ARTICLE

Parental Views on Withdrawing Life-Sustaining Therapies in Critically Ill Children

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Objective: To broaden existing knowledge of pediatric end-of-life decision making by exploring factors described by parents of patients in the pediatric intensive care unit (PICU) as important/influential if they were to consider withdrawing life-sustaining therapies.

Design: Quantitative and qualitative analysis of semi-structured one-on-one interviews.

Setting: The PICUs at 2 tertiary care hospitals.

Participants: English- or Spanish-speaking parents who were older than 17 years and whose child was admitted to the PICU for more than 24 hours to up to 1 week.

Intervention: Semi-structured one-on-one interviews.

Results: Forty of 70 parents (57%) interviewed said they could imagine a situation in which they would consider withdrawing life-sustaining therapies. When asked if specific factors might influence their decision making, 64% of parents said they would consider withdrawing life-sustaining therapies if their child were suffering; 51% would make such a decision based on quality-of-life considerations; 43% acknowledged the influence of physician-estimated prognosis in their decision; and 7% said financial burden would affect their consideration. Qualitative analysis of their subsequent comments identified 9 factors influential to parents when considering withdrawing life-sustaining therapies: quality of life, suffering, ineffective treatments, faith, time, financial considerations, general rejection of withdrawing life-sustaining therapies, mistrust/doubt toward physicians, and reliance on self/intuition.

Conclusion: Parents describe a broad range of views regarding possible consideration of withdrawing life-sustaining therapies for their children and what factors might influence such a decision.

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Approximately 40% to 60% of pediatric intensive care unit (PICU) deaths follow a decision to withdraw or limit life-sustaining treatments.[1-6] Pediatricians have described several factors that influence their consideration of withdrawing or limiting life-sustaining therapies: quality of life, an expectation of death despite aggressive medical management, suffering in the context of a poor prognosis, and societal resources.[2,5-10] Such factors may or may not correspond to those influencing parents' end-of-life decisions for their children. Most existing information on the views of PICU patients' parents comes from studies using surveys with fixed-choice responses, which may limit the depth of information obtained, or from those involving very few participants.[11-13]

We therefore sought to broaden existing knowledge of pediatric end-of-life decision making by exploring factors described by PICU patients' parents as important/influential if they were to consider withdrawing life-sustaining therapies. We specifically explore parental willingness to consider withdrawing life-sustaining therapies and the influences of quality of life, physician-estimated prognosis, patient suffering, and financial burden on such decisions.

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METHODS

DESIGN

The study took place at 2 academic tertiary care PICUs. Each hospital's institutional review board approved the study.

We conducted one-on-one semi-structured interviews from December 2002 through June 2004 using an interview guide that included 5 questions regarding withdrawing life-sustaining therapies. The first question, a general one about the option of withdrawing life-sustaining therapies, was followed by 4 others

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that represented indications cited by medical care providers when considering withdrawing life-sustaining therapies, specifically: quality of life, physician-estimated prognosis, patient suffering, and financial burden.[2,5-10] Interviewers could rephrase questions for clarification as needed.

During the patient's PICU stay, an audio-taped interview, lasting up to 90 minutes, occurred in a room separate from the patient, unless the parent(s) requested otherwise. The trained interviewers, none of whom were involved in the care of the patients whose parents we approached, included the principal investigator (K.N.M.), 3 medical students, a medical anthropologist, and an instructor of medical Spanish with experience in medical education. Three interviewers spoke Spanish and interviewed Spanish-speaking participants using a certified Spanish translation of the interview guide. Following 1 interview that included 2 parents, we conducted only one-on-one interviews because the presence of the other parent seemed to influence responses. We only present data from one-on-one interviews. Additional details about the interviews and the interview guide appear elsewhere.[14]

We obtained information about parents and patients, including demographics, from responses during the interview, parental completion of a short questionnaire following the interview, and a medical record review. Because some parents chose not to identify their ethnicity/race, we recorded the interviewer's assessment of ethnicity/race based on his/her overall impression and information gathered during the interview. We report ethnicity/race using both the interviewer's assessment and the participants' responses to an open-ended question.

PARTICIPANTS

Interviewers asked PICU-attending physicians to identify English- or Spanish-speaking parents (age >17 years) of patients admitted to the PICU for more than 24 hours to less than 1 week and not admitted for presumed or confirmed abuse, neglect, or nonaccidental trauma. Because more than 90% of children admitted to the PICU have survivable conditions, most parents interviewed did not face end-of-life decisions for their children at the time of the interview. Both parents, if present, were invited to participate.

We interviewed parents until responses reached thematic saturation.[15-17] We recruited only African American and Hispanic parents during the last 6 months of the study to improve representation of these groups.

DATA ANALYSIS

Quantitative Analysis

All interview recordings were professionally transcribed verbatim; transcripts from interviews conducted in Spanish were then professionally translated into English. Interviewers reviewed transcripts against the tapes for accuracy.

We categorized responses using a coding scheme based on the interview guide. For example, responses to the question, "Can you imagine a situation when you would consider asking the doctors to stop the use of medicines or machines even if it meant that [your child] might not survive?" were coded as "yes," "no," "not sure," "unclear response," or "not asked." Using the coding scheme, 2 coders independently coded each transcript. We assessed coder agreement using a κ statistic. $\kappa \geq 0.51$ is generally considered fair agreement.[18] Coders compared responses and resolved differences through joint transcript review to arrive at the final coding.

We present descriptive statistics based on the coded responses and the information obtained from the postinterview questionnaire and medical record review. We did not compare groups of participants because our study was not powered for such an analysis. Statistical analyses were performed using SAS, version 9.1 (SAS Institute, Cary, North Carolina).

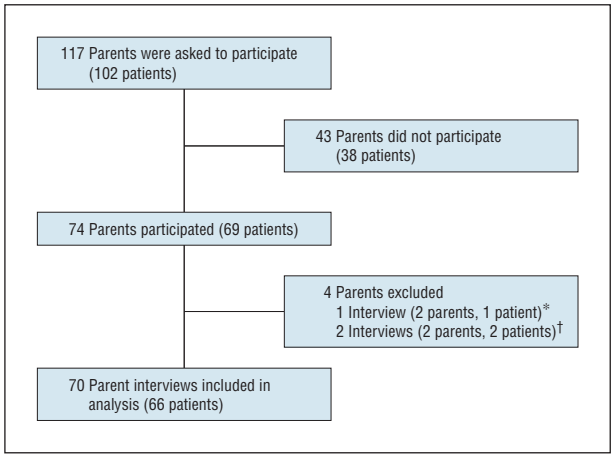

Figure. Study flowchart. *Excluded because both parents were interviewed simultaneously; †excluded because of tape recorder malfunction.

Qualitative Analysis

Transcripts were uploaded into NVivo, version 2.0, qualitative software (QSR International, Melbourne, Australia). Thematic analysis of responses to the 5 questions proceeded using the grounded theory-based inductive process of identifying categories as they emerged from the data.[19,20] Two authors separately identified categories and subcategories of common responses. Through an iterative process, the 2 authors arrived at a consensus and grouped the categories into themes. A third author reviewed the transcripts to verify the inclusiveness and accuracy of the themes and our representation of the data in this study. We could not confirm our results through "member checking" because we did not have long-term relationships with the participants.

RESULTS

We asked 117 parents of 102 patients to participate. Seventy-four parents (63%) of 69 patients (68%) participated. We completed 73 interviews. We did not analyze the one interview that included 2 parents for reasons described above. Tape recorder malfunction precluded the use of 2 interviews. We analyzed 70 interviews (**Figure**).

QUANTITATIVE ANALYSIS

Table 1 and **Table 2** present the patient and parent characteristics. **Table 3** presents the withdrawing life-sustaining therapies questions, the coded responses, and their corresponding κ statistic.

We asked parents their general view on withdrawing life-sustaining therapies before asking about specific influences. Some parents who responded "no," "not sure," or gave unclear responses to the general question responded "yes" to one of the subsequent questions. To illustrate how responses changed, **Table 4** presents the affirmative ("yes") responses to questions 2 through 5 based on the responses to the general question. Sixty-one parents (87%)

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Table 1. Patient Characteristics (n=66)

Characteristic	No. (%)
Age, mean (SD), range, y	5.7 (5.6), 0.03-18.4
Female sex	28 (42)
Insurance	
Private	33 (50)
Medicaid/none	30 (45)
Data missing	3 (5)
Indication for PICU admission[a]	
Related to a chronic disease	18 (27)
Complications from cancer treatment	5 (8)
Following an operation[b]	22 (33)
Acute disease process/other	21 (32)
PRISM score, mean (SD), range	6.1 (6.3), 0-25
Hospital length of stay,[c] mean (SD), range, d	4.0 (4.2), 1-32
PICU length of stay,[c] mean (SD), range, d	3 (1.9), 1-8
Intubation	
At the time of the interview	30 (45)
During this admission	50 (76)
Taking vasoactive medications	
At the time of the interview	17 (26)
During this admission	25 (38)

Abbreviations: PICU, pediatric intensive care unit; PRISM, Pediatric Risk of Mortality.

[a] Admissions related to a chronic disease included those of patients whose admission was the result of their chronic disease. Admissions related to an acute disease included those of otherwise healthy patients admitted for an acute disease or patients admitted for reasons unrelated to their chronic disease.

[b] Two patients were admitted for surgical evaluation and underwent a surgical procedure prior to the interview.

[c] Refers to the length of stay at the time of the interview.

Table 2. Parent Characteristics (n=70)

Characteristic	No. (%)
Parent age, mean (SD), range, y	35 (8.52), 18-55[a]
Female sex	55 (79)
Income, $	
0-24 999	19 (27)
25 000-69 999	25 (36)
≥70 000	21 (30)
Data missing	5 (7)
Education	
Did not graduate HS	12 (17)
HS graduate	36 (51)
College graduate	22 (31)
Married or lives with his/her partner	51 (73)
Ethnicity/race[b]	
African American[c]	19 (27)
White[d]	30 (43)
Hispanic[e]	18 (25)
Other[f]	3 (4)
Religion[g]	
Christian	57 (81)
Spiritual, not affiliated with organized religion	7 (10)
Other[h]	3 (4)
Unclear response	1 (1)
Not asked	2 (3)
Thought his/her child might die during this hospitalization[g]	
Yes	40 (57)
No	23 (33)
Unclear response	7 (10)

Abbreviation: HS, high school.

[a] Data missing from 3 parents (4%).

[b] Interviewer's assessment of ethnicity/race based on his/her overall impression and information gathered during the interview.

[c] People in this category described themselves as African American or black (n=12), did not identify with a particular ethnicity/race (n=4), reported a religious affiliation (n=1), identified a nationality (n=1), or responded that he/she was "all of them" when asked about race/ethnicity (n=1).

[d] People in this category described themselves as white or Caucasian (n=3), identified a nationality (n=16), did not identify with a particular ethnicity/race (n=10), or reported a religious affiliation (n=1).

[e] People in this category described themselves as Latino or Hispanic (n=7) or identified a nationality (n=10); 1 person of European background claimed to "keep the culture of the Latin people."

[f] People in this category described themselves as either Iranian, Asian, or of mixed African American and white background.

[g] Indicates coded data obtained from the parent during the interview. $\kappa > 0.51$ for all.

[h] Includes 1 person of the Eckankar faith and 1 person who did not claim an affiliation with an organized religion and was not spiritual.

answered "yes" to a least 1 of the questions. Nine parents (13%) did not respond "yes" to any question.

We also asked parents, "Who should make decisions about limiting aggressive medical care or stopping the use of medicines or machines to keep [your child] alive?" Allowing for multiple responses to this question, 67 interviewees (96%) named the parents, 37 mentioned physicians (53%), 11 identified family members (16%), and 4 mentioned the patient (6%). Of those who named the parents, 35 also named physicians (50%). Of the 2 respondents who mentioned physicians, but not parents, 1 said he/she would defer to the physicians and 1 said the physicians and the patient should decide.

QUALITATIVE ANALYSIS

From the responses to our 5 questions, we identified the following 9 themes describing important influences on parental decisions regarding withdrawing life-sustaining therapies.

Quality of Life

Parents described aspects of quality of life that might influence them to consider withdrawing life-sustaining therapies. Some parents simply used the phrase "poor quality of life." Others described suffering, neurological dysfunction/impairment, and dependence on machines. While suffering could be considered a subcategory of quality of life, we analyzed it independently for reasons noted below.

Parents often described severe neurologic dysfunction/impairment using terms like "brain dead," "coma," or "vegetable." Many described scenarios in which their child could not interact with his/her surroundings. For example, participants used phrases like, "[T]hey have no ability to communicate. They don't have any feelings. They are not thinking." Some parents would consider withdrawing life-sustaining therapies if the physicians predicted severe neurological dysfunction/impairment.

Dependence on machines was discussed frequently. Some parents discussed dependence on machines in cases with no curative options: "[I]t would be just where there is just nothing more they [doctors] can do and she's not alive on her own without the support machines." Other parents talked about dependence on machines in association with neurological dysfunction/impairment. Some felt

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Table 3. Responses to Questions on Withdrawing Life-Sustaining Therapies (n=70)

Question[a]	Coded Responses, No. (%)					κ
	Yes	No	Not Sure	Unclear Response	Not Asked	
Question 1. General question: Can you imagine a situation when you would consider asking the doctors to stop the use of medicines or machines even if it meant that [your child] might not survive?	40 (57)	17 (24)	7 (10)	5 (7)	1 (1)	0.53
Question 2. Influence of quality of life: Do you think you might consider stopping the use of medicines or machines that are keeping [your child] alive if his/her quality of life was limited as a result of his/her illness?	36 (51)	17 (24)	10 (14)	6 (9)	1 (1)	0.67
Question 3. Influence of physician-estimated prognosis: Do you think you might consider stopping the use of medicines or machines that are keeping [your child] alive if the doctors told you there was nothing else they could do to make [your child] get better?	30 (43)	25 (36)	9 (13)	3 (4)	3 (4)	0.55
Question 4. Influence of patient suffering: Do you think you might consider stopping the use of medicines or machines that are keeping [your child] alive if he/she was suffering?	45 (64)	8 (11)	12 (17)	5 (7)	0	0.52
Question 5. Influence of financial burden: Do you think you might consider stopping the use of medicines or machines that are keeping [your child] alive if his/her care was a financial burden?	5 (7)	61 (87)	3 (4)	1 (1)	0	0.70

[a] Responses to questions 2 through 5 were coded without reference to the coded response to question 1. Therefore, a parent's coded responses to questions 2 through 5 may differ from his/her coded response to question 1.

that dependence on machines itself warranted consideration of withdrawing life-sustaining therapies: "All I'm saying is if my daughter or my child needs a machine to keep them alive, then I wouldn't put them through it."

Suffering

We consider suffering to be a second theme because parents repeatedly identified suffering as important in its own right as well as in the context of other influencing factors. Most parents did not define suffering. Some identified pain, physical or otherwise, as a form of suffering that might lead them to consider withdrawing life-sustaining therapies. One parent said, "There's some physical pain but it's more mental pain and agony. . . . I will consider all sorts of suffering as a factor." Some parents would only consider withdrawing life-sustaining therapies in the presence of suffering if there was no hope for improvement: "[I]f I thought that they were just going to keep suffering and suffering and they were not going to survive anyway, then I wouldn't want them to suffer." A few parents described neurological impairment or dependence on machines as forms of suffering. One parent said, "Well, if they told me that she would be a vegetable . . . I wouldn't want her to suffer that." Another parent said, "If [he] would have to stay on that machine without ever being able to come off that, that would be a lot of suffering for him."

Ineffective Treatments

Many parents said that lack of effective therapies would influence them to consider withdrawing life-sustaining therapies. Many comments reflecting this theme came in response to the question regarding physician-estimated prognoses. In the setting of a poor prognosis, some parents said they would simply have to accept the situation. One parent said, "[I]f they said there's nothing else that they could do . . . I mean, what can we do?" Others expressed willingness to accept the physicians' prognosis: "[I]f they felt that there was nothing they could do I think we would trust that opinion. We would withdraw support." Beyond specific responses to the question about physician-estimated prognosis, some parents said they would consider withdrawing life-sustaining therapies if their child had no hope of getting better and was suffering. In the absence of suffering, some parents said they would want to continue life support even if physicians felt that treatments were not working.

Table 4. Affirmative Responses Based on Replies to the Initial Question Regarding Withdrawing Life-Sustaining Therapies

Response to General Question	Response to Subsequent Questions: Question Topic	Affirmative Response, No. (%)
Yes (n=40)	Quality of life	28 (70)
	Suffering	27 (68)
	Physician-estimated prognosis	23 (58)
	Financial burden	2 (5)
No (n=17)	Suffering	8 (47)
	Quality of life	5 (29)
	Physician-estimated prognosis	2 (12)
	Financial burden	0
Not sure (n=7)	Suffering	5 (71)
	Physician-estimated prognosis	3 (43)
	Quality of life	1 (14)
	Financial burden	1 (14)
Unclear response (n=5)	Suffering	4 (80)
	Quality of life	2 (40)
	Physician-estimated prognosis	2 (40)
	Financial burden	1 (20)

Faith

Parents discussed their faith and religious views frequently. Some described their faith or beliefs as a source of guidance in deciding to withdraw life-sustaining thera-

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pies. One parent said, "[I] would look for some kind of spiritual guidance." Prompted by our question on the influence of suffering, 1 parent talked about how in the afterlife there is no suffering: "[H]e is going to pass on to a better life, right, where he is not going to suffer anymore." One parent indicated that God or faith would direct decisions: "I can imagine a time me doing that. But it will be faith that I'm telling them this because I believe in God." Some parents talked of God's will and their belief that a higher power has the ultimate control. One person commented, "You are simply doing what God wants you to do."

Other parents explained why their faith would lead them to not consider withdrawing life-sustaining therapies. Again parents talked about God's power over such decisions. One parent said, "If God does not want me to keep him, well, He is going to take him . . . whatever may be done to him." Another person said, "[You] can't play like you're God or the higher power." While considering a child with a limited quality of life, 1 parent said, "But I feel that if the Lord put her here like that, it's a reason." Some parents said they would hope for a miracle or put their faith in a higher power, rather than physicians' actions or prognoses. One parent said, "God has been able to—to overturn what doctors have said." Prompted by the question on the influence of suffering, 1 parent likened suffering to Jesus' crucifixion and said, "Sometimes the suffering God gives us is worth it."

Time

For some parents, the passage of time had special significance. Some parents felt they could only consider withdrawing life-sustaining therapies after some indeterminate amount of time had passed: "If there had been enough time that a miracle was going to happen, it would be very hard, but I think sometimes it's the better scenario." In response to the question on physician-estimated prognosis, 1 parent said, "[I] would say I need a day or 2 to wait. You know, just to prepare." In their discussions of suffering, a number of parents said that over time, the combination of suffering without a chance of improvement would influence them to consider withdrawing life-sustaining therapies: "[I]f I thought he was suffering . . . after a month [and] his life is just going down and down, you know, I can't let him suffer no more."

Financial Considerations

Financial considerations came up primarily in response to the question regarding financial burden. Of the 5 who indicated that finances would influence their decisions, 3 parents said that without money they would have no choice: "If I didn't have the money and I end up running out of funds, it's no longer a choice for me." The majority of parents felt that issues of finance would not influence their decision: "We'd mortgage up to whatever we had to get her fixed."

General Rejection of Withdrawing Life-Sustaining Therapies

Some parents simply rejected the notion of withdrawing life-sustaining therapies. One parent said, "I don't think along the lines like that." Others insisted they would want the medical staff to continue all therapies and do everything possible to treat their child. Replying to our question about quality of life, a parent explained, "it wouldn't matter to me if she was a vegetable or . . . if I had to do everything for her like I did when she was a baby . . . I just want her here." Another parent contrasted withdrawing life-sustaining therapies in adults with actions regarding children: "[An] adult [is] more worn down oneself. But with a young [person] there are many possibilities." Only 1 parent indicated an unwillingness to consider withdrawing life-sustaining therapies because of a desire not to be responsible for making such a decision.

Mistrust/Doubt Toward Physicians

Parents who said they would continue all therapies regardless of the situation often used language that suggested mistrust or doubt of physicians. Many of these statements came in response to the question about the influence of physician-estimated prognosis. Some parents explained that they would want to "wait it out" because physicians often make mistaken predictions. One person said, "Doctors are not God and doctors have been wrong." Several parents said they would want to obtain a second opinion.

Reliance on Self/Intuition

A few parents claimed that an inner sense would drive their decisions. One parent indicated that she/he would rely on intuition and ignore poor prognoses because, "It's the feeling I would have." Another parent said, "When you are close to somebody you know one another. You know the inner part. So when it happens, she and I will know it."

COMMENT

More than half of the parents interviewed said they could imagine a situation in which they would consider withdrawing life-sustaining therapies. Thematic analysis identified 9 factors important to parents considering withdrawing life-sustaining therapies. The relatively generous sample size and inclusion of parents from different socioeconomic and racial/ethnic groups (including Spanish speakers) whose children had a wide range of medical and surgical problems distinguishes this work from previously published studies in the field.

Some themes identified, including quality of life, suffering, ineffective therapies, and financial considerations, reflect our questions and thus mirror indications for withdrawing life-sustaining therapies acknowledged by pediatricians.[2,5-10] However, parents conveyed these themes in response to our general question about withdrawing life-sustaining therapies as well as subsequent questions, suggesting broad agreement between parents and pediatricians regarding these decision-making influences.

The data highlight that parents' perceptions of their child's suffering is an important factor in their projected decision making. A large percentage of parents who responded "no," "not sure," or gave unclear responses to our initial questions about withdrawing life-sustaining thera-

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pies responded "yes" when asked about the influence of suffering. Moreover, we note the pervasiveness of this factor throughout the interviews. Others have also noted the relatively large influence of patient suffering on parents' decisions to forgo life-sustaining therapies.[11,12,21] No uniform definition of suffering emerged from our data. That the term *suffering* may have broad and varied meanings should remind clinicians to ask parents for clarification of key terms to avoid confusion.

Parents reported that physician-estimated prognosis carries less weight in their decision making. Perhaps this reflects parental mistrust of physicians (as 1 theme identified), that parents recognize physicians' limited ability to accurately prognosticate, that some parents simply refuse to consider withdrawing life-sustaining therapies (another theme identified), or that other parents have an unending sense of hope. Regardless, it highlights potential areas of discord between parents and physicians stemming from different outlooks on the meaning of ineffective therapies and parental struggles over "giving up" on their child's life.

Our findings support the previously described importance of religion and spirituality in end-of-life care and decision making.[11,22,23] In our study, parents' spiritual beliefs bolstered their inclination both to consider withdrawing life-sustaining therapies and to reject considerations of withdrawing life-sustaining therapies. This variable impact, also noted by others,[24] illustrates the complex influence that religion and spirituality have on parental end-of-life decisions.

We identified additional important influences on parents' decision making, such as the passage of time and reliance on self/intuition. In another study of PICU patients' parents, Sharman et al[11] also noted similar themes. They describe the influence of family and faith, time, and perceptions of the child's will to survive as influential factors for parents considering end-of-life decisions. Such factors, which professionals may not routinely consider, highlight another potential disconnect between how parents and professionals approach such decisions.

Our data identify a small but notable group of parents (13%) who would never consider withdrawing life-sustaining therapies. The presence of mistrust or doubt towards physicians emerged in our study and could partly explain parents' opposition to withdrawing life-sustaining therapies. The general rejection of withdrawing life-sustaining therapies reflects how some parents felt that withdrawing life-sustaining therapies simply does not accord with their personal values and life practices. While ethicists and medical professionals may regard withdrawing life-sustaining therapies as an appropriate option in certain circumstances,[15] some parents may have differing views regarding the legitimacy of withdrawing life-sustaining therapies.

Finally, our data show that parents' self-identify as key end-of-life decision makers. This conforms to reported Anglo-American norms, which support parents' role in such life-support decisions and runs contrary to fears that parents do not want that level of responsibility.[25] However, of the 67 parents (96%) who said they should participate in such decisions, 35 (52%) also identified physicians as key decision makers. Thus, our data suggest that many parents place a value on shared decision making.

The main study limitation stems from our asking parents hypothetical questions. Parents' reactions when confronting imminent end-of-life decisions could differ. Interestingly, 40 of the 70 parents (57%) interviewed thought at some point during the hospitalization that their child might die, suggesting that these questions had emotional salience for many of the participants. Though we had good participation (63%), our study is subject to the limits of recruitment bias. Parents who agreed to be interviewed could hold different views from those who refused. Attending intensivists may have biased recruitment by directing interviewers toward or away from parents of sicker patients or those facing difficult decisions. We did not focus on sicker children or children with chronic diseases. By coincidence, most parents interviewed were Christian. Thus, we caution readers that our results cannot be directly applied to all populations; further studies should be conducted to establish generalizability.

This study adds to our understanding of factors that could be important to parents of PICU patients who must make decisions about withdrawing life-sustaining therapies. Parents and pediatricians share common considerations, such as suffering and quality of life. But parents describe additional factors, including faith, time, and intuition, that are not always considered by pediatricians. Parents' perspectives on and beliefs about clinical findings may differ from those of the professionals, as demonstrated by some of our interviewees' reluctance to accept poor prognoses from physicians and by a sense of mistrust toward physicians. Such differences, along with the challenges related to using vague terms like *suffering*, represent potential areas of conflict. The range of opinions expressed by parents on withdrawing life-sustaining therapies for their children highlights the need for meticulous communication between health care providers and parents to promote understanding and effective decision making.

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REFERENCES

1. Vernon DD, Dean JM, Timmons OD, Banner W Jr, Allen-Webb EM. Modes of death in the pediatric intensive care unit: withdrawal and limitation of supportive care. *Crit Care Med*. 1993;21(11):1798-1802.
2. Garros D, Rosychuk RJ, Cox PN. Circumstances surrounding end of life in a pediatric intensive care unit. *Pediatrics*. 2003;112(5):e371.
3. Burns JP, Mitchell C, Outwater KM, et al. End-of-life care in the pediatric intensive care unit after the forgoing of life-sustaining treatment. *Crit Care Med*. 2000; 28(8):3060-3066.
4. Ryan CA, Byrne P, Kuhn S, Tyebkhan J. No resuscitation and withdrawal of therapy in a neonatal and a pediatric intensive care unit in Canada. *J Pediatr*. 1993;123 (4):534-538.
5. Mink RB, Pollack MM. Resuscitation and withdrawal of therapy in pediatric intensive care. *Pediatrics*. 1992;89(5):961-963.
6. Levetown M, Pollack MM, Cuerdon TT, Ruttimann UE, Glover JJ. Limitations and withdrawals of medical intervention in pediatric critical care. *JAMA*. 1994;272 (16):1271-1275.
7. Randolph AG, Zollo MB, Wigton RS, Yeh TS. Factors explaining variability among caregivers in the intent to restrict life-support interventions in a pediatric intensive care unit. *Crit Care Med*. 1997;25(3):435-439.
8. Burns JP, Mitchell C, Griffith JL, Truog RD. End-of-life care in the pediatric intensive care unit: attitudes and practices of pediatric critical care physicians and nurses. *Crit Care Med*. 2001;29(3):658-664.
9. Tournay AE. Withdrawal of medical treatment in children. *West J Med*. 2000;173 (6):407-411.
10. Keenan HT, Diekema DS, O'Rourke PP, Cummings P, Woodrum DE. Attitudes toward limitation of support in a pediatric intensive care unit. *Crit Care Med*. 2000; 28(5):1590-1594.
11. Sharman M, Meert KL, Sarnaik AP. What influences parents' decisions to limit or withdraw life support? *Pediatr Crit Care Med*. 2005;6(5):513-518.
12. Meyer EC, Burns JP, Griffith JL, Truog RD. Parental perspectives on end-of-life care in the pediatric intensive care unit. *Crit Care Med*. 2002;30(1):226-231.
13. Masri C, Farrell CA, Lacroix J, Rocker G, Shemie SD. Decision making and end-of-life care in critically ill children. *J Palliat Care*. 2000;16(suppl):S45-S52.
14. Michelson KN, Koogler TK, Skipton K, Sullivan C, Frader J. Parents' reactions to participating in interviews about end-of-life decision making. *J Palliat Med*. 2006; 9(6):1329-1338.
15. Giacomini MK, Cook DJ. Users' guides to the medical literature: XXIII: qualitative research in health care A, are the results of the study valid? Evidence-Based Medicine Working Group. *JAMA*. 2000;284(3):357-362.
16. Strauss AL, Corbin JM. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 2nd ed. Thousand Oaks, CA: Sage Publications; 1998.
17. Office of Behavioral and Social Sciences Research. *Qualitative Methods in Health Research: Opportunities and Considerations in Application and Review*. Bethesda, MD: National Institutes of Health; 2001.
18. Byrt T. How good is that agreement? *Epidemiology*. 1996;7(5):561.
19. Pope C, Ziebland S, Mays N. Qualitative research in health care: analysing qualitative data. *BMJ*. 2000;320(7227):114-116.
20. Patton MQ. *Qualitative Research and Evaluation Methods*. 3 ed. Thousand Oaks, CA: Sage Publications; 2002.
21. Meert KL, Thurston CS, Sarnaik AP. End-of-life decision-making and satisfaction with care: parental perspectives. *Pediatr Crit Care Med*. 2000;1(2):179-185.
22. Arnold RM. *Clinical Practice Guidelines for Quality Palliative Care*. Brooklyn, NY: National Consensus Project for Quality Palliative Care; 2004.
23. Himelstein BP. Palliative care for infants, children, adolescents, and their families. *J Palliat Med*. 2006;9(1):163-181.
24. Meyer EC, Ritholz MD, Burns JP, Truog RD. Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations. *Pediatrics*. 2006;117(3):649-657.
25. Carnevale FA, Canoui P, Cremer R, et al. Parental involvement in treatment decisions regarding their critically ill child: a comparative study of France and Quebec. *Pediatr Crit Care Med*. 2007;8(4):337-342.

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