Quality of Communication in the ICU and Surrogate's Understanding of Prognosis

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Abstract

Objective—Although misperceptions about prognosis by surrogates in ICUs are common and influence treatment decisions, there is no validated, practical way to measure the effectiveness of prognostic communication. Surrogates' subjective ratings of quality of communication have been used in other domains as markers of effectiveness of communication. We sought to determine whether surrogates' subjective ratings of the quality of prognostic communication predicts accurate expectation about prognosis by surrogates.

Design—We performed a cross sectional cohort study. Surrogates rated the quality of prognostic communication by survey. Physicians and surrogates gave their percentage estimate of patient survival on ICU day 3 on a 0-100 probability scale. We defined discordance about prognosis as a difference in the physician's and surrogate's estimates of   +/-20%. We used multi-level logistic regression modeling to account for clustering under physicians and patients and adjust for confounders.

Patients—275 patients with acute respiratory distress syndrome at high risk of death or severe functional impairment, their 546 surrogate decision makers, and their 150 physicians.

Measurements and Main Results—There was no predictive utility of surrogates' ratings of the quality of communication about prognosis to identify inaccurate expectations about prognosis. (OR 1.04 +/- 0.07, p 0.54). Surrogates' subjective ratings of the quality of communication about prognosis were high, as assessed with a variety of questions. Discordant prognostic estimates were present in 63.5% (95% CI: 59.0%-67.9%) of physician-surrogate pairs.

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Conclusions—Although most surrogates rate the quality of prognostic communication highly, inaccurate expectations about prognosis are common among surrogates. Surrogates' ratings of the quality of prognostic communication do not reliably predict an accurate expectation about prognosis.

Key words for indexing

Communication; Decision making; Prognosis; Respiratory Distress Syndrome, Adult; Cohort Studies; Cross Sectional Studies

Introduction

Surrogate decision makers of critically ill patients often have inaccurate expectations about their loved one's prognosis. (1–4)This is problematic because prognostic information influences treatment decisions. Undue optimism in particular may lead to the use of invasive treatments that are inconsistent with patients' preferences. (5, 6)Misperceptions about prognosis may also leave surrogates unprepared for their loved ones' death.(7–9)

Despite the importance of effective prognostic communication, there is no practical way to assess whether a physician has effectively communicated prognostic information to a family. Audio recording is resource intensive, difficult to interpret, and not clinically practical. Directly asking surrogates to restate the information just delivered about prognosis in the conversation (e.g., a "teach back"(10)) may be interpersonally difficult for physicians and emotionally difficult for surrogates. A potentially practical and feasible way to evaluate the effectiveness of prognostic communication is to assesssurrogates' perceptions of the quality of prognostic communication. Literature suggests that for some types of communication, such ratings of quality are useful markers of actual effectiveness(11) but not in others(12–14). Thissuggests that the utility of subjective ratings of quality of communication as an actual marker of effective communication is context dependent. We are not aware of any efforts to examine if there is any predictive utility of surrogates' ratings of the quality of communication about prognosis to identify inaccurate expectations about prognosis.

We therefore conducted this analysis to determine whether simple questioning of surrogates' subjective perceptions of the quality of prognostic communication is a reliable predictor of surrogates' expectations about prognosis.

Materials and Methods

Design

We performed a secondary data analysis of a cross sectional cohort study of surrogate decision makers for critically ill patients in medical-surgical, trauma, cardiac, and neurologic ICUs of 5 U.S academic medical centered located in California, Pennsylvania, Washington, North Carolina, and Massachusetts between November 2010 and October 2012.

Participants

The cohort includes 251 patients with acute respiratory distress syndrome (ARDS), their 546 surrogate decision makers, and their 145 physicians.

Patients were eligible if they lacked decision making capacity and had respiratory failure requiring mechanical ventilation due to ARDS as defined by a PaO2:FO2 ratio less than 300 and bilateral infiltrates on chest radiography not due to left atrial hypertension. Patients had a 50% or greater risk of hospital mortality or long-term and severe functional impairment, estimated by an Acute Physiology and Chronic Health Evaluation (APACHE) II score of at least 25 or the attending physician's estimate for patients with neurologic diagnoses. We excluded patients who were awaiting organ transplantation, imminently dying, or had no surrogate available.

We enrolled family members who self-identified as being involved in surrogate decision-making for the patient. If multiple individuals identified themselves as the surrogate for a patient, we then enrolled those who rated their role in decision making to be significant. Therefore, each patient could have more than one surrogate enrolled. To be considered, surrogates needed to be at least 18 years old and speak and read English well enough to not require an interpreter.

Physicians were the treating attending physician of record or his or her designee, defined as any physician providing clinical care to the enrolled patient under the service of the attending physician. The eligible physician was approached for participation in the study prior to their participation in any study interventions.

The study coordinator at each site obtained a daily list of all ARDS patients identified through existing ARDS network screening mechanisms. The research coordinator then assessed whether the patient met enrollment criteria for the study. If so, the study investigator sought permission from the attending physician to approach the surrogate decision-maker regarding study participation. This study was approved by the University of Pittsburgh Institutional Review Board. All subjects provided written consent for all study procedures.

Predictor Variables

Patient, surrogate, and physician demographic variables were obtained via questionnaires. Surrogate trust in physicians was measured by the by the Wake Forest Trust Scale(15). Surrogate health literacy was measured by the Short Test of Functional Health Literacy in Adults (STOFHLA)(16). Surrogate numerical literacy was measured by the Lipkus score(17).

Surrogates' subjective perceptions of prognostic communication were assessed prior to the family conference on ICU day 3 by asking the following three questions: (1) "Overall, how well have the doctors communicated with you about your loved one's chances for surviving this hospitalization?" (2) "Overall, how much do you believe the information from the doctor about your loved one's chances for surviving this hospitalization?" and (3) "Overall, how satisfied are you with the doctor's bedside manner when he/she discussed your loved

one's prognosis?" Subjective scales were measured on a 10 point Likert scale with 0 being "very poor" to 10 being "perfectly."

Outcome Variables

The primary outcome measure was discordance between the physician's prognostic estimate and the surrogate's prognostic estimate of at least 20 points on a 0-100 probability scale. We assessed the surrogate's *personal estimate* of the patient's prognosis on ICU day 3 by asking the following question: "What do you think are the chances that your loved one will survive this hospitalization if the current plan of care stays the same?" We assessed the physician's prognostic estimate with the same question, replacing "loved one" with "patient." All participants responded by marking on a 10cm long 0-100 probability scale, labeled on the left with "No chance of survival (0%)," on the right with "Will definitely survive (100%)," and "10%, 20%, …, 80%, and 90%" marked at every 1cm distance in between.

Statistical Analysis

Multilevel, mixed effect logistic regression modeling assessed for an association between surrogates' perceived quality of communication and discordance. Multilevel modeling was used to account for the hierarchical nature of the data where there can be multiple surrogates per patient and to describe those effects as fixed or random. Multilevel, multivariable, ordinal logistic regression modeling assessed for a trend between perceived quality of prognostic communication and surrogate prognostic estimates. Modeling controlled for demographic variables, Lipkus score, and APACHE score. All analyses were performed using STATA version 13 (Statcorp LP, College Station, TX) and two sided statistical significance was defined as a resultant P value of 0.05 or less.

Results

Characteristics of study participants

Table 1 shows the demographic characteristics of the patients, surrogates, and physicians who participated in the study. Of 546 surrogates in the original cohort, 464 completed the pre-family conference questionnaire. Because there was no physician enrolled for the patients of two surrogates, there are 462 physician-surrogate pairs available for analysis. The sample was diverse in terms of gender, religious affiliation, and level of education. Patients were admitted mostly from home, an outside hospital, or other acute care facility. At the time of enrollment, the patients had a mean APACHE II score of 32 (+/- 5). A majority of surrogates were the patient's spouse or child and had a least some college education with adequate health literacy. About half of surrogates had prior experience in medical decision-making. Responding surrogates were similar to non-responding surrogates except in their trust in physicians. Responders had higher trust in physicians than non-responders (20.8 +/-3.7 and 19.4 +/- 4.0, respectively; p=0.003).Clinicians were mostly attending physicians with an average of 8.7 years in practice.

Surrogates perceive high quality of prognostic communication, yet discordance is common

Figure 1 shows surrogates' mean scores to the three questions that assessed the quality of prognostic communication and the percent of discordant physician-surrogate prognostic estimates. 73% (337/464) of surrogates responded to the question asking how well the doctor communicated the prognosis and rated this question at mean score of 8 (+/- 2.4). 68% (316/464) of surrogates responded to the question asking regarding belief of prognostic information and rated this question at a mean of 8.4 (+/- 2.1). 75% (347/464) responded to the question regarding satisfaction with the doctor's bedside manner and rated this question at a mean of 9 (+/- 1.9). Overall, 63.5% (95% CI: 59.0% - 67.9%) of physician-surrogate pairs had prognostic estimates that were greater than 20% different (discordant).

Perceived quality of prognostic communication does not predict inaccurate expectations about prognosis

Table 2 shows the multivariate model analyzing the relationship between our predictor variables of and discordance while controlling for age, gender, numerical literacy, minority status, APACHE score, and surrogate relationship. In this model, there was no predictive utility of the three candidate questions assessing perceived quality of prognostic communication to identify discordance, neither individually nor when placed in the model in combination (p= 0.661). A summary score that combines the scores from the individual questions and takes the average was also not predictive of discordance after controlling for the same variables (OR=*1.01; p=0.857*). This multivariate analysis also shows that as surrogates' numerical literacy increases, discordance decreases and as patients' severity of illness increases (OR=0.89, p=0.026), discordance increases (OR=1.06, p=0.013).Figure 2 shows additional analysis performed with a receiver operator curve which shows surrogates' quality ratings of the communication about prognosis predict accurate expectations about prognosis no better than chance (AUC=0.4481).

Surrogates who rate quality of communication the highest are also the most optimistic

Figure 3 shows the ratings of prognostic communication across three groups of surrogates: those with pessimistic estimates relative to physicians (13.5%), estimates concordant with physicians (36.5%), and optimistic estimates relative to physicians (50%). Surrogates who held more optimistic prognostic estimates relative to the physician tended to also ratethe quality of prognostic communication higher.

Discussion

We found that although most surrogates positively evaluated physicians' prognostic communication, their prognostic expectations were discordant with physicians, typically being overly optimistic. Surrogates' ratings of the quality of prognostic communication do not reliably predict prognostic concordance with their physician.

We are not aware of other studies that address whether surrogate decision makers' subjective ratings of communication predict accurate expectations about prognosis by surrogates. However, several studies of the informed consent process reveal that participants often

report high subjective quality of communication, but misunderstand key information central to truly informed consent.(18–22) For example, in one randomized controlled trial of 29 patients evaluating an intervention to improve informed consent comprehension, all participants were all highly satisfied with the consent process yet the percent of information understood in the control group was 39%.(18)Our study adds to this literature by showing that in the context of critical illness and surrogate decision making, subjective quality ratings about communication are not a reliable marker for effective communication about prognosis.

We also found surrogates' with higher quality of communication scores tend to hold overly optimistic prognostic estimates, which raises the possibility that surrogates' ratings of the quality of communication may actually worsen as they more clearly understand the patient's prognosis. Although no other studies have assessed this among surrogates, Weeks et al found a similar occurrence in a study of 1193 patients' expectations about effects of chemotherapy for advanced cancer.(23) They found that patients who reported higher scores for physician communication were also at higher risk for inaccurate expectations. This finding further strengthens the argument that subjective quality ratings are not likely to be useful proxies for effective communication about prognosis.

The study has two main strengths. First,we enrolled a large, diverse cohort, which enhances the study's generalizability. Second, we used multiple methods to assess our main result. We used both a model to calculate the predictive value of each individual question about prognostic communication as well as a composite score that combines the ratings of all three questions. We also used an ROC curve to examine the predictive accuracy. The fact that each analytic approach yielded qualitatively similar results lends support to our main finding.

Our study has several limitations. Although it is the largest study of its kind, there was not adequate power to meaningfully conduct subgroup analyses to examine whether the utility of the quality ratings varied across age or racial groups. Similarly, although our sample population was diverse, some groups for whom discussions of prognosis hold particular concern, such as Navajo Indians(24), were underrepresented. Finally, our study was conducted in the ICU environment and we cannot exclude the possibility that in other clinical contexts these types of quality ratings may be a reliable marker for effective communication.

The clinical implication of our finding is that surrogates' perceptions about the quality of prognostic communication do not reliably predict prognostic concordance with their physician. The "teach back" method(10) is an evidence based tool clinicians use to assess accurate understanding of information. A large body of research shows this technique is well liked by patients and is an effective way to assess for misunderstandings.(25–28) Because surrogates may experience emotional discomfort when verbalizing their loved one's poor prognosis, clinicians may consider a modified version of the "teach back" method where the surrogate is asked to verbalize what they are going to tell other family members about their loved one's prognosis. For example, rather than saying, "can you please tell me what I just told you about your father's prognosis", clinicians could say, "We've talked about a lot of

complicated medical things and I imagine you are going to talk with other family/friends about this after our meetings. What are you going to tell them about what the future might hold for your father?"

Conclusion

Surrogates' perceptions about the quality of prognostic communication do not reliably predict prognostic concordance with their physician. Future research is needed to develop and empirically test an approach that will promote shared understanding between physicians and surrogates regarding prognostic information.

Acknowledgments

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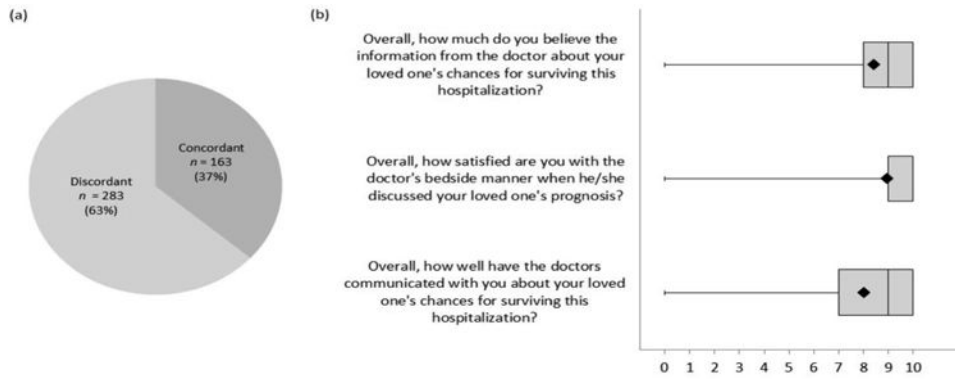
Figure 1.
Discordance about prognosis is common despite highly rated quality of communication.
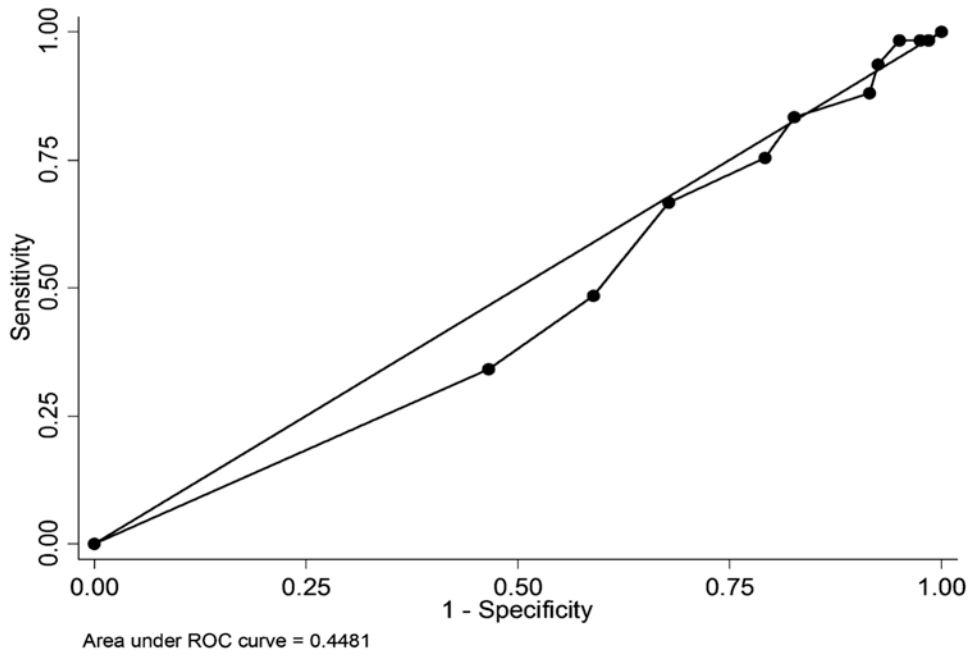
Area under ROC curve = 0.4481

Figure 2.
Analysis using receiver operator curve shows surrogates' communication quality ratings predict accurate expectations about prognosis no better than chance.
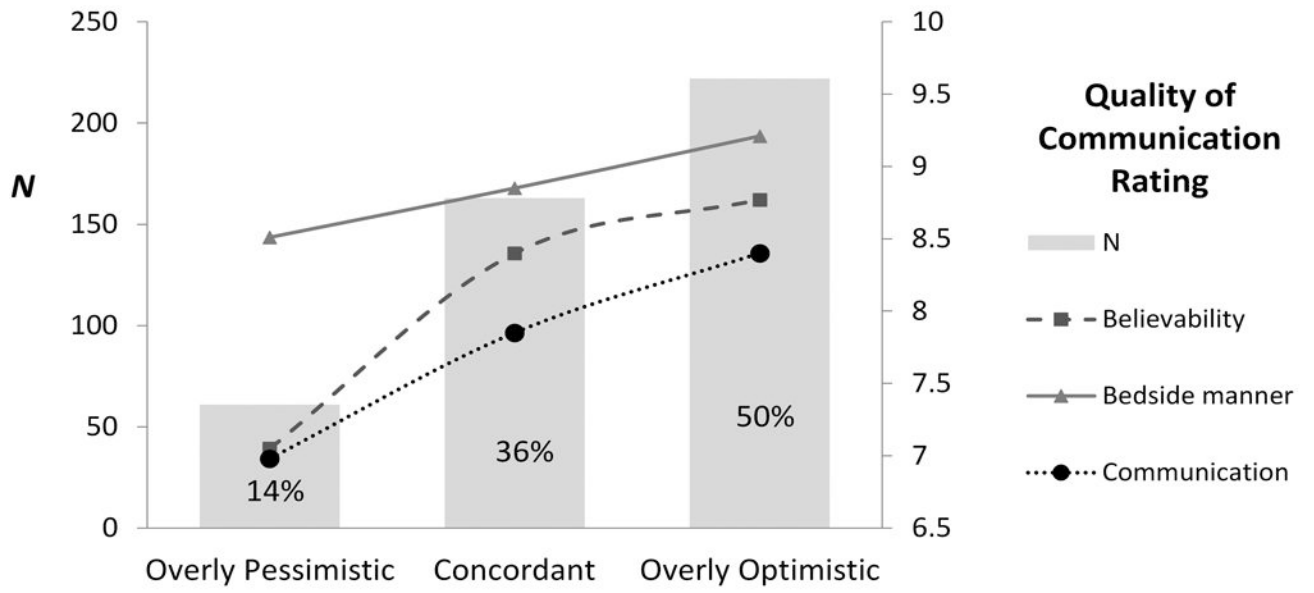
Figure 3.
Surrogates who rate quality of communication the highest are also the most optimistic.

Table 1

Characteristics of Study Participants

Characteristics		Surrogate (N=464)		Patient (N=251)		Clinician (N=145)	
Age		49.5	(14.0)	58.1	(16.6)	38.9	(10.1)
Sex	Female	301	(65.7)	115	(45.8)	44	(30.3)
	Male	157	(34.3)	136	(54.2)	101	(69.7)
Race	White	355	(80.7)	202	(81.8)	107	(77.0)
	African American	49	(11.1)	30	(12.2)	4	(2.9)
	Asian/Pacific Islander	16	(3.6)	10	(4.1)	26	(18.7)
	Native American/Alaskan Native	3	(0.7)	2	(0.8)	0	(0)
	Multiethnic	17	(3.9)	3	(1.2)	2	(1.4)
Ethnicity	Non-Hispanic	413	(90.8)	193	(90.2)	137	(95.1)
	Hispanic	42	(9.2)	21	(9.8)	7	(4.9)
Relationship to patient	Spouse/partner	100	(21.9)				
	Child	165	(36.1)				
	Parent	64	(14.0)				
	Sibling	57	(12.5)				
	Other	71	(15.5)				
Level of education	High school or less	157	(34.4)				
	Some college/college graduate	217	(47.5)				
	Graduate school/degree	83	(18.2)				
Level of English comprehension	Poorly	2	(0.4)				
	Fairly well	10	(2.2)				
	Well	33	(7.2)				
	Very well	412	(90.2)				
Lipkus et al. (2001) Numeracy Scale-Expanded, score 0-11, higher values indicating better numeracy		6.8	(3.2)				
Level of health literacy measured using STOFHLA: Reading Comprehension	Inadequate	15	(3.3)				

Characteristics		Surrogate (N=464)		Patient (N=251)		Clinician (N=145)	
Religiosity (importance of religion in everyday life)	Marginal	5	(1.1)				
	Adequate	438	(95.6)				
	Not at all important	35	(7.7)				
	Not too important	66	(14.5)				
	Fairly important	139	(30.5)				
	Very important	216	(47.4)				
Past experience as surrogate decision-maker	No	236	(52.0)				
	Yes	218	(48.0)				
Wake Forest Trust Scale (short-form) measuring trust in physicians, score 5-25, higher values indicating more trust		20.5	(3.8)				
Patient prognosis estimation		68.5	(31.1)			54.9	(29.9)
APACHE II at time of questionnaire completion measuring disease severity, score 0-71, higher values indicating more severe disease and higher risk of death				26.5	(6.6)		
In-hospital death				110	(43.8)		
Staff position	Attending					75	(51.7)
	Fellow					41	(28.3)
	Resident					27	(18.6)
	Nurse practitioner					2	(1.4)
Practice duration						8.7	(9.7)

Data given as mean (sd) or count (%); Percent may not add up to 100.0 due to rounding; 6 surrogates did not complete the Baseline Family Questionnaire and 1 clinician did not complete the Physician Questionnaire

Definitions of terms: STOFHLA = Short Test of Functional Health Literacy in Adults; APACHE = Acute Physiology and Chronic Health Evaluation

Table 2

Multivariate analysis shows no association between surrogates' quality of communication ratings and inaccurate expectations about prognosis (n=276).

Variables	Odds Ratio	*P* Value	95% Confidence Interval
Believability of physician prognostication	1.05	0.568	0.89 to 1.25
Satisfaction with physician bedside manner	1.06	0.620	0.84 to 1.35
Perceived quality of prognostic communication	1.02	0.831	0.85 to 1.23
Combine significance of all predictors of interest		0.661	
APACHE II score[a]	1.06	0.013	1.01 to 1.12
Lipkuset al. numeracyscore[a]	0.89	0.026	0.80 to 0.99
Spousal relationship with the patient[b]	1.73	0.170	0.79 to 3.77
Racial minority	1.33	0.480	0.60 to 2.95
Male[c]	1.19	0.587	0.64 to 2.20
Age in years[a]	1.00	0.708	0.97 to 1.02

[a]For every 1-unit increase;

[b]vs. other types of relationship;

[c]vs. female

Definitions of terms: APACHE = Acute Physiology and Chronic Health Evaluation; Racial minority = race/ethic group other than non-Hispanic white (i.e. blacks, Asians, Hispanic whites, Native Americans, etc.)