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Communicating with families of critically ill patients about continuing or discontinuing life-sustaining treatment

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How doctors manage conflicts with families of critically ill patients during conversations about end-of-life decisions in neonatal, pediatric, and adult intensive care

Abstract

Purpose

Intensive care is a stressful environment in which team-family conflicts commonly occur. If managed poorly, conflicts can have negative effects on all parties involved. Previous studies mainly investigated these conflicts and their management in a retrospective way. This study aimed to prospectively explore team-family conflicts, including its main topics, complicating factors, doctors' conflict management strategies, and the effect of these strategies.

Methods

Conversations between doctors in the neonatal, pediatric, and adult intensive care unit of a large university-based hospital and families of critically ill patients were audio-recorded from the moment doubts arose whether treatment was still in patients' best interest. Transcripts were coded and analyzed using a qualitative deductive approach.

Take-home message

Four factors appear to complicate the management of frequently occurring team-family conflicts in neonatal, pediatric, and adult intensive care: diagnostic and prognostic uncertainty, families' strong negative emotions, families' limited health literacy, and families' burden of responsibility. While doctors mainly use content-oriented strategies to resolve these conflicts, empathic strategies appear to be more effective, especially if conflicts linger on.

Results

Team-family conflicts occurred in 29 out of 101 conversations (29%) concerning 20 out of 36 patients (56%). Conflicts mostly concerned more than one topic. We identified four complicating context- and/or family-related factors: diagnostic and prognostic uncertainty, families' strong negative emotions, limited health literacy, and burden of responsibility. Doctors used four overarching strategies to manage conflicts, namely content-oriented, process-oriented, moral and empathic strategies. Doctors mostly used content-oriented strategies, independent of the intensive care setting. They were able to effectively address conflicts in most conversations. Yet, if they did not acknowledge families' cues indicating the existence of one or more complicating factors, conflicts were likely to linger on during the conversation.

Conclusion

This study underlines the importance of doctors tailoring their communication strategies to the concrete conflict topic(s) and to the context- and family-related factors which complicate a specific conflict.

Keywords

Intensive care, Communication, Patient representatives, Conflict resolution, Clinical decision-making, Qualitative research

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Introduction

In intensive care (IC), patients are often unable to participate in decisions regarding their life-sustaining treatment (LST). Consequently, patients' families function as their surrogate decision-makers [1]. Conflicts, such as disagreements, disputes or differences of opinion between doctors and families commonly occur in this setting [2-7]. Accordingly, conflict mediation has been identified as an essential competency needed by IC-doctors to provide high-quality care to patients and their families [2, 8-10].

Team-family conflicts seem to be reinforced by factors that are inextricably linked with the IC setting: the life-threatening situation of patients, the ensuing emotions of families, and the difficult decisions regarding (dis)continuation of LST. The lack of a longer lasting relationship between doctors and families and the constant stress families have to endure further increase the risk that conflicts will arise [11]. The incidence of team-family conflicts seems to differ per IC setting. Healthcare professionals reported conflicts in up to 48% and 31% of patients, respectively in adult intensive care units (ICU) and pediatric intensive care units (PICU) [3-5, 7, 12]. By contrast, conflicts have been reported in 12% of patients in neonatal intensive care units (NICU) [6]. However, these percentages may well be an underestimation, as healthcare professionals seem less likely to identify conflicts in comparison to families of critically ill patients [5]. Team-family conflicts mainly concern the following topics: disagreement about the treatment, discordant ideas on what is best for the patient, poor communication, inappropriate doctor or family behavior, and the unavailability of legal surrogate decision-makers [3, 4, 7, 12]. If conflicts remain unresolved, they may incite feelings of regret, distress, and distrust in families and reduce families' satisfaction with the provided care [3, 13, 14]. Likewise, unresolved conflicts have been shown to contribute to feelings of anxiety and moral distress, as well as the risk of burnout in healthcare providers [13, 15-17]. It is therefore important to identify effective ways to manage team-family conflicts in the NICU, PICU, and ICU. Several studies have retrospectively investigated conflicts by interviewing healthcare providers or family-members [3, 7, 12, 16, 18]. Few studies have examined these conflicts in real time [19, 20]. Also, none of these studies compared the NICU, PICU, and ICU.

We qualitatively explored conflicts concerning patients' current or future health or treatment that arose in real-life conversations between doctors and families in three IC settings. We aimed to (1) identify the main topics of team-family conflicts, (2) explore the factors further complicating these conflicts, (3) investigate the strategies doctors use to manage these conflicts, (4) establish which strategies appear to be (in)effective in managing conflicts and (5) explore the possible differences between the three IC settings.

Methods

Design and setting

This qualitative exploratory study was part of a larger research project (FamCom) on communication about end-of-life decisions with families in IC [21]. Data were derived from audio-recordings of family conferences (henceforth: conversations) in the NICU, PICU, and ICU of the Amsterdam University Medical Centre.

Population and sampling

Families of 36 patients and 71 doctors participated. Table 1 lists their characteristics. Maximum variation was sought regarding patients' age, sex, diagnosis, disease progression and course of treatment, and families' ethnic background, level of education, and religious beliefs. 'Families' refers to family members or close friends who attended the conversations.

Recruitment

Prior to data collection, all IC-doctors and IC-nurses received oral and written information about the study and were asked for their consent to participate. All doctors and all but one nurse gave this consent.

Data collection

The inclusion period lasted from April 2018 to December 2019. Families were eligible to participate from the moment that doubts arose whether continuing LST was still in the patient's best interest. The attending doctor or nurse introduced the study to eligible families. Interested families were further informed and asked for their oral and written consent by a member of the research team or the attending doctor. All but one family decided to participate.

Phase 1: Fragment selection

Two researchers (AS, MdV) thoroughly read the transcripts of the 101 audio-recorded conversations and identified all passages in which team-family conflicts occurred. These conflicts concerned patients' current or future health status and/or treatment (plan). In line with the literature, we defined conflicts as disputes, disagreements, differences of opinion, or conflicting points of view between families and doctors [3, 4, 12].

If doubts about the inclusion of transcripts arose, these transcripts were thoroughly discussed with four members of the research team (AS, AA, ES, MdV).

Phase 2: Code book

The preliminary codebook was based on two relevant studies in this field. The first study presented a systematic overview of the main sources of team-family conflicts [3]. The second study presented a systematic overview of doctors' communication strategies in response to conflicting points of view during conversations [19].

Three researchers (AS, ES, MdV) coded ten transcripts during four coding sessions by means of the preliminary codebook. Whenever deemed necessary, codes were added to, removed from, or adapted in the codebook. During this process, codes to describe factors that appeared to complicate conflicts were added to the codebook.

The codebook is available upon request.

Phase 3: Coding

In a second coding round, the main researcher (AS) coded all transcripts that included passages in which team-family conflicts occurred ($n=29$), including those already coded in the first round, thereby using the final codebook while simultaneously listening to the audio recordings.

The other researchers (AA, ES, MdV) randomly reviewed the coding of the new transcripts ($n=19$).

To increase validity and reliability of the coding process, doubts in coding, coding definitions, and procedures were discussed intensively by all researchers (AS, AA, ES, MdV).

Phase 4: Analysis

The coded segments were qualitatively analyzed, discussed, and reflected upon during four rounds to identify conflict topics, complicating factors, and conflict management strategies and to establish the effectiveness of these strategies. To minimize bias, all researchers (AS, AA, ES, MdV) participated in these rounds of analysis.

We considered conflict management strategies to be effective if, after being addressed by doctors, conflicts did not reappear in the remainder of the conversation. Likewise, strategies were considered ineffective if conflicts, after being addressed by doctors, reappeared during the conversation.

During two additional rounds of analysis, the researchers (AS, AA, ES, MdV) extensively discussed all results with the multidisciplinary advisory board (MS, TC, JW, MvH, AvK, MvdL, DW) and made final adjustments.

Figure 1. Four phases of coding and analysis

Setting	Patients (N = 36), n (%)	Family members (N = 104), n (%)	Doctors (N = 71), n (%)
Neonatal intensive care unit	12 (33)	33 (32)	22 (31)
Pediatric intensive care unit	12 (33)	30 (29)	35 (49)
Adult intensive care unit	12 (33)	41 (39)	14 (20)
Age (y)	Patients (N = 36), n (%)	Family members (N = 104), n (%)	Doctors (N = 71), n (%)
Premature	11 (30)		
0–1	6 (16)		
1–4	1 (3)		
4–12	2 (6)		
12–16	2 (6)		
16–21	2 (6)		
21–35	–		
35–50	3 (8)		
50–65	5 (14)		
65+	4 (11)		
Gender	Patients (N = 36), n (%)	Family members (N = 104), n (%)	Doctors (N = 71), n (%)
Male	17 (47)	41 (39)	28 (40)
Female	19 (53)	63 (61)	43 (60)
Main diagnosis	Patients (N = 36), n (%)	Family members (N = 104), n (%)	Doctors (N = 71), n (%)
Prematurity	5 (14)		
Prematurity + congenital disorder + acute illness	1 (3)		
Perinatal asphyxia	4 (11)		
Congenital disorder	13 (36)		
Acute illness	11 (30)		
Cancer + acute illness	2 (6)		
Neurological damage	Patients (N = 36), n (%)	Family members (N = 104), n (%)	Doctors (N = 71), n (%)
Yes	24 (67)		
No	12 (33)		
Total duration of care in the intensive care unit	Patients (N = 36), n (%)	Family members (N = 104), n (%)	Doctors (N = 71), n (%)
0–24 h	5 (14)		
1–7 days	10 (28)		
1–4 week	16 (44)		
1–3 months	5 (14)		

Table 1. Main characteristics of included patients, family members, and doctors

Relation to the patient	Patients (N = 36), n (%)	Family members (N = 104), n (%)	Doctors (N = 71), n (%)
Parent			46 (44)
Grandparent			8 (7)
Partner			7 (7)
Child			9 (9)
Sibling			8 (7)
Brother in law/Sister in law			2 (2)
Aunt/Uncle/Cousin			10 (10)
Friend			4 (4)
Other			5 (5)
Unknown			5 (5)
Medical specialty	Patients (N = 36), n (%)	Family members (N = 104), n (%)	Doctors (N = 71), n (%)
Neonatologist			14 (20)
Pediatric intensivist			9 (13)
Pediatrician			15 (21)
Pediatric neurologist			7 (10)
Pediatric cardiologist			3 (4)
Metabolic pediatrician			2 (3)
Pediatric pulmonologist			1 (1)
Intensivist			9 (13)
Anesthesiologist			4 (6)
Internist-hematologist			1 (1)
Neurosurgeon			3 (4)
Neurologist			1 (1)
Unknown			2 (3)
Role	Patients (N = 36), n (%)	Family members (N = 104), n (%)	Doctors (N = 71), n (%)
Resident			20 (28)
Fellow			13 (18)
Staff			36 (51)
Unknown			2 (3)

Table 1. (Continued)

IC setting	Patient	Conversations		Conversations with team-family conflicts		Number of patients with team-family conflicts	Number of conversations with effectively managed conflicts/ Total number of conversations with conflicts	Final decision	Outcome*
		Per patient (n)	Per setting (n)	Per patient (n)	Per setting (n; %)				
	1	3		0				Withdrawing LST	Died the same day
	2	3		1			0/1	Withholding LST	Died more than a week later
	3	1		1			1/1	Withdrawing LST	Died the same day
	4	3		1			1/1	Withdrawing LST	Died the same day
	5	4		1			1/1	Withdrawing LST	Died within a week
	6	9		5			2/5	Withdrawing LST	Died the same day
	7	3		0				Withdrawing LST	Died the same day
	8	1		0				Withdrawing LST	Died the same day
	9	12		1			1/1	Continuation of LST	Still alive
	10	1		1			1/1	Withdrawing LST	Died the same day
NICU (n=12)	11	9		0				Withdrawing LST	Died the same day
	12	3	52	1	12 (23%)	8 (67%)	1/1	Withdrawing LST	Died the same day
	13	5		2			2/2	Withdrawing LST	Died the same day
	14	6		1			0/1	Withdrawing LST	Died the same day
	15	3		2			2/2	Withholding LST	Died more than a week later
	16	1		0				Withholding LST	Died more than a week later
	17	1		0				Continuation of LST	Still alive
	18	1		0				Continuation of LST	Still alive
	19	1		0				Withdrawing LST	Died the same day
	20	5		3			1/3	Withdrawing LST	Died the same day
	21	2		1			1/1	Withholding LST	Still alive
	22	1		0				Continuation of LST	Still alive
PICU (n=12)	23	3		2			2/2	Withdrawing LST	Died the same day
	24	4	33	0	11 (33%)	6 (50%)		Continuation of LST	Still alive
	25	1		0				Withdrawing LST	Died within a week
	26	2		1			1/1	Withdrawing LST	Died the same day
	27	1		0				Withdrawing LST	Died the same day
	28	3		1			1/1	Withdrawing LST	Died the same day
	29	1		1			1/1	Withholding LST	Died within a week
	30	1		0				Withdrawing LST	Died the same day
	31	1		0				Withdrawing LST	Died the same day
	32	1		0				Continuation of LST	Died the same day
	33	1		0				Withdrawing LST	Died the same day
	34	2		1			0/1	Withdrawing LST	Died the same day
ICU (n=12)	35	1		1			1/1	Withdrawing LST	Died within a week
	36	1	16	1	6 (38%)	6 (50%)	1/1	Withdrawing LST	Died within a week
Total	36	101		29 (29%)		20 (56%)			

*Measured when the data inclusion ended.

Table 2. The total number of families and conversations and the number of families and conversations in which team-family conflicts occurred per intensive care setting

Results

The conversations were almost always planned before-hand on initiative of the doctor and almost never on request of families. Only incidentally conversations took place because patients' situation acutely deteriorated. From the moment of inclusion, all conversations were audio-recorded by the attending doctor until a final decision was made. All conversations took place seated around a table in one of the conference rooms on the unit. At least one nurse was present during most of the conversations. However, due to nurses' minimal (verbal) engagement in these conversations, this study focuses solely on the communication between doctors and families.

Data analysis

The audio-recordings were transcribed verbatim and anonymized. We then coded and analyzed our data, thereby using a deductive approach. This process consisted of four phases, as illustrated in Figure 1. Coding and analysis of the transcripts were performed with Max-QDA 2020.

Ethical considerations

The Amsterdam UMC institutional review board waived approval of this study (W17_475 # 17.548). Informed consent was acquired from one representative on behalf of the whole family. Consent could be withdrawn at any time.

Conflict topics	NICU (n=12)	PICU (n=11)	ICU (n=6)	Total*
Treatment decisions	10	9	4	23
Timing	1	2	2	5
Patient's current health status	4	4	2	10
Patient's future health status	8	1	1	10
Decision-making responsibility	4	0	1	5
(Presumed) wishes of the patient	0	0	2	2

NICU neonatal intensive care unit, PICU pediatric intensive care unit, ICU adult intensive care unit.

*One conflict could be related to multiple topics.

Table 3. Number of conversations in which one or more conflict topics were identified per intensive care setting

Team-family conflicts occurred in 29 out of 101 conversations (29%), concerning 20 out of 36 patients (56%). Table 2 provides additional details.

Conflicts evolved around one or more of the following topics: (1) treatment decisions, (2) timing of the decisions and/or decision-making conversations, (3) patients' current health status, (4) patients' future health status, (5) decision-making responsibility, and (6) patients' (presumed) wishes. Table 3 and Supplementary table A provide additional details. Most conflicts concerned a combination of these topics. In the NICU, conflicts about treatment decisions often co-occurred with conflicts about future health status, particularly future quality of life. In the PICU, conflicts about treatment decisions often co-occurred with conflicts about current health status or the timing of decisions. In the ICU, conflicts regarding treatment decisions often co-occurred with conflicts about the timing of the decision or the patient's (presumed) treatment wishes.

Complicating factors

We identified four factors, either context- or family-related, that complicated and deepened conflicts that arose during conversations. First, uncertainty regarding patients' diagnosis or prognosis appeared to reinforce conflicts. We noticed that when high levels of uncertainty were present, families appeared to be reluctant to follow or accept decisions proposed by the doctors.

Second, conflicts appeared to intensify if families became highly emotional. This always concerned the expression of negative emotions like fear, guilt, anger, distrust, or hostility. These emotions were expressed explicitly or implicitly, for example, by a changed tone of voice or snorting. Often it remained unclear whether conflicts triggered these emotions or vice versa.

Third, limited health literacy of families added to the complexity of conflicts. We observed that several families had a hard time understanding medical information provided by doctors, as became clear from their inability to summarize or to answer questions regarding this information. We noticed that in several conversations families' misinterpretation of information coincided with their disagreement with the proposed treatment decision.

Type of strategy ^a	Definition	Illustrative quote
Content-oriented strategies		
Arguing ^b	Arguing for or against, (dis)agreeing with or defending, a specific course of treatment or treatment decisions	Doctor: When you see that the colostomy starts to work [...] Erm, and the belly gets flatter. And you see it is all getting better. Then that's a good moment. We know from various studies and from our experience, that is the right moment to start feeding again. (NICU) Doctor: If we don't look at the acute problems, but at the long-term problems, your son not being able to live a healthy happy life, then we think it would be best for him to stop treatment. (NICU)
Acknowledging ^b	Explicitly recognizing the existence of conflicting views or recognizing someone else's opposing view on the course of treatment	Doctor: Yes, that's the hard part for us. I think – that's, I think we feel differently about this. We don't think he's doing that well now. (NICU) Doctor: But – but (.) the thing is we could differ about what we feel is best. (NICU)
Clarifying ^b	Providing factual information, illuminating one's views without being judgmental, segmenting information	Doctor: Sometimes you see this in patients with a serious neurological issue. That they squeeze their eyes as a kind of reflex. But we don't really count squeezing as real interaction. (ICU)
Recalibrating ^b	Reframing so that two sides of contradictions no longer seem oppositional	Doctor: What is really our goal here? That's of course what we've been talking about, right? Our goal, of course, is to get X seizure free or at least reasonably free. (PICU)
Reaffirming ^b	Recognizing that both sides of a contradiction have value and that contradictions are ongoing and are not likely to go away	Doctor: [...] Erm, and I don't want to give you a bad, erm, bad news, but I also want to be honest and tell you that we're having concerns. (NICU) Doctor: [...] And I agree with you, I can never say we are 100% certain, because I cannot look into a crystal ball. But our concerns are so serious that we wonder whether the treatment we are now giving in the ICU is in the best interest of X. (NICU)
Reformulating	Repeating or rephrasing what the medical team or the family previously said	Doctor: It's good that you tell us 'Okay, but you were wrong before'. Right. Let's put it like this: 'Why not this time?' Because that's actually what you're saying, isn't it? (PICU) Doctor: It's what I said before. That we consider doing an MRI. And I think... we think it could help us in making the right decision. (PICU)
Requesting more information	Posing an open question in order to identify the specific content of a conflict	Doctor: When we say: 'He has a disability, or he is disabled'. What are your thoughts about this message? What do you imagine? (NICU)
Checking in	Posing a question in order to check whether the family has correctly understood the provided information or has any more questions	Doctor: Following our yesterday's conversation, are there things I have told you that are still unclear to you? (NICU) Doctor: [...] Is that right? (NICU)
Empathic strategies		
Acknowledging emotions	Acknowledging families' emotions and emotionally straining situations	Doctor: Because this really is an impossible situation for you. (NICU) Doctor: You know, it feels so different for a parent to stop feeding; because it's such a basic thing to feed a child, right? (PICU)
Encouraging	Encouraging families to share their views and emotions	Doctor: You can tell me anything, you know. (NICU)
Supporting	Providing families with emotional support	Doctor: There's no question, you know, about you having a part in her life and that, you know, you know what's best for her, so let's be clear about that. (ICU)
Moral strategies		
Making a moral appeal	Putting forward (argumentative) moral statements	Doctor: We shouldn't do that to him. (NICU) Doctor: We are wondering if we'd – the treatment [...] is in the best interest of X. (NICU)

^aDoctors who employed these strategies did not necessarily do so in a premeditated matter, but most likely did this rather intuitively.

^bThese strategies were part of the preliminary codebook, based on Hsieh, Shannon, and Curtis' (2006) findings [19].

Table 4. Overview of the (sub)strategies doctors used to manage a conflict

Type of strategy ^a	Definition	Illustrative quote
Process-oriented strategies		
Postponing	Postponing the conversation and/or the decision	Doctor: [...] Erm.. I'd like to suggest (.) that we try to buy a little more time. To keep in touch, and to give you some time to process what I've told you just now. And to gain a little more clarity about this. But mostly for you, if I understand you correctly. (NICU)
Recentring ^b	Moving away from the contradiction and directing the conversation to another topic	Doctor: But before we get to THAT stage, I think we first need to conclude that we're that far. And if I understand you correctly from what you're telling me now, we're not yet there at all. (NICU)
Giving in	Coming to a compromise or complying with an oppositional view	Doctor: Yeah, that's good, that's good. Let's incorporate your standpoint in our discussion as doctors. And it's a very clear point of view from you both, I think. And we have two things that potentially may change our plans. If not, it's also okay to say no. (PICU)
Offering secondary resources	Offering special support or a second opinion	Doctor: Have you – have you ever felt it yourself? The – the blowing of the ventilator, it's not as uncomfortable as you think it is. [...] It's a good idea to see how it feels yourself. (PICU)
Requesting cooperation	Requesting the family to participate in the conversation	Doctor: Could you – Can you look at me for once? (NICU)
Avoiding ^b	Not directly responding	Mother: Rather be selfish and have the good Lord do it than that I do it myself and carry the guilt for the rest of my life. That I took my child's life. Something I never wanted to do. Doctor: Ah, like that, I see. (NICU)

Table 4. (Continued)

Fourth, families' burden of responsibility added another layer of complexity. Families occasionally provided cues, both implicit and explicit, that they felt disproportionately responsible for the treatment decisions that were made. For example, in one case in which a mother disagreed with the doctor's proposal to withdraw LST, this conflict was deepened by her explicit assumption to be solely and ultimately responsible for the decision to let her child pass away. In another case, a mother underlined that she felt highly burdened by her feelings of responsibility. At a later point in the conversation, she added that she could not agree with the decision to withdraw her child's LST because of her religious convictions. This was the only conversation in which religious convictions played a role in the arising and deepening of a conflict.

Complicating factors often co-occurred. For example, diagnostic or prognostic uncertainty seemed to reinforce the burden of responsibility that families experienced. Additionally, families' burden of responsibility often co-occurred with strong expressions of doubt and guilt. Families' limited health literacy was often accompanied by expressions of anger and frustration.

Doctors' conflict management practices

We identified four overarching strategies that doctors used to manage conflicts: content-oriented, empathic, moral, and process-oriented strategies. Table 4 provides an overview of these strategies, their sub-strategies, and illustrative quotes. To manage conflicts, doctors predominantly used content-oriented strategies, i.e. strategies focusing on the provision of or a request for information. These strategies specifically concerned extensive clarifying and explaining. Doctors used empathic strategies to a lesser extent. Moral and process-oriented strategies were least often used.

In contrast to the ICU, doctors in the NICU and PICU more often used empathic strategies. Yet, in most instances, short empathic responses were followed by lengthy explanations and clarifications.

Moral strategies were evenly applied in the three IC settings. Interestingly, doctors never directly inquired about families' moral values, but solely introduced their own moral standpoints. Moral strategies often co-occurred with the content-oriented sub-strategy arguing.

In all units, doctors occasionally used process-oriented strategies, especially postponement, often combined with a content-oriented or empathic strategy. For instance, one doctor proposed to postpone the decision, clarified that this was done to give the family more time, and then acknowledged how hard the situation had to be for the family.

Effective management of conflicts

Content-oriented strategies appeared to be effective in managing conflicts regarding one topic. If this was the case, doctors could easily identify and address disagreements on a rational level. In more complicated conflicts, an effective approach consisted of the acknowledgment of the complicating factor(s) in an empathic and understanding way. For example, if prognostic uncertainty played a prominent role, acknowledgment of this uncertainty and the resultant burden on families appeared to nip conflicts in the bud. In conversations in which families became increasingly emotional, it proved to be effective if doctors not only uttered an empathic remark, but also took the time to explore what families were going through and how this made them feel. In this way, doctors constructed a common ground for a content-oriented follow-up. In this follow-up, doctors not only gave additional information, but also verified families' viewpoints by asking them to expand on them. However, doctors only occasionally applied this combination of empathic and content-oriented strategies. If doctors explicated their own viewpoints, which rarely occurred, this appeared to open up a dialogue about the viewpoints and emotions of both doctors and families. This often appeared to create a common ground with families, which resulted in the resolution of conflicts. When doctors, despite the use of empathic strategies, were unable to create this common ground and the conversation threatened to end in an impasse, it often proved helpful to postpone the decision and transfer this topic to the next conversation.

Ineffective management of conflicts

In a minority of conversations, doctors' strategies appeared to be ineffective as indicated by the fact that conflicts kept reappearing throughout the conversation. These lingering conflicts predominantly occurred in the NICU and PICU as opposed to the ICU.

We identified two distinct patterns, both resulting in the perseverance of conflicts. In the first pattern, doctors did not acknowledge and respond to families' cues indicating the presence of one or more complicating factors. For instance, several families clearly hinted that they felt burdened by the prevailing diagnostic or prognostic uncertainties and/or by their responsibility for the outcome of the decision to discontinue LST. Instead of acknowledging and addressing this dual burden, most doctors kept using content-oriented strategies, especially extensive and repeated explanations. By effect, conflicts persevered and even deepened.

In the second pattern, doctors first employed content-oriented strategies after conflicts arose and then, when conflicts lingered on, switched to a moral strategy. To illustrate, in several conversations doctors stated that they would not resuscitate the patient if his or her heart would suddenly stop, because "this was not what good healthcare providers should do". This appeared to fuel the disagreements and transform them into full-blown conflicts. In another conversation, after a doctor had stressed that withdrawing LST was "what must be done in the child's best interest", the mother kept repeating, more and more desperately, that she would not allow him to kill her child.

Discussion

In this study, we found that team-family conflicts regularly – and evenly – occurred in the NICU, PICU, and ICU. Four specific factors, namely diagnostic and prognostic uncertainty, families' strong negative emotions, limited health literacy, and burden of responsibility, appeared to complicate and deepen conflicts. Most conflicts were effectively dealt with by means of content-oriented strategies on the condition that the conflict was unambiguous and uncomplicated. In the presence of one or more complicating factors, empathic and process-oriented strategies proved to be more effective. By contrast, doctors' moral strategies seemed to add to a further escalation of conflicts.

Our incidence rates of team-family conflicts in the ICU and PICU are in line with the rates reported in former studies [3-5, 7]. In the NICU, we found an even higher rate of conflicts than previously reported [6]. Conflicts may add to a careful decision-making process and to the quality of the ultimate decision [22, 23]. Yet, if this discussion is not well managed and it does not result in a decision that is agreed upon by all parties involved, disagreements may become full-blown conflicts. Such conflicts may well cause feelings of anxiety, anger, and moral distress in families as well as in healthcare providers [13, 16, 17, 24].

A striking finding in our study is that doctors generally kept explaining and clarifying their points of view without inviting families to ask questions or share their thoughts. This disproportionate explaining and clarifying appeared to silence families, which may heighten the risk that conflicts remain under the surface.

Empathic strategies, especially acknowledging emotions, seemed effective to prevent conflicts from escalating. It appeared to create a safe environment for families to share their emotions, expectations, wishes, and beliefs. Previous studies have also stressed the importance of empathic approaches in resolving conflicts and addressing uncertainties [25-29]. Although nurses in our study did hardly participate in the recorded conversations, we cannot rule out that they contributed to conflict resolution in other ways, for example by further exploring families' viewpoints or emotionally supporting families during informal bedside conversations. This is an interesting topic to explore in future observational studies [30, 31].

In line with previous research, postponing appeared to be a last resort if other strategies to manage a conflict had failed [6, 32-35]. This was especially the case in conversations in which diagnostic or prognostic uncertainty played a prominent role, as was most common in the NICU and PICU. Postponement will give families more time to reflect on all information provided to them and to come to terms with the unthinkable outcome that the patient will not survive [11, 26, 32, 36]. Moreover, it gives more time to do additional tests and carefully observe the patient's situation, thereby getting more certainties [4, 6, 37].

Doctors in our study seldom introduced moral appeals to manage conflicts. Yet, if they did, this often led to an escalation or resulted in a 'deadlock'. It may well be that families feel overruled and less able to advocate for their dear one when confronted with strong moral statements by the medical team. This feeling of powerlessness might be further strengthened by doctors' appeal to authority and the power imbalance between doctors and families [38-40].

Dutch guidelines regarding end-of-life decision-making in the NICU, PICU, and ICU advise doctors to timely discuss with families which role they wish to have in the decision-making process [41, 42]. Doctors who participated in our study did not apply this practice [21]. Yet, we observed that several families felt highly burdened by the idea that they bore final responsibility and that this deepened the conflict. It could be hypothesized that if doctors clearly, timely, and empathically discuss with families to what extent they can and wish to participate in the decision-making process, this may prevent conflicts from escalating and even from arising.

We found that lingering conflicts appeared more frequently in conversations in the NICU and the PICU than in the ICU. This may be explained by the specific nature of the parent-child relationship and – consequently – parents' highly felt responsibility for their child's well-being. Previous studies have shown that although many parents were convinced that they should bear the final responsibility for end-of-life decisions, they felt highly burdened by this responsibility at the same time [43-45]. The higher frequency of conflicts in the NICU and PICU may also be explained by the fact that prognoses tend to be more uncertain in critically ill babies and children than in adult patients. This increases the possibility that a

child will survive against all odds. This may further increase parents' sense of responsibility for whatever decision is made. In sum, doctors need to be attentive to the role of uncertainty and the burden of responsibility in the NICU and PICU. Our results underline that families with limited health literacy are extra prone for the arising and deepening of conflicts. There is growing evidence that limited health literacy and low socio-economic status negatively affect patients' active participation in medical decision-making [46, 47]. It has also been shown that doctors primarily use instrumental instead of empathic communication with this group of patients [48]. In our study, we observed the same tendency. Although previous studies suggest that religious convictions play a prominent role in team-family conflicts, this was apparent in only one emerging conflict in our study [3, 6, 23, 35-37]. This discrepancy raises the question whether doctors in retrospect overestimate the role of religion in the conflicts they experience. Yet, our result may also be due to selection bias despite our effort to include a wide variety of families, including their religious beliefs. A second limitation of our study is that we used audio-recorded conversations to minimize the intrusiveness of the data-collection. We were therefore unable to investigate the non-verbal communication between families and doctors. Third, this study only explores the practices in one NICU, one PICU, and one ICU within one medical center. Fourth, our analysis may be colored by personal interpretations. For this reason, we discussed the emerging patterns with our group of main researchers and with our advisory board in multiple rounds. Fifth, we did not ask families and doctors how they experienced the (management of) conflicts that arose. It would be interesting to further investigate whether families, doctors, and nurses experience the conflict management strategies we identified in our study to be helpful, both in the short and longer term. The main strength of our study is that we audio-recorded and meticulously analyzed real-life conversations. Furthermore, we collected a large dataset of 101 transcripts, thereby pushing for maximum variation. When conflicts arise, doctors' awareness of the topics these conflicts really concern and of the factors which complicate them are key [9, 49]. The use of empathic strategies deserves special attention, as our study and previous research indicate that these are most effective in resolving complicated conflicts and may even prevent them from arising [50-52].

Supplementary figures

Conflict topics

1. Treatment decisions

Difference of opinion concerning continuing or discontinuing treatment*

Contradictory views on what is best for the patient

Contradictory subjective experience of discontinuing LST

2. Timing

The timing of family conferences to discuss medical decisions

The timing of discontinuing LST

3. Current health status

Level of uncertainty surrounding diagnosis

Opposing observations regarding severity or progress of the underlying disease

The need to perform diagnostic tests

Disagreement on the current quality of life of the patient

Explicit disagreement regarding the quality of care

4. Future health status

Disagreement about the certainty of the prognosis

Disagreement on (the severity of) the prognosis

Contradictory views on the family's presence during the process of dying

5. Decision-making responsibility

Difference of opinion about the extent to which patients' families have decision-making responsibility

Contradictory views on the role of family members in the absence of patients' legal representatives*

6. Patient's (presumed) wishes

Difference of opinion concerning the level of mental (in)competence of the patient*

The validity of known wishes/written will and to what extent these wishes have to be taken into consideration*

*These conflict topics were part of the preliminary codebook, based on Studdert et al.'s (2003) findings [3].

Examples

Partner:	His body can't take the chemo anymore, nor can his mind.
Doctor:	And what we decided today with professor X from the haematology department is to still give him chemo again, as part of our treatment plan. (ICU)
Doctor:	But if I understand you correctly, right, you say you're not a doctor, but you- you ask me to continue to do my best. [...] But- but the thing is: we could feel differently about what is best. (NICU)
Mother:	Because it feels the same to me when you don't feed her anymore, the same as putting your hand over her mouth.
Doctor:	Yes, it's very different for a parent. (PICU)
Mother:	If you're hinting on Wednesday being the day that we need to make a decision, a big decision, that makes us very uncomfortable. (PICU)
Family (friend):	Let's wait two or three more days before stopping his treatment.
Doctor:	Well, two or three days is not, erm, I don't think we can defend that towards him. (PICU)
Mother:	Every child develops differently. One child needs more time than the other. Well, you know? So, I'm like: 'let's not immediately call it...' Children vary, so well, you know, she's still got time. (NICU)
Doctor:	But the next problem is that his epilepsy is really, well, almost back at the old level.
Mother:	I don't really agree with that right now. From what I see. (PICU)
Father:	And the [MRI] result is not going to tell us anything new. It's just... Nothing new will come out of it. Whether it's good, whether it's bad. And for that reason, I am not in favor of doing an MRI. (PICU)
Mother:	Because he is suffering? But he is still doing so well.
Doctor:	Well, that's what's hard to tell, I think. That's where we see things differently. We don't think he's doing so well right now. (NICU)
Mother:	Can he be transferred to another hospital? I think you're being negligent. (NICU)
Doctor:	And you mean, erm, if I understand you correctly, you think that I was vague yesterday about what you can expect for the future.
Mother:	Yes, so it's not sure yet. And anything that's not certain gives me hope that something can still turn out okay. For her future. (NICU)
Doctor:	It makes us very worried about his future.
Mother:	He can go to a special needs school, you know. So that's not-
Doctor:	Hm. That's a bit of a tricky thing as far as we're concerned. Because we do not know if that will be possible. (NICU)
Doctor:	If I understand you right, you're saying that both of you do not want to be present if she dies. To be honest with you, I find this a bit hard. Because I think that, erm, the best thing we can offer her now is, you know, to die in a peaceful way and there's no one that can support her better than the people that love her most, her parents. (NICU)
Doctor:	There will have to be another conversation about who is responsible for what. If not with me than with the surgeons who will have to do this operation. (NICU)
Family (friend):	Yes, and that's why we're here to speak on her behalf.
Doctor:	No, I get that.
Family (friend):	Because we know best how she feels about this. (ICU)
Family (friend 1):	Yes. Well, you know, she recognized me, so the first thing I asked was: 'X, do you want this?' 'No', she said right away, 'no'.
Family (friend 2):	She said it multiple times this week [...]
Family (friend 1):	I don't want this.
Doctor:	Right, well, the thing is that she, as long as she is in our care, she always said: 'But I still want to live and I want to be treated fully'. (ICU)
Family (friend 1):	[...] She did say that she talked about it with the GP and I thought that that was enough. But now it turns out that it's not. But I'm happy we found this. She did write this down, so now you know (sobbing).
Doctor:	You know, this is an indication. It is good that you found it. But as I already discussed with you on the phone yesterday, it is not legally valid. (ICU)

Supplementary table A. Overview of the conflict topics and subtopics

References

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Author contributions

ASS, AA, and MAV had full access to the data and bear final responsibility for the integrity of the data and the accuracy of the data analysis. ASS, AA, EMAS, MJS, TGVC, JBMW, MH, AHK, ML, DLW, and MAV contributed to the concept and design of the study and critically reviewed and revised the manuscript for important intellectual content. ASS, AA, EMAS, MJS, TGVC, MH, AHK, ML, DLW, and MAV contributed substantially to the data analysis and interpretation. The first draft of the manuscript was written by AS and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data management and sharing

Data are available upon request.

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