

# Neglect of quality-of-life considerations in intensive care unit family meetings for long-stay intensive care unit patients

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**Objective:** To examine the frequency with which quality of life and treatment limitation were discussed in formal family meetings for long-stay intensive care unit patients with high risk for mortality and morbidity.

**Design:** Descriptive observational study.

**Setting:** Five intensive care units.

**Patients:** One hundred sixteen family surrogate decisionmakers of long-stay intensive care unit patients who participated in an intensive communication system that aimed to provide weekly meetings with family decisionmakers. The structure of each meeting was to address medical update, patient preferences, treatment plan, and milestones for evaluating the treatment plan.

**Interventions:** None.

**Measurements and Main Results:** We audiotaped initial family meetings for 116 family decisionmakers for a total of 180 meetings. On average, meetings were 24 mins long with a majority of time being devoted to nonemotional speech and little (12%) spent discussing patient preferences. Quality of life was discussed in 45% and treatment limitation in 23% of all meetings. Quality-of-

life discussions were more likely to occur when patients were admitted to a medical intensive care unit (odds ratio [OR], 5.9;  $p = .005$ ), have a family decisionmaker who is a spouse (OR, 9.4;  $p = .0001$ ), were older (OR, 1.04;  $p = .01$ ), have a shorter length of stay (OR, 0.93;  $p = .001$ ), and have a family decisionmaker who was a spouse (OR, 5.1;  $p = .002$ ). For those with a treatment limitation discussion, 67% had a do-not-resuscitation order, 40% were admitted to a medical intensive care unit, 56% had a family decisionmaker who had been their caregiver, and 48% of their family decisionmakers were their children.

**Conclusions:** To guide discussion with families of the subset of intensive care unit patients with high risk of mortality and long-term morbidity, quality of life was not consistently addressed. Continued efforts to assist clinicians in routinely including discussions of quality-of-life outcomes is needed. (Crit Care Med 2012; 40:000–000)

**KEY WORDS:** communication; decisionmaking; long-stay intensive care; quality of life; treatment limitation

The challenges of communication with families of long-stay intensive care unit (ICU) patients and surrogates facing end-of-life decisionmaking have been a focus on numerous investigations and professional guidelines (1–5). Despite this attention, research continues to reflect the difficulty of implementing consistent approaches that are effective in addressing informational and support needs of surrogate decisionmakers. This is particularly true in situations in which there is considerable prognostic uncer-

tainty and questions about treatment limitations, a common occurrence for long-stay ICU patients.

Regular family meetings have been recommended as an effective approach for assuring that families receive updated information, have an opportunity to get questions answered, and receive support for shared decisionmaking with the clinical team (6). Although reports suggest having a system of regular meetings can facilitate decisionmaking, minimize use of ineffective interventions, and improve family satisfaction (7–10), there is evidence that style and elements of communication (e.g., topics, empathic statements) are equally important. Curtis (11) reported that in almost one-third of family conferences where bad news was discussed, there were missed opportunities to provide information or support. We also reported on a trial of an “intensive communication system” of regular weekly meetings with families of long-stay ICU patients (12) where meetings were not associated with length of stay, aggressiveness of care, or resource use.

In this report we describe findings from the audio recordings of 116 family meetings held as part of a larger parent study that examined the impact of a structured family meeting intervention on ICU resource use. Description and outcomes from the parent study have been presented elsewhere (12). For the descriptive study presented here, we were interested in examining the frequency with which quality of life (QOL) was discussed because of the uncertain trajectory of recovery and high mortality and morbidity associated with the long-stay ICU patient population. As part of this investigation, we wanted to describe the components of the conversation, including the frequency of emotionally oriented comments and specific meeting topics (e.g., patient preferences, medical update, prognosis) and to examine whether there were patient or family decisionmaker (FDM) characteristics that were associated with discussions of QOL. A secondary purpose was to describe the extent of treatment limitation discussion and key characteristics associated with those discussions.

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## MATERIALS AND METHODS

The parent study from which these data were obtained was conducted in five ICUs in two academic medical centers in Cleveland, OH, from November 2005 through April 2006. Study sites included a surgical intensive care unit, medical intensive care unit, and neuroscience ICU at a university-affiliated, private not-for-profit medical center and a medical intensive care unit and surgical intensive care unit at a university-affiliated public medical center in the same city. Institutional review board approvals from the two hospitals were obtained before study initiation.

**Subjects.** Eligibility criteria for patients were: 1) age  $\geq 18$  yrs; 2) 72 hrs of mechanical ventilation and no expectation by the attending physician of extubation or discharge from the ICU within the next 48 hrs; 3) lacking decisional capacity as indicated by a Glasgow Coma Scale  $< 6$  and confirmed by the ICU attending physician; 4) not on mechanical ventilation before admission; and 5) having an identified family surrogate decisionmaker present. Family surrogates were eligible if they were 1) identified as the appointed surrogate through a power of attorney or were the next of kin; 2) age  $\geq 18$  yrs; 3) available for participation in family meetings; and 4) willing to provide informed consent for participation in the study. In the case of multiple family members, the decisionmaker was defined as the person from whom consent was obtained for medical interventions.

**Data Collection.** As part of the parent study, the five ICUs implemented a change in standard practice and began weekly structured family meetings for all long-stay ICU patients. This was explained to all potential subjects and the experimental nature of the study was clarified before written consent was obtained. An Advanced Practice Nurse in each hospital was responsible for scheduling and participating in the family meetings to assure that the communication structure was implemented consistently. A formal training session was held for each ICU physician group before instituting the intervention.

The intensive communication system structure, reviewed in all training sessions, included: 1) family meeting within 5 days of ICU admission (or as soon as could be arranged) and at least weekly thereafter as long as the patient remained in the ICU; and 2) each meeting was to address medical update, values and preferences of the patient, goals of care, treatment plan, and milestones for determining if the treatment plan was effective. There was no attempt to alter the communication style of the participants or direct the decisions made.

Advanced Practice Nurses met each patient and family member as part of the family's routine orientation to the ICU environment. When the patient met eligibility criteria, the Advanced Practice Nurse explained to the fam-

ily that having routine, once-a-week family meetings, in addition to the informal bedside updates from doctors and nurses, was the standard communication structure of the ICU for long-stay patients but that they were being asked to participate in a study aimed at evaluating its effectiveness. For those who agreed to participate, a research nurse approached the family member, explained the study, and obtained consent. At the end of each meeting, a tentative date that was convenient for the family was set for the next meeting. All families were asked for signed permission to au-

diotape the meeting. If any family member or clinician refused permission, the meeting was not taped. A research nurse was responsible for taping the meeting.

**Measurements.** Demographic and clinical information about each patient was abstracted from their medical records. This included age, gender, race, Acute Physiology and Chronic Health Evaluation (APACHE) III (13), major diagnostic category, and use of interventions that reflected resource use or goals of care such as placement of tracheostomy. Treatment limitation decisions, hospital and ICU

Table 1. Criteria for coding quality of life and treatment limitation discussion

Criteria for Quality-of-Life Discussion	Criteria for Treatment Limitation Discussion
Statements that include reference to the kind of life or existence with some reference of the subjective evaluation or experience (e.g., "I think we can get him through this but I'm not sure he would find that kind of life enjoyable or meaningful.")	Any mention of code status
Questions about "what kind of life" the patient would want or what aspect of life was important to him or her	Any mention of "do not attempt resuscitation" or "comfort care"
Questions or statements about the acceptability, values or perceptions about the likely lifestyle/quality (e.g., "How would he feel about being confined to a wheelchair" or "Would he be okay with having to stay in a nursing home, on a breathing machine?")	Any discussion of treatments that will electively not be used (e.g., "We'll keep giving fluids but do not think it makes sense to use dialysis.")
Any use of the phrase, "quality of life"	Any questions to the family of interventions the patient would not want (e.g., "Do you think he would want us to do a tracheostomy" or "Would he be okay with having us put in a feeding tube or would he not want to live this way?")
	Any reference to specific interventions being more burdensome than beneficial (e.g., "Doing cardiopulmonary resuscitation would leave him worse off.")
	Any generic discussion that treatment limitation might need to be considered in the future or at another meeting
	Criteria That Do Not Count at Treatment Limitation
Prognostic statements that focus only on survival (e.g., "I think we can get him through this" or "We knew this was going to be a slow recovery but I'm optimistic that ...")	Seeking permission for more treatment without offering the option of limitation (e.g., "Because he's not ready to breathe on his own, we need to do a tracheostomy ...")
Prognostic statements that focus only on organ function (e.g., "I'm not sure he'll ever be able to breathe on his own" or "He'll need dialysis for a while but his kidneys may recover" or "We do not think he'll wake up and be able to talk with you.")	Discussion of limits that are only a function of patient condition or running out of options (e.g., "He probably has an abscess but we cannot take him back to surgery because he's too unstable" or "We have him on three medications for his blood pressure and there's not much more we can do.")
Prognostic statements that focus only on the hospital course and need for an extended care facility (e.g., "I think we can get him through this but it will be a long road ahead" or "He's going to need a lot of rehabilitation.")	

lengths of stay, discharge disposition, and ICU and hospital survival were recorded. The APACHE III is an established tool for defining the severity of illness within the first 24 hrs in the ICU and has excellent psychometric properties (13). Data from the APACHE III were used to derive the Acute Physiology Score, which uses basic physiologic variables (APACHE score = [age score + chronic illness score]) and is considered better than the APACHE II at comparing patients with different diseases (14). Location at 2 months after discharge was obtained through follow-up telephone calls to family members. Interrater reliability for medical record abstraction was assessed before data collection began and every 4 months throughout the data collection period. Pearson's correlations ranged from .6 to 1.0 for continuous variables and  $\kappa$ 's ranged from .6 to 1.0 for categorical variables.

Each audiotape was reviewed by two research staff members and audited for the following: length of meeting, topics discussed and time spent on each topic, percent of speaking time by participants, and presence or absence of discussion of QOL and treatment limitation. Explicit criteria for what constituted a QOL or treatment limitation discussion was used for the coding of each audiotape (Table 1). In classifying QOL limitation topics, we restricted our criteria to those elements of the discussion that were clearly intended to direct the conversation to references to how the patient would experience, respond to, or evaluate potential outcome states. Prognostic statements about specific organ function without description or inquiry about what this level of function would mean to the patient (i.e., would it be acceptable, would it represent an intolerable state, or one not worth pursuing) were not classified as QOL discussion. We chose this approach based on the work of Testa who identified that the individual's subjective perception of the objective health status was what constituted QOL and satisfaction with life (15). In classifying treatment limitation topics we identified any question, suggestion, or mention of the option to limit life-sustaining interventions or to withdraw current interventions.

Before data analysis, interrater reliability of QOL and treatment limitation coding was conducted between the Principal Investigators (B.J.D., S.L.D.) and the research assistant responsible for listening to and coding all tapes. Interrater reliabilities conducted for randomly selected taped meetings throughout the coding process yielded acceptable  $\kappa$ 's (.6–1.0) and correlations (.8–.9) (16, 17).

**Analysis.** Frequencies and measures of central tendency were used to describe the sample. When comparing those with and without QOL discussions and treatment limitation discussions, independent samples *t* tests for continuous variables and chi square for categorical variables were used. Effect sizes were calculated for all statistically significant differences.

We also conducted logistic regression analysis to examine relationships of FDM and patient characteristics to QOL (0 = not discussed, 1 = discussed). Each dependent outcome variable was defined using the criteria outlined in Table 1. Because there was no prior research to base hypotheses for testing, and because we were not interested in causality but in a more exploratory approach, we used backward stepwise logistic regression (18, 19) for examining predictors of QOL discussions. We included patient and FDM variables that were either significant in our univariate analyses or had been shown in prior work to relate to QOL discussion (20–22). There were no multicollinearity or independence of observation concerns and the logistic model assumption of linear relationships between the logit and the continuous covariates was verified for both logistic models. Then, the backward elimination method was used with the cutoff for elimination being a *p* value of .10. For all analyses (univariate and multivariate), *p* < .05 was considered to be statistically significant. The statistical program, SPSS Version 19 (SPSS, Chicago, IL), was used for all analyses.

## RESULTS

One hundred sixteen subjects' first taped meetings constitute the sample. A majority (69%) of subjects had only one taped meeting (range, 1–4) throughout their ICU stay and the first meeting took place, on average, 9.75 (7.9) days after the patient entered the ICU. As seen in Table 2, patients were middle-aged with moderate APACHE III scores and long hospital and ICU stays. Less than one-fourth died in the ICU with the cumulative 2-month posthospital mortality rate being 31%. For those who survived their hospital stay (*n* = 92), 92.4% were discharged to an institutional setting. Two months later, 35 (41.2%) of the 84 patients discharged to an institution were still residing in an extended-care facility and ten (11.8%) had died.

FDMs were more likely to be female, a spouse, new to caregiving, and employed. Despite long ICU stays, FDMs had an average of only 2.1 (1.3) formal meetings/patient. Meetings tended to be moderate in length with a majority of meeting time spent in instrumental speech where factual information (rather than relational or emotional topics) was discussed. A majority (71.5%) of all meetings had an attending physician participating (the remaining 28.5% of meetings had a fellow or resident); physicians were predominantly male (88.5%), white (83.5%), and highly experienced (median years as attending physician = 18).

**Table 2.** Family decisionmaker, patient, and meeting characteristics (*n* = 116)

Variable	Mean (sd)
<b>Patient and FDM characteristics</b>	
Patient age	54.1 (17.8)
Patient Acute Physiology and Chronic Health Evaluation III score	68.4 (31.9)
Patient Acute Physiology Score	59.6 (29.7)
Patient hospital length of stay, days	30.0 (17.6)
Patient ICU length of stay, days	17.7 (10.8)
FDM age, yrs	53.97 (14.18)
	No. (%)
FDM gender: female	93 (80.2)
FDM ethnicity: white	76 (65.5)
FDM relationship to patient	
Spouse	35 (30.2)
Parent	30 (25.9)
Child	28 (24.1)
Other	23 (19.8)
FDM prior caregiver to patient: yes	33 (28.4)
FDM employed: yes	67 (57.8)
FDM income	
≤\$20,000/yr	19 (17.4)
\$21,000–\$49,000/yr	50 (45.9)
>\$50,000/yr	40 (36.7)
ICU admitting service	
Medical ICU	25 (21.6)
Surgical ICU	91 (78.5)
Patient received tracheostomy in ICU: yes	68 (59.1)
Patient had do-not-resuscitate order: yes	32 (27.6)
Patient inhospital death: yes	24 (20.7)
	Mean (sd)
<b>Meeting Characteristics</b>	
Number of days from admission to first meeting	9.8 (7.9)
Length of taped meetings, mins	23.7 (11.7)
Percent time in instrumental speech	96.4 (4.6)
Percent time physician spoke	59.5 (22.9)
Percent time Advanced Practice Nurse spoke	13.9 (14.3)
Percent time family spoke	25.5 (15.1)
Number of questions asked by physician	1.9 (1.6)
Number of questions asked by Advanced Practice Nurse	2.4 (2.3)
Number of questions asked by family	7.4 (5.5)
Physician rating of news given <sup>a</sup>	59.0 (26.7)
Family rating of news received <sup>a</sup>	71.3 (30.4)

FDM, family decisionmaker; ICU, intensive care unit.

<sup>a</sup>News coded on visual analog scale: 0 = bad/discouraging news, 100 = good/encouraging news.

**Quality of Life.** Less than half (44.8%) of first family meetings had a discussion of QOL. As seen in Table 3, patients whose families had a family meeting

Table 3. Characteristics of those with and without quality-of-life discussion at first meeting (n = 116)

Variable Patient and FDM Characteristics	Quality of Life Discussed (n = 52)	Quality of Life Not Discussed (n = 64)	p	Effect Size d
	Mean (SD)	Mean (SD)		
Patient age, yrs	59.2 (15.4)	50.1 (18.8)	.006	.52
Patient Acute Physiology Score	65.2 (32.7)	55.0 (26.6)	.07	
Hospital length of stay, days	24.4 (11.4)	33.5 (18.6)	.002	.59
FDM age, yrs	55.2 (14.6)	52.6 (13.6)	.33	
Patient and FDM Characteristics	No. (%)	No. (%)		φ
Medical intensive care unit admission: yes	18 (35.3)	7 (11.1)	.002	.29
Do-not-resuscitate order: yes	21 (40.4)	11 (17.5)	.006	.26
FDM gender: female	41 (78.8)	51 (81.0)	.78	
FDM ethnicity: white	32 (61.5)	43 (68.3)	.45	
FDM relationship to patient			.005	.36
Spouse	21 (40.4)	14 (22.2)		
Child	17 (32.7)	11 (17.5)		
Sibling	3 (5.8)	10 (15.9)		
Parent	10 (19.2)	19 (30.2)		
Other	1 (1.9)	9 (14.3)		
FDM income: >\$20,000/yr	38 (79.2)	49 (81.6)	.89	
FDM prior caregiver: yes	22 (42.3)	11 (17.5)	.003	.27
Inhospital death: yes <sup>a</sup>	16 (30.8)	8 (12.7)	.02	.22
Treat. limit discussion: yes	24 (46.2)	3 (4.7)	.001	.49
Meeting Characteristics	Mean (SD)	Mean (SD)		d
Total formal meetings	1.9 (1.2)	2.2 (1.4)	.11	
Meeting time, mins	26.9 (11.5)	21.2 (11.4)	.01	.50
Percent time: instrumental	96.6 (4.6)	96.3 (4.6)	.76	
Percent time: physician spoke	56.2 (23.8)	62.2 (21.9)	.18	
Percent time: Advanced Practice Nurse spoke	15.0 (14.4)	12.9 (14.3)	.47	
Percent time: family spoke	28.6 (16.6)	22.9 (13.4)	.04	.38
Percent time: prognosis	20.3 (16.7)	20.7 (15.9)	.90	
Percent time: preferences	18.2 (16.8)	7.3 (9.4)	.001	.78
Percent time: treatment plan	19.9 (13.0)	23.3 (14.2)	.21	
Percent time: milestones	3.6 (4.9)	4.2 (5.4)	.52	
Percent time: medical update	40.2 (16.2)	47.9 (16.6)	.01	.48
Number of questions asked: physician	1.8 (1.5)	1.9 (1.7)	.75	
Number of questions asked: Advanced Practice Nurse	2.7 (2.2)	2.0 (2.3)	.17	
Number of questions asked: family	7.4 (5.4)	7.4 (5.5)	.99	
Physician rating of news given <sup>b</sup>	58.3 (30.9)	59.6 (23.1)	.81	
Family rating of new received <sup>b</sup>	65.9 (32.5)	75.1 (28.5)	.13	

FDM, family decisionmaker.

<sup>a</sup>Odds ratio, 3.06; 95% confidence interval, 1.19–7.88; *p* = .02; <sup>b</sup>news coded on visual analog scale: 0 = bad/discouraging news, 100 = good/encouraging news.

where QOL was discussed were more likely to have been admitted to a medical intensive care unit and also to have a treatment limitation discussion and their FDMs were more likely to have been a prior caregiver and to have been a spouse or child of the patient. Advanced Practice Nurses were most likely to be the first to mention the issue of QOL (59.6%) followed by the physician (23.1%) and family (17.3%). We also found that those who died were three times more likely to have had a QOL discussion than those who lived.

Meetings where QOL was discussed tended to be longer and have a greater percentage of time devoted to discussing

preferences. In addition, family members spoke a greater percentage of time and there was less time spent discussing medical update in those meetings where QOL was discussed (Table 3). As seen in Figure 1, 18.2% of meeting time was spent, on average, discussing patient preferences for those meetings where QOL was discussed—much less than time spent on medical update, prognosis, or treatment plans. In addition, as seen in Figure 2, although 66.7% of patients who died had a discussion of QOL, only 39.3% of patients who were discharged to an institutional setting had such a discussion at their first meeting (*p* = .007).

Finally, we were interested in exploring the relationships between patient and FDM characteristics and QOL discussions. To examine these relationships, we conducted backward logistic regression in which QOL (0 = not discussed, 1 = discussed) was regressed on seven independent variables (patient age, Acute Physiology Score, length of hospital stay, do-not-resuscitate order, admitting unit, FDM relationship, and prior caregiver experience). The Hosmer-Lemeshow test indicated that the calculated model fit the actual data for estimating the outcome variable (chi square [8] = 3.7, *p* = .88). As seen in Table 4, the most parsimonious model had four variables with all of them making statistically significant contributions (Nagelkerke *R*<sup>2</sup> = .40) with correct classification of 74.3%.

**Treatment Limitation.** Less than one-third (23.3%) of all meetings had a discussion of treatment limitation with the odds of dying being 5.1 times more likely (95% confidence interval, 1.9–13.4; *p* = .001) if there was a treatment limitation discussion at the first family meeting. As seen in Table 5, patients who had discussion of treatment limitation in the first meeting were older, sicker, more likely to have a do-not-resuscitate order written, and more likely to have been admitted to a medical intensive care unit. FDMs of patients who had a treatment limitation discussion were more likely to have been a prior caregiver.

Meetings where treatment limitations were discussed presented more discouraging news as rated by both the physician and FDM, had a greater emphasis on discussions of patient preferences, and spent less time discussing medical update than those meetings without treatment limitation discussions. In over half of the meetings in which treatment limitations were discussed, the physician (70.4%) was the first individual to mention the topic and family were never first to mention treatment limitations. As seen in Figure 1, the second greatest amount of time (25.7%) was spent discussing patient preferences in meetings where treatment limitations were discussed and for patients who died inhospital, 50% of the first family meetings involved a discussion of treatment limitation.

## DISCUSSION

In this study, despite the implementation of a protocol calling for formal meetings every 5 days, we found that, on av-

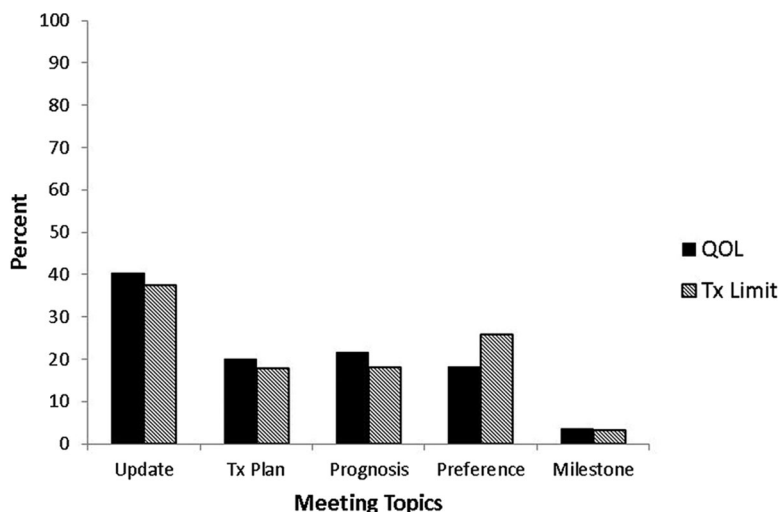


Figure 1. Comparison of percent time spent discussing key topics for first meetings where quality of life was discussed (n = 52) and first meetings where treatment limitation was discussed (n = 27). QOL, Quality of life; Tx Limit, treatment limitation; Tx, treatment.

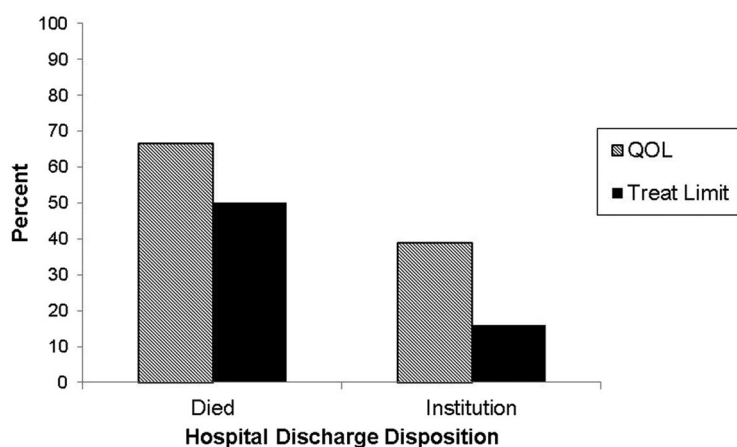


Figure 2. Percentage of subjects who died in-hospital (n = 24) or were discharged to an institutional setting (n = 85) who had either a quality of life or treatment limitation at their first family meeting. QOL, Quality of life; Treat Limit, treatment limitation.

Table 4. Logistic regression of quality-of-life discussions on patient and caregiver variables (n = 113)<sup>a</sup>

Variables	Beta (SE)	Odds Ratio	95% Confidence Interval	p
Admitting unit (0 = surgical intensive care unit, 1 = medical intensive care unit)	2.24 (0.63)	9.39	2.74–32.17	.0001
Family decisionmaker relationship: spouse (0 = other, 1 = spouse)	1.64 (0.53)	5.13	1.80–14.62	.002
Patient age, yrs	0.04 (0.02)	1.04	1.01–1.07	.01
Length of stay	–0.07 (0.02)	0.93	0.89–0.97	.001

<sup>a</sup>Quality-of-life discussion at first family meeting (0 = no, 1 = yes).

Nagelkerke  $R^2 = .40$ . Model chi square (4) = 40.14,  $p = .001$ . Overall correct classification 74.3%.

erage, patients had only two meetings during their 17-day stay in the ICU. This reflects the practical challenges of scheduling meetings around both physician and family schedules. For long-stay ICU patients, it was not uncommon

for family members to have returned to work or other responsibilities, constraining their ability to attend meetings during the day when the attending physician and Advanced Practice Nurse were available.

More importantly, we found that fewer than half of the first family meetings had discussions of QOL or patient preferences and even in the “best case” scenarios where QOL was discussed, less than one-fourth (16.8%) of those meetings mentioned patient preferences. Our results are in contrast to that of White, who reported that 86% of taped family meetings addressed expected functional status (23). This finding may be the result of differences in criteria used in coding speech in that they classified these comments as an aspect of prognosis, whereas we specifically looked for statements that addressed what the patient would experience rather than objective descriptions of respiratory status or ability to perform specific functions. In addition, we found that the topic of QOL was more likely to be introduced by a healthcare provider and was most often discussed for those patients with the greatest likelihood of in-hospital death. Despite guidelines for patient-centered communication (4), we found that our meetings were still heavily focused on the traditional approach in which healthcare providers spoke a majority of the time, family members primarily listened or asked questions, and very little time was devoted to QOL or emotionally supportive comments.

The low incidence of discussion of QOL for long-stay ICU patients highlights an area of concern and identifies an opportunity for improvement. These patients are a subgroup of ICU patients with increased mortality and morbidity and a high likelihood of continued health problems, readmission, and decrement in QOL compared with their preadmission status (24–28). Discussion of the impact of treatment, expected care needs after hospitalization, and postdischarge QOL have been found by others to be as important to patients and families as survival estimates (29, 30). It is particularly important for the treatment team to explicitly address prognosis for relevant QOL dimensions and, in many cases, patient preferences for continued use of aggressive life support technologies.

Our findings reflect a clinical norm of linking QOL discussions to situations in which prognosis is poor and risk of death is high. However, regardless of survival prospects, the relevance of discussing patient values and goals early in the course of treatment is crucial for all of these FDMs and suggests little reason to avoid the topic of QOL. For those patients who are clinically stable, it would be appropri-

**Table 5.** Characteristics of those with and without treatment limitation discussion at first meeting (n = 116)

Variable	Treatment Limitation Discussed (n = 27)	Treatment Limitation Not Discussed (n = 89)	p	Effect Size d
Patient age, yrs	63.5 (16.2)	51.3 (17.5)	.002	.71
Patient Acute Physiology Score	74.0 (35.5)	55.2 (26.6)	.004	.65
Hospital length of stay, days	25.2 (14.4)	30.7 (16.8)	.13	
FDM age, yrs	55.2 (15.1)	53.3 (13.8)	.55	
<b>Patient and FDM Characteristics</b>				
	No. (%)	No. (%)		φ
Medical intensive care unit admission: yes	11 (40.7)	14 (16.1)	.007	.25
Do-not-resuscitate order: yes	18 (66.7)	14 (15.9)	.0001	.48
FDM gender: female	21 (77.8)	71 (80.7)	.74	
FDM ethnicity: white	17 (63.0)	58 (65.9)	.78	
FDM relationship to patient			.003	.37
Spouse	9 (33.3)	26 (29.5)		
Child	13 (48.1)	15 (17.0)		
Sibling	3 (11.1)	10 (11.4)		
Parent	2 (7.4)	27 (30.7)		
Other	0 (0.0)	10 (11.4)		
FDM income: >\$20,000/yr	20 (80.0)	67 (80.7)	.60	
FDM prior caregiver: yes	15 (55.6)	18 (20.5)	.001	.33
Inhospital death <sup>a</sup> : yes	12 (44.4)	12 (13.6)	.001	.32
<b>Meeting Characteristics</b>				
	Mean (SD)	Mean (SD)		d
Total formal meetings	2.2 (1.5)	2.0 (1.3)	.69	
Meeting time, mins	25.9 (10.2)	23.1 (12.2)	.28	
Percent time: instrumental	97.6 (3.4)	96.1 (4.8)	.06	
Percent time: physician spoke	61.2 (21.7)	58.9 (23.3)	.67	
Percent time: Advanced Practice Nurse spoke	12.7 (12.2)	14.3 (14.9)	.65	
Percent time: family spoke	27.8 (16.4)	24.8 (14.8)	.36	
Percent time: prognosis	18.1 (15.7)	21.2 (16.3)	.38	
Percent time: preferences	25.7 (18.4)	8.1 (9.7)	.0001	1.44
Percent time: treatment plan	17.9 (12.2)	23.0 (14.0)	.11	
Percent time: milestones	3.1 (5.2)	4.2 (5.3)	.32	
Percent time: medical update	37.5 (16.1)	46.6 (16.5)	.01	.55
Number of questions asked: physician	2.3 (1.8)	1.7 (1.6)	.12	
Number of questions asked: Advanced Practice Nurse	2.2 (1.68)	2.4 (2.4)	.68	
Number of questions asked: family	6.6 (4.2)	7.6 (5.8)	.40	
Physician rating of news given <sup>b</sup>	45.8 (32.1)	63.0 (23.7)	.02	.57
Family rating of news received <sup>b</sup>	54.1 (36.5)	75.9 (26.9)	.01	.63

FDM, family decisionmaker.

<sup>a</sup>Odds ratio, 5.1; 95% confidence interval, 1.9–13.4; *p* = .001; <sup>b</sup>news coded on visual analog scale: 0 = bad/discouraging news, 100 = good/encouraging news.

ate to make a simple statement that explains that all patients who require prolonged critical care are likely to have a prolonged and somewhat uncertain post-hospital recovery that may involve continued limitations in functional status. Examining QOL preferences will be helpful as the family start to envision life after the ICU. For those patients who are unstable, it is important to introduce the concepts of patient preferences early so that the family can begin to have a discussion of possible decisions that might need to be made should the patient's condition deteriorate or an unacceptable out-

come become apparent. To be supported in thinking about and discussing these options before a crisis emerges is an opportunity that will benefit patients and their families alike. Without discussions related to preferences, it becomes impossible for families and the healthcare team to share in the decision about life-sustaining treatment—a goal expressed by families as well as healthcare providers (11, 31–34).

The topic of treatment limitation is more sensitive than QOL and was likely not seen as relevant in situations in which the prognosis for survival seemed

good. Nevertheless, given the relatively high incidence of postdischarge death and hospital readmission in this population, it is likely that the FDMs will continue to be faced with decisions about aggressiveness of care sometime after discharge. A study by Nelson (29) confirmed that long-stay ICU patients and their surrogates identify discussion of alternatives to treatment as an important domain in communication. Raising the issue of treatment limitation in the ICU as an option that might be appropriate at a later time, depending on the illness trajectory, could be a helpful and supportive educational intervention.

There are several limitations to the present study. First, we were not able to audiotape meetings for all subjects. Although we found no differences on the variables that we assessed (age, gender, ethnicity), there was little variability for these variables and there are many other relevant characteristics that we were not able to assess (e.g., comfort level with communicating with family or healthcare providers, religious beliefs, etc.). Second, we were limited to assessing only the communication that occurred during taped family meetings. Communication that occurred outside of this area (at the bedside, over the telephone, etc.) was not assessed and likely had an impact on the quantity, quality, and type of communication that occurred during the family meetings. In addition, we report only on first family meeting and are unable to extrapolate findings to subsequent meetings or to those who had more than one formal family meeting. A fourth limitation was that the criteria used for identifying QOL and treatment limitation discussions, although reliable over time and among coders, were developed by the study investigators. As noted in reference to the study by White (23, 31), other clinicians and researchers may conceptualize these variables differently, thus obtaining different results. Finally, our sample of FDMs primarily was comprised of middle-aged, white individuals and our sample of physicians was primarily male whites with extensive ICU experience and results cannot be generalized to all ICU FDMs or physicians.

## CONCLUSIONS

Despite the use of a structured communication protocol that included discussion of values and preferences at each meeting, less than half of all first meet-

ings had any discussion of QOL issues. There is an expectation that hospital personnel inquire of all patients or their surrogates whether they have an Advance Directive; the discussion of QOL issues for long-stay ICU patients should be as commonplace and should be considered part of the standard approach to communicating with critical care unit families. Including information about the likely post-ICU outcomes for long-stay ICU patients in the education and training of ICU physicians and nurses could serve to expand their understanding of the long-term mortality and morbidity associated with such patients and the importance of anticipatory guidance. Continued education and training for ICU healthcare providers is needed to assist them in developing more comfort with having meaningful conversations with families about patient preferences and realistic treatment goals.

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