End-of-Life Care Preferences of Pediatric Patients With Cancer

Pamela S. Hinds, Donna Drew, Linda L. Oakes, Maryam Fouladi, Sheri L. Spunt, Christopher Church, and Wayne L. Furman

ABSTRACT

Purpose
The viewpoint of the terminally ill child at the time of an end-of-life decision has not been formally investigated. We identified the preferences of children and adolescents with advanced cancer about their end-of-life care and the factors that influenced their decisions.

Patients and Methods
Pediatric patients 10 or more years of age were interviewed within 7 days of participating in one of the following three end-of-life decisions: enrollment onto a phase I trial (n = 7), adoption of a do not resuscitate order (n = 5), or initiation of terminal care (n = 8). The patient, a parent, and the primary pediatric oncologist were interviewed separately by using open-ended interview questions.

Results
Twenty patients, aged 10 to 20 years (mean, 17 years and 4 months), with a refractory solid tumor (n = 12), brain tumor (n = 4), or leukemia (n = 4) participated. Eighteen patients (90%) accurately recalled all of their treatment options and identified their own death as a consequence of their decision. The factors that were most frequently identified included the following: for patients, caring about others (n = 19 patients); for parents, the child’s preferences (n = 18 parents); and for physicians, the patient’s prognosis and comorbid conditions (n = 14 physicians).

Conclusion
These children and adolescents with advanced cancer realized that they were involved in an end-of-life decision, understood the consequences of their decision, and were capable of participating in a complex decision process involving risks to themselves and others. The decision factors most frequently reported by patients were relationship based; this finding is contrary to existing developmental theories.

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INTRODUCTION

Approximately 2,300 pediatric patients die of cancer each year in the United States, and approximately 1,815 die each year in Europe. Most pediatric patients die of progressive disease, and more than half have a do not resuscitate (DNR) order. These deaths are usually anticipated, and end-of-life decisions (eg, DNR, withdrawal of life support, aggressive symptom management only, or enrollment onto a phase I study) are not uncommon. Parents report end-of-life decisions to be the most difficult treatment-related decisions they face during their child’s cancer experience. Clinicians identify end-of-life decision making as a research priority, in part because they perceive the assistance they can offer with these decisions to be inadequate.
of patients’ preferences about their end-of-life care would enable parents and clinicians to honor those preferences where possible, an approach that could provide comfort to parents after the loss of their child and reassure clinicians about the quality of the care they provide. Inclusion in the decision process may also offer the patient a sense of control during a time when most matters are not within the patient’s control.

We conducted a descriptive study by interviewing children and adolescents within 7 days of their participation in one of three types of end-of-life decisions to identify the end-of-life care preferences of pediatric patients with advanced cancer and describe the factors that influenced their decisions. We also compared the factors considered by patients, parents, and physicians.

**PATIENTS AND METHODS**

### Patients and Interviews

The study was conducted at the pediatric oncology centers of St Jude Children’s Research Hospital in Memphis, TN, and Sydney Children’s Hospital in Sydney, Australia. Eligible patients had parent and physician approval to participate and were English speaking, between age 10 and 20 years, and directly involved in one of three end-of-life decisions (enrollment onto a phase I trial, adoption of DNR status, or aggressive symptom management only [terminal care]). Parent and physician inclusion criteria included the following: English speaking, directly involved in the end-of-life decision, and consent to participate. The patient, parent, and physician were interviewed separately within the same week. The study was approved by the institutional review boards of both centers; written informed consent or assent was obtained from patients and parents, as appropriate, and verbal consent was obtained from physicians.

We chose the descriptive decision–theoretic decision analysis model, which focuses on the decision process, including the factors that are considered and the anticipated outcomes, rather than on predicting the decision or assessing its quality (correctness). We developed and field tested open-ended interview questions about the decision, possible choices, anticipated outcomes of each choice, and influencing factors for use in interviews with patients (Table 1), parents, and physicians.

Every 2 to 3 months throughout the 22-month study period, interviewers were retrained in interviewing and in obtaining consent. The same three interviewers (P.S.H., D.D., and L.L.O.) completed all interviews, which were initiated only after the end-of-life treatment decision had been made and documented in the medical record. Patients were screened for eligibility daily during rounds of each clinical team. After the physician confirmed patient eligibility, an interviewer approached the parent and described the study in detail. With the parent’s permission, the patient was then invited to participate. All interviews were conducted face to face, tape recorded with the permission of participants, and transcribed by a trained medical transcriptionist.

### Data Analysis

The accuracy of the transcripts was verified by two members of the study team. Validated interview data were entered into the ETHNOGRAPH software program (Qualis Research, Colorado Springs, CO) for qualitative data. Each phrase of every response to an interview question was analyzed for meaning. Two members of the study team jointly reviewed the first three interviews and, using standard qualitative methods, applied labels (first-level codes) to key phrases to capture their meaning. The same team members developed a code dictionary for each group of participants that comprised all first-level codes identified. Four other team members then used the group-specific code dictionary to complete a semantic content analysis of each group’s interview data. The research team had used this method in four previous studies, and inter–rater reliability estimates (% agreement) for each code ranged from 50% to 100% within and across all interviews.

After the first-level codes were applied to all interviews, team members independently identified codes that consistently occurred together and had overlapping meaning. These codes were grouped into broader categories of response. The frequency of each category of response was calculated. Three to four members of the study team analyzed each interview; and inter–rater reliability was estimated after each of the first 10 interviews and subsequently after every third interview. Reliability estimates for each category ranged from 88% to 100% within and across all interviews.

### RESULTS

There were 36 potentially eligible patients. The parents of four patients declined permission because their child had not been involved in the decision (n = 3) or was too ill to participate (n = 1). Of the remaining 32 patients, 20 (62.5%) agreed to participate, and 12 (37.5%) declined (five patients at St Jude and seven patients at Sydney Children’s Hospital) for reasons that included “don’t want to talk about it” (n = 5), “no time to participate” (n = 4), and “feel good about it and have nothing more to say” (n = 3). Of the 12 patients who declined, seven were male, four were female, and eight were white. A phase I trial was under consideration for three patients who declined, DNR status was adopted for five patients, and terminal care was initiated for four patients.

Fourteen participating patients were female, and 17 patients were white. Their diagnoses were solid tumor (n = 12), brain tumor (n = 4), or leukemia (n = 4). Their mean age was 17 years and 4 months (range, 10 years 0 months to 20 years...
9 months). Fourteen patients were at St Jude, and six were at Sydney Children’s Hospital. Although an eligible parent was present at each patient’s consent or assent, one 20-year-old patient requested that her parent not participate in the study, and the parent agreed. Nineteen parents participated (13 mothers and six fathers). Of the 14 participating physicians (two had multiple participating patients), 12 were male. No other demographic data about parents or physicians were collected.

The decisions made were terminal care (aggressive symptom management only) versus further disease-directed therapy (eight patients), enrollment versus no enrollment onto a phase I study (defined to parents and patients as a toxicity-finding study involving a new drug for patients whose disease could not be cured; seven patients), and DNR status versus no DNR status (five patients). The decisions that had been made were defined for the study investigators by the attending physician. Six of the eight decisions about terminal care involved a choice between palliative chemotherapy (plus palliative radiation in one patient) and a more limited symptom control effort (ie, oral pain control) that would not require the patient to remain at the cancer center (referred to by four patients as returning home to die). Two of the decisions were a choice of palliative chemotherapy, oral pain control, or alternative therapies (herbs, nutritional supplements, or meditation). Four patients chose aggressive symptom control, two chose alternative therapies, and two chose to return home with oral pain control. The seven phase I trial decisions offered a choice of the phase I trial, palliative chemotherapy, or terminal care. Four patients chose the phase I study, and three chose terminal care. All of the five patients involved in the DNR decision chose DNR status.

Responses to the interview questions are described in the following sections. Only question 4 generated responses that could be combined. The number of first-level codes is given to indicate the number of times that a theme was reported; that number is followed by the number of participants who reported the theme (themes/participants).

**Interview Question: What Did You Think Would Be the Most Likely Outcome of Your Choice?**

The outcomes anticipated by the eight patients involved in terminal care decisions were “I would die/tumor would grow” (n = 10/8 themes/participants), “I could leave the hospital, see family/friends and have fun” (n = 7/7 themes/participants), “I would feel like a quitter” (n = 4/3 themes/participants), and “I would just be waiting to die” (n = 4/3 themes/participants). The outcomes anticipated by the seven patients considering a phase I study included “getting sick” (n = 19/7 themes/participants), “getting depressed” (n = 6/6 themes/participants), “might buy a little time” (n = 6/5 themes/participants), “won’t cure me/do any good” (n = 6/6 themes/participants), “being hospitalized” (n = 5/5 themes/participants), “might help others” (n = 4/4 themes/participants), and “might help my disease” (n = 2/2 themes/participants). Outcomes anticipated by the five patients involved in a DNR decision included “extend life a little” (n = 7/5 themes/participants), “life on a machine is not living” (n = 6/5 themes/participants), and “having some control/go to heaven earlier” (n = 5/3 themes/participants).

The outcomes anticipated by the eight parents involved in a terminal care decision included “giving up all hope/go crazy” (n = 13/6 themes/participants), “go home, do what child wants” (n = 10/8 themes/participants), and “child will die/child can’t be cured” (n = 9/8 themes/participants). The outcomes anticipated by the six parents considering a phase I study included “might buy a little time” (n = 5/5 themes/participants), “being hospitalized” (n = 5/5 themes/participants), “not too hard on child” (n = 5/4 themes/participants), “prolonging the inevitable” (n = 4/4 themes/participants), “getting sick” (n = 4/4 themes/participants), and “doing what my child wants” (n = 3/3 themes/participants). Outcomes considered by the eight parents considering DNR status included “child will die” (n = 5/5 themes/participants), “being able to go home” (n = 4/4 themes/participants), “extend life a little” (n = 4/4 themes/participants), and “life on a machine is not living” (n = 4/3 themes/participants).

The outcomes anticipated by the six physicians involved in a terminal care decision included “patient realizes she/he is dying” (n = 7/6 themes/participants), “not acceptable to patient/family to stop all therapeutic interventions” (n = 4/4 themes/participants), “patient wanting to go home/have fun” (n = 4/4 themes/participants), and “patient would die comfortably” (n = 4/4 themes/participants). Outcomes considered by the four physicians involved in a phase I study decision included “anticipating low toxicity” (n = 6/5 themes/participants), “possible tumor response/delay death” (n = 5/4 themes/participants), “toxicity without cure/being hospitalized” (n = 5/5 themes/participants), “cannot deprive families of hope or jeopardize future options” (n = 2/2 themes/participants), and “difficult to predict responses to a new

**Interview Question: What Choices Did You Consider?**

Eighteen patients (90%) accurately recalled the two or three offered options. The two exceptions, both adolescents, recalled only the option chosen, which was a phase I trial. The female stated, “I’m doing a new medicine but I don’t remember my choices. I lost my short-term memory from my first brain tumor.” The male stated that he knew he had been offered an additional option but did not recall it. The reported options matched perfectly across 16 (88.9%) of the 18 remaining patient/parent/physician triads. For the other two patients, the parents reported the options as an experimental drug versus doing nothing, whereas the physicians reported the options to be an experimental drug versus best clinical management.
agent” (n = 2/2 themes/participants). The outcomes reported by the four physicians involved in a DNR decision included “satisfying patient desire to avoid being on a ventilator” (n = 7/4 themes/participants), “patient going to die” (n = 5/4 themes/participants), and “satisfying patient desire to avoid being hospitalized” (n = 5/4 themes/participants).

**Interview Question: What Kinds of Things Did You Think About When You Were Trying to Make This Decision?**

Only this question generated codes that could be combined. Seven categories generated by combining two to nine codes represent the primary factors patients considered in their decision (Table 2). These were “thinking about my relationships with others” (n = 19 patients), “avoiding adverse events” (n = 14), “wanting no more” (n = 13), “ready to die and go to heaven” (n = 10), “seeing others die” (n = 10), “believing treatment now is futile” (n = 6), and “seeing a chance for cure” (n = 4). “Seeing a chance for cure” was reported only by adolescents (four of the seven adolescents) considering a phase I trial. “Believing treatment now is futile” was reported only by patients (six of eight patients) considering terminal care. The remaining five factors applied to all three types of decisions.

Nine factors were considered by the 19 parents (Table 3), and six factors were considered by the 14 physicians (Table 4). We compared the definition of each patient factor with the definitions of factors considered by the parents and physicians. The patient factor “thinking about my relationships with others,” the parent factor “deciding as my child prefers,” and the physician factor “being influenced by patient and family preferences” reflected a common consideration for the preferences (known or believed) of others involved in the decision (94.7% to 100%). Furthermore, this desire to benefit others was reported by 11 (55%) of 20 terminally ill patients, five (26.3%) of 19 parents, and seven (50%) of 14 physicians. The patient factor “avoiding adverse events,” the parent factor “avoiding negative outcomes,” and the physician factor “wanting to avoid harm” (68.4% to 78.6% of each group) reflected a common desire to prevent or reduce suffering or clinical deterioration. The patient factor “believing treatment now is futile,” the parent factor “nothing more to do,” and the physician factor “having no other option” showed the common belief that all treatment strategies had been exhausted (30% to 63.2% of each group).

**What Kinds of Things Did Your Doctor, Nurse, Social Worker, or Chaplain at the Hospital Do or Say That Helped You With the Decision or That Did Not Help You With the Decision?**

**Phase I trial decisions.** Patients reported the following helpful staff behaviors as helpful: “explained everything to me/gave us written information” (n = 16/7 themes/participants), “answered my questions and gave me time to think” (n = 13/6 themes/participants), “told me about how other patients did” (n = 4/4 themes/participants), and “told me they would be there for me” (n = 4/4 themes/participants). Parents reported the following helpful staff behaviors: “didn’t try to sway us one way or another/support any decision” (n = 10/7 themes/participants), “gave me information and time to think” (n = 8/6 themes/participants), “did not give up on our child” (n = 5/4 themes/participants), “consulted with other experts” (n = 4/4 themes/participants), and “showed caring about our child’s quality of life” (n = 3/3 themes/participants). Physicians did not commonly seek input from other staff members for a phase I trial decision but indicated that “staff agreement on option” (n = 5/4 themes/participants) was helpful. Of the seven patients involved in a phase I trial decision, two reported staff behaviors that were not helpful. They reported that being told of the possible toxicities of the experimental drug made their decision more difficult. All parents but one and all physicians involved in a phase I decision denied that staff actions or words had made the decision more difficult. The one parent reported that not having written information about the drug made the decision more difficult.

**Terminal care decisions.** Patients involved in a terminal care decision reported the following staff behaviors as helpful: “respected my preference/backed me up” (n = 10/8 themes/participants) and “answered my questions” (n = 5/5 themes/participants). Parents reported “gave support to me/my child” (n = 8/8 themes/participants), “helped us or our child identify our preferences” (n = 4/4 themes/participants), “reassured us of continued care for symptoms” (n = 4/3 themes/participants), and “gave us information” (n = 3/3 themes/participants) as helpful. Physicians reported the following two helpful staff behaviors: “validating patient/family preferences” (n = 5/5 themes/participants) and “assuring patient of continued care” (n = 5/5 themes/participants).

**DNR decisions.** Patients reported the following staff behaviors as helpful: “very clear words used to explain to me” (n = 8/5 themes/participants), “told me personal feelings” (n = 4/4 themes/participants), and “there for me” (n = 3/3 themes/participants). Parents reported “gave us the facts” (n = 5/5 themes/participants), “gave us a professional opinion” (n = 5/5 themes/participants), and “asked us to do what we believe is right for our child” (n = 4/4 themes/participants) as helpful. Physicians reported “discussions with team members about appropriateness of the options” (n = 7/6 themes/participants), “receiving moral support from staff” (n = 5/5 themes/participants), and “others on team asking for clarification of patient’s status” (n = 4/4 themes/participants) as helpful.

**What Helps You Now to Feel Okay About That Decision?**

**Patients.** Two patients considering a phase I trial did not feel okay about the decision; both chose this option in consideration of others but preferred no further disease-directed efforts. The remaining 18 patients reported feeling
<table>
<thead>
<tr>
<th>Factor</th>
<th>Definition</th>
<th>No. of Patients</th>
<th>%</th>
<th>No. of First-Level Codes (n = 252)</th>
<th>%</th>
<th>Example Quote</th>
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<tbody>
<tr>
<td>Thinking about my relationships with others</td>
<td>Decision making affected by caring for others (family, staff, future patients), preferences of others, and the desire to benefit others</td>
<td>19</td>
<td>95</td>
<td>93</td>
<td>36.9</td>
<td>“If I can help someone else, that’s wonderful, I think.” 14-year-old girl with a brain tumor</td>
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<td>“If I don’t take it, my family would support me, but they don’t want me to quit. Grandpa said he would worry himself to death if I don’t try it. My boyfriend wants me to take it for him. I don’t want to do it but for my family.” 19-year-old female with a solid tumor</td>
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<td>“I knew it would make me a little bit sick and that I would be in the hospital for a few days each time. I could also have tried vincristine, but I had that before and I didn’t think my body could get through that.” 18-year-old male with a solid tumor</td>
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<td>“It was explained to me that every new patient would get a stronger dose, every time. Mine would be the highest dose, and I could get all the symptoms the first day that others got on the 10th or 11th day.” 18-year-old female with a solid tumor</td>
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<td>“We decided not to go with chemo because I don’t want to be sick the rest of my days, and it’s not like it is going to cure me, so I just said, ‘we’ll go home and take it from there.’” 15-year-old girl with ALL</td>
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<td>“I want to die. I just want to get it over with…it feels like I’m being tortured, not tortured, not forced, they are not purposely doing this, but they might as well just chain me up to the wall and put needles in my arms.” 18-year-old with a solid tumor</td>
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<td>“When the Lord is ready for you, you are going to leave. It doesn’t matter if you are on a machine or not, you are going to leave.” 20-year-old male with a solid tumor</td>
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<td>“Why would I want a tube in my throat? I saw two other patients like that—I don’t want that. I wouldn’t be able to talk with my family or hold my Mom’s hand. That is not living.” 15-year-old girl with ALL</td>
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<td>“Seeing other members of my family on tubes. You just lay there. I don’t like it. I wouldn’t want it for me. I don’t want to be kept alive like that. If someone is ready to die, I say ‘let them die,’ you know?” 15-year-old with AML</td>
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<td>“If anything was going to work, it would have done it before now.” 16-year-old boy with a solid tumor</td>
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<td>“We’ve been through the main steps…if it was going to work, probably it already would have worked. Stuff like the radiation, the chemo stuff, and then the experimental chemo, and we have been through several chemos and stuff, so I figured if it was going to slow it down or stop it, you know, it would have done it by now. And, if it hadn’t done it by now, it’s just going to grow, so I may as well be at home having fun.” 17-year-old boy with a solid tumor</td>
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<td>“My mom told me they were getting very good results with this drug.” 16-year-old boy with a solid tumor</td>
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<td>“We were kind of really happy that they had chemotherapy, something else that we could try.” 15-year-old girl with a solid tumor</td>
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</table>

**Abbreviations:** ALL, acute lymphoblastic leukemia; AML, acute myeloid leukemia.
### Table 3. Factors That Influenced the 19 Parents’ Decisions

<table>
<thead>
<tr>
<th>Factor</th>
<th>Definition</th>
<th>No. of Parents</th>
<th>%</th>
<th>No. of First-Level Codes (n = 317)</th>
<th>%</th>
<th>Example Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deciding as my child prefers</td>
<td>Choosing as the patient would want or as the patient previously directed the parent to choose</td>
<td>18</td>
<td>94.7</td>
<td>49</td>
<td>15.5</td>
<td>“I talked with my child about what to do if we ever faced that decision, and I knew ahead of time what she wanted me to do, and that helped. I know I was doing what she would have wanted.” Mother of a 12-year-old girl with a brain tumor</td>
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<td>Trusting staff and being supported by them</td>
<td>Believing in the expertise of the treating clinicians and feeling recognized by the clinicians as contributing most significantly to their child’s welfare</td>
<td>16</td>
<td>84.2</td>
<td>49</td>
<td>15.5</td>
<td>“Nobody on the staff there is going to think that I made the wrong decision. They always made me feel like I did the right thing for my child.” Father of a 13-year-old boy with leukemia</td>
</tr>
<tr>
<td>Deciding as a good parent would</td>
<td>Considering the facts, explanations, opinions, and preferences of experts and others (eg, family members, ill child, and other bereaved parents) and then choosing the option most consonant with an internal definition of a caring, competent protector of their child</td>
<td>16</td>
<td>84.2</td>
<td>46</td>
<td>14.4</td>
<td>“The doctor gave us the facts and told us how serious this is, and we told our daughter. But the choice part has not been difficult for us. …it’s never been a question for us because she has plans, and we are going to do everything we can to see that those plans are able to be made and, if not, then she knows and we know that we have done everything we can.” Father of a 10-year-old female with leukemia</td>
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<tr>
<td>Avoiding negative outcomes</td>
<td>Choosing an option that prevents or reduces the risk of adverse effects on the child and family</td>
<td>13</td>
<td>68.4</td>
<td>36</td>
<td>11.4</td>
<td>“This would have meant extra days in the hospital…injections at home…probably less time off between treatments. He might not get the time to recuperate in between.” Mother of a 14-year-old male with a solid tumor</td>
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<tr>
<td>Being helped by my faith</td>
<td>Believing in a Greater Being and in the strength that comes from spiritual beliefs and practices</td>
<td>13</td>
<td>68.4</td>
<td>33</td>
<td>10.4</td>
<td>“I don’t care what you want to call it, my belief exists.” Mother of a 15-year-old girl with leukemia</td>
</tr>
<tr>
<td>Nothing more to do</td>
<td>Parents conclude that no acceptable curative or life-prolonging option exists</td>
<td>12</td>
<td>63.2</td>
<td>36</td>
<td>11.4</td>
<td>“I know that the hospital has done all that it could. We also know that we have done everything that we could do.” Mother of a 20-year-old male with a solid tumor</td>
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<tr>
<td>Still trying for cure or longer life</td>
<td>Parents make a choice in the hopes of keeping their child alive</td>
<td>11</td>
<td>57.9</td>
<td>45</td>
<td>14.2</td>
<td>“I am…prolonging the inevitable until a cure comes along… I want her to be healed. I keep telling her to hold on…” Mother of a 14-year-old girl with a brain tumor</td>
</tr>
<tr>
<td>Wanting time left to be good</td>
<td>Parents desire to focus on the quality of their child’s remaining days of life</td>
<td>8</td>
<td>42.1</td>
<td>13</td>
<td>4.1</td>
<td>“I have very strong convictions about quantity versus quality. Deciding to go home—I’m just tickled…She is a whole different person.” Mother of a 15-year-old girl with leukemia</td>
</tr>
<tr>
<td>Wanting to help others</td>
<td>Parents’ decision making is influenced by a desire to benefit current or future patients</td>
<td>5</td>
<td>26.3</td>
<td>10</td>
<td>3.1</td>
<td>“What my daughter goes through… would be very important to another child. It’s not just to save her but children in the near future that could possibly come down with this particular type of cancer…” Mother of a 17-year-old girl with a solid tumor</td>
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good or very good about the decision. The reasons most frequently reported for feeling okay about the decision were “not needing to be hospitalized” (n = 7/6 themes/participants), “being able to do something” (n = 6/6 themes/participants), and “now feeling more positive about a chance to survive” (n = 3/3 themes/participants). For patients involved in a terminal care decision, the most frequently reported reasons included “nothing else could be done” (n = 4/4 themes/participants), “others understand my decision” (n = 4/3 themes/participants), and “doing what I want” (n = 4/4 themes/participants). The most frequently reported reasons for feeling okay about a DNR decision included “the Lord is waiting for me” (n = 6/5 themes/participants), “doing what I want” (n = 5/5 themes/
participants), “this choice helps others” (n = 3/3 themes/participants), and “nothing else will help me” (n = 3/3 themes/participants).

Parents. All parents reported feeling positive about the decision. The most frequently reported reasons in a phase I trial decision were “didn’t have to just do ‘nothing’” (n = 10/5 themes/participants), “my faith carries me” (n = 6/5 themes/participants), “the drug is not making my child sick” (n = 5/3 themes/participants), “my faith carries me” (n = 6/5 themes/participants), and “seeing patient happy with decision” (n = 4/3 themes/participants). For a DNR decision, physicians reported the following reasons: “easier death for my patient” (n = 6/4 themes/participants), “consistent with my ethical standards” (n = 5/4 themes/participants), and “seeing patient happy with decision” (n = 3/3 themes/participants).

DISCUSSION

How end-of-life decisions are made and what factors influence those decisions, particularly from the perspectives of children, adolescents, and their parents, is not well understood. Almost all patients (18 of 20 patients) in this study accurately recalled their treatment options and were able to identify the likely outcome of each. They identified their death as an outcome of their decision and, therefore, understood that they were participating in a decision about the end of their own life and recognized the consequences of their decision. Additional responses indicated that they understood what would happen as a result of their decision in the short term (eg, get sick from an experimental drug), the intermediate term (eg, delay the inevitable of dying), and the longer term (eg, dying). The patients considered these outcomes and the impact of their decision on others (loved ones, staff, and future patients unknown to them). These

<table>
<thead>
<tr>
<th>Factor</th>
<th>Definition</th>
<th>No. of Physicians</th>
<th>No. of First-Level Codes (n = 181)</th>
<th>%</th>
<th>Example Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being influenced by patient and family preferences</td>
<td>Particular consideration is given to the expressed wishes of the terminally ill child and the parents</td>
<td>14</td>
<td>100</td>
<td>56</td>
<td>30.9</td>
</tr>
<tr>
<td>Considering the prognosis and comorbid conditions</td>
<td>Concluding that survival was unlikely or impossible given the patient’s medical status</td>
<td>14</td>
<td>100</td>
<td>32</td>
<td>17.7</td>
</tr>
<tr>
<td>Wanting to benefit my patient and others</td>
<td>Considering potential positive outcomes that could result from certain decisions</td>
<td>13</td>
<td>92.9</td>
<td>28</td>
<td>15.5</td>
</tr>
<tr>
<td>Wanting to avoid harm</td>
<td>Considering the negative outcomes of a decision option for the patient and the family</td>
<td>11</td>
<td>78.6</td>
<td>36</td>
<td>19.9</td>
</tr>
<tr>
<td>Patient/family understand and accept</td>
<td>Parent and ill child’s grasp of the seriousness of the clinical situation facilitates efforts to assist them with end-of-life decision making</td>
<td>8</td>
<td>57.1</td>
<td>16</td>
<td>8.8</td>
</tr>
<tr>
<td>Having no other option</td>
<td>Recognizing that all therapeutic possibilities had been pursued but without lasting benefit</td>
<td>8</td>
<td>57.1</td>
<td>13</td>
<td>7.2</td>
</tr>
</tbody>
</table>
patients were able to negotiate a complex decision process during which they considered more than one element at a time and were able to integrate these diverse elements into a decision. These abilities are the characteristics of competent decision making when risk is involved.\textsuperscript{15,16,24} Taken together, our findings support the ability of children and adolescents between 10 and 20 years old with advanced cancer to participate in end-of-life decision making.

Decision making at the end of a child’s life is a multi-step, involved process that is further complicated by individual values and patient and parent understanding of the clinical situation and of the available options.\textsuperscript{25,26} Although our study design did not allow us to assess the sequence in which specific factors were considered, the factors typically mentioned first by patients were avoiding adverse effects (n = 9) and information from health care professionals (n = 6). The factors most frequently mentioned first by parents were continuing to try for cure or longer life (n = 5), trusting staff and being supported by them (n = 4), and deciding as my child prefers (n = 4). The factors most frequently mentioned first by the physicians were the patient’s prognosis and comorbid conditions (n = 8) and patient and family preferences (n = 6). It is likely that these factors were considered first or were most compelling for each of the three groups of participants. Similar future studies would benefit from asking the patients to identify the sequence in which they considered factors and the weight they gave to each one.

A striking finding is the wish of patients and parents to benefit others as a factor in their decisions. This concern for others, particularly for unknown others as identified by 11 of the 20 patients, was not anticipated and is not reflected in existing theories of child development.\textsuperscript{27} Altruism or the intention to benefit another is incorporated into some child developmental theories but tends to reflect a child’s expectation of personal benefit along with the help given another.\textsuperscript{28} In contrast, the patients in our study reported considering participation in a phase I study because it could benefit another, although it might harm self. This concern for others may reflect what has been referred to as the maturational effect of a life-ending illness on a child or adolescent.\textsuperscript{29} Parent altruism has also been reported. A survey of pediatric oncologists in the United Kingdom (n = 53) and North America (n = 78) concluded that parents generally enroll their child onto phase I trials for reasons of medical benefit, hope, and altruism.\textsuperscript{30} Adult oncology patients do not report altruism as a major factor in their decisions about a phase I study.\textsuperscript{31}

Consideration of others’ preferences was the factor most frequently reported by patients, parents, and physicians, indicating that human relationships strongly influence end-of-life decisions in pediatric oncology. Children, even older adolescents, do not have legal decisional authority in the United States or Australia unless they are emancipated minors, and patient preferences do not have legal standing. However, as shown here and reported elsewhere,\textsuperscript{31} some families and health care professionals involve pediatric patients with advanced cancer in decisions. One report described the inclusion of patients as young as 6 years old in end-of-life decisions and described the children as directing the decision in most cases.\textsuperscript{32} That report and our own findings show that the patient’s perspective is important to the parents and physicians and that it influences the decision. The patient’s influence on end-of-life decisions is at odds with the reported inability of pediatric patients and their parents to influence treatment decisions during hospitalization for non–life-threatening procedures.\textsuperscript{33} The source of this difference in end-of-life care versus active treatment should be scrutinized.

Although the study was conducted at only two sites and involved a small sample, the nearly universal report of the patients that their decision making was relationship-based is a particularly striking finding. Although patients absorbed the factual information about their treatment options, concern and care about family, friends, health care providers, and even unknown others influenced the patients’ decision making. Several adolescents in our study sample referred to their decision as their chance to do something good for someone else; one referred to his decision as his final gift to his parent. It is important that the relationship-based decision making be anticipated by pediatric oncology professionals when facilitating end-of-life care preferences and that more research be completed on this type of decision making. Kane et al\textsuperscript{34} have noted that the end-of-life illness experience is a relational process and that the suffering inherent in this experience can be endured because of the presence of meaningful relationships.

In conclusion, pediatric oncology patients are involved in making decisions about their own end-of-life care. Patients in this study were able to accurately identify their treatment options and understood that their death would be one of the outcomes of their decision. Their decision making was relationship based, and concern and caring about others was the most frequently reported factor influencing their decision making. Patient, parent, and physician decision making had important similarities, including sensitivity to the others preferences. Although key aspects of pediatric end-of-life decision making remain unexplored, our findings support the ability of some pediatric oncology patients to participate in end-of-life decisions on their own behalf.
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The authors indicated no potential conflicts of interest.

REFERENCES