Family and Nurse Prognostication in Chronic Critical Illness

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Abstract

Aims: The aim of this study was to describe similarities and differences over time in expectations held by family members of long-term critically ill patients and the nurses caring for those patients.

Materials: In addition to demographic data, outcome expectations of family decision makers and ICU nurses were obtained by asking each participant to indicate expectations for the patient, 6 months in the future, for survival, cognition, and functional status. Families also were asked what kind of information was most important in understanding the patient's condition and what was most important in making decisions.

Methods: This was a descriptive correlational analysis. Nurses and family members were surveyed on the 3rd–5th day of the patient's stay, and every 5 days until discharge or death. Correlations between nurse and family predictions were examined using Pearson R. Repeated measures analysis of variance (RMANOVA) was used to explore the relationship between the family member's rating of what was most important in the care of the patient (survival vs. quality of life) and that individual's prediction of the likelihood of survival, over time.

Results: Family members consistently predicted better outcomes than nurses, with >80% of families predicting a high likelihood of survival, while <50% of nurses thought survival probability was high. There were similar differences in expectations for functional status and cognition. Between 14% and 23% of families indicated it was talking with the nurses that were most important.

Conclusions: Results suggest a need for design and tests of nurse interventions aimed at improving family understanding of patient prognosis and future outcomes.

Keywords

Chronically critically III; Critical care nurses; Outcomes; Prognosis

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Introduction

The chronically critically ill is a growing population of patients who present enormous challenges both to the clinical staff of critical care units and to the family members who usually must assume decision-making responsibilities.[1] There are varied criteria for what defines "chronic critical illness," but the phrase generally refers to adult patients requiring prolonged periods of mechanical ventilation and long stays in an intensive care unit.[1] Zilberberg *et al.,* using data from the United States Agency for Healthcare Research and Quality, have reported that the number of patients in the U.S. requiring >96 h of mechanical ventilation increased >5% per year from 2000 to 2008 and is projected to grow from 300,000 in the year 2000 to 625,298 by the year 2020.[2]

The outcomes of patients requiring prolonged periods of mechanical ventilation in critical care units have not improved over past decades, reflecting increasing ability to prolong survival through aggressive and sophisticated technology, but little change in our ability to restore states of health.[3] Early in the history of reports of the chronically critically ill, a 44% 1-year mortality rate was noted, with >50% of patients still dependent on a caregiver for activities of daily living (ADL).[4] Post-discharge outcomes also have been poor; in a sample of 203 chronically critically ill adults, 43.8% were alive at 6 months, but only 15.8% were living at home, and 43.8% of those were dependent in all ADL.[5] Similarly, in Carson and associates' evaluation of patients receiving >21 days of mechanical ventilation, the overall 1-year mortality was 48%.[6] In-hospital mortality rates do appear to be decreasing, but this is likely related to the increasing use of long-term acute care facilities in the United States which allows for hospital discharge of patients who are still acutely ill. In a recent study of patients experiencing >5 days of mechanical ventilation, only 27.3% of patients died in the hospital, but 52% had died by 3 months post-discharge.[7]

Given the prolonged use of highly technical and often invasive interventions, including mechanical ventilation, the need for surrogate decision making is a common feature of the chronic critical illness. Family members routinely are faced with the on-going challenge of making decisions regarding new diagnostic tests and procedures, such as tracheostomy or dialysis, as well as overall goals of care.[3] The communication that family members receive from the care team has long been recognized as essential to providing effective decision support to families and one of the most important determinants of satisfaction with care.[8] However, most of the research conducted has focused on physician communication, prognostication, and areas of conflict between physicians and families regarding goals of care.[9–12] While there is a general recognition that nurses are an integral part of the critical care team, and communication between nurses and families has been well studied,[13,14] there has been relatively less study of nurses' attitudes, beliefs, and communication specifically regarding likely patient outcomes.

We describe here the similarities and differences over time in the expectations held by family members of the CCI and the nurses caring for those patients. Data are drawn from a larger study of the factors influencing complex decisions about aggressiveness of care.[7] We previously reported the comparison of physician and family expectations and predictors of goals of care[15] and focus here on nurse and family comparisons.

Materials and Methods

Design

The parent study used a descriptive correlational design. The Institutional Review Board of the study site provided ethical and regulatory approval. Critical care nurses, physicians, and family decision makers of eligible patients were surveyed regarding outcome expectations and treatment preferences on the 3rd–5th day of the ICU patient's stay, and every 5 days until ICU discharge or death. The interval of 5 days was chosen to obtain data often enough to reflect changing clinical conditions but allow for all participants to process observations and incorporate changes in expectations. This report focuses on nurse and family expectations for patient outcomes 6 months in the future, using descriptive data from the parent study and examining relationships among selected variables.

Statistics

For analysis, we describe measures of central tendency and compared differences between nurses and family members in outcome predictions using Chi-square. The correlations between predictions at the different time points were examined using Pearson R. RMANOVA was used to explore the relationship between the family member's rating of what was most important in the care of the patient (survival vs. quality of life [QOL]) and that individual's prediction of the likelihood of survival, accounting for change over time.

Participants

Three adult intensive care units (medical, surgical, and neuroscience) in a 950-bed tertiary academic institution in the Midwest United States were the study sites. The registered nurse caring for the patient on the day on which the family member completed a survey was interviewed. Agency nurses were not employed in this facility, so all nurses interviewed were either full- or part-time staff assigned to the critical care units.

Family decision makers were eligible to be approached for consent to participate if they were the next of kin or legally authorized decision maker for a patient who had been in the ICU for at least 3 days, who lacked the capacity for decision-making and were expected to remain in the ICU for at least the next 48 h. In addition, the family member had to be over 18 years of age, English-speaking, and the same family member available for all interviews. While our focus was on decisions for patients who progressed to states of chronic critical illness, to observe changes over time, we sought to identify patients early in the ICU course who were not following the more typical trajectory for ICU patients in the U.S. of a 2–3 days stay in the ICU. For this report, we limited data analysis to those family decision makers of patients who remained in the ICU at least 13 days, which corresponded to 3 potential data collection time points (Time 1 = ICU day 3–5; Time 2 = ICU day 8–10; and Time 3 = ICU day 13–15). Although we collected data for as long as the patient was in the ICU, the numbers at later time points were too small for analysis.

Procedures

Research assistants (RA) made rounds every day in the three study ICUs and identified eligible patients. Before approaching families about the study, the RA checked with one of

the teams caring for the patient to ask if there was any reason not to approach the family member that day (e.g., family distress at getting bad news). Family members were then approached for informed consent for their participation and also for permission to obtain data from the patient medical record. Data were collected every 5 days, until ICU discharge or patient death. An iPad was used for data collection; the RA read the question to the family member and entered the response on the iPad. Family members were called after discharge at months 1, 2, and 3 to ascertain patient location. All consent procedures, including the use of family permission for recording patient data, were approved by the study site's Institutional Review Board.

Nurses were informed of the study at staff meetings before the study began and asked to provide consent for participation and provide demographic data. The nurse caring for each patient was then interviewed on the same day as family data collection at each time point, using the same procedure as was done for families. While the family member for each patient was, thus, the same person at each time point, most often the nurses were different at each time point.

Measures

Patient characteristics included demographic data, admission diagnosis, length of stay, discharge disposition, and location at 3 months post-discharge. Nurse and family demographics were collected on enrollment.

Nurse and family outcome expectations were measured by asking each family participant and the nurse caring for the patient on the day of the interview to indicate his/her expectations for the patient, 6 months in the future, for survival (very unlikely, not likely, probably, or very likely), for cognitive status (completely impaired, mildly impaired, or intact), and functional status (completely dependent in ADL, partially dependent, or completely independent). This was an investigator-designed instrument that was developed with input from experienced critical care physicians and nurses, but not previously validated. In addition, families were asked, "What kind of information is most important to you today in understanding your loved one's condition?" Response options were: Results of tests; seeing how he/she looks; Hearing the doctor's opinion; Talking with the nurses, and other. Families were also asked, "Right now, what is most important to you in making decisions for your loved one," using a visual analog scale, anchored by "Comfort/QOL" at one end and "Survival, Length of Life" at the other.

Results

Patient and family demographics are shown in Table 1. In total, 420 family members were approached for consent; of these, 154 (37%) refused and two consented but subsequently dropped out. Of the 264 enrolled patients in the parent study, 72 (27.3%) died and 115 (43.5%) were discharged from the ICU before Time 3, leaving a sample of 77 (29%) eligible for inclusion (remained in the study for at least three of the scheduled time points, or a minimum of 13 days in the ICU). There was on-going attrition, resulting from an inability to reach family members for data collection within the specified time window. This resulted in 69/77 participants (89.6%) at Time 2 and 60/77 (77.9%) at Time 3. The study protocol

included the plan of stopping the interview and immediate referral to a member of the clinical team (nurse, social worker, or clergy) if the family member became distressed by data collection, but this was not necessitated for any participant.

The family decision makers for these patients and the nurses ($n = 67$) caring for the patients at each time point comprise the sample for this paper. As can be seen in Table 1, the sample was evenly divided between genders, and predominantly in late middle age. Most were cognitively intact before the acute illness that led to the prolonged ICU stay and the family member rated the overall QOL as moderately good. Of the family members, the most common relationship was a spouse, followed by an adult child. The average age of surrogates was slightly lower than the patients, and the majority ($n = 58$, 75%) were female.

Nurse characteristics are shown in Table 2. Most had spent the majority of their time in practice in the ICU and had several years of ICU nursing experience, with median years in practice of 4.0.

Figures 1–3 show the comparisons of family expectations versus nurse expectations for the patient's status 6 months in the future. For analysis of differences, response categories were collapsed for all questions because the number of family respondents who predicted the worst outcomes was small. For survival, responses of "very unlikely" and "not likely" were classified as "probable poor outcome" and "probable" and "very likely" were classified as "probable good outcome." Similarly, for cognitive function, "completely impaired," and "mildly impaired" were considered "probable poor outcome" and "completely intact" were termed "probable good outcome." Functional status expectations were categorized as "completely dependent" and "partially dependent" equaling "probable poor outcome" and "completely independent" were classified as "probable good outcome." The bar graph illustrates, for each group (family members vs. nurses), what percent of each group, at each time point, predicted a poor versus good outcome. Differences in the proportion of respondents predicting a good or poor outcome, comparing nurses with family members, were tested with Chi-square. As indicated on the figures, family members consistently predicted better outcomes than nurses at all time points. The differences reached statistical significance at Time 3 for all domains, and also at Time 2 for cognitive status. In general, there were only slight increases in the percent of each group predicting poor outcomes over time.

Table 3 displays the mean responses to the question of families, "right now, what is most important to you in making decisions for your loved one?" Categorized according to whether the family member rated the probability of survival 6 months in the future as either "very unlikely" or "unlikely," compared to those who rated survival as "probable" or "very probable." Responses to the "importance" question were provided on a visual analog scale calibrated to 100, with 0 = QOL and 100 = survival/length of life. Using RMANOVA, there was no statistically significant difference in the change of rating of QOL versus survival over time between low and high expectations of survival groups ($P = 0.89$). The analysis revealed a statistically significant difference in response to the "importance" question (mean QOL vs. survival score) between those in the low (survival very unlikely or unlikely) versus high expectation survival (survival probable or very probable) groups ($P = 0.008$). Family

responses to the important question were relatively stable from time point to time point, with all correlations (T1–T2, T2–T3, and T1–T3) significant at *P* < 0.005.

Families were also asked at each time point to identify the "kind of information most important for making decisions for your loved one." "Hearing the doctor's opinion" was consistently the most frequently chosen response. However, as can be seen in Table 4, between 14% and 23% of families indicated it was talking with the nurses that was most important.

Discussion

The results of this study have several important implications for nursing care of this growing population. Analysis of the results in the parent study confirmed reports from others documenting the overly optimistic expectations of families for patient outcomes and marked discordance between physician and family estimates of prognosis.[16-18] Given the lack of medical experience and knowledge of many families, combined with the power of hope, it is understandable that family members would maintain unrealistic expectations for good outcomes, despite poor prognostic signs. In addition, there is evidence that families have varying faith in the ability of critical care physicians to accurately estimate prognosis.[19,20]

Of concern, however, is the possibility that these families are not receiving clear communication of likely outcomes, which can impair adequately informed decision-making and present barriers to both emotional preparation and planning for practical realities associated with post-discharge needs. Multiple investigations have documented the barriers to or lack of clear discussion of prognoses in critical care. For example, in Azoulay's large study of communication in French ICUs, he reported that 54% of 76 family surrogates failed to understand the diagnosis and prognosis of the patient.[21] Poor comprehension was more likely in the families of patients with >40% risk of death. Nelson *et al.* surveyed 100 families of chronically critically ill patients in the United States; 80% reported receiving no information about expected functional status at discharge, and 93% reported receiving no information about the prognosis for the next year.[22]

The marked differences in expectations between family members and nurses raise several questions. First, it seems likely that, given the relatively large percentage of nurses who predicted a poor outcome in every domain, continuing to administer aggressive and burdensome interventions to these patients could be a source of significant moral distress. In examining moral distress among ICU nurses, continuing aggressive interventions that were viewed as "futile" has been identified as among the most common factors associated with high levels of distress.[23-25]

The surprising finding that slightly more than half of families, when asked, did not identify communication from the physician as most important also has implications for nurses. First, although the data indicate that families use information from varied sources, clearly nurses were the key informants in some of these cases and probably secondary sources in many others. The effectiveness of nurses as facilitators of information gathering and decision-making by families has been documented by others.[13,14] Thus, it is critical that nurse-

family communication be intentional, thoughtful, and clear. Varied barriers to providing decision support have been identified and include time constraints, fear of contradicting what the physician has said, lack of confidence in their ability to prognosticate, or belief that such judgment is not within the scope of their practice in their culture.[26-28]

While we do not have any data about the nurse's perception of the value or impact of his/her communication with families, it is possible that nurses underestimate how influential their discussion with families can be. Establishing routine processes for the ICU team, as a whole, to reach consensus about prognosis and specific plans for clear communication to families could be a nurse-driven initiative in the ICU. In addition, providing equal attention to communication skill training as is done for teaching technical skills should be a priority for those responsible for initial and on-going nurse education.

Our data also suggest a need for design and tests of nurse interventions aimed at improving family surrogate understanding of patient prognosis and future outcomes. There has been some report of nurse-driven initiatives, but almost no large randomized controlled trials focused on ICU nurse communication and decision support.[29,30]

There are several limitations to the study that should be noted. As can be seen on the tables, there were increasing instances of missing data over time. As patients remained in the ICU for longer periods, it became increasingly difficult to locate and interview some families at scheduled time points. In addition, there were relatively few family members in the group predicting poor outcomes, which limits confidence in the patterns identified despite statistical differences.

The visual analog scale was investigator designed and not previously validated. However, it is similar in concept to the rating scales used in other research. For example, in Meropol's study of patients with cancer, investigators asked patients to choose, among five options, whether QOL was all that mattered, whether quality and length of life were both important but quality was more important, whether quality and length were equally important, both mattered but length was more important, or whether length of life was all that mattered.[31] Our use of the value added services essentially presented participants with the same options but in a different format.

Finally, in that this study was conducted in the United States it may not represent families or nurses from other locations. Nevertheless, we believe these data point to important opportunities for nurses to partner with other ICU colleagues in better preparing families for the likely outcomes of chronic critical illness.

Conclusions

The results of this study confirm that family decision makers for patients experiencing prolonged critical illness often have unrealistic expectations for outcomes, including survival, regaining functional independence, and cognitive status. Nurses can play an important role in designing and testing interventions aimed at improving family understanding of patient prognosis and future outcomes.

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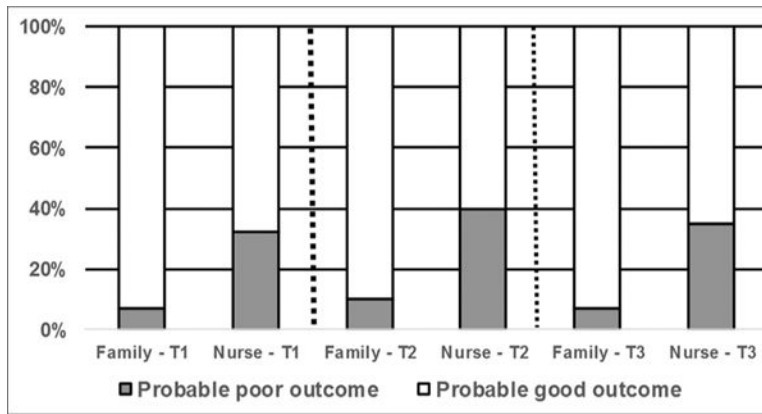
Figure 1:

Expectations for future survival by time point (T1 $n = 77$; T2 $n = 69$; and T3 $n = 60$), family versus nurse. *Differences in proportion of poor versus good outcome predictions, family versus nurse, by Time: T1 $P = 0.181$; T2 $P = 0.333$; and T3 $P < 0.005$
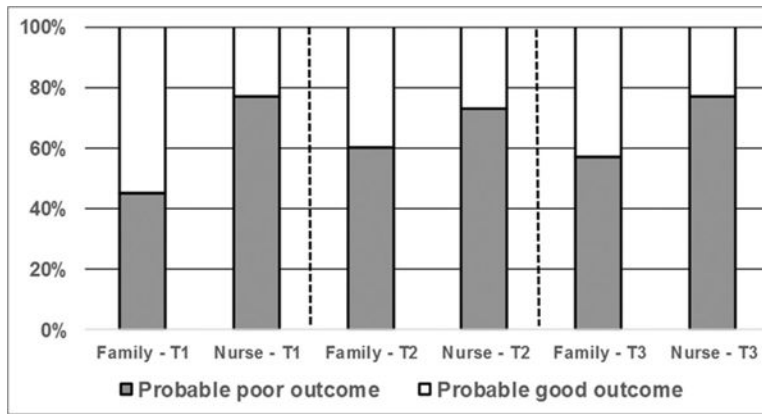
Figure 2:
Expectations for future cognitive function by time point (T1 $n = 77$; T2 $n = 69$; and T3 $n = 60$), family versus nurse. *Differences in proportion by Time: T1 $P = 0.086$; T2 $P = <0.000$; and T3 $P = 0.028$
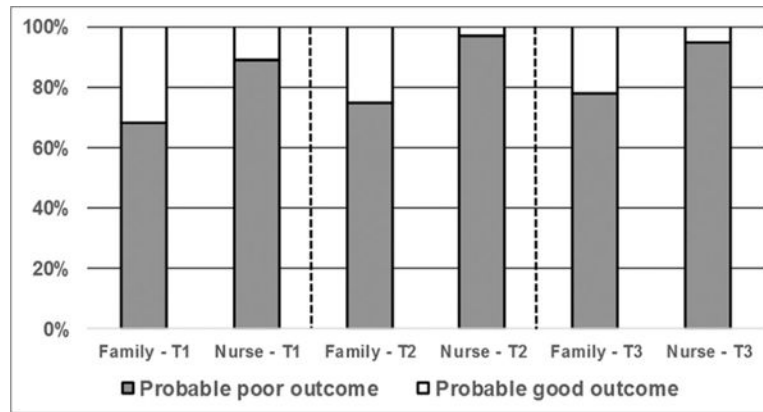
Figure 3:
Expectations for future independence in activities of daily living by time point (T1 $n = 77$; T2 $n = 69$; and T3 $n = 60$), family versus nurse. *Differences in proportion by Time: T1 $P = 0.653$; T2 $P < 0.081$; and T3 $P = 0.001$

Table 1:

Patient and caregiver demographics

Patient (*n*=77)	Mean (SD)
Age	58.8 (13.6)
Hospital length of stay	31.8 (15.9)
ICU length of stay	22.8 (8.3)
	n (%)
Gender	
Female	39 (50.6)
Race	
Caucasian	58 (75.3)
African American	17 (22.1)
Other	2 (2.6)
ICU	
Surgical	30 (39.0)
Neurologic	26 (33.8)
Medical	21 (27.3)
Pre-admission cognitive status	
Intact	64 (83.1)
Mild impairment	13 (16.9)
Living will	
Yes	22 (28.6)
Discharge disposition	
Died/in-pt. hospice	18 (23.4)
LTAC/SNF/Rehab [*]	52 (67.5)
Home	5 (6.5)
Other hospital	2 (2.6)
Status at 3 months	
Died	30 (38.9)
LTAC/SNF	13 (16.9)
Home	21 (27.3)
Lost to follow-up	13 (16.9)

Caregiver (n=77)	Mean (SD)
Age (years)	53.4 (12.4)
	n (%)
Gender	
Female	58 (75.3)
Race	
Caucasian	57 (74.0)
African American	16 (20.8)
Other	4 (5.2)

Marital status	
Married	57 (74.0)
Relationship	
Spouse	34 (44.2)
Child	23 (29.9)
Other	20 (26.0)
Religion	
Catholic	23 (29.9)
Protestant	33 (42.9)
Jewish	2 (2.6)
Other/none	19 (24.7)

[*]LTAC: Long-term acute care facility, SNF: Skilled nursing care facility, Rehab: Rehabilitation facility

Table 2:

Nurse demographics

Variable	Mean (SD)	Median	Range
Age	32.0 (8.79)	28.0	23–57
Years in practice	7.4 (7.45)	4.0	0.5–28
Years in ICU	6.0 (6.34)	3.0	0.4–24
	n (%)		
Gender			
Female	56 (83.6)		
Race			
Caucasian	59 (88.1)		
African American	2 (3.0)		
Other	6 (9.0)		
Religion			
Catholic	37 (55.2)		
Protestant	14 (20.9)		
Other	3 (4.5)		
None	13 (19.4)		

Table 3:

Mean family ratings on a 100 mm visual analog scale of what is most important (quality of life vs. survival) by family prediction of survival probability[1]

Information	T1 (*n*=77)	T2 (*n*=69)	T3 (*n*=60)
Survival very unlikely/unlikely	25.26 (43.0)	30.12 (24.9)	19.29 (22.3)
Survival probable/ very likely	63.18 (34.1)	62.68 (34.4)	55.06 (35.7)

[1] Responses to the question, "right now, what is most important to you in making decisions for your loved one," were indicated on a visual analog scale, with the 0 anchor labeled "comfort/quality of life" and the 100 anchor labeled "Survival/Length of Life." Four response options to the question, "what are your expectations for survival 6 months from now" were dichotomized into two categories: "Survival very unlikely/unlikely" and "survival probable/very likely"

Table 4:

Kind of information ranked most important by family

Information	T1 *n*=77 (%)	T2 *n*=69 (%)	T3 *n*=60 (%)
Hearing the doctor's opinion	44.2	49.3	48.3
Talking with the nurses	23.4	14.5	15
Results of tests	11.7	17.4	15
Seeing how he/she looks	13.0	10.1	16.7
Other	6.5	8.7	5.0