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Doubt and belief in physicians' ability to prognosticate during critical illness: The perspective of surrogate decision makers

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Abstract

Objectives: Although discussing a prognosis is a duty of physicians caring for critically ill patients, little is known about surrogate decision-makers' beliefs about physicians' ability to prognosticate.

We sought to determine: 1) surrogates' beliefs about whether physicians can accurately prognosticate for critically ill patients; and 2) how individuals use prognostic information in their role as surrogate decision-makers.

Design, Setting, and Patients: Multicenter study in intensive care units of a public hospital, a tertiary care hospital, and a veterans' hospital. We conducted semistructured interviews with 50 surrogate decision-makers of critically ill patients. We analyzed the interview transcripts using grounded theory methods to inductively develop a framework to describe surrogates' beliefs about physicians' ability to prognosticate. Validation methods included triangulation by multidisciplinary analysis and member checking.

Measurements and Main Results: Overall, 88% (44 of 50) of surrogates expressed doubt about physicians' ability to prognosticate for critically ill patients. Four distinct themes emerged that explained surrogates' doubts about prognostic accuracy: a belief that God could alter the course of the illness, a belief that predicting the future is inherently uncertain, prior experiences where physicians' prognostications were inaccurate, and experiences with prognostication during the patient's intensive care unit stay. Participants also identified several factors that led to belief in physicians' prognostications, such as receiving similar prognostic estimates from multiple physicians and prior experiences with accurate prognostication. Surrogates' doubts about prognostic accuracy did not prevent them from wanting prognostic information. Instead, most surrogate decision-makers view physicians' prognostications as rough estimates that are valuable in informing decisions, but are not determinative. Surrogates identified the act of prognostic disclosure as a key step in preparing emotionally and practically for the possibility that a patient may not survive.

Conclusions: Although many surrogate decision-makers harbor some doubt about the accuracy of physicians' prognostications, they highly value discussions about prognosis and use the information for multiple purposes. (Crit Care Med 2008; 36: 2341–2347)

Keywords

prognosis; proxy; decision-making; intensive care unit; critical care

One in five deaths in the United States occur in or shortly after discharge from an intensive care unit (ICU) (1). Most of these deaths are preceded by decisions made by physicians and surrogate decision-makers to limit life-sustaining treatment (2,3). Disclosure of prognosis by physicians is viewed as an essential part of this decision-making process (4,5). Despite the importance of clear communication about prognosis in successful shared decision-making, surrogates are frequently dissatisfied with physicians' communications and misunderstandings about prognosis are common (6-9).

Christakis and colleagues found that 80% of physicians believe patients and families expect too much certainty in physicians' predictions (10,11). Most physicians also believe that errors in prognostication will be viewed negatively by patients (10). A recent study of audiotaped physician-family conferences in ICUs revealed that physicians frequently omit important prognostic information from discussions about whether to limit life support in ICUs (12). However, when prognosis is discussed, most physicians offer opinions couched in terms of whether the individual patient will live or die, rather than what prior experience suggests will happen to groups of similarly ill patients (13). There are substantial gaps in knowledge about how surrogates view physicians' prognostications and how they subsequently use this information. These gaps in knowledge pose barriers to designing empirically grounded interventions to improve communication about prognosis in patients at high risk of death or functional impairment.

Therefore, we conducted this study to determine 1) surrogates' beliefs about whether physicians can accurately prognosticate for patients in intensive care units, and 2) how family members and loved ones use prognostic information in their role as surrogate decision-makers.

MATERIALS AND METHODS

Study Design, Patients, and Setting

Between June 2006 and March 2007 we conducted a multicentered study using semistructured interviews of surrogate decision-makers in intensive care units of three California hospitals including the University of California, San Francisco Medical Center, San Francisco General Hospital, and the San Francisco Veterans Affairs Medical Center. All study procedures were approved by the Institutional Review Board at each participating center.

Study investigators identified eligible surrogates of ICU patients by screening 1 day per week at each institution. Subjects were eligible if they spoke English well enough not to require the use of an interpreter, were at least 18 yrs of age, and were functioning as a surrogate decision-maker for an incapacitated, critically ill patient. If the responsibility for surrogate decision-making was shared between family members, we enrolled those who self-reported having the most responsibility for decision-making. Because of the sensitive nature of the research topic, we excluded surrogates of patients who were actively dying or were about to have life support withdrawn. Before approaching potential subjects, we obtained permission from the patient's attending physician to do so. Surrogates who agreed to participate completed a demographic questionnaire and participated in a one-on-one semistructured interview which was audiotaped and transcribed. We assessed subjects' religiosity using the following question, answered on a

4-point Likert scale: How important are religious or spiritual beliefs in your everyday life? (14).

Before the interview participants were read the following:

I'd like you to imagine the following situation: Your loved one is admitted to the intensive care unit with a life-threatening illness. S/he is on a breathing machine and cannot speak for him/herself and you are asked to make decisions for him/her. The doctors sit down to discuss your loved one's situation with you and say that your loved one's prognosis is poor.

During the interview, participants were asked a series of open-ended questions, beginning with "Should family members of ICU patients believe the doctor's predictions when the doctor says that a patient probably will not survive? Why or why not?" The interviewer followed up participants' responses, pursued themes as they arose, and sought clarification or elaboration. Sample follow-up questions from the interview guide include the following: "What do you think determines whether a patient will live or die? If the doctor told you s/he felt there was very little chance that your loved one would survive, would this affect the decisions you would make about life support? How?" The interview guide was modified to clarify themes emerging from the data as the interviews and analyses progressed.

Qualitative Data Coding

The audiotaped interviews were transcribed verbatim by a medical transcriptionist. We used grounded theory methods to develop a framework to describe surrogates' beliefs about physicians' ability to prognosticate. Grounded theory is a general methodology for developing theory inductively from data that are systematically gathered and analyzed. It is a qualitative research method that is often employed when existing conceptual frameworks for the topics under study are inadequate (15,16).

To develop the preliminary coding scheme, two investigators (LSZ, DBW) independently performed open coding in which they read and performed line by line coding of a subset of the transcripts to identify themes and concepts relating to surrogates' beliefs about prognostication. Specifically, the coders identified and named reasons given by surrogates for belief or doubt in physicians' prognostications. The goal of the initial coding was to be as detailed and comprehensive as possible to avoid missing important themes. We subsequently created a list of these reasons and organized them according to similarities. As concepts further accumulated and distinctions between concepts became more refined, similar concepts were grouped into conceptual categories. These categories were developed further by comparing the categories between transcripts. All investigators reviewed this preliminary framework and, through a series of investigator meetings, arrived at consensus on the coding framework (15,17). We modified the framework iteratively over the study period when interviews yielded new themes or ideas.

For the purposes of coding, we defined *doubt in prognosis* as any statement that indicated uncertainty about physicians' ability to accurately prognosticate. We defined *belief in prognosis* as any statement that indicated support for the ability of physicians to accurately prognosticate.

Reliability of the Coding

Using the final coding framework, one investigator (LSZ) coded all of the interviews by listening to the audiotapes and reading the transcripts. To assess intercoder reliability, another investigator (AKC) coded a random sample of 20% of the transcripts. Both coders were blinded to the demographic characteristics of the subjects, and to one another's coding. The average

kappa statistic for assigning individual codes in the transcripts was 0.86 (range: 0.66–1.00). A kappa value greater than 0.8 represents excellent interrater reliability (18).

Validity of the Findings

We used two techniques to ensure the validity of our findings (19–21). First, we used a multidisciplinary approach in developing the coding framework. Areas of investigator expertise included critical care medicine, general internal medicine, doctor-patient communication, bioethics, and end-of-life care. A multidisciplinary approach minimizes the chance that individual bias threatens the validity of the findings. Second, near the end of the study, we presented the preliminary conceptual framework to study subjects for confirmation and/or modification, a process known as member checking (21). These insights were incorporated into the final organizing framework for the data.

RESULTS

Participant Characteristics

Of 58 eligible surrogates, 53 (91%) agreed to participate. Two participants agreed to be interviewed at a later date but were lost to follow-up and one participant was unable to complete the interview because of an emergency, yielding an enrollment rate of 86% (50/58). Demographic characteristics of the individuals who participated in the interviews are described in Table 1. Eighty-four percent endorsed some form of religious affiliation; 40% indicated that religion was very important in their everyday life. Sixty-six percent reported good or better communication about the patient's prognosis with ICU physicians. The number of surrogates interviewed for each patient ranged from 1 to 3 with a mean of 1.6 ICU surrogates per patient. Table 2 describes the demographic characteristics of the ICU patients.

Doubt about the Accuracy of Physicians' Prognostications

Overall, 88% (44 of 50) of participants expressed doubt in physicians' ability to prognosticate. Table 3 contains the organizing framework of reasons for surrogates' doubt in physicians' prognostications with representative passages from interviews. We identified four major explanatory categories: a belief that God could alter the course of the illness, a belief that predicting the future is inherently inaccurate, prior experiences in which physicians' prognostications were inaccurate, and experiences with prognostication during the patient's ICU stay.

The Influence of God

Most participants (37 of 50) felt that God influenced the outcome of an ICU admission through predetermination or direct intervention. Half of participants (25 of 50) felt that ICU outcomes were predetermined by God in a manner outside of physicians' knowledge, thus limiting accurate prognostication:

I think it's whether God says it's [the patient's] turn to die. If you feel that God's in control, and I do, then no matter what a doctor will tell me, or what a doctor says, he's only human. He doesn't have all of the answers. And I believe that God does. He may choose to not let that person live and use that disease, or that problem, to take his life. But if He is not finished with that person yet, and has a reason for that person to still be here, then I do not think what the doctors say makes any difference; he'll survive.

Some participants (18 of 50) believed that God could directly intervene in the course of an ICU admission. Because physicians could not anticipate this, surrogates doubted the accuracy of their prognostic estimates:

[Physicians] can say, “Well, this person is not going to survive...” and then, here comes God who plays a role and just pick ‘em up. Could be on their dying bed, getting, you know, CPR or anything and they think they gonna lose ‘em, flat line. And they just jump back, with a heartbeat. And I think that's the hands of God.

The Inherent Inaccuracy of Predicting the Future

Some participants (19 of 50) believed that, independent of their religious beliefs, the practice of foretelling a patient's future was inherently inaccurate. This belief appeared to relate to the perceived technical difficulties inherent in predicting such a complex event. One participant stated:

There's too many factors. I mean, all of us would like to say that a person will live, but we do not know that, for certain. And as humans we make mistakes. I mean, no one wants to make a mistake, especially when it's a life and death situation. But, no one can predict the future.

Prior Experience with Physicians' Inaccurate Prognostications.

Participants also identified previous experiences which influenced them to doubt physicians' prognostications. These experiences were most often associated with first-hand encounters with inaccurate prognostication:

[Family members] should believe that [the prognosis] is what the doctors believe at the time that they're saying [the prognosis]. But the doctors told my parents that my brother was going to never come out of the coma and, if he did, he'd never be able to have a good life. He was able to feed himself, he was able to communicate. So, they do the best they can, based on the history and based on their education.

Current Experiences in the Intensive Care Unit

Participants identified several aspects of their experiences during the patient's stay in the ICU that mitigated their confidence in physicians' prognostications, including the perception that the physician was inexperienced (4 of 50) and receiving discrepant prognostic estimates from different physicians (8 of 50) One subject described how the perceived experience of a communicating physician affected the belief in prognosis:

Maybe it feels like the doctor has that background where he has [made predictions] before. Most likely I would tend to believe him, a little bit more than someone who it feels like this is their first or second or third time. The likelihood of me believing the first timer would be rather slim.

The mother of a trauma victim described the difficulty in interpreting prognoses from multiple physicians:

So many doctors tell you so many different things; nurses tell you things. It's hard to believe. One tell you she gonna make it. One tell you, “Oh, her lung's really bad.” They say that if they take the ventilator off, she might die for not catchin' on right. Then one says, “Oh, nothin' wrong with her, we just keepin' it to drain the fluid.” It's so many doctors, so many different reports, in the ICU. It's just that you do not know what to believe in.

Others (10 of 50) described the need to “see for themselves” that physicians' prognostications were true. For these individuals, concordance between the patient's physical appearance and the physicians' prognostications was important; doubt arose if the prognostications did not match the surrogates' own observations of whether the patient's condition was improving or worsening. One family member remarked:

I would consider [the physician's prognosis] a lot. But I would still give it a little time to see if anything changes with the patient, if there was some kind of improvement in them. But if they are laying there, like a vegetable, and you do not see no improvement, then what the doctor says is gonna happen, is gonna happen.

Surrogates Confidence in the Ability of Physicians to Accurately Prognosticate

Surrogates identified several factors that would enhance their confidence in the accuracy of physicians' prognostications. Table 4 describes the coding framework we developed, with representative passages from interviews.

Participants' Attitudes about Disclosure of Prognostic Estimates

Although doubt about the accuracy of prognostic information was common, all participants (50 of 50) wanted physicians to disclose their prognostic estimates, even when the prognosis was poor. One participant remarked:

I would want the [prognostic] opinion to prepare. Whether I believe it depends on the history that we've had with the doctor and also his expertise in the field.

Surrogates' Use of Prognostic Estimates

There was considerable variation in how surrogate decision-makers said they would use prognostic information. Some (16 of 50) stated that specific prognostic estimates would play a role in their decision-making, but that they generally would not choose to limit treatment if there remained hope that the patient would survive. Many surrogates approached decision-making with the belief that small chances of success are acceptable when the only other option is death:

SUB: You always take the chance that [the patient] is going to survive, not the chance that they're not going to survive. So if [the doctor] said it's a 5% chance of survival you say, "Well, she has 5% chance and you forget the 95% that [the patient] is not going to survive.

INT: So, if there's a little chance of survival....

SUB: You always take it regardless of the number.

Most participants reported that physicians' prognostications facilitated important processes distinct from decision-making. Many surrogates (29 of 50) stated that prognostic estimates were important because they allow the family to prepare for the possibility of an impending death. These preparatory processes involved both emotional and practical preparation.

When you are a member of the family, you want to know and you want to realize and to be prepared for what's going to happen. If you think, in your mind, that [the patient] is going to survive and they are not, then there's going to be a big strong decision that you have to face. But I think, if the doctor said that she has a small chance [of survival], when you are waiting through a surgery that she might not be able to survive, well, your mind is ready to accept the fact that she's dying ... or that she has died.

Another subject stated:

When the doctor discusses prognosis the family can plan ahead and consider all the options that they have ... That way the patient does not have to suffer while the family is preparing to stop life support.

Physicians' prognostications also alerted families of the need to begin practical preparations important to their perception of a "good death":

Prognosis is important because we need to make arrangements. We need to know. We need to bring family to at least see their loved one before she passes away, to bring all the family together. We also may need to get all funeral arrangements ready.

DISCUSSION

The goal of this study was to begin the development of a systematic, empirically derived body of knowledge about surrogates' perspectives on the value and limitations of physicians' prognostications. We found that most surrogates harbor a degree of doubt about physicians' ability to prognosticate for critically ill patients. We identified several distinct reasons for this doubt, including a belief that God rather than medical science controls life and death, a belief that predicting the future is inherently uncertain, and surrogates' prior experiences with inaccurate prognostication. Despite this doubt, surrogates were unanimous in their desire to receive physicians' prognostic estimates and identified the act of prognostic disclosure as a key step in preparing emotionally and practically for the possibility that a patient may not survive.

Physicians are reluctant to prognosticate, in part because they believe patients and families expect too much certainty about prognosis and will judge them negatively for inaccurate predictions (10). Our findings suggest that physicians misjudge surrogates' expectations about the accuracy of prognostication. Rather than demanding certainty, it appears that surrogates ascribe considerable uncertainty to the accuracy of physicians' predictions. Although several experts have speculated that doubt in physicians' predictions may be one cause of conflict in decision-making (22), we are aware of no empirical studies which have focused on surrogates' attitudes about physicians' abilities to prognosticate in the ICUs.

Why might this empirical insight into the surrogate's perspective be valuable? First, it suggests that there is a shared belief among physicians and surrogates that predicting the future is difficult. This shared belief creates an opportunity for a more nuanced view of the role of prognostic information. Rather than simply being a "hard fact" to be used in making optimal medical decisions, our results suggest that the act of discussing prognosis appears to prompt surrogates to begin to prepare emotionally and practically for the possibility that they will be bereaved. Several investigators have documented that deaths perceived by surrogates as sudden are associated with higher rates of adverse bereavement outcomes such as depression, posttraumatic stress disorder and complicated grief (23-25). This is an area ripe for further investigation to determine whether early discussion about prognosis improves bereavement outcomes in the ICUs.

Second, because uncertainty is a dominant concern for both physicians and families, the language physicians use to discuss prognosis could reflect this. The uncertainty in applying population-based data (or one's clinical experience) to individual patients could be addressed by discussing prognosis in terms what happens to groups of similarly ill patients, and acknowledging that it is not possible to know with certainty whether the particular patient will survive or die. This "population-based" approach to discussing prognosis is advocated by risk communication experts (26,27). A recent study of audiotaped ICU family conferences revealed that few physicians express their prognostic estimates in population-based terms (28).

What may explain the seemingly discrepant observations that surrogates harbor doubt about the accuracy of physicians' prognostications yet overwhelmingly want prognostic disclosure? It appears that surrogates view prognostic uncertainty as an unavoidable reality. Our findings also suggest that surrogates accept this limitation and are willing to accept physicians' prognostications as the best information available. Surrogates neither categorically accept nor reject physicians' prognostications. Instead, they use physicians' prognostications as one piece of information to better inform their decisions and prepare themselves for the future. Perhaps

it is not surprising that prognostic uncertainty does not prevent surrogates from using the information to begin to prepare for the possibility of bereavement, since the very presence of uncertainty reveals that death is a possible outcome. An important question for future study is how this prognostic uncertainty influences surrogates' decisions about life support (29).

A broader view of our findings raises the possibility that delays in discussing prognosis could be a factor in prolonged use of nonbeneficial life support (30-32). Several surrogates in the study made a direct connection between receiving prognostic information and the beginning of a multistep process leading up to a willingness to withdraw life support. If these preparations take time, which they appear to based on surrogates' descriptions, then delays in disclosing a poor prognosis may also delay family members' preparations for death, and hence their willingness to authorize withdrawal of life support. This theory is supported by prior qualitative work in which family members perceived deaths in ICUs to be sudden despite long ICU stays (33). Future research is needed to determine whether such a "preliminary mention" about the possibility the patient will die improves the patient-centeredness of life support decisions and decreases the use of nonbeneficial treatment.

This study has several limitations. As with many qualitative research endeavors, the results of this study are hypothesis generating and do not provide definitive answers about how prognostic information should be communicated. We used a hypothetical scenario to prompt surrogates of critically ill patients to discuss their beliefs about prognostication. It is possible that surrogates' responses to these hypothetical situations do not reflect the breadth of beliefs about this issue. However, we feel that it is a strength of our study that subjects had been involved in at least one formal discussion with physicians about treatment goals for an ICU patient. This allowed us to elicit the beliefs of surrogates who were likely to be "primed" by real-time events. Moreover, the diversity of themes that emerged and the strong endorsement we received from subjects during the process of member checking argue for the validity of our findings. Next, although our sample was diverse in terms of race, ethnicity, level of education, and religious background, the study was designed to gather rich descriptive data rather than to determine quantitatively whether demographic factors were associated with doubt about physicians' ability to prognosticate. This is an important area for future research. Fourth, although polling reveals that 59% of Americans consider religion very important in their day-to-day lives (34), only 40% of subjects in our study endorsed this belief. This difference may be due to our small sample size or may be representative of the San Francisco Bay area. It is important to note that our results therefore may underestimate the extent to which religious beliefs influence individuals' beliefs about physicians' ability to prognosticate. Finally, we did not ask subjects to quantify the extent of their doubt or confidence in prognostic estimates, and therefore were not able to judge whether differences in the degree of doubt yielded different interpretations of the utility of prognostic disclosure.

Our findings challenge the belief among physicians that patients and surrogate decision-makers expect certainty from physicians' prognostic estimates. Perhaps most importantly, the doubt surrogates have about physicians' ability to predict the future does not lessen their desire to discuss prognosis, nor lessen the importance of prognostic disclosure as a key step in preparing emotionally and practically for the possibility that a patient may not survive.

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REFERENCES

1. Angus DC, Barnato AE, Linde-Zwirble WT, et al. Use of intensive care at the end of life in the United States: An epidemiologic study. *Crit Care Med* 2004;32:638–643. [PubMed: 15090940]
2. Prendergast TJ, Claessens MT, Luce JM. A national survey of end-of-life care for critically ill patients. *Am J Respir Crit Care Med* 1998;158:1163–1167. [PubMed: 9769276]
3. Cohen S, Sprung C, Sjøkvist P, et al. Communication of end-of-life decisions in European intensive care units. *Intensive Care Med* 2005;31:1215–1221. [PubMed: 16041519]
4. Charles C, Whelan T, Gafni A. What do we mean by partnership in making decisions about treatment? *BMJ* 1999;319:780–782. [PubMed: 10488014]
5. Thompson, BT.; Cox, PN.; Antonelli, M., et al. Challenges in end-of-life care in the ICU: Statement of the 5th International Consensus Conference in Critical Care. *Crit Care Med*; Executive summary; Brussels, Belgium. Apr. 2003 2004 p. 1781-1784.
6. Azoulay E, Pochard F, Chevret S, et al. Half the family members of intensive care unit patients do not want to share in the decision-making process: A study in 78 French intensive care units. *Crit Care Med* 2004;32:1832–1838. [PubMed: 15343009]
7. Hanson LC, Danis M, Garrett J. What is wrong with end-of-life care? Opinions of bereaved family members. *J Am Geriatr Soc* 1997;45:1339–1344. [PubMed: 9361659]
8. Abbott KH, Sago JG, Breen CM, et al. Families looking back: One year after discussion of withdrawal or withholding of life-sustaining support. *Crit Care Med* 2001;29:197–201. [PubMed: 11176185]
9. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. *JAMA* 1995;274:1591–1598. [PubMed: 7474243]
10. Christakis NA, Iwashyna TJ. Attitude and self-reported practice regarding prognostication in a national sample of internists. *Arch Intern Med* 1998;158:2389–2395. [PubMed: 9827791]
11. Christakis, NA. *Death Foretold: Prophecy and Prognosis in Medical Care*. The University of Chicago Press; 1999.
12. White DB, Engelberg RA, Wenrich MD, et al. Prognostication during physician-family discussions about limiting life support in intensive care units. *Crit Care Med* 2007;35:442–448. [PubMed: 17205000]
13. White, DBER.; Wenrich, MD.; Lo, B., et al. Annual Meeting. Society for Medical Decision Making; Boston, MA: 2006. The language of prognostication in intensive care units. Abstr
14. *Multidimensional Measurement of Religiousness/Spirituality for Use in Health Research: A Report of the Fetzer Institute/National Institute on Aging Working Group*. John E. Fetzer Institute; Kalamazoo: 1999.
15. Strauss, AL.; Corbin, J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. Sage; Thousand Oaks, CA: 1998.
16. Glaser, BG.; Strauss, AL. *Discovery of Grounded Theory*. Adeline; Chicago: 1967.
17. Charmaz, KC. *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. Sage; 2006.
18. Sackett, DLRBH.; Guyatt, GH.; Tugwell, P. *Clinical Epidemiology: A Basic Science for Clinical Medicine*. Second Edition. Brown and Company; Boston, Little: 1991.
19. Patton, MQ. *Qualitative Evaluation and Research Methods*. Sage; London, England: 1990.
20. Patton MQ. Enhancing the Quality and Credibility of Qualitative Analysis. *Health Serv Res* 1999;34 (5 Pt 2):1189–1208. [PubMed: 10591279]
21. Giacomini MK, Cook DJ. Users' guides to the medical literature: XXIII. Qualitative research in health care A. Are the results of the study valid? Evidence-Based Medicine Working Group. *JAMA* 2000;284:357–362. [PubMed: 10891968]
22. Goold SD, Williams B, Arnold RM. Conflicts regarding decisions to limit treatment: A differential diagnosis. *JAMA* 2000;283:909–914. [PubMed: 10685716]
23. Barry LC, Kasl SV, Prigerson HG. Psychiatric disorders among bereaved persons: the role of perceived circumstances of death and preparedness for death. *Am J Geriatr Psychiatry* 2002;10:447–457. [PubMed: 12095904]

24. Yates P, Stetz KM. Families' awareness of and response to dying. *Clin J Oncol Nurs* 2000;4:46. [PubMed: 10865585]
25. Hebert RS, Dang Q, Schulz R. Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: Findings from the REACH study. *J Palliat Med* 2006;9:683–693. [PubMed: 16752974]
26. Thomson R, Edwards A, Grey J. Risk communication in the clinical consultation. *Clin Med* 2005;5:465–469. [PubMed: 16268328]
27. Gigerenzer G, Edwards A. Simple tools for understanding risks: From innumeracy to insight. *BMJ* 2003;327:741–744. [PubMed: 14512488]
28. White DB, Engelberg RA, Wenrich MD, et al. The language of prognostication in intensive care units. *Med Decis Making*. In Press
29. Luce JM, White DB. The pressure to withhold or withdraw life-sustaining therapy from critically ill patients in the United States. *Am J Respir Crit Care Med* 2007;175:1104–1108. [PubMed: 17379853]
30. Schneiderman LJ, Gilmer T, Teetzel HD, et al. Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: A randomized controlled trial. *JAMA* 2003;290:1166–1172. [PubMed: 12952998]
31. Campbell ML, Guzman JA. A proactive approach to improve end-of-life care in a medical intensive care unit for patients with terminal dementia. *Crit Care Med* 2004;32:1839–1843. [PubMed: 15343010]
32. Campbell ML, Guzman JA. Impact of a proactive approach to improve end-of-life care in a medical ICU. *Chest* 2003;123:266–271. [PubMed: 12527629]
33. Russ AJ, Kaufman SR. Family perceptions of prognosis, silence, and the “suddenness” of death. *Cult Med Psychiatry* 2005;29:103–123. [PubMed: 16108205]
34. The Pew Global Attitudes Project. The Pew Research Center for the People & The Press; 2002. *Among Wealthy Nations: US stands alone in its embrace of religion.*

Table 1
Demographic characteristics of surrogate decision-makers

| Surrogate Characteristics | Family Members or Loved Ones (N = 50), n (%) |
|---|--|
| Age (yrs) | 55.2 (SD 13.4) |
| Gender | |
| Male | 16 (32) |
| Female | 34 (68) |
| Race/ethnicity ^a | |
| Caucasian or white | 20 (40) |
| African American or black | 12 (24) |
| Hispanic or Latino | 10 (20) |
| Asian | 5 (10) |
| Native American | 2 (4) |
| Pacific Islander | 1 (2) |
| Other/undocumented | 1 (3) |
| Relationship to patient | |
| Spouse/partner | 14 (28) |
| Sibling | 11 (22) |
| Child | 8 (16) |
| Parent | 5 (13) |
| Other relative | 5 (13) |
| Friend | 4 (8) |
| Other | 3 (6) |
| Level of education | |
| 8th grade or less | 0 (0) |
| Some high school | 4 (8) |
| High school diploma or GED | 15 (30) |
| Some college or trade school | 17 (34) |
| 4-year college degree | 5 (10) |
| Graduate or professional school | 9 (18) |
| Primary language ^b | |
| English | 48 (96) |
| Spanish | 6 (12) |
| Cantonese | 3 (6) |
| Mandarin | 1 (2) |
| French | 1 (2) |
| German | 1 (2) |
| Armenian | 1 (2) |
| Religious preference | |
| Christian | 17 (34) |
| Catholic | 8 (16) |
| Protestant | 6 (12) |
| No religious affiliation | 4 (8) |
| Declined response | 4 (8) |
| Baptist | 3 (6) |
| Methodist | 3 (6) |
| Lutheran | 2 (4) |
| Jewish | 1 (2) |
| Seventh Day Adventist | 1 (2) |
| Apostolic | 1 (2) |
| Importance of religion in everyday life | |
| Declined response | 4 (8) |
| Not at all important | 2 (4) |
| Not too important | 7 (14) |
| Fairly important | 17 (34) |
| Very important | 20 (40) |
| Reported quality of communication about patient's prognosis | |
| Excellent | 14 (28) |
| Very good | 14 (28) |
| Good | 5 (10) |
| Fair | 6 (12) |
| Poor | 2 (4) |
| No communication | 9 (18) |

^a Sums are greater than 50 surrogates because some individuals identified with more than one race/ethnicity

^b sums are greater than 50 surrogates because some individuals cited more than one primary language. GED, general educational development.

Table 2
Demographic characteristics of intensive care unit patients

| Patient Characteristics | Patients (N = 31), n (%) |
|---------------------------------------|--------------------------|
| Age (yrs) | 65.2 (sd 19.7) |
| Gender | |
| Male | 21 (68) |
| Female | 10 (32) |
| Race/ethnicity ^a | |
| Caucasian or white | 15 (48) |
| African American or black | 6 (19) |
| Hispanic or Latino | 4 (13) |
| Asian | 2 (6) |
| Native American | 2 (6) |
| Pacific Islander | 1 (3) |
| Other/undocumented | 1 (3) |
| Admitting diagnosis | |
| Cardiac failure/myocardial infarction | 9 (29) |
| Intracranial aneurysm/ hemorrhage | 4 (13) |
| Sepsis/infection | 3 (10) |
| Respiratory failure | 3 (10) |
| Trauma | 2 (6) |
| Renal failure | 2 (6) |
| Gastrointestinal bleeding | 2 (6) |
| Other | 6 (19) |

^aSums are greater than 31 patients because some individuals identified with more than one race/ethnicity.

Table 3

Coding framework and reasons that participants doubted physicians' ability to accurately prognosticate

| Coding | Reasons |
|--|--|
| Influence of God | |
| ICU outcome predetermined by God | Well, I think God is the one who determines whether you live or die. If it is your time to go, you're gonna go and it doesn't matter whether it's in the ICU or walkin' down the street, or in the operating room. [Doctors] are trained and they use everything that they have to do a good job. But, if your time here on earth is not meant to be, it won't matter what they think or predict |
| Intervention by God in the course of an ICU illness | With my faith in the Lord I know that sometimes He does intervene and miracles do happen. Not that you should be Pollyanna about it, but it has happened many, many times |
| Physicians as divine instruments | I believe that [physicians are] just an instrument of God. I think that God gives them the knowledge to make the right decision and, ultimately, it's God's call. Doctors are just like a little second hand on earth to help. But they can't do the healin' without God |
| Inaccuracy of foretelling the future | |
| I think a doctor can make a guesstimation. But I don't think any human alive can really totally predict whether someone is gonna live or die | |
| Prior experiences with inaccurate prognostication | |
| I have had two experiences where doctors say, "He's not going to make it. He'll be gone." These people lived 15 years and beyond when they were supposed to die in a couple months...That is why I say that I wouldn't always just believe in the doctor's predictions | |
| Current ICU experiences with prognosis | |
| Discordant prognostic estimates from multiple physicians | I just don't listen to the doctors' predictions. When I do listen, I have to sit down and think which one I want to believe. Because sometimes [the prognoses will] go up and down, and some words are true and some not |
| Inexperienced physician | [Belief in prognosis] depends on the doctor's experience. For a doctor, fresh out of med school, who has just book learning, but no practical experience, no, I would not be confident in his judgment |
| Disagreement between surrogates' perception of patient's condition and prognosis | I would have to watch, sit around, and see if she gets better or gets worse. If she worsens, I would just have to wait. And if I see does not get better, and [the doctors] are tellin' me, "She's getting worse, she's getting worse," maybe then I would believe them |

ICU, intensive care unit.

Table 4

Coding framework and reasons that participants believed in the ability of physicians to accurately prognosticate

| Coding | Reasons |
|---|---|
| <p>Prior experiences with accurate prognostication Based on my mother-in-law's case, the doctors told us all the factors that were leading to the [prognosis] that they gave us. They explained all the factors and how she wasn't getting any better, and that there probably wasn't gonna be anything that would make it better. It happened and so I believe them</p> | |
| <p>Current intensive care unit experiences with prognosis Concordant prognostic estimates from multiple physicians</p> | <p>If I heard the [prognostic] opinion of more than one doctor and they were similar, I would certainly believe [the initial prognosis] more</p> |
| <p>Experienced physician</p> | <p>A doctor who's been in the same kind of practice for 30, 40 years, who has seen the symptoms repetitively and has a better grasp of the workings, as the person slowly is walking down that road, I would be more comfortable with their prognosis</p> |
| <p>Agreement between surrogates' perception of patient's condition and prognosis</p> | <p>The way I see it, if they tell me that a patient probably will not survive, when you see it, with your own eyes then I believe 'em. But I'm the type of person, I have to see to believe</p> |