

Talking With Parents About End-of-Life Decisions for Their Children

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abstract

BACKGROUND AND OBJECTIVE: Retrospective studies show that most parents prefer to share in decisions to forgo life-sustaining treatment (LST) from their children. We do not yet know how physicians and parents communicate about these decisions and to what extent parents share in the decision-making process.

METHODS: We conducted a prospective exploratory study in 2 Dutch University Medical Centers.

RESULTS: Overall, 27 physicians participated, along with 37 parents of 19 children for whom a decision to withhold or withdraw LST was being considered. Forty-seven conversations were audio recorded, ranging from 1 to 8 meetings per patient. By means of a coding instrument we quantitatively and qualitatively analyzed physicians' and parents' communicative behaviors. On average, physicians spoke 67% of the time, parents 30%, and nurses 3%. All physicians focused primarily on providing medical information, explaining their preferred course of action, and informing parents about the decision being reached by the team. Only in 2 cases were parents asked to share in the decision-making. Despite their intense emotions, most parents made great effort to actively participate in the conversation. They did this by asking for clarifications, offering their preferences, and reacting to the decision being proposed (mostly by expressing their assent). In the few cases where parents strongly preferred LST to be continued, the physicians either gave parents more time or revised the decision.

CONCLUSIONS: We conclude that parents are able to handle a more active role than they are currently being given. Parents' greatest concern is that their child might suffer.



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WHAT'S KNOWN ON THIS SUBJECT: Retrospective studies have shown that the majority of parents, independent of their country of origin, prefer a shared approach over a paternalistic approach or an informed approach when an end-of-life decision must be made for their children.

WHAT THIS STUDY ADDS: In actual conversations parents act in line with their preference for a shared approach. This behavior contrasts with the "some sharing" approach of physicians who carefully prepare parents for an end-of-life decision already being made by the medical team.

After the death of a child, parents' lives are never the same again. Despite their immense grief, most parents find a way to continue living as best as they can. The factors that support them in coping with the loss of their child have received growing attention.¹⁻¹⁵ Recent studies show that most parents find it helpful to share in their child's daily care during the dying process. Most of them also find it helpful to share in decisions to withhold or withdraw life-sustaining treatment (LST), decisions that often precede a child's death.^{2,3,5,9,11,16-20} Parents' perception of a shared approach may even lower their grief in the long term.²¹ The extent to which parents want to share in the decision-making process differs from parent to parent. Some want to share in all stages of the decision-making process, including exchanging information, deliberating about preferred options, and making the final decision together (Table 1). Others want to share information and preferences with their child's physician but feel it is too great a burden to

make the final decision. Therefore, recent studies have concluded that the way parents are involved should be highly tailored to their individual preferences and needs.^{2,16,22-31} What we do not yet know is how parents are actually being involved in end-of-life decision-making. Little information is available about how these decisions are made in PICUs. We therefore performed a prospective exploratory study aimed at answering 2 questions: How do physicians and parents communicate about decisions to withhold or withdraw LST, and to what extent do parents share in the decision-making process?

METHODS

Study Setting and Inclusion of Parents

We conducted our study in the PICUs of 2 Dutch university medical centers. Both PICUs are combined medical and surgical tertiary facilities, including all specialty care except that involving prematurely born infants. The institutional review boards gave their approval for the study. To identify eligible conversations, the main researcher (M.A.V.) contacted the supervising pediatric intensivist twice a week. Upon being informed about an intended conversation in which a decision to withhold or withdraw LST would be discussed with parents, she contacted the physician who would be speaking with the parents. This physician then informed the parents about the study and asked for their consent. Parents were informed about the main purpose of the study: to help physicians to improve their communication with parents about treatment choices in critically ill children. It was stressed that parents had full liberty to refuse and could end their study participation at any time. We strived to achieve a large variation of cases according to the following patient-related characteristics: age, gender, prognosis, preexisting neurologic damage, total duration of care, and length of PICU stay. Similarly,

we sought variation according to the following parent-related characteristics: gender, ethnic background, first language, religion, marital status, and length of physician-family relationship. The first inclusion period lasted from April 2008 to April 2009, the second from April 2010 to April 2011 (see Table 2 for details, including the consent rates of parents and physicians).

Coding and Analysis

The recorded conversations were transcribed verbatim and anonymized. Transcripts were then uploaded to MAXQDA (VERBI GmbH, Berlin, Germany).³² We performed a search in PubMed for schemes used to codify physicians' and parents' communication in end-of-life decisions. In the pediatric literature we did not find any such schemes. In the adult medical literature our search eventually led to 2 relevant and useful publications. First, Charles et al³³ described a conceptual framework for decision-making in the medical encounter, consisting of different analytic stages: information exchange, deliberation, and deciding on treatment to implement. Second, White et al³⁴ described a coding instrument to assess the extent of shared decision-making in relation to specific physician communication behaviors.

In the first draft of our coding scheme we incorporated the 3 analytical stages and the coded physician behaviors. After having closely read the first 10 transcripts, we elaborated the coding elements describing physician behaviors and added coding elements describing parents' communication behaviors. After additional refinement of this extended coding scheme, transcripts were coded by 2 researchers (M.A.V. and B.M.G.). This included a recoding of the first 10 transcripts. Conflicting views about the applied codes were resolved by discussion. Next, we composed worksheets containing all retrieved conversation segments per applied code over all cases. We

TABLE 1 Definition and Stages of Shared Decision-Making

In this study we define shared decision-making as a decision-making process in which the physicians and the patient or his or her representatives exchange information, deliberate together, and decide together which treatment should be implemented or should not be implemented anymore.
This process therefore consists of 3 analytical stages, which may occur together or iteratively.
Stage 1. 2-way exchange of information
The physician provides information about available treatment options, the benefits and risks, and the potential effects on the patient's well-being.
The patient or the representatives provide information about preferences, values, lifestyle, beliefs, and knowledge about the illness, prognosis, and treatment.
Stage 2. Deliberation
All parties express and discuss their treatment preferences.
This may also include the preference to wait and see or to forgo LST while prolonging palliative treatment.
Stage 3. Reaching a decision
All parties work toward reaching a joint decision to which they all agree.

Adapted from Charles et al (1999).³⁵

TABLE 2 Quantitative Context of the Study

	PICU 1, <i>n</i> (%)	PICU 2, <i>n</i> (%)	Totals in Both PICUs, <i>n</i> (%)
First inclusion period, April 1, 2008–April 1, 2009			
Included cases	5	10	15 ^a
Missed cases ^b	3	5	8
Deaths (percentage of patients admitted to both PICUs)	9	13	22 (4%)
Patients dying after a decision to forgo LST (percentage of total number of deaths)	6 (67%)	5 (38%)	11 (50%)
Second inclusion period, April 1, 2010–April 1, 2011			
Included cases ^c	0	4	4 ^d
Deaths (percentage of patients admitted to both PICUs)	12	16	28 (5%)
Patients dying after a decision to forgo LST (percentage of total number of deaths)	8 (67%)	11 (69%)	19 (68%)
Consent rate of parents	100%	93% ^e	95%
Consent rate of physicians	88% ^f	100%	96%
Consent rate of nurses ^g	100%	100%	100%

^a 13 of 15 children died within 12 mo after the decision to forgo LST had been made, and 2 of 15 children survived.

^b In these cases, conversations with parents took place before the researchers were informed.

^c Analysis of the 15 cases included in the first period showed that cases with the following characteristics were underrepresented: preexisting neurologic damage in the child, long-term physician–family relationship, or religious parents. In the second period we included 4 more cases with ≥ 1 of these characteristics by purposeful sampling.

^d 2 of 4 children died within 12 mo after the decision to forgo LST had been made, and 2 of 4 children survived.

^e Of the 39 parents we approached, 2 parents (1 couple) refused to participate.

^f Of the 28 physicians we approached at the start of our study, 1 physician refused to participate.

^g A total of 26 nurses participated. They were present at 32 of 47 meetings.

qualitatively and quantitatively analyzed this material and thoroughly discussed the results in several discussion rounds with all researchers. Coding scheme and worksheets are available on request.

RESULTS

Characteristics of Participants and of the Decision-Making Process

Overall, 37 parents of 19 patients and 27 physicians participated. Table 3 lists their demographic characteristics. In Supplemental Table 8 we present the main characteristics of the decision-making process for each patient.

Speaking Time and Contribution of Nurses

Forty-seven conversations were audio recorded. The number of meetings ranged from 1 to 8 per patient, with a median of 2 meetings. The mean duration of meetings was 30 minutes. On average, physicians spoke 67% of the time, parents 30%, and nurses 3%.

Whenever a nurse was present, his or her contribution to the conversation always occurred at the end of the meeting and consisted of

a combination of emotional and practical support, as indicated by remarks such as “This must be difficult to hear” or “We’ll arrange for you both to stay with your child tonight.” The nurse then accompanied parents back to their child’s room or got parents coffee and stayed in the conference room with them for some time.

Communication Behaviors Throughout the Decision-Making Process

In all but 1 case, physicians and parents went through all stages of the decision making process: providing and receiving information, deliberating about whether to withhold or withdraw LST, and reaching a final decision. In none of the cases this was a linear chronological process. Instead, within a conversation physicians and parents moved back and forth between the stages of information exchange and deliberating before reaching a decision to withhold or withdraw LST at the end of the meeting or postponing this decision to a subsequent meeting. The next meeting typically started with an extensive update about the child’s situation and a renewed deliberation

about the pros and cons of treatment continuation or discontinuation.

In 6 cases it took 1 meeting to reach a final decision, in 7 cases 2 meetings, and in the 5 most complex cases ≥ 3 meetings. In the remaining case the child died just after the first meeting. In this meeting the physician cautiously announced that there could come a time when continuation of LST had to be considered futile.

Stage I. Providing and Receiving Information

Table 4 gives an overview of the specific communication behaviors physicians and parents showed in the first stage of decision-making, the number of cases in which we identified these behaviors, and illustrative quotes extracted from the transcripts.

Although physicians occasionally started the meeting by explaining its goal and presenting a short agenda, in most meetings he or she immediately started with an extensive and detailed update about the child’s current serious condition, the grave prognosis, and the remaining treatment options. Much of this information was repeated several times throughout the meeting. Most physicians emphasized that everything was being tried to overcome the patient’s life-threatening problems but that treatment was becoming increasingly burdensome for the child.

In one third of cases, the physicians asked parents to provide their perspectives about their child’s situation, especially their observations about symptoms of discomfort and their child’s ability to make any form of contact. None of the parents were invited to share their views about their child’s prognosis or the remaining treatment options.

In half of the cases, parents took the initiative to ask clarifying questions throughout the meeting. These questions showed that they wanted to understand exactly what was

TABLE 3 Main Characteristics of Included Patients, Parents, and Physicians

Characteristics	Patients (<i>N</i> = 19), <i>N</i> (%)	Parents (<i>N</i> = 37), <i>N</i> (%)	Physicians (<i>N</i> = 27), <i>N</i> (%)
Age (y)			
0–1	5 (26)	—	—
1–4	8 (42)	—	—
4–12	4 (21)	—	—
12–17	2 (11)	—	—
Mean age (y)	4	—	—
Gender			
Female	4 (21)	19 (51)	12 (44)
Male	15 (79)	18 (49)	15 (56)
Main diagnosis			
Congenital disorder	11 (58)	—	—
Acute illness	2 (10)	—	—
Neurotrauma	2 (10)	—	—
Sudden infant death syndrome	2 (10)	—	—
Cancer	1 (6)	—	—
Perinatal asphyxia	1 (6)	—	—
Total duration of medical care			
0–24 h	1 (6)	—	—
1–7 d	4 (21)	—	—
1–4 wk	4 (21)	—	—
1–6 mo	2 (10)	—	—
>6 mo	8 (42)	—	—
Long-term physician–family relationship ^a			
Yes	3 (16)	—	—
No	16 (84)	—	—
Interval between final decision and death			
<24 h	5 (26)	—	—
1–7 d	8 (42)	—	—
1–4 wk	0 (0)	—	—
>1 mo	3 (16)	—	—
Still alive	3 (16)	—	—
Ethnic background			
Dutch	9 (47)	—	26 (96)
Other Western country	1 (6)	—	0
Non-Western country	9 (47)	—	1 (4)
First language of parents			
Dutch	—	23 (62)	—
Other	—	14 (38)	—
Religion of parents			
Christian	—	13 (35)	—
Islamic	—	6 (16)	—
None	—	2 (6)	—
Unknown	—	16 (43)	—
Marital status of parents			
Married or living together	—	35 (94)	—
Divorced or living apart	—	1 (3)	—
Single	—	1 (3)	—
Pediatric specialty			
Intensivist	—	—	15 (56) ^b
Neurologist	—	—	5 (19)
Metabolic pediatrician	—	—	3 (11)
Others	—	—	4 (14)
Experience as medical specialist			
0–5 y	—	—	12 (44)
5–10 y	—	—	2 (8)
>10 y	—	—	13 (48)

^a Defined as follows: There was 1 physician in charge who had treated the patient for >6 mo and had had regular conversations with the parents about the patient's diagnosis, prognosis, and treatment plan over this period (with a minimum of 3 times a year).

^b This large number is explained by 2 factors. First, in both PICUs intensivists mainly chaired the meetings with parents, accompanied by another intensivist or by a specialist also involved in the child's care. Second, successive meetings were frequently chaired by a different intensivist.

TABLE 4 Stage I: Providing and Receiving Information

Coded Behaviors	From Physicians to Parents		From Parents to Physicians	
	Cases (<i>N</i> = 19), <i>n</i> (%)	Illustrative Quotes	Cases (<i>N</i> = 19), <i>n</i> (%)	Illustrative Quotes
1. Asking for information about actual situation and treatment effects	6 (32%)	“Perhaps you can tell me more about what has actually happened. Because as far as I know, up until this morning your daughter was completely healthy?” “Did you manage to have any contact with your son today?”	8 (42%)	“The EEG showed no activity, but we were told that he shows some activity when you look at him. What causes this activity? Where are these signals being made? In his cerebral cortex?”
2. Providing information about actual situation and treatment effects	18 (95%)	“Her lungs have difficulty getting enough oxygen and transporting it to all her organs. Slowly we are approaching the last remaining options. And we have started with the last option today by giving her extra medication.”	11 (58%)	“I observe my son every day, and I see that he is frightened. And when he gets his feeding by his percutaneous endoscopic gastrostomy tube he becomes nauseated.”
3. Asking for information about prognosis	0 (0%)	—	10 (53%)	“She is in a coma now. But what is the chance that she will recover from it, and how damaged will she be?”
4. Providing information about prognosis	18 (95%)	“All his organs will suffer. But the organs that need the most energy—his brain, lungs, and heart—will be the first to decline. And we have no cure.”	1 (5%)	“I don’t expect to see a miracle anymore. Everything has been tried.”
5. Asking for information about remaining options, including pros and cons	0 (0%)	—	11 (58%)	“Are there no more antibiotics you can give him? Because he has so much sputum.”
6. Providing information about remaining options, including pros and cons	19 (100%)	“If your son is able to breathe well, we will try to get him out of the ICU and home as soon as possible. If it does not work out and breathing proves difficult, it would not be right to intubate him again, because he has an underlying illness that cannot be cured.”	0 (0%)	—
7. Asking for a summary	3 (16%)	“I would like to begin by asking you to tell me what you remember from our conversation earlier this afternoon.”	0 (0%)	—
8. Providing a summary	0 (0%)	—	3 (16%)	“In short, we heard that our son is brain damaged and that none of his functions can be saved anymore.”
9. Inviting to ask additional questions	15 (79%)	“Have you understood everything? Do you have any questions? Please let us know.”	—	—

—, indicates not applicable.

happening to their child. Furthermore, they specifically asked which treatments were being giving to their child, whether they were working, and whether everything was being done to protect their child from pain and other symptoms. Toward the end of the meeting most physicians asked the parents whether they had any additional questions.

Occasionally physicians asked them to summarize their understanding of the situation. In these cases, the parents typically demonstrated good understanding of the key issues.

Stage II. Deliberating

In Table 5 we present the specific communication behaviors physicians and parents showed in the second

stage of decision-making, the number of cases in which we identified these behaviors, and illustrative quotes.

In none of the cases did the physicians ask the parents how they preferred to be involved in the decision-making process. In 1 case, the parents spontaneously expressed their preference and explained that they wanted to fully share in the decision-making process,

TABLE 5 Stage II: Deliberating

Coded Behaviors	From Physicians to Parents		From Parents to Physicians	
	Cases (<i>N</i> = 19), <i>n</i> (%)	Illustrative Quotes	Cases (<i>N</i> = 19), <i>n</i> (%)	Illustrative Quotes
1. Asking which role in decision-making would be preferred	0 (0%)	—	0 (0%)	—
2. Providing information about which role in decision-making would be preferred	0 (0%)	—	1 (5%)	“Does the doctor make the final decision? Or will it be done together with us? Because I think that we already share the same opinion.”
3. Asking about values and preferences regarding continuation or discontinuation	4 (21%)	“If he were to catch severe pneumonia, what would you say? Should we continue to treat him in the ICU?”	4 (21%)	“We know his brain is severely damaged. When we look at the long term, what can you offer our boy?”
4. Providing information about values and preferences regarding continuation or discontinuation	17 (89%)	“Technically we can do almost everything to keep your son alive. But in fact we would only be prolonging his suffering and not giving him a real future.”	16 (84%)	“I am not scared about how it will look. I just want to see him alive.” “I understand that you and your colleagues want to try everything, but at a certain point this has to stop.” “It is a dilemma. Because I don’t want him to suffer, not for 1%. At the same time, I want to have him with me for some more time.”
5. Expressing objections to the other’s preferences	3 (16%)	“Of course I understand that this is against your parental intuition. Parents never want treatment to be stopped for their child. But everything we do should be in the interests of your daughter, not in our own interests.” “We can only stop once, and we therefore must be convinced as medical team that this is the only right choice. We should not be pressured by the emotional reaction that this process is taking so much time.”	7 (37%)	“I don’t think mechanical ventilation is too burdensome for him. Moreover, according to my beliefs I am not allowed to make these decisions on behalf of my son.” “If I were allowed to decide, I would ask you to give me 2 more days to be with my girl. Just 2 more days.” “We don’t see any improvement. So we thought, ‘Today it will all be over.’ But now we hear that his treatment will be continued.”
6. Inviting to share emotions	2 (11%)	“You were upset by what I was telling you, weren’t you? Please tell me.”	0 (0%)	—
7. Expressing emotions of grief, fear, despair, and frustration	0 (0%)	—	19 (100%)	“No, no, no. Oh Jesus, Jesus [crying for several minutes]. You will give him time, please?” “He has had so many punctures in his back [crying]. Don’t you tell me that this has done him any good.” “How can we ever continue living? How can we ever forget?”
8. Acknowledging emotions	15 (79%)	“It is totally understandable that this frightens you.”	1 (5%)	“It is difficult, isn’t it? It is also hard for his nurses.”

—, indicates not applicable.

including making decisions about whether to discontinue LST together with their physician.

Almost all physicians at some point explained which decision they would prefer. They presented these preferences as team preferences rather than personal preferences.

In most cases, physicians stated that according to the team’s shared opinion it would be best if LST was withheld or withdrawn, whether in the short term or longer term. Depending on the child’s specific condition and prognosis, physicians explained this preference as follows:

Despite full support it was becoming clear that the child was deteriorating very fast and would die soon (in 7 of 19 cases), continued use of LST could not overcome the underlying problems and was only causing the child suffering (in 6 of 19 cases), or reinstating LST would put the child’s

already fragile quality of life under even more pressure (in 4 of 19 cases).

In the remaining 2 cases, the physicians explained in the first meetings that they preferred LST to be continued. In their opinion, more time should be given to await the child's possible recovery. This preference contrasted with the parents' preference to withdraw LST to spare their already severely disabled child more suffering. Over time the child's condition deteriorated, and in later meetings the physicians emphasized that LST had clearly become inappropriate and therefore should be withdrawn.

In the majority of cases (in 16 of 19 cases) parents presented their preferences about additional treatment, often without being invited to do so. One third of these parents (5 of 16 cases) expressed a preference for treatment to be continued or restarted, in contrast to the preference presented by the physician to withhold or withdraw LST in the near future. In these cases, the parents explained that they were not yet certain that all had been tried and that they still thought and hoped their child could recover. Several parents added that their religious beliefs strengthened this hope. Two thirds of the parents (11 of 16 cases) emphasized that they did not want treatment to be continued at all cost. In most cases this preference was in line with that of the physician; in 2 cases (mentioned earlier) the parents' preference that LST would be withdrawn was not yet shared by the physicians. The parents of both children emphasized that their wish to try everything to save their child by now was outweighed by their wish to protect their child from pointless suffering and from living a life they considered inhumane.

All parents reacted emotionally when the physicians indicated that a decision to withhold or withdraw LST could become inevitable or had become inevitable. These emotions

varied between anxiety, dismay, grief, confusion, and disbelief. The parents of the 2 children mentioned earlier described how they felt a strange combination of deep sadness and relief for their child's sake. Several other parents described how they felt trapped in the dilemma of wanting their child to be near them as long as possible and wanting to spare their child more suffering. Parents' often intense emotions did not prevent them from taking the initiative to ask clarifying questions and present their preferences. Although most physicians acknowledged the parents' emotions and were empathic, none of them explored these feelings further. Occasionally, physicians addressed parents' needs for emotional and social support.

Stage III. Reaching a Decision

Table 6 gives an overview of the specific communication behaviors physicians and parents showed in this third stage, the number of cases in which we identified these behaviors, and illustrative quotes.

In 2 cases the physicians asked the parents which decision they thought should be made. In these conversations, a differentiated "package of decisions" was formulated, including withholding of future resuscitation, withholding of LST in case of severe, lasting problems, and initiating LST in case of "bridgeable" problems such as an epileptic seizure or pneumonia.

In the remaining cases, the physicians did not invite parents to share in making the final decision. Instead, during the (last) meeting physicians explained that the medical team had reached the conclusion that LST had become "futile" and should therefore be forgone. In almost half of these cases, physicians added that this decision was a medical decision and not a decision parents should make. In the majority of cases parents' reactions made it clear that they did not feel taken by surprise and

understood the inevitable need to withhold or withdraw LST. Nevertheless, in 4 cases the parents repeated their strong wish that LST be continued. After acknowledging how difficult this process was for the parents, all physicians suggested a follow-up meeting for additional discussion. In this meeting the physicians again emphasized the child's critical condition and the duty of all caregivers to not prolong the child's suffering. Yet they also gave the parents the opportunity to clarify their points of view. The parents of 2 children eventually agreed that there remained no other choice than to withdraw LST (in both children death was clearly imminent). In the other 2 children, the physicians and the parents agreed that not all life-sustaining treatments would be withheld.

At the end of the (last) meeting, all parents expressed their great concern that their child might suffer in the process of dying. In turn, the physicians promised that everything would be done to ensure the child's comfort and peace. Moreover, several parents asked whether it would be possible to let their child regain consciousness so they could speak with him or her for the last time.

Extent of Shared Decision-Making

In Table 7 we provide an estimate of the extent of sharing which we identified in our study. In most cases the interaction between the physicians and the parents could best be described as "some sharing."³⁵ This implied that information and preferences were shared, mostly at the parents' initiative, but the decision-making was not.

DISCUSSION

When an end-of-life decision has to be made for a child, most parents, independent of their country of origin, seem to prefer a shared approach by their physicians over a paternalistic approach or an informed

TABLE 6 Stage III: Reaching a Decision

Coded Behaviors	From Physicians to Parents		From Parents to Physicians	
	Cases (<i>N</i> = 18), ^a <i>N</i> (%)	Illustrative Quotes	Cases (<i>N</i> = 18), ^a <i>N</i> (%)	Illustrative Quotes
1. Asking whether and which decision should be made	2 (11%)	"We could reach a point where it is necessary to perform cardiac massage or start mechanical ventilation. Should we do this or shouldn't we?"	0 (0%)	—
2. Informing about decision being reached	16 (89%)	"We think his condition is so severe that we have reached a point where continuing ventilation is not appropriate anymore. This is the only treatment still keeping him alive. We want to stop the ventilation. This means that he will die." "If her heart stops we will not start resuscitation. It is in her best interests."	7 (39%)	"When he further deteriorates and reaches a vegetative state, it is over. Then it is his time to go, but only if nothing can be achieved anymore." "When he is really deteriorating and he has pneumonia and is in pain, then we should not continue just because we think we have to continue."
3. Stressing that team should make final decision	8 (44%)	"Of course we will discuss the decision [to withdraw ventilation] with you, but we never let parents decide. That would be impossible for you in a situation like this."	0 (0%)	—
4. Asking for agreement regarding proposed decision	5 (28%)	"We are not going to resuscitate him for a second time because that would be too much damage for his already damaged brain. Do you agree with this decision?"	—	—
5. Expressing agreement or assent	—	—	12 (67%)	"We understand." "We already thought so." "So this is it. This is just the end of the story."
6. Expressing dissent	—	—	4 (22%)	"It can't happen so fast. I won't give up." "I want everything to be done that can be done, until the end. I want to do this for him."
7. Expressing worries about suffering	—	—	18 (100%)	"Is our son in any way aware of what will happen when ventilation is withdrawn?" "She may not have any pain." "His epileptic seizures are horrifying. Sometimes I think, 'Please die, because then it is all over.' But at the same time I can't lose him."

—, indicates not applicable.

^a In the remaining 19th case the child died before this last stage was reached in the conversations with the parents.

approach.^{10,12,21–23,26,27,31,36–38} Our findings indicate that in actual conversations parents act in line with this preference. Most parents in our study made an effort to actively participate in the decision-making process, especially when their initial preferences regarding the course of treatment did not correspond with those of the medical team. By contrast, most physicians were

focused primarily on carefully preparing the parents for the decision to withhold or withdraw LST. This approach seemed motivated by their dual wish to not overburden parents with too much responsibility while letting them grow toward accepting the inevitability of this decision. Studies investigating end-of-life communication with families in adult ICUs have reported a comparable

focus by physicians on providing medical technical information.^{39–44} What our study adds is the insight that parents appreciated receiving this detailed information, as evidenced by their reactions and their questions in return. It may be postulated that the provision of relevant information helps parents to grasp what is happening to their child and regain some feeling of control.

TABLE 7 Extent of Sharing Between Physicians and Parents

Process of Decision-Making	Characteristics of a Shared Process ^a	Extent of Sharing Identified in Our Study + Rarely ++ Sometimes +++ Very Often ++++ Always
Stage I: Providing and receiving information	1. Exchanging information:	
	1.1. Physician informs parents about actual situation, prognosis, treatment options, and their risks and benefits.	++++
	1.2. Parents inform physician about their observations and considerations.	+++ (in most cases not elicited by physicians but at parents' own initiative)
	2. Helping parents understand:	
Stage II: Deliberating	2.2. By inviting to ask questions.	+++
	2.3. By checking understanding.	+
	3. Discussing which role parents prefer to have in decision-making.	+ (at the parent's own initiative)
	4. Discussing treatment preferences:	
Stage III: Reaching a decision	4.1. Physician expresses preference.	+++
	4.2. Parents express preference.	+++ (in most cases not elicited by physicians)
	4.3. Exchanging underlying values and deliberations.	++ (especially when parents have different preferences than physicians)
	5. Making the final decision together.	+
Overall	6. Reaching agreement (eventually) about the most appropriate decision.	++++
		++ / +++

^a Based on Charles et al (1999),⁵³ White et al (2007),⁵⁴ and Nguyen et al (2014).⁵⁵

Although in most cases there seemed to be the right balance between parents' and physicians' communication behaviors in the first decision-making stage (exchanging information), our data also suggest that physicians' and parents' behaviors in the second stage (deliberating) and third stage (reaching a final decision) were often out of balance. In these cases a better balance could have been reached if the physicians had actively invited the parents to explain their points of view. Moreover, although the physicians firmly believed that they had the final responsibility for whatever decision was reached, the parents would have appreciated and preferred an affirmation that the decisions were being reached in collaboration with them and with respect for their views and values.

Parents' striving to fully share in all decision-making stages and physicians' striving to act as the final decision-maker both seemed strongly motivated by an urge to protect. Parents wanted to guard their child's

life and, even more important, to protect their child from suffering. Physicians wanted to guard the child's life and well-being, but they also wanted to protect the parents from (later) worries and guilt. Yet, this protection was not in line with what parents asked for, as indicated by their efforts to actively participate in all decision-making stages. In this respect our findings have important practical implications. First, they may help physicians become more alert to parents' communication behaviors and to how these behaviors interact with their own. This alertness will help them tailor their approach to parents' approaches in the different decision-making stages. Second, our findings may also prove helpful in the ongoing debate, at least in the Netherlands, regarding the role of minors and their parents in end-of-life decision-making. According to Dutch law, the judgment about the appropriateness of treatment continuation or discontinuation is a medical professional judgment in which the views of minors and their

parents should be taken into account.⁴⁵ It could seriously be questioned whether this law is still suited to the actual practice in which parents want to share in deciding whether treatment has become inappropriate.

In our study, most parents eventually expressed their assent to the decision being presented to them, convinced that there remained no other choice. In a minority of the cases the parents kept their resistance, mainly because they still hoped and believed that their child's situation would improve. In these cases the physicians did not put pressure on the parents. Instead they either gave them more time to be with their child and to witness the ongoing deterioration despite full support or revised their decision to meet the parents' wishes. This outcome confirms the finding of earlier studies that physicians make considerable efforts to prevent potential conflicts from escalating.⁴⁶⁻⁴⁸ Seen in this light, the choice of physicians to come forward to the wishes of the parents who

disagreed could be characterized as a conflict-solving strategy. At the same time it could be considered unfair that parents who express their strong objections may influence the decision-making process to a greater degree than parents who comply with the decision being proposed. We do not yet know which emotional effects compliance or noncompliance may have for parents in the long term. On one hand, it can be hypothesized that parents who comply to the recommendation to forgo LST may later feel that they have given up too soon and blame themselves for not expressing their doubts and concerns. On the other hand, parents who resist the recommendation to forgo LST may later feel guilty about not allowing their child to die peacefully. Follow-up studies of these long-term effects are needed to better support individual parents throughout the decision-making process and in their later bereavement after their child's death.

Our study suggests that in most cases parents' intense emotions of anxiety, grief, and distress did not hinder them from asking relevant questions and from clearly explaining their considerations and preferences. It could even be argued that these emotions, especially the parents' fear of losing their child and their anxiety of seeing their child suffer, heightened their alertness and awareness. In this respect there was no apparent difference between parents whose child had acutely fallen ill and parents whose child had a congenital disorder. This finding implies that the capacity of parents to understand complex issues should not be underestimated, despite their stress and grief. At the same time, it remains

important that physicians use clear, unambiguous words, do not lose themselves in too many details and complex hypothetical scenarios, and keep encouraging parents to ask questions and present their points of view.^{40,43,49-53}

Our study has several limitations. An important limitation is that our study was restricted to 2 medical centers, which was unavoidable given the logistical demands of the study. Moreover, we cannot rule out that the presence of a researcher influenced the course of the conversations. The greatest strength of our study is that we were able to explore in detail how physicians and parents communicate about end-of-life decisions. To do this we developed a coding instrument to systematically explore their communication behaviors. This instrument needs greater validation but may prove useful in international comparative research of actual end-of-life discussions by parents, physicians, and nurses. Although our study did not find evidence that nurses contributed to the decision-making during the "key conversations" we observed, this does not imply that nurses did not play an important role in other settings. Sometimes it was the nurses who first raised the issue of redirecting care in multidisciplinary team meetings. In addition, at the bedside nurses often spoke with parents about the information they had received earlier that day and explored parents' reactions. It may be that the views that parents expressed in follow-up meetings were views that they had come to develop in these conversations at their child's bedside. In future research it would be of interest to observe both formal and

informal discussions between parents and caregivers and compare their impact on the decision-making process.

CONCLUSIONS

Most parents in our study took considerable effort to actively participate in the decision-making process, especially when their initial preferences did not correspond with those of the medical team. By contrast, most physicians were focused primarily on carefully informing the parents and not on actively inviting them to share in the decision-making. In most cases parents' intense emotions of anxiety, grief, and distress did not hinder them from asking relevant questions and explaining their considerations and preferences. Physicians made considerable efforts to prevent potential conflicts from escalating. Our study reveals that parents feel the same double duty as physicians, making certain that everything is tried to save their child's life while protecting their child from suffering, without sufficient quality of life. What parents fear most is that their child will suffer in the process of dying.

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REFERENCES

- Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulsy JA. Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. *Crit Care Med*. 2001;29(1):197–201
- Brinchmann BS, Førde R, Nortvedt P. What matters to the parents? A qualitative study of parents' experiences with life-and-death decisions concerning their premature infants. *Nurs Ethics*. 2002;9(4):388–404
- Carnevale FA, Benedetti M, Bonaldi A, Bravi E, Trabucco G, Biban P. Understanding the private worlds of physicians, nurses, and parents: a study of life-sustaining treatment decisions in Italian paediatric critical care. *J Child Health Care*. 2011;15(4):334–349
- Cremer R, Hubert P, Grandbastien B, Moutel G, Leclerc F; GFRUP's study group on forgoing treatments. Prevalence of questioning regarding life-sustaining treatment and time utilisation by forgoing treatment in francophone PICUs. *Intensive Care Med*. 2011;37(10):1648–1655
- Cuttini M, Rebagliato M, Bortoli P, et al. Parental visiting, communication, and participation in ethical decisions: a comparison of neonatal unit policies in Europe. *Arch Dis Child Fetal Neonatal Ed*. 1999;81(2):f84–f91
- Feudtner C, Carroll KW, Hexem KR, Silberman J, Kang TI, Kazak AE. Parental hopeful patterns of thinking, emotions, and pediatric palliative care decision making: a prospective cohort study. *Arch Pediatr Adolesc Med*. 2010;164(9):831–839
- Hexem KR, Mollen CJ, Carroll K, Lanctot DA, Feudtner C. How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times. *J Palliat Med*. 2011;14(1):39–44
- Latour JM, van Goudoever JB, Schuurman BE, et al. A qualitative study exploring the experiences of parents of children admitted to seven Dutch pediatric intensive care units. *Intensive Care Med*. 2011;37(2):319–325
- Meert KL, Thurston CS, Briller SH. The spiritual needs of parents at the time of their child's death in the pediatric intensive care unit and during bereavement: a qualitative study. *Pediatr Crit Care Med*. 2005;6(4):420–427
- Meert KL, Eggly S, Pollack M, et al; National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network. Parents' perspectives on physician–parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatr Crit Care Med*. 2008;9(1):2–7
- 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
- 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
- Pector EA. Views of bereaved multiple-birth parents on life support decisions, the dying process, and discussions surrounding death. *J Perinatol*. 2004;24(1):4–10
- Ranchod TM, Ballot DE, Martinez AM, Cory BJ, Davies VA, Partridge JC. Parental perception of neonatal intensive care in public sector hospitals in South Africa. *S Afr Med J*. 2004;94(11):913–916
- Williams C, Cairnie J, Fines V, et al. Construction of a parent-derived questionnaire to measure end-of-life care after withdrawal of life-sustaining treatment in the neonatal intensive care unit. *Pediatrics*. 2009;123(1). Available at: www.pediatrics.org/cgi/content/full/123/1/e87
- Armentrout D, Cates LA. Informing parents about the actual or impending death of their infant in a newborn intensive care unit. *J Perinat Neonatal Nurs*. 2011;25(3):261–267
- Bartel DA, Engler AJ, Natale JE, Misra V, Lewin AB, Joseph JG. Working with families of suddenly and critically ill children: physician experiences. *Arch Pediatr Adolesc Med*. 2000;154(11):1127–1133
- Burns JP, Rushton CH. End-of-life care in the pediatric intensive care unit: research review and recommendations. *Crit Care Clin*. 2004;20(3):467–485, x
- Garros D, Rosychuk RJ, Cox PN. Circumstances surrounding end of life in a pediatric intensive care unit. *Pediatrics*. 2003;112(5). Available at: www.pediatrics.org/cgi/content/full/112/5/e371
- Jones BL, Contro N, Koch KD. The duty of the physician to care for the family in pediatric palliative care: context, communication, and caring. *Pediatrics*. 2014;133(suppl 1):s8–s15
- Caeymaex L, Jousset C, Vasilescu C, et al. Perceived role in end-of-life decision making in the NICU affects long-term parental grief response. *Arch Dis Child Fetal Neonatal Ed*. 2013;98(1):f26–f31
- 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
- Madrigril VN, Carroll KW, Hexem KR, Faerber JA, Morrison WE, Feudtner C. Parental decision-making preferences in the pediatric intensive care unit. *Crit Care Med*. 2012;40(10):2876–2882
- McHaffie HE, Laing IA, Parker M, McMillan J. Deciding for imperilled newborns: medical authority or parental autonomy? *J Med Ethics*. 2001;27(2):104–109
- 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
- Michelson KN, Koogler T, Sullivan C, Ortega MP, Hall E, Frader J. Parental views on withdrawing life-sustaining therapies in critically ill children. *Arch Pediatr Adolesc Med*. 2009;163(11):986–992
- Orfali K, Gordon EJ. Autonomy gone awry: a cross-cultural study of parents' experiences in neonatal intensive care units. *Theor Med Bioeth*. 2004;25(4):329–365
- 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
- Wocial LD. Life support decisions involving imperiled infants. *J Perinat Neonatal Nurs*. 2000;14(2):73–86
- Wilfond BS. Tracheostomies and assisted ventilation in children with profound disabilities: navigating family and

- professional values. *Pediatrics*. 2014; 133(suppl 1):s44–s49
31. Sullivan J, Monagle P, Gillam L. What parents want from doctors in end-of-life decision-making for children. *Arch Dis Child*. 2014;99(3):216–220
 32. Lewins A, Silver C. *Using Software in Qualitative Research*. London, England: Sage Publications; 2007
 33. Charles C, Gafni A, Whelan T. Decision-making in the physician–patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med*. 1999;49(5):651–661
 34. White DB, Braddock CH III, Berekenyi S, Curtis JR. Toward shared decision making at the end of life in intensive care units: opportunities for improvement. *Arch Intern Med*. 2007;167(5):461–467
 35. Nguyen F, Moumjid N, Charles C, Gafni A, Whelan T, Carrère MO. Treatment decision-making in the medical encounter: comparing the attitudes of French surgeons and their patients in breast cancer care. *Patient Educ Couns*. 2014;94(2):230–237
 36. McHaffie HE, Lyon AJ, Hume R. Deciding on treatment limitation for neonates: the parents' perspective. *Eur J Pediatr*. 2001; 160(6):339–344
 37. Payot A, Gendron S, Lefebvre F, Doucet H. Deciding to resuscitate extremely premature babies: how do parents and neonatologists engage in the decision? *Soc Sci Med*. 2007;64(7):1487–1500
 38. Rapoport A, Shaheed J, Newman C, Rugg M, Steele R. Parental perceptions of forgoing artificial nutrition and hydration during end-of-life care. *Pediatrics*. 2013;131:861–869
 39. Cohen S, Sprung C, Sjøkvist P, et al. Communication of end-of-life decisions in European intensive care units. *Intensive Care Med*. 2005;31(9): 1215–1221
 40. Curtis JR. Communicating about end-of-life care with patients and families in the intensive care unit. *Crit Care Clin*. 2004; 20(3):363–380, viii
 41. Fine E, Reid MC, Shengelia R, Adelman RD. Directly observed patient–physician discussions in palliative and end-of-life care: a systematic review of the literature. *J Palliat Med*. 2010;13(5): 595–603
 42. Levin TT, Moreno B, Silvester W, Kissane DW. End-of-life communication in the intensive care unit. *Gen Hosp Psychiatry*. 2010;32(4):433–442
 43. Lind R, Lorem GF, Nortvedt P, Hevrøy O. Family members' experiences of “wait and see” as a communication strategy in end-of-life decisions. *Intensive Care Med*. 2011;37(7):1143–1150
 44. Uy J, White DB, Mohan D, Arnold RM, Barnato AE. Physicians' decision-making roles for an acutely unstable critically and terminally ill patient. *Crit Care Med*. 2013;41(6):1511–1517
 45. From Law to Practice. Implementation of the WGB0 [in Dutch]. Utrecht, The Netherlands: Koninklijke Nederlandsche Maatschappij ter bevordering der Geneeskunst (KNMG); 2004
 46. de Vos MA, van der Heide A, Maurice-Stam H, et al. The process of end-of-life decision-making in pediatrics: a national survey in the Netherlands. *Pediatrics*. 2011;127(4). Available at: www.pediatrics.org/cgi/content/full/127/4/e1004
 47. Verhagen AA, de Vos MA, Dorscheidt JH, Engels B, Hubben JH, Sauer PJ. Conflicts about end-of-life decisions in NICUs in the Netherlands. *Pediatrics*. 2009;124(1). Available at: www.pediatrics.org/cgi/content/full/124/1/e112
 48. Luce JM. A history of resolving conflicts over end-of-life care in intensive care units in the United States. *Crit Care Med*. 2010;38(8):1623–1629
 49. Billings JA. The end-of-life family meeting in intensive care part II: Family-centered decision making. *J Palliat Med*. 2011; 14(9):1051–1057
 50. Pantilat SZ. Communicating with seriously ill patients: better words to say. *JAMA*. 2009;301(12):1279–1281
 51. Tan A, Manca D. Finding common ground to achieve a “good death”: family physicians working with substitute decision-makers of dying patients. A qualitative grounded theory study. *BMC Fam Pract*. 2013;14:14
 52. Eggly S, Penner LA, Greene M, Harper FW, Ruckdeschel JC, Albrecht TL. Information seeking during “bad news” oncology interactions: question asking by patients and their companions. *Soc Sci Med*. 2006;63(11):2974–2985
 53. Siminoff LA, Ravdin P, Colabianchi N, Sturm CM. Doctor–patient communication patterns in breast cancer adjuvant therapy discussions. *Health Expect*. 2000;3(1):26–36

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