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Association between physicians' beliefs and the option of comfort care for critically ill patients

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Abstract

Purpose—For critically ill patients at high risk of death, reasonable treatment options include attempts at life prolongation and treatment focused on comfort. Little is known about whether and how physicians present the option of comfort care to surrogates. This study assessed how comfort care is presented to surrogates and whether physicians' beliefs are associated with whether comfort care is presented as an option.

Methods—Mixed-methods study of 72 audio-recorded family conferences about treatment decisions in 5 ICUs at 2 hospitals in San Francisco, California. 169 family members and 54 physicians participated. Patients were at high risk of death or severe functional impairment. Transcripts of audio-recorded conferences were coded to identify whether physicians offered comfort care as an alternative to life-sustaining treatment and to characterize the stated risks and benefits. Physicians completed a questionnaire indicating the strength of their belief that life support should be foregone.

Results—The inpatient mortality rate was 72%. Using a broad definition of comfort-oriented treatment, this option was presented in 56% [95% CI, 44%-67%] of conferences. In clustered multivariate models, the only independent predictor of offering comfort care as an option was the strength of the physician's belief that life support should be foregone (OR 1.38 [1.14-1.66], $p=.01$).

Conclusions—Clinicians did not explicitly inform surrogates about the option of comfort-oriented treatment in roughly half of clinician-family meetings. Physicians who more strongly believe that the appropriate goal of care is life prolongation are less likely to inform surrogates about the option of comfort care.

Introduction

Reasonable goals of care for critically ill patients at high risk of death include: attempts at life prolongation using mechanical ventilation and other invasive measures, and treatment focused solely on comfort using medications for symptom control in place of invasive technologies. Life support decisions are complex and preference-sensitive, meaning the best choice depends on individual values and preferences. [1] Family members often act as surrogates because patients are unable to participate, and critical care societies endorse shared decision making between physicians and surrogates as the optimal approach to life

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support decisions. [2-4] Previously documented problems with surrogate decision making include inadequate communication [5-9], psychological distress [10-13], and the use of unwanted aggressive treatment at the end of life. [14-17]

Physicians' presentation to surrogates of reasonable treatment options underpins shared decision making and guides discussion about the best treatment choice. [18] Scholars have voiced concerns that shared decision making in other clinical settings may be threatened by a constrained presentation of options. [18-21] For patients with advanced illness, failure to discuss alternatives to life-sustaining treatment may limit surrogate participation and/or lead to decisions that do not match patients' values. However, little is known about how treatment options are presented to surrogates in the ICU or what factors may influence whether physicians inform families of the option of comfort-oriented treatment.

We therefore conducted a mixed-methods study in a cohort of ICU patients at high risk of death to 1) describe whether and how comfort care was presented as an option in family conferences about treatment options, and 2) assess whether the strength of the physician's belief that life support should be withdrawn was associated with the presentation of comfort care.

Methods

Study design, patients and setting

We audiorecorded conferences and surveyed participants in 5 ICUs at two academic hospitals in San Francisco, California from January, 2006 through August, 2008. One hospital is a tertiary care center; the other is a county hospital. Study procedures are described in a single previous manuscript published from this dataset [22]; no previous report has described how physicians present treatment options.

Physician-family conferences were identified through daily contact with nurses. In these ICUs, conferences are initiated at the discretion of the interdisciplinary care team. We included only conferences that occurred on weekdays, included family and physicians, concerned an adult patient, and were conducted in English. To identify conferences about life-sustaining treatment decisions, we asked physicians beforehand if they anticipated discussion of withholding or withdrawing treatment or bad news. For the purposes of this analysis, we excluded conferences that did not ultimately include a treatment discussion.

Clinical staff gave permission to approach each family. We obtained surrogate consent in accordance with California law AB2328 specifying a primary and descending order of surrogates. [23] All conference participants completed informed consent prior to audio-recording. Institutional Review Boards at each hospital approved all procedures.

Coding and analysis of the audiotapes

A medical transcriptionist transcribed audio-recorded conferences verbatim. Three investigators (YS, DBW and GT) developed a codebook designed to capture 1) the presentation of comfort care by the physician, 2) discussion of risks and benefits of comfort care by the physician, and 3) treatment options discussed when comfort care was not offered.

We used a broad definition of comfort care, defined *a priori* as withdrawal of life sustaining treatment and/or a plan of care focused primarily on maximizing patient comfort rather than prolonging life. Comfort care was coded as present even if physicians only mentioned the possibility of foregoing life support without describing what palliative measures would replace it.

We used the analytic technique of qualitative description to develop a framework to categorize risks and benefits of comfort care that were disclosed to surrogates and treatment options discussed in conferences in which comfort care was not offered. [24] We categorized these treatment options as 1) unlimited intensive care, defined as treatment aimed at survival without specified limits, or 2) limited intensive care, defined as treatment aimed at survival with specified limits related to specific therapies, patient symptoms, or clinical endpoints.

To account for the possibility that comfort care may have been discussed in prior conferences, we developed a code to apply to statements referencing a previous discussion of comfort care.

We used Atlas.ti software, version 5.7.1 (Berlin, Germany) for qualitative data management.

Coder Training and Inter-rater reliability

The primary coder (GT) received training from two additional members of the study team (YS and DBW). Two investigators (YS and GT) coded an initial subset of 5 transcripts line-by-line and discussed as a group. Representative examples of each code from additional transcripts were highlighted and compared in additional training sessions. Subsequent coding questions were discussed as a group until consensus was achieved.

Inter-rater reliability was assessed on a random sample of 20% of conferences. The kappa statistic for our main result, whether the option of comfort care was presented, was 0.87, considered excellent inter-rater reliability [25]. Coders were blinded to participants' demographic information and questionnaire responses.

Assessment of demographics and conference characteristics

Physicians and surrogates completed demographic questionnaires. We asked the physician leading the conference to answer the following question immediately afterwards: "Prior to the family conference, how strongly did you believe that life support should be withheld or withdrawn? Please answer for yourself, not for the family or other healthcare providers" (0 [not strongly at all] to 10 [extremely strongly]). We abstracted patient demographics, including APACHE II score on the day of the conference, from the medical record. [26]

Statistical analysis

Patient, surrogate, and physician characteristics are presented as frequencies and percents or means and standard deviations. We used summary statistics to describe the frequency of option presentation and risks and benefits.

We used chi square and t tests to compare participant characteristics by the presentation of comfort care. For these analyses we used the primary surrogate for each conference, as defined by the California statute for surrogate research consent. We used hierarchical logistic regression to assess the association between the physician's belief that life support should be withdrawn and the presentation of comfort care, adjusting for clustering by physician that arose because some physicians led more than one conference. We used hierarchical Poisson regression to assess the association between the physician's belief that life support should be withdrawn and the number of unique benefits of comfort care described. In all adjusted analyses we controlled for APACHE-II score and number of days in the ICU prior to the conference because we hypothesized that physicians would be more likely to present comfort care as an option when patients were sicker or had been hospitalized for longer. We additionally adjusted for all demographic variables associated with the presentation of comfort care ($p < 0.2$) in bivariate analyses.

Results

Of the 105 eligible conferences identified, 74 were audio-recorded. For 5 of 105 eligible conferences the physician refused to allow the researchers to approach the family for participation, and for 26 of 105 eligible conferences the family declined to participate after learning about the study. Two audio-recorded conferences were excluded because they did not contain discussion of treatment plans, leaving 72 conferences for this analysis.

Characteristics of participating physicians, family members and patients are shown in Table 1. The inpatient mortality rate was 72%. Life support was eventually withdrawn for 72% of the total sample. A total of 54 different physicians led the 72 conferences. Forty-one physicians conducted a single conference, 10 conducted 2 conferences, 2 conducted 3 conferences, and 1 conducted 5 conferences. Sixty-seven percent of the physicians leading the conferences were attending physicians and 33% were residents or fellows. Audio-recorded conferences occurred an average of 10 (range 0 to 78) days after ICU admission; on average, 60% of the ICU stay had elapsed at the time of the conference. The average conference length was 35 minutes (range 10 to 105 minutes).

Table 2 summarizes participants' characteristics, stratified according to whether the option of comfort care was presented. Comfort care was presented as an option in 40 of 72 conferences (56%, 95% CI 44-67%). Clinicians' descriptions of comfort care varied broadly. In some conferences, comfort care was clearly discussed as an alternative treatment option. For example: "In that case what we would do is to take out the breathing tube, to give her medicines, as she needs them, if she needs them for breathing. And with the intent to keep her comfortable, but not to prolong her life." In other conferences, comfort care was described more briefly as the option of not continuing treatment. For example: "you know, we could withdraw support." One conference mentioned a prior offer of comfort care and discussion of this option was continued.

Comfort care was not presented as an option in 32 of 72 conferences (44%, 95% CI 33-56%). Of the 32 conferences in which comfort care was not discussed, 25 (78%) included only discussion of continued unlimited intensive care and 3 (9%) included only discussion of limited intensive care. Four conferences (13%) included discussion of both unlimited intensive care and placing some limit on intensive care. In many conferences, physicians described intensive care as the default option. For example: "we think we're at the point of needing to do the tracheostomy. Although it's difficult to say, we think it'll be more comfortable for her." Another physician explained: "basically, until we hear otherwise, from family, we always do everything, as much as we can for the patient." Some physicians implied that it was not yet time to discuss other options and emphasized that they were not giving up on the patient. For example: "I didn't, at this point at all ... want or need to have decisions about doing less for him ... that's not the issue. It may become an issue, though, so I wanted you to know that."

Among conferences in which comfort care was presented as an option, the mean number of risks of comfort care described per conference was 0.4 (SD 0.6, range 0-2); the mean number of benefits was 1.5 (SD 0.9, range 0-4). Five of the 40 conferences in which comfort care was offered contained no description of risks or benefits. Table 3 contains frequencies and examples of unique risks and benefits.

In bivariate analyses, the strength of the physicians' belief that life support should be withdrawn was the only variable associated with presentation of comfort care (see Table 2). In multivariate analyses, the strength of the physicians' belief remained strongly associated with whether comfort care was presented as an option. For every one-unit increase in strength of belief that life support should be withdrawn, there was a 38% increase in the

odds of presentation of comfort care (adjusted OR 1.38 [1.14-1.66], $p=0.01$). APACHE II score and number of days in the ICU prior to the conference were not associated with the presentation of comfort care in multivariate analyses. (See Table 4).

Among the 40 conferences in which comfort care was presented, there was a positive association between the strength of the physician's belief that life support should be withdrawn and the number of unique benefits of comfort care discussed (MV-adjusted IRR 1.12 [1.01-1.25], $p=0.04$).

Discussion

During formal clinician-family conferences in a cohort of critically ill patients with a high mortality rate, clinicians did not explicitly inform surrogates about the option of comfort-oriented treatment in roughly half of the conversations.

Physicians who believed more strongly that life support should be withdrawn were more likely to present comfort care as an option and, when it was presented, described more benefits of comfort care.

Our finding that clinicians frequently did not inform surrogates about the option of comfort care after on average nearly 2 weeks of intensive care is surprising and may pose a threat to the quality of shared decision making in ICUs. Comfort-oriented treatment is widely agreed to be a reasonable alternative to life extending treatment in patients with advanced critical illness. [27,28] There is also widespread agreement that patients or their surrogates should have the opportunity to participate in highly value-laden decisions near the end of life. Shared decision making is predicated on explicit discussion of reasonable treatment options [29,18], which sets the stage for subsequent deliberation about how best to match medical care to patients' values. [30] A constrained presentation of treatment options, referred to in decision psychology as a type of framing problem, may limit surrogates' ability to function as adequately informed participants in decision making. [18]

Some may argue that clinicians should not inform surrogates about the option of comfort care until they believe it is the most appropriate treatment pathway. However, this approach entails several risks. First, clinicians vary widely in what they perceive to be appropriate care in advanced critical illness. [31-33] For example, Garland and colleagues found that decisions to limit life support among over 1300 ICU admissions varied 15-fold between physicians, and that these decisions were more strongly related to the identity of the intensivist than to co-morbidities or illness type. [33] Furthermore, clinicians' views about end-of-life care often differ from the views of patients or families. [34,35] Thus while clinician beliefs inevitably influence medical decision making - strict neutrality is not possible to achieve - it would be problematic if these beliefs resulted in an incomplete discussion of accepted, available treatment options.

Second, failure to mention the option of comfort care earlier in the ICU course may work against the goal of helping family members to be emotionally prepared for withholding or withdraw life-sustaining treatment later in the hospitalization. This is concerning because perceived suddenness of death is an independent risk factor for adverse bereavement outcomes among family members. In her writing on death in American hospitals, medical anthropologist Sharon Kaufman has described this as "death without dying." [36-38]

Why might physicians fail to present comfort care as an option? This may be an unconscious reaction by physicians who are simply not focused on alternatives to continued intensive care. Alternatively, psychological factors such as a struggle to face death may inhibit physicians from talking about non-curative treatment options. [39] Some physicians

described intensive care as “doing everything” and may conversely view comfort care as doing less for their patients.

Another possibility is that failure to mention the option of comfort care represents a conscious attempt by physicians to protect families from the emotional difficulty of thinking about the possibility of a loved one’s death. Although well intentioned, this approach may be problematic because many individuals expect doctors to initiate sensitive end-of-life discussions. [40,41,36] An important area of future investigation is to determine whether physicians were aware that they did not discuss comfort care, and if so why they did not. One way for physicians to initiate discussion of treatment options without overwhelming families might be to say: “There are several potential treatment options. Would it be OK if we talked about the different approaches now?”

Our study had several limitations. First, conferences took place at two hospitals in San Francisco; findings may not generalize to other regions of the country. Second, selection bias is possible. While our participation rate compares favorably with other communication studies in the ICU [6,42], 30% of eligible conferences were not audio-recorded because either the physician or family declined. Third, it is likely that some critically ill patients never had a family conference and participants may have altered their behaviors because they were aware that this was a study about communication. In both cases, our findings may underestimate the true magnitude of the problem. Fourth, we audio-recorded a single conference per patient and did not collect information on family readiness to hear about comfort care. It is possible that physicians delayed discussion of comfort care until a later conference because they correctly perceived that families were not ready to hear about this option, though, on average, audio-recorded conferences took place after 60% of the ICU stay had elapsed, suggesting that - at a minimum - forecasting the option of comfort care during these discussions would not have been unreasonable. It is also possible that comfort care was discussed in earlier conferences. However, we coded for any mention of prior discussion of comfort care and found only one, in a conference that involved continued discussion of this option. Finally, we did not collect information on patient treatment preferences or nurses’ views, which may also have influenced whether comfort care was discussed.

In conclusion, we found that among a cohort of critically ill patients with a high mortality rate, comfort care was not presented as an option in nearly half of clinician-family conferences. Physicians who more strongly believed that the appropriate goal of care was life prolongation were less likely to inform surrogates about the option of comfort care. These findings merit further research and ethical debate about what treatment pathways should be routinely presented to the surrogates of patients with advanced critical illness.

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Table 1

Demographic Characteristics of Patients, Surrogates and Physicians

	Patients (n=72) N (%) or Mean (SD)	Surrogates (n=169) N (%) or Mean (SD)	Physicians (n=54) N (%) or Mean (SD)
Male	42 (58)	66 (39)	32 (59)
Race/Ethnicity			
Non-Hispanic white	34 (47)	57 (34)	37 (69)
Non-Hispanic black	11 (15)	36 (21)	0 (0)
Hispanic	14 (19)	36 (21)	2 (4)
Asian/Pacific Islander	12(17)	23 (14)	14 (26)
Native American	1 (1)	8 (5)	0 (0)
Other/undocumented	0 (0)	9 (5)	1 (2)
Age, years, mean (SD)	62(18)	47 (15)	37 (9)
Admission diagnosis			
Neurologic failure	27 (38)	--	--
Gastrointestinal failure (including pancreatitis)	1 (1)	--	--
Cardiac failure or shock (including sepsis)	21(29)	--	--
Hepatic failure	4 (6)	--	--
Metastatic cancer	3 (4)	--	--
Respiratory failure	15 (21)	--	--
Renal failure	1 (1)	--	--
APACHE II Score on day of conference, mean (SD)	29 (6)	--	--
Number of days in ICU prior to conference, mean (SD)	10 (12)	--	--
Died during this hospitalization	52(72)	--	--
Relationship to patient			
Spouse/partner	--	20(12)	--
Child	--	64 (38)	--
Sibling	--	32 (19)	--
Parent	--	16(10)	--
Other	--	35 (21)	--
Staff position			
Attending physician	--	--	36 (67)
Resident or fellow	--	--	18 (33)
Medical specialty			
Internal medicine	--	--	29(54)
Neurology	--	--	8 (15)
Surgery	--	--	3 (6)

	Patients (n=72) N (%) or Mean (SD)	Surrogates (n=169) N (%) or Mean (SD)	Physicians (n=54) N (%) or Mean (SD)
Medicine Subspecialty	--	--	4 (7)
Cardiology	--	--	4 (7)
Oncology	--	--	4 (7)
Hepatology	--	--	1 (2)
Pulmonology	--	--	
Palliative Care	--	--	1 (2)
Years in practice, mean (SD)	--	--	7 (9)

Table 2

Participant characteristics by presentation of comfort care as an option

	Comfort Care presented as an option		p value *
	Yes(n=40) N (%) or Mean (SD)	No (n=32) N (%) or Mean (SD)	
Patient Characteristics			
Male	24 (60)	18(56)	0.75
Race/Ethnicity			0.78
Non-Hispanic white	19 (48)	15 (47)	
Non-Hispanic black	5 (13)	6 (8)	
Hispanic	9 (23)	5 (7)	
Asian/Pacific Islander	7 (18)	5 (7)	
Native American	0 (0)	1 (1)	
Other/undocumented	0 (0)	0 (0)	
Age, years, mean (SD)	63(17)	61(18)	0.59
Admission diagnosis			0.81
Neurologic failure	14 (35)	13 (41)	
Gastrointestinal failure (including pancreatitis)	0 (0)	1 (3)	
Cardiac failure or shock (including sepsis)	13(33)	8 (25)	
Hepatic failure	3 (8)	1 (3)	
Metastatic cancer	2 (3)	1 (3)	
Respiratory failure	7 (10)	8 (25)	
Renal failure	1 (1)	0 (0)	
APACHE II Score, mean (SD)	30 (6)	28 (6)	0.19 1
Number of days in ICU prior to conference, mean (SD)	12 (15)	8 (8)	0.54
Died during this hospitalization	31 (78)	21 (66)	0.26
Surrogate characteristics[†]			
Male	21 (53)	13 (41)	0.32
Race/Ethnicity			0.67
Non-Hispanic white	18(45)	14 (44)	
Non-Hispanic black	5 (13)	6 (19)	
Hispanic	8(20)	5 (16)	
Asian/Pacific Islander	6 (15)	4 (13)	
Native American	0 (0)	2 (6)	
Other/undocumented	3 (8)	1 (3)	
Age, years, mean (SD)	49 (15)	50 (13)	0.78
Relationship to patient			0.96
Spouse/partner	9 (23)	9 (28)	

	Comfort Care presented as an option		p value*
	Yes(n=40) N (%) or Mean (SD)	No (n=32) N (%) or Mean (SD)	
Child	19(26)	14 (44)	
Sibling	4 (10)	4 (13)	
Parent	4 (10)	3 (9)	
Other	4 (10)	2 (6)	
Physician Characteristics^{††}			
Male	20(50)	22 (69)	0.109 1
Race/Ethnicity			0.61
Non-Hispanic white	28 (70)	20 (63)	
Non-Hispanic black	0 (0)	0 (0)	
Hispanic	2 (5)	4 (13)	
Asian/Pacific Islander	9 (23)	8 (25)	
Native American	0 (0)	0 (0)	
Other/undocumented	1 (3)	0 (0)	
Age, years, mean (SD)	35 (7)	37 (9)	0.75
Staff position			0.58
Attending physician	31 (78)	23(72)	
Resident or fellow	9 (23)	9 (28)	
Medical specialty			0.68
Internal medicine	20(28)	14 (44)	
Neurology	9 (13)	10 (31)	
Surgery	1 (1)	2 (6)	
Medicine Subspecialty	10(14)	6 (19)	
Years in practice, mean (SD)	6 (7)	8 (10)	0.82
Strength of belief that life support should be withdrawn (0-10 scale), mean (SD)	7 (3)	4 (4)	<0.001

* All p values represent bivariate analyses

[†] Data shown for primary surrogate for each conference "Each physician conducted between one and five conferences

^{††} Each physician conducted between one and five conferences

Table 3
Frequency of Risks and Benefits described for Comfort Care

Risks	Example	% of Conferences (N=40)
Patient may die sooner	“But understanding that, if we stop these medicines, it is very likely that she will pass on.”	20%
Family discomfort with patient symptoms or change in focus of care	“And if she shows some signs of a gag reflex, and again, that’s a reflex, it’s not that she’s feeling that, we can actually increase the medicines primarily for your comfort, so she doesn’t show that.”	13%
Not in accordance with patient’s wishes	“I mean I don’t at all want you to feel like you’re doing something that would’ve been against what he wanted. And that’s really the last thing that we would want.”	3%
Benefits	Example	
Comfortable	“She’ll be receiving enough medication that she will be comfortable and will not be aware of any pain or discomfort.”	75%
In accordance with patient’s wishes	“You know, and even if you decide that she would’ve wanted less aggressive measures, that’s not you taking away something from her, it’s just honoring her wishes.”	35%
Natural	“Just know that the goal is to try to get her into a much more natural state where she’s able to show us what she wants to do and not ... you know, not interfere with that process, just let her do what she’s gonna do.”	23%
Allows patient to die with dignity	“We allow her to go with as much peace and as much dignity as possible, keeping that as the absolute primary goal.”	20%

Table 4

Predictors of presentation of comfort care as an option

	Unadjusted OR [95% CI][*]	P value	MV-Adjusted OR [95% CI][†]	P value
Strength of physician belief that life support should be withdrawn, per 1-pt increase on 0-10 scale	1.33[1.13-1.57]	.01	1.38 [1.14-1.66]	.01
APACHE II score	1.05[0.97-1.15]	.22	1.04 [0.94-1.15]	.41
Number of days in ICU prior to conference	1.03[0.98-1.09]	.25	1.04 [0.97-1.11]	.27

^{*} OR adjusted for clustering by physician

[†] OR adjusted for strength of physician belief that life support should be withdrawn, APACHE II score, number of days in ICU prior to conference, physician gender, and clustering by physician