Variability in Physician Opinion on Limiting Pediatric Life Support

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ABSTRACT. Objective. We conducted this study to investigate how physicians in a pediatric intensive care unit (ICU) currently make decisions to withdraw and withhold life support. Consultation with the patient’s primary caregiver often precedes decisions about withdrawal and limitation of life support in chronically ill patients. In these scenarios, the patient’s primary caregiver was the pediatric oncologist. To evaluate the influence of subspecialty training, we compared the attitudes of the pediatric intensivists and the oncologists using scenarios describing critically ill oncology patients.

Design. Cross-sectional survey. Each physician was randomly assigned 4 of 8 potential case scenarios.

Setting. A total of 29 American pediatric ICUs.

Participants. Pediatric intensive care and oncology attendings and fellows.

Intervention. Systematic manipulation of patient characteristics in two hypothetical case scenarios describing 6-year-old female oncology patients presenting to the ICU after the institution of mechanical ventilator support for acute respiratory failure. Cases 1 through 4 described a patient who, before admission, had a 99% projected 1-year probability of survival from her underlying cancer and suffered from severe neurologic disabilities. Cases 5 through 8 described a patient who was neurologically normal before admission and had a <1% chance of surviving longer than 1 year because of her underlying cancer. Each physician was randomly assigned 2 cases from cases 1 through 4 and 2 cases from cases 5 through 8. Within each of these case scenarios, parental preferences (withdraw or advance support or look for guidance from the caregivers) and probability of survival (5% vs 40%) were manipulated. Before distribution, the survey instrument was pilot-tested and underwent a rigorous assessment for clinical sensitivity.

Primary Outcome Measures. Physicians ratings of the importance of 10 factors considered in the decision to withdraw life support, and their decisions about the appropriate level of care to provide. Respondents were offered five management options representing five levels of care: 1) discontinue inotropes and mechanical ventilation but continue comfort measures; 2) discontinue inotropes and other maintenance therapy but continue mechanical ventilation and comfort measures; 3) continue with current management but add no new therapeutic intervention; 4) continue with current management, add additional inotropes, change antibiotics and the like as needed, but do not start dialysis; and 5) continue with full aggressive management and plan for dialysis if necessary. Respondents also were asked whether they would obtain an ethics consultation.

Results. A total of 270 physicians responded to our survey (165 of 198 potentially eligible pediatric intensivists and 105 of 178 pediatric oncologists for response rates of 83% and 59%, respectively). The respondents considered the probability of ICU survival and the wishes of the parents regarding the aggressiveness of care most important in the decision to limit life-support interventions. No clinically important differences were found when the responses of oncologists were compared with those of intensivists. In six of eight possible scenarios, the same level of intensity of care was chosen by less than half of all respondents. In three scenarios, ≥10% of respondents chose full aggressive management as the most appropriate level of care, whereas another ≥10% chose comfort measures only when viewing the same scenario. The most significant respondent factors affecting choices were professional status (attending vs fellow) and the self-rated importance of functional neurologic status. The majority of respondents (83%) believed that the intensive care and the oncology staff were usually in agreement at their institution about the level of intervention to recommend to the parents. Respondents reporting that they were more likely to withdraw life support than their colleagues were more likely to limit life-support interventions in the scenarios than those who reported that they were less likely to withdraw life support. At least 50% of respondents would request an ethics consult when 1) the probability of acute survival was 40% and the parents wanted to withdraw support in the patient with neurologic disabilities and 2) when the probability of survival was 5% and the parents wanted to advance support in the patient with a <1 year life expectancy from her underlying cancer.

Conclusions. Acute prognosis, parental wishes, and functional status are significant determinants of limitations of life support for critically ill children. However, responses to these hypothetical patient scenarios reflect marked variability in decision-making across pediatric intensivists and oncologists. The degree to which this variability in decision-making exists in actual patient care requires additional study. Variability in decision-making may lead to unnecessary suffering, lack of fairness when making decisions about neurologically handicapped individuals, and inappropriate use of scarce resources in futile cases. Increased efforts should be directed at developing clearer recommendations for limiting life support in critically ill children. Pediatrics 1999; 103(4). URL: http://www.pediatrics.org/cgi/content/full/103/4/46; life support, withdrawal, decision-making, survey, end of life.
When a patient’s chance of survival is low or quality of life is markedly diminished, intensive care interventions aimed at prolonging life may prolong suffering without clear benefit. In these situations, adult patients can inform the decisions of caregivers directly or through living wills and durable powers of attorney. When the life of a young child is at stake, caregivers elicit the wishes of the parent or legal guardian to make decisions on behalf of the patient. Family preferences are rated as being a powerful influence over the decisions that caregivers make about the level of intensity of care to provide for a child in the intensive care unit (ICU). However, when treating individual patients, the caregivers may disagree strongly with the wishes of a parent or guardian and may disagree among themselves regarding the appropriate level of interventions to deliver to sustain life.

There is a paucity of data defining what influences pediatric health care workers to make decisions. Frequently, the patient’s illness severity is so great that the likelihood of survival is slim. Imminent death was the reason cited most frequently justifying restriction of life-support interventions in one retrospective study. However, factors independent of patient characteristics, such as the characteristics of the care providers, also have proved to be influential. Subsequently, under pressure to make decisions and end-of-life decision-making. Exposure to patients over longer periods of time in an outpatient setting may lead primary care providers to have a different view of quality of life than that of intensive care specialists.

We conducted this study to investigate how physicians in a pediatric ICU currently make decisions to withdraw and withhold life support. Consultation with the patient’s primary caregiver often precedes decisions about withdrawal and limitation of life support in chronically ill patients. In these scenarios, the patient’s primary caregiver was the pediatric oncologist. To evaluate the influence of subspecialty training, we compared the attitudes of the pediatric intensivists and the oncologists using scenarios describing critically ill oncology patients. We surveyed pediatric ICUs across North America that had agreed previously to consider participation in research studies.

METHODS

Instrument Development and Testing

Decision Factor Presentation

We constructed two baseline case scenarios. One baseline scenario (used for cases 1 through 4) described a patient who, before admission, had a 99% probability of survival from her underlying cancer and suffered from severe neurologic disabilities. The other baseline scenario (used for cases 5 through 8) described patient who was neurologically normal before admission and had a <1% chance of surviving longer than 1 year because of her underlying cancer. Within each of these scenarios, we presented two decision factors at two levels. The first factor was parental preferences and the second was probability of survival. For the neurologically disabled patient (cases 1 through 4), parental preferences were presented as either requesting withdrawal of support or requesting the help of the attending physician to make the decision. For the neurologically normal patient with fatal cancer (cases 5 through 8), parental preferences were presented as either requesting maximal support or requesting the help of the attending physician to make the decision. The probability of survival from the acute illness was presented at two levels (5% vs 40%) using information derived from mortality prediction models and the expertise of the group of clinicians caring for the patient.

A total of 2154 scenarios described 6-year-old female oncology patients presenting to the ICU after the institution of mechanical ventilator support for acute respiratory failure. Meetings with the parents were held on a daily basis in every scenario. Here is an example of the scenario describing the neurologically disabled patient with an acute survival probability of 5% whose parents requested withdrawal of support (case 1).

A 6-year-old girl was admitted to the pediatric ICU with respiratory failure attributable to viral pneumonia. She is ventilator-dependent and has a PEEP of 15 and an FiO2 of 60% with Pao2 values in the mid-60s. She has been in oliguric renal failure for the past 2 days. She requires a dobutamine infusion of 10 µg/kg per minute because of myocardial dysfunction from sepsis. She has a coagulopathy from liver dysfunction (total bilirubin, 3.7) requiring infusions of fresh frozen plasma to keep her PT <16. Although it is difficult to estimate this child’s probability of survival with accuracy, the best estimate is 5% (based on the admission PRISM score, the patient’s current status, and the consensus of the involved ICU attendings) is ~5%.

Three years ago, she underwent successful treatment for acute lymphoblastic leukemia (the chance of recurrence is now 5% to 10%). During an episode of chemotherapy-induced neutropenia she contracted Escherichia coli meningitis. Despite early detection and treatment, this infection resulted in severe permanent neurologic damage. The patient is developmentally delayed and has spastic quadriplegia. She walks with the assistance of devices, has slurred speech but is capable of two-word sentences, still requires diapers, and receives nutrition via a gastrostomy tube.

The parents feel that their daughter is suffering and have requested that all measures being used to prevent her death be discontinued.

Below is an example of the scenario in which the neurologically intact patient has a chronic fatal illness and an acute survival probability of 40% whose parents want all life-support interventions available to be offered (case 6).

A 6-year-old girl was admitted to the pediatric ICU 5 days ago with respiratory failure attributable to viral pneumonia. She is ventilator-dependent and has a PEEP of 6 and an FiO2 of 50% with Pao2 values in the mid-80s. She has been in oliguric renal failure for the past 2 days as a result of her hypotension during her initial few days of admission. She is on a dopamine infusion at 3 µg/kg per minute. All other organ systems are now normal. Although it is difficult to estimate this child’s probability of survival with accuracy, the best estimate (based on the admission PRISM score, the patient’s current status, and the consensus of the involved ICU attendings) is ~40%.

This child underwent a bone marrow transplant for stage IV neuroblastoma 6 months ago but neuroblastoma cells were found on her last bone marrow biopsy performed 3 weeks ago. She was doing well in school before her diagnosis of recurrence and acute illness. The oncologists have told the parents that at this stage, she is incurable and there are no
other treatment options for her cancer. They predict her chance of surviving 1 year to be <1%.

The parents are very devoted to her. They state that they are not ready for her to die and request that everything be done to prolong her life. They believe that if she dies despite full intervention, they will at least feel that they did everything they could.

**Questionnaire Format**

We asked respondents to read each case scenario, to “assume that you are the primary physician making decisions for this patient and are meeting with the parents on a daily basis,” and then to choose a management strategy for each case vignette. Respondents were offered five management options: 1) discontinue inotropes and mechanical ventilation but continue comfort measures; 2) discontinue inotropes and other maintenance therapy but continue mechanical ventilation and comfort measures; 3) continue with current management but add no new therapeutic intervention; 4) continue with current management, add additional inotropes, change antibiotics and the like as needed, but do not start dialysis; and 5) continue with full aggressive management and plan for dialysis if necessary. These five management strategies represent the five levels of care tested.

To ensure that they found the scenario believable, clinicians were asked if they agreed with the probabilities of survival (assuming the use of full life-support interventions) and, if they disagreed, to write in their own estimate. They then chose from the following list the words they would use, in a hypothetical conversation with the parents, to describe the child’s probability of surviving to ICU discharge to the parents: almost zero, very low, low, moderate, or high.

Respondents considered whether they would obtain an ethics consultation and rated the influence of 10 factors on their decisions regarding life support. They also rated the likelihood of their withdrawing life support in comparison with their colleagues. Finally, they estimated how frequently the oncology and intensive care staff in their ICU would be in agreement regarding the level of intervention recommended to the parents.

**Pilot Testing**

To ensure clarity of the questionnaire and realism of the scenarios, we pilot-tested it on two pediatric oncologists and four pediatric intensive care attendings. We were especially interested in the believability of the short- and long-term mortality estimates. Based on these evaluations, we modified the illness descriptions until the clinicians found the mortality rates to be believable.

**Clinical Sensibility Assessment**

Twenty-two pediatric ICU caregivers (5 ICU attendings, 5 oncology attendings, 9 critical care nurses, 3 critical care fellows) rated the potential ability to discriminate among respondents, and its clarity, face validity and comprehensiveness. Ratings were as follows:

- **Discriminability**—86% of respondents believed that the questionnaire was likely or very likely to discriminate between the opinions of caregivers.
- **Clarity**—86% of respondents thought the response options were easy to understand.
- **Utility**—86% of respondents believed that the questionnaire was likely or very likely to elicit candid information about the attitudes and approaches of intensivists and oncologists.
- **Face validity**—100% of respondents stated that the parental decisions for advancing support, withdrawing support, or looking for guidance were believable. Eighty percent of respondents thought that the probabilities of survival were believable based on the information given. Eighty-six percent of respondents believed that the questionnaire was directed at important elements of decisions regarding the level of appropriate care in the ICU.
- **Content validity**—18% of respondents thought that the questionnaire omitted important information. Three of the oncologists believed that the etiology of the respiratory failure (the type of virus), the preillness renal function, and the character of the relationship with the parents should be included.

- **Redundancy**—no respondent believed that the questionnaire was redundant to the extent that response accuracy would be compromised.

**Questionnaire Administration**

Each respondent received 4 cases (2 cases of the neurologically normal patient with disseminated cancer and 2 of the neurologically disabled patient cured of her cancer). To minimize order effects, we generated a list of all possible case combinations and randomly allocated one combination to each respondent. One full randomized set was generated for oncologists and one for intensivists to maximize the possibility that equal numbers of survey combinations would be distributed to each group. We surveyed pediatric intensive care attendings and fellows and pediatric oncology attendings and fellows. The institutional review board at Children’s Hospital of Wisconsin approved the study.

Of 80 coordinators of pediatric ICUs enrolled in the Pediatric Critical Care Study Group (PCCSG) that received an initial introductory letter, 29 participated in the study. The PCCSG site coordinator was responsible for survey distribution, reminders, and monitoring return rates. Cover letters accompanying each survey stated that the surveys were coded for tracking purposes, that these codes would be removed once the survey was returned, and that the results would be published. Participants were told that they had the option to decline participation but were requested to return the incomplete survey with a reason for declining.

**Statistical Analysis**

We tested whether ICU physicians and oncologists differed in their response regarding the determinants of withdrawal of life support by analysis of variance. We used the Student’s *t* test to compare continuous variables and the χ² test to compare proportions. Continuous variables are reported as mean and standard deviation (mean, SD).

Using a method similar to that of Cook and colleagues, we evaluated multiple variables under the categories of respondent characteristics, respondent beliefs, and patient-related factors. Respondent characteristics were sex, profession, level of training, years of experience in current medical specialty, years since graduating medical school, amount of clinical time, and religious affiliation. Respondent beliefs were their ratings of the importance of 10 factors that could influence decisions regarding life support. The patient-related factors varied in the scenarios were the parental preferences for aggressiveness of support, the probability of surviving of the acute illness, the probability of survival >1 year, and the patient’s functional status.

The effect of each variable was tested univariately and again in the presence of other variables in a multivariable regression model. Because the baseline case scenarios were different, cases 1 through 4 (poor functional neurologic status but normal long-term survival) were analyzed separately from cases 5 through 8 (normal pre-ICU neurologic status but <1% chance of surviving >1 year). Linear regression was used to compare respondent’s self-reported likelihood of withdrawing life support with the level of care they chose in the four scenarios.

We used multiple regression to quantify the influence of the variable had on respondent’s choices regarding the level of care in the presence of other variables. Because the response options are not truly continuous, we used ordinal logistic regression. Each subject responded to 2 case scenarios for each regression model (2 cases from cases 1 through 4 and 2 from cases 5 through 8), which could inflate the *P* values. Therefore, we confirmed the results using a mixed effects model controlling for the random effects of subjects.

### RESULTS

**Questionnaire Response Rate**

Surveys were returned from 29 PCCSG sites with 376 surveys distributed to physicians and 270 surveys returned completed, for an overall response rate of 72%. The completed survey response rate for intensivists was higher (165/198 = 83%) than that for oncologists (105/178 = 59%). Only one nonrespondent specified a reason for not participating, which

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was because he or she felt that there was insufficient information presented in the cases to make a decision. The distribution of pediatric ICU beds at participating sites was four sites (13.7%) with 4 to 8 beds; eight sites (27.6%) with 9 to 14 beds; nine sites (31%) with 15 to 20 beds; and seven sites (24.1%) with >20 beds. One site did not report a bed number.

Respondent Characteristics

Table 1 summarizes the demographic characteristics of the respondents. Of the ICU attending staff, 89.7% were subboard certified in pediatric critical care, 12.7% were subboard certified in pediatric anesthesiology, 8.7% were subboard certified in either pediatric cardiology or pediatric pulmonology, and 92.1% were board certified in general pediatrics (73% had two and 19.8% had three different board certifications). Of the oncology attending staff, 96.6% were subboard certified in pediatric oncology and 85.1% were board certified in general pediatrics.

For all participants, 27% were Catholic, 35% were Protestant, 18% were Jewish, 14% had no religious affiliation, and 6% were of other religious beliefs (2% Hindu, 1% Muslim). The mean percent of time spent in research was 21% (SD, 20.8) for intensivists and 25.5% (SD, 27.4) for oncologists. For intensivists, 66% did clinical research, 29% did basic science research, and 5% did both. For oncologists, 72% did clinical research, 25% did basic science research, and 4% did both.

Determinants of Withdrawal of Life Support

Table 2 presents the ratings of importance for each of the 10 potential determinants of withdrawal of life support. Two factors were rated as significantly (P < .05) more important influences on decision-making by intensivists than by oncologists: patient wishes (1.1 vs 1.2) and neurologic status (2.0 vs 2.3). No other significant differences were found in the average responses of intensivists versus oncologists or fellows versus attendings. Given that these statistically significant differences were felt to be clinically insignificant, we combined the responses of all respondents for additional analyses.

Agreement with Estimated Probability of Survival

The majority (71%) of respondents agreed with the estimated probability of acute survival (assuming full life-support interventions) for each scenario. The average probabilities of survival estimated by the respondents did not differ markedly from the probabilities in the scenarios. For cases 1, 3, 5, and 7, with a 5% estimated probability of survival, the mean (SD) acute survival probabilities estimated by the respondents were 6.6 (6.0), 8 (7.9), 5.1 (3.5), and 5.9 (6.2), respectively. For cases 2, 4, 6, and 8 with a 40% estimated probability of survival, the mean (SD) acute survival probabilities estimated by the respondents were 47.2 (15.0), 44.2 (11.8), 40.8 (19.7), and 41.8 (18.0), respectively.

Responses to Scenarios

Every scenario showed marked variability among respondents in the level of support believed to be appropriate. The distribution of responses for the eight scenarios from all respondents is presented in Fig 1. In six of eight possible scenarios, the same level of intensity of care was chosen by less than half of all respondents. In three scenarios, ≥10% of respondents chose full aggressive management as the most appropriate level of care, whereas another ≥10% chose comfort measures only when viewing the same scenario. At least 50% of respondents requested an ethics consult when 1) The probability of acute survival was 40% and the parents wanted to withdraw support in the patient with neurologic disabilities, and 2) when the probability of survival was 5% and the parents wanted to advance support in the patient with a life expectancy of <1 year as a result of her underlying cancer.

We report the resultant multivariable models for the two sets of cases in Table 3. Variables were included in the final model if P < .05 in the multivariable analyses. The two primary factors varied in the scenarios [1] the probability of acute survival and 2) the parental wishes] were strongly significant predictors of the likelihood of limiting life-support interventions (P < .0001) in both models.

For cases 1 through 4 (describing a patient with functional neurologic disability), attending physi-

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**Table 1. Demographic Description of Respondents**

<table>
<thead>
<tr>
<th></th>
<th>Intensivists (n = 165)</th>
<th>Oncologists (n = 105)</th>
<th>Total (n = 270)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female, N (%)</td>
<td>43 (26)</td>
<td>41 (39)</td>
<td>84 (31)</td>
</tr>
<tr>
<td>Attendings (%)</td>
<td>125 (76)</td>
<td>88 (84)</td>
<td>213 (80)</td>
</tr>
<tr>
<td>Fellows (%)</td>
<td>37 (22)</td>
<td>15 (14)</td>
<td>52 (19)</td>
</tr>
<tr>
<td>Years since medical school graduation, mean (SD)</td>
<td>12.4 (5.6)</td>
<td>16.9 (9.2)</td>
<td>14.1 (7.5)</td>
</tr>
<tr>
<td>ICU experience, mean years (SD)</td>
<td>6.6 (5.1)</td>
<td>11.4 (6.6)</td>
<td>8.4 (7.1)</td>
</tr>
<tr>
<td>% Time devoted to clinical work, mean (SD)</td>
<td>58 (22)</td>
<td>58 (26)</td>
<td>57 (24)</td>
</tr>
</tbody>
</table>
Physicians were more likely to limit support (mean, 2.7) than were fellows (mean, 3.0) ($P = .0097$ by ordinal logistic regression). Respondents who rated the importance of neurologic status in decision-making as more important also tended to limit life-support interventions. The following is the rated importance of neurologic status in decision-making as more important also tended to limit life-support interventions. The following is the rated importance of neurologic status in decision-making as more important also tended to limit life-support interventions.
The odds of limiting support decreased as respondents rated the importance of a patient’s diagnosis higher \((P = 0.0157 \text{ by ordinal logistic regression})\).

For cases 5 through 8 (normal neurologic status but fatal cancer), as the rating given by respondents to the importance of family wishes increased, their tendency to be influenced by the direction of family wishes also increased \((P = 0.018 \text{ by ordinal logistic regression})\). Respondents who marked family wishes as extremely important were likely to choose aggressive support (mean level of support chosen = 4.1) than were those who marked family wishes as moderately important (mean level of support chosen, 3.6) in those cases in which the family requested that everything possible be done.

The mean chosen level of intensity of care according to the probability of acute survival and parental wishes is shown in Table 4. On the average, physician recommendations to the parents when asked for guidance were lower levels of intervention for the patient with normal neurologic status but fatal cancer than for the neurologically impaired patient whose cancer was cured. Increasing the probability of ICU survival shifted the recommended level of intensity of care higher. Parental wishes to advance or withdraw shifted the average recommended level of intensity of care in the direction of the request.

Across the 8 cases, respondent’s ratings of how they would describe the “probability of surviving to ICU discharge despite full life-support interventions” to the parents and their own estimated probability of survival for the patient (not the probability listed in the case) were associated as follows (mean, SD): almost zero (4.3, SD 1.4); very low (7.8, SD 8.5); low (33.1, SD 12.5); moderate (44.4, SD 10.6); high (70.4, SD 17.6). Although this seems consistent, Fig 2 shows variability in the words used by respondents to describe the probability of survival to the parents in individual cases.

### Table 4. Average Level of Intensity of Care Chosen According to Probability of Acute Survival and Parental Wishes*

<table>
<thead>
<tr>
<th>Type of Case</th>
<th>Severe Neurologic Disability†</th>
<th>Normal Neurologic Status‡</th>
</tr>
</thead>
<tbody>
<tr>
<td>Probability of ICU Survival‡</td>
<td>5%</td>
<td>40%</td>
</tr>
<tr>
<td>Parental wishes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advance</td>
<td>2.8</td>
<td>3.8</td>
</tr>
<tr>
<td>Ask for guidance</td>
<td>1.6</td>
<td>2.0</td>
</tr>
<tr>
<td>Withdraw</td>
<td></td>
<td>4.3</td>
</tr>
</tbody>
</table>

* For each baseline scenario: probability of ICU Survival \((P < 0.001)\); parental wishes \((P < 0.0001)\). Scale used is 1 indicates comfort care only; 2, mechanical ventilation; 3, no new intervention; 4, don’t start dialysis; 5, full aggressive management.
† Before admission to the ICU.
‡ Based on admission PRISM score, the patient’s current status, and the consensus of ICU attendings involved.

**DISCUSSION**

The most important finding of this study is the marked variability in respondent choice of level of care for the same scenario. In only two of eight

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**Self-comparison with Colleagues**

The majority of respondents (83%) believed that “in general, if they were jointly managing one of the patients in the scenarios, the intensive care and the oncology staff at our hospital would be in agreement about what level of intervention to recommend to the parents” almost always or usually \((217/270 = 83\%)\) versus occasionally or almost never \((53/270 = 17\%)\). In general, respondents thought they were slightly more likely to withdraw care than were their colleagues (mean response, 2.62 on a scale in which 2 was more likely and 3 as likely). Respondents reporting that they were more or less likely to withdraw life support than their colleagues were more likely to limit life-support interventions in the scenarios than were those who reported that they were less likely to withdraw life support (Table 5) \((P < .001)\).
scenarios did >50% of respondents choose the same level of intensity of care. Opposite extremes of care intensity were chosen by >10% of the respondents in three of eight scenarios. Caregivers who rated themselves as more likely to withdraw support than colleagues were more likely to limit care in the scenarios. If the decision-making in the scenarios reflects decisions made in actual patient care, the same critically ill child thus may receive full aggressive care from one physician and only comfort measures from another.

The strengths of this study include the use of both direct and indirect (the scenarios) strategies for eliciting physician beliefs and opinions, the inclusion of physicians at multiple centers, the sampling of a wide variety of critical care units, and random distribution of the subset of cases given to each clinician to prevent order effects. Our goal was to tap the beliefs of physicians who have decision-making authority, and we evaluated both the primary pre-ICU caregiver (oncologists) and intensivists. The major limitation of this study is the use of paper scenarios that may not reflect decisions made in actual cases. We also did not evaluate the beliefs of nonphysician caregivers, such as nursing staff, who may play a major role in end of life decision-making in the ICU.

The degree of variability in the level of support chosen by respondents in individual scenarios is comparable with that found in a survey of adult ICU caregivers in Canada (149 ICU attendings, 27 fellows, 1070 ICU nurses). This Canadian study avoided the influence of patient or family preferences by presenting scenarios in which the adult could not help with the decision and no family or friend was available for consultation. Because children rarely have no parent or parent surrogate decision-maker available, we evaluated the influence of parental preferences. Consistent with results of the Canadian study, we found that certain characteristics and beliefs of respondents were significant predictors of their willingness to limit life-support interventions in the scenarios. In certain scenarios, professional status (attendants vs fellows) and being a critical care fellow were predictors of the level of life support believed to be appropriate. Respondents who ranked the importance of neurologic status highly were more likely to limit life-support interventions in the cases in which the patient suffered from moderately severe neurologic disabilities. Respondents who ranked the family wishes as extremely important were more likely to give aggressive care in the cases in which parents requested aggressive care, despite the fact that the child had an extremely poor prognosis for long-term survival.

In contrast to results found in a recent study of adult cancer patients in which patient preferences did not drive aggressiveness of care, parental preferences were a powerful factor driving the decisions of caregivers in these scenarios. When the probability of surviving to ICU discharge was 5% in a patient who had a <1% chance of surviving 1 year before this acute illness, the average clinician would recommend comfort care, stopping inotropes, and continuing mechanical ventilation. If given the same scenario, the parents requested aggressive care, on average a clinician would continue to escalate care with the exception of dialysis.

From the difference in responses to the two baseline scenarios, it appears that functional neurologic status is a strong determinant of the intended level of support. The patient described in one baseline scenario was very handicapped but did walk with assistance and could communicate using words. It was interesting to find that when the parents did not express a preference, the average clinician would withhold dialysis from this patient despite a 40% acute probability of surviving to ICU discharge with full intervention.

Physicians do have insight into their different management styles. Self-rated likelihood of withdrawing support in comparison with colleagues is a powerful predictor of level of support in the scenarios. The respondent’s belief in the importance of the functional neurologic status in decision-making around life-support issues also predicted the level of support given to the neurologically disabled child.

The terms chosen to describe the patient’s probability of survival to the parents also were variable for respondents describing the same scenario. The majority of respondents chose “almost zero” or “very low” to describe cases with a 5% probability of survival and “low” or “moderate” to describe cases with a 40% probability of survival. However, a small percentage of respondents chose “very low” or “high” to describe a 40% probability of survival and “low” to describe a 5% probability of survival. How parents interpret these terms is unknown. It has been argued that preferably physicians should be using a syntax of verbal expressions of probability to decrease the potential for ambiguity in interpretation.

Confirming the findings of previous studies, it is possible that critically ill adults and children can face different attitudes about the appropriateness of limiting life-support interventions depending on the physician supervising their care. In general, there was marked variability across providers faced with the same patient scenario. Ethical guidelines for limiting and withdrawing life support may decrease the variability in decision-making. According to our findings, ethics consultations may be more common when physicians disagree with the level of care that the parents request. Physicians were least likely to solicit the advice of an ethics committee when the parents looked to them for guidance. Ethics committees may play a role in assisting clinicians in dealing with the complexities surrounding end-of-life decision-making. There is evi-
dence that intensive educational interventions for physicians and broad institutional programs can be effective at changing care at the end of life.16

We recognize that individual physicians have different opinions on what level of care is appropriate for the same critically ill child. Although physicians showed marked variability in decision-making when confronted with the same hypothetical scenarios, the degree to which this variability in decision-making exists in actual patient care requires additional study. Variability in decision-making may lead to unnecessary suffering, lack of fairness when making decisions about neurologically handicapped individuals, and inappropriate use of scarce resources in futile cases. Efforts should be directed at developing clearer recommendations for limiting life support in critically ill children.17

APPENDIX

The following site coordinators and institutions in the Pediatric Critical Care Study Group participated in this study: Lucian K. DeNicolai, MD, University Medical Center, Jacksonville, FL; Curt Steinhart, MD, Medical College of Georgia, Augusta, GA; Robert Beck, MD, Bronson Methodist Hospital, Michigan State University, Kalamazoo, MI; Michele Moss, MD, Arkansas Children’s Hospital, Little Rock, AR; Jeffrey H. Hill, MD, PhD, St. Joseph’s Hospital and Medical Center, Phoenix, AZ; Jeffrey E. Thompson, MD, Gunderson Lutheran Medical Foundation, LaCrosse, WI; Brahm Goldstein, MD, Oregon Health Sciences University, Portland, OR; David H. Beyda, MD, Phoenix Children’s Hospital, Phoenix, AZ; Stephen Liben, MD, Montreal Children’s Hospital, Montreal, Quebec; Craig Downs, DO, St. John’s Regional Health Center, Springfield, MO; Carl G.M. Weigle, MD, Children’s Hospital of Wisconsin, Milwaukee, WI; Robert E. Lynch, MD, PhD, Cardinal Glennon Children’s Hospital, St. Louis, MO; Edward Cullen, DO, Alfred I. DuPont Institute of the Nemours Foundation, Wilmington, DE; Larry E. Easterling, MD, Cook-Fort Worth Children’s Medical Center, Fort Worth, TX; Susan Bratton, MD, Children’s Hospital and Medical Center, Seattle, WA; Frank Castello, MD, UMDNJ-Robert Wood Johnson Medical School, New Brunswick, NJ; Gwenn E. McLaughlin, MD, University of Miami, Jackson Memorial Hospital, Miami, FL; Barry Frank, MD, Washoe Medical Center, Reno, NV; John B. Gordon, MD, University of Maryland Hospital, Baltimore, MD; Thomas P. Green, MD, Children’s Memorial Hospital, Chicago, IL; James P. Orlovsky, MD, University Community Hospital, Tampa, FL; Stephanie A. Stor- gion, MD, LeBonheur Children’s Medical Center, Memphis, TN; Timothy Yeh, MD, Children’s Hospital of Oakland, Oakland, CA; James Royall, MD, University of Iowa, Iowa City, IA; Edward E. Conway, Jr., MD, Montefiore Medical Center, Bronx, NY; Donald Vernon, MD, Primary Children’s Medical Center, Salt Lake City, UT; Barry P. Markovitz, MD, St. Louis Children’s Hospital, St. Louis, MO; Susan A. Keckses, MD, University of Illinois, College of Medicine at Chicago, Chicago, IL; Joel Cochran, MD, Medical University of South Carolina, Charleston, SC; Frank R. Gioya, MD, Humana Children’s Hospital of Las Vegas, Las Vegas, NV.

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Variability in Physician Opinion on Limiting Pediatric Life Support

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