Communication About Chronic Critical Illness

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Background: Despite poor outcomes, life-sustaining treatments including mechanical ventilation are continued for a large and growing population of patients with chronic critical illness. This may be owing in part to a lack of understanding resulting from inadequate communication between clinicians and patients and families. Our objective was to investigate the informational needs of patients with chronic critical illness and their families and the extent to which these needs are met.

Methods: In this prospective observational study conducted at 5 adult intensive care units in a large, university-affiliated hospital in New York, New York, 100 patients with chronic critical illness (within 3-7 days of elective tracheotomy for prolonged mechanical ventilation) or surrogates for incapacitated patients were surveyed using an 18-item questionnaire addressing communication about chronic critical illness. Main outcome measures included ratings of importance and reports of whether information was received about questionnaire items.

Results: Among 125 consecutive, eligible patients, 100 (80%) were enrolled; questionnaire respondents included 2 patients and 98 surrogates. For all items, more than 78% of respondents rated the information as important for decision making (>98% for 16 of 18 items). Respondents reported receiving no information for a mean (SD) of 9.0 (3.3) of 18 items, with 95% of respondents reporting not receiving information for approximately one-quarter of the items. Of the subjects rating the item as important, 77 of 96 (80%) and 69 of 74 (93%) reported receiving no information about expected functional status at hospital discharge and prognosis for 1-year survival, respectively.

Conclusions: Many patients and their families may lack important information for decision making about continuation of treatment in the chronic phase of critical illness. Strategies for effective communication in this clinical context should be investigated and implemented.

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ADVANCES IN INTENSIVE CARE unit (ICU) care have paradoxically created a growing population of patients with prolonged dependence on life-sustaining therapies including mechanical ventilation.[1,2] For patients with "chronic critical illness,"[1] prognosis is poor: the majority are dead within 6 months, and institutionalization with extreme functional dependence and severe cognitive impairment is typical for survivors.[2-4] Costs of care are enormous for the health care system as a whole and for tens of thousands of individual families.[5]

Despite these outcomes, many patients and their families choose to continue life-sustaining therapies when critical illness enters a chronic phase. Evidence suggests that this may be owing in part to a lack of understanding of chronic critical illness resulting from inadequate communication between clinicians and patients and families. In the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), less than 40% of patients treated in ICUs for more than 2 weeks reported having a discussion with their physician about prognosis or preferences for life-sustaining treatment.[6] Almost 50% of those who preferred care focused solely on their comfort even at the expense of shorter life thought that the treatment they received was contrary to their preference, and approximately 25% did not know the clinical team's approach to their care.[6] At a university-affiliated ICU, 54% of families failed to comprehend the diagnosis, prognosis, or treatment after meeting with a physician.[7] Almost 20% of 70 surrogate decision makers for patients expected to stay more than 3 days in medical or surgical ICUs at 2 medical centers reported receiving no prognostic information.[8] In ICU family conferences, physicians commonly missed opportunities to explore comments about patient treatment preferences, as would be required for appropriate clinical decision making.[9]

We previously used qualitative methods to determine what information is rel-

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Table 1. Characteristics of 100 Patients With Chronic Critical Illness[a]

Characteristic	Patients
Age, median [range], y	74 [21-100]
Male sex, No. (%)	55 (55)
Race/ethnicity, No. (%)	
White, non-Hispanic	42 (42)
Black, non-Hispanic	26 (26)
Hispanic	24 (24)
Asian	8 (8)
Residence prior to hospital, No. (%)	
Home	81 (83)
Other hospital/nursing home	15 (15)
Adult residence	2 (2)
Marital status, No. (%)	
Married	53 (54)
Divorced/separated	11 (11)
Widowed	22 (22)
Never married	12 (12)
Unknown	1 (1)
Religious identification, No. (%)	
Catholic	35 (35)
Protestant	10 (10)
Jewish	24 (24)
Other/unknown	31 (31)
Insurance coverage, No. (%)	
Medicare	54 (54)
Private	27 (27)
Medicaid	19 (19)
Charlson Comorbidity Index, mean [SD]	3.2 [2.7]
ICU at time of tracheotomy/study enrollment, No. (%)	
Medical ICU	61 (61)
Neurosurgical ICU	20 (20)
Surgical ICU	10 (10)
Cardiothoracic surgical ICU	6 (6)
Cardiac care unit	2 (2)
Cardiac progressive care unit	1 (1)
Primary ICU admitting diagnosis, No. (%)	
Pulmonary	32 (32)
Cardiovascular	25 (25)
Neurological	16 (16)
Surgical	14 (14)
Other	12 (12)
Length of ICU stay, median [range], d	15 [1-178]
Apache II score at study entry, mean [SD]	19.5 [5.4]
Cause of prolonged respiratory failure, No. (%)[b]	
Acute lung disease	52 (27)
Chronic lung disease	18 (10)
Cardiac disease	19 (10)
Neurologic disease	36 (19)
Postoperative condition	20 (11)
Other	45 (24)
Length of hospital stay, median [range], d	51 [15-224]
Hospital mortality, No. (%)	26 (26)

Abbreviation: ICU, intensive care unit.
[a] Sum is less than 100 for items for which data were unavailable for some subjects.
[b] Sum is greater than 100 because prolonged respiratory failure was typically multifactorial.

evant and important for discussion and decision making when critical illness becomes chronic,[10] a juncture that we and others have defined by the placement of tracheotomy for ICU failure to wean from mechanical ventilation.[1,4] Families described distress about what they perceived to be inadequacies in communication from clinicians and particularly regretted that such communication typically occurred, if at all, only after prolonged, unsuccessful treatment of chronic critical illness, when the patient was near death or discharge to a skilled nursing facility for permanent custodial care.[10] We undertook the present study to explore further the informational needs of patients with chronic critical illness and their families, to evaluate the extent to which these needs are met in current practice, and to identify factors associated with communication of information about chronic critical illness.

METHODS

SETTING AND SUBJECTS

We conducted this study between 2003 and 2005 in our large (1100-bed), tertiary care, university-affiliated hospital in New York, New York. Each weekday, our research nurse (A.F.M.) visited the hospital's 5 adult ICUs (medical, surgical, cardiac, cardiothoracic surgical, and neurosurgical) to identify all patients with chronic critical illness, ie, those undergoing tracheotomy for failure to wean from mechanical ventilation.[4,5] Within 3 to 7 days after the tracheotomy, we sought research consent from the individual (patient or surrogate) who had given consent for the tracheotomy. These decision makers (2 patients and 98 surrogates) and the patients were our study subjects (n=100), to whom the research nurse administered our study questionnaire in-person on the same day that research consent was obtained. A priori, we excluded patients who had a history of tracheotomy (and their surrogates) and subjects with insufficient English proficiency to participate without translation. Our study received institutional review board approval.

QUESTIONNAIRE DEVELOPMENT

Through a computerized bibliographic literature review and use of qualitative research methods, we previously identified the following 6 general domains of information that are considered by patients, families, and clinicians to be relevant and important for decision making when critical illness continues into a chronic phase[10]: (1) nature of the patient's illness and treatments; (2) prognosis for outcomes including ventilator independence, function, and quality of life; (3) impact of treatment on patient experience, including symptom burden; (4) potential complications of treatment; (5) expected care needs after hospitalization; and (6) alternatives to continuation of treatment.[10] For the present study, we developed items within each of these domains asking (A) whether the information was considered important by the respondent (4-point Likert scale: strongly agree, agree, disagree, and strongly disagree) and (B) whether this information was communicated by the clinicians (primary or ICU physician, nurse, social worker, or other clinician).

We pretested the instrument with 10 surrogates of patients receiving treatment for chronic critical illness at our hospital and incorporated their feedback in revising the questionnaire. With the main questionnaire, we then distributed a clinical sensibility questionnaire addressing face and content validity as well as clarity, utility, redundancy, and discriminability[11] to the physician and nursing directors (n=10) of our adult ICUs and to 10 staff nurses in our medical ICU, where tracheotomy for failure to wean from the ventilator is frequently performed. Using the sensibility ratings and additional suggestions, we further modified the main questionnaire. We then obtained written and oral feedback from a national interdisciplinary panel of 8 physician- and nurse-researchers who are recognized as experts in

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clinician-patient communication. Our final questionnaire contained questions about 18 specific topics of information within the 6 general domains as well as demographic questions about the respondent and the patient.

QUESTIONNAIRE ADMINISTRATION

The research nurse administered the questionnaire and recorded all responses. For patients (n=2) who had provided their own consent to tracheotomy, we assessed cognition at the time of administration of the questionnaire using the 6-item Orientation-Memory-Concentration test[12] and the Confusion Assessment Method for the ICU.[13]

DATA ANALYSES

We summarized the clinical sensibility ratings using means (and standard deviations). We used regression analysis to examine associations between sociodemographic and health characteristics of patients and of respondents' sociodemographic characteristics with respondents' ratings of items as important and their reports of receiving or lacking information on the topics covered in the questionnaire. For the latter analyses, we used as our dependent variable the number of topics on which respondents reported receiving no information.

RESULTS

The clinical sensibility of the questionnaire was rated highly (on a 1-5 scale): face validity, mean (SD) of 4.6 (0.4); content validity, 4.7 (0.7); clarity, 4.3 (0.7); utility, 4.2 (0.7); redundancy, 4.0 (1.0); and discriminability, 4.1 (0.7).

During the study period, 162 patients underwent tracheotomy for failure to wean in our institution's adult ICUs, of whom 125 (77%) met eligibility criteria for this study (37 patients were excluded for the following reasons: underwent a prior tracheotomy [n=5], lacked English-language proficiency [n=3], lacked a surrogate decision maker for a patient without capacity [n=24], or met other a priori exclusion criteria [n=5]). Among 125 consecutive, eligible, decision makers whom we approached for study participation, we enrolled 100, an overall response rate of 80%. With respect to sex, age, race/ethnicity, ICU site, hospital length of stay and hospital mortality of the patients, subjects enrolled in the study were not significantly different from eligible subjects who did not participate in the research.

Characteristics of our respondents and the patients are given in **Table 1** and **Table 2**, respectively. As is true nationally,[5,14,15] our patients with chronic critical illness were mainly older adults, with a median age of 74 years (interquartile range, 59-80 years) and multiple comorbid illnesses and reasons for prolonged mechanical ventilation. Almost all (98 of 100) patients lacked the capacity to participate in the decision to undergo tracheotomy and continued critical care treatment. Most respondents were family members, among whom the largest group (n=46 [47%]) were adult offspring. Our responding group was racially and ethnically diverse, and two-thirds were college educated.

Respondents confirmed the importance of information in the domains addressed by our questionnaire. For 16 of 18 items, more than 98% of the respondents agreed that information about this topic was important for their decision making when the critical illness entered a chronic phase, as indicated by the need for tracheotomy (**Table 3**). The remaining items, both of which related to prognosis for mortality from the illness, were rated as important by 89% (86 of 97 respondents [chances of death in the hospital]) and 78% (74 of 97 respondents [chances of death within a year after hospital discharge]). Regression analyses did not show any significant variation in ratings of the importance of questionnaire items according to characteristics of either the patients or their surrogates.

Almost half of the respondents reported receiving no information about the majority of items in our questionnaire (Table 3). By these reports, among the 18 items, clinicians provided no information for a mean (SD) of 9.0 (3.3) items. All respondents stated that they did not receive information about more than 1 item, and 95% stated that they were given no information for one-quarter of these items (**Figure**). As reported by our respondents, most received information about the need for tracheotomy and its immediate implications (eg, impact on speaking and eating). Fewer reported receiving information about short-term consequences of chronic critical illness (eg, distressing symptoms, complications, and risk of mortality in the hospital). For items relating to long-term burdens and effects (eg, expected functional status after hospitalization and death within a year), the majority of respondents reported receiving no information (Table 3).

One item in the questionnaire asked whether the respondent considered it important in deciding about tra-

Table 2. Characteristics of 98 Surrogates Responding to Chronic Critical Illness Communication Questionnaire[a]

Characteristic	Surrogates, No. (%)
Relationship to subject	
Spouse/partner	28 (29)
Child	46 (47)
Parent	7 (7)
Other relative	12 (12)
Other	5 (5)
Years known patient	
<10	2 (2)
≥10	96 (98)
Male sex	33 (33)
Ethnicity	
White, non-Hispanic	35 (36)
Black, non-Hispanic	28 (29)
Hispanic	24 (25)
Asian	9 (9)
Other	1 (1)
Religious identification	
Catholic	39 (41)
Protestant	22 (23)
Jewish	22 (23)
Other	13 (14)
Education	
College	64 (66)
High school graduate	21 (22)
No/some high school	12 (12)

[a] Two patients as well as these 98 surrogates were our questionnaire respondents.

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Table 3. Communication About Topics Rated Important by Family Decision Makers for Patients With Chronic Critical Illness

Topic of Information	Respondents, No. (%)	
	Rating as Important[a]	Reporting No Information Received[b]
Why mechanical ventilation is needed	100 (100)	3 (3)
Why tracheotomy is needed	100 (100)	1 (1)
How tracheotomy might affect ability to speak	100 (100)	16 (16)
How tracheotomy might affect ability to eat	100 (100)	25 (25)
Chances of liberation from mechanical ventilation	100 (100)	40 (40)
Time to ventilator liberation	100 (100)	53 (53)
Symptoms during continued treatment	100 (100)	44 (44)
Complications that might develop	99 (100)	22 (22)
Risk of death during hospitalization	87 (89)	40 (46)
Benefits and risk of cardiopulmonary resuscitation	97 (99)	55 (57)
Discharge site from hospital (eg, home or nursing home)	97 (100)	53 (55)
Choices other than continuing mechanical ventilation	98 (98)	81 (83)
Expected functional status after hospitalization	97 (99)	78 (80)
Quality of life after hospitalization	97 (99)	70 (72)
Cognitive status after hospitalization	97 (99)	63 (65)
Death within a year after hospital	74 (77)	69 (93)
Services that might be needed after discharge	97 (100)	80 (82)
Financial burden of the illness for family	93 (98)	70 (75)

[a] Subjects responded "agree" or "strongly agree" with the statement "It is important for me to know. . ." for each of these topics. Although there were 100 respondents overall, not all answered with respect to every topic.
[b] For the denominator, we used the number of respondents rating the item as important to know.

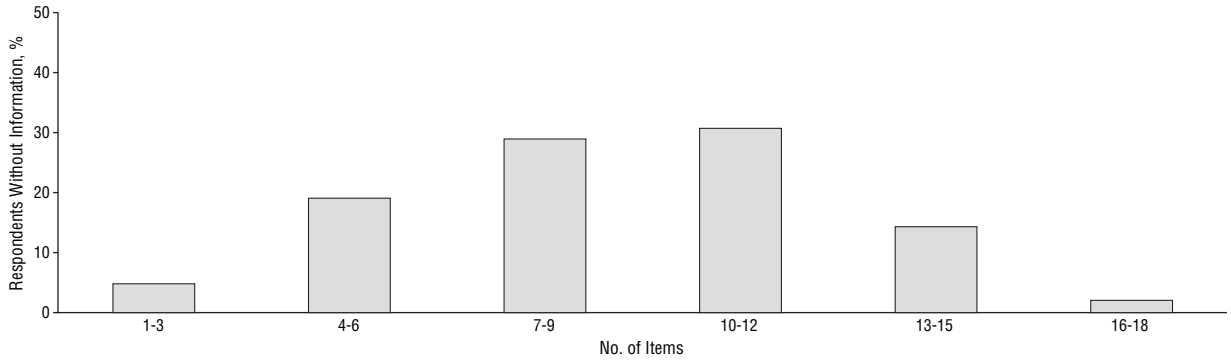

Figure. Distribution of items in Chronic Critical Illness 18-item questionnaire on which respondents (n=100) reported receiving no information.

cheotomy and continuation of critical care treatments "to know about choices other than continuing mechanical ventilation. (For example, taking the patient off the ventilator, even if he cannot breathe on his own, with treatment for shortness of breath or other symptoms.)" Of 97 respondents who accorded importance to this information, 80 (83%) reported that they did not receive it. Eighty percent (77 of 96 respondents) also reported receiving no information about the patient's expected functional status at hospital discharge, while two-thirds (63 of 96 respondents) stated they were given no information about "what the patient's cognitive status (ability to think and understand, mental state) is expected to be when he leaves the hospital." Of 74 respondents who considered it important to know "the chances that the patient might die within a year after he leaves the hospital," 69 (93%) reported they did not receive this information. Length of stay in the ICU and in the hospital emerged as the only factors that were associated (Spearman correlation coefficients, 0.21 and 0.23, respectively) with the number of items on which respondents reported that information was inadequate: decision makers for patients with longer lengths of stay reported lacking information on a greater number of topics they considered important.

COMMENT

This study focused on information communicated by clinicians when ICU patients and their surrogates face decisions about continuing treatment into the chronic phase of critical illness. Using qualitative methods, we previously identified domains of information that patients, families, and clinicians consider relevant and important

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for such decision making.[10] In this quantitative study, we conducted "real-time" interviews in ICUs of a prospective cohort of decision makers (almost all surrogates) for patients with chronic critical illness to determine the importance of specific topics within those informational domains and the extent of communication about these topics. We identified a series of items considered important by the respondents, including information about "choices other than continuing mechanical ventilation (for example, removing the ventilator even if the patient cannot breathe on his own, with treatment for shortness of breath or other symptoms);" about "pain, shortness of breath, and other sources of distress and suffering that the patient might experience with continuing mechanical ventilation;" about expected functional and cognitive status after treatment; and about prospects for survival in the year following hospital discharge. All respondents reported that they did not receive information on important topics, and approximately half of the respondents reported that for the majority of topics, clinicians provided no information.

Prior research has documented deficiencies in ICU communication and associations with adverse consequences for patients, families, and professional caregivers.[6,7,16,17] Families in a large teaching hospital's medical ICU lacked a basic understanding of diagnosis, prognosis, and treatments.[7] Further research conducted in multiple centers showed a high prevalence of anxiety and depression among families, which was associated with factors related to communication.[18] "Usual care" in a leading US academic medical center consisted primarily of informal communication of essential information by nurses and trainees, without involvement of attending physicians or coordination among providers; formal family meetings were deferred until further critical care treatment was considered futile, leading to delay in identifying of appropriate care goals and prolongation of nonbeneficial ICU care.[17] A large, international study found that without direct discussion, clinicians presumed preferences favoring cardiopulmonary resuscitation for most mechanically ventilated patients admitted to their ICUs, whereas half of patients with explicit directives preferred not to be resuscitated in the event of arrest.[19] Our study is consistent with these reports but specifically addresses communication at the juncture of acute and chronic critical illness, as indicated by the placement of tracheotomy for failure to achieve ventilator independence after prolonged ICU treatment. To our knowledge, this is the first study to focus on communication in this context.

In our study, patients and surrogates identified information that they considered important for decisions about continuing treatment into the chronic phase of critical illness. Previous studies also suggest that such information would influence decision making. For example, Fried et al[20] found that most older adults with serious illness would refuse life-sustaining treatments if the expected outcome were survival with severe functional or cognitive impairment; the prospect of such impairment influenced treatment preferences even more than the likelihood of death, and many subjects stated that they would decline treatment if there was even a 50% chance of severe functional or cognitive impairment. Several studies have shown that information about the probability of survival after cardiopulmonary resuscitation significantly lowers the proportion of individuals who say they would want this intervention.[21-23] Among 1-year survivors of mechanical ventilation for at least 2 days, many stated that knowledge of the intensity of pain and discomfort during treatment would influence their decision making about such ventilation, leading them to refuse treatment at higher levels of symptom distress.[24] A small group of survivors of a week or more of mechanical ventilation reported that future decision making about mechanical ventilation would be influenced by their health status and by the resulting financial burdens for their families.[25] Thus, although the present study did not directly measure the impact of perceived inadequacies in communication on actual decision making, our results suggest that efforts to improve communication about chronic critical illness would be valued by patients and families and might help to align treatment decisions with their values and preferences. In addition, evidence indicates that these efforts would also promote other desirable outcomes, including higher levels of family satisfaction[26-28]; less anxiety, depression, and posttraumatic stress among family members[29,30]; fewer conflicts[31,32]; and earlier establishment of realistic and appropriate care goals and more efficient use of ICU resources.[17,33-35] Patients with chronic critical illness and their families often misinterpret the placement of tracheotomy as a sign of hope for full recovery[10] and go on to experience grave disappointment, disillusionment, and anger toward caregivers as the reality of protracted and typically progressive illness becomes clear. Even if earlier communication about expected outcomes does not change decision making at the outset, such communication may help to prepare patients and families for events, discussions, and decisions they are likely to face later.

Although we are unable to predict the experience and outcomes of individual patients with absolute certainty, existing evidence provides a solid foundation for communication about the benefits and burdens of treating chronic critical illness. Such treatment is burdensome for many patients and families and is expensive for them and for our health care system, while achieving limited clinical benefits.[2,4,5,36-39] It is known that mortality rates during and soon after treatment for chronic critical illness are high.[2,4,40] It is also known that a large proportion of patients with chronic critical illness remain permanently dependent on life-sustaining therapies.[2,4,40] Few of these patients return to functional lives in the community; most are extremely dependent for their daily activities and require institutional care.[4,37,39,40] Perhaps of greatest concern to patients and families,[20,41] brain dysfunction including coma and delirium is highly prevalent and often permanent.[4] Skilled clinicians can communicate this information in a clear, understandable, and compassionate way. Some patients and families will still choose to continue life-prolonging treatments, and this may at times be appropriate. However, decision making needs to be appropriately informed—that is, informed to the extent desired by the decision makers and to the degree supported by relevant prior research. Our findings indicate that communication to support decision making about treatment of chronic critical illness can be im-

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proved. They also help to focus attention on areas of information that patients and families value and need most.

Several strategies to improve communication during acute critical illness have been tested with success. Two rigorous trials demonstrated benefit from distribution of printed informational materials for ICU families, with[29] or without[30] a proactive, protocol-directed approach to family conferencing. An "intensive communication intervention" consisting of a mandatory, interdisciplinary meeting with ICU families proved superior to "usual care" in a before-after comparison.[17] Consultations by ethics teams when "value-laden treatment conflicts" arose in ICU patient care,[34] decreased ICU and hospital stays and days of "nonbeneficial" treatments compared with standard treatment, and patients, families, and clinicians generally rated the intervention as informative and helpful. Appropriate training of clinicians in communication yields sustained improvements in these essential skills.[42-44]

Several inferences are possible from our finding that the lengths of ICU and hospital stay were associated with the extent of communication as reported by the respondents. It may be that patients or families who wished to continue life-prolonging treatments for longer periods were less receptive to clinician communication or had different informational needs. Alternatively, the clinicians may have avoided discussions with such patients and families. Involvement of multiple clinicians over extended periods in the hospital may have blurred lines of responsibility for communication or exposed patients and families to contradictory information from different caregivers. Another possibility is that inadequate communication about prognosis and treatment led to delayed implementation of appropriate care plans and prolongation of therapies with limited clinical benefit.

Our study has limitations. First, since we did not directly observe communications, our findings about the extent of information may not reflect with complete accuracy the information actually provided by clinicians. Fried et al[45] found a low level of agreement between patients and clinicians on whether the clinician had discussed prognostic information. Stress, anxiety, and depression[18,46] may impair families' comprehension through mechanisms including denial and distraction and introduce bias in reporting about the ICU experience. We believe it is valuable, however, to investigate communication from the perspective of critically ill patients and their families, who are the focus of our care and who require the information we communicate because they have the authority and responsibility to make decisions about treatment. Second, "prolonged mechanical ventilation" has been defined for other purposes in terms of duration of time on the ventilator,[47] whereas we and others have identified patients with chronic critical illness by the placement of tracheotomy after ICU weaning failure.[4,5,48,49] A third limitation is that this study was conducted in a single institution and may not be fully generalizable to other care settings; New York, where our hospital is located, does not have long-term acute care facilities, which might affect length of hospital stay (although not overall duration of care for chronic critical illness). On the other hand, we recruited subjects from 5 ICUs across a broad spectrum of case mix and clinical practice and studied a patient group with characteristics and outcomes that are similar to those reported from diverse settings.[2,37-39,50] Other strengths include our use of "real-time" data collection from patients and families who were actually making treatment decisions, rather than retrospective interviews of a limited group of survivors or questioning of subjects about hypothetical scenarios; the response rate, which compares favorably with that achieved in other research conducted with ICU families in the United States; and the rigorous process we used to develop a valid questionnaire.

CONCLUSIONS

Chronic critical illness is now known to be a devastating condition imposing heavy burdens on patients, families, professional caregivers, health care systems, and society as a whole. When critical illness becomes chronic, continuation of intensive care treatment requires extraordinary resources but entails significant distress for patients and families while yielding limited clinical benefits. In specific situations, a choice to continue this treatment may be reasonable, particularly if the therapeutic trial is time limited, progress is periodically reevaluated, and attention is given simultaneously to the palliative needs of the patient and family. It will never be appropriate, however, to treat chronic critical illness without a thorough discussion of benefits and burdens and an exploration of the needs, values, preferences and goals of the patient and family as they relate to the proposed treatment. This study suggests that many patients with chronic critical illness and their families are making crucial medical decisions in a "black hole," without essential information. At the same time, our findings can help to guide improvement in communication by identifying topics as well as patients and families requiring special attention. Together with recent research about the process of ICU communication and studies testing the effectiveness of communication strategies in the context of acute critical illness, the present study of informational content strengthens the evidence base for clinical practice and for future interventional research focusing specifically on communication about chronic critical illness.

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