Original Investigation | CARING FOR THE CRITICALLY ILL PATIENT

# Prevalence of and Factors Related to Discordance About Prognosis Between Physicians and Surrogate Decision Makers of Critically Ill Patients

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**IMPORTANCE** Misperceptions about prognosis by individuals making decisions for incapacitated critically ill patients (surrogates) are common and often attributed to poor comprehension of medical information.

**OBJECTIVE** To determine the prevalence of and factors related to physician-surrogate discordance about prognosis in intensive care units (ICUs).

**DESIGN, SETTING, AND PARTICIPANTS** Mixed-methods study comprising quantitative surveys and qualitative interviews conducted in 4 ICUs at a major US medical center involving surrogate decision makers and physicians caring for patients at high risk of death from January 4, 2005, to July 10, 2009.

**MAIN OUTCOMES AND MEASURES** Discordance about prognosis, defined as a difference between a physician's and a surrogate's prognostic estimates of at least 20%; misunderstandings by surrogates (defined as any difference between a physician's prognostic estimate and a surrogate's best guess of that estimate); differences in belief (any difference between a surrogate's actual estimate and their best guess of the physician's estimate).

**RESULTS** Two hundred twenty-nine surrogate decision makers (median age, 47 [interquartile range {IQR}, 35-56] years; 68% women) and 99 physicians were involved in the care of 174 critically ill patients (median age, 60 [IQR, 47-74] years; 44% women). Physician-surrogate discordance about prognosis occurred in 122 of 229 instances (53%; 95% CI, 46.8%-59.7%). In 65 instances (28%), discordance was related to both misunderstandings by surrogates and differences in belief about the patient's prognosis; 38 (17%) were related to misunderstandings by surrogates only; 7 (3%) were related to differences in belief only; and data were missing for 12. Seventy-five patients (43%) died. Surrogates' prognostic estimates were much more accurate than chance alone, but physicians' prognostic estimates were statistically significantly more accurate than surrogates' (C statistic, 0.83 vs 0.74; absolute difference, 0.094; 95% CI, 0.024-0.163; $P = .008$). Among 71 surrogates interviewed who had beliefs about the prognosis that were more optimistic than that of the physician, the most common reasons for optimism were a need to maintain hope to benefit the patient (n = 34), a belief that the patient had unique strengths unknown to the physician (n = 24), and religious belief (n = 19).

**CONCLUSIONS AND RELEVANCE** Among critically ill patients, discordant expectations about prognosis were common between patients' physicians and surrogate decision makers and were related to misunderstandings by surrogates about physicians' assessments of patients' prognoses and differences in beliefs about patients' prognoses.

*JAMA*. 2016;315(19):2086-2094. doi:10.1001/jama.2016.5351

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In 2010, it was estimated that nearly half of US adults near the end of life were unable to make decisions for themselves about whether to accept life-prolonging technologies.[1] Family members or other individuals are asked to serve as surrogate decision makers for these often difficult decisions. To effectively function in this role, surrogates require a clear understanding of the likely outcomes of treatment. Numerous studies over the last 3 decades indicate that surrogates of patients with advanced illness often have optimistic expectations about prognosis.[2-4] This is problematic because optimistic expectations are associated with more use of invasive treatments in dying patients and delayed integration of palliative care.[5-7] Clinicians cite unrealistic expectations by surrogates as one of the most important barriers to high-quality end-of-life care in seriously ill patients.[8]

Although misperceptions about prognosis by surrogates are well documented, an important barrier to progress is the lack of a clear understanding of the causes of these misperceptions. The conventional assumption is that surrogates' inaccurate expectations arise from misunderstandings of physicians' assessments of prognosis.[3,9] However, insights from decision psychology suggest that other mechanisms may plausibly influence individuals' risk perceptions, such as optimism biases and alternative value systems that lead surrogates to have beliefs about prognosis that differ from physicians'. Several small qualitative and simulation-based studies among surrogates in intensive care units (ICUs) suggest that such considerations may contribute to physician-surrogate discordance about prognosis,[7,10-12] but these hypotheses have not been empirically validated in surrogates making actual decisions for incapacitated patients. Without clarity about factors that contribute to discordance, it will be difficult to design interventions targeting the key barriers to effective conversations about prognosis.

We therefore sought to quantitatively determine the prevalence of physician-surrogate discordance about prognosis and to qualitatively understand reasons that surrogates sometimes hold beliefs about prognosis that differ from physicians' assessments.

## Methods

We conducted a study combining quantitative measurement of physicians' and surrogates' perceptions of prognosis with qualitative interviews ("mixed methods") to explore what factors were related to surrogates' perceptions of patient prognosis. We enrolled surrogate decision makers for incapacitated patients at high risk of death in 4 ICUs at the University of California, San Francisco Medical Center from January 4, 2005, to July 10, 2009. The ICUs included 2 medical-surgical ICUs, a neurological ICU, and a cardiac ICU. Patients were eligible if they were aged 18 years or older, lacked decision-making capacity on day 5 of their ICU stay, had respiratory failure requiring mechanical ventilation, and had an Acute Physiology and Chronic Health Evaluation (APACHE) II score of 25 or higher, which predicts a roughly 40% risk of in-hospital mortality.[13] Patients were excluded if they were awaiting organ transplantation or if they lacked a surrogate decision maker.

After obtaining permission from patients' attending physicians, research staff approached the patients' surrogates about study participation. If the responsibility for surrogate decision making was shared between multiple individuals, we enrolled those who self-reported having a significant amount of responsibility for decision making. Thus, more than 1 surrogate per patient could be enrolled. All participating surrogates and physicians provided written informed consent; surrogates provided proxy written consent for incapacitated patients. The institutional review board approved all study procedures.

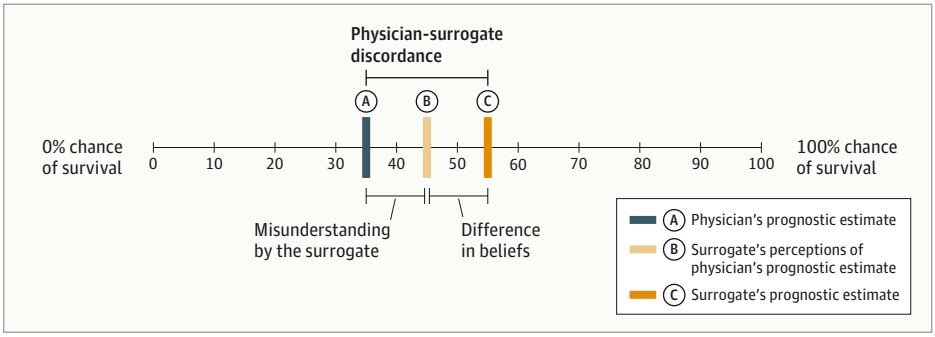
### Study Procedures

On a patient's fifth day of receiving mechanical ventilation, physicians estimated the likelihood that the patient would survive the hospitalization using a previously validated question and a 0% to 100% scale: "What do you think are the chances that the patient will survive this hospitalization if the current plan of care stays the same?"[10,14,15] Within 1 hour, surrogates independently answered the same question on the same 0% to 100% probability scale, blinded to the physician's response. The study did not mandate or facilitate physician-surrogate conversations about prognosis prior to asking these questions, but the near simultaneity of measures minimized the possibility that changes in a patient's condition could contribute to differences in physician-surrogate estimates. Surrogates were also asked to record what they perceived to be the physician's assessment of prognosis with the question "If you had to guess, what do you think the doctor thinks is the chance that your loved one will survive this hospitalization if the current plan of care stays the same?" A standard probability scale was used to record participants' prognostic estimates, with the anchors comprising simple expressions of risk ("0% chance of survival"; "100% chance of survival") to minimize the chance of response errors among study participants with limited numeracy (**Figure 1**).[16-18] Race and ethnicity information was collected by self-report from participants. The eAppendix in the Supplement contains a description of other covariates included in the questionnaire.

### Semistructured Interviews

An interviewer blinded to physicians' prognostic estimates conducted one-on-one, semistructured interviews with surrogates immediately after they completed the questionnaire. The interviewer showed each participant his/her responses to the 2 questions about prognosis (ie, "What do you think are the chances that your loved one will survive ...?" and "What do you think the doctor thinks are the chances that the patient will survive ...?"). Next, the interviewer read the following standardized prompt: "Please take a moment to look at your responses. I notice that what you think is the patient's prognosis [differs from/is the same as] what you think the physician thinks is the prognosis. Can you tell me a little bit about this?" The interviewer used techniques of cognitive

Figure 1. Probability Scale Used to Record Study Participants' Prognostic Estimates of Patients' Survival to Hospital Discharge and Example Responses




Physicians (A) and surrogates (C) independently recorded their estimates of the patient's chances of survival to hospital discharge in response to the question "What do you think are the chances that the patient/your loved one will survive this hospitalization if the current plan of care stays the same?" Surrogates also recorded their perceptions of the physician's prognostic estimate (B). Not all surrogates and physicians reported that a conversation about prognosis had occurred and therefore, some surrogates had no explicit prognostic information from physicians on which to base their estimates. Physician-surrogate discordance was defined as physician-surrogate differences of at least 20% (difference between A and C). Differences of any magnitude between the surrogate's prognostic estimate (C) and the surrogate's perceptions of the physician's prognostic estimate (B) were classified as differences in belief. Differences of any magnitude between the physician's prognostic estimate (A) and the surrogate's perceptions of the physician's prognostic estimate (B) were classified as surrogate misunderstandings.

interviewing[19] and standardized probes to pursue and clarify emergent themes as they arose. The content of the semistructured interview was expanded over time to pursue and clarify themes that emerged in prior interviews.[19-21]

## Quantitative Analyses

We defined physician-surrogate discordance about prognosis as at least a 20% difference between the physician's and surrogate's prognostic estimates based on a modified time-trade-off experiment in patients with serious illness in which patients' willingness to receive ongoing life support declined substantially when their prognosis worsened by 20%.[22] We categorized surrogates' estimates as discordant pessimistic (prognostic estimate at least 20% lower than physician's) or discordant optimistic (prognostic estimate at least 20% higher than physician's) Among cases with physician-surrogate discordance about prognosis, we quantified the proportion due to misunderstandings by surrogates (any difference between the physician's prognostic estimate and the surrogate's best guess about that estimate) and the proportion due to differences in belief (any difference between the surrogate's prognostic estimate and their best guess about the physician's estimate) (Figure 1).

We reviewed the medical record to determine hospital survival and compared the accuracy of physicians' and surrogates' prognostic estimates by comparing the area under the receiver operating characteristic curves generated using mixed-effects regression models with patients nested within surrogates within physicians, patient mortality as a dependent variable, surrogate and physician survival estimates as independent variables, and physician as a random intercept (see the eAppendix in the Supplement for additional details).[23] We used Stata version 14.0 (Stata Corp) for all quantitative analyses and considered as statistically significant a 2-sided $\alpha<.05$.

We estimated that a sample size of 229 surrogates would be required to detect a prevalence of physician-surrogate discordance of 50% (based on the prevalence observed in a prior study in France[2,24]) with a confidence interval range (upper to lower bound) of less than 15%, assuming statistical power of 80% and a 2-sided $\alpha = .05$.

## Qualitative Analyses

A medical transcriptionist transcribed the audiorecorded interviews verbatim. We used constant comparative methods to inductively develop a framework to describe participants' reasons for the congruence or incongruence of their prognostic estimates with what they believed to be the physician's prognostic estimates. Constant comparative methods are a general method for inductively analyzing systematically gathered qualitative data. The method is most useful when existing conceptual frameworks for the topics under study are inadequate.[19-21]

To develop the preliminary coding scheme, 4 investigators independently coded a subset of transcripts line by line. As themes and concepts accumulated, we refined distinctions between concepts and grouped similar concepts into conceptual categories. These categories were developed further by comparing transcripts. Through a series of meetings, investigators arrived at consensus on the final coding framework (see the eAppendix in the Supplement for additional details).

Two investigators blinded to participants' demographic characteristics and each other's work listened to the audiotapes, read the transcripts, and coded all interviews using the final coding framework. The mean $\kappa$ statistic based on a random sample of 20% of interviews was 0.86 (range, 0.71-1.00), indicating excellent interrater reliability.[25] All discrepancies between coders were reviewed and resolved through dialogue between the coders and the first author.

To ensure coding validity,[26,27] we used a multidisciplinary approach in developing the framework, which reduced the chance that individual bias threatened the validity of the findings, and we presented the preliminary findings to a sample of study participants for confirmation and/or modification, a process known as member checking. There was strong support for the framework among participants and no new themes were raised during the process of member checking.

## Results

### Patient and Participant Characteristics

Of 222 eligible physician-patient dyads, 174 (79%) agreed to participate; 20 (9%) attending physicians and 27 (12%) families declined to participate. There were no important differences between enrolled and nonenrolled patients in demographic characteristics, admission diagnosis, or severity of illness. Forty patients had more than 1 surrogate (median number of surrogates, 1 [interquartile range {IQR}, 1-1; range, 1-5] per family). Restricting the analyses to 1 surrogate per patient did not change the findings; therefore, we report data from all surrogates.

Demographic characteristics of the patients, surrogate decision makers, and physicians are shown in **Table 1**, **Table 2**, and **Table 3**, respectively. The sample was diverse in terms of sex, race, ethnicity, religious affiliation, and level of education. At enrollment, patients had a median APACHE II score of 28 (IQR, 26-32) and 75 patients (43%) died in the hospital. The median time between surrogate participation and patient death was 7 days (IQR, 3-21 days). A conversation about prognosis by day 5 of mechanical ventilation was reported by 183 surrogates (80%), 199 physicians (87%), and 213 (93%) of either.

### Physician-Surrogate Discordance

Physician-surrogate discordance about prognosis occurred in 122 of 229 instances (53%; 95% CI, 46.8%-59.7%). Among the 229 surrogates participating in the study, 98 (43%) were more optimistic than physicians and 24 (10%) were more pessimistic. Sixty-five instances (28%) were related to a combination of misunderstandings by surrogates and differences in belief between the physician and surrogate about the patient's prognosis; 38 (17%) were related to misunderstanding only; 7 (3%) were related to different beliefs; and data were missing for 12.

### Accuracy of Physicians' and Surrogates' Prognostic Estimates

Surrogates' estimates of prognosis were much more accurate than random guessing, but physicians' estimates were statistically significantly more accurate than surrogates' (C statistic, 0.83 vs 0.74, respectively; absolute difference, 0.094; 95% CI, 0.024-0.163; $P$ = .008) (**Figure 2**).

### Surrogates' Explanations for Optimism and Pessimism

Seventy-one of 156 surrogates who participated in the semi-structured interview were more optimistic than physicians. Three main themes emerged from the interviews about why surrogates held beliefs about a patient's prognosis that were more optimistic than what they perceived to be the physician's prognostic estimate (**Table 4**). First, some surrogates (n = 34) believed that maintaining optimism would improve the patient's outcomes or protect themselves from emotional distress. One surrogate said "I really believe in good vibrations .... So I think if we put everything that is in our power to have good vibrations ... we might be able to help him with that." Another surrogate explained "I'm told to always think positive and so I'm kinda trying to make myself feel better."

Second, some surrogates (n = 24) expressed a belief that the patient has unique strengths unknown to the physician. For example, one surrogate of a 63-year-old man in respiratory failure explained "I know him personally. The doctors

**Table 1. Patient Characteristics**

| Characteristics | Patients, No. (%) (n = 174)[a] |
|---|---|
| Women | 77 (44) |
| Age, median (IQR), y | 60 (47-74) |
| Race and ethnicity | |
| Non-Hispanic white | 98 (56) |
| Asian or Pacific Islander | 36 (21) |
| Hispanic | 20 (11) |
| Non-Hispanic black | 16 (9) |
| Multiethnic | 4 (2) |
| Admission diagnosis | |
| Respiratory failure | 48 (28) |
| Neurological failure | 46 (26) |
| Cardiac failure or shock (including sepsis) | 43 (25) |
| Gastrointestinal failure (including pancreatitis) | 14 (8) |
| Hepatic failure | 13 (7) |
| Metastatic cancer | 7 (4) |
| Renal failure | 3 (2) |
| Enrolled surrogates per patient | |
| 1 | 134 (77) |
| 2 | 28 (16) |
| 3 | 10 (6) |
| 4 | 1 (0.5) |
| 5 | 1 (0.5) |
| APACHE II score, median (IQR)[b] | |
| Day 0 | 29 (27-32) |
| Day 5 | 28 (26-32) |
| Hospital mortality | 75 (43) |
| Patients who died in the hospital (n = 75) | |
| Death in ICU | 67 (89) |
| Life support withdrawn | 66 (88) |
| Duration of hospitalization, median (IQR), d | 17.5 (9-28) |
| Duration of ICU stay, median (IQR), d | 8 (4-19) |
| Time from study eligibility to death, median (IQR), d | 9 (5-21) |
| Duration of mechanical ventilation, median (IQR), d | 8 (4-18) |

Abbreviations: ICU, intensive care unit; IQR, interquartile range.

[a] Data are No. (%) of patients unless otherwise indicated.

[b] The Acute Physiology and Chronic Health Evaluation (APACHE) II provides a general measure of severity of disease. Scores range from 0 to 71, with higher scores indicating higher severity.

Table 2. Surrogate Decision Maker Characteristics

| Characteristics | Surrogates, No. (%) (n = 229)[a] |
|---|---|
| Women | 156 (68) |
| Age, median (IQR), y | 47 (35-56) |
| Race and ethnicity | |
| Non-Hispanic white | 130 (57) |
| Asian or Pacific Islander | 37 (16) |
| Hispanic | 33 (14.5) |
| Non-Hispanic black | 22 (10) |
| Native American | 1 (0.5) |
| Multiethnic | 4 (2) |
| Declined response | 2 (1) |
| Relationship to patient | |
| Child | 86 (38) |
| Spouse or partner | 57 (25) |
| Other relative | 29 (13) |
| Parent | 24 (10) |
| Sibling | 24 (10) |
| Other | 9 (4) |
| Level of education | |
| Some high school or less | 15 (6.5) |
| High school graduate or GED | 44 (19) |
| Some college or technical school | 77 (34) |
| 4-y college graduate | 46 (20) |
| Graduate or professional school or graduate degree | 46 (20) |
| Declined response | 1 (0.5) |
| Primary language | |
| English | 185 (81) |
| Spanish | 17 (7.5) |
| Chinese (Mandarin or Cantonese) | 10 (4) |
| Tagalog | 8 (3.5) |
| Other | 9 (4) |
| Religious preference | |
| Catholic | 75 (33) |
| None, agnostic, or atheist | 46 (20) |
| Protestant | 44 (19) |
| Other Christian | 33 (14) |
| Other | 12 (5) |
| Declined response | 19 (8) |
| Importance of religion or spiritual beliefs in everyday life[b] | |
| Very important | 101 (44) |
| Fairly important | 56 (25) |
| Not too important | 37 (16) |
| Not at all important | 16 (7) |
| Declined response | 19 (8) |
| Health literacy score, median (IQR)[c] | 35 (34-36) |
| Trust in physicians score, median (IQR)[d] | 19 (18-21) |
| Perceived quality of communication score, median (IQR)[e] | |
| General communication | 9.2 (8-9.8) |
| Communication about end-of-life care | 5.9 (3.3-7.6) |
| Depression screening score, mean (SD)[f] | 3.4 (1.7) |

Abbreviations: ICU, intensive care unit; IQR, interquartile range.

[a] Data are No. (%) of surrogates unless otherwise indicated.

[b] Characterized using the Brief Multidimensional Measure of Religiousness or Spirituality (1 = not at all important; 2 = not too important; 3 = fairly important; 4 = very important).

[c] Measured using the Short Test of Functional Health Literacy in Adults. Scores range from 0 to 36, with higher scores indicating higher health literacy.

[d] Measured using the Wake Forest Scales Measuring Trust. Scores range from 1 to 25, with higher scores indicating more trust.

[e] Measured using the 17-item Scale for Clinician-Family Communication in ICUs. Scores range from 0 to 10, with higher scores indicating better communication.

[f] Assessed using the Patient Health Questionnaire 2. Scores range from 0 to 6, with higher scores indicating more potential for depression.

Table 3. Physician Characteristics

| Characteristics | Physicians, No. (%) (n = 96)[a] |
|---|---|
| Women | 36 (37.5) |
| Age, median (IQR), y | 40 (35-48) |
| Race | |
| Non-Hispanic white | 63 (66) |
| Asian or Pacific Islander | 25 (26) |
| Hispanic | 4 (4) |
| Non-Hispanic black | 1 (1) |
| Multiethnic | 2 (2) |
| Declined response | 1 (1) |
| Religious preference | |
| None, agnostic, or atheist | 31 (32) |
| Christian | 22 (23) |
| Jewish | 19 (20) |
| Other | 9 (9) |
| Declined response | 15 (16) |
| Importance of religion or spiritual beliefs in everyday life[b] | |
| Very important | 11 (11) |
| Fairly important | 17 (18) |
| Not too important | 38 (40) |
| Not at all important | 27 (28) |
| Declined response | 3 (3) |
| Staff position | |
| Attending physician | 93 (97) |
| Resident or fellow | 3 (3) |
| Medical specialty | |
| Internal medicine (includes cardiology, hepatology, and liver transplantation) | 55 (57) |
| Surgery (including oral/maxillofacial, neurosurgery, and orthopedic) | 21 (22) |
| Neurology | 15 (16) |
| Anesthesia | 4 (4) |
| Other | 2 (2) |
| Years in practice, median (IQR) | 8.5 (4.75-14) |
| Self-assessed skill in discussing prognosis, median (IQR)[c] | 8 (7-9) |

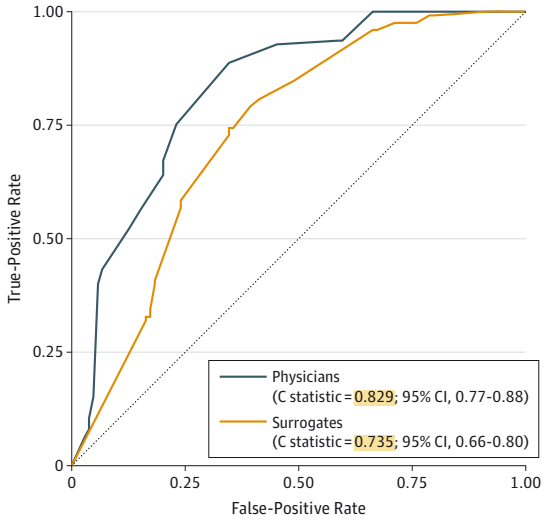
Abbreviation: IQR, interquartile range.

[a] Data are No. (%) of physicians unless otherwise indicated. Three physicians did not complete the demographic information questionnaire.

[b] Characterized using the Brief Multidimensional Measure of Religiousness or Spirituality (1 = not at all important; 2 = not too important; 3 = fairly important; 4 = very important).

[c] Measured on a 0- to 10-point Likert scale, with higher scores indicating being more skilled.

Figure 2. Receiver Operating Characteristic Curves for Accuracy of Prognostic Estimates of Patient Survival to Hospital Discharge




On the patient's fifth day of mechanical ventilation, surrogates and physicians independently estimated the probability that the patient would survive the hospitalization (on a 0%-100% scale). Receiver operating characteristic curves were generated using mixed-effects regression models with patients nested within surrogates within physicians, patient mortality as a dependent variable, surrogate and physician survival estimates as independent variables, and physician as a random intercept (see eAppendix in the Supplement for additional details). The dotted diagonal line represents no predictive power. The prognostic accuracy of physicians was superior to that of surrogates ($P$ = .008).

don't know him personally, don't know his will to live and his will power and how strong he is and his family history."

Third, some surrogates (n = 19) explained that their optimism was grounded in their religious beliefs. For example, one surrogate said "I really believe whether someone can live or not is up to God. If God wants someone to heal, even though the doctor thinks it's impossible, I think someone can recover."

Surrogates cited several reasons for holding a more pessimistic belief about a patient's prognosis than what they understood to be the physician's estimate (Table 4). The most common reason was a belief that the physician was intrinsically optimistic. A second reason was the physician's lack of knowledge of the patient's unique attributes that negatively affected their prognosis, such as the patient's weak physical baseline or loss of will to live. Additional reasons included a belief that the physician's judgment was clouded by emotional investment in the patient and that the surrogate needed to be pessimistic to brace or prepare themselves for the possibility of the patient's death.

## Discussion

Among a diverse cohort of critically ill patients at high risk of death, we found a high prevalence of physician-surrogate discordance about prognosis. The discordance was associated with both misunderstandings by surrogates of physicians' assessment of prognosis and by surrogates holding different beliefs about a patient's prognosis compared with what they perceived to be the physician's assessment of prognosis. The findings suggest that interventions are needed not only to improve the comprehensibility of prognostic information but also to attend to the emotional and psychological factors that influence surrogates' prognostic expectations.

Four empirical studies have addressed reasons for physician-surrogate discordance about prognosis in ICUs[10-12,28] (eAppendix in the Supplement). Two small studies using hypothetical vignettes found that surrogates' misperceptions

Table 4. Reasons for Overly Optimistic or Overly Pessimistic Prognostic Estimates by Surrogates

| Reason | Exemplar |
|---|---|
| Overly optimistic expectations | |
| Surrogate believes the patient has unique strengths unknown to the physician | "I feel that my brother's a fighter and I know him more than what the doctor do. And when you don't know a person, it's pretty much, 'This is what I read in a book.' And I'm not reading from no book. I'm reading from experience. I think I know my brother a little bit better."<br>"I don't think they know her … these people, I think they've just met her for the first time. And I think they have to be as honest as they can with what information that they have. It's hard for them to know how well she can respond, unless you've actually been with her through other illnesses. We can just guess all we want, but from her response to her illnesses before, she's been OK." |
| Surrogate has a need to maintain hope for their own benefit or for the patient's benefit | "It goes off of purely me trying to have a positive outlook. I almost feel like if I circle 50%, then it may come true. If I circle 50%, then I'm not putting all my positive energy towards my dad." |
| Optimism grounded in religious beliefs | "I believe the doctor would only believe what he can do for my son. But I believe what he can do and what God can do."<br>"Probably would be the feeling of our association with God and the fact that we believe in prayer. We believe in miracles." |
| Surrogate believes the physician is dispositionally pessimistic | "Just in my dealings with physicians, in the last 10 years or so, I would say I don't see a lot of optimism any more in the medical professions, in general. They're not very overt in the way that they present it. They're very guarded in their emotions."<br>"Maybe they've seen more people die than I have … well, I just know that when you are around something a lot more, you become desensitized to it as a result. So that's really what I mean by being a little less invested." |
| Overly pessimistic expectations | |
| Surrogate has a need to be pessimistic for his/her own benefit | "Maybe I'm just trying to protect myself. I'm trying to stay at that baseline, so that I'm not completely surprised if it doesn't go well. So I'm trying not to get too excited or … optimistic about anything, because I don't have the information."<br>"I think if I estimate less and he'll survive, it will be even better than to estimate more and then to be disappointed … It's better to have worse expectation now. If he survives, then it will be even better … so we will be very happy. If otherwise, we will think that he will survive … and then it will be the opposite, so we will be very upset. So, it's better to think this way, for me." |
| Surrogate believes the patient has weaknesses unknown to the physician | "I guess my difference is, I don't know if [he] wants it, my brother. I don't know how much fight he's got left in him."<br>"He's [the physician] more optimistic than I am because he's not fully aware of her medical problems from throughout the years, the last dozen years or so and I am … so, they're being a little more optimistic about it, right now, than I am. Only because I know her better." |
| Surrogate believes the physician is dispositionally optimistic | "I think that doctors, and particularly certain types of doctors, can tend to be a little overoptimistic. Say, for example, surgeons, they don't emphasize the possible down sides and risks of a procedure."<br>"For being a doctor, I think you have to be optimistic. If the doctor is not optimistic, then what are the family members gonna think about him? They're doing this job to save the patient." |

about prognosis arose in part from optimistic biases rather than only from misunderstandings.[10,12] Two studies using in-depth interviews of small numbers of surrogates found that surrogates' religious beliefs, a need to maintain hope, and skepticism about physicians' prognostic accuracy contributed to differences in beliefs about prognosis between physicians and surrogates.[11,28] The limitations of these studies are that they involved small sample sizes and hypothetical cases and did not simultaneously provide quantitative estimates of misperceptions about prognosis and qualitative insights about the factors that contributed to those misperceptions. The present study overcomes these limitations to demonstrate that in actual cases in ICUs, both misunderstandings by surrogates of physicians' prognostications as well as differences in belief about patients' prognoses contribute to physician-surrogate discordance about prognosis.

The pattern of our findings fits with insights from social psychology about biases in individuals' risk perceptions. One such insight, termed the better-than-average effect, refers to the tendency of individuals to rate themselves as likely to have better outcomes than most others.[29] Our results may in part be explained by a similar phenomenon. If so, our findings suggest that this bias is not limited to individuals predicting their own outcomes but also extends to individuals predicting outcomes of their loved ones.

A noteworthy finding from our semistructured interviews is that some surrogates intentionally held overly optimistic prognostic estimates with the hope that doing so would improve the patient's outcome. This phenomenon has previously been described as performative optimism, which is the belief that by thinking optimistic thoughts, an individual may influence their (or others') likelihood of experiencing a positive outcome. Sulmasy et al[30] found that 36 of 45 research participants explained their optimistic expectations regarding phase 1 trial participation in terms of believing that maintaining an optimistic attitude would improve their outcomes.

Should clinicians and policy makers be concerned that a large proportion of surrogates in ICUs hold overly optimistic expectations about prognosis? In one view, it is encouraging that the accuracy of surrogates' prognostic estimates was substantially better than chance alone and comparable with the accuracy of many accepted clinical risk prediction models. However, surrogates' expectations differed substantially from physicians', and physicians' predictions were statistically significantly more accurate. This finding raises concerns that one of the fundamental assumptions of shared decision making—agreement between parties about the likely outcomes of treatment—is often not achieved.[31]

Another concern is that the prevalent optimism among surrogates may lead to overuse of expensive, life-prolonging treatments in dying patients and underuse of palliative treatments. This concern is supported by a series of studies indicating that individuals' willingness to undergo intensive treatment near the end of life is strongly influenced by the

likely outcomes. For example, among a cohort of seriously ill outpatients, Fried et al[32] found that as the likelihood of successful treatment declined, so too did individuals' willingness to undergo intensive treatment. Among a cohort of patients with advanced dementia, Mitchell et al[5] found that patients with surrogates who had accurate expectations of the patients' prognoses were less likely to receive invasive treatments near the end of life. Among parents of children with incurable cancer, Wolfe et al[6] found that parents with accurate expectations about incurability of the cancer focused treatment more on lessening discomfort and integrating palliative care compared with those who had delayed recognition of the child's poor prognosis.

There are at least 2 clinical implications of our findings. First, given the high rates of discordance about prognosis, clinicians communicating with surrogates of patients with advanced critical illness should routinely check in with surrogates about their perceptions of prognosis prior to engaging in decision making about goals of care. Second, when clinicians recognize that surrogates' expectations about prognosis diverge from their own, they should explore the possibility that causes other than misunderstanding may be contributing, such as a belief that the patient is stronger than average, a belief that expressing optimism will improve the patient's outcome, or a belief that religious rather than biomedical considerations will determine the patient's outcome. This is important because interventions to reconcile discordance about prognosis may differ for misunderstandings compared with differences in belief. Our findings raise the possibility that standard informational interventions such as decision aids may be insufficient because they do not attend to the emotional and psychological sources of optimism that influence surrogates' prognostic expectations.

This study has several strengths. First, we used a mixed-methods approach, which allowed for both quantification of discordance and qualitative exploration of the reasons behind surrogates' beliefs. We validated our qualitative findings through a process of member checking in which we returned the results to research participants for their review and comment. The study was conducted in a large and diverse cohort. Additionally, we interviewed actual surrogates facing actual decisions rather than using simulation, which established the clinical relevance of our findings.

This study also has several limitations. Although we recruited a diverse cohort, our sample was limited to one region of the country, which may not account for some geographic or cultural factors. An inherent limitation of using interviews to understand what influences individuals is that it only allows for identification of beliefs of which individuals have conscious awareness and are willing to express, and we cannot exclude that processes surrogates were not conscious of or were unwilling to discuss may also have contributed.

## Conclusions

Among critically ill patients receiving care in ICUs, discordant expectations about prognosis were common between patients' physicians and surrogate decision makers and were related to both misunderstandings by surrogates about physicians' assessments of patients' prognoses and differences in beliefs about patients' prognoses.


### ARTICLE INFORMATION

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**Conflict of Interest Disclosures:** All authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest and none were reported.

**Funding/Support:** This project was supported by National Institutes of Health grants KL2 RR024130 and R01 HL094553 and by the Greenwall Foundation (Dr White).

**Role of the Funders/Sponsors:** The funders had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; or decision to submit the manuscript for publication.

**Additional Contributions:** We thank Leslie Scheunemann, MD, MPH (University of Pittsburgh School of Medicine; Pittsburgh, Pennsylvania), for assistance in preparing the systematic review summarized in the Discussion section. We thank the following individuals for assistance with data collection and coding of interviews with surrogates: Elizabeth Boyd, PhD, University of California, Berkeley; Leah Evans-Wong, MD, University of Massachusetts Medical School, Worcester; and Grave L. Malvar, MD, Beth Israel Deaconess Medical Center and Harvard Medical School, Boston, Massachusetts. No financial compensation was received.



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