condolence cards, make phone calls, or have meetings with families. It can also include collaboration with palliative care teams who have expertise, resources, and education on the best type of follow up with families and bereavement after care for caregivers [20,21].

Finally, another option may include a bereavement visit at the family's home if it is culturally appropriate and desired by the family, as described by Stein in Israel where the pediatric oncologist, the primary nurse, and the social worker all attend a home visit that is paid for by a philanthropic organization and that is part and parcel of the work the healthcare team does in their day [9]. As the authors note, 'Participation of staff members in this story-telling process [at the family home visit] can be mutually therapeutic for all involved.' (p. 3705). Moreover, they noted, 'These visits permit us, as staff of the oncology unit, an act of closure with the memories of the patient in whom we invested our skills, our work, our time, and in most cases, our love.' (p. 3707).

## Limitations

While the purpose of qualitative research is to understand a phenomenon in-depth, and while the smaller sample size allowed us to understand the whole range of follow-up practices by pediatric oncologists, the study is limited in its ability to decipher what the majority of pediatric oncologists do in terms of follow-up protocol when their patients die. Moreover, because the participants were self-selected, it is possible that those who chose not to participate in the research may have different follow-up practices than those who did take part. Further survey research is needed to both identify these differences between pediatric

oncologists and to quantify what follow-up practices pediatric oncologists use across the country and the world when patients die. Further research may also explore the types of follow-up practices bereaved parents' desire and when is the optimal time to follow up these families during their bereavement trajectory.

## Conclusions

Our study findings indicate that while the majority of pediatric oncologists in two Canadian centers engage in follow-up practices with bereaved families, these practices are complex and challenging because of the emotional nature of these interactions. It is desirable that medical institutions

provide both structured time for this follow-up work with families, as well as medical education and financial and emotional support to pediatric oncologists who continue caring for these families long after their child has died.

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## Conflict of interest

The authors have declared that there is no conflict of interest.

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