End-of-life experience of children undergoing stem cell transplantation for malignancy: parent and provider perspectives and patterns of care

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The end-of-life (EOL) experience of children who undergo stem cell transplantation (SCT) may differ from that of other children with cancer. To evaluate perspectives and patterns of EOL care after SCT, we surveyed 141 parents of children who died of cancer (response rate, 64%) and their physicians. Chart review provided additional information. Children for whom SCT was the last cancer therapy (n = 31) were compared with those for whom it was not (n = 110). SCT parents and physicians recognized no realistic chance for cure later than non-SCT peers (both \( P < .001 \)) and were more likely to have a primary goal of cure at death (parents, \( P < .001 \); physicians, \( P = .02 \)). SCT children were more likely to suffer highly from their last cancer therapy and die in the intensive care unit (both \( P < .001 \)), with less opportunity for EOL preparation. SCT parents who recognized no realistic chance for cure more than 7 days before death along with the physician were more likely to prepare for EOL, and if their primary goal was to reduce suffering, to achieve this (\( P < .001 \)). SCT is associated with significant suffering and less opportunity to prepare for EOL. Children and families undergoing SCT may benefit from ongoing discussions regarding prognosis, goals, and opportunities to maximize quality of life. (Blood. 2010;115(19):3879-3885)

Introduction

Hematopoietic stem cell transplantation (SCT) may provide a curative option for children with high-risk malignancies. Significant advances in transplantation techniques have improved survival rates and extended the possibility of cure to growing numbers of children with cancer and other conditions.1,4 Progress in supportive care5,6 and increasing attention to quality of life7-10 have also improved the morbidity and mortality associated with SCT. Despite such developments, however, SCT remains a relatively high-risk endeavor, and a significant number of SCT recipients die of disease relapse or treatment-related complications.

Over the past decade, inroads in understanding the end-of-life (EOL) experience of children with cancer have been made. Several studies have documented patterns of care and symptoms and suffering that such children experience.11-19 Exploration of parent and physician perspectives has also revealed their communication patterns and understanding of prognosis at EOL.20,21 EOL experiences have often been evaluated according to factors, such as the child’s cancer diagnosis,12,13,16,17,19 age,12,18 location of EOL care, or type of death (ie, progressive disease or treatment-related complication).11,19 Others have primarily focused on children who died of progressive disease.13,16

As an intense therapy delivered with curative intent, with high risk for life-threatening toxicity, SCT may uniquely impact aspects of a recipient’s EOL experience. Despite this, very little is known about the experience of children who undergo SCT but do not survive. Studies of children with cancer have occasionally included SCT recipients,11,14,15 but only 1 specifically describes outcomes in this group.14 By review of medical records, Bradshaw et al demonstrated that children who underwent SCT were more likely to experience a pulmonary or cardiovascular complication, were less likely to die at home, and had a do-not-resuscitate (DNR) order in place for a shorter period of time before death.15

Multiple other aspects of EOL, including understanding of prognosis, goals of care, symptoms and suffering experienced, and additional detail regarding patterns of care, remain unexplored. The aim of this study is to characterize the EOL experience of pediatric SCT patients by describing the experience of children who underwent SCT as their last cancer-directed therapy. Such an understanding may delineate opportunities to maximize comfort and quality of life, which could be pursued in concert with curative therapy in this group of patients.

Methods

The analyses presented here represent a secondary analysis of a dataset previously presented by Wolfe et al.22,23 The setting, survey instrument, and data collection methods have been previously described22,23 and are summarized here. The institutional review boards of Dana-Farber Cancer Institute/Children’s Hospital Boston (DFCI/CHB) and the Children’s Hospitals and Clinics, St Paul and Minneapolis (CHC) approved the study.
Study population

Parents of children who died from cancer were eligible if: (1) they were English-speaking, (2) they resided in North America, (3) their child received care at DFCI/CHB or CHC, and (4) the child’s oncologist granted permission for them to be contacted. Interviews were conducted between 1997 and 2001, at least 1 year after the child’s death. Parents were contacted via a mailed letter with a postage-paid opt-out card (DFCI/CHB) or opt-in card (CHC), as determined by the corresponding institution’s institutional review board. One parent per family, designated by the family, was interviewed by 1 of 3 trained interviewers or 1 of 3 investigators. The majority of interviews were conducted by telephone; 35 were conducted in person on parental request. All participating parents gave oral informed consent to participate. To evaluate EOL experiences most likely to be influenced by SCT, we identified children whose last cancer-directed therapy was SCT (SCT group). As a comparison, we also evaluated the EOL experiences of children whose last cancer therapy was not SCT (non-SCT group).

Data collection

Parent survey. The parent survey instrument was a 390-item semistructured questionnaire. Whenever possible, questions were drawn from previously validated surveys, although some were developed de novo from literature review and focus groups of parents and medical caregivers. All questions reported in this analysis were close-ended, with categorical responses or Likert scales. Domains included demographic and socioeconomic data, types of cancer-directed therapy pursued, goals of cancer therapy, symptoms and suffering experienced by their child, parental understanding of prognosis, and other aspects of the child’s EOL experience, as previously reported.22,23 Parents were asked about their perspectives regarding the child’s location of death and their preparedness for their child’s death. They were also asked whether they had discussed topics, such as their child’s prognosis, withdrawing or withholding life-sustaining treatment, and autopsy, and what the outcome of such discussions were. Questions regarding the child’s experience of symptoms in the last month of life included frequency or degree of suffering from symptoms (response categories: a great deal, a lot, some, a little, not at all). Parents were asked to estimate the timing of their understanding that the child had no realistic chance for cure, defined as the EOL period.

Parents were also asked about their goals for the last cancer-directed therapy, with response options consisting of “to cure your child’s cancer,” “for you and/or your child to keep hoping,” “to ensure you had done everything,” “to extend life without hope for cure,” “to lessen suffering,” “to help cancer research,” and “other.” Parents were also asked about their primary goal of medical care during the period when they understood that their child had no realistic chance for cure as well as at the time of death, with response options of “to extend life,” “to minimize suffering,” and “other.”

Physician survey. For every child whose parent completed a survey, their physician also completed a survey. Physicians were surveyed after the last cancer-directed therapy was completed at the child’s death, and information regarding the physician’s background, including age, experience (number of years in practice), and training status (fellow vs attending physician), was collected. Physicians were asked what had been their primary goal of care 1 month before the child’s death, as well as at the time of death, with response options consisting of “to minimize suffering,” “to extend life/cure,” and “both.”

Medical record abstraction. Trained research assistants abstracted data from the inpatient and outpatient medical records of children as previously described.22,23 Data collected included the child’s sex, diagnosis, dates of birth, diagnosis, and death, types and dates of cancer-directed therapies, and type of death (categorized as progressive disease or treatment-related toxicity). For children in the SCT group, the date of last cancer-directed therapy was considered to be day 0 of transplantation. For non-SCT children, the date of last cancer therapy was the last date they received chemotherapy, radiation therapy, or surgery. Other data collected included patterns of care, including whether the child was intubated in the last 24 hours of life, whether resuscitation status was discussed, and whether and when a DNR order had been written, location of death, timing of the first discussion with the family that the child had no realistic chance for cure, and whether and when hospice was discussed.

The timing of the physician’s recognition that the child had no realistic chance for cure was defined as the first date when chart documentation included a statement consistent with there being no realistic chance for cure, indication of referral to hospice or home care for terminal care, or reference to DNR status. Whether the physician realized that the child had no realistic chance for cure at least 7 days before the child’s death was used to evaluate outcomes associated with earlier recognition of no realistic chance for cure. This was derived directly from the timing of the first documentation in the medical record in which the physician indicated that the child had no realistic chance for cure.

Statistical analysis

Analyses were conducted using the SAS statistical package (SAS Institute Inc.). Children for whom the responding parent did not answer a particular item or for whom data were not available by chart review were not included in the analysis of a given data element. Descriptive statistics were used to report characteristics of children and their cancer therapy, parent and physician understanding of prognosis and goals of care, patterns of care, and the child’s symptoms and suffering. Categorical data were dichotomized into clinically meaningful categories. Variables relating to the child’s suffering in the last month were collapsed into “suffering highly” (suffering “a great deal” or “a lot”) and “not suffering highly” (suffered “some,” “a little,” or “not at all”).

To test associations between variables of interest and last cancer therapy, absolute risk differences or differences of medians (and their 95% confidence intervals) between the SCT and non-SCT groups were determined. Bivariate analyses using a 2-tailed Fisher exact test, t test, or Wilcoxon rank-sum test were also conducted, as appropriate. To account for possible recall bias in parent-reported outcomes, multivariate logistic regression or linear regression modeling was performed, adjusting for time between the child’s death and survey administration. For variables relating to autopsy, we additionally adjusted for the location of death because this may have influenced whether an autopsy was performed.24 Because of physician overlap in the SCT and non-SCT groups, physician characteristics between the 2 groups could not be compared. However, given the possibility that children with the same physician may have had similar outcomes, we conducted regression analyses to adjust for physician clustering.

In addition, we explored whether earlier parent and physician recognition that the child had no realistic chance of cure was associated with goals or patterns of care using the same analysis approach described in the paragraph above.

Results

Of 244 eligible parents, 222 were located, and 141 completed interviews, for a response rate of 64%. Parental survey responders and nonresponders did not differ with regard to the child’s diagnosis, age, or time elapsed since the child’s death. Of the 141 children, 31 of 141 (22%) underwent SCT as their last cancer-directed therapy and 110 of 141 (78%) did not. Although 23 of 110 (21%) non-SCT children had previously undergone SCT, it was significantly earlier in their course (median interquartile range, IQR), 352 [192, 601] days before death) compared with SCT children (median [IQR], 65 [30, 127] days, P < .001). Demographic and clinical characteristics of the children and their parents are reported in Table 1. Other than diagnosis, there were no significant differences between the SCT and the non-SCT groups. Those in the SCT group were more likely to have had a hematologic malignancy than those in the non-SCT group (risk difference [RD] = 48%; 95% confidence interval [CI], 31%-65%), P < .001).

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Table 1. Sample demographics and clinical characteristics

<table>
<thead>
<tr>
<th>Child characteristics</th>
<th>SCT (n = 31)</th>
<th>Non-SCT (n = 110)</th>
<th>Total sample (n = 141)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site of care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boston, n (%)</td>
<td>24 (77)</td>
<td>78 (71)</td>
<td>102 (72)</td>
</tr>
<tr>
<td>Minneapolis/St Paul, n (%)</td>
<td>7 (23)</td>
<td>32 (29)</td>
<td>39 (28)</td>
</tr>
<tr>
<td>Female sex, n (%)</td>
<td>15 (48)</td>
<td>51 (46)</td>
<td>66 (47)</td>
</tr>
<tr>
<td>Mean age at death, y (SD)</td>
<td>9.3 (6.9)</td>
<td>10.5 (6.5)</td>
<td>10.3 (6.6)</td>
</tr>
<tr>
<td>Mean time since death, y (SD)</td>
<td>3.5 (2.0)</td>
<td>3.8 (2.2)</td>
<td>3.7 (2.2)</td>
</tr>
</tbody>
</table>

Parent characteristics

| Mean duration of illness, y (SD) | 3.0 (4.1) | 2.6 (2.9) | 2.7 (3.2) |
| Cancer type                      |           |           |           |
| Hematologic malignancy, n (%)    | 27 (87)   | 43 (39)   | 70 (50)   |
| Solid/brain tumor, n (%)         | 4 (13)    | 67 (61)   | 71 (50)   |

There were no significant differences between the stem cell transplantation (SCT) and the non-SCT groups other than diagnosis. Those in the SCT group were more likely to have had a hematologic malignancy than a solid/brain tumor (P < .001).

All children in the study had a physician who completed a survey (response rate, 100%). Fifty-three unique physicians cared for the children, among whom 18 (33%) were female and 21 (39%) were trainees. The physicians had a mean (SD) of 8.6 (5.7) years of experience. Adjustment for physician clustering did not alter any outcomes.

Last cancer-directed treatment

Among children in the SCT group, 22 of 31 (71%) underwent allogeneic and 9 of 31 (29%) autologous SCT. In the non-SCT group, last cancer therapies included chemotherapy (n = 79), radiation therapy (n = 23), chemotherapy and radiation (n = 2), and surgery (n = 6). The median (IQR) interval between last cancer treatment and death was 65 (30, 127) days for the SCT group and 25 (8, 59) days for the non-SCT group (P < .001).

According to the medical record, causes of death among all children in the SCT group included relapsed disease (n = 6), veno-occlusive disease (n = 3), graft-versus-host disease alone (n = 3), infection alone (n = 3), graft-versus-host disease and infection (n = 8), multiorgan system failure (n = 2), primary respiratory failure (eg, pulmonary hemorrhage, acute respiratory distress syndrome; n = 5), and posttransplant lymphoproliferative disease (n = 1). Most (25 of 31, 81%) children in the SCT group died of treatment-related toxicity, compared with 7 of 110 (6%) of children in the non-SCT group (RD = 75%; 95% CI, 58%-91%; P < .001).

Similar proportions of parents felt that their child benefited from their last cancer-directed therapy (9 of 26 [35%] of the SCT group vs 33 of 88 [38%] of the non-SCT group, P = .82). Among parents who reported no benefit from the last cancer-directed therapy, SCT parents were more likely to report no benefit because they perceived that the therapy shortened their child’s life (5 of 17 [29%] of SCT vs 1 of 50 [2%] of non-SCT parents; RD = 27%; 95% CI, 1%-53%, P = .003). Although 48% of non-SCT parents reported lack of benefit because their child’s cancer progressed or recurred, no SCT parents reported lack of benefit for this reason (RD = 48%; 95% CI, 30%-66%, P < .001).

Understanding of prognosis

When asked whether they could identify when they became aware that their child had no realistic chance for cure, 28 of 30 (93%) and 107 of 108 (99%) of SCT and non-SCT parents, respectively, could define this time (P = .13). For all SCT parents, this occurred after starting SCT. For the majority (20 of 27, 74%) of SCT parents, this realization occurred when their child experienced a treatment-related complication; and for the majority (68 of 105, 63%) of non-SCT parents, this realization occurred at the time of disease progression or relapse (P < .001). The interval between parent realization that the child had no realistic chance for cure and the child’s death was significantly shorter for SCT parents compared with non-SCT parents (median [IQR] of 16 [2, 30] days before death vs 84 [29, 166] days; median difference, −69 days; 95% CI, −95 to −41 days, P < .001).

Similarly, the first physician documentation in the medical record that the child had no realistic chance for cure was closer to the time of death for the SCT group, a median (IQR) of 4 (18,22) days before death, compared with 84 (29, 237) days for the non-SCT group (mean difference, −80 days, 95% CI, −17 to −43 days, P < .001). Within the SCT and non-SCT groups, the median (IQR) difference between physician and parent recognition that there was no realistic chance for cure was 5 (IQR, −24 to 81) days and 0 (−14 to 7) days, respectively (P = .37).

The percentages of children whose parent and/or physician recognized that the child had no realistic chance for cure by the last 7 days of the child’s life are presented in Figure 1. For the majority (87 of 110 [79%]) of non-SCT children, both the parent and physician recognized that the child had no realistic chance for cure within this timeframe, compared with 13 of 31 (42%) of SCT children (P < .001). Indeed, for nearly half (14 of 31 [45%]) of SCT children, neither the parent nor the physician had this realization by the last 7 days of the child’s life, significantly more than non-SCT children (P < .001).

Goals of care

The proportions of parents reporting a primary goal of curing their child/extending the child’s life are summarized in Table 2. For both groups, the proportion of parents reporting a primary goal of cure/life extension decreased as the child approached the EOL. SCT parents were more likely than non-SCT parents to have a primary goal of cure/life extension at all time points. Physicians of
Patterns of care

Patterns of care in the SCT and non-SCT groups are summarized in Table 3. Children in the SCT group spent more days in the hospital in their last month of life, to die in the intensive care unit (ICU), with less opportunity for location of death to be planned or hospice to become involved. When asked about the location of death, SCT parents were more likely to have preferred an alternative location than non-SCT parents (15 of 29 [52%] of SCT parents vs 9 of 107 [8%] of non-SCT parents, \( P < .001 \)).

Although resuscitation was discussed with equal frequency in the 2 groups, these discussions occurred later and were associated with fewer DNR orders being written in the SCT group. Life-sustaining treatments, (ie, ventilatory support, antibiotics, transfusions, and artificial nutrition and hydration) were more likely to be withdrawn in the SCT group.

Symptoms and suffering

Children in the SCT group were more likely to suffer highly (a great deal/a lot) from their last cancer-directed therapy (\( P = .023 \)). Physical and psychologic symptoms from which children suffered are summarized in Table 4. On average, children in the SCT group suffered from more physical and psychologic symptoms than children in the non-SCT group.

Outcomes associated with earlier recognition of no realistic chance for cure

To evaluate whether the timing of parent and physician recognition of no realistic chance for cure was associated with EOL care outcomes in the SCT group, SCT children were dichotomized into 2 groups based on whether both the physician and parent recognized no realistic chance for cure more than 7 days before the child’s death. The (13 of 31 [29%]) children whose parent and...
physician both recognized no realistic chance for cure were more likely to have resuscitation status discussed (13 of 13 [100%] vs 11 of 18 [61%], RD = 39%; 95% CI, 10%-68%, \( P = .03 \)), and had DNR orders implemented earlier (median 13 days before death [IQR 8, 50] vs 1 day [IQR 0, 1], median difference 12 days, [IQR 8, 35], \( P < .001 \)). They were also more likely to have location of death planned (7 of 13 [54%] vs 2 of 18 [11%], RD = 43%; 95% CI, 5%-80%, \( P = .02 \)). If the parent’s primary goal was to reduce suffering, their goal was more likely to be achieved if they, along with the physician, recognized no realistic chance for cure at least 7 days before death (9 of 11 [82%] vs 5 of 18 [28%], RD = 54%; 95% CI, 16%-92%, \( P = .01 \)).

### Discussion

SCT is a high-intensity therapy that may offer a better prospect of cure for high-risk malignancies compared with other cancer therapies. SCT parents and physicians most often embark on this intensive therapy with a primary goal of cure. Despite such hopes, the risks of life-threatening complications and relapse are high: 5-year survival is 50% to 60% in many series.\(^{25,26}\) There is often little time for a child’s diminishing chance for survival to be recognized and for the focus of care to include aims other than cure, particularly when life-threatening complications occur after SCT. With less time to prepare for EOL, the experience of SCT children is often distinct from that of other children with cancer. Non-SCT children are more likely to die of disease that has advanced despite potentially curative therapies, including SCT, providing more opportunity to prepare for EOL.

In this cohort, later recognition that the child had no realistic chance for cure was associated with several outcomes, including less opportunity to plan location of death, discuss resuscitation status, and reduce suffering. Although the long-term impact of such outcomes on bereaved SCT families is not fully known, it is known that parents of children with cancer who underwent SCT and died report higher levels of depression, anxiety, and stress than parents of children with cancer who died but did not undergo SCT.\(^{27}\) Opportunities to maximize quality of life and promote meaningful experiences may well reduce the suffering of SCT recipients and families, and warrant further study.

Prognostication in the setting of SCT complications may pose a particular challenge for physicians. Few specific and reliable predictors of mortality for serious SCT-related complications requiring admission to the ICU, other than the need for mechanical ventilation, cardiovascular, hepatic, or neurologic failure, or previous intubation within the past 6 months, are known.\(^{28,29}\) In addition, outcomes of SCT patients admitted to the ICU may be improving.\(^{28,29}\) For children who relapse, the duration of survival is uncertain; and in some cases, the possibility of a second transplant remains. With such prognostic uncertainty, combined with intent to cure, parents and physicians may opt for interventions to extend life with the hope that complications may be reversed. The inclination to pursue such measures may be even stronger when a complication arises from treatment, as opposed to the underlying cancer.

Hilden et al found that pediatric oncologists report the most important factor in discussing supportive and palliative care with families is the absence of effective treatment.\(^{31}\) However, waiting until it is certain that a child is dying may deprive families of the opportunity to prepare for and to shape their child’s EOL experience. Given the high risk and prognostic uncertainty that accompanies SCT, an alternative strategy that proactively creates opportunities to discuss possible outcomes, goals, and options, even while pursuing every opportunity for cure, may greatly benefit families. Such a model has been proposed by Baker et al,\(^{32}\) and prospective studies to evaluate this approach are needed.

When sights are set only on cure, families and care teams tend to not consider less desired outcomes, even if such considerations do not preclude maximal efforts to achieve a cure. For example, adults embarking on SCT often do not engage in advance care planning, despite the known high risks of morbidity and mortality of SCT.\(^{33,34}\) Indeed, those at highest risk for death are the least

### Table 4. Symptoms and suffering experienced by children in the last month of life by parent report

<table>
<thead>
<tr>
<th>Symptom</th>
<th>SCT (n = 31)</th>
<th>Non-SCT (n = 110)</th>
<th>Difference, percentage (95% CI)</th>
<th>( P )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent at least a bit prepared for symptoms/medical problems at EOL, n (%)</td>
<td>16/29 (55)</td>
<td>88/110 (80)</td>
<td>−25 (−47, −3)</td>
<td>.014</td>
</tr>
<tr>
<td>Suffered highly from last cancer therapy, n (%)</td>
<td>23/31 (74)</td>
<td>54/108 (50)</td>
<td>24 (4, 44)</td>
<td>.023</td>
</tr>
<tr>
<td>Pain</td>
<td>20/31 (65)</td>
<td>54/108 (50)</td>
<td>15 (−7, 36)</td>
<td>.22</td>
</tr>
<tr>
<td>Anorexia</td>
<td>8/30 (27)</td>
<td>19/108 (18)</td>
<td>9 (−10, 29)</td>
<td>.301</td>
</tr>
<tr>
<td>Fatigue</td>
<td>20/30 (66)</td>
<td>48/108 (44)</td>
<td>22 (1, 44)</td>
<td>.039</td>
</tr>
<tr>
<td>Nausea/vomiting</td>
<td>10/31 (32)</td>
<td>18/108 (16)</td>
<td>15 (−8, 35)</td>
<td>.078</td>
</tr>
<tr>
<td>Constipation</td>
<td>1/31 (3)</td>
<td>21/109 (19)</td>
<td>−16 (−28, −4)</td>
<td>.046</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>13/31 (42)</td>
<td>12/107 (11)</td>
<td>31 (10, 51)</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Breathing difficulties</td>
<td>18/31 (58)</td>
<td>45/106 (42)</td>
<td>16 (−6, 37)</td>
<td>.153</td>
</tr>
<tr>
<td>Seizures</td>
<td>2/30 (7)</td>
<td>16/109 (15)</td>
<td>−8 (−21, 5)</td>
<td>.361</td>
</tr>
<tr>
<td>Fever/infection</td>
<td>13/32 (41)</td>
<td>32/109 (29)</td>
<td>15 (−6, 38)</td>
<td>.124</td>
</tr>
<tr>
<td>Mean no. of physical symptoms causing high suffering (SD)</td>
<td>3.5 (2.0)</td>
<td>2.4 (1.9)</td>
<td>1.3 (−0.1, 2.7)</td>
<td>.009</td>
</tr>
</tbody>
</table>

Crude (unadjusted) results are presented. Denominators are based on number of respondents for each item and may differ from total sample size. Differences correspond to absolute risk differences (for proportions) or differences in means. Adjustment for time since death was performed for these outcomes, with no change in \( P \) value significance. SCT indicates stem cell transplantation; CI, confidence interval; and EOL, end-of-life.
likely to have planned in advance, perhaps because they are most focused on the possibility of cure. 34

Given these challenges, systematic prompts to revisit goals of care, facilitating shared decision-making and preparation for possible outcomes, may be needed. Developments indicating that a child is becoming more seriously ill, such as transfer to the ICU or initiation of dialysis, may serve as triggers for discussions regarding possible outcomes and goals of care. Although providers may fear that such discussions diminish a family’s hope, parents of children with cancer report that disclosure of prognosis can indeed support their hope, even when the prognosis is poor.21 Parents appreciate the opportunity to address these issues, as well as the affirmation that ongoing open and honest communication is possible, and such communication is associated with parental ratings of high quality care.

Our findings are based on parental report, which may not accurately reflect the child’s experience, particularly for the outcomes reported. Discrepancies between children and parent proxy reports with regard to quality of life have been documented. However, the direction of such discrepancies is inconsistent and has variable significance.35,36 Although the child’s report should be considered the “gold standard,” as the health status of seriously ill children declines, it becomes increasingly difficult to obtain self-report measures,37 and studies regarding the experience of children declines, it becomes increasingly difficult to obtain self-report measures, and studies regarding the experience of children at the EOL must therefore often rely on parent report.12,17,18

Given the cross-sectional, retrospective nature of this study, findings based on parent and physician report are subject to recall bias. We attempted to mitigate the impact of such bias by adjusting for time since death, although longitudinal, prospective studies are in order. Other studies of the EOL experience of children with cancer do lend credence to our findings. Such studies have found that children with hematologic malignancies or those dying of complications of cancer therapy were more likely to die in hospital, after a longer hospital stay, and less likely to have a DNR order in place.19 Such characteristics may indeed be markers for having undergone SCT. Studies of larger SCT populations may further elucidate the relationships between these factors and particular EOL outcomes.

The patterns of care for SCT children demonstrated in this study, however, are consistent with those observed in solid organ transplantation populations, who have a similar focus on cure and for whom interventions aimed at extending life are undertaken. For example, adults with cystic fibrosis who maintain hope in the possibility of lung transplantation (ie, are listed for transplantation or have been transplanted) are less likely to participate in decisions and more likely to die in the ICU,38,39 remain intubated at or shortly before death, with later implementation of DNR orders and alternatives to hospital death rarely discussed.39

Palliative care aims to optimize quality of life and address suffering, regardless of the likelihood of cure. Integration of a palliative care approach with hematopoietic stem cell or solid organ transplantation has been recently proposed.40,42 Song et al have found that barriers to integrating palliative care with lung transplantation include providers’ misconceptions that palliative care is equivalent to EOL care, difficulty in discussing palliative care with families, and uncertainty about prognosis.43 Pediatricians and nurses report similar barriers to the provision of pediatric palliative care in ICU and non-ICU settings, including prognostic uncertainty.44 Clarification among families and staff that the aims of palliative care may be congruent with maximal treatment aimed at sustaining life, and need not be reserved for the dying, is needed.

As SCT success rates improve, attention to outcomes beyond cure is mounting. The field of SCT has historically included significant advances in supportive care administered during transplantation, including patient-controlled analgesia,6,45,46 treatment of chemotherapy-induced nausea and vomiting,47,48 and management of mucositis.49,50 Over recent years, attention to other outcomes for survivors, such as health-related quality of life and functional outcomes, has also increased.5,7-10 However, no studies focused on SCT recipients who do not survive exist, although they may suffer significantly at EOL. The symptoms and suffering experienced by SCT patients, particularly those at EOL, warrant much greater attention.

SCT is an invaluable therapy for many children and adults with high-risk cancers. It also affords a wealth of opportunities to enhance symptom management and facilitate communication and support for dual goals of cure and relief of suffering. Such advances would be welcome contributions to a host of other fields. For patients and families who opt for a chance of cure through SCT, such strategies are urgently needed, so that they have optimal opportunities for comfort and meaning regardless of treatment goals or outcomes.

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Authorship

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