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Speaking a Different Language: A Qualitative Analysis Comparing Language of Palliative Care and Pediatric Intensive Care Unit Physicians

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Abstract

Background—Family conferences in the pediatric intensive care unit (ICU) often include palliative care (PC) providers. We do not know how ICU communication differs when the PC team is present.

Aim—To compare language used by PC team and ICU physicians during family conferences.

Design—A retrospective cohort review of ICU family conferences with and without the PC team.

Setting—Forty-four bed pediatric ICU in a tertiary medical center.

Participants—Nine ICU physicians and 4 PC providers who participated in 18 audio-recorded family conferences.

Results—Of the 9 transcripts without the PC team, we identified 526 ICU physician statements, generating 10 thematic categories. The most common themes were giving medical information and discussing medical options. Themes unique to ICU physicians included statements of hopelessness, insensitivity, and “health-care provider challenges.” Among the 9 transcripts with the PC team, there were 280 statements, generating 10 thematic categories. Most commonly, the PC team offered statements of support, giving medical information, and quality of life. Both teams promoted family engagement by soliciting questions; however, the PC team was more likely to use open-ended questions, offer support, and discuss quality of life.

Conclusion—Pediatric ICU physicians spend more time giving medical information, whereas the PC team more commonly offers emotional support. The addition of the PC team to ICU family conferences may provide a balanced approach to communication.

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Declaration of Conflicting Interests

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Keywords

critical illness; child; health communication; qualitative; social support; decision-making; palliative medicine

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Introduction

Communication is one of the most important skills for a physician, especially during critical illness.^{1–4} In the intensive care unit (ICU), high-quality communication is imperative for building satisfaction and trust with the medical team.^{3,5,6} An important source of communication for families of critically ill children is the pediatric ICU family conference.^{7–10} This unique opportunity allows for various members of a child's clinical team to meet with families in order to provide medical updates, discuss medical or surgical treatments, and present options to change therapies from a curative approach to a palliative one.^{11,12} Palliative care team members are often integrated into these high-stakes family conferences in the ICU.^{13–15}

The palliative care team is invited to the family conference to offer an additional layer of psychosocial and emotional support during times of critical illness, such as aiding with family conflict and initiating discussions about goals of care,^{16–19} and although palliative care team communication is essential,²⁰ we do not know what the palliative care team actually says to accomplish that goal. Previous studies have highlighted the importance of language during a family conference in relation to family satisfaction.^{21–24} Elements associated with higher family satisfaction include increased proportions of empathetic statements, question-asking, and emotional talk,²² as well as assurance and support of a family's decision.²⁴ Whether the palliative care team adds these language elements to the ICU family conference is still unknown.

In this study, we compared the language used by the palliative care team and pediatric ICU physicians during family conferences to assess the added value of the presence of palliative care team.

Methods

Study Design and Setting

We conducted a single-center retrospective cohort study comparing family conferences in the pediatric ICU with the palliative care team present to conferences without the palliative care team. The unit is a 44-bed mixed medical-surgical pediatric ICU in an urban, tertiary medical center in the United States.

Data Collection

Data were originally collected from April 2012 to August 2014 for a cross-sectional, prospective study aimed at gaining a baseline understanding of what happens during pediatric ICU family conferences. Family conferences were audio recorded and transcribed. Methods for data collection of the original population were previously described.²² Briefly,

English-speaking parents of children in the pediatric ICU making a treatment decision, defined as a decision to initiate, escalate, or withdraw medical interventions, for their child were eligible for enrollment. The pediatric ICU attending physician on service was approached daily by a study team member to determine whether he/she anticipated conducting a family conference. Of the original 39 audio-recorded family conferences, we randomly selected 7 that included the palliative care team. We then randomly selected 7 transcripts of pediatric ICU family conferences without the palliative care team present. We continued this iterative process of adding additional transcripts for analysis until saturation was met (no new themes emerged). Saturation was attained after 9 transcripts of ICU family conferences with the palliative care team present were reviewed. Saturation of transcripts without the palliative care team present was met after review of the original 7 transcripts; however, we included 2 additional conferences to match the number of palliative care team present transcripts. In total, we collected and analyzed 18 transcripts. This study was approved by our institutional review board, protocol number Pro00002376. Written informed consent was obtained from all participants in the family conference.

Data Analysis

We used descriptive statistics to generate frequencies and analyze demographic variables. A Fisher exact test was used for comparison of categorical data and the Mann-Whitney *U* test for continuous variables. For qualitative analysis, we identified statements made by the pediatric ICU physicians and palliative care teams only. Statements made by other participants of the family conference, such as the clinical nurse, ICU social worker, or other consultant physicians, were not analyzed. Each individual statement was analyzed using qualitative content analysis, the systematic extraction and description of narrative content.²⁵ A code book was created and each new statement was repeatedly compared to other statements to determine recurring codes or create unique codes. Codes that emerged were then developed into themes. An iterative process of comparing codes and themes led to reductions and merging of similar themes. Two independent coders evaluated statements to inductively determine codes and themes.²⁶ After reduction of codes, 20% of the individual responses were analyzed for inter-rater reliability between the 2 coders; Cohen kappa was 0.9 ($P < .0001$).

Results

Demographic data did not differ between the cohorts (Table 1). In general, the purpose of the family conference included overall goals of care, tracheostomy, and other medical or surgical procedures. Nine pediatric ICU physicians participated in the 9 conferences without the palliative care present. Our ICU physician group includes 10 physicians, representing 90% of the group in the audio recordings. The palliative care team had 4 providers present during the 9 conferences with their involvement. The palliative care team at our institution consists of 2 nurse practitioners and 2 physicians, all of whom participated in the ICU family conferences.

Of the 9 transcripts of family conferences without the palliative care team present, we identified 526 pediatric ICU physician statements representing 10 thematic categories (Table

2). Most commonly, ICU physicians gave medical information to families. The second most common theme from the ICU physicians included discussing medical options. Six of 10 themes were also found in transcripts with the palliative care team present. The 4 themes unique to ICU physicians included prognosticating, statements of hopelessness, insensitivity, and health-care provider challenges. We defined hopelessness as statements declaring a patient's status irreversible, with no expectation of a favorable outcome. Insensitivity includes statements lacking tact and disregarding the family or patient's feelings. Health-care provider challenges are defined as statements acknowledging difficulties that this patient's case presents for the medical team, including emotional burden, time-commitments, and workflow stressors. They are health-care team-centric, not family-centric, statements.

Among the 9 palliative care team conferences, there were 280 statements generating 10 thematic categories (Table 3). The most common themes included statements of support, giving medical information, and quality of life. The palliative care team had unique categories of statements of encouraging consulting services, summarizing, praise, and normalizing emotions. Encouraging consulting services included leading questions directed at other members of the medical team, such as another consultant or clinical nurse, often to clarify medical treatment. Summarizing reflected on prior discussions or relationships as well as simplifying the medical team's language to the family. Normalizing emotions included statements that put the family's feelings within the scope of other families who have had a similar experience. Of the 6 overlapping themes with the ICU team, the palliative care team was more likely to offer supportive statements, discuss quality of life, and encourage family engagement. The palliative care team was less likely to give medical information or discuss medical options or uncertainty.

Another difference noted between the languages used by the palliative care team compared to that of ICU physicians was that the palliative care team was more likely to use open-ended questions. Finally, during qualitative analysis, the research team had difficulty categorizing ICU team statements, in that the language was often cumbersome and lengthy. This was not only noted by coders but was also demonstrated by the ICU team having almost twice as many statements (526 vs 280) during the same number of conferences.

Discussion

The pediatric ICU team and palliative care team appear to speak different languages during family conferences. Although ICU physicians spent a majority of time (54%) presenting medical information (either giving information or discussing medical options), the palliative care team offered support and discussed quality of life 51% of the time. The palliative care team used a more supportive language and included phrases of praise, encouragement, and emotional reassurance.

This study provides insight into the potential value the palliative care team can bring to pediatric ICU family conferences. In the literature, 2 types of social support have been identified—emotional support and instrumental support.^{27,28} Emotional support refers to the things people do or say that make us feel loved and cared for, whereas instrumental support

refers to the tangible help that others provide.²⁷ Both are necessary to promote physical and mental well-being,^{28–31} yet in our pediatric ICU, the ICU physicians deliver mainly instrumental speech. This gap in support can detrimentally affect the relationship between families and the clinical team.

Our field notes showed a recurrent pattern of short, supportive statements made by the palliative care team. The ease at which the palliative care team statements and sentiments were understood by the coders is likely received in a similar manner by families. And the emotional supportive language the palliative care team delivers provides an opportunity to achieve support balance and truly provide family-centered care.

The strengths of the pediatric ICU team cannot be understated. For families to make critical decisions, they also need to hear the medical information, discuss options and prognosis, and balance that information with the effects on quality of life. Medically focused language is equally important for decision-making. We would, however, recommend limiting negative language, language that fell into categories of hopelessness, insensitivity, and health-care provider challenges. These categories shift the focus away from the family, can create conflict or erode trust and damage relationships that are critical to shared decision-making. We suspect physicians making these comments were not intentionally aiming to disregard families' emotional needs. We did not see any of these types of statements among the 280 statements made by the palliative care team. This may be a result of palliative care training inherently including communication skills and techniques, which is frequently lacking in ICU training.^{32–36} Offering communication skills training to all physicians may change the value the medical field places on communication.

To our knowledge, this is the first study comparing language of palliative care and pediatric ICU team. With their combined strengths, the palliative care and pediatric ICU teams may create a well-rounded, family-centered communication experience for families that delivers important medical information while simultaneously offering support.

Limitations

This article offers a unique exploration of the ICU family conference, but it does have several limitations to report. First, the number of family conferences constitutes a small sample size with a total number of 18 transcripts representing language from 13 physicians. Because there were a large number of statements, we were able to reach saturation with this small number of recordings. Of the 13 physicians, we recognize that the 4-person palliative care team comprised 2 physicians and 2 nurse practitioners, and there is a possibility that this cross-disciplinary mix may also factor into the types of statements made by the palliative care team. Unfortunately, the transcripts do not provide enough identification of the speakers. We also recognize that as a single-center study, we are limited in our ability to generalize our findings to other centers. Third, this study restricted enrollments to decision-making family conferences only and did not include conferences providing medical updates or delivering serious news. We chose this selected group of conferences because of the high-stakes of medical decision-making and the likelihood that families would be more engaged. From our previous work, we found there was more family-physician dialogue in decision-making family conferences compared to other indications for family conferences. Although

this research gives us eye-opening information about decision-making family conferences, this is not the only form of communication we have with families, and thus we cannot draw conclusions about bedside conferences, family-centered rounds, or other methods of family-physician communication.

Conclusion

During pediatric ICU family conferences, ICU physicians mainly provide instrumental support by giving medical information, whereas the palliative care team offers emotional support to families. Intensive care unit physicians at times use language that may be perceived by families as insensitive. Including palliative care consultants into the ICU family conference may be an ideal way to balance the support needs of the family and optimize family-centered communication.

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Table 1**Patient and Physician Characteristics.**

	Palliative Care Team Present	Palliative Care Team Not Present	P Value
Patient Characteristics	n = 9 (%)	n = 9 (%)	
Sex: male	6 (67)	6 (67)	1
Age, months, median (IQR)	60 (132)	17 (17)	.42
Race			.62
African American	5 (56)	7 (78)	
Non-Hispanic white	4 (44)	1 (11)	
Other	0 (0)	1 (11)	
Treatment decision discussed			.29
Overall goals of care	4 (45)	1 (11)	
Tracheostomy	3 (33)	6 (67)	
Procedure	2 (22)	2 (22)	
Disposition upon discharge			1
Home	4 (45)	5 (56)	
Subacute facility	2 (22)	2 (22)	
Death	2 (22)	2 (22)	
Other hospital	1 (11)	0 (0)	
Provider Characteristics	Palliative Care Team ^a n = 4 (%)	Pediatric ICU Team, n = 9 (%)	
Sex male	2 (50)	4 (44)	.33
Years of experience			.13
<5 years	1 (11)	8 (67)	
>5 years	8 (89)	4 (33)	

Abbreviations: ICU, intensive care unit; IQR, interquartile range.

^aPalliative care team includes both physicians and nurse practitioners.

Table 2

Pediatric Intensive Care Unit Medical Team Thematic Categories.

Themes	Frequency, n = 526 (%)	Sample Quotes
Medical information giving	219 (42)	"And what we've done, stepwise, is that every day we've gone up on one medication"
Medical options	65 (12)	"But, one thing that we could potentially do is to put him on something that's very similar to a heart-lung machine, and take blood out of his body, put oxygen in it, and then send the blood back to his body"
Support	57 (11)	"It's a place no parent ever wants to be, and I can't imagine what it's like to be in your shoes right now, but we want you to know that we will support you through either path"
Prognostication	44 (8)	"We can't say anything definitively, but at this stage, we do not expect a recovery"
Uncertainty	32 (6)	"We don't really know"
Encourage family engagement	30 (6)	"So, other questions guys?"
Hopelessness	30 (6)	"We sat down, we talked with the neurology team, we talked together, the rehab docs talked together and, you know, there are some kids that, that don't recover. Just flat out don't recover"
Insensitivity	18 (3)	"Basically they're movements that you wouldn't expect a – a normal child to make"
Quality of life	17 (3)	"It's not that he's crazy, it's that he has been given a burden. He doesn't know any different, but at times he, it's burdensome to him. It's hard on him"
Health-care provider challenges	14 (3)	"I can speak for the team. I mean this is such a hard – you know we do what we do because many times we have good things to tell families and when we have to sit down and tell these bad things and give you this tremendous burden, um, we do it with a heavy heart and we are absolutely committed to him"

Table 3

Palliative Care Team Thematic Categories.

Themes	Frequency, n = 280 (%)	Sample Quotes
Support	78 (28)	"So we really want to try and think of what's gonna be best not just for {patient} but for all of you and your family to try to help her the most"
Medical information giving	47 (17)	"He'll need 24 hour care that can handle his trach and his ventilator"
Quality of life	36 (13)	"And sometimes helping {her} the best is just loving her and making her comfortable"
Medical options	23 (8)	"Or versus not doing the treatment and knowing that if he has active disease that that could also cause his death"
Encourage consulting services	22 (8)	"Dr. {PICU} do you think she'll ever breathe off of the ventilator on her own?"
Summarize	22 (8)	"And so these are new changes in the last few months since then, is what I'm hearing you say"
Encourage family engagement	19 (7)	"Why don't you talk a little bit about what the GI doctors told you and what your understanding is of what they said? That might help all of us to understand a little bit more"
Praise	14 (5)	"It's very clear that you both love her dearly and that you'll do anything you can to support her through this"
Normalizing emotions	13 (5)	"It's very normal to have the feelings that you are having and almost every parent that we – we care for with a child who is so sick like this has the same kinds of feelings that you have"
Uncertainty	8 (3)	"Also one of the difficult things is that, um, we don't know how much he will recover"