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Diversity of Parent Emotions and Physician Responses During End-of-Life Conversations

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abstract

BACKGROUND AND OBJECTIVES: To provide support to parents of critically ill children, it is important that physicians adequately respond to parents' emotions. In this study, we investigated emotions expressed by parents, physicians' responses to these expressions, and parents' emotions after the physicians' responses in conversations in which crucial decisions regarding the child's life-sustaining treatment had to be made.

METHODS: Forty-nine audio-recorded conversations between parents of 12 critically ill children and physicians working in the neonatal and pediatric intensive care units of 3 Dutch university medical centers were coded and analyzed by using a qualitative inductive approach.

RESULTS: Forty-six physicians and 22 parents of 12 children participated. In all 49 conversations, parents expressed a broad range of emotions, often intertwining, including anxiety, anger, devotion, grief, relief, hope, and guilt. Both implicit and explicit expressions of anxiety were prevalent. Physicians predominantly responded to parental emotions with cognition-oriented approaches, thereby limiting opportunities for parents. This appeared to intensify parents' expressions of anger and protectiveness, although their anxiety remained under the surface. In response to more tangible emotional expressions, for instance, grief when the child's death was imminent, physicians provided parents helpful support in both affect- and cognition-oriented ways.

CONCLUSIONS: Our findings illustrate the diversity of emotions expressed by parents during end-of-life conversations. Moreover, they offer insight into the more and less helpful ways in which physicians may respond to these emotions. More training is needed to help physicians in recognizing parents' emotions, particularly implicit expressions of anxiety, and to choose helpful combinations of responses.

WHAT'S KNOWN ON THIS SUBJECT: Physicians often miss opportunities to respond adequately to parents' emotions. Inadequate responses appear to negatively affect the decision-making process and parents' coping in the short and longer term. Recognizing and addressing these emotions is pivotal yet challenging for physicians.

WHAT THIS STUDY ADDS: This explorative study reveals that parents (implicitly) expressed intertwining emotions during crucial conversations, including anxiety, anger, devotion, grief, relief, hope, and guilt. Physicians' cognition-oriented responses limited opportunities for parents. Insights may help physicians to respond adequately to parents' emotions.

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Ms Prins conceptualized and designed the study, collected, analyzed, and interpreted the data, and drafted and finalized the initial manuscript and figures; Dr Linn conceptualized and designed the study, analyzed and interpreted the data, and drafted the initial manuscript; Ms Akkermans collected data and conceptualized and designed the study; Drs van Kaam, van de Loo, van Woensel, van Heerde, Dijk, Kneyber, de Hoog, Simons, and Smets conceptualized and designed the study; (Continued)

Dr de Vos collected, coordinated, and supervised data collection, conceptualized and designed the study, analyzed and interpreted the data, and drafted the initial manuscript; and all authors

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The admission of a child to the NICU or PICU is an emotional and stressful experience for parents.[1–5] The authors of previous studies use terms, such as "rollercoaster of emotions"[1] or "storm of emotions,"[4] implying that parents' experiences are not only intense and ambivalent but may also vary over time.[1,6,7] Such emotions may become even more intense if doubts arise about whether life-sustaining treatment (LST) is still in the child's best interest.

Despite its intensity, neither patients nor family members typically express their emotions in an explicit way during conversations with health care providers (HCPs).[8–14] Their indirect hints are not always detectable for HCPs, who often fail to observe these emotions and subsequently address them.[14–17] Previous studies reveal that if HCPs respond adequately to parents' emotions, it offers parents the opportunity to verbalize their emotions and share valuable information.[18] This facilitates trustful relationships and shared decision-making.[19–23] HCPs often take on the role of advising and providing information when responding to emotions.[15,16,24,25] In turn, this results in limited explorations and in reduced opportunities for parents to elaborate on their emotions.[10,14–16,24] Despite the benefits of adequately responding to parents' emotions, HCPs are not routinely trained in how to recognize and respond to these emotions.[26–28]

Obtaining evidence of parents' actual emotional expressions and HCPs' direct responses is the first step to better knowing how to adequately respond to these emotions. The authors of most studies used retrospective (self-report) questionnaires and interviews.[25–27] These methods provide useful insights into parents' emotional experiences but are prone to recall bias, selection bias, and increased social desirability.[29] Thus, additional prospective observational studies are needed to examine how parents express their emotions in real-life conversations in the NICU and PICU.

By qualitatively analyzing audio-recorded conversations between parents and HCPs, we aim to (1) investigate which emotions parents express verbally and in nonverbal vocalizations during conversations in the NICU or PICU about the (dis)continuation of their child's LST, and how parents express these emotions, (2) explore how HCPs respond to these emotions, and (3) examine which emotions parents express throughout such conversations after HCPs' responses.

METHOD

Procedure and Participants

This study was part of a larger research project examining end-of-life communication with families in ICUs (FamICom).[30–33] Before data collection, all physicians and nurses from the participating medical centers received oral and written project information. All but 1 NICU nurse gave their consent to participate. The inclusion period lasted from April 2018 to December 2019. For the current study, we analyzed the audio recordings of 49 conversations between physicians, nurses, and parents of children admitted to the NICUs and PICUs of 3 Dutch university medical centers, using a qualitative inductive approach.[34] Data were coded and analyzed with the qualitative software tool MAXQDA 2020,[35,36] and the Standards for Reporting Qualitative Research were followed.[37]

The physician in charge informed the researchers when during the child's care doubts had arisen within the medical team or by the parents whether continuing LST was still in the child's best interest. From that moment on, parents were eligible to participate. A member of the research team or the attending physician then approached eligible parents to provide more information about the project and to ask whether they wished to participate. Parents could withdraw their consent to participate at any moment. All parents who were approached wished to participate, except for 1 family. From the moment of inclusion, audio recordings were made of all physician-parent conversations until a final decision was reached to either continue or discontinue LST. One university's institutional review board approved the study protocol on behalf of all centers (W17_475 #17.548).

Sampling

The dataset of the FamICom-project consisted of audio recordings of HCP-parent conversations concerning 36 children (NICU [$n = 19$], PICU [$n = 17$]). Purposive sampling was used to strive for maximum variation regarding the children's age, diagnosis, disease progression, and course of treatment, and to parents' ethnicity, level of education, and religion.

Coding and Analysis

Audio recordings were transcribed verbatim, including nonverbal vocalizations (eg, crying, sobbing) and verbal expressions. Anonymized transcripts were inductively coded and analyzed until saturation was reached.[38] Details of the steps of coding and analysis are provided in Supplemental Fig 2.

A researcher with experience in health communication and qualitative research methods (SP), a researcher in the field of health communication and patient-provider interactions (AJL), and a behavioral scientist, ethics consultant, and researcher who is an expert in the field of family-centered care, end-of-life conversations, and qualitative research methods (MAdV) carefully read and reread the transcripts, while simultaneously listening to the audio recordings.[39] The 3 researchers decided to code inductively because previously described lists and codebooks did not fully capture the range of emotions

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and responses in the current study.[39–42] Because nurses rarely spoke in the audio-recorded conversations, the researchers solely focused on physician-parent interaction. The researchers coded which emotions parents expressed in each turn of talking and physicians' direct responses to these expressions. The researchers also coded whether parents explicitly or implicitly expressed their emotions. In accordance with definitions in the literature, the researchers identified emotional expressions to be explicit if they directly referred to an emotional state (eg, "I am angry"). The researchers identified emotional expressions to be implicit if they indirectly referred to an underlying emotion (eg, "Come on, that's why you are a physician, right?").[43,44]

Parents could express multiple types of emotions in 1 single turn of talking. Similarly, physicians could use a combination of responses to these various emotions. The researchers, therefore, coded all expressed emotions and all physician responses to these emotions. As such, the total number of parents' emotional expressions does not equal the total number of physicians' responses. A preliminary codebook was developed iteratively. The applied codes and descriptions of these codes were extensively discussed by the researchers. Coding continued until saturation was reached.[38] This concretely meant that the researchers stopped the inclusion of new transcripts and the corresponding audio recordings from the moment on that they did not identify any new parental emotions nor any new physician responses. The applied codes were then elaborately analyzed, discussed, and reflected on during 15 discussion rounds with the research group in different constellations to identify patterns of overarching emotions and responses.

On the basis of the "Phases of Illness" classification within palliative care,[45,46] we categorized all conversations into 3 phases of illness and decision-making to structure the conversations and grasp the emotional context: the initial phase (ie, the child's condition was unstable, and additional diagnostics and care planning were urgent), the middle phase (ie, the child's condition deteriorated and treatment options depleted), and the last phase (ie, the child's death was expected within days; Supplemental Table 4).

RESULTS

Forty-nine conversations (NICU [n = 29]; PICU [n = 20]) regarding 12 patient cases (NICU [n = 6]; PICU [n = 6]) were included before we reached saturation. In all but 1 PICU case, physicians and parents had multiple conversations (range 2–10) (Table 1). In total, 12 mothers, 10 fathers, and 46 physicians participated in the conversations. In all 49 conversations, parents expressed at least 1 emotion implicitly (range 2–28). We identified a total number of 499 implicit expressions of emotions. Parents expressed their emotions less frequently explicitly. Thirty-seven conversations (76%) contained at least 1 explicit emotional expression (range 1–16). Overall, we identified 186 explicit expressions of emotions. In 23 conversations, parents expressed their emotions in nonverbal vocalizations, particularly by crying.

Types of Emotions

Across all 49 analyzed conversations, we identified 22 distinct emotions expressed by parents. These emotions (henceforth: sub-emotions) were categorized into 7 overarching emotions: anxiety, anger, devotion, grief, relief, hope, and guilt (Table 2).

Anxiety

Anxiety contained the broadest array of sub-emotions, which parents mostly uttered implicitly. All conversations were fraught with such expressions of anxiety.

During initial-phase conversations, parents' expressions of anxiety concerned various topics, ranging from the child's uncertain diagnosis to worries about diagnostic tests, the course of treatment, and its consequences. In middle-phase conversations, parents mainly expressed anxiety regarding the treatment plan and associated risks. They also voiced their feelings of powerlessness and insecurity as they felt unable to take care of their children. In last-phase conversations, parents expressed their despair and fear for their child's wellbeing during the dying process.

Anger

Parents expressed their anger verbally and in nonverbal vocalizations (eg, slamming their fists on a table). In initial-phase conversations, parents uttered their anger about how their situation deviated from their expectations of parenting. They also expressed their jealousy, for instance, of parents with healthy babies. In middle-phase conversations, parents' anger focused on the timing, amount, and quality of the provided information. Parents also expressed anger about the perceived inadequacy of their child's care and the perceived incompetence of certain HCPs. Additionally, parents shared their frustration about the situation or the lack of understanding from others. During last-phase conversations, parents rarely expressed anger.

Devotion

In all cases, parents expressed their devotion to their child (eg, "when you see his heart dip, it is like my own heart is pounding"). In initial-phase conversations, parents stressed their strong bond and desire to care for their child. In middle-phase conversations, parents either implicitly or explicitly expressed their strong urge to protect their child. Some parents did so by underlining their wish that everything should be done to keep

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TABLE 1 Patient Case Characteristics[a]	
# Case	Description
NICU #1 trajectory	Prematurely born boy with sudden onset disease of unknown origin.
	Situation suddenly improved, but future development uncertain.
	Continuation of life-sustaining treatment.
Data	Two conversations between parents (non-Dutch), 2 neonatologists, 2 nurses.
NICU #2 trajectory	A baby boy (admitted to the NICU a few days after birth). Tentative diagnosis: incurable metabolic disease. Discontinuation of life-sustaining treatment. Boy's death was likely within days.
Data	Two conversations between parents (Dutch), 2 neonatologists, 1 nurse.
NICU #3 trajectory	Prematurely born girl with a rare congenital disorder. Continuation of life-sustaining treatment, despite severe epilepsy and high probability of lasting cognitive impairment.
Data	Three conversations between parents (Dutch mother, non-Dutch father; religious), 2 neonatologists, 1 pediatrician, 3 nurses, 2 guardians, 1 behaviorist, 1 social worker, and 1 grandfather.
NICU #4 trajectory	Prematurely born girl with congenital myotonic dystrophy. Situation remained unchanged (ie, did not improve but also did not get worse) while receiving life-sustaining treatment.
Data	Three conversations between parents (Dutch), 2 neonatologists, a pediatric neurologist, 2 nurses, 1 social worker, and 1 grandmother.
NICU #5 trajectory	Prematurely born boy with respiratory distress syndrome. Situation deteriorated. Discontinuation of life-sustaining treatment and child would die soon.
Data	Nine conversations between 1 single mother (Dutch) and 5 neonatologists, 1 pediatrician, 2 nurses, 2 medical social workers, 1 social worker, 1 aunt, 1 uncle, and grandparents.
NICU #6 trajectory	A full-term born girl with a critical congenital heart defect. Successfully extubated. Sudden deterioration. Child got intubated again.
	Discontinuation of life-sustaining treatment when no indications that situation would improve.
Data	Ten conversations between parents (Dutch) and 2 neonatologists, 1 pediatric cardiologist, 2 nurses, 1 medical social worker, 1 half-brother, and 1 grandfather.
PICU #1 trajectory	A baby boy (age range 0–1 y) with sudden onset disease of unknown origin. Continuation of life-sustaining treatment. Certain future physical and cognitive disabilities.
Data	Two conversations between parents (Dutch), 2 pediatricians, and 2 nurses.
PICU #2 Trajectory	A teenage boy (age range 12–14 y) with a congenital disorder. Heart transplantation not possible because of severe situation. Discontinuation of life-sustaining treatment. Boy would die soon.
Data	One conversation between parents (Dutch), 1 pediatrician, 1 pediatric intensivist, and 1 nurse.
PICU #3 trajectory	A female toddler (age range 1–4 y) with a congenital disorder. Rare syndrome. Severe cognitive impairment. Medical team advised discontinuation of life-sustaining treatment; parents disagreed. Sudden stable situation, and child was discharged from the hospital. Situation deteriorated, child was readmitted to the PICU. Discontinuation of life-sustaining treatment and the child died.
Data	Six conversations between parents (Dutch, religious), 3 pediatric intensivists, 2 pediatricians, 1 pediatric neurologist, 1 pediatric geneticist, 3 nurses, and 1 third party.
PICU #4 trajectory	A girl (age range 16–21 y) with a congenital disorder. Poor quality of life. Discontinuation of life-sustaining treatment and focus on palliative care.
Data	Six conversations between a mother (Dutch), 3 pediatric intensivists, 3 pediatricians, 3 pediatric neurologists, 2 nurses, 1 aunt, and 1 grandmother.
PICU #5 trajectory	A girl (age range 12–16 y) with severe epilepsy (and cognitive impairment due to perinatal asphyxia). Child's situation remained unchanged (ie, did not improve but also did not get worse) while receiving life-sustaining treatment.
Data	Two conversations between parents (Dutch), 2 pediatric neurologists, 1 pediatric intensivist, 2 nurses, and 1 grandmother.
PICU #6 trajectory	A boy (age range 12–16 y) with a congenital disorder and sudden onset disease of unknown origin. Discontinuation of life-sustaining treatment. Situation quickly deteriorated, and the boy died.
Data	Three conversations between parents (Dutch), a pediatrician, 2 pediatric intensivists, 1 anesthesiologist, 1 nurse, 1 social worker, and 1 sibling.

[a] Because of privacy regulations, we report age ranges instead of exact ages.

their child alive, whereas other parents expressed that their child should not be treated "at all costs." In last-phase conversations, parents stated their desire to be close to their child and do everything to help and comfort their child, no matter how unbearable this would be for themselves.

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TABLE 2 Emotions Expressed by Parents During End-of-Life Conversations, and Illustrative Quotes				
Overarching Emotion	No. (%),* $n = 685$	Type of Sub-Emotion	Description	Illustrative Quotes
Anxiety	273 (40)	Despairing	Assuming/expecting the worst. Loss of hope. The belief that nothing can be changed about the difficult situation and/or that one can do nothing to improve the child's condition.	"And then I ask myself, is it positive, is it negative? You know, you're only expecting the worst." (Father, NICU)
				"Imagine that she would never come home . . . ." (Mother, NICU)
Implicit	200 (29)	Afraid	Scared for a perceived or real threat, for example the possibility of a negative outcome. Feeling afraid because (of the feeling that) something bad is going to happen.	"You don't want to think about [worst-case diagnosis], but it's in my head all the time. So that is really scary." (Mother, NICU)
				"I'm quite afraid that she would be diagnosed with a metabolic disease that is untreatable." (Mother, NICU)
Explicit	73 (11)	Distraught	Extremely upset to the point that one cannot think clearly. Not knowing what to do or say. Being extremely confused.	"I don't know, I just don't know anymore I really don't know what to say or think." (Mother, PICU)
				"I really can't think clearly." (Father, PICU)
		Disconcerted	Shocked, feeling suddenly overwhelmed and uncertain, for instance, by an unexpected decision/action plan.	"I honestly didn't expect this. It hits me hard and I really didn't expect it." (Mother, PICU)
				"I must say, it's a rude awakening." (Mother, PICU)
		Insecure	Sense of vulnerability. Not feeling confident about (oneself within) the situation, also when thinking about the future/the longer term. Uncertain about one's own competence/ability.	"Others may think of me as a terrible father." (Father, NICU)
				"I know our kid needs us, but we also need some rest. So, I'm feeling a little insecure, what would be the best thing to do." (Father, NICU)
		Worried	Concerned. Nervous/restless especially due to a personal connection with and interest in the welfare of one's child or oneself, and not per se because of a specific threat/outcome.	"He has a host of infections, but he is already so fragile." (Father, PICU)
				"Consciously or unconsciously, you worry about your child." (Father, NICU)
		Powerless	Feeling helpless, unable to act/to care. Lacking control or influence over someone, a situation or outcome.	"You want to be there for your baby in any way possible, but you're just standing on the sideline. You can't do a nything." (Father, NICU) "There's nothing I can do. I'm entirely dependent on your care for her and the information you give me." (Mother, PICU)
Anger	121 (18)	Distrusting	Lacking trust, faith or confidence in the physician/ the medical team. Believing that someone is untrustworthy, and therefore having negative expectations about his or her care/motives/ actions.	"Can he be transferred [to another hospital]? I think you guys are too negligent. You're going to wait because you think he's stable" (Mother, NICU)
				"But I also have this feeling like; should I just leave my child with you?" (Mother, NICU)
Implicit	99 (15)	Suspicious	Ambiguity about the motives or actions of the physician/medical team/other health care providers; thinking that they can have negative intentions or hidden motives.	"Well I think you . . . others say something else, then again others say something different again." (Mother, NICU)
				"We have not been informed about anything . . . " (Father, NICU)
Explicit	22 (3)	Enraged	Feeling mad/furious about someone/something. Feeling treated unfairly. Having strong negative feelings about perceived offense/violation of one's rights, needs or expectations.	"Come on, that's what physicians do, RIGHT??" (Father, PICU)
				"We're still enraged that we received that information too early." (Mother, NICU)
		Frustrated	Annoyance, irritation. Disappointment/dissatisfaction. Feeling bothered/agitated/hindered by someone or something.	"That everyone keeps nagging at you to stay positive but I just CAN'T." (Father, NICU)
				"When they [the department] call you, you want to be with your child as soon as possible. But, f*** you have to wait, wait, wait, because that door is still closed and won't open" (Mother, PICU)
		Jealous	Feeling a sense of resentment toward others, particularly toward other parents, because of a perception of inequity - that others possess something or are in a situation that one lacks or is not experiencing.	"You hear a baby cry over here [in the NICU], which I don't want to hear. I also want to hear my baby, but that's impossible, cause she is intubated and has a tube down her throat." (Mother, NICU)

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TABLE 2 Continued

Overarching Emotion	No. (%),* n = 685	Type of Sub-Emotion	Description	Illustrative Quotes
				"When I'm walking here in the hospital, and then you see a woman walking behind a stroller. Then, yeah, I don't know. That's what I want." (Mother, PICU)
		Cynical	Expressing carelessness, indifference, as if lacking interest in others and disbelieving/disparaging their motives.	"[laughs/sighs] Nothing bothers me at the moment." (Mother, PICU)
				"Pfff, whatever." (Mother, NICU)
Devotion	81 (12)	Protective	Strong feeling/desire/need to protect the child from hurt, danger, or unwanted situations. Determined, wanting to ensure safety, security, well-being. Setting boundaries. Motivated by sense of responsibility, care, love.	"I don't want my kid to be in this machine and have another medical intervention. I don't want him to suffer." (Father, PICU)
Implicit	78 (11)			"But I feel that he needs more time. I really want to give him more time." (Father, PICU)
Explicit	3 (1)	Loyal	Sense of dedication. Strong emotional attachment and identification, proud, willing to make sacrifices or endure difficulties, out of love and a sense of belonging.	"Obviously, I do not want to lose her. But who am I to deter mine that she can't pass away?" (Mother, NICU)
				"My strong and only desire is to look my own daughter in her eyes. Share in her pain." (Mother, PICU)
Grief	72 (11)	Sorrow	Deep feeling of sadness, grief, pain, sense of separation. In tears, crying, sobbing.	"I feel so much pain and sorrow." (Mother, NICU)
Implicit	37 (6)			"I'm having an emotional breakdown, everything triggers a sense of immense sadness within me." (Mother, PICU)
Explicit	35 (5)	Affected	Feeling moved, emotionally impacted by a challenging, difficult, heartbreaking situation or experience.	"It's extremely hard. You know. It's not easy to deal with." (Father, PICU)
				"It's a mixture of disappointing, sad to be in this situation, challenging." (Father, PICU)
Relief	68 (10)	Joyful	Expressing happiness, joy, because of something positive, meaningful or satisfying; or relieved because of the absence or decrease of something painful or negative.	"I can only be happy that he's no longer suffering." (Father, PICU)
				"That [the child's situation did not further deteriorate] is just going to make things a bit lighter" (Father, PICU)
Implicit	42 (6)	Thankful	Expressing gratitude/appreciation for actions, empathy, or support from the physician/the medical team; thankful for (aspects of) the care, the situation. Acknowledgment.	"Thank you for delivering such great care. My daughter wouldn't be where she is right now, without you all." (Mother, NICU)
				"We are pleased and greatful that you [physician] swung by. Your presence is already somewhat comforting to us." (Father, NICU)
Explicit	26 (4)	Trusting	Expressing confidence in the physician/medical team/situation/care. Believing in good or honest intentions, even in the face of uncertain or unfavorable outcomes. Sense of acceptance.	"I know she's in good hands here, so that is one less worry." (Mother, NICU)
				"It's so helpful to know that you are there for him, just in case something suddenly happens." (Father, NICU)
Hope	55 (8)	Hopeful	Optimism, positive expectations, believing in the possibility of positive outcomes/development. Believing that challenges/difficulties can be overcome.	"But he rolled over. So he may improve quickly, and go off of the machi ne again." (Father, PICU)
Implicit	31 (5)			"You secretly hope that the MRI will reveal the underlying cause of the symptoms." (Mother, PICU)
Explicit	24 (3)			
Guilt	15 (2)	Guilty	Sense of responsibility or regret for something one has done, failed to do or is about to do. Actions or inactions that have caused or may cause hurt to others or oneself. Wishing one had acted differently, knowing or feeling that this might have changed the outcome or development, for instance by saying: "if we had . . . .".	"So uhm it's not that we should have raised the alarm sooner?" (Mother, NICU)
Implicit	12 (2)			"It feels like giving up. I've always said that I'll never let [name of child] down, but now it feels like I'm doing it after all." (Father, PICU)
Guilt	3 (<1)			

* Because of rounding, percentages do not total 100%.

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Grief

Parents expressed their grief verbally and in nonverbal vocalizations, by crying and sobbing. In initial-phase conversations, parents uttered sorrow in response to the negative news they had just heard and about the fact “of being in this situation.” In middle-phase conversations, parents expressed grief in response to the bad news provided by the physician. Notably, parents showed fewer expressions of grief in this middle phase compared with the other phases. In last-phase conversations, parents expressed grief about the impending loss of their child. They uttered grief at witnessing their child suffer and realizing that their child would never come home again.

Relief

Parents uttered relief verbally and in nonverbal vocalizations by laughing or sighing. During initial-phase conversations, parents expressed relief when the physician clearly explained that the child’s situation was not the parents’ fault. In middle-phase conversations, parents expressed relief when physicians provided relatively “good” news, for instance, that the child’s condition had not further deteriorated. Occasionally, parents voiced their relief by thanking their physician for the provided information or the care given to their child. In the few instances in which parents disclosed relief during last-phase conversations, they stated to be grateful for the “silver linings” (eg, that they could hold their child during the dying process).

Hope

Parents expressed their hopefulness explicitly and implicitly. The latter occurred in 2 ways: (1) asking loaded questions with hopeful implications (eg, “if he deteriorates, you can help him, right!?) or (2) sketching a positive scenario (eg, “let’s assume that it is going to be alright”).

In initial-phase conversations, parents’ expressions of hopefulness primarily concerned the hope that the child’s condition would improve. In middle-phase conversations, parents redirected their hope to wishing that their child’s condition would not further deteriorate. Parents also more explicitly uttered the hope that the cause of the child’s illness would be found. In last-phase conversations, parents’ expressions shifted to the hope that their child would die peacefully. Parents also uttered the hope that their child would “choose” the moment to pass away so that they themselves would not have to make this decision.

Guilt

Parents expressed feelings of guilt mostly in an implicit way. In conversations in the initial phase, parents uttered feelings of guilt about whether it was their fault that their child had become so ill or whether they should have acted differently to prevent their child’s situation from becoming so severe. In middle-phase conversations, parents stated that “they could never forgive themselves” if their child’s remaining quality of life would be extremely poor, especially in the case in which they had decided to continue their child’s life-sustaining treatment. At the same time, parents expressed how guilty they would feel if they had not done everything to let their child survive. Some parents explicitly verbalized how “ambivalent this all felt.”

In last-phase conversations, when deciding on the discontinuation of treatment, parents worded their feelings of guilt as “giving up” on their child.

Physicians’ Responses and Parents’ Emotional Reactions

We identified 13 types of physician responses to parents’ emotions, ranging from cognition-oriented to affect-oriented. Table 3 contains all responses and specifies whether these responses provided or reduced the opportunity for parents to further elaborate on their emotions. Below, we describe prevalent or notable patterns in physicians’ responses to parents’ emotions and parents’ emotional reactions during a conversation (illustrative quotes presented in Table 3).

Anxiety

We noticed that parents did not further disclose and elaborate on their primary expressions of often implicit anxiety if physicians responded in a cognition-oriented way to these expressions (Table 3, Q2.1 and Q6.1). In the remainder of the conversation, parents started to stress their strong devotion to their child, also in combination with anger (Table 3, Q5.2). In response to the changed pallet of emotions, physicians continued their information provision rather than identifying parents’ covert anxiety and then inviting them to elaborate on these anxieties. By contrast, when physicians immediately responded to parents’ implicit anxiety by explicating these expressions (Table 3, Q10.1) and further exploring it (Table 3, Q11.1), parents subsequently clearly worded what they were afraid of. Physicians were then able to provide detailed and targeted explanations that addressed these specific anxieties.

Anger

When the physician continued providing explanations or started to defend the chosen course of action in response to parents’ expressions of anger, this seemed to intensify parents’ distrust toward the medical team and sense of protectiveness toward their child (Table 3, Q1.1). Such cognition-oriented responses particularly occurred when parents expressed anger about a topic for which they

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TABLE 3 Physician Responses to Parents' Emotional Expressions During End-of-Life Conversations					
	Type of Response	No. (%),* n = 760	Description	Illustrative Quotes	Mainly Reduces or Provides the Opportunity to Elaborate on Emotion
Cognition-oriented	1. Defending	21 (3)	Justifying the provided information, proposed treatment plan, or medical actions.	Q1.1 Mother: "It's just, that information has been provided to us too early It was a real slap in the face."	Reduces opportunity
				Physician: "We have no choice, we have to be honest about what we see and what we think. That is also in the law, we have no choice."	
				Mother: "Well I think you ... Others say something else, then again others say something different again." (NICU)	
				Q1.2 Mother: "But his growth is stunted, because you are withholding food from him."	
				Physician: "No, no, no, that's not our fault, because even with parenteral nutrition growth should be possible."	
				Mother: "Pfff, whatever." (NICU)	
	2. Recentering	44 (6)	Directing the conversation away from parents' emotional expression(s) toward another issue.	Q2.1 Mother: "But then, yeah, I think what kind of consequences this will have for our future."	Reduces opportunity
				Physician: "Yes, yes I get it. A clinical geneticist can explain that to you. Eh, but now let's focus on [name of child]." [Physician continued information provision] (NICU)	
				Q2.2 Father: "So .... That's what very ill meant.."	
				Physician: "You are religious people?"	
				Father: "Hmm, I wouldn't, yeah, uh, we have, eh, we are sure that we have a kind of sensitivity ...." (NICU)	
	3. Rephrasing (in a steering way)	8 (1)	Repeating or reframing previously uttered issues; seemingly in an attempt to steer the conversation.	Q3.1 Mother: "The side effects of a surgery are not certain and everything that's uncertain gives me the reason to be hopeful."	Reduces opportunity
				Physician: "Yesterday, I was under the impression that you - at least that was my feeling listening to you- that you did not want that for your child, because he would suffer, but now you are saying something different."	
				Mother: "Yes, because it's still my child, and I hold on to the hope and belief that she chose to be born and to be here in my family." (NICU)	
				Q3.2 Mother: "That's not the life I want for her."	
				Physician: "And then we're circling back to the matter of ventilation that we previously discussed. Remember how you thought about that? If we discontinue ventilation, it also means that we won't intubate her again. In that case, she has to breathe on her own. Well, maybe, that's a sign, that she shows that she can't do it."	
				Mother: "But I'm not blindly accepting your plan and this scenario. You forget other potential scenarios, such as the possibility that she can breath on her own." (PICU)	
	4. Arguing	16 (2)	Arguing/contradicting/objecting parents' emotional expressions (eg, by stating "but ...").	Q4.1 Mother: "I feel like, just give her some more time [Name of other child] also did not always do what he was supposed to do right after he was born."	Reduces opportunity
				Physician: "But, the situation of your other child was completely different. He was able to breath on his own."	
				Mother: "At this time, I haven't given up on her, and I will not do so." (NICU)	
				Q4.2 Father: "I want to give him another chance. I've seen other children who were also resuscitated and they also turned out fine."	
				Physician: "But, it's important to note that further brain damage can occur due to lack of oxygen, if we resuscitate him."	

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TABLE 3 Continued

	Type of Response	No. (%),* n = 760	Description	Illustrative Quotes	Mainly Reduces or Provides the Opportunity to Elaborate on Emotion
				Father: "Since we're already going beyond what we initially discussed, by intubating him again, I am willing to take this extra step for my own child." (PICU)	
	5. Explaining	221 (29)	Providing explanations and medical information to parents about the child's situation and possible future developments.	Q5.1 Mother: "I am hopeful that the cause of her symptoms, whether small or serious, will be found."	Reduces opportunity
				Physician: "Yes, something small, the challenging thing is that within metabolic diseases there are diseases that you can treat more easily, for instance diabetes. I would not say that diabetes is an easy disease. However, there are also diseases that require a significant change in lifestyle, frequent hospital readmissions, and so on."	
				Mother: "I get it, and for me it's like, considering the numerous types, it can be something easy to treat as well." (NICU)	
				Q5.2 Mother: "I'm quite shocked and frightened by this news."	
				Physician: "Yeah, we think that we have to give her this medication. And that we have to wait and see and monitor her response for at least a week, why is that, because we at least need a week to determine the proper dosage[..]."	
				Mother: "I honestly have my doubts about this plan, I really did not expect this from you, and I actually don't think it'll work." (PICU)	
				Q5.3 Mother: "But yeah, I mean, could we have prevented this?"	
				Physician: "You did not do anything wrong. What you did is giving your child some food, and that is very important, but for some children with metabolic diseases this can lead to extremely high ammonium levels. You could have prevented that by not giving him any food, but then I would have been mad at you, because it's natural for parents to feed their baby and it would have been wrong if you did not give him any food."	
				Mother: "No, okay, I see that we could not have done anything about this." (NICU)	
	6. Providing short confirmations	74 (10)	Using minimal language to factually affirm or validate parents' emotional expressions, without explicitly referring to the emotion, or further exploring or explaining.	Q6.1 Mother: "But, then, uhm, there is a chance that she may not survive . . . "	Reduces opportunity
				Physician: "That's a correct statement." "In the medical team we discussed that we know for sure there are some abnormalities and now we want to investigate the cause of all this."	
				Mother: "I don't understand. You really want to proceed with such actions?? I want to spare her from any form of pain." (NICU)	
				Q6.2 Mother: "But it is MY child."	
				Physician: "That's right."	
				Mother: "She's my own flesh and blood. Therefore, I want to keep all options open." (NICU)	
	7. Managing expectations	37 (5)	Helping parents to realize/prepare for an outcome or a situation.	Q7.1 Mother: "We need to keep hope."	Provides opportunity or reduces opportunity
				Physician: "I think that is good and very important because otherwise things can feel really hopeless. And also, I think it is important to acknowledge and	

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TABLE 3 Continued					
	Type of Response	No. (%),* $n = 760$	Description	Illustrative Quotes	Mainly Reduces or Provides the Opportunity to Elaborate on Emotion
				realize the seriousness of the situation your son is facing."	
				Mother: "At the same time, you know that there is no kind of 'red bull' for your child, or panacea. And that makes me think . . . " (NICU)	
				Q7.2 Father: "And and how long is that process when you take the tube out?"	
				Physician: "I suspect that it would be fast. What we are going to do is to stop the ventilator. It's also important to know that we turn off all the alarms and all the monitoring. We can see everything from where we as physicians are sit ting, but then you don't get disturbed."	
				Father: "It's helpful to know that you guys are there, and that it can be a personal moment for us as well." (PICU)	
	8. Reassuring	53 (7)	Making a statement in an attempt to remove or attenuate parents' emotions/concerns.	Q8.1 Mother: "We think, did we do something wrong or.."	Provides opportunity or reduces opportunity
				Physician: "You could not forsee this."	
				Mother: "So, it's not that we should have raised the alarm sooner?" (NICU)	
				Q8.2 Mother: "We constantly ask ourselves if she's experiencing any pain."	
				Physician: "The thing that is most important to us is to ensure that she is comfortable, and so far, we haven't observed any signs of pain."	
				Father: "Oh, thank you. It's so hard to see her, with all those monitors and everything. That makes you wonder if she is in pain." (NICU)	
	9. Acknowledging	114 (15)	Recognizing parents' emotions and emotionally draining situations (eg, by stating "I understand" or "I know").	Q9.1 Mother: "All I want is to hold my baby in my arms."	Provides opportunity or reduces opportunity
				Physician: "I understand. I understand."	
				Mother: "No, because you can take care of her, but I want to be the one caring for her. It's really frustrating that all I can do is watch." (NICU)	
				Q9.2 Father: "We really don't want him to go through anything unnecessary."	
				Physician: "That's clear. And of course we will respect that, because you are his parents."	
				Father: "You know, we understand, you come from a medical point of view, and really you all are doing a great job." (PICU)	
	10. Making it explicit	14 (2)	Clearly stating or naming the emotion(s) that parents expressed implicitly.	Q10.1 Mother: "Could it become worse?"	Provides opportunity
				Physician: "Is it possible that you're feeling afraid?"	
				Mother: "Yes, I'm scared." (NICU)	
				Q10.2 Mother: "(sighing)"	
				Physician: "You are angry, is that right?"	
				Mother: "Hmm hmm yes."	
				Physician: "And are you angry because he is ill? Or because of the situation you are in? Or is your anger directed at the medical team? Or at me?" (NICU)	
				Q10.3 Mother: "Yeah, sorry, but the physicians at the other hospital were not even familiar with the name of this disease. I felt like I was being accused of lying."	

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TABLE 3 Continued

	Type of Response	No. (%),* $n = 760$	Description	Illustrative Quotes	Mainly Reduces or Provides the Opportunity to Elaborate on Emotion
				Physician: "Are you maybe concerned that if your daughter is transferred to another department or hospital, she may not receive the best care?"	
				Mother: "Yes, because her condition is stable now, and I don't want it to deteriorate again."	
				Physician: "Okay, I see. If that time comes, we will contact the physicians at the other hospital and explain everything thoroughly to ensure your daughter will receive the best care. You really don't have to worry about that." (NICU)	
	11. Exploring	51 (7)	Encouraging or inviting parents to share and disclose emotional expressions (eg, by posing questions, to obtain more information about the expressed emotion).	Q11.1 Physician: "What specifically are you anxious about?"	Provides opportunity
				Mother: "His brains."	
				Physician: "Alright, let me give you a more detailed explanation about that, is that okay?" (NICU)	
				Mother: "Hmmm, yes."	
				Q11.2 Mother: "Yeah, but WE have to deal with this."	
				Physician: "You know, there is space to say everything, even if you're angry, and I just want to tell you that you can share what you are angry about, if you want to, but if you don't want to, then that's also fine."	
				Mother: "I don't have anything to say (sobbing)." (PICU)	
				Q11.3 Mother: "I really don't get it."	
				Physician: "Can you share what you're thinking or feeling right now?"	
				Mother: "I just don't get it. I don't see how ill he is. I don't see any improvement. I don't see anything at all." (NICU)	
	12. Being silent	73 (10)	Providing a clear pause/ silence (>5 s).	Q12.1 Mother: "He is still fighting (crying)."	Provides opportunity
				Physician: "(8.0 seconds)."	
				Mother: "It is so extremely hard." (NICU)	
				Q12.2 Mother: "(crying)."	
				Physician: "(whispering) It's okay (17.5 seconds)."	
				Mother: "You know, it comforts me, and I'm glad to know with certainty that it is in her best interest to not prolong her life in her current condition, that this is not a life." (PICU)	
	13. Expressing compassion	34 (4)	Imagining what parents might be thinking or feeling, showing sympathy and sadness.	Q13.1 Mother: "She is all I have."	Provides opportunity
				Physician: "It must be terrible for you to go through this as a parent. You are fighting for her life such a long time, I admire how well you are managing the situation. It must be extremely difficult."	
				Mother: "It's especially difficult and scary to feel so overwhelmingly powerless." (PICU)	
Affect-oriented				Q13.2 Father: "We just have to deal with this (sobbing)."	
				Physician: "It's an impossibly painful situation for you, I can't imagine."	
				Father: "I never thought that I would outlive my own child. That I'm going to bury my own child. It's truly unbelievable. A father wants that his children outlive him, that they carry my coffin, instead." (PICU)	

* Because of rounding, percentages do not total 100%.

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held the physician or other HCPs accountable, like the withholding of important medical information. Conversely, affect-oriented responses seemed to occur when parents' anger concerned a topic that could be perceived as being "beyond anybody's control" (eg, a pessimistic prognosis). When physicians responded in an affect-oriented way to parents' expressions of anger (Table 3, Q10.2, Q10.3, and Q11.2), it appeared that parents' anger dissipated, and instead gave way to expressions of anxiety and grief in the remainder of the conversation.

Devotion

When physicians responded in a cognition-oriented way to parents' expressions of devotion, for instance, by arguing or rephrasing (Table 3, Q3.2, Q4.1, and Q4.2), parents re-expressed their devotion or started to express mistrust in the medical team. We observed a similar pattern when physicians briefly acknowledged parents' expressions of devotion (ie, affect-oriented), for example, by stating "I understand" or "I know." Subsequently, parents also started to stress what they really wanted for their child and to emphasize their frustration (Table 3, Q9.1). In turn, these combined expressions of devotion and anger appeared to elicit a defensive response from physicians. By contrast, when physicians acknowledged parents' expressions of devotion, for instance, by wording their respect for it or attempting to understand parents' viewpoints, parents reacted differently (Table 3, Q9.2). Then, they started to disclose their fears, while at the same time expressing their gratitude for the medical team's efforts in doing everything possible to keep their child alive.

Grief

When parents expressed grief, we noticed that physicians primarily responded in an affect-oriented way (Table 3, Q12.1, Q12.2 and Q13.1). This especially occurred in conversations when the child's death was imminent. After such affect-oriented responses, parents further expressed their grief and disclosed their anxiety. In turn, physicians responded in an affect- and cognition-oriented way, for example, by showing compassion (Table 3, Q13.2) and providing detailed information to prepare parents for what would await them and address their fears (Table 3, Q7.2). In the rest of the conversation, parents expressed a variety of emotions ranging from anxiety to relief.

Hope

When physicians solely responded in a cognition-oriented way to parents' expressions of hope (Table 3, Q3.1 and Q5.1), these expressions kept reappearing throughout the remainder of the conversation. On the contrary, when physicians responded in both an affect- and cognition-oriented way, for instance, by acknowledging parents' hope while also managing their expectations (Table 3, Q7.1), parents did not further dwell on their hopes, but seemingly felt the opportunity to express their underlying anxiety.

Guilt

We noticed a different pattern when physicians briefly responded in an affect-oriented way to parents' expressions of guilt and did not provide any explanations (Table 3, Q8.1). In these instances, parents' expressions of guilt appeared to persist during the remainder of the conversation. By contrast, in 1 case the physician immediately clearly explained that the parents were not responsible and could not have prevented the severity of their child's situation (Table 3, Q5.3). In this case, the parents did not express any further guilt throughout the rest of the conversation and instead expressed a sense of peace with their situation.

DISCUSSION

Our study offers detailed and real-life insights into the various emotions that parents expressed during conversations in the NICU and PICU when faced with doubts about whether continuing LST was in their child's best interest. Physicians mainly responded to parents' emotions in a cognition-oriented way. These types of responses appeared to reduce the opportunity for parents to further elaborate on their emotions. In turn, the parents' emotions seemed to persist or intensify in the remainder of the conversation. A complementary approach, in which physicians first provide parents the opportunity to disclose their emotions, followed by a cognition-oriented response, may offer parents both emotional and informational support.

The observed variety of parents' emotions, especially within the overarching emotions of anxiety and anger, was more diverse than previously reported in studies in the NICU and PICU,[1,2,4,12,47,48] as well as in other medical contexts.[6,13,17,49] A thorough insight into the wide array of emotions that parents may express during end-of-life conversations is especially important because these emotions also reflect how parents perceive and evaluate their child's situation and care. Moreover, these emotions may influence parents' treatment preferences and the role they wish to have in the decision-making process.[15,50,51] More knowledge about helpful and less helpful responses to parents' emotions, either implicitly or explicitly expressed, enables physicians to choose the most appropriate approach, for example, taking sufficient time to empathically explore what parents concretely fear. This information will add to a shared understanding and to mutual trust between physicians and parents.[50,52] When physicians are less attentive to parents' diverse emotions, they may easily miss

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opportunities to deepen the conversation. By effect, valuable information likely remains unknown, and this may even hinder the making of a balanced treatment decision.[2,15,52]

We found that all conversations were fraught with parents' often implicit expressions of anxiety. When physicians responded to parents' emotions in an affect-oriented way, particularly by exploring, parents started to disclose this anxiety, irrespective of the type of emotion they had expressed before. Anxiety seemingly becomes apparent when parents are given the opportunity to elaborate on it. If not, other emotions tend to mask it.

Physicians particularly seemed to respond in an affect-oriented way when parents' emotions were more "tangible" (eg, grief when the child's death was imminent), "explicit" (eg, clearly stating they feel anxious), or being beyond anybody's control (eg, anger concerning the pessimistic prognosis). More often, physicians responded in a cognition-oriented way to parents' emotions, which is in line with previous studies across various medical settings.[8,10,13,53–57] After such cognition-oriented responses, parents' anxiety remained under the surface. Instead, expressions of anger and protectiveness predominated the remainder of the conversation. This seemed to make it even more difficult for physicians to uncover parents' specific fears. Previous studies reveal that physicians find it hard to adequately respond to emotions and instead choose to focus on providing medical information.[26,50,55,58–62] Our findings reveal that it might be more constructive to explicitly explore what parents are specifically anxious, angry, or protective about before providing medical information. This enables physicians to first uncover hidden anxieties and then provide tailored information that aligns with parents' fears and feelings. According to October et al,[18] unburied empathy (eg, asking open-ended questions to explore emotions instead of using medical terminology or "but" statements) can be an effective way to address and explore families' emotions, thus making them feel heard. This approach also allows physicians to understand the values that are most important to the family, which can increase feelings of trust and control, improve the physician-parent relationship, and can lead to better decision-making.[18,63]

Additionally, former studies reveal that when physicians "provide space" to patients to express their emotions, this helps physicians to subsequently choose the most appropriate approach to respond to these emotions.[10,55,57,60] In line with these outcomes, we found that when physicians provided parents the opportunity to further elaborate on their emotions, most parents subsequently expressed their emotions more explicitly. This indeed seemed to help physicians to choose adequate responses.

Notably, some responses that were previously classified in the literature as providing space (eg, reassuring and acknowledging[40]) sometimes appeared to reduce space in our study. In these instances, emotions intensified, for instance, into anger, or parents kept repeating the same emotion throughout the conversation, for instance, feelings of guilt. This may partly be explained by how physicians express their reassurance or acknowledgment. If they do so too briefly or prematurely and without really listening to parents' perspectives, such responses may be counterproductive.[18,64] When emotional support is not accompanied by additional explanations, this may also be counterproductive.[65] Thus, it may be important that physicians primarily give parents the openness and trust to express what is really on their minds. Based on this trust, there is room for physicians to give tailored information, ultimately providing parents with support in both affective and cognitive ways.[65–67]

Limitations and Strengths

Although presenting novel and in-depth insights, our study is subject to several limitations. The most significant limitation is that we do not know for sure that the emotions we identified were indeed the emotions felt by parents at that point in time, especially when it comes to the emotions that parents expressed in an implicit way. Although we cannot be certain that we have correctly identified all emotions, our study may well serve as the first cornerstone for future research in this specific field of communication. Additionally, we were unable to investigate all nonverbal communication because we only audio-recorded HCP-parent conversations to minimize intrusion. Besides, we could not audio-record informal bedside conversations because of privacy regulations. Although we have reached saturation regarding the emotions that parents expressed in our dataset and regarding physicians' responses, future research regarding end-of-life conversations in other ICUs may well reveal other emotions and responses and, by effect, identify additional patterns in how these emotions evolve under the influence of HCPs' responses. Particularly, research in other countries may reveal new insights and shed light on cross-cultural differences. In addition, we do not know how parents themselves would define their emotions, nor do we know how they experienced physicians' responses to their emotions. We also do not know how physicians experienced the different types of emotions that parents expressed, nor do we know how they evaluated their own responses in retrospect. In that respect, our exploratory research can be seen as the first step in this important but also complex field of research. To both validate and expand our findings, it would be necessary to combine the analysis of video-recorded conversations with retrospective interviews with the families, physicians, and nurses who participated in these conversations. Exploring how HCP's responses affect parents' emotions not only during but also after conversations is also a worthy subject for future studies.

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I. Increased knowledge and awareness of the **broad diversity of emotions** that parents may express could help to **quickly recognize** these emotions during a complex conversation, especially because emotions are often **implicitly expressed**.

II. Providing parents with the opportunity to **further elaborate** on their emotions may lead to more **explicit emotional expressions**. In turn, this could help to choose **additional appropriate and fitting responses** (including providing tailored information).

III. The ***manner*** in which one responds may be as important as the *type* of response (eg briefly acknowledging could be **counterproductive** and may result in lingering emotions).

IV. Using affect-oriented responses, such as **explicating** the emotion (*eg "Is it possible that you are afraid?"*) and **further exploring** (*eg "What specifically are you anxious about?"*) could be particularly helpful in response to emotions that are **less tangible**, **ambiguous**, or in situations in which **health care providers are held accountable**.

V. Such affect-oriented responses may help to **uncover underlying emotions**, particularly anxiety, and **prevent emotions from intensifying or lingering** throughout the rest of the conversation.

FIGURE 1
Preliminary practical recommendations to support physicians in responding to emotions, based on our findings.

The main strength of our study is that we meticulously analyzed real-life conversations. This enabled us to present a detailed overview of parents' actual emotional expressions and physicians' responses during complex and emotionally charged conversations in the NICU and PICU. (Figure 1. Practice Recommendations)

CONCLUSIONS

Parents expressed a broad diversity of emotions in all conversations, mostly in an implicit way. In responding to these emotions, physicians appeared to reduce the opportunity for parents to elaborate on their emotions by predominantly responding in a cognition-oriented way. Subsequently, the parents' emotions seemed to persist or intensify. Affectively exploring and explicating parents' emotions appeared an effective response in uncovering complex emotions and hidden anxieties. If presented in a sincere way, a complementary approach of affect- and cognition-oriented responses could provide parents the opportunity to elaborate on their emotions and offer parents emotional and informational support during turmoil times.

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ABBREVIATIONS

HCP: health care provider
LST: life-sustaining treatment

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