

Hope, Truth, and Preparing for Death: Perspectives of Surrogate Decision Makers

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Background: Although many physicians worry that openly discussing a poor prognosis will cause patients and families to lose hope, surrogate decision makers' perspectives on this topic are largely unknown.

Objective: To determine surrogate decision makers' attitudes toward balancing hope and telling the truth when discussing prognosis.

Design: Prospective, mixed-methods cohort study.

Setting: 4 intensive care units at the University of California, San Francisco, Medical Center, San Francisco, California.

Participants: 179 surrogate decision makers for incapacitated patients at high risk for death.

Measurements: One-on-one, semistructured interviews with surrogates were conducted on the patients' 5th day of receiving mechanical ventilation. Constant comparative methods were used to inductively develop a framework to describe participants' responses. Validation methods included multidisciplinary analysis and member checking.

Results: Overall, 93% (166 of 179) of surrogates felt that avoiding discussions about prognosis is an unacceptable way to maintain hope. The main explanatory theme was that timely discussion of

prognosis is essential to allow family members to prepare emotionally and logistically for the possibility of a patient's death. Other themes that emerged included surrogates' belief that an accurate understanding of a patient's prognosis allows them to better support the patient and each other, a moral aversion to the idea of false hope, the perception that physicians have an obligation to discuss prognosis, and the notion that some surrogates look to physicians primarily for truth and seek hope elsewhere. A few surrogates (6 of 179) felt that physicians should withhold prognostic information because of a belief that discussing death could be emotionally damaging to the family or could negatively affect the patient's health.

Limitation: The authors did not longitudinally assess whether early disclosure about prognosis predicts fewer adverse bereavement outcomes.

Conclusion: Most surrogates of critically ill patients do not view withholding prognostic information as an acceptable way to maintain hope, largely because timely discussions about prognosis help families begin to prepare emotionally, existentially, and practically for the possibility that a patient will die.

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Discussing prognosis is a challenging task for physicians, both because the news of a poor prognosis is emotionally difficult (1) and also because there is considerable prognostic uncertainty for many illnesses and for most individual, seriously ill patients (2). Physicians often rely on clinical experience and judgment in formulating prognostic estimates (3). Previous research suggests that 90% of physicians are reluctant to provide specific prognostic information, 75% shade their prognostic estimates to be more optimistic than they believe are true, and 44% wait to be asked before discussing prognosis (1, 4). Research on audiotaped clinician-family conferences in intensive care units confirms that physicians frequently omit important prognostic information from discussions or use vague language when discussing prognosis (3, 5). Christakis (6) found that 1 reason for physicians' reluctance is a concern that their words may extinguish patients' and families' sense of hope; these physicians perceive the act of non-disclosure to be a humane attempt to minimize suffering.

When patients are suddenly incapacitated by severe illness, physicians turn to surrogate decision makers for guidance about setting goals of care and making decisions to limit life-sustaining treatment (7, 8). Families report that the surrogate decision-making process is often problematic and poses substantial emotional burdens (9-12).

Conflict about these decisions is common within families and between the family and the health care team (13, 14). Although several empirical studies in oncology have addressed the attitudes of patients on the topic of hope and telling the truth about prognosis (4, 15-17), no studies have focused on the perspective of family members who act as surrogate decision makers. Specifically, it is unknown whether surrogates share physicians' perceptions that discussing a poor prognosis may extinguish hope. In addition, little is known about the ways that surrogates use prognostic information or why possessing such information might be important to them.

These gaps in knowledge hinder the development of empirically derived interventions to improve surrogate decision making and the support of family members of pa-

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Context

Physicians caring for critically ill patients are often reluctant to discuss poor prognoses with family members.

Contribution

Family members interviewed in this study believed that physicians should not withhold information about poor prognosis as a way of preserving their hope.

Caution

The study did not assess psychological outcomes of family members who did and did not receive the prognostic information they said they wanted.

Implication

Physicians should not withhold information about poor prognosis solely to preserve family members' hope.

—The Editors

tients who will probably die. We conducted this study to determine the attitudes of a diverse group of surrogate decision makers toward balancing hope and telling the truth in the care of seriously ill patients at high risk for death.

METHODS**Design, Patients, and Setting**

From January 2006 to October 2007, we conducted face-to-face, semistructured interviews with surrogate decision makers in a prospectively defined cohort of critically ill patients at high risk for death in 4 intensive care units at the University of California, San Francisco, Medical Center, San Francisco, California. The intensive care units (ICUs) included 2 medical-surgical ICUs, a neurologic ICU, and a cardiac ICU. Inclusion criteria for patients were age older than 18 years, respiratory failure requiring mechanical ventilation, lack of decision-making capacity, and an Acute Physiology and Chronic Health Evaluation II score greater than 25 (predicting in-hospital death of at least 40%). All interviews took place between days 3 and 5 of the patients' mechanical ventilation.

Eligible participants were at least 18 years of age, spoke English well enough not to require the use of an interpreter, and were self-identified as a surrogate decision maker for the patient. If the responsibility for surrogate decision making was shared among family members, we enrolled those who self-reported having the most responsibility for decision making. Thus, more than 1 participant per patient could be enrolled. Study investigators identified eligible surrogates by screening daily in each ICU. Before approaching potential participants, we obtained permission from the patient's attending physician to do so. All participants provided written consent to participate in the study. The institutional review board at University of California, San Francisco, approved all study procedures.

Surrogates who agreed to participate completed a demographic characteristic questionnaire and participated in a 30-minute, one-on-one, semistructured interview, which was audiotaped and then transcribed. The interview focused on surrogates' attitudes about discussing prognosis in ICUs. The current report focuses on their responses to the following prompt and question: "Some physicians are reluctant to discuss news of a poor prognosis with family members of a critically ill patient because they do not want to take away the families' hope. Do you think physicians should avoid discussing prognosis in order to maintain hope?" We began the interview with a closed-ended question to focus participants on the question of whether non-disclosure about prognosis is an acceptable way to maintain hope. The interviewer followed up participants' responses with open-ended questions to understand the reasons for their choice, pursued themes as they occurred, and sought clarification or elaboration as interviews progressed. All interviews were conducted by 1 interviewer who was trained in techniques of cognitive interviewing. As part of the iterative approach to data collection that is central to qualitative research, the content of the semistructured interview was expanded over time to pursue and clarify themes that emerged in previous interviews (18–20).

Qualitative Data Coding

A medical transcriptionist transcribed the audiotaped interviews verbatim. We used constant comparative methods to inductively develop a framework to describe participants' attitudes about discussing prognosis. Constant comparative methods are a general methodology for inductively analyzing systematically gathered, qualitative data. The method is most useful when existing conceptual frameworks for the topics under study are inadequate (18–20).

To develop the preliminary coding scheme, 4 investigators independently coded a subset of transcripts line by line. We identified recurrent themes relating to surrogates' attitudes about disclosure of prognostic information and maintaining hope. As themes and concepts accumulated, we refined distinctions between concepts and then grouped similar concepts into conceptual categories. We developed these categories further by comparing across transcripts. All investigators collaborated on developing the preliminary framework and, through a series of investigator meetings, arrived at consensus on the final coding framework. We modified the framework iteratively during the study period as interviews yielded new insights.

Reliability of the Coding

Using the final coding framework, 2 investigators independently coded all 179 interviews by listening to the audiotapes and reading the transcripts. We blinded both coders to the demographic characteristics of the participants and to one another's coding. To assess intercoder reliability, we calculated a κ statistic on a random sample

of 20% of the interviews. The average κ statistic for identifying individual themes within an interview was 0.86 (range, 0.71 to 1.00). A κ value greater than 0.8 represents excellent interrater reliability (21). The coders and the senior authors reviewed and resolved all discrepancies between coders through discussion.

Validity of the Findings

We used 2 techniques to ensure the validity of our findings (22, 23). First, we used a multidisciplinary team to develop the coding framework. Areas of investigator expertise included critical care medicine, bioethics, sociology, general internal medicine, physician–patient communication, and end-of-life care. A multidisciplinary approach minimizes the chance that individual bias threatens the validity of the findings. Second, we presented the preliminary conceptual framework to a sample of study participants for confirmation or modification, a process known as member checking (23). We incorporated these insights into the final organizing framework for the data.

Role of the Funding Source

This project was supported by a National Institutes of Health grant (KL2 RR024130) from the National Center for Research Resources, a component of the National Institutes of Health Roadmap for Medical Research and the University of California Student Research Fellowship. The funding sources had no involvement in study design, analysis, or interpretation or in the decision to submit the manuscript for publication.

RESULTS

Among 183 eligible patients, the families of 19 (10%) were not approached at the request of the attending physician and 22 (12%) families declined to participate after learning about the study (Figure). The overall enrollment rate was 78%. In some cases, a family indicated that more than 1 individual would be involved in surrogate decision making, and therefore we enrolled 2 surrogates each for 23 patients and 3 surrogates each for 7 patients.

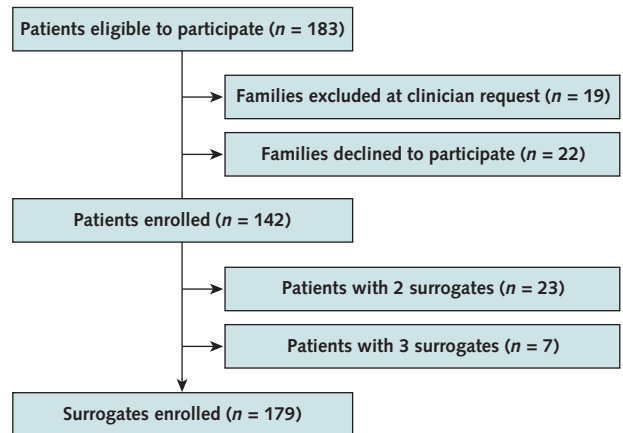
Table 1 shows the demographic characteristics of the surrogate decision makers and patients who participated in the study. Eighty-two percent of the surrogates were immediate family members of the ICU patients. The sample was diverse in terms of sex, race/ethnicity, religious affiliation, and level of education. Forty-five percent of patients died during hospitalization (64 of 142).

Overall, 93% (166 of 179) of the surrogates believed that avoiding discussions about prognosis was not an acceptable way to maintain families' hope. Table 2 summarizes the main explanatory themes, which are discussed in detail in the following paragraphs.

Preparing for the Future

The main explanatory theme was that timely discussion of prognosis is essential to allow family members to prepare emotionally and logistically for the possibility of a patient's death.

Figure. Study flow diagram.



Emotional Preparation

A total of 87 of 179 participants described this as predominantly a process of emotional preparation. A 48-year-old woman explained, “If you know something, you can think about it. You can discuss and you can prepare yourself emotionally.” Not knowing about a poor prognosis, according to another surrogate, meant that a bad outcome would “come as a shock to my system.”

Surrogates described this emotional preparation as a process that requires time to unfold. Many surrogates mentioned that early discussion about prognosis was especially important to them, because, as one said, “You can’t start dealing with bad information until you know about it.” One surrogate explained that the stages of processing such a loss take time: “First, you just don’t believe it and then you try to figure a way out of it. You kind of go through all of those cycles of starting to accept something that’s hard. I don’t think you can do that in a short time. So, I think the sooner you have information, the better.”

Some surrogates expressed concern that delayed discussion of prognosis could also result in inappropriately delayed decision making and prolongation of the time a patient receives life support. One explained that if surrogates “have all the information and they can think about it all along the way while the doctors are working on the patient . . . then if the time comes, they have a decision ready and they can give it to the doctor, as opposed to letting the patient linger on.”

Knowing about a poor prognosis also meant that family members would have the chance to say final words. One explained, “Even if the patient isn’t able to communicate, [the family] can at least sort of unburden themselves.”

Logistical and Practical Preparation

Forty percent (72 of 179) of surrogates described a second aspect of preparation—a logistical and practical preparation—that physicians’ prognostic disclosures facili-

Table 1. Demographic Characteristics of Patients and Surrogate Decision Makers*

Characteristic	Total
Patients	142 (100)
Men	78 (55)
Race/ethnicity†	
White	83 (58)
Asian/Pacific Islander	30 (21)
Hispanic	17 (12)
Black	14 (10)
Native American	2 (1)
Other, multiethnic, or undocumented	3 (2)
Admission diagnosis	
Neurologic failure	40 (28)
Respiratory failure	38 (27)
Cardiac failure or shock (including sepsis)	34 (24)
Gastrointestinal failure (including pancreatitis)	11 (8)
Hepatic failure	11 (8)
Metastatic cancer	5 (4)
Renal failure	3 (2)
Death	64 (45)
Mean Acute Physiology and Chronic Health Evaluation II score (SD)	30 (4)
Surrogate decision makers	179 (100)
Women	125 (70)
Race/ethnicity†	
White	109 (61)
Asian/Pacific Islander	28 (16)
Hispanic	26 (15)
Black	19 (11)
Native American	2 (1)
Other, multiethnic, or undocumented	12 (7)
Relationship to patient	
Child	66 (37)
Spouse or partner	39 (22)
Other	31 (17)
Sibling	23 (13)
Parent	18 (10)
Friend	2 (1)
Level of education	
Some college or trade school	58 (32)
Some high school (including diploma or GED)	48 (27)
Graduate or professional school	38 (21)
4-year college degree	35 (20)
8th grade or less	0 (0)
Primary language	
English	145 (81)
Spanish	13 (7)
Other‡	10 (6)
Tagalog	6 (3)
Cantonese	5 (3)
Religious preference	
Catholic	57 (32)
None, agnostic, or atheist	38 (21)
Protestant	37 (21)
Other Christian (Latter Day Saints/Mormons, or Jehovah's Witness)	22 (12)
Did not respond	12 (7)
Jewish	5 (3)
Other (including Spiritualist)	5 (3)
Hindu	1 (0.5)
Buddhist	1 (0.5)
Muslim	1 (0.5)
Importance of religion or spiritual beliefs in everyday life	
Very important	86 (48)
Fairly important	38 (21)
Not too important	30 (17)
Not at all important	12 (7)
Declined to respond	13 (7)

GED = General Education Development.

* Values are reported as number (percentage), unless otherwise indicated.

† Sums are greater than 142 (patients) and 179 (surrogate decision makers) because some individuals identified with more than 1 race or ethnicity.

‡ Includes Vietnamese, Mandarin, Korean, Russian, Italian, Farsi, Greek, and unspecified.

tate. One surrogate explained, “There are things that people need to get ready—wills or funeral arrangements or, you know, practical considerations.” Surrogates said they would also use the information to gauge whether they should start contacting other family members who might want to be present with the patient. The surrogate of a 68-year-old man with a ruptured aneurysm said, “I’d be so grateful that I had the time to call his sisters, call everybody in the family, let them know what’s going on, and you have your chance to come here and be with your brother.”

Supporting the Patient and Family

Thirteen percent (23 of 179) of surrogates felt that a clear understanding of the patient’s prognosis would allow them to better support the patient and other family members. For some, this involved changes in how they prayed for the patient. According to one surrogate, she could “pray better” if she understood the gravity of the prognosis. Another explained, “I would rather know . . . and have the opportunity to be here for him.” In addition, knowing clearly the seriousness of the patient’s prognosis would give family members the “chance to be with family, to help support the whole family,” and to “start to . . . help each other deal with it.”

Aversion to False Hope

Thirteen percent (22 of 179) of surrogates were strongly averse to nondisclosure on the grounds that it would lead to “false hope.” Surrogates described false hope as “cruel” and “morally wrong.” One noted, “If you don’t know . . . you’re under that false pretense and you think everything is okay.” The 44-year-old surrogate of a man with fulminant liver failure said, “I . . . was never one for raising someone’s hope falsely. I just, I don’t think that’s fair to give. That’s like pickin’ someone up to drop ‘em from a greater height.”

Physicians’ Obligation to Discuss Prognosis

Thirteen surrogates felt that physicians are obligated to present the full picture of what is happening with the patient. These surrogates felt strongly that physicians should not attempt to “shield” them from the truth. Although the information might be hard to hear, one explained, “I don’t want a doctor to filter. I don’t want them to make a decision about what they think I can handle.” Another surrogate explained, “They need to tell the truth. That’s their job.”

Outside Sources of Hope

Seventeen percent (30 of 179) of surrogates felt that hope came from sources other than the physician. One explained, “Hope has to come from me.” For others, it came from “God,” “faith,” “belief in miracles,” the patient’s “will to live,” or the family’s ability to “hold each other up.” Some surrogates felt that hope came from prognostic uncertainty. Another surrogate made it clear that being informed provided an important context for hope, “I

Table 2. Coding Framework and Quotes: Should Physicians Withhold Prognostic Information to Maintain Hope?

Theme	Description	Quoted Example
Preparing for the future, emotionally and logistically	Families used information to start coming to terms with the patient's condition and start the logistical preparation for death.	"I think that people cope better from a standpoint of knowledge. If there's going to be bad news, they have to learn it sometimes, they might as well begin preparing themselves for it." "And we should know whether we're in it for a long haul or a short haul, because then we can manage our lives differently. We can schedule and we can support our family and call in different resources."
Supporting the patient and family	Prognostic information allows the family to choose to act differently (be present at bedside more, pray more or differently).	"Depending on what is going on with him, I can try to focus positive energy on those specific things. . . . I personally believe in the power of positive thought putting positive energy into the universe. . . . All knowledge is better than no knowledge, for me." "Oh [sigh] because I think I would rather hear the truth and see where I'm standing at, and, you know, and prepare myself emotionally for whatever's going to come. So I can be more supportive to my mother or my sisters."
Aversion to false hope	Families feel that fostering false hope is wrong.	"Well, if there's no hope, I think that to encourage the family's hope would be wrong, because then it comes as a real shock, if something does go wrong." "Doctors should just be honest. You know, it's hard enough, like, going through all this. And if we are steered in the wrong direction or given false hope, then it's just gonna set us up for more hardship, in the long run."
Physicians' obligation to discuss prognosis	Families view disclosing prognosis as a central duty of physicians.	"Also, I think it's a matter of respect and I wouldn't want a doctor assuming that I couldn't handle something or that I wouldn't understand something. That's demeaning to me. So, I think it's a matter of honor and respect." "Because it's their responsibility. That's the role they play in becoming a doctor." "I think their job is to tell us, based on medicine, the truth about what they think."
Outside sources of hope	Families find hope outside of what is offered by the physician.	"And hope? Doctors don't give hope. Do you know what I mean? I don't believe that that's what they're here to do. I think that they're here to do their job and do things the best that they can, but hope comes from somewhere else, I think." "My hope is not based on what doctors tell me, it's based on how I feel as a person, my spiritual beliefs, my . . . you know, how my family and I interact with each other and hold each other up and whatever."
Importance of how prognosis is discussed	Families feel that physicians should avoid expressing absolute certainty while delivering prognosis.	"I intensely resent when doctors say, 'Well, he's only got so long to live.' How do they know? Are they gonna kill him?" "I think it would always be good for the doctor to end with, 'But, you know, anything's still possible.'"

think there's a difference between hope and sort of uninformed, wishful thinking. So hope is sort of hoping that, against the odds, she'll pull through."

Nondisclosure or Ambivalence about Prognosis

Three percent (6 of 179) of surrogates felt that physicians should withhold prognostic information to maintain surrogates' hope. In particular, one surrogate of a 45-year-old man with severe delirium tremens felt that hearing news of a grim prognosis might be devastating for family members. This surrogate felt that it might also adversely affect the patient, through a belief that patients could be negatively affected by families' grief or that "some families

might just start backin' out and not comin' and then that'd get to a person that's ill."

Four percent (7 of 179) of surrogates were ambivalent about whether physicians should avoid discussing prognosis. Their main concern was that, depending on individual circumstances, families might react positively or negatively to receiving prognostic information.

The Importance of How Prognosis Is Discussed

Although we did not question surrogates directly about how prognostic information should be disclosed by physicians, some volunteered their perspectives. One theme that emerged was that physicians should avoid expressing absolute certainty about a patient's outcome and

acknowledge the difficulty in predicting outcomes for individual patients.

Once they interpret facts and they form an opinion, it's an opinion. Um, so, I think factual information should be shared and given to the family, but I also think . . . and I . . . in my experience, doctors have done a good job with this, to be sure to let them know it is an opinion. Nothing's 100% percent. Nothing's for certain.

Other surrogates reported that avoiding absolute statements provided a balanced sense of the prognosis. As one said, he wants the “the downside, as well as the upside.” Two surrogates mentioned that an iterative approach to discussing prognosis may be most effective. A man whose wife ultimately died after life support was withdrawn said, “I think it's best done through multiple communications. A bomb on 'em once . . . is not gonna help anybody.”

DISCUSSION

In this diverse sample of surrogates of critically ill patients, the vast majority felt that it is unacceptable for physicians to avoid discussions about a poor prognosis as a way to maintain hope. Surrogates view timely discussions about prognosis as a key step in beginning to prepare emotionally, existentially, and practically for the possibility that a patient will die (Table 3). Our findings suggest that there is a relationship between early disclosure about a patient's prognosis and families' initiation of preparatory processes that may mitigate adverse bereavement outcomes.

This study fills several important gaps in knowledge about disclosure of prognosis. It reveals that surrogate decision makers have a substantially different view from many physicians on whether avoiding discussions about prognosis is an acceptable strategy to maintain hope. Most participants in this study rejected this practice on ethical and practical grounds. The work of Christakis and others (1, 6) suggest that omission of prognostic information is common, and one reason for this is the physicians' belief that the information will be too emotionally difficult for patients or their families to accept. Our results reveal that surrogates generally feel they are resilient enough to hear

news of a poor prognosis and also need this information to begin to come to terms with the possible death of a loved one. These findings highlight the need to investigate how physicians can best balance the priorities of truthful disclosure about prognosis and empathic support of surrogates. Our data suggest that physicians should avoid expressing absolute certainty when disclosing their prognostic estimates. Experts in the field of physician–patient communication advocate beginning with a “warning shot” to patients about impending bad news, both to alert patients to what is about to be discussed and to allow the physician to gauge whether the patient is ready for such a discussion (24–26). Empirical data from patients support this approach (27). Although these investigators did not address surrogate decision making, their recommendations seem appropriate for discussions with surrogates.

Our results expand the conceptual understanding of why early disclosure about prognosis may be important for surrogate decision makers. Most research in the field has focused on the value of prognostic information in allowing surrogates to be informed participants in making decisions for incapacitated patients (28). This study reveals that surrogates use prognostic information for more personal purposes related to beginning a process of preparation for bereavement. Our findings suggest that this process is multidimensional. It involves practical aspects, such as gathering legal documents; psychosocial elements, such as informing distant relatives who may want to be at the bedside to support the patient; and emotional and spiritual elements. An important feature of these preparatory processes is that they require time. In critical illness, in which the trajectory of dying can be quite rapid, even a few days of forewarning may therefore be useful.

An emerging body of research suggests that lack of preparation for death may be an important contributor to adverse bereavement outcomes, such as anxiety, depression, and complicated grief (29). For example, among bereaved family members of patients with cancer or dementia, those who perceived the patient's death as sudden had substantially higher rates of psychiatric illness after bereavement and were less satisfied with the process of end-of-life care than those who did not perceive the death to be sudden (29–31). Our study suggests that early disclosure about prognosis could facilitate surrogates' preparation for death and thereby improve bereavement outcomes.

Our findings also suggest that surrogates' degree of preparation for death may affect their ability to engage in decision making. This may merit special attention in light of empirical evidence that patients frequently die receiving technological treatments that they would not choose for themselves (33). We hypothesize that a degree of preparedness is required for surrogates to authorize the withholding or withdrawal of life support. Surrogates who do not understand the possibility of death early in an ICU stay may have a delayed initiation of preparing for death and thus may not consent to withdrawing life support in situations

Table 3. Numerical Data for Each Explanatory Theme

Theme	Surrogates, n (%)*
Preparing for the future, emotionally	87 (49)
Preparing for the future, logistically	72 (40)
Outside sources of hope	30 (17)
Aversion to false hope	22 (13)
Importance of how prognosis is discussed	16 (9)
Physicians' obligation to discuss prognosis	13 (7)

* Percentages total more than 100% because many surrogates expressed multiple themes.

in which such a decision is in the patient's best interest (29).

We believe that our findings provide empirical support for the approach advocated by Back and colleagues (34) to help patients and families "hope for the best and prepare for the worst." In this approach, physicians, patients, and family members work together to discuss, plan, and come to terms with the possible outcome of death but concurrently hope for the patient's survival. Our finding that some surrogates look outside of physicians for hope (especially to religious faith and hope for a miracle) is an important reminder that the end of life is a time when many people give normative weight to both medical expertise and religious faith. Perhaps the starkest example of this is the finding from a recent study that 57% of Americans believe that divine intervention could save a person when physicians believe treatment is futile. Twenty percent of physicians also endorsed this belief (35).

This study has several strengths. First, the sample size is large for a qualitative research study. The enrollment rate is high, particularly for a study that involved in-depth interviews about a sensitive topic with family members coping with critical illness in a loved one. The sample is diverse in race/ethnicity and educational level. Rather than use hypothetical vignettes to study this question, we studied family members of critically ill patients at high risk for death. Although this posed practical and ethical challenges, we feel this approach substantially increased the representativeness of the study findings to family members in ICUs. Finally, we undertook efforts to validate our findings, including analysis by a multidisciplinary team and member checking—a process by which the preliminary study results are presented to participants for comments and modifications.

The study also has several limitations. Our study did not include participants from 2 ethnic groups (Navajo Indians and Hmong people) for whom previous research reveals a belief that discussing the possibility of death can be harmful to the patient (36, 37). Our findings therefore should be applied with caution to these ethnic groups and others for whom such beliefs are common. We did not enroll surrogates who could not speak English, and these individuals may have different perspectives on end-of-life issues than English speakers. The manner in which we asked the main interview question may have forced participants to choose between disclosure and nondisclosure in a way that did not reflect the complexity of their beliefs about how prognostic information should be discussed. However, we believe the first important question to answer is whether nondisclosure about prognosis is an acceptable way to maintain hope. Research is needed to identify strategies to disclose news of a poor prognosis to surrogates in a way that does not inappropriately extinguish hope (27). We interviewed participants during the first week of a patient's ICU stay. It is possible that their perspectives would be different if they were interviewed retrospectively. How-

ever, we feel it is important to understand the perspective of surrogates who are in the midst of coping with critical illness in a loved one. Although many participants described a causal link between receiving prognostic information and starting to prepare for the possibility of death, we did not follow participants longitudinally to assess whether those who received prognostic information earlier actually had better bereavement outcomes.

In conclusion, most surrogates of critically ill patients do not view withholding prognostic information as an acceptable way to maintain hope, in large part because physicians' disclosures about prognosis trigger family members to begin to prepare emotionally, existentially, and practically for the possibility that a patient will die. Future studies are needed to determine whether interventions that increase early discussion of prognosis and facilitate the process of preparedness for death could improve bereavement outcomes in ICUs.

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