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Physicians Perceptions of Shared Decision-Making in Neonatal and Pediatric Critical Care

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Abstract

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Background—Most children die in neonatal and pediatric intensive care units after decisions are made to withhold or withdraw life-sustaining treatments. These decisions can be challenging when there are different views about the child's best interest and when there is a lack of clarity about how best to also consider the interests of the family.

Objective—To understand how neonatal and pediatric critical care physicians balance and integrate the interests of the child and family in decisions about life-sustaining treatments.

Methods—Semistructured interviews were conducted with 22 physicians from neonatal, pediatric, and cardiothoracic intensive care units in a single quaternary care pediatric hospital. Transcribed interviews were analyzed using content and thematic analysis.

Results—We identified 3 main themes: (1) beliefs about child and family interests; (2) disagreement about the child's best interest; and (3) decision-making strategies, including limiting options, being directive, staying neutral, and allowing parents to come to their own conclusions. Physicians described challenges to implementing shared decision-making including unequal power and authority, clinical uncertainty, and complexity of balancing child and family interests. They acknowledged determining the level of engagement in shared decision-making with parents (vs routine engagement) based on their perceptions of the best interests of the child and parent.

Conclusions—Due to power imbalances, families' values and preferences may not be integrated in decisions or families may be excluded from discussions about goals of care. We suggest that a systematic approach to identify parental preferences and needs for decisional roles and information may reduce variability in parental involvement.

Keywords

ICU/critical care issues in palliative care; pediatric palliative care; pediatric communication issues; physician–patient communication; shared decision-making; pediatric bioethics; family-centered care

Background

Decision-making in neonatal and pediatric critical care is complex and has significant consequences for children and their families. Improved survival in the neonatal and pediatric intensive care unit (ICU) means that some of these children will go on to live with chronic conditions and disability.¹ Furthermore, death in neonatal and pediatric ICUs most commonly occurs after decisions to withhold or withdraw life-sustaining treatments. Families of critical care patients often report symptoms of acute and posttraumatic stress disorder^{2–6} that are associated with communication problems^{7–9} and can impede their ability to make decisions.¹⁰ Family-centered care, a partnership approach that supports and engages the family in the care of their hospitalized child, is endorsed by professional organizations as a practice that improves outcomes for both children and families as a whole.^{11–15}

Shared decision-making, a key part of family-centered care, involves developing a shared understanding of the patient's condition and agreement on a treatment plan that is consistent, whenever possible, with patient and family preferences, values, and goals.¹⁶ Shared decision-making entreats critical care physicians to invite parents to share in decisions about life-sustaining treatments to promote both the child's and family's interests and as a way to

help families manage distress.^{17–20} Studies have shown, however, that neonatal and pediatric ICU physicians vary in the extent to which they engage parents in decision-making, and how they integrate families' values and preferences into clinical decisions.^{12,21–26} This is due in part to the ethical complexity of determining a child's best interest.

Pediatric shared decision-making relies on the best interest standard, given that children generally lack capacity to give informed consent until adolescence and/or have not developed or expressed preferences that could guide decision makers.^{27,28} While there is general agreement about best interests as a guiding standard, there is often disagreement about how a child's best interest is defined and who has the authority to make decisions at the end of life.²⁹ Physicians' obligations to involve parents in decisions are sometimes in conflict with their obligations to the child, especially when physicians perceive parental preferences to be at odds with their own view of the child's best interest.^{17,19} While the child's best interests are intended to be the overriding factor, most physicians also consider the interests of the family as a whole.¹⁷ At times, this leads physicians to assume responsibility for life-sustaining treatment decisions and limit parental participation in shared decision-making to reduce parental guilt or regret.^{12,22,25,30}

It is not clear how neonatal and pediatric critical care physicians balance the interests of the child and family, nor how they engage parents in life-sustaining treatment decisions when they perceive tensions between the child's and family's interests. We used qualitative methods to explore (1) physicians' perspectives about child and family interests and (2) what factors about the clinical situation and family interests inform how physicians choose from a range of decision-making strategies regarding decisions about life-sustaining treatments.

Methods

Study Design and Participants

The study was approved by the institutional review board at Seattle Children's Hospital (approval number 13098). We contacted the majority of Seattle Children's attending critical care physicians. All 22 agreed to enroll in the study and provided written consent. E.B. conducted in-person, semistructured interviews.³¹ The interviews averaged 47 minutes (range 20–76) and were recorded, transcribed, and entered in Dedoose qualitative data analysis software version 7.5.0 (2016).³² Interview questions (see Appendix A) were broad and open ended. Participant descriptors are listed in Table 1.

Data Analysis

We used content and thematic analysis to examine physicians' descriptions of child and familial interests, and how their perceptions of interests guided their approach to engaging parents in decision-making.^{33,34} The primary author (C.A.R.) coded all the transcripts, looking for examples of decision processes, values, attitudes, and beliefs about communication and decision-making from both clinicians and families (as conveyed by the physicians).³⁵ This was followed by identifying specific decision-making strategies, including whether parents were invited to participate in decisions, whether and how they gave recommendations for treatment decisions, and what contextual features (including

time, the child's suffering, and physician–family relationship) contributed to choosing different strategies.³⁶ C.A.R. met regularly with coauthor mentors (H.S., M.R.O., E.B., and A.Z.D.) who provided expert guidance for methodological and analytic decisions.³⁷ In addition, findings were discussed with experienced clinician and researcher peers. Data analysis was performed between May and November 2016.

Results

We identified 3 main themes related to (1) beliefs about child and family interests, (2) disagreements about the child's best interest, and (3) decision-making strategies. Each of these broader themes comprises a range of decision-making strategies and considerations of when to use them.

Beliefs About Child and Family Interests

Physicians said it was difficult to separate the child's interests from those of the parents and family. Seventeen physicians described the child's best interest as a balance between the expected benefits and burdens of life-sustaining treatment, especially when prognosis was poor and interventions contributed to the child's suffering. In these situations, multiple parental interests were described, including wanting a sense of control over the decisions made so they can have a sense of peace about them; needing time to adjust to or accept a poor outcome prior to making end-of-life decisions, and/or to say goodbye and interact with their child prior to the child's death.

When it was expected that a child would survive with significant cognitive and/or physical impairments and ongoing health-care needs, 3 physicians described best interests as they related to quality of life and the future potential that parents wanted for their child. As 1 of these physicians said:

... it really does change how they think about things; like, "Oh, I wouldn't want my child to live if they can't participate in their activities," and some people are like, "Doesn't matter. As long as they have a heartbeat, that's enough for me...."
(CICU-01).

Four physicians also spoke of wanting parents to consider their own and the whole family's interests and to be aware of potential burdens and long-term stressors due to the child's future health-care needs that could result in financial strain, divorce, or reduced parental attention for other children. For example:

...the worst for me is to see a family like a year later, and they've just been devastated by some intervention that we've done, and they didn't realize the weight of it in their family and the family's fallin' apart or the parents get divorced....
(PICU-05)

Disagreements About the Child's Best Interest

Physicians described several scenarios involving disagreements between the clinical team and family regarding whether life-sustaining treatment was in the child's best interest. One physician described preventing a family from discontinuing life-sustaining treatment when

he was still uncertain about the outcome. However, it was more common that parents were described as having biases toward initiating more interventions rather than focusing on comfort: “Many of our families come here wanting that bias because that’s why they chose to come here. They want everything possible to be done” (NICU-04).

Half of the physicians described disagreements resulting from the family’s denial, disbelief, or lack of acceptance of a poor prognosis. Often physicians had developed a sense of confidence that the child would inevitably die or have severe neurological impairment, while the family was still uncertain and hopeful for a different outcome:

Some of the patients that we take care of are sort of frustrating; I look at them and I honestly wonder, “What sort of quality of life do you have? What is going on within you that is so satisfying? Are we doing this for the family or are we really still focusing on our patient?” (PICU-05)

Two physicians were skeptical of their own and other clinicians’ assessments of suffering as the basis for reframing goals and recommending to withhold or withdraw life-sustaining treatments. These physicians thought that their perceptions of suffering varied over time and became more acute when they recognized their own inability to effect change, given the child’s clinical status. One of these physicians described parents as being the most capable of assessing whether the child was suffering, “Who knows what suffering is? The best that I can say for a child that can’t speak for themselves as to whether they’re suffering is the parents are the best assessors of suffering” (CICU-01).

Decision-Making Strategies

Seventeen physicians described using 1 to 3 (median of 2) decision-making strategies in different clinical circumstances (see Table 2).

Limiting options—Nine physicians described choosing not to discuss certain types of resource-intensive life-sustaining treatment with families, such as extracorporeal membranous oxygenation (ECMO), cardiopulmonary resuscitation, or renal replacement therapy on the basis of futility and certainty of a poor outcome. Physicians reasoned that they should not discuss therapies that are “not a standard of care” and are not “indicated” or “appropriate” unless families asked about them.

...we don’t talk about bringing up whether you should use antibiotics or not in someone that has a neurological process that’s not an infection. I see ECMO as a different category of therapy that doesn’t really apply in this situation. (PICU-02)

In addition, physicians described parents as having a harder time withdrawing than withholding life-sustaining treatments and that offering these treatments was unfair because it gave parents unrealistic expectations, “Should they go on ECMO? Is it fair to ask the family that? Cuz all the family hears is, ‘There’s something more that can be done’” (PICU-14). Another physician told a story about starting life-sustaining treatment emergently and then getting “stuck” there. Two physicians described limiting treatment options as their professional obligation when they are certain that they cannot change the outcome, “It seems almost unfair to say, ‘Well, I could do these antibiotics’” (PICU-05). In

contrast, 1 physician reported discomfort with how other physicians didn't offer treatment limitations because they wanted greater clinical certainty, "The bias here is that you try to do everything so that you know you've done every possible procedure that could've saved this kid's life" (NICU-04).

Being directive or owning the decision—Four physicians described making decisions to initiate life-sustaining treatments when hopeful that the child could survive and informing parents later. While physicians generally did not make unilateral withdrawal decisions, 1 physician described making an exception if parents were unable to make a decision because of their religion *and* the parents thought that the child was suffering, "...they felt that their child was suffering, but they felt because of their religion that they couldn't stop life support, even though they thought that that is what should happen" (CICU-01). In cases like this, she would tell the parents that she was going to assume the burden of decision-making, provided that the parents did not disagree, "I told them outright, I'm taking the moral burden and I'm telling you it's time to stop."

Eight physicians described being more direct, clear, or blunt and increasing the strength of their recommendation to with-hold or withdraw life-sustaining treatment when they were certain that the child would die or have severe neurological impairment.

It's the ones that are ... not interactive, they're basically on a ventilator, sedated, muscle relaxer, whatever, that it's sort of hard in that case to justify an existence. In those cases, we're more heavy handed in pushing families. (CICU-03).

This strategy was considered when physicians thought that their recommendations would give parents' permission to make difficult choices. In some cases, physicians framed their recommendations as a decision.

I'll just be more firm with what I say. If I've had that rapport with them, they'll respect that. They're gonna say, "Okay." Maybe they actually needed to hear it from someone they've trusted and come to respect as the doctor. (NICU-03)

Staying neutral—Five physicians described the importance of not making recommendations about life-sustaining treatments, even when asked to do so by parents, because they did not want to influence value-laden decisions that most impacted the interests of the family and did not want parents to feel judged or create mistrust. Physicians offered options by saying that there was no right or wrong choice and that different families make different decisions, without any being better than others. Two physicians described making emotionally supportive statements, such as "Everybody has a different way of loving their child. We just wanna support you through this" (PICU-06).

Allowing parents to come to their own conclusions—Physicians described situations in which they were certain that the child was going to eventually decompensate. Three physicians described delaying discussion about life-sustaining treatments with families because they believed that the parents needed an opportunity to witness the dying process and come to their own conclusions that death was inevitable, "There's one thing to say we've done all we can, and there's another thing ... for people to see that that is true"

(PICU-02). For example, 1 physician described postponing discussions about mechanical ventilation because the parents had stated their goal was to interact with their child. He recognized that mechanical ventilation would conflict with that goal and so did not offer it until bilevel positive airway pressure could no longer provide sufficient breathing support. He believed that if they had offered mechanical ventilation earlier, the parents would have felt pressured to intubate their child: "...we stretched our ability to utilize that modality based on a goal that the family had defined, but had not placed a limit on our care, because they weren't at that point yet" (PICU-04). As a result, he thought that the child and parents had a higher-quality end-of-life experience because they were able to interact until the child died.

Discussion

The objective of this study was to describe how neonatal and pediatric critical care physicians balance the interests of critically ill children and their families when life-sustaining treatment decisions are on the horizon. The participating physicians described a range of factors that influence when and how they engage parents in treatment decisions. When physicians expected a good outcome, they made decisions to initiate life-sustaining treatments based on the child's best interest, with the assumption that parents shared the same goals. When physicians expected a poor outcome but were uncertain about the correct course of action, physicians engaged more with families, recognizing that they needed to work together to elicit and integrate the family's values into decision-making. However, when physicians expected a poor outcome but felt certain that life-sustaining treatment was medically futile, they limited the options offered to parents or worked to convince parents of their perceived "correct" course of action. Although shared decision-making has been conceptualized as a continuum between paternalism and informed choice,³⁸ physicians did not describe negotiating parental involvement but instead described determining the parental role based on their perceptions of child and parental interests. Our results reflect broader challenges to implementing family-centered care in neonatal and pediatric critical care including unequal power and authority in decision-making, clinical uncertainty, and the complexity of determining and balancing multiple child and family interests.¹²

Unequal power and authority stems from the fact that physicians are the ones to determine the level of engagement in shared decision-making with parents (vs routine engagement) based on the physicians' perceptions of the child's and parent's best interests. They are also the ones to assert claims of uncertainty or certainty about the outcome based on their clinical experience. A study comparing decision-making practices between physicians in French and American neonatal ICUs found that French physicians sometimes limited the role of parents in decision-making by transforming ambiguity into medical certainty.³⁹ In contrast, the American physicians evoked prognostic uncertainty to continue treatment and didn't offer treatment limitations.³⁹ Our findings were similar: when physicians were uncertain about outcomes, they presumed that families shared their goals for the child and initiated life-sustaining treatments without offering limitations.

Physicians described their own desires to "move the case along" once their view of the end point was clear, such as when a patient's clinical situation was not changing.⁴⁰ Futility

arguments guided when and how physicians engaged parents in decisions and were sometimes based on perceptions of suffering or that the child's anticipated quality of life would be poor. These quality-of-life concerns are in the context of increasing proportions of patients admitted to pediatric critical care with preexisting complex chronic illness, who have longer hospital stays, higher mortality rates, and more dependence on medical technology.⁴¹⁻⁴³

Yet physicians commonly underestimate a child and family's quality of life when a child survives with neurological impairment or chronic illness.^{41,44,45} Given the subjective nature of futility estimations, it is important for physicians to be clear about who is establishing the goals for the child and be self-reflective about their values.^{39,41,44,46} Regardless of the certainty that physicians have about outcomes, it is important that physicians offer noncoercive recommendations that are informed by the patient's and families' values about those outcomes.^{47,48} Topics to discuss include the interests of the parents, siblings, and family as a whole when formulating those recommendations.⁴⁹ Given the variation in decision-making strategies used by physicians, we suggest a systematic approach to involving parents such as a checklist to identify unmet family needs for goals of care conversations and preferences for prognostic information and recommendations and decision-making roles.^{12,50} Since parental preferences may change over time, regular reassessment should be performed.¹²

This analysis is limited by the fact that this study was done only with physicians at 1 quaternary care pediatric hospital and does not describe multidisciplinary health-care provider or family perspectives. The strategies and scenarios were prompted by questions about difficult communication and thus generally focused on when the physician and family disagreed about care. Physicians described the most difficult and ethically complex decision-making processes that may not represent typical communication that occurs on a more regular basis.

Conclusions

We have described several challenges to implementing shared decision-making in neonatal and pediatric ICUs, including unequal power and authority, clinical uncertainty, and complexity of determining and balancing child and family interests. Families may be excluded from discussions about goals of care and their values and preferences may not be integrated in decisions.^{39,51} We suggest a systematic approach to identify parental needs and preferences for information and roles in decision-making, with regular reassessment.

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Appendix A

Table A1

Interview Questions.

Opening

- 1 I'm curious, how did you get into this field? (Pediatric critical care)
- 2 How long have you been here?
- 3 What is most stressful about being a clinician in the ICU?
- 4 What do you think is the most stressful for families who have a child in the ICU?

Family communication

- 5 With the stress of the ICU, you are inserted into families' lives at one of the most difficult times for them. In that short amount of time, how do you figure out what kind of family you're working with or what kinds of things you need to do to be able to effectively communicate with them? What are you looking for?
- 6 How do you establish a relationship with a family?
- 7 How do you change how you communicate? How might you communicate with one family versus another one that you think is in a different kind of group?
- 8 If parents are overwhelmed how do you convey information to them?
- 9 How do you help families make decisions? How do you ask parents to make decisions that are not comfortable?
- 10 How do you communicate with families when there is a disagreement or you feel they're not quite understanding?
- 11 Do families look to you for advice of "What would you do if this was your child?"
- 12 Can you think of a case where you thought, wow, things went really well or really bad?
- 13 What makes a family a difficult family? What makes a family a likeable family?
- 14 What would trigger you to call a care conference?
- 15 Do you think there is anything we can do to train families to be better communicators about what's happening, to orient them differently?

Pediatric advanced care team (PACT)

- 16 What do you see as the role of PACT?
- 17 When do you call in the PACT team? (Clinical triggers? Patient not going to make it out of the ICU/assessing family values/medically complex/length of stay/continuity)
- 18 How do you decide which patient should be receiving a PACT consult and when they should be?
- 19 When wouldn't you call in the PACT team?
- 20 What are your experiences with the PACT team—good/bad?
- 21 Do you see differences between the families that have a PACT member involved and those that don't that are in similar kinds of circumstances?
- 22 Do you see a difference between PACT and social work? How do you see the social worker in your unit? What things would you go to them for versus what you could go to PACT for?
- 23 What's the value addition of PACT?
- 24 What are the qualities of the consultants? Do you find that certain ones are more helpful in certain situations than others?
- 25 How could PACT improve?

Wrapping up

- 26 If you had advice to give to a clinician about how to help families with a child in the ICU, what would you suggest?

27Is there anything else you would like to share with me before we bring this interview to a close?

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Table 1

Physician Characteristics.

Descriptor	n (%)
Experience	
Attending physician at hospital <5 years	10 (45)
Attending physician at hospital ≥ 5 years	12 (55)
Gender	
Female	7 (32)
Male	15 (68)
Pediatric critical care unit	
Cardiothoracic intensive care (CICU)	4 (18)
Pediatric intensive care unit (PICU)	4 (18)
Neonatal intensive care unit (NICU)	14 (64)

Table 2

Decision-Making Strategies.

Decision-Making Approach	Representative Quotes
Limiting options	<p>We will discuss this and say, “Oh, I wasn’t gonna talk to them about [renal replacement therapy]” ... a very invasive therapy ... All we’re doing is dragging this out. Dragging the inevitable out. That is not the best interest of the child in my opinion (PICU-01)</p> <p>We don’t talk about bringing up whether you should use antibiotics or not in someone that has a neurological process that’s not an infection. I see it as [extracorporeal membranous oxygenation’s] a different category of therapy that doesn’t really apply in this situation (PICU-02)</p>
Being directive or owning the decision	<p>Then when we really didn’t have anything, they felt, I think, satisfied that someone could say, “It’s time now,” and support them in that decision and make sure that they felt like they weren’t alone in deciding to, as I mom said, “You’re asking me to kill my child.” (PICU-05)</p> <p>My sense was that they were so stressed for a lack of a better word, with the circumstance that they just wanted to control that stress and the way to control that stress was to just stop what we were doing. And so my approach with them was to acknowledge that they were in this horrible situation but to acknowledge that it was horrible but to say this is not the moment when you’re coming to terms with this reality to make rash decisions. (CICU-04)</p>
Staying neutral	<p>All I do is I say, “These are our options: 1, 2, and 3. Any of them is the right answer, depending on what you think, cuz it’s your child, but I cannot make that decision for you. You have to choose between these 3 options.” (PICU-03)</p> <p>I say, “My belief system is not the same as yours, and you have to be comfortable with it. You can’t be comfortable with what I would tell you. I could tell you what I would do, but that doesn’t mean that’s what you should do.” Sometimes they push you for an answer, and then I tell ‘em what I would do, but I say, “That shouldn’t weigh your-shouldn’t sway your- you need to be comfortable with your decision, because you’re gonna have to live with it for the rest of your life. I’m not.” (CICU-02)</p>
Allowing parents to come to their own conclusions	<p>There were some moments where, the last week or 2, where I can perceive that the patient’s coming to an end. Yeah, that’s important to be able to just sometimes sit back I’m willing to do that.... You shouldn’t be put in a situation where you force things, to force everything, just force the issue and get what you want. I think it’s important to give parents the time to get the same conclusion. If it takes 1 week, 2 weeks, whatever it takes to get there, then, at least for myself, I think it’s respectful to give them to time to get to that point. (PICU-08)</p> <p>My clue into this was like- I was a fellow once and I was very struck by why we didn’t do CPR on this patient that was not DNR and I realized I saw that the attending was there ... and they kind of walked the family through ... and it worked because ... there’s one thing to say we’ve done all we can, and there’s another thing for people to see that is true. (PICU-02)</p>