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Deciding in the Dark: Advance Directives and Continuation of Treatment in Chronic Critical Illness

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Keywords

prolonged mechanical ventilation; prolonged critical illness; do not resuscitate; decision making; withholding treatment; withdrawing treatment

Introduction

Advances in ICU care have enabled more patients to survive acute critical illness, but created a new population who are chronically critically ill (1). Patients with chronic critical illness have persistent respiratory failure, dysfunction of other organs, and complications including neuropathy/myopathy, anemia, pressure ulcers, and recurrent infections (2–4). Chronic critical illness can be identified by the placement of tracheotomy for prolonged mechanical ventilation (5). It is a devastating condition, imposing heavy burdens on patients, families, professional caregivers, and the health care system. Distressing symptoms are common, resource utilization and costs are enormous, return to the community is rare, and 6-month mortality rates exceed those for most malignancies (6–14).

Most patients with acute critical illness lack capacity to make decisions about limitation of life-supporting treatments (15–17). Still, the majority of ICU deaths are preceded by such decisions, which may be based on treatment preferences previously expressed by the patient as an advance directive, or on the judgment of an appropriate surrogate decision-maker including a legally-appointed health care proxy (18–22). After tracheotomy, critically ill patients typically receive less sedation and analgesia (23), but the prevalence of brain dysfunction remains high and continues to compromise decisional capacity, often permanently (13). Absent a surrogate with authority to limit life-sustaining therapies or clear evidence of the patient's treatment preferences, it may be difficult to discontinue such therapies for a chronically critically ill patient, even after a prolonged trial has failed to achieve meaningful clinical benefit. When an appropriate surrogate has been identified, decision-making may still be compromised by deficiencies in communication and comprehension of relevant medical information (24).

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We conducted this prospective study of a cohort of chronically critically ill patients to determine how often advance directives and appropriate surrogates were available to guide decisions about life-sustaining treatments. In light of prior research by our group and others showing poor outcomes for chronic critical illness (9,10,13,14), we also examined the extent to which such treatments were limited, i.e. withheld or withdrawn. Finally, we sought to identify factors related to the patients, to their illness or treatment, or to care processes, that might be associated with limitation of a range of life-sustaining therapies.

Materials and Methods

Respiratory Care Unit

This prospective cohort study was performed in the Respiratory Care Unit (RCU) at our hospital as part of a larger study of characteristics and outcomes of chronically critically ill adults. The hospital is a large, tertiary, university-affiliated, medical center in New York City. The 14-bedded RCU accepts patients with tracheotomy who have failed ICU weaning from mechanical ventilation, but are thought to have potential for ventilator liberation. In the RCU, primary care responsibility is assumed by the pulmonologist, who with a nurse practitioner directs care in accordance with a comprehensive care-map to standardize treatment including ventilator weaning (25). The transferring physician can participate in discussions to establish goals with patients and families. The RCU team may involve consultants, including the Palliative Care Service, composed of a physician, nurse practitioner, social worker and chaplain; palliative care consultation is available upon request by a physician or nurse practitioner involved in the patient's care. Patients are discharged from the RCU after liberation from the ventilator or a clinical determination that ventilator dependence is permanent.

Patient Enrollment

As previously described (13), we screened patients consecutively admitted to the RCU between 2003 and 2005, including all ≥ 21 years old, while excluding those lacking English proficiency and those with tracheotomy in a prior hospitalization, prior admission to the RCU, or transfer from another hospital. Our Institutional Review Board approved this study and we obtained informed consent from all subjects or appropriate surrogates.

Data Collection

We reviewed patients' records and interviewed the RCU care team to identify the following: durable power of attorney for health care (health care proxy [HCP]), written "living will" or oral statement of treatment preferences (advance directive), and directive regarding resuscitation. In accordance with JCAHO's mandate, all patients are asked at admission whether they have appointed a HCP, and if so to provide documentation for placement in the medical record; others are given an opportunity to appoint a proxy. We considered study patients to have a HCP or living will if the medical record contained the completed legal document or clear documentation that a physician or nurse practitioner personally reviewed the document. For an oral advance directive, we required one of the following: 1) documentation in the medical record that the patient had explicitly stated treatment preferences to a professional caregiver; 2) documentation of the report of a family member or other individual close to the patient that the patient had discussed treatment preferences; or 3) a statement in the proxy document that the patient had made the proxy aware of treatment preferences. We considered a patient to have a resuscitation directive if the medical record included a "Do Not Attempt Resuscitation" order or if there was clear documentation of a patient's preference for resuscitation.

We reviewed medical records and interviewed caregivers to determine whether life-sustaining treatments were limited. We focused on mechanical ventilation, renal replacement therapy,

artificial nutrition, intravenous hydration, and vasopressor treatment. For purposes of this study, treatment was considered to be limited if a deliberate and explicit decision was made to withhold or withdraw it despite a perceived potential to prolong life. We recorded the date of each limitation as well as the date of each endotracheal intubation and extubation; dates of cardiopulmonary resuscitation (CPR); dates of admission and discharge from the hospital, ICU, and RCU; and vital status at hospital discharge and, for survivors, at 3- and 6- month telephone follow-up. For patients undergoing CPR, we also determined vital status at one year post discharge.

We recorded whether and when the Palliative Care Service evaluated patients. From medical records, interviews of patients, families, and RCU caregivers, and hospital databases, we collected information about patients' sociodemographics and health, including complications and outcomes of treatment for chronic critical illness. We collected additional information including diagnoses and data for APACHE II (26) and Charlson Comorbidity Index scores (27).

Statistical Analysis

We used multivariate logistic regression to identify factors associated with limitation of treatment. Candidate variables included demographic characteristics (age, gender, race/ethnicity, religion, insurance status, marital status, residence before hospital admission), clinical information (Charlson Index, number of acute comorbidities, transferring ICU, severity of illness, number of complications during RCU treatment, evaluation by Palliative Care Service) and advance directives (HCP, oral advance directive/living will, do-not-attempt-resuscitation directive). These were entered into a forward regression equation (entry criterion of 0.05 for the final model).

Results

Among 330 tracheotomized patients consecutively admitted to the RCU during the study period, 230 were eligible, 100 were excluded, (37, 30, 20, and 13 patients were excluded for prior ventilator dependence or RCU treatment, transfer from another hospital, language barrier, or other reasons, respectively) and 203 (88.2%) were enrolled (consent by 56 patients, 147 surrogates). Consent was refused for 24 patients and not sought for 3 because death supervened. Eighty-nine patients were discharged alive from the hospital and all but 4 (lost to follow-up) were followed for 6 months.

Characteristics of the patients are in Table 1. Most were older adults (median age 72 years) with multiple, chronic comorbid conditions. Our cohort comprised individuals of differing racial and ethnic backgrounds, including significant representation for blacks (26%) and Hispanics (18%) as well as whites (52%). Of patients for whom information about religious identification was available (n=181), 40% were Catholic and 30% Jewish. Most patients had health care insurance (Medicare, Medicaid, or private sources). Clinical outcomes were generally poor, as previously described for this cohort (13). More than two-thirds of these patients experienced a major complication during treatment for chronic critical illness, half remained ventilator-dependent, more than half were dead by six-months after hospital discharge, many had permanent brain dysfunction, and the vast majority of survivors required permanent custodial care in skilled nursing facilities (13).

Cardiopulmonary resuscitation was performed on 22 (11%) patients during the period of RCU treatment. Of these, 13 (59%) died within 24 hours. Three patients survived to hospital discharge after CPR, but none was discharged to home and all were dead within one year.

Prior to RCU admission, 31 of 203 (15%) patients had expressed their treatment preferences in a written living will (8 patients) or oral advance directive (23 patients), as shown in Table 2. A directive not to attempt resuscitation (DNAR) had been entered for 27 (13%) of patients. Although on average, patients were hospitalized for 23 days including 2.5 weeks in the ICU before tracheotomy and transfer to the RCU, fewer than 20% (37/203) had appointed a health care proxy by this time. Eight (4%) additional patients specified treatment preferences or designated a health care proxy after RCU admission. DNAR orders were entered in the RCU for 44 (22%) patients (Table 2). The average length of RCU stay was 23 days (range 13–35 days).

Table 3 summarizes limitation of life-sustaining treatments, which occurred for 39 (19%) of our study patients. Among 5 therapies under study, vasopressors were limited most often (32 patients, 16%), while mechanical ventilation, nutrition, and hydration were least often limited (18 patients, 9% for each therapy). Median number of days from hospital admission to the first limitation of treatment was 39. After transfer to the RCU, limitation still occurred late, a median of 13 days from RCU admission; median time to limitation of nutrition was almost 3 weeks. Seventy-nine percent of RCU deaths were preceded by withdrawal or withholding of life-sustaining treatment. Median time from the first treatment limitation to death ranged from 3 days for mechanical ventilation and hydration to 7 days for renal replacement (Table 3).

In our multivariate regression analysis, variables significantly associated with a limitation of treatment were appointment of a health care proxy prior to study entry (time of tracheotomy and transfer to the RCU) (OR=6.7, 95% confidence interval [CI], 2.3–20.0, P=0.0006) and evaluation by the Palliative Care Service during the period of RCU treatment (OR=40.9, 95% CI, 13.1–127.4, P<0.0001).

Discussion

In this prospective study of 203 patients receiving treatment for chronic critical illness in a hospital-based, in-patient respiratory care unit, we found that most patients had failed to designate a surrogate decision-maker (21% appointed a health care proxy) or to express preferences regarding life-sustaining treatments (16% provided an oral or written advance directive). For these older adults with multiple co-morbid conditions who underwent weeks of intensive care without recovery, medical decision-making proceeded in the absence of direct input from either the patient or an individual appointed by the patient for this purpose. Although our prior research has documented substantial suffering from symptoms during treatment of chronic critical illness (11), high rates of in-hospital and early post-discharge mortality and extreme functional dependence for most survivors (13), limitation of life-sustaining treatment was rare (19%) for our cohort and occurred late in the hospital course (median 39 days). Multivariate regression analysis showed that limitation of treatment was more likely for patients with a health care proxy and those evaluated by the Palliative Care Consultation Service for clarification of care goals and preferences.

To our knowledge, this is the first prospective, comprehensive, and longitudinal examination of the use and timing of multiple forms of advance directive and treatment limitation in a group of patients with chronic critical illness, as defined by the placement of tracheotomy for prolonged mechanical ventilation after ICU weaning failure. Kelley et al. reported a retrospective review of data on advance directive documentation that had been collected between 1997–1999 and 2000–2003 for studies with other research aims (28). In that report chronic critical illness was defined by use of mechanical ventilation for 72 hours or more. At 72 hours in the ICU, documentation of whether or not there was a proxy decision-maker or living will or both was found for 82% and 57% of patients in the earlier and later cohorts, respectively (28). In a retrospective chart review of patients randomly assigned either to remain

in an ICU or transfer to a "special care unit (SCU)" after 5 ICU days, Daly et al. found that the frequency of DNAR orders was 43% for the entire sample and did not differ significantly between the ICU and SCU groups (29). In another retrospective chart review, Ankrom et al. focused on elective discontinuation of mechanical ventilation for nursing home patients with permanent ventilator dependence (30). Thirteen of 98 (13%) patients, among whom the majority had capacity to make their own medical decisions, chose "terminal weaning" from mechanical ventilation (30). Bigatello et al. reported outcomes of 210 patients in an in-patient respiratory unit who required prolonged mechanical ventilation via either an endotracheal tube or non-invasive methods after critical illness (31). For 60 of 80 patients who died (75%), death followed "consensual withdrawal of support," but the report does not include further information about the nature or timing of such decisions or their implementation (31).

In 1990, the Patient Self-Determination Act mandated that patients in hospitals receiving federal funding be asked and educated about advance directives (32). Since that time, JCAHO incorporated a similar mandate and the use of advance directives has generally risen, especially after vigorous efforts in public education (33–36). As shown in our study and others in different clinical contexts, most patients still lack a designated decision-maker and have not expressed their preferences for treatment (34,37,38). This poses a particular problem in states like ours (New York), where surrogate decisions to limit life-supporting treatment can be made only by a legally-appointed health care proxy or on the basis of "clear and convincing evidence" of the patient's preferences (39). Among patients with chronic critical illness, severe brain dysfunction including coma and delirium is highly prevalent and often permanent (13). Thus, without a health care proxy or an advance directive, limitation of critical care treatment may be impossible, even though professional and family caregivers believe that the burdens of this treatment outweigh potential benefits.

Narrow restrictions on life-support decision-making in New York State may partly explain why we observed such a low frequency (19%) of treatment limitation. A variety of other factors may also explain infrequent treatment limitation, even when such a decision would be legally authorized. Communication by clinicians with chronically critically ill patients and their families is often lacking, leaving them without information they need to make realistic decisions about treatment including limitation of life support (24,40,41). For example, most families of patients with chronic critical illness report that they were not apprised of the risk that the patient might die during the hospitalization or within a year thereafter, of the likelihood of permanent cognitive and functional impairment, of risks and benefits of CPR, or of alternatives to continuing mechanical ventilation (24). Others may have religious or moral views that are interpreted to prohibit treatment limitation. In addition, those who pursued aggressive treatment in the ICU, and then chose to continue this treatment even after the patient remained dependent on life-sustaining therapies despite extended ICU care, may represent a selected group that is less likely to initiate or accept treatment limitation when critical illness becomes chronic and remains refractory.

In our cohort, renal replacement therapy and vasopressors were limited more often than mechanical ventilation, nutrition, and hydration. Typically, the latter therapies were initiated early and continued without a deliberate decision to withdraw the therapy, whereas limitation of renal replacement therapy and vasopressors often involved a decision to withhold rather than discontinue a treatment that had already been given. Although there is general agreement that they are legally and ethically equivalent, withholding and withdrawal are still approached differently in clinical practice (42–46). A recent survey of internists' views on limitation of life support found that respondents were significantly more likely to withhold than withdraw treatment (45). This may seem unjustified, in that withdrawal allows for a trial of treatment that can demonstrate whether the treatment is effective and clarify its risks and benefits.

However, withdrawal may appear as the proximate cause of death whereas withholding may be seen as a passive strategy, allowing for natural progression of the patient's illness (43).

Artificial nutrition and hydration were limited less often than other treatments studied, and only after the longest time in the hospital, just before death. New York State imposes stricter standards for limitation of nutrition and hydration than for limiting other forms of life support (47,48). Under NY law, even a legally-appointed health care proxy may not withhold or withdraw nutrition or hydration unless the patient's wishes are reasonably known or can be determined with "reasonable diligence" (39). In addition, the view that food and water must always be offered – by invasive means, if necessary – has deep roots in a range of cultures and religions (49). Many patients and families and even physicians continue to fear "starvation" and "dehydration," even though patient comfort can be maintained by skilled clinicians (50, 51).

Most hospital deaths in our cohort (58 of 203 patients died in the hospital [13]) were preceded by limitation of life-sustaining treatment (31/58, 53%). This observation is consistent with the results of studies examining deaths of patients with acute critical illness in North American ICUs (20,52), and with recent findings with respect to patients requiring prolonged invasive or non-invasive mechanical ventilation (31). We looked specifically at the timing of treatment limitation in relation to hospital and RCU admission and in relation to subsequent death. Our findings suggest that in this chronically critically ill group, decisions to limit treatment were not made proactively, based on balancing of expected burdens and benefits, but were deferred until the last days of a very prolonged and complicated hospital course, when the patient was already close to death. Extended and resource-intensive hospitalizations impose heavy burdens on these patients, families, clinicians, and the health care system, yet produce only limited clinical benefits. Broader knowledge and communication of the outcomes of treatment for chronic critical illness and of the burdens of this treatment, as described in previous research, might help to inform medical decision-making and facilitate earlier establishment of realistic care goals (11,13,41). Earlier identification of an authorized medical decision-maker with knowledge of the patient's values and preferences would support this important process.

Patient demographic and health characteristics including severity of illness were not significant determinants of limitation of life-sustaining treatment. Controlling for other variables, factors we found to predict limitation were prior appointment of a health care proxy and involvement of the Palliative Care Service in the patient's care. We suspect that the main contribution of each of these factors was clarification of goals, values, and preferences, thereby facilitating decisions and enabling clinicians to achieve patients' and families' objectives. In a large study of patients with acute critical illness receiving mechanical ventilation in ICUs, Cook et al. also found no association between withdrawal of the ventilator and the patient's age, pre-morbid status, severity of illness or organ dysfunction, but observed a significant association between withdrawal of ventilation and physicians' perceptions of patients' preferences about use of life support (18). Other studies have shown that personal characteristics and experiences of physicians may influence decisions to limit life-sustaining treatment, but we did not collect physician-related variables in this study (53–56).

Our study has several limitations. First, it was conducted in a single center and may not be fully generalizable to other care settings. Laws governing limitation of life support and surrogate decision-making in New York State, where our hospital is located, are some of the most stringent in the nation. We note, however, that the proportion of do-not-attempt-resuscitation directives was also low, even though less stringent standards apply to these decisions. Reports from across the country of outcomes and resource utilization for patients with chronic critical illness suggest that our findings reflect a widespread, not a state-specific phenomenon. Second, we collected data on a defined group of treatments, which could have

led us to underestimate the frequency with which therapies (including, e.g., blood transfusion or antibiotics) are withheld or withdrawn. Third, inconsistent documentation in the medical record may have caused us to underestimate the number of verbal advance directives, though we included such directives in our tabulations if the record was clear and consistent. Finally, we did not collect data on factors that may have influenced surrogates' decisions whether to opt for resuscitation or limit life-sustaining treatment.

Conclusions

More and more patients survive acute critical illness only to remain dependent on life-sustaining therapies on a chronic basis. Despite continuing intensive care either in the hospital, a long-term acute care facility, or another care setting, few of these patients achieve functional recovery and many have permanent brain dysfunction (13). Treatment is prolonged, expensive, and burdensome, but typically ends in death or total dependence requiring permanent custodial care (6–14).

If patient comfort is maintained and families are supported, a time-limited trial of treatment for chronic critical illness may sometimes be appropriate. However, continuation of treatment in the chronic phase of critical illness should never be driven by default – that is, in the absence of conscious medical decisions that are informed by effective communication and take account of the patient's goals, preferences and values. It will always be necessary to weigh the benefits and burdens of treatment and to reevaluate this balance as the clinical situation evolves. In ideal circumstances, the patient would participate directly in this process, but the reality of both acute and chronic critical illness is that decisional capacity is typically lacking. Neither a proxy nor another advance directive is a perfect alternative, but both may help to illuminate decision-making from the patient's perspective. Patients should be encouraged to make their preferences known in this regard at the time of hospital admission if they have capacity to do so. Involvement of specialists in palliative medicine will also help to clarify care goals and preferences of the patient and to support the family. The low frequencies we observed for proxy appointment, other advance directives, and treatment limitation, and the long duration of hospitalization and refractory critical illness prior to active decision-making about life-supporting treatments, suggest that opportunities exist to improve communication and decision-making for the chronically critically ill. Future research should focus on interventions for this purpose.

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Table 1

Characteristics of Chronically Critically Ill Study Patients (N = 203)

Median age, yrs (range)	72	(21–99)
Male	117	(58)
Race/Ethnicity		
• White, non-Hispanic	106	(52)
• Black, non-Hispanic	53	(26)
• Hispanic	36	(18)
• Other	8	(4)
Marital Status[a]		
• Married	93	(48.9)
• Divorced/Separated	17	(8.95)
• Widowed	45	(23.7)
• Never married	35	(18.4)
Religion[b]		
• Catholic	73	(40.3)
• Protestant	12	(6.63)
• Jewish	55	(30.4)
• Muslim	6	(3.31)
• Other	35	(19.3)
Insurance[c]		
• Medicare	136	(75.1)
• Medicaid	30	(16.6)
• Private/Commercial	34	(18.8)
• None	1	(0.55)
Residence Before Hospital Admission[c]		
• Home	153	(76)
• Rehabilitation Facility	8	(4)
• Nursing Home	24	(12)
• Other	16	(8)
Charlson Comorbidity Index Score(27), mean ± S.D.	4.5	± 2.7
Cognitively Impaired at Hospital Admission[d]	37	(18)
Cognitively Impaired at Study Entry[e]	143	(75)
Multiple Acute Comorbidities[f]	98	(48.3)
Primary ICU Admitting Diagnosis		
• Cardiovascular	45	(22)
• Pulmonary	75	(37)
• Neurologic	33	(16)
• Surgical	31	(15)

• Other	19	(9)
ICU transferring to RCU		
• Medical	128	(63)
• Surgical	23	(11)
• Cardiothoracic	2	(1)
• Neurosurgical	40	(20)
• Cardiac Care	10	(5)
ICU Length of Stay, median (IQR), days	16.0	(11–22)
APACHE II Score(26) (at study entry), mean ± S.D.[c]	20.5	± 5.1
Number of days of Mechanical Ventilation, median (IQR), days[g]	40.0	(28–51)
RCU Course with Complications[h]	167	(83)

[a] N = 190 (data unavailable for 13 patients);

[b] N = 181 (data unavailable for 22 patients);

[c] N = 201 (data unavailable for 2 patients);

[d] Defined as history of dementia, decreased level of consciousness, confusion, memory loss, or other cognitive impairment reported by the family or documented in the medical record;

[e] Defined as score of > 10 on 6-Item Orientation-Memory-Concentration Test(57) (n=19); lacking sufficient cognitive capacity to respond to this screen (n=124); 13 patients refused screen;

[f] Patients experiencing > 3 acute comorbidities, defined *a priori*, before RCU treatment;

[g] Calculated as number of days from intubation to extubation, death, or hospital discharge;

[h] Patients experiencing complications defined, *a priori*, during RCU treatment.

Table 2

Advance Directives in Chronic Critical Illness (N = 203)

	Before RCU Admission	After RCU Admission	Total
Health Care Proxy Appointment			
N (%)	37 (18.2)	6 (3.0)	43 (21.2)
Advance Directive[a]			
N (%)	31 (15.2)	2 (1.0)	33 (16.2)
Do-Not-Attempt-Resuscitation Directive			
N (%)	27 (13.3)	44 (21.7)	71 (35.0)

[a]Includes living wills or other written and verbal advance directives (but not health care proxy appointment nor resuscitation directive, which are given separately

Table 3

Limitation of Treatment in Chronic Critical Illness (N = 203)

	Limitation					
	Mechanical Ventilation	**Renal Replacement Therapy**	**Nutrition**	**Hydration**	**Vasopressors**	**Any**
Patients with Treatment Limitation, Number (%)	18 (8.9)	30 (15.0)	18 (8.9)	18 (8.9)	32 (15.8)	39 (19.2)
Mortality[a], N (%)	14 (77.8)	25 (83.3)	15 (83.3)	15 (83.3)	27 (84.4)	31 (79.5)
Time to Treatment Limitation						
Hospital Admission to Limitation[b], median days (IQR)	39.0 (31.0–45.0)	40.0 (26.0–61.0)	46.5 (29.0–60.0)	41.0 (25.0–60.0)	39.0 (26.0–61.0)	
RCU Admission to Limitation[c], median days (IQR)	19.0 (13.0–26.0)	14.5 (9.0–30.0)	20.5 (13.0–30.0)	19.0 (13.0–30.0)	13.0 (8.0–29.0)	
Time from Limitation to Death[d]						
Median days (IQR)	3.0 (0.0–9.0)	7.0 (4.0–11.5)	4.0 (1.0–7.0)	3.0 (0.0–7.0)	5.0 (1.0–11.0)	

[a] Patients with treatment limitation who died in the hospital (categories are not mutually exclusive);

[b] Number of days from hospital admission to first treatment limitation;

[c] Number of days from RCU admission to first treatment limitation;

[d] For those patients who had treatment limited and died in the hospital, number of days from first limitation to death.