Understanding of Prognosis Among Parents of Children Who Died of Cancer
Impact on Treatment Goals and Integration of Palliative Care

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Context Parents’ understanding of prognosis or decision making about palliative care for children who die of cancer is largely unknown. However, a more accurate understanding of prognosis could alter treatment goals and expectations and lead to more effective care.

Objectives To evaluate parental understanding of prognosis in children who die of cancer and to assess the association of this factor with treatment goals and the palliative care received by children.

Design, Setting, and Participants Survey, conducted between September 1997 and August 1998, of 103 parents of children who received treatment at the Dana-Farber Cancer Institute and Children’s Hospital, Boston, Mass, and who died of cancer between 1990 and 1997 (72% of those eligible and those located) and 42 pediatric oncologists.

Main Outcome Measure Timing of parental understanding that the child had no realistic chance for cure compared with the timing of physician understanding of this prognosis, as documented in the medical record.

Results Parents first recognized that the child had no realistic chance for cure a mean (SD) of 106 (150) days before the child’s death, while physician recognition occurred earlier at 206 (330) days before death. Among children who died of progressive disease, the group characterized by earlier recognition of this prognosis by both parents and physicians had earlier discussions of hospice care (odds ratio [OR], 1.03; 95% confidence interval [CI], 1.01-1.06; P = .01), better parental ratings of the quality of home care (OR, 3.31; 95% CI, 1.15-9.54; P = .03), earlier institution of a do-not-resuscitate order (OR, 1.03; 95% CI, 1.00-1.06; P = .02), less use of cancer-directed therapy during the last month of life (OR, 2.80; 95% CI, 1.05-7.50; P = .04), and higher likelihood that the goal of cancer-directed therapy identified by both physician and parent was to lessen suffering (OR, 5.17; 95% CI, 1.86-14.4; P = .002 for physician and OR, 6.56; 95% CI, 1.54-27.86; P = .01 for parents).

Conclusion Considerable delay exists in parental recognition that children have no realistic chance for cure, but earlier recognition of this prognosis by both physicians and parents is associated with a stronger emphasis on treatment directed at lessening suffering and greater integration of palliative care.

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In children, communication about end-of-life issues may be more challenging because the parent is almost always the surrogate decision maker.10-12 Saunders13 has validated the clinical impression that parental grief is more severe and longer lasting than other types of grief. The anticipation of losing a child may impede discussions about the terminal prognosis and, in turn, may impact decision making and integration of palliative care.14 It is also possible that physicians of children with advanced cancer have difficulty confronting the loss of a young patient since the intent in pediatric cancer care is generally curative.15 As such, greater barriers may exist to optimal communication about end-of-life issues in children with advanced cancer and may result in poorer quality-of-life outcomes for the 25% of children who will eventually die of their disease.1

We interviewed parents, surveyed the primary oncologist, and reviewed the medical records of children who died of cancer to answer the following questions: When do parents and physicians become aware that the child has no realistic chance for cure? What factors are associated with a greater concordance in timing of parent and physician awareness that the child has no realistic chance for cure? Does understanding of the child’s prognosis alter parents’ treatment goals? What outcomes are associated with earlier parent-physician recognition that the child has no realistic chance for cure?

**METHODS**

As previously described,2 the study was conducted at Children’s Hospital and the Dana-Farber Cancer Institute, Boston, Mass.

**Study Population**

Subjects included parents of children who died of cancer between 1990 and 1997. Parents were eligible if they were (1) English-speaking, (2) residents of North America, (3) their child had died of cancer more than 1 year before enrollment, and (4) the child’s former physician permitted contact with the family (permission was denied for 15 families). Eligible parents were sent a letter containing a postage-paid “opt-out” postcard. Of 165 eligible parents, 143 were located, and 107 agreed to participate. We conducted a single interview of 1 parent per family; which parent participated was left to the family’s discretion. One hundred three parents were interviewed between September 1997 and August 1998 for a response rate of 72% (103/143). The mean duration of the interview was 113 minutes. The parent interview was conducted a mean (SD) of 3.1 (1.6) (range, 1.1-8.0) years following the death of the child. We also surveyed the child’s primary oncologist and reviewed medical charts.

**Data Collection**

**Instrument Development.** Relevant domains and draft items were developed from literature review and focus groups of parents and medical caregivers.2 Whenever possible, items were taken from previously validated surveys.16 However, the majority of items were newly created following guidelines suggested by Streiner and Norman.17 All items were closed-ended with categorical responses or Likert scales. A pretest of the instrument assessed content, wording, response burden, cognitive validity, and parental willingness to participate.

**Parent Survey.** A trained interviewer and 1 of the investigators (J.W.) conducted the parent interviews. The majority of interviews were administered by telephone; 5 were conducted in person at the request of the parent. Parents were asked to estimate the timing of the onset of their understanding that the child had no realistic chance for cure, also defined as the end-of-life care period. They were asked if they had ever discussed this prognosis with medical caregivers, and if so, who participated in this discussion, whether the topic was appropriate to discuss, and how comfortable they were with the manner in which this was discussed. Parents also reported their understanding of the primary goal of cancer-directed therapy at the time of diagnosis, during the period when they understood that the child had no realistic chance for cure, and what they currently believed the primary goal of cancer-directed therapy should be during the end-of-life care period for children with cancer. Response categories included “to cure your child’s cancer,” “for you and/or your child to be able to keep hoping,” “to make sure you have done everything,” “to extend your child’s life as long as possible but without hope of cure,” “to lessen your child’s suffering as much as possible,” “to help cancer research,” and “other.” Parents were asked about their primary goal of treatment of symptoms during the end-of-life care period (“to extend life as long as possible,” “to lessen suffering as much as possible,” or “other”). Additional data collected in the parent interview included understanding of the child’s likelihood of cure at the time of diagnosis, level of preparedness for symptoms experienced during the end-of-life care period, quality of care provided by the primary team, quality of communication with the primary team, involvement of a home care team (hospice or visiting nurse association) and/or a psychosocial clinician (psychologist or social worker) during the end-of-life care period, peacefulness of the child’s death, and parent demographics (age, sex, race, education, income, and religion). Parents were informed in the introductory letter and interview that psychosocial support was available to them if desired.

**Physician Survey.** Physicians were asked what they believed to be the child’s likelihood of cure at diagnosis, the primary goal of treatment at 1 month prior to death, and perceived peacefulness of the death. We determined the number of years of experience by subtracting the physician’s date of beginning internship from the patient’s date of death. The physician’s sex also was recorded.

**Chart Review.** Charts of the children of all eligible parents were abstracted by trained research assistants. Every tenth chart also was abstracted by one of the study investigators. When discrepancies were found, the chart was reviewed by both abstractors, and the ap
propriate response was determined by consensus. The timing of the onset of the end-of-life care period by physician determination was defined as the first date when chart documentation included a statement consistent with there being no realistic chance for cure, any reference to do-not-resuscitate status, or any reference to hospice or home care to provide terminal care. Additional data collected by chart review included sex; diagnosis; dates of birth, diagnosis, and death; number, types, and timing of cancer-directed regimens and enrollment in clinical studies; cause of death classified as progressive disease with or without a treatment-related complication or a treatment-related complication alone; intubation in the last 24 hours of life; use of cardiopulmonary resuscitation; and location of death.

Human Subjects Approval
The institutional review boards of the 2 participating institutions approved the study. All parents gave verbal informed consent.

Statistical Methods
Analyses were conducted using the SAS statistical package (SAS Institute Inc, Cary, NC). Respondents who did not answer a specific question or for whom data were not available from chart review were excluded from the analyses of that data element. Variables using Likert scales were dichotomized as specified in text and tables. The χ² statistic was used to look for agreement between physician and parental views regarding elements of end-of-life care. The McNemar test was used to compare the direction of discordance, when present.

We determined the mean difference between physician and parent estimates of the onset of the end-of-life care period and looked for factors associated with this discrepancy using linear regression analyses. We adjusted for physician clustering to account for the possibility that children might have more similar data by virtue of sharing the same physician. Among clinical, sociodemographic, and attitudinal variables were examined in bivariate analyses. Factors found to be associated with P<.05 were entered into multivariate models.

We also examined factors associated with the parent-physician group in which there was recognition that the child had no realistic chance for cure at 50 days prior to death among children who died of progressive disease, using logistic regression analyses. We selected 50 days because at that point the physician and parent for half the cohort (51%) recognized that the child had no realistic chance for cure, and for the other half, the physician, parent, or both did not believe that the child had entered the end-of-life care period. Again, we adjusted for physician clustering. All models were fit using the SAS Genmod procedure.

RESULTS
Subject Characteristics
Parents. The mean (SD) age of parents at the time of the interview was 43 (7.7) years. Most were white (91%) and women (86%). The range of reported median household income was $25000 to $49999 per year. Seventy-six percent of parents had some postsecondary education and 50% were Catholic.

Children. The clinical characteristics of the children are summarized in Table 1. More than one third of the cohort underwent bone marrow transplantation; 5% underwent 2 bone marrow transplantsations. Twenty percent of children died as a result of a treatment-related complication.

When compared with the children of parents who were interviewed, children of nonrespondents did not differ significantly with regard to sex, diagnosis, age at death, duration of disease, enrollment in a clinical study, having undergone bone marrow transplantation, or place of death. Children of parents who did not participate were more likely to have undergone cardiopulmonary resuscitation (26% vs 6%; P = .03).

Physicians. Of the 42 pediatric oncologists who cared for the children, 13 (31%) were women. They had a mean (SD) of 7.1 (4.7) years of experience at the time of death of the child.

Understanding of Prognosis
Fifty-six percent of parents and 43% of physicians reported that they believed cure was likely at the time of diagnosis (κ = 0.492; 95% confidence interval [CI], 0.32-0.66). Among physicians and parents whose recalled prognostic estimates differed, parents were significantly more likely to believe that the child would be cured (odds ratio, 3.0; 95% CI, 1.2-7.6; P = .02).

For parents, the first recognition that the child had no realistic chance for cure occurred a mean (SD) of 106 (150) days prior to death. There was no significant association between estimates of the duration of this period and the length of time elapsed between the child’s death and the parent’s interview. In contrast, the mean (SD) length of time between the first physician documentation that the child had entered the end-of-life period and the child’s death was 206 (330) days.

**Table 1. Characteristics of Patients, Disease, and Cancer Treatment**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Values (N = 103)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient</strong></td>
<td></td>
</tr>
<tr>
<td>Female, No. (%)</td>
<td>46 (45)</td>
</tr>
<tr>
<td>Age at diagnosis, mean (SD), y</td>
<td>8.1 (6.1)</td>
</tr>
<tr>
<td>Duration of disease, mean (SD), y</td>
<td>2.7 (3.3)</td>
</tr>
<tr>
<td>Age at death, mean (SD), y</td>
<td>10.8 (6.7)</td>
</tr>
<tr>
<td><strong>Disease</strong></td>
<td></td>
</tr>
<tr>
<td>Type of cancer, No. (%)</td>
<td></td>
</tr>
<tr>
<td>Leukemia or lymphoma</td>
<td>50 (49)</td>
</tr>
<tr>
<td>Brain tumor</td>
<td>23 (22)</td>
</tr>
<tr>
<td>Other solid tumors</td>
<td>30 (29)</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td></td>
</tr>
<tr>
<td>No. of cancer-directed regimens, mean (SD)</td>
<td>3.7 (2.1)</td>
</tr>
<tr>
<td>Enrollment in clinical studies, No. (%)</td>
<td></td>
</tr>
<tr>
<td>Any type of study</td>
<td>76 (74)</td>
</tr>
<tr>
<td>Phase 1</td>
<td>24 (23)</td>
</tr>
<tr>
<td>Bone marrow transplantation, No. (%)</td>
<td>1</td>
</tr>
<tr>
<td>1</td>
<td>37 (36)</td>
</tr>
<tr>
<td>2</td>
<td>5 (5)</td>
</tr>
<tr>
<td>As last cancer-directed regimen</td>
<td>22 (21)</td>
</tr>
<tr>
<td>Cause of death, No. (%) Treatment-related complication</td>
<td>21 (20)</td>
</tr>
<tr>
<td>Progressive disease</td>
<td>81 (79)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (1)</td>
</tr>
</tbody>
</table>

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each child was 101 (314) days. Factors associated with smaller differences between parent and physician estimates of the onset of the end-of-life care period are summarized in Table 2. The differences were smaller if the child had a hematological malignancy (P = .04), if the parent had no more than a high school education (P = .02), and if a psychosocial clinician was involved in the end-of-life care (P = .02). These factors remained significant in multivariate analyses. The difference between physician and parent estimates of the onset of the end-of-life period was not statistically significantly associated with any of the end-of-life care outcomes examined.

Ninety-five percent of parents reported having had a discussion at some point about their child having no realistic chance for cure. Seventy-four percent reported that the primary oncologist participated in this discussion, 27% that a primary nurse was involved, and 30% that a psychosocial clinician was involved. Only 16% of children participated in this discussion. Ninety percent of parents felt that it was appropriate to discuss this topic but only 38% were very comfortable with the manner in which it was discussed.

When asked how they first came to understand that their child had no realistic chance for cure, only 49% of parents reported that this resulted from a discussion with the medical team; 30% reported that this understanding came from a perceived change in the way their child looked or acted; and 9% reported that this understanding came from a feeling or dream.

### Goals of Therapy

Eighty percent of parents reported that at diagnosis, they believed that the primary goal of cancer-directed therapy was to cure their child (Table 3). During the parent-defined end-of-life care period, the majority of parents continued to report that the primary goal of cancer-directed therapy was to extend life, specifically to cure (28%), to keep hoping (13%), to have done everything (10%), or to extend life without hope of cure (15%). Only 13% of parents reported that the primary goal of cancer-directed therapy during this period was to lessen suffering. When asked what they now think should be the primary goal of cancer-directed therapy during the end-of-life care of children with cancer, the proportion of parents who responded to lessen suffering was higher at 34% (odds ratio, 6.5; 95% CI, 2.3-18.6; P < .001).

In the last month of life, among the 41 children who continued to receive cancer-directed therapy, 42% of physicians but only 19% of parents reported that the primary goal of this treatment was to lessen suffering (κ = 0.16; 95% CI, −0.11−0.42).

Seventy percent of parents reported that they believed that the primary goal in treating symptoms during the end-of-life care period was to lessen suffering. Overall, 59% of parents reported that the primary goal of treating symptoms during this period was to lessen suffering while also reporting that the primary goal of cancer-directed therapy was to extend life. Furthermore, when asked what they currently believe should be the primary goal of treatment of symptoms during the end-of-life care period for children with cancer, the proportion of parents who responded to lessen suffering was higher at 79% (odds ratio, 2.8; 95% CI, 1.1-7.2; P = .04).

### Outcomes Associated With Earlier Parent and Physician Recognition of No Realistic Chance For Cure

To assess the relationship between the timing of recognition that the child had
no realistic chance for cure and the outcomes of end-of-life care, children were classified into groups based on whether parent and physician recognition occurred more or less than 50 days prior to death. The outcomes for the group in which there was recognition by both parent and physician 50 days or more prior to death were compared with outcomes for all other children, adjusted for physician clustering (Table 4). In this group, there was earlier documentation of a discussion of hospice (P = .01), better parental ratings of the quality of care delivered by the home care team (P = .03), earlier institution of a do-not-resuscitate order (P = .02), less use of cancer-directed treatment in the last month of life (P = .04), and higher likelihood that both physician and parent identified the primary goal of cancer-directed therapy to be to lessen suffering (P = .002 for physician and P = .01 for parents).

COMMENT

We sought to evaluate the understanding of prognosis among parents of children who died of cancer and to assess the relationships between this understanding, their perceptions of the goals of treatment, and adoption of palliative care strategies. We found that at diagnosis, when both physicians and parents were relatively optimistic about the child’s prognosis, there was fairly good concordance between parents and physicians’ beliefs about the likelihood of cure (κ = 0.492). However, as the children’s cancer advanced, parents’ understanding that the child no longer had a realistic chance for cure was delayed, lagging behind the explicit documentation of this fact by the primary oncologist by more than 3 months. One explanation for these findings is that communication about prognosis between physicians and parents at the time of diagnosis may be clearer than when a child’s cancer is more advanced. Since 75% of children with cancer will be cured of their disease, pediatric oncologists have comparatively less experience communicating about terminal prognoses and may find it difficult to do so. This hypothesis is supported by the finding that although nearly all parents reported having a discussion at some point with a medical caregiver about their child having no realistic chance for cure, only 49% of parents reported that they came to understand that their child was terminally ill through this discussion.

Greater concordance between the timing of physician and parental understanding that the child had no realistic chance for cure was not associated with end-of-life care outcomes. However, when both the physician and parent recognized earlier that the child had no realistic chance for cure, elements of palliative care were more likely to be integrated into the child’s care. Specifically, hospice was introduced earlier, and parents were more satisfied with the quality of home care during the end-of-life care period. Furthermore, the child was less likely to continue to receive cancer-directed therapy in the last month of life, and importantly, both the physician and parent were more likely to have identified the primary goal of treatment to be to lessen suffering. These outcomes are congruent with recommendations for optimizing care at the end of life. In a cross-sectional retrospective study design such as this, the direction of the causal relationship between these factors cannot be established with certainty. For example, discussions of hospice or resuscitation status may have precipitated, rather than resulted, from parental understanding of the child’s terminal prognosis. Future prospective studies are needed to fully delineate these relationships. Nonetheless, our findings sug-

Table 4. End-of-Life Care Outcomes Among Children Who Died of Progressive Disease: A Comparison of Those Whose Parent and Physician Both Recognized That the Child Had No Realistic Chance for Cure for a Minimum of 50 Days Prior to Death With All Others

<table>
<thead>
<tr>
<th>Outcome Description</th>
<th>Both Parent and Physician Recognized Prognosis For a Minimum of 50 d Prior to Death*</th>
<th>All Others*</th>
<th>Odds Ratio (95% Confidence Interval)</th>
<th>P Value†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time from documentation of discussion of hospice to death, mean (SD), d</td>
<td>91 (95)</td>
<td>25 (22)</td>
<td>1.03 (1.01-1.06)</td>
<td>.01</td>
</tr>
<tr>
<td>Parents describe quality of care delivered by home care team as very good or excellent, No. (%)</td>
<td>26/32 (81)</td>
<td>19/32 (59)</td>
<td>3.31 (1.15-9.54)</td>
<td>.03</td>
</tr>
<tr>
<td>Time from documentation of do-not-resuscitate order to death, mean (SD), d</td>
<td>56 (81)</td>
<td>16 (15)</td>
<td>1.03 (1.00-1.06)</td>
<td>.02</td>
</tr>
<tr>
<td>Child did not receive cancer-directed therapy in last month, No. (%)</td>
<td>20/30 (67)</td>
<td>15/37 (40)</td>
<td>2.80 (1.05-7.0)</td>
<td>.04</td>
</tr>
<tr>
<td>Physician’s primary goal of treatment in last month was to lessen suffering, No. (%)</td>
<td>31/37 (84)</td>
<td>19/38 (50)</td>
<td>5.17 (1.86-14.4)</td>
<td>.002</td>
</tr>
<tr>
<td>Parent’s primary goal of last cancer-directed therapy was to lessen suffering, No. (%)</td>
<td>11/37 (30)</td>
<td>2/34 (6)</td>
<td>6.56 (1.54-27.86)</td>
<td>.01</td>
</tr>
<tr>
<td>Parents felt very prepared for symptoms child experienced during last month, No. (%)</td>
<td>15/40 (37)</td>
<td>8/40 (20)</td>
<td>2.45 (0.93-5.44)</td>
<td>.07</td>
</tr>
<tr>
<td>Physician described child’s death as very peaceful, No. (%)</td>
<td>18/36 (50)</td>
<td>10/38 (26)</td>
<td>2.60 (0.89-7.56)</td>
<td>.08</td>
</tr>
</tbody>
</table>

*Denominator varies because of missing data. †Adjusted for physician clustering.

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suggest that interventions aimed at facilitating earlier recognition by both physicians and parents that an illness may be fatal could contribute to improving quality of life at the end of life.

We also found that parents of children with advanced cancer can maintain dual goals of care concurrently. Specifically, during the parent-defined end-of-life care period, 39% of parents reported that the primary goal of treating symptoms was to lessen suffering at the same time that they reported that the primary goal of cancer-directed therapy was to extend life. These views might be considered incompatible with the traditional model of palliative care that involves a definitive transition from curative to supportive care. Our findings indicate that parents may not have to fully acknowledge their child’s poor prognosis to be willing to emphasize lessening of suffering. There is a growing consensus that in patients with life-threatening illness, palliative care should be integrated early and concurrent with treatment of the underlying disease.26 Parents may be comfortable with such an approach, and our findings suggest a framework in which caregivers could broach the topic of integrating palliative care earlier while not eroding hope.

One of the more intriguing findings of our study was that when a psychosocial clinician (psychologist or social worker) was involved in the child’s care there was greater concordance in the timing of physicians’ and parents’ understanding that the child had no realistic chance for cure. Further study to determine whether an interdisciplinary approach to care of children with advanced disease enhances communication of outcomes may be warranted. However, the failure of the Study to understand prognoses and preferences for outcomes and risks of treatments to demonstrate a benefit in end-of-life care outcomes from involvement with a specially trained nurse is a cautionary lesson.8 While our data suggest that interventions that focus on strengthening interdisciplinary interactions could be one way to enhance communication around palliative care, rigorous evaluation is clearly needed.27-29

Our study has a number of limitations. The parent-defined onset of the end-of-life care period was determined an average of 3.1 years after the child’s death and may not accurately reflect their perceptions at the time of their child’s actual experience. However, estimates of the duration of the end-of-life care period did not vary with the amount of time that had elapsed from the child’s death to the parent’s interview. Furthermore, every parent was able to provide information on the timing of the onset of this end-of-life period. Perhaps coming to understand that one’s child has no realistic chance for cure is such a significant event that it is readily recalled. It is also important to note that physician estimates of the onset of the end-of-life care period were taken from the chart documentation at the time of the illness, which we believed was a more accurate way to estimate when this recognition occurred than to rely on physician recall. It is not possible to know for certain whether this accurately reflects the true onset of physician understanding of the child’s prognosis or whether the timing of documentation coincided with the timing of the actual discussion with parents. At a minimum, however, the timing of this documentation reflects when effective communication should have taken place, and it appears that this did not occur, whether due to physician factors, parental factors, or both. Future prospective studies are needed to more fully characterize the dynamics of this process.

Selection bias also may have influenced our study findings. Physicians denied us permission to contact 8% of families, and 22% of parents declined to participate. The only characteristic that differed between children of respondents and nonrespondents was the proportion who underwent cardiopulmonary resuscitation. This is a significant end-of-life event and it is not possible to know whether findings would have differed in this group. Importantly, we studied the patterns of care at a single institution. However, the care of pediatric oncology patients is often regionalized because of the need for subspecialty trained personnel.30 Thus, the findings from this 1 large referral center may reflect experiences of most children with cancer.

Finally, our conclusions about causality among the associations demonstrated in this cross-sectional study must be made with caution. It is possible that parents who are more willing to involve a psychosocial clinician in the care of their child may also be better able to hear and understand what physicians are saying about the child’s prognosis. Furthermore, unidentified parental factors may enable certain families to both accept prognostic information and integrate palliation more readily. However, our findings provide preliminary support for the possibility that the quality of caregiver communication played an important role in the integration of palliative care.

This study represents one of the first efforts to evaluate the quality of communication between physicians and parents of terminally ill children regarding prognosis, treatment goals, and care at the end of life. We have demonstrated that there may be significant barriers to effective communication about these emotionally laden issues. Yet, interventions aimed at enhancing communication around end-of-life care could result in a greater focus on palliation and less suffering experienced by children with cancer at the end of life. The potential benefits of such interventions to patients, their families, and society could be substantial.

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A good death does honor to a whole life.
—Petrarch (1304-1374)

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