

A Randomized Trial of Two Methods to Disclose Prognosis to Surrogate Decision Makers in ICUs

Running title: Testing Strategies to Disclose Prognosis in ICUs

Susan J. Lee Char, MD, JD*
Leah R. Evans, MEd†
Grace L. Malvar, BA‡
Douglas B. White, MD, MAS§

* Department of Surgery, University of California, San Francisco, School of Medicine; San Francisco, CA

† Boston University School of Medicine

‡ Harvard Medical School

§ Program on Ethics and Critical Care Medicine, Department of Critical Care Medicine, University of Pittsburgh Medical Center

At a Glance Commentary

Scientific Knowledge on the Subject: Surrogate decision makers and clinicians often have discordant perceptions of prognosis in patients with advanced critical illness. There is a paucity of empirical data to guide communication about prognosis.

What This Study Adds to the Field: We tested whether numeric or qualitative statements more effectively convey prognostic information. Numeric prognostic statements were not significantly better than qualitative statements to convey news of a poor prognosis in ICUs. In addition, most surrogates' personal estimates of the patient's prognosis were more optimistic than what they understood to be the physician's prognostic estimate. Factors other than ineffective communication, such as lack of confidence in physicians' prognostications or alternative explanatory models of illness, may contribute to physician-surrogate discordance about prognosis.

Corresponding Author:

Douglas B. White, MD, MAS

Program on Ethics and Critical Care Medicine, Department of Critical Care Medicine

University of Pittsburgh Medical Center

3550 Terrace St., 6th Floor Scaife Hall, Room 608

Pittsburgh, PA 15261

Phone: 412-864-3757; Fax: 412-647-8060; Email: whitedb@upmc.edu

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ABSTRACT

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Rationale: Surrogate decision makers and clinicians often have discordant perceptions about a patient's prognosis. There is a paucity of empirical data to guide communication about prognosis.

Objective: To assess (1) whether numeric or qualitative statements more reliably convey prognostic estimates and (2) whether surrogates believe physicians' prognostic estimates.

Methods: 169 surrogate decision makers for ICU patients were randomized to view 1 of 2 versions of a video portraying a simulated family conference involving a hypothetical patient. The videos varied only by whether prognosis was conveyed in numeric terms ("10% chance of surviving") or qualitative terms ("very unlikely" to survive).

Measurements and Main Results: We assessed (1) surrogates' personal estimates of the patient's prognosis and (2) surrogates' understanding of the physician's prognostic estimate. Neither surrogates' personal estimates nor their understanding of the physician's prognostication differed when prognosis was conveyed numerically versus qualitatively (surrogates' estimate: 22% \pm 23 chance of survival vs. 26% \pm 24, $p=0.26$; understanding of physician's estimate: 17% \pm 22 chance of survival vs. 16% \pm 17; $p=0.62$). One in 5 surrogates estimated the patient's prognosis was > 20 percentage points more optimistic than the physician's prognostication. Less trust in physicians was associated with larger discrepancies between surrogates' personal estimates and their understanding of the physician's estimate.

Conclusions: Neither numeric nor qualitative statements reliably convey news of a poor prognosis to surrogates in ICUs. Many surrogates do not view physicians' prognostications as absolutely accurate. Factors other than ineffective communication may contribute to physician-surrogate discordance about prognosis.

INTRODUCTION

Surrogate decision makers require a clear understanding of a patient's prognosis in order to make decisions that reflect the patient's values and treatment preferences. However, surrogates and physicians frequently have discordant estimates of a patient's prognosis.(1-3) The reasons for this discordance have not been fully explored. Most commentators have ascribed it to ineffective communication.(4-5) Physicians do not typically receive training in how to communicate prognostic estimates.(6) A recent study identified substantial heterogeneity in how physicians disclose prognostic information.(7) Some physicians relied exclusively on qualitative statements (e.g., "I think he is unlikely to survive"), while others used numeric expressions (e.g., "80% of patients in this situation do not survive").(7) No studies have examined whether using numeric versus qualitative terms improves surrogates' understanding of prognosis.

Our clinical experience is that even with excellent communication, a gap sometimes remains between physicians' and surrogates' expectations about a patient's prognosis. This raises the possibility that surrogates' *personal estimates of* the patient's prognosis may differ from their *understanding* of the prognostic estimate the physician intended to convey. For example, some surrogates may believe that prognostication is outside physicians' professional capabilities.(8-9) Denial and optimism may also affect patients' and surrogates' perception of a poor prognosis.(10-11)

We therefore conducted a randomized controlled trial to determine whether numeric or qualitative prognostic statements more reliably conveyed physicians' prognostic estimates. We also assessed whether surrogates' own estimates of the patient's prognosis were different from what the physician told them.

METHODS

Subjects and Setting

Eligible participants were surrogate decision makers for any critically ill patient in intensive care units at the University of California, San Francisco Medical Center (UCSF). The ICUs included 2 medical-surgical ICUs, a neurological ICU, and a cardiac ICU. Surrogates were excluded if they were < 18 years old or required an interpreter to understand written or spoken English. We also excluded family members and friends who visited the patient but were not centrally involved in decision making. A study coordinator screened for participants daily by identifying family members present in each ICU waiting room or at the patient's bedside. Prior to approaching a potential participant, the study coordinator contacted the attending physician for permission. Between February 2005 and May 2008, we identified 214 eligible surrogates. 171 individuals provided written consent, 169 completed the survey. The UCSF Institutional Review Board approved all study procedures. This study did not require clinical trial registration because there was no intervention affecting any patient's health outcome.

Video Content and Development

Participants were randomly assigned to view 1 of 2 versions of a 10-minute video of a simulated physician-family conference discussing end-of-life care issues in a hypothetical, incapacitated ICU patient. The 2 videos differed only by whether the physician used a numeric or qualitative prognostic estimate. Half of the participants saw a version of the video where the physician used qualitative statements to convey his prognostic estimate: "I would say it's very unlikely that he will survive. Saying it another way, that means it's very likely he's going to die." The other half saw a version of the video using a numeric prognostic estimate: "I would say he has

about a 10% chance of surviving. Saying it another way, that means there's about a 90% chance that he's going to die." Full transcripts of the family conference are provided in Appendix I.

The videos were developed through extensive collaboration with experts in bioethics, critical care medicine, palliative care medicine, and sociology.(12) The ICU family conference addressed a common "type" of life support decision, involving a patient with a small chance of short term survival but a high likelihood of substantial functional impairment, including ventilator dependence. We "created" a physician who was empathic and adhered to recent evidence about quality communication in ICUs.(7, 13-19) The physician explained the medical scenario, expressed empathy, explained principles of surrogate decision-making, discussed the patient's prognosis, asked a series of questions to elicit information about the patient's values, and explained the treatment options.

Outcomes Measurement

We assessed surrogates' *personal estimates* of the patient's prognosis with the following question: "What do you think are the chances that this patient will survive the hospitalization, if intensive treatment is continued?" We assessed surrogates' *understanding* of the physician's prognostic estimate with the following question: "What do you think the doctor in the video thinks are the chances that this patient will survive this hospitalization, if intensive treatment is continued?" All participants, in both the numeric and qualitative prognosis groups, responded by marking a standard 0 to 100 probability scale, labeled on the left with "0% chance of survival" and on the right with "100% chance of survival."(20) (See Appendix II.) We chose the qualitative descriptor "very unlikely to survive" because in 2 studies, medical professionals assigned the term "unlikely" a mean probability of 14%(21) and 20%.(22) Another study found that the adverb "very" served as a "multiplier" of qualitative terms, increasing their value by 1.25 to 1.32 times.(23) In light of these

studies, “very unlikely” would have a mean probability between 9.5% and 15%, a range that includes 10%, the value used in our study.

We defined *discordance* as the absolute difference between surrogates’ personal prognostic estimates and their understanding of the physician’s prognostic estimate.

The question assessing surrogates’ understanding of the physician’s prognostic estimate was added after the study had commenced because intercurrent findings from our group suggested that surrogates may not believe physicians’ prognostications.(8-9) In the subset of 126 participants who completed the question about understanding, none of the demographic characteristics differed significantly between the groups receiving a qualitative versus numeric prognosis.

Staff members responsible for data entry were blinded to group assignments.

Assessment of Covariates

In addition to standard demographic information, the questionnaire included 3 questions adapted from Schwartz et al. to assess numeracy,(24) with 1 point for each correct response, resulting in a maximum numeracy score of 3. To measure surrogates’ trust in their loved one’s current ICU physicians, we used the abbreviated physician trust scale developed and validated by Hall et al.(25) Surrogates answered 5 questions rating the physicians on a 5-point Likert scale. Totaling the responses generated a cumulative scale, with 25 representing the greatest physician trust. To minimize respondent burden and because of surrogates’ limited exposure to the physician in the video, their trust in that physician was measured using a single question with a 7-point Likert scale. A 4-point Likert scale was used to measure the importance of “religious or spiritual beliefs in . . . [the surrogate’s] day-to-day life.”

Statistical methods

We used STATA version 10 for all statistical analyses and defined a two-sided p-value ≤ 0.05 to be statistically significant for the main outcomes. Unpaired t-tests were used to compare: (1) surrogates' personal estimates of the patient's prognosis when it was conveyed numerically versus qualitatively and (2) surrogates' understanding of the physician's prognostic estimate when it was conveyed numerically versus qualitatively. A paired t-test was used to compare surrogates' personal estimates of the prognosis with their understanding of the physician's prognostic estimate.

To determine which factors predicted greater discordance between surrogates' personal estimates of the prognosis and their understanding of the physician's intended prognostic estimate, we generated a linear regression model with the following variables: relationship to patient, importance of religion, physician trust, and receiving numeric rather than qualitative prognostic information. We included these variables because their coefficients had p-values < 0.2 in univariate analyses. Component plus residual plots confirmed approximately linear relationships between predictors and the outcome. All other demographic variables -- age, gender, race (Caucasian versus non-Caucasian), education (\leq high school, some college or college degree, or some post-graduate education or post-graduate degree), English comprehension (understanding English well or very well versus fairly well or not at all), and numeracy -- had p-values ≥ 0.2 in univariate analyses.

RESULTS

Demographic characteristics

The demographic characteristics of surrogates did not differ significantly between study arms (Table 1). Less than half of surrogates had attained a college degree.

Surrogates' personal estimates of the patient's prognosis

There was no significant difference in surrogates' personal estimates of the patient's prognosis between the 2 groups. Surrogates receiving numeric prognostic estimates reported a mean chance of survival of 22% (SD 23). Surrogates receiving qualitative prognoses reported a mean chance of survival of 26% (SD 24). The difference in means was not significant ($p=0.26$), nor was precision improved with numeric prognostic statements ($p=0.71$), as assessed by comparing the standard deviations of the 2 groups. Both groups demonstrated marked variability, with personal estimates in each group ranging from 0% to 100% survival.

Surrogates' understanding of physician's prognostication

Understanding of the prognosis the physician intended to convey did not differ between surrogates who received numeric versus qualitative prognostic statements (mean estimated chance of survival $17\% \pm 22$ vs. $16\% \pm 17$, respectively; $p=0.62$). Again, both groups demonstrated marked variability, but with slightly less variability in the group receiving qualitative prognostic statements (SD 22 vs. 17, $p = 0.05$). For subjects who received the numeric prognostic estimate, only 52% correctly reported the prognosis that the physician conveyed (10% chance of survival).

Discordance between understanding and personal estimates

In both groups overall, there was a significant difference between surrogates' understanding of the physician's prognostication and their personal estimates of the patient's prognosis ($p < 0.0001$). Surrogates' average understanding of the physician's prognostic estimate was $16\% \pm 19$,

whereas surrogates believed the patient's chance of survival was $23\% \pm 22$, which was more than twice the prognostic estimate presented in the video (10% chance of survival). Forty-five percent of surrogates believed the patient's prognosis was better than the prognosis conveyed by the physician. Twenty-one percent of surrogates were 20 percentage points or more optimistic about the prognosis than their understanding of the physician's estimate. Fifteen percent were more pessimistic than their understanding of the physician's prognostic estimate.

Univariate analyses identified 4 predictors of discordance between surrogates' understanding of the physician's prognostic estimate and their estimate of the patient's prognosis (Table 2). A linear regression model incorporating these 4 predictors demonstrated that greater trust in their loved one's physicians was associated with less discordance (coef = -0.85, $p = 0.04$) (Table 3). Conveying the prognosis numerically was also associated with less discordance (coef = -9.2, $p = 0.001$) (Table 3).

DISCUSSION

Numeric statements were no better than qualitative statements when disclosing news of a poor prognosis to surrogates. Regardless of whether numeric or qualitative terms were used, surrogates' personal estimates of the patient's prognosis were significantly more optimistic than their understanding of the physician's prognostication. This discordance was greater among surrogates with less trust in physicians.

Several studies have reported that lay persons and clinicians interpret qualitative prognostic statements in highly variable ways.(4-5, 21, 26) This has led some to speculate that numeric prognostic estimates might convey prognostic information more reliably.(4-5) Prior to the current study, only one study had addressed this question directly. Man-Son-Hing and colleagues tested

whether communicating risk using numeric versus qualitative terms affected subjects' understanding of the risk of stroke and major bleeding from anticoagulation for atrial fibrillation. They found that numeric terms improved subjects' ability to quantify risk on a numeric scale, but led to no difference in rank ordering the risk associated with each treatment option.(27)

What may explain the somewhat surprising finding that numeric expressions appear to be no more effective than qualitative expressions in communicating prognosis? In contrast to prior studies in which volunteers were asked to interpret an isolated prognostic statement,(4-5, 26) we situated the prognostic statements in the context of a goals of care discussion between physicians and surrogates, which generally requires surrogates to assess and understand multiple pieces of information in a relatively short amount of time. This approach more closely mirrors actual practice and is a more difficult task than scrutinizing a single prognostic statement. In addition, we tested surrogates during the highly stressful circumstances of actually serving as a surrogate decision-maker for a critically ill patient. It is possible that these factors may have diluted any potential benefit of quantitative precision observed in "laboratory" based experiments of risk communication.(4-5, 26)

We also found significant discordance – in the direction of optimism – between surrogates' personal estimates of the patient's prognosis and their understanding of the physician's prognostication. When asked what the physician's prognostic estimate was, surrogates were on average off by only 6 percentage points, which seems unlikely to represent a clinically significant difference. In contrast, when asked what they thought the prognosis was, surrogates on average estimated the patient was more than twice as likely to survive as the physician did. Appelbaum and colleagues have previously described the conceptual distinction between "understanding" and "appreciation,"(28-29) but we are aware of no other empirical data confirming that such a distinction exists in the clinical context. Our data raise the possibility that the physician-surrogate discordance

about prognosis observed in prior studies(1-2) may not be fully explained by poor communication. Other factors, such as the need to express optimism,(11) skepticism about physicians' ability to predict the future, different belief systems about illness,(8) or distrust of physicians may also explain the discordance.

Surrogates with less trust in physicians had greater discordance between their understanding of the physician's prognostications and their own prognostic estimate. This finding provides empirical evidence for an association between the quality of the physician-family relationship and the degree to which surrogates incorporate physicians' expertise into their considerations. Physicians in ICUs often have no prior relationship with their patients and therefore must establish their trustworthiness quickly and under very stressful circumstances.(30-31) Further research is needed to identify ways for ICU physicians to better establish trust with families under these challenging circumstances.

Our study has several limitations. First, we did not assess whether misperceptions about prognosis affected decisions to continue life sustaining treatment. Second, although the sample was diverse, there was insufficient power to robustly analyze subgroups based on factors such as religiosity and numeracy. Third, the findings are limited to discussing poor prognoses. It is possible that the same psychological phenomena may not occur when the prognosis is favorable. Fourth, the method of outcome assessment may have favored greater precision in the numeric prognosis group by using a numeric probability scale to measure surrogates' prognostic estimates. If so, one would expect to find the numeric group's prognostic understanding and personal estimates to be more accurate and precise compared to the qualitative group. We found no such difference. Fifth, discordance between surrogates' own prognostic estimates and their understanding of the physician's prognostic estimate was measured in only 126 of 169 participants. However, the

subgroup of 126 participants was still randomly assigned to receive either a qualitative or numeric prognosis and demographic characteristics were not significantly different between the 2 groups.

Regardless of whether numeric or qualitative terms were used to convey poor prognosis, surrogates' prognostic estimates were on average more than twice as optimistic as the physician's prognostic estimate. This discordance was greater for surrogates with less trust in physicians. To improve discussions about prognosis in ICUs, we speculate that successful interventions will need to address both the cognitive and emotional aspects of discussing a poor prognosis. Cognitive interventions should target clearly conveying prognostic information (e.g., visual aids, checking behaviors, teach-backs, and multiple conversations). Emotional and psychological interventions should foster trust between clinicians and family, and provide emotional support to family members for coming to terms with the news of a poor prognosis.

Until data are available to support specific interventions, we propose that physicians should explicitly check whether surrogates have understood the information presented. Such "checking behaviors" are advocated broadly in medicine and have improved patients' self-management of chronic diseases such as diabetes,(32) but are rarely used in ICUs.(33) If there appears to be disagreement regarding the patient's prognosis, we also suggest that clinicians inquire about the surrogate's beliefs about disease and prognosis. Questions geared towards understanding different explanatory models of illness may help elucidate factors beyond ineffective communication that contribute to discordance about prognosis.(34)

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TABLES

Table 1. Demographic features of surrogates who received numeric versus qualitative prognostic estimates

	Numeric (n=83)	Qualitative (n=86)	
Average age (years)	51±14	53±16	p=0.48*
Male gender	37	38	p=0.96†
Race			
Hispanic	16	12	
Non-Hispanic	67	74	p=0.35†
Asian	5	6	
African/Black American	4	5	
Caucasian/White	55	61	
Native American	0	3	
Pacific Islander	1	3	
Multiethnic/Mixed	13	7	
Don't know/No response	5	1	p=0.18†
Education			
Less than high school degree	3	1	
High school degree	17	19	
Some college	22	24	
College degree	21	18	
Some post-graduate education	5	4	
Post-graduate or professional degree	14	20	p=0.74†
Average numeracy score (0 to 3)	1.5±0.99	1.4±1.1	p=0.64*
Religion			
Christian	51	53	p=0.45†
Catholic	23	18	
Buddhist	3	1	
Hindu	1	1	
Muslim	0	1	
Jewish	1	2	
Mormon	2	1	
Wiccan	0	1	
None	15	21	
No response	9	5	p=0.69†
Relationship to patient			
Spouse/partner	31	35	
Child	27	18	
Sibling	9	11	
Friend	0	2	
Parent	9	14	
Other relative	4	5	
Other	3	0	p=0.23†

* Unpaired t-test

† Chi-square test

Table 2. Univariate analyses of discordance between surrogates' prognostic estimate and surrogates' understanding of physician's prognostic estimate

	Coefficient	p-value	95% confidence interval
Age (n=125)	0.08	0.35	-0.09 to 0.26
Male gender (n=125)	-0.13	0.96	-5.7 to 5.4
Caucasian race (n=123)	-2.3	0.46	-8.4 to 3.8
Education (n=124)			
≤ High school degree	1 (reference)		
Some college education or college degree	2.9	0.42	-4.1 to 9.9
Some post-graduate education or more	-1.7	0.67	-9.7 to 6.3
Understands English well or very well (n=125)	6.6	0.31	-6.3 to 19.5
Christian (n=114)	2.2	0.49	-4.1 to 8.6
Relationship to patient (n=124)*			
Spouse/partner	1 (reference)		
Child	-6.1	0.07	-12.8 to 0.59
Other	2.9	0.37	-3.6 to 9.4
Religiosity (n=121)*	1.9	0.16	-0.80 to 4.6
Trust in patient's physician (n=125)*	-0.80	0.06	-1.6 to 0.02
Trust in physician in video (n=125)	-0.37	0.77	-2.8 to 2.1
Numeracy (n=125)	-0.67	0.63	-3.3 to 2.0
Receiving prognostic information in numbers (n=125)*	-9.7	0.001	-15 to -4.4

* Univariate predictors with $p < 0.2$ were included in the multivariate analysis.

Table 3. Multivariate analysis predicting discordance between surrogates' prognostic estimate and surrogates' understanding of physician's prognostic estimate (n=120)

	Coefficient	p-value	95% confidence interval
Relationship to patient			
Spouse/partner	1 (reference)		
Child	-4.5	0.18	-11.1 to 2.1
Other	2.7	0.39	-3.6 to 9.1
Religiosity	1.6	0.24	-1.1 to 4.2
Trust in patient's physician	-0.85	0.04	-1.7 to -0.04
Receiving prognostic information in numbers	-9.2	0.001	-14.5 to -3.8