Missed Opportunities during Family Conferences about End-of-Life Care in the Intensive Care Unit

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***Background*: Improved communication with family members of critically ill patients can decrease the prolongation of dying in the intensive care unit (ICU), but few data exist to guide the conduct of this communication. *Objective*: Our objective was to identify missed opportunities for physicians to provide support for or information to family during family conferences. *Methods*: We identified ICU family conferences in four hospitals that included discussions about withdrawing life support or delivery of bad news. Fifty-one conferences were audiotaped, including 214 family members. Thirty-six physicians led the conferences and some physicians led more than one. We used qualitative methods to identify and categorize missed opportunities, defined as an occurrence when the physician had an opportunity to provide support or information to the family and did not. *Main results*: Fifteen family conferences (29%) had missed opportunities identified. These fell into three categories: opportunities to listen and respond to family; opportunities to acknowledge and address emotions; and opportunities to pursue key principles of medical ethics and palliative care, including exploration of patient preferences, explanation of surrogate decision making, and affirmation of nonabandonment. The most commonly missed opportunities were those to listen and respond, but examples from other categories suggest value in being aware of these opportunities. *Conclusions*: Identification of missed opportunities during ICU family conferences provides suggestions for improving communication during these conferences. Future studies are needed to demonstrate whether addressing these opportunities will improve quality of care.**

Keywords: communication; critical care; death; dying; end-of-life care

The majority of deaths that occur in the intensive care unit (ICU) throughout North America and Europe involve withholding or withdrawing life-sustaining therapy (1–5). At the time this decision occurs, most patients are unable to communicate for themselves and therefore communication about decision making is often delegated to family members and clinicians (6). In this setting, communication with families is complicated by the fact that family members report significant financial and health burdens as a result of their loved one's critical illness (7) as well as a significant burden of symptoms of anxiety and depression (8). Although communication with clinicians is extremely important to family members (9), studies suggest that clinician–family communication in the ICU frequently does not meet families' needs (10–12).

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Recent recommendations call on critical care clinicians to improve communication with families and to consider this an important part of high-quality care (13–15). Several studies also suggest that increased focus on communication with family members through routine ICU family conferences (16, 17), palliative care consultation (18), or ethics consultation (19–21) can reduce ICU length of stay for those patients who ultimately die in the ICU. Each of these interventions included improved communication with family members as an important component, although the details of exactly how communication is improved are limited in most of these studies.

We conducted a study of communication occurring during ICU family conferences concerning withdrawing life-sustaining treatments or the delivery of bad news to understand how critical care clinicians currently conduct this communication and how communication might be improved. The overall aims of the study were to describe the content and process of clinician–family communication about end-of-life care occurring as part of ICU family conferences (22). The aim of the current report emerged during the qualitative analysis process as investigators identified circumstances in which physicians missed important opportunities for communication with families during these conferences. Awareness of the types of missed opportunities that occur in this setting may allow critical care clinicians to recognize and capitalize on some of these opportunities when they arise and thereby improve the quality of communication with families.

METHODS

Identification and Enrollment of Family Conferences

We identified ICU family conferences during which the attending physician anticipated discussion of withdrawal of life-sustaining therapy or delivery of bad news. The study was conducted in four Seattle hospitals, including a county hospital, a university hospital, and two community hospitals. Study procedures were described previously (22, 23). Family conferences were identified through daily contact with charge nurses in each ICU. Once a conference was identified, we contacted the attending physician by telephone. Conferences had to meet the following criteria: (*1*) the conference had to be scheduled to occur on a weekday; (*2*) the attending physicians had to anticipate a discussion of withholding or withdrawing life support or the delivery of bad news; and (*3*) all conference participants had to speak and understand English. We excluded patients younger than 18 years. If the attending physician consented to participate and granted permission for the study staff to approach the family, the nurse caring for the patient asked the family if they were willing to talk with study personnel. If all conference participants agreed and signed a consent form, two recording devices were placed and activated in the conference room for the duration of the family conference. The institutional review board of each hospital approved all procedures.

Of 111 eligible family conferences identified, 19 were excluded because a physician or nurse requested we not contact the family (two family conferences were excluded for risk management reasons related to potential litigation and 17 were excluded because the attending physician or nurse believed the family was too distraught to participate). Twenty-four families declined to speak with study personnel. Of 68

families approached, 51 agreed to participate. The proportion of all eligible conferences identified that were recorded was 46% (51 of 111).

Qualitative Analyses

A medical transcriptionist with qualitative research experience transcribed the conference audiotapes verbatim. Personal identifiers were removed from all recordings and transcripts. Investigators performed qualitative analyses of the transcripts using methods of grounded theory. Grounded theory is a general methodology for developing theory that is based on qualitative data systematically gathered and analyzed (24–26). Initial methods and results of these analyses were reported previously (22). As part of this analysis, we completed axial coding in which we linked codes under higher level concepts or explanations. One of the higher level concepts we developed, encompassing both content (e.g., information exchange, decisions) and style codes (e.g., process techniques, emotional support, team support), was the concept of "missed opportunities." Missed opportunities were defined as passages during which all members of the clinical team present at the conference failed to provide information or support to the family.

The development of the concept of missed opportunities grew out of a consensus achieved from all the analysts (n = 8) working initially in dyads and then convening as a full group. Each dyad included one clinical analyst (nurse or physician) and one nonclinical analyst (sociologist or health services researcher.) These analyses were conducted as part of an analysis described previously to identify the content and process of family conferences (22). Missed-opportunity passages could be identified by one or both investigators in a dyad, but inclusion in this analysis required that the two members of a dyad agreed on the designation of a missed opportunity. Once all missed-opportunity passages were identified, one investigator (J.R.C.) reviewed these passages to independently confirm they represented a missed opportunity, and developed a framework for categorizing the passages. The family conferences in this study represent over 100 hours of audiotape, and review and analysis of each transcript required more than 4 hours per investigator. All transcripts were reviewed by at least four investigators, and many transcripts were reviewed by all eight, resulting in over 1,600 hours of analysis time.

To check the trustworthiness of the coding of the missed opportunities, representative passages with missed opportunities were given to two investigators not involved in the development of the missed-opportunities categorizations. These investigators were asked to identify which category was the appropriate one for the passage. The percentage of agreement with the primary investigator was 83% overall, with 89% agreement for one investigator and 78% for the other.

Finally, we also assessed family satisfaction with the communication occurring during the family conferences with eight previously validated questions. In response to queries from an anonymous reviewer, we examined the hypothesis that family conferences with missed opportunities might have lower family satisfaction than those conferences without missed opportunities. This association was examined both using the median score from all family members within a conference and also using generalized estimating equations to account for clustering of family members within a conference. Details of the assessment of family satisfaction and these additional analyses are shown in the online supplement. In brief, family satisfaction was significantly lower for conferences with missed opportunities for five of the eight questions about satisfaction, using nonparametric analyses of the median response for a family, and was significantly lower for one of the eight questions about family satisfaction, using generalized estimating equations (*see* online supplement).

RESULTS

Audiotapes were obtained for 51 family conferences. Table 1 shows demographic characteristics of the patients and of the conference participants, including family members and physicians leading the conference. A total of 221 clinicians participated in the conferences, including 36 physicians who led the conferences (*see* Table 1). The number of clinicians present ranged from 1 to 12, with a mean of 4.3. A total of 50 nurses participated in 41 of the family conferences; 25 social workers participated in 24 of the family conferences; and 12 chaplains, priests, or nuns participated in 12 of the family conferences. A total of 227 family members participated in the conferences, ranging from 1 to 13 family members per conference, with a mean of 4. 5. The patients' primary ICU admission diagnoses are also shown in Table 1. The proportion of patients who died during the hospital stay was 81% (41 of 51). Of the 51 conferences, 44 (86%) involved discussions of withholding or withdrawing life-sustaining treatments. The remaining conferences included delivery of bad news, which focused primarily on discussions of the patient's prognosis or a worsening of the patient's clinical status. The mean conference time was 32.0 minutes, with a standard deviation of 14.8 minutes and a range from 7 to 74 minutes.

We identified missed opportunities in 15 of the 51 conferences (29%). These missed opportunities fell into three categories: missed opportunities to listen and respond to family members; missed opportunities to acknowledge and address emotions; and missed opportunities to explain key tenets of medical ethics and palliative care, including exploration of patient treatment preferences, explanation of surrogate decision making, and affirmation of nonabandonment. Table 2 shows these missed

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF THE 51 PATIENTS, THEIR FAMILY MEMBERS WHO WERE PRESENT AT CONFERENCES AND RETURNED QUESTIONNAIRES, AND THE PHYSICIANS LEADING THE FAMILY CONFERENCES

Characteristics	Patients (*n = 51*) n (%)	Family Members (*n = 169*) n (%)	Physicians Leading Conferences (*n = 35*) n (%)
Sex			
Female	26 (51)	101 (60)	12 (34)
Race/ethnicity			
White	31 (61)	136 (81)	30 (86)
African American	7 (14)	14 (8)	0
Hispanic	2 (4)	6 (4)	2 (6)
Asian/Pacific Islander	1 (2)	5 (3)	4 (11)
Native American	1 (2)	10 (6)	0
Other/undocumented	9 (18)	0	1 (3)
Primary ICU admission diagnosis			
Intracranial hemorrhage	9 (17)		
End-stage liver disease or GI bleed	8 (16)		
Trauma	8 (16)		
Sepsis or infection	7 (14)		
Respiratory failure	6 (12)		
Cardiac failure or acute MI	5 (10)		
Other	8 (16)		
Relationship to patient			
Spouse/partner		17 (10.1)	
Child		35 (20.7)	
Sibling		34 (20.1)	
Parent		20 (11.8)	
Friend		9 (5.3)	
Other relative		52 (30.8)	
Other		1 (0.6)	
Staff position			
Attending physician			20 (57)
Resident or fellow			15 (43)
Medical specialty			
Internal medicine			26 (74)
Neurology			5 (14)
Surgery			3 (7)
Internal medicine/anesthesia			1 (3)
Age, yr, mean (SD)	60 (20.3)	48 (15.8)	38 (9.5)
Years in practice, mean (SD)			12.4 (9.7)

Definition of abbreviations: GI = gastrointestinal; ICU = intensive care unit; MI = myocardial infarction.

opportunities and the number of conferences in which we identified each of these missed opportunities. We provide examples of each of these categories below.

Listening and Responding to Family Member Comments

The most common missed opportunity occurred when clinicians failed to listen and respond appropriately and directly to comments made by family members. Occasionally, clinicians avoided answering a question completely. More commonly, clinicians answered a different question than the family was asking; often, these answers took the form of providing physiologic or technical information. In the following exchange, a family member asked if the patient had permanent brain injury that would affect her quality of life.

> Family: Okay, is there a way in the next couple of days to find out, and I may have missed this, but to find out if there is brain damage?
>
> Physician: Oh, actually we examine her twice a day, at least once in the morning and once in the evening, and when the person is in the intubated condition, we give them some medicine to keep them sedated whether they are unconscious or not, because when you have the tube inside you, it's very uncomfortable for the patients. And during that period, when you do the neurological exam, it's not reliable. So at least twice a day we take that medicine off and examine the patient, how she is doing. So this is how we test the brain function.

In providing technical details about *how* brain function is tested, the physician missed the opportunity to answer directly the family member's question about *whether* the patient has brain damage. In this conference, the family asked the question of whether the patient has brain damage on two occasions and the physician did not answer the question either time.

Another commonly missed opportunity occurred when family members raised unspecified issues or concerns and clinicians failed to ask for clarification. These issues slowed the progress of the conference, becoming the focus of repeated or unresolved questions. For example, in the following passage, the family member used the phrase "tough job" twice, but the clinicians did not explore what she meant by that phrase and whether she had underlying concerns about withdrawal of life support that were not addressed.

> Physician: I think it's very clear to us from a medical perspective that his chance of a meaningful recovery is extremely, extremely small. So, both by the medical standpoint and certainly by his own wishes, we should not persist in doing what we're doing.
>
> Family: Okay.
>
> Physician: We should make him comfortable.
>
> Family: We know that you would like to fix him, that even if you could, he doesn't want that.
>
> Physician: Right.
>
> Family: So . . . the tough job now is up to you guys.
>
> Physician: What we'll do is try to concentrate on removing things that don't add comfort and try to make him as comfortable as possible. He's relying on a lot of support and medications that don't necessarily add to comfort and those can be removed.
>
> Family: Okay.
>
> Physician: So we're very comfortable with this approach.
>
> Family: Well, we've done our tough job, now it's yours.
>
> Physician: Do you have any further questions of us?

Acknowledging or Addressing Emotions

The second category of missed opportunities arose out of the clinician's failure to acknowledge or address the expression of family members' emotions during the conference. In this category, we have included examples where investigators believed that an explicit expression of compassion or response from the clinician was needed. For example,

> Physician: He bled from his brain and the fluid sac that's there. Whenever that happens, part of the brain doesn't get much blood. But that wasn't the major problem because he was sick from that but got better. I wasn't looking after him then, but from everything that we read, he was improving.
>
> Family: He looked good and he was responding to us. He was on medication and oxygen and he was answering [questions].
>
> Physician: Then he had a very severe infection. Our best guess is that he got infected from one of the tubes or lines that you saw being removed and that was the site of entry for a very severe bacterium and that's actually very common.
>
> Family: Isn't that sad then?
>
> Physician: It's a common complication and the most common thing that people die from after strokes. If they don't die from the stroke, they die from infection or pneumonia or something else.
>
> Family: Sad.

TABLE 2. DESCRIPTION OF THE MISSED OPPORTUNITIES DURING INTENSIVE CARE UNIT FAMILY CONFERENCES CONCERNING END-OF-LIFE CARE OR DELIVERY OF BAD NEWS

	No. Passages	No. Conferences (%)
Overall missed opportunities	32	15 (29)
Listen and respond		
Opportunity to answer family member questions	14	8 (16)
Opportunity to clarify meaning or follow up on important statement by family member	6	5 (10)
Acknowledge or address emotion		
Opportunity to acknowledge emotions or support family grief	2	2 (4)
Opportunity to address or attempt to alleviate family guilt	4	4 (8)
Address important tenet of palliative care		
Opportunity to explore family statements of patient preferences	2	2 (4)
Opportunity to explain basis for surrogate decision making	5	4 (4)
Opportunity to affirm medical team nonabandonment	1	1 (2)

Physician: It's very frustrating for the neurosurgeons because they can work their magic and then have people get into problems from other things.

In this exchange, the family member used the word "sad" twice yet the physician missed the opportunity to acknowledge and discuss the meaning, significance, or impact of this sadness with the family. There were also instances of family members crying without any verbal expression of emotion, and clinicians occasionally missed the opportunity to provide verbal acknowledgment of this emotion, but nonverbal examples of emotion were not included in these analyses.

In addition, there were instances when family members expressed feelings of personal guilt that offered an opportunity for a supportive response from clinicians. In the following example, the physician discussed the important principles of surrogate decision making, but missed the opportunity to explore the emotional reaction expressed by the family member that she is "killing" her son when she considers withdrawing life-sustaining treatments.

Physician: Well, I guess the decision today is that we should not do the trach, since that is more of a long-term decision, and that we're going to go ahead and stick with things [current treatments] and give him a few more days to see whether he's going to turn around, but not to go ahead with the trach. What do you think about that?

Family: It sounds appropriate to me. I just . . . I don't like the idea that I killed my son.

Physician: No.

Family: I just can't, mentally, it bothers me.

Physician: I think that it is very, very important that you remember what he said and that this is the decision that he would make.

Explaining Key Tenets of Medical Ethics and Palliative Care

The final category was missing an opportunity to explain key tenets of medical ethics and palliative care. First, some clinicians missed an opportunity to explore family comments regarding patient treatment preferences. Because a thorough understanding of patient preferences is a key to clinical decision making in the ICU setting, this represents an important missed opportunity. For example,

Physician: So, just kind of summarizing things. What would you like us to do in regards to his care. We talked about different options of doing a tracheostomy and moving him to a different type of hospital. He's getting sicker and not getting better. Then there's the option of delaying the tracheostomy and seeing how he does and seeing if he gets better or worse and then making a decision at that point.

Family: Right. I'd like you to go ahead with the tracheostomy. If the situation gets any worse than it already is, then I'll agree to stopping . . .

Physician: Now, I don't want you to think of it as agreeing.

Family: He always said, "Don't make me, don't let me live there [nursing home] forever," you know.

Physician: Okay, okay.

In this example, clinicians missed the opportunity to explore the patient's prior statement to his mother about his feelings about living in a nursing home. Second, clinicians occasionally missed opportunities that would have allowed them to accurately explain the basis for surrogate decision making to family members involved in this decision-making process. One physician inaccurately described the basis for surrogate decision making as follows:

Physician: This is not something that needs to be answered yes or no right now, but, in regards to resuscitation in the event that he has a cardiac arrest, if his heart would stop suddenly . . . would you or would he have wanted us to do CPR or would you want us to do that?

Family: I don't want you to.

Physician: Okay.

Family: Yeah, if he has a heart attack, I would say no.

Physician: I think that is a good decision because if it happened, it would be really unlikely that he would have recovered from it anyway.

Family: He might say something different, but I'm going to say no.

Physician: That's fine.

In this example, the physician missed the opportunity to correctly explain surrogate decision making and, as a result, the family member made a decision that may have gone against the wishes of the patient, by the family member's own admission. Finally, there were occasions during which the physician missed an opportunity to affirm nonabandonment during care for the dying.

Family: And with comfort [care], if you extubate him, would you immediately ship him out to a floor or what's the scenario there?

Physician: Right. I would probably in approximately 24 hours. I mean, if he's going to succumb in an hour or two, I don't want to put him through the move.

Family: That's what I was wondering, how long you would hang in there.

Physician: Right. I would probably kind of wait kind of a day. So, say, Monday you decide, okay, enough. You know, he's not getting any better, we want to stop. We would extubate him Monday; if by Tuesday morning he has not succumbed, then we would say, okay, let's go ahead and move him down to the floor.

Family: Okay.

In this example, the physician missed the opportunity to explicitly state that the patient will not be abandoned in the process of transitioning to palliation as the primary goals of care.

DISCUSSION

We have identified a taxonomy for missed opportunities that, if addressed, may have enhanced communication with and understanding by families of patients in the ICU. We were able to identify examples of these particular missed opportunities in nearly one third of the 51 family conferences audiotaped for this study. One cannot expect a clinician to capitalize on every possible opportunity to provide support to family members and enhance communication or decision making. However, the taxonomy we developed demonstrates the types of opportunities that critical care clinicians appear to more commonly miss. Capitalizing on some of these opportunities may improve the communication clinicians have with family members during discussions about withholding or withdrawing life-sustaining treatments or delivering bad news. The opportunity to listen carefully to family members' concerns and respond directly to these concerns is an important component of these discussions. In a prior report from this study, we demonstrated that when clinicians spend a greater proportion of their time during family conferences listening

rather than speaking, family members report increased satisfaction with the communication (23). The current report provides some examples of ways that clinicians can listen for and respond to families' questions. We have also identified instances during which clinicians may acknowledge and support the emotions of family members that arise during these conferences. Acknowledging emotions has been recognized as an important component of palliative care (27), but is less commonly addressed in the critical care setting. Finally, we identified a number of different opportunities to clarify key tenets of medical ethics and palliative care in the ICU, including exploring patient preferences for life-sustaining treatments, the ethical basis for surrogate decision making, and affirming nonabandonment. These tenets have been cited in prior review articles (13, 14, 28, 29), and our report provides some specific examples when clinicians might state and clarify these practices with the family during the conference.

A number of recent important studies have suggested that focusing on communication with families in the ICU setting can reduce the prolongation of dying that occurs in our ICUs (16–21). However, the specific tools and mechanisms for improving communication have not been thoroughly described. There is evidence that clinicians can learn communication skills and improve their ability to communicate (30). The categories of missed opportunities identified in this report may provide guidance for clinicians interested in improving their communication with families in the ICU setting; these categories may also suggest specific content for educators interested in training critical care clinicians to improve their communication skills.

This study has several important limitations. We were able to audiotape less than 50% of the conferences identified. Families refusing to participate may differ from those in the study, and, although there is no ethical alternative, these findings may not generalize to all families. In particular, families willing to participate may have better relationships with their clinicians; conversely, families refusing to participate or for whom doctors or nurses refused contact may represent more difficult communication and therefore may have more missed opportunities during ICU family conferences. Therefore, these results may not generalize to all family conferences. Second, we were limited in the verbal communication available to us for study. Much ICU clinician–family communication occurs outside the family conference setting, especially nurse–family communication; this study cannot address such important forms of communication. In addition, there are important components of nonverbal communication that we could not assess adequately with audiotapes. We did not videotape family conferences because we were concerned this would be too intrusive, but future studies should consider ways to address nonverbal communication. Fourth, this qualitative study has a relatively small sample size that does not permit us to determine whether there are patient, family, or clinician characteristics that predict the occurrence of missed opportunities in general or specific types of missed opportunities. Fifth, this study took place in one city with a predominantly non-Hispanic, white group of patients, family members, and clinicians; there may be important geographic and cultural differences in the conduct and assessment of family conferences. Therefore, our findings may not generalize to other geographic and cultural areas. Finally, we cannot assess how these conferences would have gone if the clinicians had responded to the opportunities described and whether these responses would have improved the quality of decision making, family satisfaction, or family understanding. Although we have addressed issues of reliability and generalizability of these findings, their validity ultimately rests primarily in the readers' assessment of the usefulness of these categories and examples.

Improved communication with family members of critically ill patients has been associated with decreasing the prolongation of dying in the ICU, but few data exist to guide physicians in how to conduct this communication. The identification of missed opportunities during ICU family conferences provides some suggestions for critical care clinicians interested in improving communication during these conferences. Future studies are needed to demonstrate whether addressing these opportunities will improve quality of care and family satisfaction with this care.

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