

The Use of Family Conferences in the Pediatric Intensive Care Unit

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Abstract

Background: Data about pediatric intensive care unit (PICU) family conferences (FCs) are needed to enhance our understanding of the role of FCs in patient care and build a foundation for future research on PICU communication and decision making.

Objective: The study's objective was to describe the use and content of PICU FCs.

Design: The study design was a prospective chart review comparing patients who had conferences with those who did not, and a sub-analysis of patients with chronic care conditions (CCCs).

Setting/subjects: The study setting was an academic PICU from January 2011 through June 2011.

Measurements: Medical events under consideration were placement of tracheostomy or gastrostomy tube; initiation of chronic ventilation; palliative care involvement; use of extracorporeal membrane oxygenation, continuous renal replacement, or cardiopulmonary resuscitation; care limitation orders; death; length of stay; and discharge to a new environment.

Results: From 661 admissions, we identified 74 conferences involving 49 patients. Sixty-four conferences (86%) were held about 40 patients with CCCs. Having a conference was associated with ($p < 0.05$): length of PICU admission; palliative care involvement; initiation of chronic ventilation; extracorporeal membrane oxygenation; cardiopulmonary resuscitation; death; discharge to a new environment; and care limitation orders. Twenty-nine percent of patients who had a new tracheostomy or gastrostomy tube placed had a conference. We identified two categories of discussion topics: information exchange and future management.

Conclusions: Most identified FCs involved complex patients or patients who faced decisions affecting the child's quality of life or dying. For many patients who faced life changing decisions we did not identify a FC. Further research is needed to understand how to best utilize FCs and less formal conversations.

Introduction

THERE IS GROWING INTEREST in family conferences (FCs) conducted in intensive care units (ICUs).¹⁻⁵ Important uses for FCs include giving "bad news," discussing medical decisions, and eliciting family values and perspectives.²⁻¹¹ Data from adult ICUs demonstrate that certain clinician communication behaviors during FCs correlate with increased family satisfaction.^{12,13} One study showed that a protocol for conducting FC discussions involving end-of-life care decisions lessened the burden of bereavement for families.¹⁴ Experts argue that FCs provide opportunities "in-

corporat[ing] most of the recommended strategies for enhancing communication and optimizing end-of-life care."¹⁵ Thus FCs may be an important mode of communication in ICUs and *well-conducted* FCs could benefit families and patients, particularly those facing difficult end-of-life care decisions.

Despite the potential benefits of FCs, minimal data exist on FCs held in the pediatric intensive care unit (PICU), leaving pediatric critical care providers without basic data about when and for whom PICU FCs occur. In our recent retrospective qualitative study of PICU end-of-life care, bereaved parents commented very little on FCs in descriptions of

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communication about key decisions.¹ The data did not permit us to assess whether the paucity of comments from parents reflected an absence of FCs held for the patients whose parents we interviewed or if FCs were not memorable experiences for those parents. Little information exists about the population for whom PICU FCs are held.

In this study we describe the use of FCs in one PICU. We characterize the patients for whom we identified FCs and compare them with patients for whom we did not identify a FC. We describe the content of discussions during FCs based on documentation in the medical record. These data enhance our understanding of the role of FCs in care and decision making for PICU patients.

Methods

We identified FCs in a university-based, tertiary care children's hospital PICU from January 1, 2011 through June 30, 2011. Patients in the 42-bed "closed" PICU (a pediatric intensivist is the attending physician for all patients) include those with medical conditions as well as general or cardiac surgical patients. The PICU medical teams include an attending, PICU fellow, pediatric residents, or PICU advance practice nurses (APNs). Subspecialists collaborate with the PICU medical team in caring for subspecialty patients admitted to the PICU. The project was approved by the hospital's institutional review board.

We defined FC as a planned meeting involving parents, multiple health care professionals (such as physicians, APNs, nurses, social workers, chaplains, and others), and when present, nonhealth care professionals providing support to the parents (such as family, friends, etc). Hereafter, we also refer to these as 'formal' meetings. We did not include information about documented bedside conversations, such as impromptu parent updates or one-on-one conversations, or discussions held during daily family centered rounds (parents are invited to participate in rounds). To identify FCs, one person reviewed all PICU patients' notes (the header and body of notes) from the electronic medical record each weekday; this included all notes from physicians (PICU and subspecialty physicians), bedside nurses and APNs, social workers, case managers, and any other hospital personal. We used the following terms to identify a FC: "patient care conference," "care conference," "family conference," "family meeting," and "meeting." If the chart referred to but was unclear about whether a FC happened or was likely to happen, we asked members of the PICU medical team if a conference had been held, using the definition and terms described above. We also inquired daily of the PICU medical team about FCs and asked all PICU physicians and APNs to contact us when a conference was planned. Finally, in an effort to identify FCs we might have missed through the weekday review, two investigators retrospectively reviewed the medical records of patients for whom we did not prospectively identify a FC, using the process described above.

We recorded the following for all patients: age; sex; primary language; race/ethnicity; insurance status; PICU admission and discharge dates; presence of care limitations at admission, such as a do not resuscitate (DNR) order; and previous palliative care consultations. Two patients ≥ 40 years old were excluded from the analysis. We also recorded the occurrence during the PICU stay of an *a priori* determined

list of medical events: placement of tracheostomy tube; placement of gastrostomy tube; initiation of chronic ventilation; introduction of palliative care services; use of extracorporeal membrane oxygenation (ECMO); use of continuous renal replacement therapies (CRRT); use of cardiopulmonary resuscitation (CPR); new orders describing care limitations, such as a DNR order; death; and discharge to a new environment (e.g., if the patient had been living at home and was discharged to an alternative site, such as a long-term care facility). We chose these events based on their high association with mortality (e.g., ECMO and CPR) and/or their relevance as potentially life changing events impacting the patient's quality of life and/or end-of-life experience, and their likelihood to involve parental decision making.¹⁶

For patients with a documented FC, we recorded the date of the conference; information about use of vasopressors and mechanical ventilation at the time of the FC; and the percent risk of mortality, using pediatric index of mortality 2 (PIM2) scores.¹⁷ Because PIM2 scores were not available for all PICU patients admitted during the study period, we compared PIM2 scores from patients with an identified FC to PIM2 scores for all PICU patients admitted from January through June 2010, collected from the hospital PICU database. To focus on the occurrence of FCs in patients with complicated medical problems, we identified a subpopulation of PICU patients who had any complex chronic condition (CCC) defined by a previously developed set of ICD-9 codes.¹⁸

Patient demographics and PICU medical events of interest were summarized with percentages for categorical variables and mean, median, and range for continuous variables. Bivariate analysis was performed using Mann-Whitney U, Pearson's chi-square, and Fisher's exact tests to determine significant associations between the presence of a FC for the general PICU population and the subpopulation of patients with a CCC. All analyses were conducted using SPSS 20.0 (SPSS Inc., Chicago, IL). We used $p < 0.05$ to define statistical significance.

To learn more about FC discussions, we did a content analysis of all provider documentation about FCs. Content analysis seeks to describe the content or topics of communication (in this case the content of documentation about PICU FCs).¹⁹ We analyzed documentation from any provider (physician, nurse, social worker, case manager, etc.). Two researchers (NHB and CR) reviewed the FC documentation and separately defined topics discussed. Based on their individual lists, those same researchers agreed upon an inclusive list of topics, or codes. Two researchers (one involved in developing the coding schema, NHB, and one not involved in that process, KM) coded the documentation separately using the agreed-upon codes. Discrepancies between the coders were resolved by consensus. Via group discussion, all three researchers identified broad topic categories. To determine the frequency of topics documented we counted a topic once for each FC even if it was mentioned multiple times in the same note and/or by two different people documenting about the same conference. We used ATLAS.ti Version 6.0.15 (ATLAS.ti scientific software development GMBH, Berlin, Germany) for the qualitative data analysis.

Results

During the study period there were 661 admissions to the PICU involving 562 patients. We identified 74 FCs during 51

admissions of 49 patients. Eight FCs had no documentation in the medical record; we identified these meetings through conversations with the PICU medical team. We found 54 FCs via our weekday surveillance and 20 via retrospective chart review. We did not identify a FC for 515 patients. Three patients had 2 FCs and 5 patients had greater than 2 FCs. There were 490 admissions of 401 patients with a CCC. From this subgroup we identified 64 FCs during 41 admissions of 40 patients. Thus FCs about patients with a CCC comprised 86% (64/74) of all identified FCs.

Table 1 describes the demographic variables for patients with and without an identified FC, stratified by all PICU patients and those with a CCC. We found no statistically significant associations between the demographic variables and having a FC for the general PICU population or for those with a CCC.

Table 2 describes the *a priori* defined medical events of interest as well as previous involvement of the palliative care team for patients with and without an identified FC, stratified by all PICU patients and those with a CCC. For the general PICU population and patients with a CCC, events associated with having a FC included length of PICU admission; previous and new involvement of palliative care; initiation of chronic ventilation; ECMO; CPR; death; discharge to a new environment; and a new DNR order. For all patients (but not for those with a CCC), placement of a gastrostomy tube was also significantly associated with having a FC.

Many patients who had a medical event of interest during their PICU admission never had a FC. Specifically, only 29% of patients who had CRRT, a new tracheostomy tube, or a new gastrostomy tube placed during their admission had a FC. Fewer than half (45%) of patients who had CPR during their

admission had a FC. Only 67% of patients who had initiation of chronic ventilation or ECMO had a FC.

Mean and median time from admission to first FC was one and three days respectively (range 1–128 days). Three patients had prolonged PICU stays prior to the first FC we identified; these patients had been admitted before we started data collection for this study. Excluding those three patients, the mean and median time from admission to first FC was one and three days respectively (range 1–27).

Using PIM2 scores, the mean and median predicted mortality for patients who had a FC were 15% and 4.6% respectively (range 0.4%–97.7%), compared to 0.9% and 0.9% respectively (range 0.02%–99.5%) for all patients admitted to the PICU during a similar period (January through June 2010). Thirty (41%) FCs involved patients requiring invasive mechanical ventilation at the time of the FC. Eighteen (24%) FCs involved patients who were on vasopressors at the time of the FC.

We analyzed the documentation of 60 FCs. Eight FCs had no documentation, as described above, and for six FCs, the medical record documentation indicated a FC occurred but provided no information about the conference content. We found no consistent documentation with respect to format, content, or person doing the documentation (social worker, attending physician, etc.).

Content analysis identified two broad categories of documented FC discussion topics: information exchange (see Table 3) and discussion about future management (see Table 4). Regarding information exchange, professionals documented that they told families about the patient’s medical condition in just over half (52%, *n*=31) of FCs. Clinicians commented on family understanding of the child’s medical situation in 78% (*n*=47) of the notes. Other topics included discussions about

TABLE 1. DEMOGRAPHIC DATA FOR PATIENTS WITH AND WITHOUT FAMILY CONFERENCES

Variable	All admissions with a FC ^a (n=74)	All admissions without a FC ^a (n=587)	P value	CCC admissions with a FC ^a (n=64)	CCC admissions without a FC ^a (n=426)	P value
Average age (median, range)	7.2 (5, 0–21)	6.5 (4, 0–25)	0.423	7.6 (6, 0–21)	6.5 (4, 0–25)	0.194
Sex			0.653			0.600
Male	41 (55%)	309 (53%)		35 (55%)	218 (51%)	
Female	33 (45%)	278 (47%)		29 (45%)	208 (49%)	
Ethnicity			0.414			0.365
White	30 (40%)	242 (41%)		27 (42%)	182 (43%)	
Hispanic/Latino	25 (34%)	175 (30%)		19 (30%)	123 (29%)	
Black	17 (23%)	113 (19%)		16 (25%)	79 (18%)	
Asian	0	29 (5%)		0	25 (6%)	
American Indiana/Alaska Native	0	1 (0)		0	1 (0%)	
Other	2 (3%)	25 (4%)		2 (3%)	15 (4%)	
Unknown	0	2 (0)		0	1 (0%)	
Primary language			0.261			0.234
English	59 (80%)	503 (86%)		51 (80%)	368 (86%)	
Spanish	15 (20%)	79 (13%)		13 (20%)	54 (13%)	
Other	0	5 (1%)		0	4 (1%)	
Insurance			0.554			0.935
Private ^b	25 (34%)	219 (37%)		24 (37%)	162 (38%)	
Public	49 (66%)	368 (63%)		40 (63%)	264 (62%)	

^aIncludes all patient admissions. Some patients were admitted to the PICU >1 time during the study period.

^bIncludes one patient whose family paid for his or her medical care.

CCC, complex chronic condition; FC, family conference.

TABLE 2. MEDICAL EVENTS DURING THE PICU ADMISSION

Variable	All patients with a FC ^a (n=74)	All patients without a FC ^a (n=587)	P value	CCC patients with a FC ^a (n=64)	CCC patients without a FC ^a (n=426)	P value
Average length of PICU admission (median, range)	41.1 (25, 1–173)	6.9 (3, 1–211)	<0.001	43.2 (27, 1–173)	7.2 (4, 1–211)	<0.001
Palliative care involved prior to PICU admission			0.001			0.001
Yes	5 (7%)	3 (1%)		5 (8%)	3 (1%)	
No	69 (93%)	584 (99%)		59 (92%)	423 (99%)	
Palliative care introduced during PICU admission			<0.001			<0.001
Yes	10 (13%)	3 (1%)		10 (16%)	3 (1%)	
No	64 (87%)	584 (99%)		54 (84%)	423 (99%)	
Placement of a tracheostomy tube			0.179			0.505
Yes	2 (3%)	5 (1%)		1 (2%)	4 (1%)	
No	72 (97%)	582 (99%)		63 (98%)	422 (99%)	
Placement of a gastrostomy tube			0.010			0.106
Yes	6 (8%)	15 (3%)		5 (8%)	15 (4%)	
No	68 (92%)	572 (97%)		59 (92%)	411 (96%)	
Initiation of chronic ventilation			<0.001			<0.001
Yes	14 (19%)	7 (1%)		13 (20%)	7 (2%)	
No	60 (81%)	580 (99%)		51 (80%)	419 (98%)	
CRRT			0.179			0.229
Yes	2 (3%)	5 (1%)		2 (3%)	5 (1%)	
No	72 (97%)	582 (99%)		62 (97%)	421 (99%)	
ECMO			<0.001			0.003
Yes	6 (8%)	3 (1%)		4 (6%)	2 (1%)	
No	68 (92%)	584 (99%)		60 (94%)	424 (99%)	
CPR			<0.001			<0.001
Yes	10 (14%)	12 (2%)		9 (14%)	9 (2%)	
No	64 (86%)	575 (98%)		55 (86%)	417 (98%)	
Death			<0.001			<0.001
Yes	15 (20%)	4 (1%)		12 (19%)	2 (1%)	
No	59 (80%)	583 (99%)		52 (81%)	424 (99%)	
Discharge to a new environment			<0.001			<0.001
Yes	17 (23%)	4 (1%)		12 (19%)	0 (0%)	
No	57 (77%)	583 (99%)		52 (81%)	426 (100%)	
New DNR			<0.001			<0.001
Yes	20 (27%)	5 (1%)		18 (28%)	4 (1%)	
No	54 (73%)	582 (99%)		46 (72%)	422 (99%)	

^aIncludes all patient admissions. Some patients were admitted to the PICU >1 time during the study period.

CCC, complex chronic condition; CPR, cardiopulmonary resuscitation; CRRT, continuous renal replacement therapy; DNR, do not resuscitate order; FC, family conference; PICU, pediatric intensive care unit.

brain death (8%, $n=5$), when a brain death exam had been done or was being considered, and comments about the health care team's intent to support the family (18%, $n=11$). There was documentation that clinicians attempted to obtain information about families' religious beliefs and needs in 8% ($n=5$) of FCs.

In the discussion of future management, we identified four subcategories: general care plans, use of invasive mechanical therapies, limitation(s) of therapies, and end-of-life care management. The medical record indicated that goals of care were discussed in only 23% ($n=14$) of documented conferences. Use of mechanical therapies involved discussions about tracheostomy tube placement (20%, $n=12$), gastrostomy tube placement (2%, $n=1$), use of chronic ventilation (12%, $n=7$), and use of ECMO (2%, $n=1$). Forty-two percent

($n=25$) of documented conferences involved discussions about DNR and 15% ($n=9$) addressed withdrawing life-sustaining therapies. Topics within the end-of-life management subcategory included conversations about the dying process (28%, $n=17$), comfort care (30%, $n=19$), and organ donation (2%, $n=1$).

Discussion

We present data about the use and content of FCs in one PICU. In this PICU FCs occurred for a minority of patients, often soon after admission, generally involved sicker than average patients, based on PIM2 scores, and more commonly involved patients with CCCs. A notable percentage of patients without an identified FC experienced potentially life

TABLE 3. FAMILY CONFERENCE DOCUMENTATION: INFORMATION EXCHANGE

<i>Discussion topic</i>	<i>Explanation</i>	<i>Occurrence in FC (n=60)</i>
Update clinical status	Discussion of the patient's medical situation	31 (52%)
Brain death	Conversations explaining brain death and/or discussing the results of brain death exams	6 (10%)
Family understanding	Comments indicating the family seems to understand the medical situation	47 (78%)
Attention to religious issues	Asking the family about their need for a religious leader, a chaplain, a quiet place to pray, relevant religious rules	5 (8%)
Family support	Report that the health care team provided and/or will continue to provide support ^a to the family	11 (18%)

^aThe type of support was not defined. FC, family conference.

changing or life limiting medical events. Eleven percent of FCs identified had no documentation in the medical record. From available documentation we found that FC discussions involved information exchange between health care professionals and families and future planning discussions about care and medical decisions.

Our findings suggest, consistent with previous publications, that FCs provide one venue for communication and decision making.^{1-3,7,15} Our previous work indicated clinicians attribute considerable importance to FCs.¹ These data, however, suggest that clinicians use FCs for only some patients who face serious, potentially life changing decisions and that FCs sometimes occur weeks after admission to the PICU. Given the gravity and impact of the information exchanged during PICU FCs, optimizing the timing, content, and process of determining when to have FCs is imperative to facilitate

discussion, foster family trust, and maximize family centered decision making.

These data provide information about the patients for whom FCs took place and equally important information about patients for whom we did not identify a FC. We identified a FC in only 29% of patients who had CRRT, a new tracheostomy, or a new gastrostomy tube placed, and 45% who had CPR. Seemingly many families faced serious life changing decisions or events without having a FC. If clinicians believe in the importance and benefit of FCs, perhaps they should identify triggers for holding FCs, such as illness severity markers, ongoing or anticipated need for decisions requiring family input, and/or extended PICU stays. A similar kind of approach is used by some to identify patients for palliative care consultation.²⁰ Clinicians should also consider checklists or scripts to ensure discussion of

TABLE 4. FAMILY CONFERENCE DOCUMENTATION: DISCUSSION OF FUTURE MANAGEMENT

<i>Discussion topic</i>	<i>Explanation</i>	<i>Occurrence in FC (n=60)</i>
<i>General plans</i>		
Goals of care	Discussion of goals in order to define a treatment plan	14 (23%)
Discharge planning	Discussion of any discharge plans	9 (15%)
Diagnostic testing	Discussion of tests that may need to be performed	3 (5%)
<i>Use of mechanical therapies</i>		
Tracheostomy	Discussion or decision about tracheostomy	12 (20%)
Gastrostomy tube	Discussion or decision about G-tube placement	1 (2%)
Chronic ventilation	Discussion or decision about initiation of chronic ventilation	7 (12%)
ECMO	Discussion or decision about ECMO	1 (2%)
<i>Limitation of therapies</i>		
DNR/DNI	Discussion or decision about DNR/DNI limitations	25 (42%)
Withdrawing life-sustaining therapies	Discussion or decision about withdrawing life-sustaining therapies	9 (15%)
<i>End-of-life care management</i>		
Death	Discussion of the dying process and parents' wishes regarding their child's death	17 (28%)
Comfort care	Defining comfort care, what the family expects from comfort care, and what the health care team can offer	18 (30%)
Organ donation	Discussion or decision about the option of organ donation	1 (2%)

DNR/DNI, do not resuscitate/do not intubate; ECMO, extracorporeal membrane oxygenation; FC, family conference; G-tube, gastrostomy tube.

important topics during FCs and/or prompt clinicians about key components of FCs, including assessing parental understanding, acknowledging parents' emotional states, considering religious beliefs, and eliciting parental attitudes about recommendations.

For patients who had significant events but no identified FC, we assume some discussion and decision making occurred outside of formal meetings. FCs represent one mode of communication. Information exchange and discussion between clinicians and families in the PICU occurs in many settings: daily rounds, impromptu bedside conversations, and spontaneous encounters outside the PICU (e.g., in the hallway).²¹ A few ethnographic studies have examined less formal modes of communication in adult and neonatal ICUs, but we have found no similar studies of PICUs.^{22–25} A recent study used physician recall to describe the importance of bedside conversations.²⁶ More research on PICU communication and decision making is needed to identify and characterize the conduct and impact of discussions outside of FCs.

Perhaps the absence of FCs for patients who faced challenging decisions demonstrates that clinicians or families may prefer other, less formal modes of communication. Certainly some families may prefer one-on-one bedside conversations with a trusted health care team member to formal meetings. This study cannot clarify why one mode of communication took place versus another, if decisions about having FCs were made intentionally, and/or who benefits most (families or health care providers) from a particular mode of communication. Such topics deserve further study.

Our review of FC documentation provides some insight into the content of FC discussions, though of limited quality. Surprisingly, documentation in only 52% of FCs described updating families about the patient's medical status. The literature suggests that providing such updates are a fundamental component of FCs.^{4,5,8,10} However, the documentation about FCs provides limited information about the content of these meetings; perhaps updates occurred but were not documented. Guidelines note the importance of good documentation about discussion during FCs.^{5,8} In this study, 20% (14/74) of FCs were not documented at all ($n=8$) or provided no information about conference content ($n=6$). We believe at least one clinician attending the FC should document the basic content of the discussion; ideally, each different type of professional who participated (social worker, chaplain, etc.) should record information relevant to his or her expertise. Others describe the importance of documenting the FC time, date, location, and participants.⁸

It is intriguing that in 78% of the documented conferences a provider noted that the family seemed to understand their child's medical situation. We cannot assess the accuracy of such comments. Clinicians sometimes incorrectly believe families understand medical facts and treatment options. Data from adult patient-provider interactions show that clinicians often do a poor job of speaking in understandable language.^{27–29} In one study, bereaved parents of PICU patients noted problems understanding clinicians' complex vocabulary.³⁰ Data from studies of informed consent in pediatric cancer trials demonstrate poor understanding among parents of children eligible for clinical trial enrollment.³¹ Future research should assess actual family understanding of PICU FC discussions.

We recognize limitations to this work. The medical record may not reflect actual FC discussions. Accurate assessment of FC content could involve direct observation and/or recording conferences. Obtaining information about FCs in only one PICU represents another limitation. The use and content of FCs may differ at other hospitals for many reasons, including institutional culture and patient population. A study including multiple PICUs could improve generalizability and would provide information on more FCs. Because we have data on only 74 FCs, some of the associations found between the studied variables and FCs may be misleading. Finally, we may have missed some FCs that occurred. We tried to avoid this through prospective chart review, inquiries with the medical team, and follow-up retrospective chart review.

Conclusions

FCs in this PICU typically involve sicker patients, often those with CCCs, and patients who face decisions impacting end-of-life care or the child's future quality of life. For many patients who faced important decisions, we did not identify a FC, suggesting a potential need to identify triggers for convening FCs. These results demonstrate the need for more research on FCs and on the many, less formal conversations occurring in the PICU. Further research should explore mechanisms to identify families that might benefit from FCs and those families who would be better served by less formal modes of communication. This information would help shape interventions to improve and maximize family centered communication and decision making in the PICU.

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References

1. Michelson KN, Emanuel L, Carter A, Brinkman P, Clayman ML, Frader J: Pediatric intensive care unit family conferences: One mode of communication for discussing end-of-life care decisions. *Pediatr Crit Care Med* 2011;12(6): e336–e343.
2. Cypress BS: Family conference in the intensive care unit: A systematic review. *Dimens Crit Care Nurs* 2011;30(5): 246–255.
3. Billings JA: The end-of-life family meeting in intensive care part II: Family-centered decision making. *J Palliat Med* 2011; 14(9):1051–1057.
4. Billings JA: The end-of-life family meeting in intensive care part I: Indications, outcomes, and family needs. *J Palliat Med* 2011;14(9):1042–1050.

5. Billings JA, Block SD: The end-of-life family meeting in intensive care part III: A guide for structured discussions. *J Palliat Med* 2011;14(9):1058–1064.
6. Davidson JE, Powers K, Hedayat KM, et al.: Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005. *Crit Care Med* 2007;35(2):605–622.
7. Boyle DK, Miller PA, Forbes-Thompson SA: Communication and end-of-life care in the intensive care unit: Patient, family, and clinician outcomes. *Crit Care Nurs Q* 2005;28(4):302–316.
8. Nelson JE, Walker AS, Luhrs CA, Cortez TB, Pronovost PJ: Family meetings made simpler: A toolkit for the intensive care unit. *J Crit Care* 2009;24(4):626, e627–e614.
9. Fineberg IC, Kawashima M, Asch SM: Communication with families facing life-threatening illness: A research-based model for family conferences. *J Palliat Med* 2011;14(4):421–427.
10. Curtis JR, White DB: Practical guidance for evidence-based ICU family conferences. *Chest* 2008;134(4):835–843.
11. Gay EB, Pronovost PJ, Bassett RD, Nelson JE: The intensive care unit family meeting: Making it happen. *J Crit Care* 2009;24(4):629, e621–e612.
12. Stapleton RD, Engelberg RA, Wenrich MD, Goss CH, Curtis JR: Clinician statements and family satisfaction with family conferences in the intensive care unit. *Crit Care Med* 2006;34(6):1679–1685.
13. McDonagh JR, Elliott TB, Engelberg RA, et al.: Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction. *Crit Care Med* 2004;32(7):1484–1488.
14. Lautrette A, Darmon M, Megarbane B, et al.: A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med* 2007;356(5):469–478.
15. Lautrette A, Ciroldi M, Ksibi H, Azoulay E: End-of-life family conferences: Rooted in the evidence. *Crit Care Med* 2006;34(11 Suppl):S364–S372.
16. Michelson KN, Patel R, Haber-Barker N, Emanuel L, Frader J: End-of-life care decisions in the PICU: Roles professionals play. *Pediatr Crit Care Med* 2013;14(1):e34–e44.
17. Slater A, Shann F, Pearson G: PIM2: A revised version of the Paediatric Index of Mortality. *Intensive Care Med* 2003;29(2):278–285.
18. Feudtner C, Christakis DA, Connell FA: Pediatric deaths attributable to complex chronic conditions: A population-based study of Washington State, 1980–1997. *Pediatrics* 2000;106(1 Pt 2):205–209.
19. Wilkinson S: Focus group research. In: Silverman D (ed): *Qualitative Research: Theory, Method and Practice*. Thousand Oaks, CA: SAGE Publications, 2008, pp. 177–199.
20. Friebert S, Osenga K: Pediatric Palliative Care Referral Criteria. www.capc.org/tools-for-palliative-care-programs/clinical-tools/consult-triggers/pediatric-palliative-care-referral-criteria.pdf. (Last accessed July 3, 2013.)
21. Michelson KN, Siegel L: Palliative care in the pediatric intensive care unit. In: Wheeler DS, Wong HR, Shanley TP (eds): *Pediatric Critical Care Medicine: Basic Science and Clinical Evidence. Vol. 1, Care of the Critically Ill or Injured Child*. London: Springer-Verlag. (In press.)
22. Heimer C: Your baby's fine, just fine: Certification procedures, meetings, and the supply of information in neonatal intensive care units. In: Short J, Clarke L (eds): *Organizations, Uncertainties, and Risk*. Boulder, CO: Westview Press, 1992, pp. 161–188.
23. Zussman R: *Intensive Care: Medical Ethics and the Medical Profession*. Chicago, IL: The University of Chicago Press, 1992.
24. Anspach R: *Deciding Who Lives: Fateful Choices in the Intensive Care Nursery*. Berkeley and Los Angeles, CA: University of California Press, 1997.
25. Cassell J: *Life and death in Intensive Care*. Philadelphia, PA: Temple University Press, 2005.
26. October TW, Watson AC, Hinds PS: Characteristics of family conferences at the bedside versus the conference room in pediatric critical care. *Pediatr Crit Care Med* 2013;14(3):e135–e142.
27. Mercer LM, Tanabe P, Pang PS, et al.: Patient perspectives on communication with the medical team: Pilot study using the Communication Assessment Tool-Team (CAT-T). *Patient Educ Couns* 2008;73(2):220–223.
28. Makoul G, Krupat E, Chang CH: Measuring patient views of physician communication skills: Development and testing of the Communication Assessment Tool. *Patient Educ Couns* 2007;67(3):333–342.
29. Myerholtz L, Simons L, Felix S, et al.: Using the communication assessment tool in family medicine residency programs. *Fam Med* 2010;42(8):567–573.
30. Meert KL, Eggly S, Pollack M, et al.: Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatr Crit Care Med* 2008;9(1):2–7.
31. Kodish E, Eder M, Noll RB, et al.: Communication of randomization in childhood leukemia trials. *JAMA* 2004;291(4):470–475.

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