Challenges Faced by Pediatric Oncology Fellows When Patients Die During Their Training

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Abstract
Purpose: Given the paucity of research on the experience of pediatric oncology fellows regarding patient death, the purpose of this study was to explore the specific challenges that pediatric oncology fellows face when patients die during their training.

Methods: Six pediatric oncology fellows at two academic cancer centers in Ontario, Canada, were interviewed about their experiences with patient death during their fellowship training. The grounded theory method of data collection and data analysis was used. Line-by-line coding was used to establish themes, and constant comparison was used to establish relationships among emerging codes and themes.

Results: Fellows reported structural challenges that included ward duty and lack of follow-up opportunities with bereaved families. Personal challenges included feelings of vulnerability as a result of being a trainee, inexperience with patient death, and feeling alone with one’s reactions to patient death. Relational challenges included duration of relationships with families and with supervising staff and perceived lack of modeling on how to cope with patient deaths.

Conclusion: Structural changes to the fellowship model can be made in order to enhance support with patient death, including informing fellows of all patient deaths and incorporating fellows into follow-up practices with bereaved families. Moreover, integrating fellows’ debriefing (facilitated by grief counselors) after a patient death into fellow training, as well as greater involvement with palliative care physicians, can lessen feelings of isolation and help fellows learn effective strategies for dealing with patient deaths from experienced palliative care physicians.

Introduction
Patient death is a frequent and expected component of pediatric oncology, and yet, few studies have examined how pediatric oncologists (POs) react to patient loss. In previous studies, our research team qualitatively examined PO responses to patient death and found that POs reported a range of reactions including sadness, self-questioning, guilt, and feelings of failure and helplessness. Moreover, we found that these oncologists, who varied in experience, participated in broad array of follow-up practices with bereaved families including attending funerals, making phone calls, and meetings with families (Granek et al, manuscript in preparation). Although the literature on POs’ reactions to patient death is sparse, the research on pediatric oncology fellows is almost nonexistent. The majority of studies have focused on the trainees’ knowledge of palliative care and end of life care (ie, pain and symptom management, communication skills, care of patient at end of life, etc). One study focused on pediatric residents personal and professional experiences of death and found that these trainees experienced frequent patient loss in their work and often felt guilt about these deaths. However, the specific challenges that pediatric oncology fellows face when patients die during their training needs to be examined in more depth.

Pediatric Oncology Fellowship Model
In Canada where this study took place, the pediatric oncology fellowship (under the auspices of the Canadian Ministry of Health) is a 3-year fellowship that includes 2 years of clinical practice and 1 year of combined research and clinical practice or research only. Pediatric fellows care for primary patients under the supervision of senior staff. In addition, fellows do a significant number of calls on nights and weekends with staff supervision (up to seven calls per month). Clinical rotations are 1 or 2 months in length and include rotations in all inpatient and outpatient settings within hematology-oncology. These include consult services, rotations through different laboratories and, related specialties like radiation oncology and bone marrow transplantation. Teaching is provided daily by the supervising staff. In addition, there is a weekly academic half-day with comprehensive hematology-oncology curriculum alongside the regular bedside teaching provided by staff physicians. Within these clinical rotations, fellows have substantial contact with patients who subsequently may die in their care, either as a primary patient, or as a patient they monitored on the ward.

Given the paucity of research on the experience of pediatric oncology fellows in the context of patient death, the purpose of this report was to explore the specific challenges that pediatric oncology fellows face when patients die during their training.

Methods
Study Design and Participants
We used the grounded theory method of data collection and analysis in the study design. Research ethics board approvals
at each participating center were obtained before the launch of the study. This study that focused on the challenges experienced by fellows was part of a larger project examining POs’ experiences of patient death (Granek et al, manuscript in preparation).

Pediatric oncology fellows from two participating academic hospitals in Ontario, Canada were informed about the study. Eligibility criteria included having had a patient die in their care during their fellowship training. Six pediatric oncology fellows agreed to participate in the study after hearing more about the research and the time commitment involved. Participant demographic characteristics are listed in Table 1.

Participants were interviewed using a semi-structured interview guide that was revised in the ongoing process of data collection and analysis. Questions were open-ended and focused on experiences of patient death in general (eg, How did you feel when patients died? Who, if anyone, did you talk to about your experiences? etc) and in the context of fellowship (Can you tell me how your fellowship is structured? How do you feel when patients died? etc; Table 2). Interviews were recorded and transcribed verbatim, with all identifiable information removed from the transcripts. Interviews took place at a location and time convenient to the participant and ranged from 45 minutes to 1.5 hours in length.

Data Analysis
Data collection and analysis took place concurrently and we used line-by-line coding of the transcripts. L.G. and a research assistant separately coded the first few transcripts with an eye toward understanding the challenges for the fellows, followed by team discussions on the developing coding scheme to ensure consistency between coders and validity of the emerging findings. L.G. met with the research assistant every week to discuss emerging concerns over definitions of codes and categories. Analysis was inductive, with codes and categories emerging from participants’ stories. As the analysis continued, the descriptive codes were further distilled to capture the major themes and subthemes emerging from the narratives. Constant comparison was used to examine relationships within and across codes and categories. L.G. wrote memos on her thoughts, reflections, and reactions extensively throughout the process of data collection and analysis, which later were incorporated into the writing of the manuscript and the interpretation of the findings. We used NVivo 9 computer software to organize, code, and store the data. Data saturation was reached within the larger sample of POs; however, this analysis was based on a convenience sample of the six fellows who participated in the study.

Results
Pediatric oncology fellows described a range of challenges when confronting patient deaths during their training. These challenges fell into three domains: structural factors, personal factors, and relational factors. Challenges caused by structural factors included ward duty and the perceived lack of ability of the fellows to follow-up with families after patients died. Challenges caused by personal factors included feeling vulnerable as a trainee, inexperience, and feeling alone with one’s feelings about patient death. Lastly, challenges caused by relational factors pertained to relationships with patients’ families and with supervising staff, including perceived limited professional modeling on how to deal with patient deaths. These findings are presented with supporting quotations in Table 3.

Table 1. Participant Demographic Characteristics

<table>
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<th>Characteristic</th>
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<td>Third</td>
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Structural Challenges

Ward duty. As a result of the pediatric oncology fellowship requirements, fellows do a significant amount of ward or “on call” duty during their training. While on the ward, fellows spoke about the burden of having to pronounce a large number of patient deaths, and being present with children and their families when patients were hospitalized and near death. As a result of frequent ward duty, fellows faced two emotional challenges. In the first instance, they had constant exposure to patient death because they were the ones pronouncing the deaths. In the second instance, they described developing attachments to patients they cared for on the ward that weren’t recognized or acknowledged by others on the health care team when the patients died because the team was not aware of these relationships. As a result, the fellows felt bereft of support in coping with the death or were uninformed about the death when it occurred.

Lack of access to follow-up with bereaved families. Fellows spoke about not being able to follow up with bereaved families after patients had died as a result of the limitations placed on them by their role as trainees. Many noted that although they had close relationships with patients and families, they often did not hear about the death until days or weeks later, and thus may not have had the opportunity to attend a funeral, send a card, or to say good-bye to the family. Moreover, because the fellow was often not part of the primary team that cared for the patient, they felt they had little access to the follow-up information needed to contact the families. This lack of closure with the family and with the patient was described as causing the fellows some distress and difficulty dealing with the patient’s death.
had died. and whether to follow up with bereaved families after a child much affect to show in front of their patient’s families, and how to assess how to handle their own emotional reactions, how

Fellows reported that as a result of being in train-

Feeling alone. Related to the theme of feeling vulnerable as a trainee and being inexperienced, fellows described feeling alone with their feelings and reactions to patient death and wanted more places in which to debrief about these issues.

Relational Challenges

Relationships with families. Fellows reported on how the frequent clinical rotations that are part of the fellowship model affected their ability to cope with and respond to patient death as well as their own feelings about patient loss. Because relationships with patients on clinical rotations could last anywhere between a few days and a few months, the variability in the level of intensity and attachment to patients also fluctuated considerably. Some fellows described forming relationships with patients after only a few days, and others after a longer amount of time. This unpredictability and fluctuation made reacting to and coping with patient deaths emotionally challenging.

Personal Challenges

Feeling vulnerable as trainee. Our research indicated that pediatric oncologists at all career stages described showing emotion as potentially a sign of weakness and a vulnerability. For fellows, this was an especially salient issue because they reported feeling vulnerable to criticism and evaluation at this stage in their training, and thus thought it was prudent to keep their feelings about patient deaths to themselves in order to protect their professional image. Their perception was that losing composure may appear weak and unprofessional.

Inexperience. Fellows reported that as a result of being in training they struggled with how to cope with, and respond to, patient death (or an impending death of a child), emotionally and practically. Their lack of experience made it more difficult to assess how to handle their own emotional reactions, how much affect to show in front of their patient’s families, and how and whether to follow up with bereaved families after a child had died.
Pediatric Oncology Fellows and Patient Death

Table 3. Structural and Personal Challenges Faced by Pediatric Oncology Fellows When Patients Die

<table>
<thead>
<tr>
<th>Category</th>
<th>Theme</th>
<th>Supporting Quotations</th>
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<tr>
<td>Structural factors</td>
<td>Ward duty</td>
<td>I had one other patient who wasn’t mine but who, whenever he came into hospital, it seemed like I was always with them. I was with him while he was on transplant, and I was with him right at the beginning when he was really sick, and after his transplant he had recurrence of his disease and I told them about the recurrence...to the family, and I told the child that he was going to die. And that was probably the hardest moment so far in my Fellowship; he was 11, and he understood.</td>
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<td></td>
<td>Lack of access to follow-up</td>
<td>I wanted to know what happened with the patient and I wanted to be with them at the end, but the experience kind of gets robbed from you because you’re not on service anymore and you’re not able to see them anymore. That’s disappointing to me, that we’re not able to be there with them. And sometimes they disappear and you don’t know what happened to them, and exactly where they are right now. What happens when a patient’s dying, you go and spend time with them...that gives me closure. And makes the patient feel supported and makes them feel that someone is there for them. So when the patient disappears and you don’t hear anything about what’s happening to them until the death occurs, you feel that the experience was robbed from you.</td>
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<td>Personal factors</td>
<td>Feeling vulnerable as a trainee</td>
<td>Sometimes you feel like crying in front of somebody...I think I should...you should just suck it up and not show those emotions necessarily at work. Because, you know, people may perceive something that you aren’t comfortable [with] if they don’t know you very well. So emotions in general can be a sign of weakness.</td>
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<td></td>
<td>Inexperience</td>
<td>I can see that when they’re in the palliative course and at the end of the life, it may be more appropriate to show those emotions [of sadness, crying etc.], I find these situations sometimes more appropriate when the patient needs someone, not only who’s commiserating with them at the end of life, but someone who is strong and supportive at the end of life.</td>
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<td>Feeling alone</td>
<td>Debriefing sessions at the end of the month...or maybe, you know, within a few days of the patient’s death. Those would be useful...you could at least vent out your feelings and your guilt, and your sadness, and you’d find out that everyone shares those feeling and you wouldn’t feel isolated.</td>
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<td>Relational factors</td>
<td>Relationships with families</td>
<td>I think for the majority of them, you do develop some kind of a relationship. Again there’s such different degrees to the relationship because you may look after them; for instance, like one patient, or two actually, I looked after them during their bone marrow transplant. I was their primary kind of Fellow for the month that they were on bone marrow transplant. You know, one of whom went on to die three months after I looked after her, and another patient that went on to relapse a year later who then, I then looked after for a handful of days on the inpatient ward a year later before he died. So for Fellows it’s so variable how much contact you have. But I mean again, looking after a patient for a month, you do develop some kind of a relationship.</td>
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<td>Relationships and modeling with supervising staff</td>
<td>I would love to see a round table with a few staff going, “This is how I deal with things when a patient dies. This is how I dealt with it when I was more junior. This is how I’ve learned to deal with it. Yeah, I feel sad. Yeah, I feel guilty. Sometimes I cry.” So, you know, just a little bit more honesty about how they’re dealing with it and not so much stone-faced.</td>
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<td>I haven’t seen my supervisors grieving; I don’t think professionally we’ve been that open about it. Because you’re a trainee, you’re trying to just reciprocate or repeat, replicate what you’ve seen because that’s the right thing to do. You learn that for pneumonia you give this antibiotic, for this you give this and so we also learn that when someone dies you do the following...I’ve never seen staff crying together. I’ve never seen them go to the office and, and hold each other’s hands and cry through it. If two people caring for the same patient went through the grief, it would seem natural to kind of, go out for a coffee after and just vent about it. Or even just talk about it together.</td>
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<td>I think what we need is guidance from more senior physicians. And I feel like many of us probably aren’t comfortable going to them because...they don’t talk about that, I’ve...had one person sit down with me and talk about what they’re feeling...what they feel when they have to deliver bad news or, or you know, tell somebody they’re going die or deal with the death of a patient. Patients die all the time. There’s bad outcomes all the time and nobody really sits down and talks about what’s that like for them. Why don’t we ever really sit down and talk about the emotional toll that...this work takes on us? We just...work 24 hours straight, you tell parents at 2:00 in the morning that their child has leukemia or the child’s going to die...you’re tired, the families are crying...it’s just like, it just happens all the time.</td>
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Relationships with supervising staff and lack of modeling. Fellows reported wanting more modeling from senior oncologists and open communication on how to cope with patient deaths. They noted that although patient deaths were a frequent occurrence in the pediatric oncology context, fellows had rarely seen or heard senior staff talking openly about their feelings or about their coping strategies regarding this issue. As fellows, they did not feel comfortable seeking help with this matter.

Discussion

Our study examined the specific challenges that pediatric oncology fellows face when patients die during their training.
Fellows reported structural challenges that included the impact of ward duty and the subsequent exposure to patient death and perceived lack of access to follow-up with bereaved families after a patient died. Personal challenges included feelings of vulnerability as a result of being in the fellowship stage, inexperience with patient death, and feeling alone with one’s emotional reactions to patient death. Finally, relational challenges included relationships with patients and families, relationships with supervising staff, and perceived lack of modeling by senior staff regarding how to cope with patient deaths.

There have been few studies that have looked at the personal challenges and needs of pediatric oncology fellows when it comes to patient death. One report that described a lecture series held at Memorial Sloan Kettering Cancer Center focusing on the “Art of Medicine” for oncology fellows who treat adults provided some insight into what fellows may need in their training on these issues. The lecture series included senior physicians describing their own reactions to patient deaths, communication skills at the end of life, and a session on dealing with their own grief and burnout in the profession. This report did not evaluate the impact of these series quantitatively; however, the author reported that the lectures were well received by fellows and corroborate some of our findings on the challenges that fellows face in training with regard to dealing with patient death.15

Implications

One of the most compelling findings from this study is the insight into how structural factors such as clinical rotations, ward duty, call schedules, lack of consistent relationships with patients and families, and lack of continuity in professional modeling affect pediatric oncology fellows’ ability to react to, cope with, and respond to patient deaths emotionally and practically. Although the personal factors reported on in this study, including inexperience and feelings of vulnerability, will likely ameliorate with time, structural changes can be made in order to support fellows coping with patient death.

For example, informing fellows of all patient deaths so that they can follow up with families can assist with the sense of being disconnected and uninformed about patients and families that they cared for. Although this may be one particularly useful clinical intervention, it should be noted that this is complicated by issues of privacy. Typically, a notice of a child’s death may be sent out to the health care team, or the subspecialty unit (eg, neuro-oncology) that cared for the child and their family. Although the trainee who looked after that family on the ward or in a clinical rotation may not be included in that list because they may be in another clinical rotation, the health care team could be advised to direct information to those fellows who cared for the child and the family. Implementing this intervention would take some careful thought and consideration on how to keep pediatric oncology fellows informed without violating issues of privacy and patient and family confidentiality.

Another implication has to do with instituting formal debriefing sessions and pedagogical initiatives into fellowship training by senior healthcare team members in order to lessen feelings of isolation and help fellows learn effective strategies for dealing with patient deaths. While debriefing sessions are a routine in most pediatric institutions, the irregularity of the schedule during the fellow training period (one day off after on-call; elective at another institution, etc) may not allow the fellow to attend. Debriefing sessions have proven to be particularly effective in helping other health care professionals such as nurses16 and palliative care physicians17-19 manage their stress when patients die.

Another example of a supportive intervention can include Balint groups. These groups are designed to allow physicians to share clinical cases with other physicians in order to explore the various aspects of the doctor-patient relationship. These groups meet regularly and are normally moderated by a physician and a psychologist who facilitate the process, and who can help with the emotional aspects of practicing medicine, including dealing with patient death. In the fellowship context, one study examined the effectiveness of a Balint-like physician group for oncology fellows and found that group enhanced the fellows’ development as physicians and increased their comfort with discussing stressful work events at home.20 Another study found that a monthly Balint group for oncology residents helped decrease symptoms of burnout.21 A number of additional studies have documented the benefits of professional and peer support for oncology fellows.20,22-23

One way to effectively implement training would be to incorporate palliative care professionals into the oncology fellowship training program. While pediatric palliative care is becoming increasingly available in medical centers, physicians in training report that their education about caring for patients at the end of life is inadequate.10,24-25 Moreover, it has been documented that there is a need for increased training and education on palliative care and related issues for pediatric oncology fellows and senior staff.26-33 This training typically includes (but is not limited to) modules on establishing goals of care with patients and the their families, pain and symptom management, communication strategies, legal and ethical issues with patients at end of life, cultural sensitivity, and providing support and comfort for patients and families at end of life.16 Palliative care professionals can extend their role and also be incorporated into training pediatric oncology fellows on how to cope with their emotional reactions to patient deaths based on their experiences with patient deaths. This training can include education on compassion fatigue and burnout that can be long-term consequences of caring for patients at the end of life.15,34-41 This may be a particularly effective intervention for fellows. For example, one study that measured burnout in 254 second-year oncology fellows found that nearly a quarter reported high emotional exhaustion, a third reported high depersonalization, and nearly 30% reported low personal accomplishment. Fellows who were taught about issues related to the end of life scored significantly lower on emotional exhaustion.23
Limitations
Our study took place at two tertiary academic hospitals in Ontario, Canada and was limited to six participants who took part in a larger study on oncologists’ experiences of patient death. Although data saturation was reached within the larger sample from the project, it is possible that additional interviews with fellows would have revealed more nuances about their experiences. It is also plausible that oncology fellows in smaller centers may face different challenges with patient deaths. Moreover, our study cannot report on how frequently these challenges are faced by pediatric oncology fellows. Further survey research is needed to evaluate the prevalence of these findings and their applicability in other medical centers.

Although limited in scope, to our knowledge, this is one of the few studies that provides a window into the specific challenges that pediatric oncology fellows face when dealing with patient deaths, and our small sample size was sufficient in exploring a range of significant issues. As such, it is a unique contribution to the literature on the well-being of trainees in oncology and provides insight into challenges that fellows face when confronted by pediatric patient death.

Conclusion
Pediatric oncology fellows experience structural, personal, and relational challenges when patients die that are unique to their career stage. Structural changes to the fellowship model can be made in order to aid fellows with this difficult part of their job. Caring for the health care team that looks after sick and dying children and their families can improve quality of life for both the physicians and for the patients and their families.

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Collection and assembly of data: All authors
Data analysis and interpretation: All authors
Manuscript writing: All authors
Final approval of manuscript: All authors

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References

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