

# Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers\*

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**Objective:** Many intensive care unit (ICU) physicians have withdrawn life-support from a patient who lacked decision-making capacity and a surrogate decision-maker, yet little is known about the decision-making practices for these patients. We sought to determine how often such patients are admitted to the ICU of a metropolitan hospital and how end-of-life decisions are made for them.

**Design:** Prospective, observational cohort study.

**Patients and Setting:** Consecutive adult patients admitted to the medical ICU of a metropolitan West Coast hospital during a 7-month period in 2003 to 2004.

**Measurements:** Attending physicians completed a questionnaire about the decision-making process for each patient for whom they considered limiting life-support who lacked decision-making capacity and a legally recognized surrogate decision-maker.

**Main Results:** Of the 303 patients admitted during the study period, 49 (16%; 95% confidence interval [CI], 12–21%) lacked decision-making capacity and a surrogate during the entire ICU stay. Compared with all other ICU patients, these patients were

more likely to be male (88% vs. 69%;  $p = .002$ ), white (42% vs. 23%;  $p = .028$ ), and  $\geq 65$  yrs old (29% vs. 13%;  $p = .007$ ). Physicians considered withholding or withdrawing treatment from 37% (18) of the 49 patients who lacked both decision-making capacity and a surrogate decision-maker. For 56% (10) of these 18 patients, the opinion of another attending physician was obtained; for 33% (6 of 18), the ICU team made the decision independently, and for 11% (2 of 18), the input of the courts or the hospital ethics committee was obtained. Overall, 27% of deaths (13 of 49) during the study period were in incapacitated patients who lacked a surrogate (95% CI, 15–41%).

**Conclusions:** Sixteen percent of patients admitted to the medical ICU of this hospital lacked both decision-making capacity and a surrogate decision-maker. Decisions to limit life support were generally made by physicians without judicial or institutional review. Further research and debate are needed to develop optimal decision-making strategies for these difficult cases. (Crit Care Med 2006; 34:2053–2059)

**KEY WORDS:** surrogate decision-maker; end-of-life treatment decisions; life-sustaining treatment; intensive care unit patients

Many patients admitted to intensive care units (ICUs) are unable to participate in decisions about their medical care (1, 2). As a result, surrogate decision-makers are often asked to make end-of-life treatment decisions for them, using either the substituted judgment standard or the best interest standard (3). This approach promotes patient autonomy and informed decision-making, central tenets of Western bioethics (3–5). However, some decisionally incapacitated patients do not have anyone available to serve as a surrogate decision-maker (6–

9). Asch and colleagues (6) documented that one third of ICU physicians have acknowledged discontinuing mechanical ventilation in such a patient. These cases raise ethical and legal questions about who should make decisions for incapacitated patients without surrogates and under what circumstances it is permissible to forego life-sustaining treatment.

Most states do not have laws that address how decisions to limit life-sustaining treatment should be made for decisionally incapacitated adults without surrogates (10). In states that do have such laws, some give physicians complete

authority to limit life-sustaining treatment, whereas others require that a legal guardian be appointed by the court to make the decision (10). Guidelines from the American Medical Association recommend judicial review for such cases, and those of the American Geriatrics Society advise against routine involvement of the courts and recommend an institutional multidisciplinary review for such decisions (11, 12). It is unknown which recommendations, if any, physicians follow when making treatment decisions for these patients. Moreover, no studies have determined how frequently incapacitated patients without surrogates are admitted to ICUs, nor have studies systematically analyzed the process by which decisions to limit life-sustaining treatment are made for them.

Therefore, we sought to determine how often decisionally incapacitated patients without surrogates are admitted to the ICU of a metropolitan hospital and how decisions to limit life-sustaining treatment are made for them.

\*See also p. 2238.

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## METHODS

*Study Design, Patients, and Setting.* This prospective longitudinal cohort study included all adult patients admitted to the medical ICU of a metropolitan West Coast hospital during a 7-month period in 2003 to 2004. The study was approved by the hospital's institutional review board.

Patients were considered to lack decision-making capacity if the ICU physician determined they were unable to participate in decisions about their medical care. We used the physicians' assessments of decisional capacity rather than performing formal cognitive testing in order to capture how decisions were made in clinical practice, although physicians' assessments of decision-making capacity correlate highly with the results of formal cognitive testing (13). Patients were considered to lack a surrogate decision-maker if they had no family, legally appointed guardian, or health care proxy available and willing to participate in decisions about their medical care. Written advance directives were defined as documents signed by the patient delineating any aspect of their end-of-life treatment preferences.

The study institution serves many of the uninsured residents of the region. Many of the patients are homeless or marginally housed. The hospital does not have an institutional policy addressing how end-of-life treatment decisions should be made for decisionally incapacitated patients who lack a surrogate decision-maker and an advance directive.

*Initial Evaluation and Follow-Up.* Daily, we contacted the ICU physician to determine whether a patient had been admitted in the previous 24 hrs who lacked decision-making capacity, a surrogate decision-maker, and an advance directive. If so, we recorded the patient's demographic and clinical characteristics (age range, gender, race/ethnicity, reason for ICU admission) from the physician. Thereafter, we contacted the ICU team on a daily basis to determine whether the patient had regained decision-making capacity or a surrogate decision-maker had been located. Physicians were aware that the purpose of the study was to understand processes of care for patients without surrogates, but they were not aware of the specific research questions. We recorded from the ICU physicians the number of days each patient lacked both decision-making capacity and a surrogate decision-maker in the ICU and whether they survived to ICU discharge. In addition, for each patient identified, we contacted the attending ICU physician twice weekly to determine whether he or she had either written or considered writing a "do not resuscitate" (DNR) order or an order to withdraw life-sustaining treatments. If so, the attending physician completed a questionnaire about the decision-making process, which is described below. At the end of the study period, we used the ICU admission log and administrative records to determine the demographic characteristics and

mortality rate for all other patients admitted to the medical ICU during the study period.

*Process by Which Surrogate Decision-Makers are Located.* When a decisionally incapacitated patient was admitted, the ICU social workers and clinicians regularly took several steps to determine whether a surrogate decision-maker was available. First, the team reviewed the patient's medical record to locate contact information for anyone who may have had knowledge of the patient's values or treatment preferences. Then the social workers made telephone calls to any noted contacts, including the patient's primary care physician, the next of kin, or supervisors from facilities from which the patient came. If these attempts did not yield a surrogate, the police were dispatched to the patient's listed address to attempt to locate anyone with knowledge of the patient. If the patient's name and address were unknown, he or she was fingerprinted and the police attempted to identify the patient and locate relatives or friends. The process continued until a surrogate was found or until all options were exhausted.

*Questionnaire Development.* The questionnaire addressed basic patient and physician demographic characteristics and physician attitudes about making decisions for incapacitated patients. In addition, physicians were asked to indicate what factors influenced the decision of whether life-sustaining treatment should be limited and who was involved in the decision-making process. The items on the questionnaire were generated from expert opinion and review of the medical and legal literature on decision-making for decisionally incapacitated patients without surrogates (10, 14–18). The questionnaire is available from the authors.

*Pretesting.* To ensure the clarity of the questionnaire, we conducted semistructured interviews with seven attending physicians and five housestaff. All 12 had prior experience treating decisionally incapacitated patients without surrogates. After completing the questionnaire, physicians underwent cognitive interviewing with the study investigator in which they verbalized what they thought each question meant and why they selected each answer. Through this process, the questionnaire was refined for both clarity and brevity. To assess the quality of the final instrument, three research methodologists were asked the following three questions: Are the response options easy to understand (clarity)? Are the questions directed at important elements of the decision-making process (face validity)? Is the questionnaire likely to distinguish between different approaches to decision-making for these patients (utility and discriminability)? All three experts endorsed the instrument's clarity, face validity, utility, and discriminability (19). The reliability of the questionnaire was assessed with use of hypothetical test cases administered to a group of intensivists not involved in the study. Questionnaires were completed on two occasions, 2 wks apart. Test-retest reliability was assessed with use of the kappa statistic, a measure of agreement beyond

chance. The average kappa value was 0.84, and all values were above 0.70. A kappa value of 0.75 is considered excellent reliability.

*Legal Considerations.* Physicians may believe that they are in legal jeopardy if they forego life-sustaining treatment for a patient who cannot give informed consent and who has no legally recognized surrogate decision-maker available. Therefore, we took several steps to protect the physicians' and patients' identities. The study was anonymous for both patients and physicians. We recorded only general demographic characteristics that could not be used to identify specific physicians or patients. To further protect the physicians who participated in this research from the potential for legal prosecution, all identifying information about the physicians and the institution have been removed from the article. To minimize the chance that study records would allow a direct link between individual physicians and specific treatment decisions for particular patients, no chart review was performed. We also obtained a Federal Certificate of Confidentiality from the National Institutes of Health, which permits the study investigators to refuse to turn over study records in the event of a legal inquiry (20).

*Statistical Analysis.* Statistical analyses were performed with STATA version 8 (Stata, College Station, TX). All tests were two-tailed. Categorical data were analyzed with the chi-square test. Normally distributed interval variables were analyzed with unpaired Student's *t*-tests. ICU length of stay had a severe right skew. Therefore, we used medians, interquartile ranges, and the Mann-Whitney rank-sum test for this variable.

## RESULTS

*Patients.* Of the 303 patients admitted to the medical ICU during the study period, 24% lacked decision-making capacity and a surrogate decision-maker during the first 2 days of the ICU stay (72 of 303; 95% confidence interval [CI], 19–29%) (Fig. 1). None of these 72 patients had an advance directive specifying end-of-life treatment preferences. The demographic and clinical characteristics of these patients are described in Table 1. In comparison with all other patients admitted to the medical ICU during the study period, decisionally incapacitated patients without surrogates were more likely to be male (88% vs. 69%;  $p = .002$ ), white (42% vs. 23%;  $p = .028$ ), 65 yrs of age or older (29% vs. 13%;  $p = .007$ ), and admitted for respiratory failure (49% vs. 34%;  $p = .001$ ).

*Course in the Intensive Care Unit.* Of the 72 patients who initially lacked decision-making capacity and a surrogate decision-maker, outcome data were available on 71 (Fig. 1). Twenty-four percent

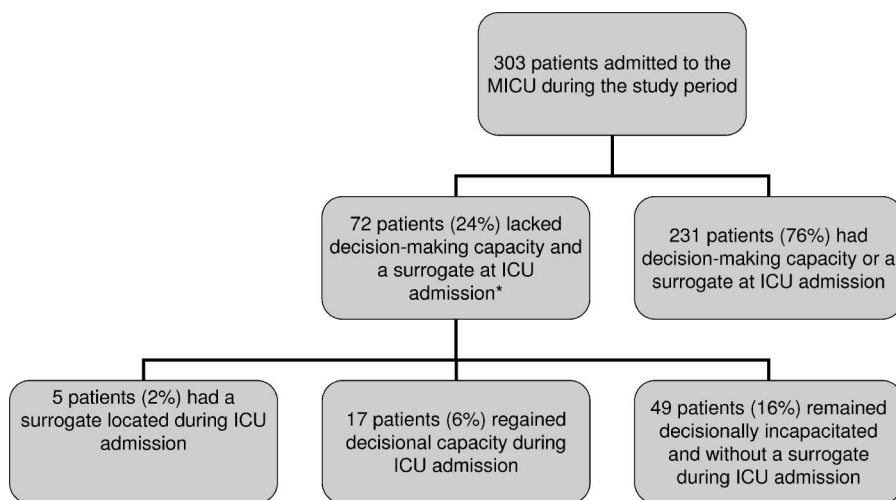


Figure 1. Profile of patients admitted to the medical intensive care unit (MICU) during the study period. Percentages are given, with the denominator expressed as the total number of ICU admissions during the study period. \*Data on one subject were missing.

Table 1. Demographic and clinical characteristics of the 303 study patients

Characteristic	No. (%) of Patients		p Value
	Incapacitated, Without Surrogate (n = 72)	With Decision-Making Capacity or a Surrogate (n = 231)	
Age, yrs			.007
<40	13 (18)	60 (26)	
40–64	38 (53)	140 (61)	
>64	21 (29)	31 (13)	
Male	63 (88)	159 (69)	.002
Race/ethnicity <sup>a</sup>			.028
White	30 (42)	52 (23)	
Black	21 (29)	78 (34)	
Asian	10 (14)	31 (13)	
Hispanic	8 (11)	50 (22)	
Other	3 (4)	12 (5)	
Primary organ dysfunction			.001
Respiratory	35 (49)	79 (34)	
Cardiovascular	11 (15)	43 (19)	
Neurologic	18 (25)	34 (15)	
Hepatic	3 (4)	4 (2)	
Gastrointestinal	2 (3)	45 (20)	
Hematologic	2 (3)	1 (0)	
Renal	1 (1)	8 (3)	
Endocrine	0 (0)	17 (7)	

<sup>a</sup>Data are missing on eight subjects who had decision-making capacity or a surrogate decision-maker.

(17 of 71) regained decision-making capacity before a surrogate decision-maker could be located. For another 7% (5 of 71), a surrogate decision-maker was located after a median of 4 days in the ICU (range, 3–31 days). The remaining 69% (49 of 71) did not regain decision-making capacity, nor was a surrogate decision-maker located. The ICU length of stay for these 49 patients was significantly longer than that for patients who had decision-making capacity or a surrogate decision-maker (median of 6 days, with interquartile range [IQR] of 4–10 days, vs. median

of 3 days, with IQR of 2–6 days), respectively ( $p < .0001$ ).

The overall ICU mortality rate during the study period was 16% (49 of 303; 95% CI, 12–20%). There was not a statistically significant difference in mortality rates between decisionally incapacitated patients without surrogates and all other ICU patients (18% vs. 15%;  $p = .56$ ). Twenty-seven percent of deaths (13 of 49) during the study period involved incapacitated patients who lacked a surrogate decision-maker (95% CI, 15–41%).

*Decisions to Write a DNR Order or Withdraw Life Support.* The attending physician considered writing a DNR order for 37% (18) of 49 patients who remained decisionally incapacitated and without a surrogate decision-maker during their entire ICU stay (Table 2). The median time in the ICU before such consideration was 10 days (range, 3–41 days). Figure 2 delineates the decision-making and outcomes for these 49 patients. For 13 of 18 patients, a DNR order was ultimately written. The decision was made solely by the attending ICU physician and his or her team for four of the 13 patients. For seven patients, the opinion of a second attending physician or the patient's primary care physician was obtained before a DNR order was written. The hospital ethics committee was involved in making decisions for one patient, and for another there was an institutional review of the case and the court was petitioned to appoint a legal guardian.

Physicians cited a number of reasons why they considered writing a DNR order or withdrawing treatment (Table 3). Poor prognosis for survival to hospital discharge was the most commonly cited reason for considering a DNR order (12 of 18). For 11 of 18 patients, judgments about future quality of life were factors in the decision-making process. For nine of 18 patients, ICU physicians based their decision, at least in part, on input from the primary care physicians indicating that the patients may not have wanted further treatment. Concerns about inappropriate use of scarce resources influenced the decision for three patients. When a DNR order was considered but not written ( $n = 5$ ), all physicians reported that writing a DNR order was not medically appropriate. For two of these five patients, physicians also reported legal concerns about writing a DNR order.

Physicians considered withdrawing life support from 15 of the 18 patients for whom they considered writing a DNR order. Treatment was ultimately withdrawn for eight of these patients. The breakdown of who was involved in the decision to withdraw treatment was similar to that for writing a DNR order (data not shown). Physicians cited poor prognosis for short-term survival as a reason for the decision in all eight withdrawal cases (Table 3). All eight patients died in the ICU. For the seven other patients, physicians considered writing an order to withdraw life support but did not do so. Physicians reported they ultimately decided it was

Table 2. Characteristics of the 18 patients for whom physicians considered writing a do not resuscitate (DNR) order

Age, yrs	Gender	Race	Primary Organ Dysfunction	Days in ICU Before Consideration of Writing DNR Order	Outcome	Persons Involved in the Decision-Making Process						
						ICU Team	PMD or Another Attending MD	Ethics Committee	Institutional Review	Judicial Review	Other	
DNR order not written												
40-64	M	Black	Respiratory	24	Survived	+	+	-	-	-	-	-
>64	M	Black	Respiratory	4	Died	+	-	-	-	-	-	-
<40	M	White	Respiratory	12	Survived	+	-	-	-	-	-	-
>64	M	White	Respiratory	16	Survived	+	+	-	-	-	-	-
<40	F	Hispanic	Hematologic	3	Survived	+	+	-	-	-	-	-
DNR order written												
40-64	F	Black	Respiratory	3	Died	+	-	-	-	-	-	-
40-64	M	Black	Respiratory	8	Survived	+	-	-	-	-	-	-
>64	M	Asian	Respiratory	23	Died	+	+	+	-	-	-	-
>64	M	Black	Renal	41	Survived	+	+	-	-	-	-	-
40-64	M	White	GI	18	Died	+	+	-	-	-	-	+
												(Neighbor)
40-64	M	Asian	Cardiovascular	15	Died	+	+	-	+	+	-	-
>64	M	Asian	Respiratory	10	Died	+	+	-	-	-	-	-
40-64	M	Black	Respiratory	7	Died	+	+	-	-	-	-	-
40-64	M	Am. Indian	Hepatic	4	Survived	+	-	-	-	-	-	-
40-64	M	White	Respiratory	N/A <sup>a</sup>	Survived	+	+	-	-	-	-	-
>64	M	White	Respiratory	N/A <sup>a</sup>	Died	+	-	-	-	-	-	+
												(Prior ICU MD)
>64	M	Asian	Respiratory	N/A <sup>a</sup>	Died	+	+	-	-	-	-	-
40-64	M	Hispanic	Respiratory	N/A <sup>a</sup>	Died	+	+	-	-	-	-	-

ICU, intensive care unit; PMD, primary outpatient physician.  
<sup>a</sup>Data are missing or not collected for these four patients.

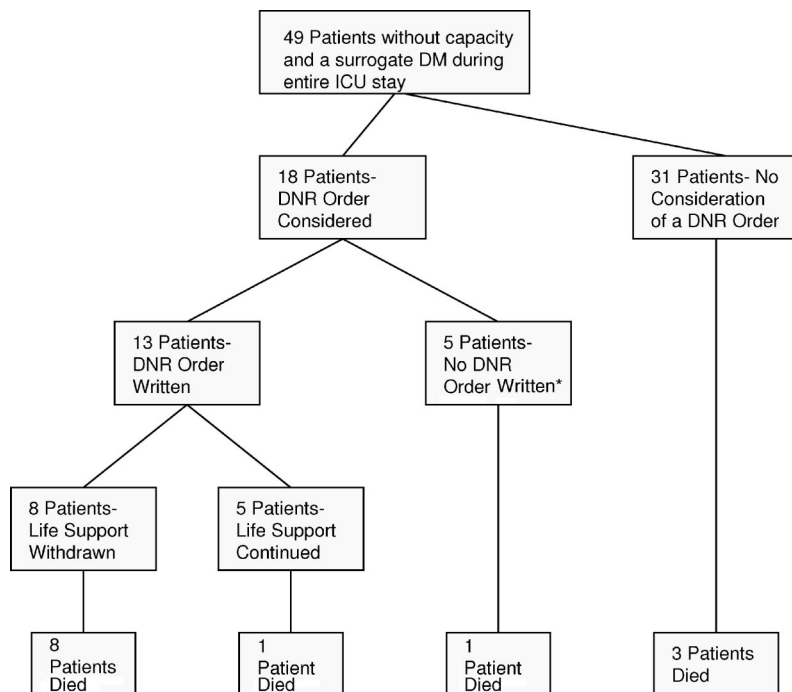


Figure 2. Flow diagram for the 49 patients who lacked both decision-making capacity and a surrogate decision-maker during the entire intensive care unit (ICU) admission (DM, decision-maker; DNR, do not resuscitate). \*Physicians considered withdrawing treatment from two of these patients but ultimately did not do so.

not medically appropriate to withdraw life support from these seven patients, and all but one patient survived. For three of these seven patients, physicians also cited legal concerns about withdrawing treatment, and for two patients there were disagreements among the physicians about whether it was appropriate to withdraw life support.

## DISCUSSION

This is the first study to provide information about the proportion of ICU patients who lack both decision-making capacity and to examine how end-of-life decisions are made for them. Sixteen percent of patients admitted to the medical ICU of this metropolitan West Coast hospital were not able to participate in their medical decisions and lacked a surrogate decision-maker. In addition, one of every four deaths in the medical ICU occurred in this patient population. We found wide variation in the process by which physicians decided whether to limit life-sustaining treatment for these patients. Some decisions were made independently by the treating physicians, some were

**Table 3.** Considerations used in deciding whether to limit life-sustaining treatment for 18 incapacitated patients without surrogate decision-makers

Rationale Cited For DNR Order	No. (%) of Patients		
	DNR Order Considered But Not Written (n = 5)	DNR Order Written (n = 13)	Total (n = 18)
Poor prognosis for hospital survival	2 (40)	10 (77)	12 (67)
Predicted poor quality of life	2 (40)	9 (69)	11 (61)
Evidence that further treatment may not be consistent with patient's wishes	3 (60)	6 (46)	9 (50)
Treatment was not in the patient's best interest	1 (20)	5 (39)	6 (33)
Inappropriate use of limited resources	2 (40)	1 (8)	3 (17)

For withdrawing life support	Withdrawal Considered But Not Carried Out (n = 7)		Life Support Withdrawn (n = 8)	Total (n = 15)
	Poor prognosis for hospital survival	3 (43)		8 (100)
Predicted poor quality of life	4 (57)		5 (63)	9 (60)
Evidence that further treatment may not be consistent with patient's wishes	2 (29)		5 (63)	7 (47)
Treatment was not in the patient's best interest	1 (14)		4 (50)	5 (33)
Inappropriate use of limited resources	2 (29)		0 (0)	2 (13)

DNR, do not resuscitate.

made in conjunction with other physicians, and, rarely, the hospital ethics committee or the courts were involved.

Several prior studies and a case-series have documented that limitation of life-support occurs for decisionally incapacitated patients who lack a surrogate (2, 7, 8, 21–23). In a survey administered to 879 physicians practicing in adult ICUs in the United States, one third of the respondents indicated that they had withdrawn mechanical ventilation for at least one decisionally incapacitated patient without a surrogate (6). Smedira et al. reported that 11% of decisions to limit life-sustaining treatment involved incapacitated patients who did not have a family member available to serve as a decision-maker (7). A study of similar design performed 5 yrs later at the same institution yielded similar findings (21). Although these investigations identified end-of-life decision-making for this patient population as a common issue in the ICU, they did not address who was involved in these ethically challenging decisions or what factors influenced the

ultimate choice of whether to withdraw life-support.

The current study adds several important pieces of knowledge to our understanding of decision-making for this population. First, patients without surrogates are encountered in the ICU; one in six patients admitted to this medical ICU remained incapacitated and without a surrogate during their entire ICU stay. Comparable data from other institutions do not exist, but it is likely that this is a common problem in other hospitals that serve a similar patient population. A study of decisionally incapacitated nursing home patients in New York state revealed that more than one third did not have a surrogate decision-maker available to make decisions about DNR orders (24).

Second, the median ICU length of stay for incapacitated patients without surrogates was twice that of all other ICU patients. One possible explanation for this is that incapacitated patients without surrogates had more-severe illness than other ICU patients. Although we were unable to record APACHE II scores because

of the strict confidentiality protections required to conduct the study, this hypothesis is supported by the observation that incapacitated patients without surrogates were older and had a higher proportion of respiratory failure than all other ICU patients. Another possible explanation for the longer length of stay is that, in the absence of information about a patient's wishes, physicians tended to continue treatment longer than they would have for a similarly situated patient who either had decision-making capacity or a surrogate. Commentators have raised concern that, depending on the reimbursement structure of the individual hospital, there may be a systematic bias in favor of either overtreatment or undertreatment of these patients (25). Further research is needed to determine the relative contribution of each of these factors to the longer length of stay observed in this patient population.

This study provides new information about the factors important to physicians when making actual end-of-life treatment decisions for critically ill, incapacitated patients who lack surrogate decision-makers. Physicians based these decisions predominantly on the patients' chances to survive the hospitalization but also on more subjective criteria, such as the patients' anticipated quality of life, their own perception of what was in the patients' best interest, and concerns about appropriate resource allocation. Prior studies suggest that some of these criteria may be problematic (26, 27). First, there is evidence that physicians' ratings of patients' quality of life are systematically lower than patients' own assessments (28). Second, physicians often project their own treatment preferences onto their patients (29). Many of the patients cared for in the study ICU are homeless or marginally housed, and these patients tend to prefer more aggressive life-sustaining treatment than physicians (30). These studies suggest that physicians may not be well positioned to independently decide when to limit life-sustaining treatment if the decision is based on value judgments about quality of life.

Last, we found considerable variation in who was involved in the decisions to limit life-sustaining treatment when neither the patient nor family could participate in the decision. The ICU team often involved other physicians, sometimes made the decision unilaterally, and rarely involved the courts or the hospital ethics committee. The inconsistent approach to

decision-making for these patients is not surprising, given the lack of agreement in state laws (10) and professional society policies on this issue (11, 12). These documents differ significantly in the role of the courts in end-of-life decision-making for these patients, the amount of authority granted to physicians, and the situations in which it is permissible to withdraw life support. Several commentators and ethicists have raised concerns about the absence of due process and the potential for conflict of interest when physicians assume sole decision-making responsibility for patients (15, 25, 31, 32). Additionally, a number of studies have documented that physicians vary widely in their beliefs about when it is appropriate to limit life-sustaining treatment for critically ill patients (33–36). These studies suggest that, in the absence of input from the patient or the patient's surrogate, reliance on physicians as decision-makers may result in similarly situated patients receiving different levels of treatment.

Despite their procedural differences, expert recommendations consistently stress the need for a due process procedure when making decisions to forego life support in incapacitated patients without surrogates, such as an internal multidisciplinary committee or external judicial review (10, 12, 37). Ideally, decisions made by these committees would be patient-centered, free from conflicts of interest, and based upon the expertise of a diverse group (10, 37). Additionally, the committee must be available to make decisions in a timely manner (25). Several investigators have described the development of such procedures (10, 15), but more research is needed on their practical implementation and effectiveness.

There are several limitations of our study. Information about the decision-making process was collected directly from the physicians who were making the treatment decisions. It is possible that the physicians' decision-making process was influenced by the knowledge that they were being studied. It is also possible that, out of fear of professional scrutiny or legal action, physicians reported a more normative approach to decision-making. We took measures to minimize the possibility that this would occur, including making the surveys anonymous and obtaining a Federal Certificate of Confidentiality. Second, because the study was conducted at a single hospital, the results may not be generalizable to other institu-

tions, particularly those with a patient population substantially different from that of the study hospital. Nonetheless, with increasing numbers of disenfranchised individuals in the United States (38), it seems likely that this is a common problem in the many hospitals serving these individuals. Next, we did not record information about the decision-making process for patients who had decision-making capacity or a surrogate decision-maker and therefore could not compare end-of-life decision-making practices between these two groups. This is an important area for future research. Finally, our sample size was too small to determine whether there were significant differences between patients for whom physicians limited life-support and those for whom they considered doing so but ultimately decided to continue full treatment.

This study documents that dilemmas are common regarding end-of-life treatment for patients who lack both decision-making capacity and a surrogate decision-maker. The decision-making practices for these patients were variable but generally involved decision-making solely by physicians. It is unclear if this approach provides adequate safeguards to ensure that decisions for these patients are fair and consistent. Further research and debate are needed to develop optimal decision-making procedures for these difficult cases.

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