Title

Medical Prophecy in Critical Illness: Understanding Doubt Amongst Surrogate Decision-Makers in the Ability of Physicians to Accurately Prognosticate

Author

Zier, Lucas S

Publication Date

2007-04-01

Medical Prophecy in Critical Illness: Understanding Doubt Amongst Surrogate Decision-Makers in the Ability of Physicians to Accurately Prognosticate

by

Lucas Stange Zier

B.A. (Cornell University) 2004

A thesis submitted in partial satisfaction of the

requirements for the degree of

Master of Science

in

Health and Medical Sciences

in the

Graduate Division

of the

University of California, Berkeley

Committee in Charge:

Professor Jeffrey Burack, Chair
Professor Douglas B. White
Professor Guy Micco
Professor Claudia Landau

Spring 2007

The thesis of Lucas Stange Zier is approved:

Chair ____________________ Date 3/21/07
GMiller ____________________ Date 3/26/07
Claudia ____________________ Date 3/23/07
____________________ Date 4/4/07

University of California, Berkeley

Spring, 2007

To my father Ben, my mother Cindy, and my brother Travis for their constant love and support and for inspiring me to examine end of life care

Acknowledgements

I would first and foremost like to thank my thesis committee for their support and dedication throughout the thesis process. I would like to thank Dr. Douglas White for inspiring this project and for serving as a patient and thoughtful mentor. Through his efforts I have become a more informed student of medicine, a more complete future physician, and a more intuitive researcher. I would to thank Dr. Jeffrey Burack for compelling me to develop my ideas into a viable thesis and for providing perceptive feedback. To Guy Micco I would like to extend my gratitude for his insightful comments, for offering me assistance during difficult periods of my project, and for his continued friendship. Finally, I would like to thank Dr. Claudia Landau for her helpful input during my manuscript development.

Without access to the intensive care units at San Francisco General Hospital and the San Francisco Veterans Affairs Medical Center I would not have been able to conduct this project, and for that I am grateful to Dr. John Luce and Dr. James Frank. I would also like to thank Dr. Coco Auerswald and Jessea Greenman without whose vigilance and assistance I would not have been able to complete this work. I am indebted to Dr. Stephen Eyre for teaching me qualitative methodology, for developing my interview skills, and for consulting on my thesis. I would also like to thank Anne Chipman for her assistance with data analysis and Dr. Ameena Ahmed for assisting me in the early development of my ideas. For all those who provided constant help and encouragement during the thesis process I am greatly indebted. In particular I would like to thank my mother, father, and brother as well as the faculty, staff, and students of the JMP.

Finally, I owe a great debt of gratitude to the family members of the ICU patients, who not only agreed to participate in this study, but who also allowed me to in share their experiences as they dealt with the painful reality of critical illness. I would like to thank them for their generosity and insight during incredibly difficult periods and for demonstrating the true nature of compassion.

Table of Contents

Part I: Belief and Doubt about Physician's Ability to Prognosticate: Interviews with ICU Surrogate Decision-Makers

Part II: Communicating Futility at the Bedside: A Strategy to Facilitate Understanding of Futility Predictions Developed through Interviews with ICU Surrogate Decision-Makers

Appendices

Tables and Figures

Tables

Figures

Past history does not predict the future and physicians cannot predict the future. They can just say, "This is what happens when we try this treatment, and this is what happens when we give this drug. Most o' the time people get better when we do this surgery. Most o' the time people get worse when we try this medication. Which way do you want to go?"

Of course most people are going to go with the best treatment. But we're not coming to physicians to answer the question: "Are you going to find the miracle pill to keep us alive for the rest of our lives?" We're all going to die. The question is: "Are we going to die with dignity?"

-ICU family member before the death of a loved one

Part I

Belief and Doubt about Physician's Ability to Prognosticate

Interviews with ICU Surrogate Decision-Makers

Abstract

Rationale: Experts suggest that the high prevalence of disagreement about prognosis in ICUs is due to poor physician-surrogate communication, yet little is known about surrogate attitudes toward physicians' ability to prognosticate.

Objectives: We sought to determine 1) family attitudes about whether physicians can accurately prognosticate for individual patients in ICUs and 2) how family members use prognostic information in their role as ICU surrogate decision-makers.

Design: Multi-center, cross-sectional study

Methods: We conducted semi-structured interviews with 38 family members of ICU patients. We analyzed the interview transcripts using Grounded Theory methods to inductively develop a framework to describe family attitudes about prognostication. Validation methods included triangulation by multidisciplinary analysis and member checking.

Main Results: Overall, 89% of family members expressed doubt about physicians' ability to prognosticate. Participants identified several distinct reasons why they doubted physicians' prognostic estimates, including prior formative experiences where communicated prognosis was inaccurate, the inherent inaccuracies of predicting future events, and the belief that God could alter the course of the illness. Participants also identified several factors that made them more likely to believe prognostic information from physicians, including the perception that the treating physician was highly experienced, receipt of concordant prognostic estimates from multiple physicians, and prior formative experiences where prognostic estimates were accurate. Despite doubting the accuracy of physicians' predictions, family members unanimously endorsed the importance of physicians discussing prognosis with families. While prognostic information does not appear to be determinative for decision-making, it is highly valued by families for preparatory reasons including arranging for friends and family to say final goodbyes to the patient and readying emotionally for an impending death.

Conclusions: Most family members doubt physicians' ability to prognosticate, yet want to hear physicians' prognostic estimates because surrogates use this information when planning for the future.

Introduction

In recent decades there has been substantial ethical change in American medicine from a model of paternalism to a model of patient autonomy [1]. With the concurrent evolution of life-prolonging technology, the demographic of the dying and critically ill has come to include a significant number of patients who are silenced by illness and are therefore unable to express their autonomous goals for treatment. In 1975, conflict between the principle of respect for autonomy and the ability of medical technology to prolong life came to the forefront when the case of 21 year-old Karen Quinlan was brought before the New Jersey Supreme Court. In their opinion, the justices concluded that, under the protection of an implicit privacy right granted by the Constitution, Karen Quinlan had the right to refuse mechanical ventilation. Furthermore, because she was in a persistent vegetative state, her parents could act as surrogate decision-makers and make a substituted judgment[1] on her behalf [2]. In *Barber v Superior Court* the California Court of Appeal upheld the principle of substituted judgment. [3] Thus was formalized in law the concept of surrogate decision-making, whereby a patient who is unable to communicate is allowed a proxy to act autonomously on the patient's behalf. Since the widespread legal acceptance of this doctrine, physicians and bioethicists have demonstrated the ethical importance of this idea within the autonomy paradigm of medicine. [4-6]

---

[1] The objective of substituted judgment is to respect the autonomy of the incompetent or incapacitated patient by, as much as is possible, imagining that patient's own wishes regarding care permitted. This means that the person authorized to give consent on behalf of such a patient attempts to determine what the patient would have wanted had he or she fully been able to understand the circumstances under which treatment or procedures would be provided. The AMAs statement on withholding and withdrawing life support mandates respect for choices of surrogate decision-makers when made according to proper substituted judgment.

Yet the practice of substituted judgment has undergone considerable change since its inception. The SUPPORT study demonstrated significant deficiencies in communication between family members and physicians, adversely affecting substituted judgment during critical illness. [7] As a result, whereas initially proxy decision-making was the sole responsibility of the surrogate [8], more recent conceptions of this principle have advocated a shared decision-making approach between the surrogate and physician. [9, 10]

Charles et al. outline four key characteristics of the shared decision-making model: (1) that at least two participants, either the physician and patient or physician and surrogate, be involved; (2) that both parties share information; (3) that both parties take steps to build a consensus about the preferred treatment; and (4) that an agreement is reached on the treatment to implement. [11] Research has demonstrated that physician communicated prognosis is important to family members deciding whether to withhold or withdraw life support [12, 13] and thus physician delivery and family member understanding of prognosis is central to successful shared decision-making. [10]

Yet the challenges in communicating prognosis have been well documented. Among these, physicians feel poorly prepared for prognostication, find the act of prognostication stressful and difficult, and believe that patients and family members expect too much certainty and might judge them adversely for prognostic errors. [14, 15] As a result, a number of algorithms have been developed to alleviate these challenges and facilitate communication. [16-19] Yet despite these efforts family members continue to report high rates of misunderstanding about prognosis and poor communication with physicians. [20-22]

Research regarding family-physician conflicts in critical illness has been limited [23], and thus the reasons underlying family-physician misunderstandings about prognosis remain unclear. Experts suggest that the high prevalence of disagreement about prognosis in ICUs is due to poor physician-surrogate communication [24], yet little is known about surrogate attitudes toward physicians' ability to prognosticate. We conducted this study to determine (1) family attitudes about whether physicians can accurately prognosticate for individual patients in ICUs and (2) how family members use prognostic information in their role as ICU surrogate decision-makers.

Methods

Study Design, Patients, and Setting

Between June 2006 and February 2007 we conducted a multi-center, cross-sectional study in three San Francisco hospitals including a university hospital, a county hospital, and a Veterans Affairs hospital. Institutional Review Boards at each hospital approved all procedures.

Interviews with family members of ICU patients yielded data that we analyzed and developed into a conceptual model. This process, called "grounded theory" is a general methodology for developing theory from data that is systematically gathered and analyzed. It is a qualitative research method that is often employed when conceptual frameworks for the topics under study are inadequate. [25]

Each day, one of the study investigators (LSZ) identified eligible family members of ICU patients. Eligibility criteria for enrollment included English-speaking family members of ICU patients who were greater than 18 years of age and who were involved in decision-making for a critically ill patient. After eligible subjects were identified, the attending physician of the ICU patient was contacted in order to obtain consent to approach family members for enrollment. Family members were approached individually to obtain consent for enrollment if the attending physician granted approval. If, after talking with the study staff the participant gave informed consent, a semi-structured interview was conducted and audio-taped.

During the interview, participants were asked a series of open-ended questions. The interviewer followed up participant's responses, pursued appropriate themes as they arose, and sought clarification or elaboration as required. Specifically, participants were asked whether they thought physicians were capable of accurately prognosticating in the ICU setting, whether ICU physicians should provide family members with prognostic estimates, and whether they believed physician communicated prognosis. Sample questions from the initial interview guide included the following: Do you think doctors can accurately predict whether a particular patient will live or die? Why or why not? Should family members of ICU patients believe doctor's predictions when the doctor says that a patient probably will not survive? Why or why not? The interview guide was modified to follow up themes emerging from the data as the interviews and analysis progressed.

Qualitative Data Coding

The audio-taped interviews were transcribed verbatim by a medical transcriptionist and grounded theory methods were employed to develop a framework describing the processes by which family members express doubt or confidence towards physician communicated prognosis. To develop the preliminary coding scheme one of the investigators (LSZ) first employed an analytic method known as open coding whereby a subset of the transcripts were read and text segments that related to a theme or idea were identified and given a conceptual label. As concepts accumulated and distinctions between concepts became more refined, similar concepts were grouped into conceptual categories. A process known as axial coding was then employed whereby the conceptual categories were developed further by comparing the categories between transcripts with an emphasis on identifying causal relationships. Investigators then reviewed the codes with a subset of transcripts and the coding framework was reorganized and modified until all investigators agreed on a final coding framework. [25]

Family members expressed doubt and belief towards prognosis both qualitatively and quantitatively. To limit ambiguity in analysis we defined doubt in prognosis as any statement, quantitative or qualitative, which indicated concern or uncertainty about physician's ability to accurately prognosticate. Belief in prognosis was defined as any statement, qualitative or quantitative, which indicated confidence in the ability of physicians to accurately prognosticate.

Reliability of the Coding

To ensure the reliability of our analysis we employed three validation techniques. Investigators with varied training and backgrounds collaborated during the development of the coding framework in a process known as multidisciplinary analysis. Areas of expertise included critical care medicine, pulmonology, bioethics, end of life care, epidemiology, statistics, and qualitative methodology. Member checking, the process of bringing the analyzed results back to study participants for confirmation and/or modification was also performed.

Finally, using the final coding framework, one investigator (LSZ) coded all of the interviews by listening to the audiotapes and reading the transcripts. Another investigator

(AC) coded 20% of the transcripts in order to assess intercoder reliability. Both coders were blinded to the demographic characteristics of the conference participants. Overall, the kappa statistic between coders for identifying the content of prognostic statements was 0.86. A kappa value that is greater than 0.8 is considered excellent interrater reliability. [26]

Results

Participant Characteristics

Of 45 eligible ICU family members 41 (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 due to a family emergency thereby yielding 38 participants and an enrollment rate of 84%. Demographic characteristics of the ICU family members and patients who participated in the interviews are described in **Table 1**. Among participants, 10 (26%) reported excellent communication by the attending physician about the patient's prognosis while 11 (29%) reported very good communication, 5 (13%) reported good communication, 6 (16%) reported fair communication, and 1 (3%) reported poor communication. 5 (13%) participants stated that there had been no communication by the attending physician about the patient's prognosis. Thus, 68% (26/38) reported good or better communication about prognosis with ICU physicians. The number of family members interviewed for each patient ranged from 1 to 3 with a mean of 1.6 ICU family members per patient. The interviews ranged from 5 minutes 11 seconds to 30 minutes 59 seconds with a mean length of 10 minutes 38 seconds.

Table 1: Demographic Characteristics of Family Members and Patients

Characteristics	Family Members or Loved Ones N - 38 n (%)	Patients N – 23 n (%)
Gender		
Male	12 (32)	13 (57)
Female	26 (68)	10 (43)
Race/Ethnicity*		
Caucasian or White	9 (24)	9 (39)
African American or Black	12 (32)	6 (23)
Hispanic or Latino	10 (26)	4 (17)
Asian	5 (13)	2 (9)
Pacific Islander	1 (3)	1 (4)
Native American	1 (3)	0 (0)
Other/Undocumented	1 (3)	1 (4)
Admitting Diagnosis		
Cardiac failure/myocardial infarction		5 (22)
Intracranial aneurysm/hemorrhage		4 (17)
Sepsis/infection		3 (13)
Respiratory failure		2 (9)
Trauma		2 (9)
Renal failure		2 (9)
GI bleed		2 (9)
Other		3 (13)
Relationship to Patient		
Spouse/Partner	8 (21)	
Child	5 (13)	
Sibling	10 (26)	
Friend	3 (8)	
Parent	5 (13)	
Other relative	5 (13)	
Other	2 (5)	
Level of Education		
8th grade or less	0 (0)	
Some high school	3 (8)	
High school diploma or GED	11 (29)	
Some college or trade school	12 (32)	
4 year college degree	4 (11)	
Graduate or professional school	8 (21)	
Primary Language+		
English	37 (97)	
Spanish	6 (16)	
Cantonese	3 (8)	
Mandarin	1 (3)	
French	1 (3)	
German	1 (3)	
	Mean (SD)	**Mean (SD)**

Age (years)	52.8 (13.9)	63.1 (21.7)

[*] Sums are greater than 38 family members/loved ones and 23 patients because some individuals identified with more than one race/ethnicity

[+] Sums are greater than 38 family members/loved ones and 23 patients because some individuals cited more than one primary language

Participant Belief and Doubt in the Ability of Physicians to Accurately Prognosticate

Participants doubted the ability of physicians to accurately prognosticate in 89% (34/38) of interviews while 55% (21/38) believed in the accuracy of physician's prognostications. Percentages do not total to 100 because certain participants doubted and believed in the ability of physicians to accurately prognosticate at different points of the same interview. **Table 2** describes the reasons that surrogates doubted and believed physician prognostications. Reasons for doubting or believing physician prognostications fell into three categories: belief systems, formative experiences, and alternative interpretations.

Table 2: Reasons for Doubt and Belief in Prognostic Estimates

	Reasons for Doubt	Reasons for Belief
Belief Systems	Divine Influence Inaccuracy of Foretelling the Future	
Formative Experiences	Discordant Secondary Opinions Inexperienced Physician Prior Experience Improving Illness Trajectory of Patient	Concordant Secondary Opinions Experienced Physician Prior Experience Declining or Unchanging Illness Trajectory of Patient
Alternative Interpretations	Worst Case Scenario Refusal	Absolute Truth

Belief Systems

Analysis of the transcripts yielded two systems of belief which certain family members employed when addressing whether they believed prognostic estimates: the influence of God, and the inherent inaccuracy of foretelling. These systems of belief were identified when coding demonstrated that the participant answered questions using a consistent theme.

Influence of God

The most frequent system of belief was characterized by the involvement of God in influencing the outcome of an ICU admission. 84% (32/38) of participants felt that God influenced the outcome of an ICU admission either through predetermination, direct intervention, or by using physicians as divine instruments.

53% (20/38) of participants believed in divine fatalism, stating that ICU outcomes were predetermined by God and therefore that prognosis was unknowable to physicians:

> Frankly, I think it's whether God says it's his turn...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, I ... he's only human. He doesn't have all of the answers. And I believe that God does. So, you know, He may choose to not let that person live and use that disease, or that problem, to take his life or to remove him. But, if He ... if He is not finished with that person yet, has a reason for that person to still be here, then I don't think what the doctors say makes any difference, he'll survive.

Similarly, 39% (15/38) of participants believed that God might directly intervene in the course of an ICU admission, and therefore that physician communicated prognosis was inherently inaccurate as it could not take this factor into account:

> [Physicians] can say, "Well, this person not going to survive ..." in the doctor's hand and then, here comes God play 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 heart beat. And I think that's the hands of God...

Finally, 16% (6/38) of participants felt that physicians were tools of God and therefore incapable of prognosticating with absolute certainty:

> …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, just like my daughter, ultimately it's God's call, you know.
>
> Doctor's just like a little second hand on earth to help. But they can't do the healin', or whatever, without God…

Inaccuracy of Foretelling the Future

Although less prevalent than the influence of God belief system, 34% (13/38) of participants believed that the practice of foretelling the future was inherently inaccurate and therefore that physician communicated prognosis was inherently inaccurate:

> INT: Do you think that doctors can accurately predict whether a patient will survive in the intensive care unit?
>
> SUB: … I think they're really guessing. I think they really don't know and the family members wanna know. They wanna know whether, you know, a person's going to get better or not. But, you really can't predict. Just like you can't predict when a virus is going to affect one person vs. another, you know. So, uhm, I think they try to do the best they can to do a good educated guess. And the better education they have, the better that they're guessing and weighing all the factors, but I believe it's a guess. And I have to tell you that I have a personal belief that, when doctors stop practicing and get it right, I'll go to them.

Another participant stated the following:

> …there's too many factors. I mean, all of us would like to say that a person will live, but we don't know that, for certain. And as humans, we are … we make mistakes. I mean, no one wants to make a mistake, especially when it's a life and death situation. But, you can't predict. That's like, I go out that door and… and I have all the intentions that I'm gonna be all right, but who knows? There could be someone on the other side that could be mentally ill and could end my life … or our lives. But … so we can't predict. No one can predict the future. If they could, they would be quite rich.

Formative Experiences

Participants identified various experiences which influenced belief in prognosis: the perceived experience of the physician, the variability of prognostic estimates from multiple physicians, prior experiences with prognosis, and the stability of the illness trajectory of the patient

Prior Experiences

Prior experience with medical prognostication was a reason for both doubting and believing prognostic estimates. However, prior experiences were far more associated with doubt than belief. 34% (13/38) of participants identified prior experiences which influenced them to doubt physician communicated prognosis. These experiences were most often associated with first hand experiences:

> [Family members] should believe that that's 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.

A participant who was a nurse provided a similar perspective:

> Seen it happen too many times. They were dead wrong. Well, I've been at this hospital for 27 years. I've been in their NICU...And I cannot tell you how many times we have thought a baby was just ... you know, just came in, this little train wreck. Had everything in the world wrong with him and I have seen babies actually just sittin' there waitin' to be pronounced dead and the mother of one of 'em does my hair now. She ... you know, this girl is goin' to college and she's gonna be a pediatrician. You know, we have babies that you know the parents stick with 'em and the nurses stick with 'em, because the parents want to stick with 'em. You know, 'cause we're like "O-o-o-oh," you know, "I don't think little Johnny's gonna be there, tonight, when I get back." And little Johnny is still there. And now, little Johnny is graduatin' high school. You know I ... My mother-in-law's another case, you know. Seen it too many times.

In contrast 8% (3/38) of participants related prior experiences which influenced them to believe physician communicated prognosis, as in the following example:

> INT: Do you think family members of ICU patients should believe doctors' predictions, when a doctor says that a patient probably will not survive?

> SUB: Uhm, yes. They should. Because uhm, because it happened to me, with my mother. They... the doctors told me, "She's not gonna live through the night. She's gonna pass away." And she did...the doctors explain that since she was advancing age that it was gonna be hard uhm, for her to ... to have those pipes that they put them to ... oxygen, I think it is. That it was better if we would let her die in peace, with the family. But since we were in a lot of panic, we didn't want her to die. So, we told 'em to put the tubes ... and they didn't work. She died.

Therefore past experiences with family members or medical situations affected whether participants doubted or believed prognostic estimates. However, the vast majority of these experiences facilitated doubt.

Prognostic Estimates from Multiple Physicians

Among participants 13% (5/38) identified discordant prognostic estimates as a factor that would cause doubt in the prognosis communicated by the primary treating physician. A similar proportion, 15% (6/38), stated that other prognostic estimates concordant with the primary physician's estimate would improve belief in the communicated prognosis. Therefore the variability of prognostic estimates affected family member belief in prognosis. One man described both aspects of this dichotomy:

> SUB: Well, that's a tough decisions right there. That's life or death. Uhm, I feel they should take his word for it, but I don't feel like ... like they should give him a 100% or your decision to him. I mean, it's tough, but uh, I mean you can't really like ... If you love your pers... you love the person that is in there, then you'll take his word for it, but you're not 100% sure that he's right. You might want to get another opinion or

> somethin'. Yeah. 'Cause you're not ... you can't just trust one person's word for ... for that situation. You can't! Yeah, you can't.
>
> INT: Mhmm. So, if you ... like say like a lotta doctors were telling you that somebody probably wouldn't survive, would you be more likely to believe the doctors?
>
> SUB: Probably, probably. If more doctors tell you the same thing, yeah. Yeah you will believe it more. But if only one doctor tells you, then can't really just trust that one person's word...because you're not sure, maybe he's trying something ... maybe another doctor will try something else that he hasn't tried, maybe...And then you just want to like just try different opinions, different things...Yeah. You don't want to just put it all on him and then that's it.

One woman with a daughter in the ICU addressed the complexity of interpreting differing prognostic information:

> 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, she ... really her lung's really bad." That she might ... they take the ventilator off, she might die for not catchin' on right. Then one, "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 really, you don't know what to believe in.

Perceived Experience of Physician

Perception of the communicating physician as experienced or inexperienced also affected belief in prognosis. 11% (4/38) of subjects described how their perception of the communicating physician as inexperienced would cause doubt in the prognostic estimate:

> [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.

In contrast, 29% (11/38) of participants related how they would believe the communicated prognosis if the physician was perceived as very experienced. An adult son of an ICU patient stated the following:

> SUB: 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, yes, I would be more comfortable with the … what he would say.
>
> INT: And let's say we're talking about a very experienced doctor. Would you be confident in assuming that they could accurately predict than less experienced doctors?
>
> SUB: I would … my expectations would be higher of him having better judgment, over a newer doctor.

Stability of Illness Trajectory of the Patient

26% (10/38) of participants also described the need to see the patient in a poor physical state over time before believing poor prognostic estimates:

> INT: Do you think family members of ICU patients should believe doctors' predictions when the doctor says that a patient probably won't survive?
>
> SUB: Well, it depends on how far along that person is. But, you know, the way I see it, if they tell me, when you see it, with your own eyes, and you know, then I believe 'em. But, I'm the type of person, I have to see to believe.

Another subject described how the medical equipment would provide clues as to the physical state of the patient:

> … You see a lotta stuff on TV. Ok, you see ER or that other one, Grey's Anatomy or, you know, those medical shows and you know what goes on. So, if you see like a defibrillator there, you know, and something that's not out of the ord… something that's not supposed to be there, in your mind. All right, so you walk into a hospital room and see all these different machines in there, you gotta think well, first of all, if it's a breathing machine, and as long as it's properly explained by the doctors, then it should alleviate that. But once you've seen a breathing machine, you know that the person's not breathing on their own, which is not good, ok?…People should understand that, given the high tech world and how you can determine stuff from just looking at what's going on there. But whether a person lives or dies, I think that maybe the amount of equipment that's in there [explains a lot].

Alternative Interpretations

For some participants, prognostic estimates carried alternative meanings. For these subjects doubt or belief in prognosis was dependent on the alternative interpretation of the prognostic estimate.

Worst Case Scenario

11% (4/38) participants felt that a communicated prognosis represented the physician's effort to convey the worst-case scenario of the patient's condition. As a result, these participants doubted the absolute accuracy of the prognostic estimate:

> I feel that they ... I feel that the doctor gives you more like the... like the worst of it, I think. So, I think he gives the worst of it, so you won't be surprised and if anything better than what they tell you happens, then it was like it's better for the family, it's better for the person. I ... that's what I feel they do. I mean, I'm not sure if that's what they do, but ...

Absolute Truth

In contrast to those participants, 21% (8/38) of subjects interpreted prognosis as absolute truth and therefore believed prognostic estimates:

> I feel like the doctors are right, you know, with what they say [about prognosis]. So ... I mean, they're not gonna sit there and tell you something that's gonna hurt you, even though, you know it does affect the family. But they're not gonna sit there and tell you something that's not true.

Refusal

While not an alternative interpretation but more a lack of interpretation, 21% (8/38) described a process of actively refusing or being unable to accept a poor communicated prognosis. The sister of an ICU patient described this process in the following manner:

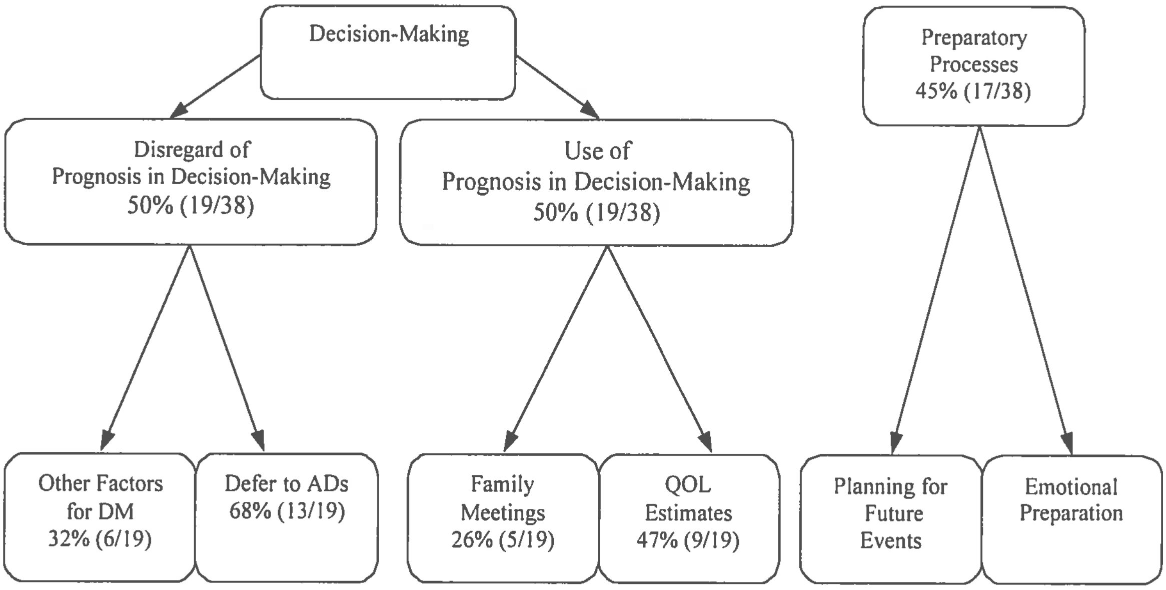
> INT: So, do you think family members of ICU patients should believe doctors' prediction, when a doctor says that a patient probably will not survive?
>
> SUB: Well, it's one o' these things, where you believe it, but deep down within, you don't want to, so you really don't, if they say they're not gonna make it. You believe it, but you don't want to believe it...Because it's not something you want to happen. So you ... you uhm, oh, what do I want to say? You...I guess, put your head in the sand and say it's not gonna happen. However, when it does happen, you were told and you ... it's a possibility it could happen, but you don't want it to happen, so you kind of put your head in the sand, 'til it does.

Participant Attitudes Towards Disclosure of Prognostic Estimates

Although 89% of subjects expressed some doubt about prognostic estimates, 100% (38/38) of participants wanted physicians to disclose prognostic estimates, even when the communicated prognosis was poor.

Participant Use of Prognostic Estimates

Figure 1 describes the varied use of prognostic information among participants. 50% (19/38) stated that physician communicated prognosis would play no role in their decision to limit life-sustaining treatment for a patient in the ICU. Of these participants 68% (13/19) indicated that the decision to limit life-sustaining treatment would be based solely on advance directives or orally communicated patient wishes while 32% (6/19) indicated that it would be based on other factors.



(DM: Decision-making, ADs: Advance directives, QOL: Quality of life)

Figure 1: Participant Use of Prognostic Information

Of the participants who indicated that prognostic estimates would play a role in their decision to limit life-sustaining treatment, 47% (9/19) stated that the patient's anticipated quality of life following recovery would be a necessary adjunct to the prognostic estimate when making decisions about life support. One woman described this need for quality of life estimates:

> If my mother, say, had a really debilitating stroke and stuff, you know, would I, uh, want to keep her on a vent for ever and ever and stuff like that? No, I wouldn't, you know. I haven't really talked to her about it, but she's the type of woman who, I don't think would want to be kept alive, in definitely, if she's gonna be, you know, just there, you know...You know, if she's just gonna be you know, this vegetable and she's not gonna be able to enjoy the Giants games, when it comes on, you know. I have to drive her around now...if she gets debilitated to the point where she can't function and she's just this little vegetable, I think that she would want to just be allowed to go.

For 26% (5/19) of participants who indicated they would use prognosis in decision-making, prognostic estimates would trigger intra-family meetings where decisions about life support would be discussed.

Yet the act of prognostication facilitated important processes other than life support decision-making. 45% (17/38) stated that prognostic estimates are important to communicate because they allow the family to prepare for the possibility of an impending death. Preparation includes bringing in family members to say final farewells, initiating funeral arrangements, and preparing emotionally for the loss:

> That's important because uh, we need to make arrangements. We need to know uhm ... we need to bring family, at least to see their loved one, before she passes away, to bring all the family together. Uh, make arrangements and so we'll know, ok, if she ... if we need to get all funeral arrangements.

Another participant described the process of emotional preparation:

> Because, when you have … you are a member of the family, you want to know and you want to have … to realize and to be prepared what's going to happen. If you think, in your mind, that she's going to survive and she's not, that's going to be a big … a big … a big strong decision after, that you have to face. But I think, if the doctor said that she has a small chance, you … you … it's … you're getting use … by the time you are waiting through the surgery that she might not … she won't be able, probably, to survive, well, your mind is ready to accept the fact that she's dying … she has died. Ok?

Thus half of the participants stated that prognostic estimates would factor into decisions about life-support while half said they would not. However, even among these participants, communicating prognostic estimates was important because surrogates used this information to plan and prepare for the future.

Discussion

Although miscommunication between physicians and surrogates during critical care decision-making has been well documented [7, 21, 22, 27], this is the first attempt to examine whether surrogates believe prognostic information and furthermore how this information is used during critical illness. There were varied reasons that participants believed or doubted the ability of physicians to accurately prognosticate. Certain participants held systems of belief about God or the general ability of people to foretell the future which led them to doubt the accuracy of prognostic estimates. Notably there were no identified systems of belief which led to belief in the ability of physicians to accurately prognosticate. Other subjects described formative experiences as reasons to both doubt and believe in physician's prognostications, such as situations where previous prognostications either came to pass or did not. Also, in accordance with prior studies, some of our subjects drew upon formative experiences with television shows when explaining the reasons for doubting the accuracy of prognostic estimates. Indeed, previous research has demonstrated that medical television shows can provide individuals with unrealistic expectations about medical outcomes [28, 29] and our research not only corroborates this finding but also demonstrates how it can influence decision-making during critical illness. Finally, some participants interpreted prognostic statements in specific ways such as worst-case scenarios or absolute truth. Depending on the interpretation, participants were inclined to doubt or believe the prognostic estimate.

Perhaps the most striking finding from this study is that while 89% of participants doubted the accuracy of physician's prognostications, they unanimously endorsed the importance of discussing prognostic estimates with families. 50% of participants stated that communicated prognosis would play a role in decision-making about life support, while the other 50% said a physician's prognostications would not play a role. This finding is striking given that current critical care communication strategies stress the importance of communicating prognostic estimates solely for shared decision-making. [10] This research suggests that there are many surrogates who do not use prognostic information during decision-making, preferring to defer to advance directives or simply disregarding estimates. However they may nonetheless value the information because it allows them to prepare for the possibility of an undesirable ICU outcome.

Thus for surrogate decision-makers of critically ill patients, both belief in the ability of physicians to accurately prognosticate, and surrogates' use of prognostic estimates in decision-making may be limited. Yet these findings should not discourage physician prognostication. Instead it perhaps places greater value on the need to communicate prognostic estimates because family members use this information in other ways, most importantly to plan for the possibility of an impending death. Christakis has argued that achieving a good death, or one that is consistent with a patient's wishes, often depends on some advance warning. [15] This research suggests that even for those surrogates who stated that they would not incorporate prognostic estimates into decision-making, the act of prognostication may trigger preparatory family processes which ultimately facilitate a better death for both the patient and family. The patient and family may be offered the opportunity to say final farewells, and the family may be offered the opportunity to prepare emotionally for the loss, as well as to make arrangements for ceremonies following the death. Even if a low prognostic estimate of survival turns out to be false, all participants felt it better to be prepared for an undesirable outcome than to be completely uninformed.

Thus, more than ever physicians have a duty to communicate prognostic estimates if not for decision-making than for preparation. We propose that prognosis communication should be framed in a manner that better addresses how surrogates interpret and use prognostic estimates. Research in risk communication has led to an evidence base about appropriate and effective ways to communicate prognosis to patients and their families. Experts suggest that prognostic estimates be framed in numeric expressions of risk, such as "two out 10 people survive this procedure," rather than qualitative expressions of risk, such as "it is unlikely that someone will survive this procedure." [30] Furthermore since prognostic information refers to populations of patients rather than individual patients, research suggests framing prognostic estimates in terms of outcomes of populations. Thus the communicating physician should state " about 20 out of 100 people with this illness die" rather than "your loved one has a 20% chance of dying from this illness." [31] Finally, because all methods of prognosis communication are open to error, and in some cultures there exist strong reasons to avoid prognostic information [32, 33] experts recommend an "Ask-Tell-Ask" approach to prognosis communication. Under this model, physicians first ask permission to discuss prognosis and subsequently ask families their understanding of the prognosis after the discussion to ensure comprehension. [34]

We strongly advocate adhering to these guidelines but suggest some important additions. Prior to communicating prognostic information to family members physicians should compare prognostic estimates in an interdisciplinary team meeting. Research has demonstrated that averaging prognostic estimates from multiple physicians improves prognostic accuracy [15] and this meeting may provide an appropriate forum to do so. However, it furthermore allows the primary communicating physician to assess the concordance or discordance of multiple estimates for eventual communication to family members. Our research suggests that multiple concordant estimates are likely to enhance surrogates' faith in communicated prognosis.

During family conferences physicians should seek permission to communicate prognostic information. If permission is granted we recommend first assessing the ways that family members may interpret the estimates. Our experience conducting interviews with ICU surrogates suggests that asking the simple question "What do you think determines whether your loved one will survive this hospitalization?" can provide rich insight into the ways that particular family members interpret prognostic information. During the discussion that ensues it may be appropriate for physicians to probe for belief systems that affect how prognosis is interpreted because it will be important to acknowledge these belief systems during communication. We recommend also asking if family members have had prior experiences with prognostic information, be it experiences inside or outside of the medical setting.

When a prognostic estimate is communicated we suggest communicating a prognostic average, and referring to it as an average, and subsequently communicating each individual estimate that was included in the average. From this information family members should not only receive a more accurate prognostic estimate, but also an understanding of how multiple physicians estimated the patient's chances of survival, and furthermore of the degree to which these estimations were similar or different. It is also imperative that the communicating physician frame the prognostic estimate as occurring over a particular time interval and that the physician explain what information was used to formulate the estimates. Finally, if family members have communicated prior experiences with prognosis or belief systems that will affect interpretation of the estimates, physicians should make reference to these factors during communication and explain how they relate to the prognostic estimates. Thus, a hypothetical statement of prognosis to an ICU family member who wants prognostic information and believes God can influence the outcome of the ICU admission may take the following format:

I met with two other doctors and we discussed your loved one's chances for surviving this ICU admission. One doctor who specializes in taking care of the heart estimated that out of 100 patients with your loved one's condition, about 10 would survive. He based this prediction on multiple heart exams, lab tests, and general observation of your loved one for three days. Another doctor who specializes in caring for the lungs estimated that out of 100 patients with your loved one's condition 50 would survive. She based this prediction on lab tests, and observing your loved one for one day. I specialize in taking care of patients in the ICU and I predict that out of 100 patients with your loved one's *condition 20 would survive. I am basing this prediction on lab tests, experience that I have treating patients in a similar condition, and observations that I have made over one week. I can explain these observations in more detail if you would like. There is some information that says that when you average different doctor's predictions together it is more accurate than individual predictions. I averaged my prediction with the other doctor's and that average indicates that out of 100 patients with your loved one's condition, 27 would survive. From our discussion I understand that for you and your loved one, God will play a major role in affecting the course of their illness. I think it is important that you pray, speak with your religious clergy, and do whatever you need to do to engage God in this situation. I want to emphasize that while we have worked hard to estimate your loved one's chances for survival, these are all predictions that were based on our experience, lab tests, and observation of your loved one.*

Following communication of the prognostic estimates, physicians should ask if the family understands what the physician has communicated and provide the opportunity for the family members to ask questions and receive clarification. This is an appropriate time for physicians to determine if family members are interpreting the information in an alternative manner such as the absolute truth or the worst-case scenario. Physicians may directly ask about alternative interpretations, or may emphasize that the communicated prognoses were predictions and not the truth or worst-case scenario.

Even the best prognosis communication strategies are irrelevant if physicians do not actually communicate prognostic estimates. Research has identified a variety of barriers toward communication including the perception that family members and patients expect too much certainty and might judge physicians adversely for prognostic errors. [14, 15] While physicians should make every effort to communicate as accurate a prognostic estimate as possible using strategies previously outlined, our data suggest that the vast majority of surrogates expect uncertainty in prognostic estimates and therefore do not require absolute accuracy. Thus the perception that families expect too much certainty when physicians prognosticate seems unfounded and this perception should not limit communication of prognostic estimates.

This study has several limitations. By defining doubt in prognosis as any statement which indicated concern or uncertainty about physician's ability to prognosticate perfectly, and belief in prognosis as any statement which indicated confidence in the ability of physicians to accurately prognosticate, we may have arbitrarily grouped participants into distinct categories: those who doubted the accuracy of physician prognostications, and those who believed in physician prognostications. Our experience conducting this research suggests that there are degrees of doubt and belief in prognostic estimates that were not entirely captured in our analysis as evidenced by the fact that certain participants both doubted and believed in the ability of physicians to prognosticate in the same interview using our definitions. Furthermore while participants were not aware of the specific aims of the study, responses to the hypothetical interview questions may reflect participants' anticipated reactions and responses to certain scenarios rather than their actual reactions.

While this research has addressed preliminary questions about surrogate interpretation and use of prognostic information during critical care decision-making it also highlights the importance of further research in this area. Perhaps the most clinically applicable finding from this study is that surrogates use prognostic information in preparatory processes. Future research should attempt to characterize how prognosis communication leads to these processes so that effective ways can be developed to communicate prognostic estimates for surrogate use in preparatory processes. We have also outlined specific guidelines for communication of prognostic estimates. Research should assess the effectiveness and usability of these guidelines in actual ICU conferences. Finally, it is evident from our data that there are levels of doubt and levels of belief in the ability of physicians to accurately prognosticate yet, as stated previously, our preliminary analysis of this finding was limited in its ability to delineate these differences. It is important that future research clarify these levels of doubt and belief so that family members are not simplistically viewed as believers or doubters of prognostic information in the clinical setting. We anticipate that this dichotomy would facilitate more conflict than understanding between physicians and surrogates during critical care decision-making.

Effective and appropriate communication of prognostic estimates is vital to surrogate decision-making in the ICU. Physicians should understand that family members need prognostic information for a variety of reasons, and while some may decide not to use this information in the decision-making process, the simple act of prognostication may trigger preparatory processes that are important for both patients and families during critical illness. Paramount among these processes is the ability for families to plan and prepare for the future.

Part II

Communicating Futility at the Bedside

A Strategy to Facilitate Understanding of Futility Predictions Developed through Interviews with ICU Surrogate Decision-Makers

Abstract

Rationale: Although many physicians and ethicists accept futility as a rationale for limiting life support in certain circumstances, little is known about the attitudes of surrogate decision-makers toward physicians' ability to predict quantitative futility or whether such prognostication would sway them to stop life support.

Objectives: We sought to determine 1) the attitudes of ICU family members of critically ill patients about the ability of physicians to predict medical futility and 2) how ICU family members would incorporate statements of futility into decision-making about life support.

Design: Multi-center, cross-sectional study

Methods: We conducted semi-structured interviews with 38 family members of ICU patients. Using Grounded Theory methods we developed a framework to describe family member attitudes towards the futility rationale to limit life support. We also presented subjects with a hypothetical scenario of a critically ill patient and used a modified time trade-off to vary physicians' quantitative prognostic estimates and asked them to indicate the prognosis at which they felt it would be appropriate to withdraw life support. Validation methods included multidisciplinary analysis and member checking.

Main Results: 61% of participants expressed doubt about physician's ability to predict medical futility. Yet although a significant number of participants doubted the ability of

physicians to predict quantitative futility, data analysis revealed a multi-step process that participants engaged in when determining the accuracy of physician's futility statements. This process was not based on participant's doubt or belief in the ability of physicians to predict futility, rather it consisted of forming an assessment of the patient's condition, comparing that assessment with the physician's futility prediction, and then judging the perceived accuracy of the statement and its utility in decision-making. In the modified time tradeoff analysis, although the likelihood of continuing treatment decreased as prognostic estimates of survival decreased, 18% of participants indicated that they would continue treatment if a physician indicated that there was zero chance for the patient to survive.

Conclusions: Doubt about physicians' ability to predict medical futility is common among ICU surrogates. Yet by actively taking surrogates to the bedside of the critically ill patient and visually explaining how a determination of futility was reached, communicated futility could lead to trust and understanding between surrogates and physicians and facilitate shared decision-making.

Introduction

Definitions and conceptions of medical futility date to the era of Hippocrates for whom one of the three major goals of medicine was "refusal to treat those who were overmastered by disease." [35] Throughout much of medical history, little effort was devoted to developing the concept of futility because, as Fine and Mayo explain, it was reasonably easy to know when a patient was overmastered by illness. [36] However, as life-sustaining technology improved in the latter half of the twentieth century, the ability of the physician to determine when a patient was overcome by disease, and therefore that treatment would be ineffective, became more difficult. Nonetheless, studies began to appear that discussed the physiologic ineffectiveness of life-sustaining interventions for certain classes of patients. [37-39]

In response to this problem, by the early 1990s, the medical profession began efforts to formally articulate the concept of medical futility. A number of initial approaches promoted a quantitative methodology whereby a treatment is considered futile when there is a low probability that it will achieve specific physiologic objectives. Perhaps the most widely known quantitative definition is by Schneiderman et al. which asserts that if an intervention does not work in at least 1% of attempts it should be considered futile. [40] This conception of futility has been refuted both because research has demonstrated that physicians cannot reliably estimate prognostic outcomes [15, 41], and because as the VHA National Ethics Committee has postulated, "patients might reasonably choose a very small chance of leaving the hospital alive-even 1 in 1 million-over certain death." [42] Similarly, attempts to define futility and identify futile care for individual patients based on statistical severity of illness models [43, 44] have been criticized due to the inability to translate these models to settings other than where they were developed. [45] Thus consensus has been that such models are not useful for identifying futile care for individual patients. [46]

Qualitative approaches to futility are based on the assumption that physicians should not be required to provide treatments to achieve objectives that are not worthwhile medical goals. [42] Evaluative conceptions of qualitative futility are based on the *value* of the proposed outcome. Value is defined not only by medical worth but psychosocial worth as well. Thus continuing mechanical ventilation for a patient with metastatic cancer because a close family member is in transit to say a final farewell to the patient could be considered appropriate because there is social value to the intervention.

In physiologic futility the definition is couched in terms of whether an intervention offers the *reasonable prospect* of a desired physiologic outcome. Thus attempting to treat metastatic cancer with antibiotics would be considered physiologically futile by this rubric. Rubin has argued that the predictive claim of qualitative futility always includes a value based evaluative component and therefore when physicians decline treatments, patients and families are not asked for input but simply told of the refusal. [47] Therefore, because current paradigms of ethics stress patient autonomy and shared decision-making, the idea that a physician could unilaterally determine the appropriateness of medical goals and interventions has been criticized from an ethical basis. [48]

There has been little clarification from the legal community. Both the *Wanglie* [49] and *Baby K* [50] cases never fully addressed the question of futility. In *Gilgunn v Massachusetts General Hospital* [51] a jury found that the hospital and attending physicians were not liable for discontinuing ventilator support on the basis of futility, however, the case was a lower court ruling and not an appellate opinion and thus did not set any legal precedent. [42]

As debate over medical futility progressed with little definitive resolution, institutions developed policies for addressing possible cases of futile care. [52] In 1999 the AMA Council on Ethical and Judicial Affairs issued a report advocating a fair process[2] approach in futility cases. Since the dissemination of this report in the medical literature both California and Texas have adopted statutes [53, 54] providing for the resolution of cases of medical futility using a process approach similar to the one outlined by the AMA report. Yet these fair process approaches to futility continue to be debated as experts worry about the potential for coercion, the competing definitions of futility and "medical appropriateness," and the role of ethics committees in such an approach. [55]

Although formal cases of conflict between physician and surrogates regarding medical futility are relatively rare [56, 57] research has demonstrated that they are a very common source of ethics consultations. [58, 59] While steps have been taken to articulate a

---

[2] Most experts now concede that an objective, concrete definition of futility is unattainable. Therefore, they recommend adopting an approach for mediating futility cases that is based on sequential steps aimed at resolving conflict. This has been termed a fair process approach.

definition of medical futility and develop approaches to resolve conflicts between physicians and decision-makers, medical futility remains an area of controversy. The vast majority of disagreements about futility involve surrogate decision-makers and physicians because patients are typically incapacitated. Yet despite this fact there has been little research investigating how surrogates view medical futility. By speaking directly with surrogates in this study we sought to determine (1) the attitudes of ICU family members of critically ill patients about the ability of physicians to predict quantitative medical futility and (2) how ICU family members would incorporate quantitative futility statements into decision-making about life support.

Methods

Study Design, Patients, and Setting

Between June 2006 and February 2007 we conducted a multi-center, cross-sectional study in three San Francisco hospitals including a university hospital, a county hospital, and a Veterans Affairs hospital. Institutional Review Boards at each hospital approved all procedures.

Interviews with family members of ICU patients yielded data that we analyzed and developed into a conceptual model. This process, called "grounded theory" is a general methodology for developing theory from data that is systematically gathered and analyzed. It is a qualitative research method that is often employed when conceptual frameworks for the topics under study are inadequate. [25]

Each day, one of the study investigators (LSZ) identified eligible family members of ICU patients. Eligibility criteria for enrollment included English-speaking family members of ICU patients who were greater than 18 years of age and who were involved in decision-making for a critically ill patient. After eligible subjects were identified, the attending physician of the ICU patient was contacted in order to obtain consent to approach family members for enrollment. Family members were approached individually to obtain consent for enrollment if the attending physician granted approval. If, after talking with the study staff the participant gave informed consent, a semi-structured interview was conducted and audio-taped.

During the interview, participants were asked a series of open-ended questions. The interviewer followed up participant's responses, pursued appropriate themes as they arose, and sought clarification or elaboration. Specifically, participants were asked about their attitudes towards statements of medical futility. Sample questions from the initial interview guide included the following: If a doctor thought there was absolutely no chance for your loved one to survive the hospitalization, would you believe the doctor? Why or why not? Would information about your loved one's chances for surviving affect how you would make decisions about whether to continue full life support? How ?

Following the interview participants were presented with the following scenario:

> Imagine that for the past two weeks, your loved has been in the ICU because of a life-threatening illness. During this time, s/he has been on a mechanical ventilator because s/he is not able to breathe on her own. A ventilator is a machine that breathes for your loved one. It involves a tube being placed through your loved one's mouth and into their windpipe. While on the ventilator your loved one has not been able to eat, talk, or get out of bed. S/he has been fed through a tube placed through his/her mouth and into his/her stomach. Friends and family have been able to visit your loved one, but they have not been able to stay with them all the time. The ventilator occasionally has been uncomfortable for your loved one, but doctors have given him/her medicines to help. The medicines have kept your loved one sleepy most of the time.
>
> The main doctor come to you and explains that your loved one has not improved as quickly as hoped. He informs you that in order to have any chance of surviving, your loved one will need to remain in the ICU for 1 month followed by 1 one month of

> rehabilitation in a nursing facility. This plan of care would involve the placement of a surgical breathing tube in his/her neck. In addition, a surgical feeding tube would be placed into his/her stomach through their skin. If your loved one survived, the doctors think that he/she would be able to return to the same level of functioning s/he had before this hospitalization.

Following this scenario participants were told that the patient's estimated chance of survival was X% with X taking on the values of 100%, 80%, 50%, 20%, 10%, 5%, 1%, <1% and 0%. For each orally communicated value of X subjects were shown a visual depiction of the survival estimate. The graphic depiction of an estimated 50% chance of survival is shown in **Figure 1** as a reference. For example, the participant was asked, "Do you think it would be appropriate to pursue the treatments I just mentioned for your loved one if the doctors felt there was a 100% chance of survival?" as the participant was shown the graphic depiction of an estimated 100% chance of survival. If the participant answered yes, than the question would be repeated with an 80% chance of survival. This process continued until the survival benefit was not deemed sufficient to continue the described treatments. Thus for each value of X there were two options: withhold treatment or consent to the treatment plan.

Several methods are available for assessing treatment preferences including the standard gamble and time tradeoff. [60] Research has demonstrated that different methods yield different results [61-63], however, studies have not demonstrated that one method is better for assessing preferences than any other. We chose the modified time tradeoff technique described above, which is similar to the method employed by Lloyd et al. [12], to facilitate participant understanding of the scenario and to allow comparison of our data to similar studies. Previous studies have successfully employed this methodology for treatment tradeoffs and have found it extremely successful as a way to accurately and efficiently communicate with study participants. [12, 64-66] The form of visual probability communication used in adjunct with verbal communication during communication of the sequential survival estimates has been shown to be an effective form of risk communication in the medical setting. [30, 67]

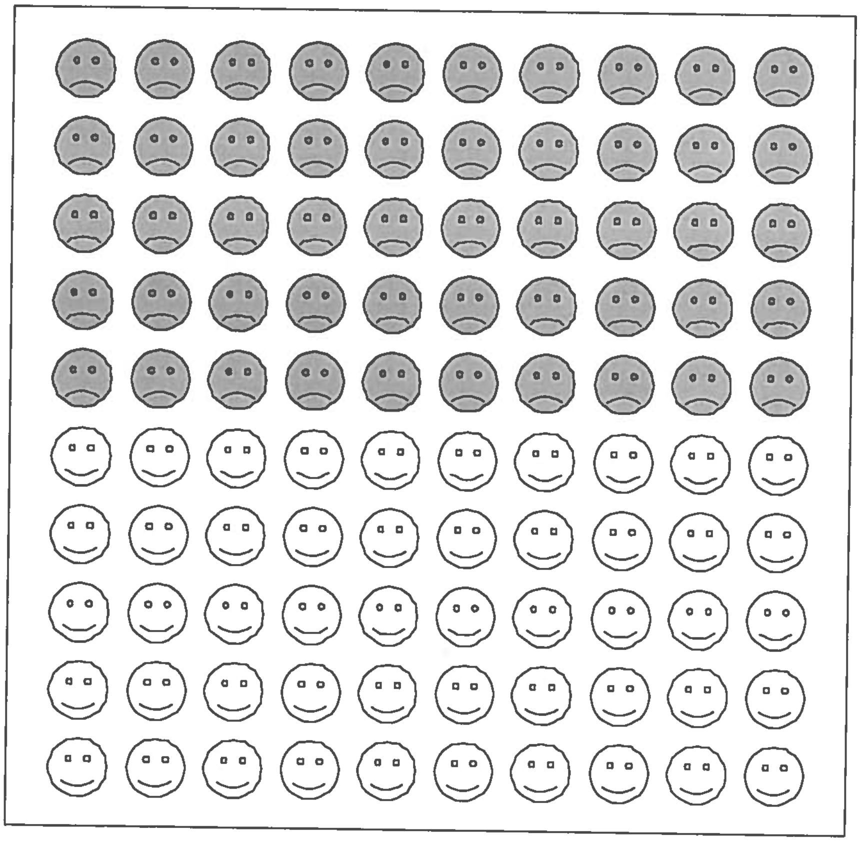


Figure 2: Visual Aid for Estimated 50% Chance of Survival used for Modified Time Trade-off

Qualitative Data Coding

The audio-taped interviews were transcribed verbatim by a medical transcriptionist and grounded theory methods were employed to develop a framework describing the processes by which family members believe or doubt the ability of physicians to predict medical futility. To develop the preliminary coding scheme one of the investigators (LSZ) first employed an analytic method known as open coding whereby a subset of the transcripts were read and text segments that related to a theme or idea were identified and given a conceptual label. As concepts accumulated and distinctions between concepts became more refined, similar concepts were grouped into conceptual categories. A process known as axial coding was then employed whereby the conceptual categories were developed further by comparing the categories between transcripts with an emphasis on identifying causal relationships. Investigators then reviewed the codes with a subset of transcripts and the coding framework was reorganized and modified until all investigators agreed on a final coding framework. [25]

To limit ambiguity in analysis we defined doubt towards the ability of physicians to predict futility as any statement which indicated uncertainty about physician's ability to accurately prognosticate about futility. Belief in the ability of physicians to predict futility was defined as any statement which indicated confidence in the ability of physicians to accurately prognosticate about futility.

Reliability of the Coding

To ensure the reliability of our analysis we employed three validation techniques. Investigators with varied training and backgrounds collaborated during the development of the coding framework in a process known as multidisciplinary analysis. Areas of expertise included critical care medicine, pulmonology, bioethics, end of life care, epidemiology, statistics, and qualitative methodology. Member checking, the process of bringing the analyzed results back to study participants for confirmation and/or modification was also performed.

Finally, using the final coding framework, one investigator (LSZ) coded all of the interviews by listening to the audiotapes and reading the transcripts. Another investigator (AC) coded 20% of the transcripts in order to assess intercoder reliability. Both coders were blinded to the demographic characteristics of the research participants. Overall, the kappa statistic between coders for identifying the content of futility statements was 0.95. A kappa value greater than 0.8 is considered excellent interrater reliability. [26]

Statistical Analysis

We totaled the number of consenting responses for continuing treatment for each value of X% for the time trade-off scenario. We then plotted the percentage likelihood of participants pursuing the described course of treatment against each hypothetical survival estimate (X). All analysis was performed using Microsoft Excel.

Results

Participant Characteristics

Of 45 eligible ICU family members 41 (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 due to a family emergency thereby yielding 38 participants and an enrollment rate of 84%. Demographic characteristics of the ICU family members and patients who participated in the interviews are described in **Table 1**. Among participants, 10 (26%) reported excellent communication by the attending physician about the patient's prognosis while 11 (29%) reported very good communication, 5 (13%) reported good communication, 6 (16%) reported fair communication, and 1 (3%) reported poor communication. 5 (13%) participants stated that there had been no communication by the attending physician about the patient's prognosis. Thus, 68% (26/38) reported good or better communication about prognosis with ICU physicians. The number of family members interviewed for each patient ranged from 1 to 3 with a mean of 1.6 ICU family members per patient. The interviews ranged from 5 minutes 11 seconds to 30 minutes 59 seconds with a mean length of 10 minutes 38 seconds.

Table 3: Demographic Characteristics of Family Members and Patients

Characteristics	Family Members or Loved Ones N - 38 n (%)	Patients N – 23 n (%)
Gender		
Male	12 (32)	13 (57)
Female	26 (68)	10 (43)
Race/Ethnicity*		
Caucasian or White	9 (24)	9 (39)
African American or Black	12 (32)	6 (23)
Hispanic or Latino	10 (26)	4 (17)
Asian	5 (13)	2 (9)
Pacific Islander	1 (3)	1 (4)
Native American	1 (3)	0 (0)
Other/Undocumented	1 (3)	1 (4)
Admitting Diagnosis		
Cardiac failure/myocardial infarction		5 (22)
Intracranial aneurysm/hemorrhage		4 (17)
Sepsis/infection		3 (13)
Respiratory failure		2 (9)
Trauma		2 (9)
Renal failure		2 (9)
GI bleed		2 (9)
Other		3 (13)
Relationship to Patient		
Spouse/Partner	8 (21)	
Child	5 (13)	
Sibling	10 (26)	
Friend	3 (8)	
Parent	5 (13)	
Other relative	5 (13)	
Other	2 (5)	
Level of Education		
8th grade or less	0 (0)	
Some high school	3 (8)	
High school diploma or GED	11 (29)	
Some college or trade school	12 (32)	
4 year college degree	4 (11)	
Graduate or professional school	8 (21)	
Primary Language+		
English	37 (97)	
Spanish	6 (16)	
Cantonese	3 (8)	
Mandarin	1 (3)	
French	1 (3)	
German	1 (3)	
	Mean (SD)	**Mean (SD)**

Age (years)	52.8 (13.9)	63.1 (21.7)

[*] Sums are greater than 38 family members/loved ones and 23 patients because some individuals identified with more than one race/ethnicity

[+] Sums are greater than 38 family members/loved ones and 23 patients because some individuals cited more than one primary language

Participant Attitudes Towards the Ability of Physicians to Predict Medical Futility

61% (23/38) of participants doubted the ability of physicians to predict medical futility while 39% (15/38) believed that physicians could predict medical futility. Data analysis revealed a multi-step process that participants engaged in when determining the accuracy of futility statements for an individual ICU patient. This process, outlined in **Figure 2**, is composed of three distinct, linear stages: assessment, comparison, and judgment.

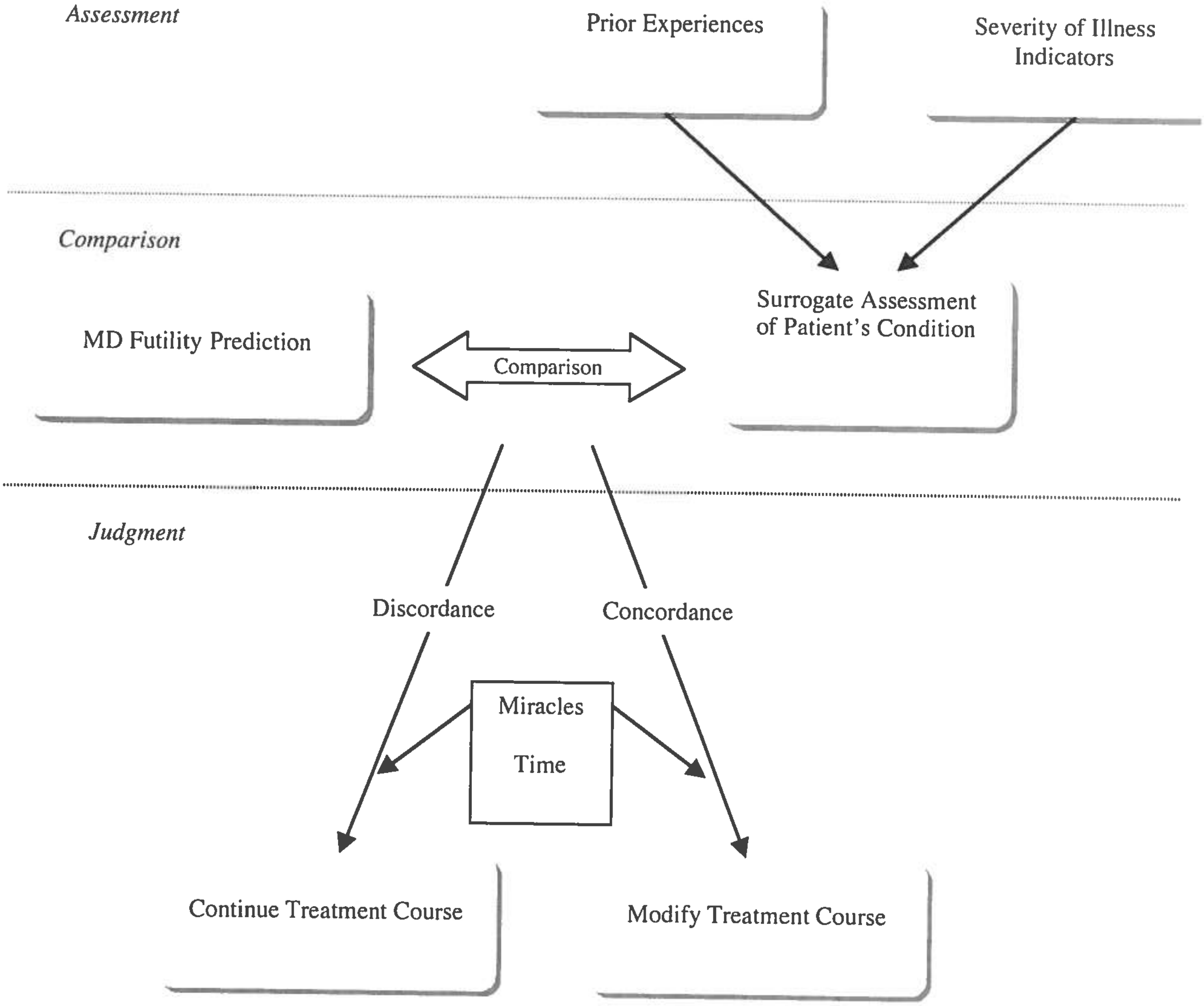


Figure 3: ICU Surrogate Process of Determining Accuracy of Physician Futility Predictions

Family Member Assessment of the Patient's Condition

During a patient's critical illness, participants described the continual process of assessing the patient's condition in an attempt to determine if the patient's illness was improving or worsening. To make this assessment family members visually observed the patient and either looked for specific illness severity indicators and/or compared observations to previous experiences with severely ill loved ones.

Observation of Illness Severity Indicators

32% (12/38) of participants related how illness severity indicators would allow them to assess the patient's condition. In the following example a participant describes how a patient's breathing and heart function would allow him to determine the severity of the patient's illness:

> It depends on what's goin' on, at that moment. If he's been in the hospital for days and there's no vital signs, everything is gone, that only the machines are breathing, or whatever, then yeah, it's time to let go...As long as they can breathe on their own, as long their heart is beating, you hang in there...You're in there 'til the last breath.

Another participant described how the number of tubes connected to the patient would allow her to determine the severity of the patient's condition:

> INT: And what are you looking for, when you're observing a patient?
>
> SUB: Are they in pain? Is there any physical signs that I can see, like moaning or crying...Or are there tubes comin' all off their body and [and they are just a] vegetable, you know.

Comparison to Prior Experiences

16% (6/38) of participants explained the process of comparing prior medical experiences with the patient's current state in order to determine the patient's condition and illness course. In the following example, the sister of an ICU patient explains that because she watched her mother pass away in an ICU, she can therefore compare that prior experience to her sisters current illness state in order to assess the severity of her sisters illness:

> INT: What if a doctor told you that they thought there was absolutely no chance for your loved one to survive the hospitalization? Would you believe the doctor?
>
> SUB: I'd have to see that, with my own eyes. Then I would be able to answer that question.
>
> INT: And what would you have to see to believe the doctor?
>
> SUB: The patient. See that she actually is dying. Because I've seen it, with my own eyes already, with my mother. And I know, now, what it's like. I know what to look for, in a person, when the person's dying.

Assessment-Futility Prediction Comparison

While the assessment stage is a continually ongoing process, communication of a futility prediction triggers a comparison between the prediction and the family member's assessment of the patient's condition. 37% (14/38) of participants described this process of comparison:

> I'm trying to be...unemotional about what I'm hearing. I'm trying to assess through experience and with my eyes, what I'm seeing. And taking all these things into account. And then trying to come up with an accurate judgment [of the physician's prediction of futility].

Judgment of Futility Prediction

Following comparison between family member's assessment of the patient's condition and the futility prediction, two outcomes existed. If there was concordance between the assessment and futility prediction participants indicated that they would be confident in their own assessment and would believe the futility prediction. Discussion would then ensue about modifying the treatment course. If however there was discordance, participants indicated that they would elect to continue life-sustaining treatment. One participant described the desire to continue treatment if there was discordance between family member assessment and the futility prediction:

> That's hard. Yeah, but I wouldn't be able to [believe the prediction], within me. I wouldn't want to believe [the doctor] because I wouldn't want the [prediction] to be true. If it was something like that, that was told to me, I would believe myself.

Modifying Factors

There were two modifying factors that affected judgment of the futility prediction. 13% (5/38) of subjects believed that God was capable of directly healing the patient and therefore that regardless of whether the assessment and prediction were concordant, a miracle could cure the patient:

> INT: If a doctor told you he thought there was absolutely no chance for your loved one to survive the hospitalization, do you think you would believe the doctor?
>
> SUB: Maybe, 90%. I'd still have to hold onto somethin'.
>
> INT: Mhmm. And what would it be that you would hold onto, do you think?
>
> SUB: Well, I'd be prayin' and be hopin' for a miracle.

Finally, the passage of time could modify judgment of the futility prediction in that the patient's actual condition could change, family member assessment of the patient's condition could change, or with time family members could fully process the rationale and implications of the futility prediction. One participant stated the following:

> SUB: I would consider [the prediction] a lot, but I would still give it a little time to see if anything changes with the patient.
>
> INT: And what would you have to see in the patient that would make you believe or not believe the doctor?
>
> SUB: I mean, if they're sitting there, layin' there, like a vegetable and you don't see no improvement…then what the doctor says is gonna happen, is gonna happen.

The Role of Survival Estimates in Decision-Making

Figure 3 represents the percentage of family members consenting to treatment with decreasingly optimistic survival estimates. As estimates for survival decreased, fewer families consented to treatment. Notably, 35% of participants elected to continue treatment with a <1% survival estimate and 18% of family members elected to continue treatment when the survival estimate was zero.

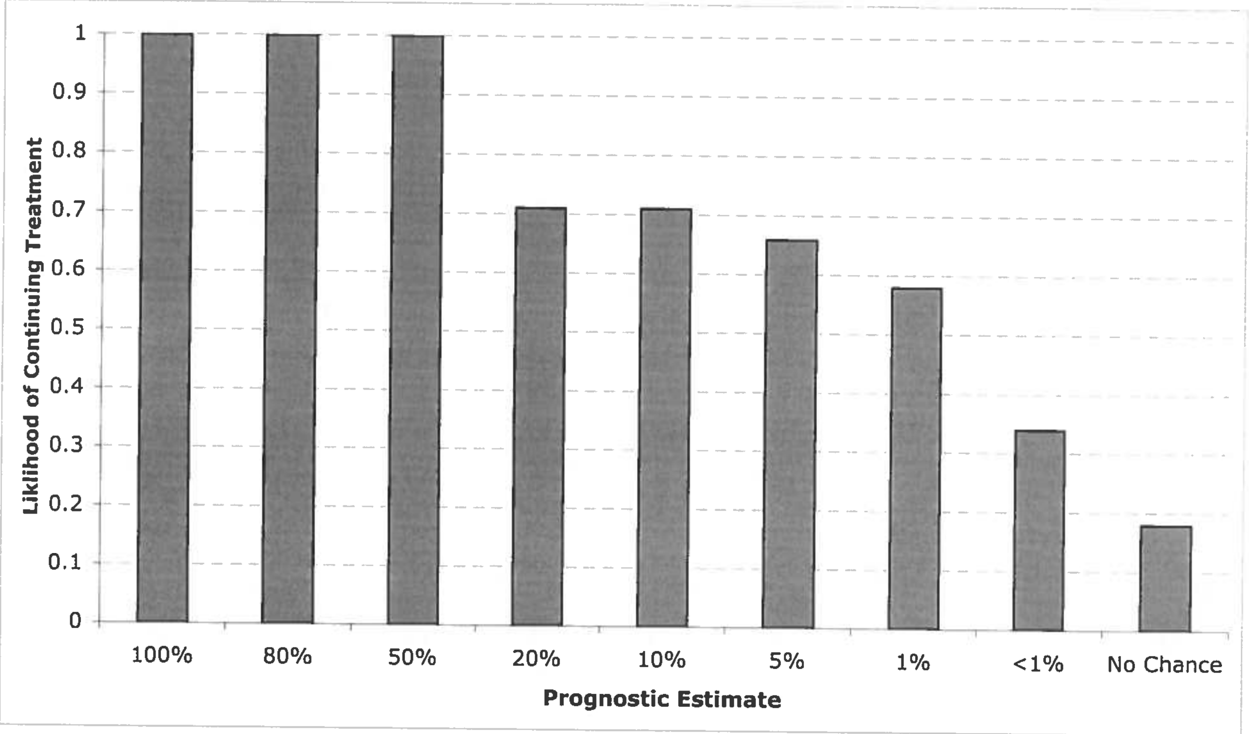


Figure 4: Likelihood of ICU Surrogates Continuing Treatment when Communicated Varying Survival Estimates

Discussion

The data from this study suggests that doubt about the ability of physician's to predict medical futility is common among ICU surrogate decision-makers. Moreover, just as there are differences among physicians about an appropriate definition of quantitative futility, so too are there differences among surrogate decision-makers about the appropriateness of initiating life-sustaining interventions when communicated low patient survival estimates. In this study a significant number of ICU surrogates elected to continue treatment for a patient even when communicated survival estimates that were below proposed quantitative thresholds for futility. Indeed, 35% of participants elected to continue treatment when communicated a survival estimate of <1%, a threshold similar to the proposed Schneiderman et al. quantitative definition of futility [40], while 18% of participants elected to continue treatment when communicated a survival estimate of zero. Given these differences, it is perhaps time to fully abandon the search for a quantitative definition of futility. Community consensus about a quantitative threshold seems impossible as demonstrated by previous research [68-70] as well as this study and, moreover, even if such a consensus could be reached, almost two-thirds of surrogates doubt the ability of physicians to accurately predict quantitative futility.

Yet there remains a necessity for a definition of medical futility and the failure to agree upon a quantitative meaning has demonstrated this need. If medical interventions were judged by physicians and surrogates solely on physiological outcomes then a quantitative definition could more easily be reached: those interventions that would only serve to prolong the final stages of the dying process would be considered futile. However, the failure of quantitative futility has demonstrated that medical interventions are judged on far more than quantitative physiological benefit For example some may consider the emotional, physical, or financial burden of aggressive intervention not worth the purpose of prolonging a seemingly meaningless life. Others may see benefit in even short-term prolongation of life. Thus, physicians and bioethicists have suggested that futility disputes are rooted in differences in value judgments about the benefit of an intervention, where a benefit is judged on physical, emotional, financial, practical, and physiologic worth. [71]. Understood in this regard, the utility of a usable definition of futility would be its ability to address and resolve differences in value judgments about the comprehensive benefit of an intervention, not simply the physiologic benefit.

The most current and widely accepted method for resolving futility disputes futility was proposed by the AMA and has been recently adopted into California [53] and Texas [54] law. This method stresses the importance of mutual understanding between surrogates and physicians about value judgments and concedes that the utility of global definitions of futility is extremely limited instead advocating individual definitions. It is characterized by a fair process approach consisting of four distinct steps: deliberation and resolution, two steps aimed at securing alternative care in cases of irreconcilable differences, and closure. In the deliberation and resolution step the goal should be to deliberate over and negotiate a prior understanding between physician and surrogate about what constitutes futile care. The AMA recommends that this understanding is best achieved before critical illness occurs. Joint decision-making should then proceed using outcome data and the shared value judgments about what constitutes futile intervention.

If irresolvable disagreements occur, the next step should be to involve a physician consultant. If no agreement is reached, the council recommends involvement of an ethics committee and again if no agreement is reached, attempts should be made to transfer the patient to another institution. If transfer is impossible because no physician and no institution can be found to follow the surrogate's wishes, by "ethics standards" the interventions in question need not be provided. [71]

The findings from this study indicate that the fair process approach is well suited in providing guidance about how to make futility determinations because it allows physicians and surrogates the opportunity to discuss individual value judgments about what constitutes futile care. However, we believe that this study also demonstrates that important additions must be made. While the fair process approach stresses understanding about *what* constitutes futile intervention, data from this study suggests that mutual understanding about *why* a futility prediction is being made is equally important. During the assessment and comparison stages of our model of how ICU surrogates determine the accuracy of physician futility statements, surrogates formulate an assessment of the patient's condition and then compare that assessment with the physician's futility prediction. Data analysis has demonstrated that assessment of the patient's condition is both a visual and experiential process as surrogates gather information to inform their analysis of the patient's condition. In order to make an informed comparison between their own assessment and the physician's prediction, we believe surrogates require not just a statement of futility, but also an understanding of the various factors that led to the futility prediction.

As Rubin has argued, a futility prediction by a physician is inherently value laden because by its very nature it suggests that, given the patient's condition, there is no purpose to further medical intervention. [47] This is true regardless of whether the prediction is communicated via a fair process approach or another method. As Rubin has further explained there has been a historical tendency for physicians to simply state that interventions will be withheld rather engaging in discussion about why the interventions ought be withheld. Thus medical futility has in the past been a way to limit discussion with family members about treatment that physicians deem useless. [47] Futility determinations using a fair process approach promote development of a consensus definition of futile care, however, this approach does not provide an adequate forum for disclosure of the rationale behind the prediction. Therefore, physicians may simply communicate a futility prediction and, because they assume that surrogates remember and agree with the previously deliberated consensus definition, provide no further explanation. Thus, this situation becomes similar to the very scenario that the fair process approach intends to avoid: a unilateral determination that an intervention will be withheld.

For example, imagine a patient with terminal cancer who is only receiving IV chemotherapy narcotics for pain. If a surrogate based their assessment of the patient on the number of machines that were connected to the patient, because they had a previous experience with a critically ill loved one who was attached to many machines towards the end of their life, they may assess the patient as relatively healthy. If they were then communicated a futility prediction that lacked explanation, yet was concordant with a previously discussed broad based consensus about the definition of futile care, the surrogate would understandably have difficulty reconciling their assessment of the patient with the physician's prediction. Thus while broad consensus definitions of futile care are necessary for decision-making, communication about the rationale behind a futility prediction provides surrogates with understanding about the patient's condition from the physician's perspective and allows the surrogate to make a more informed comparison.

Fair process approaches do possess adequate safeguards to prevent unilateral communication of medical futility without associated explanation. However, these steps are time consuming and require the involvement of outside consultants. We believe that the data from this study provides insight about how to effectively communicate both a prediction of medical futility and the rational*e* for the prediction.

Family members from our study cohort relied extensively on visual observation in order to formulate their assessment of the patient's condition. Therefore we suggest that communication of a futility estimate should occur at the patient's bedside where physicians can explain their rationale for making such a prediction by making visual reference to the patient and their environment. For example, using the hypothetical case of the patient with terminal cancer receiving IV chemotherapy and narcotics for pain control, the physician should explain what medicines are being delivered to the patient and their role in treating the patient's condition. Communication of a futility prediction should then include a discussion of why, in the opinion of the physician, the current treatment and other available treatment options will not lead to curative therapy. Importantly, physicians should then ask surrogates directly for their own assessment of the patient and then discussion should ensue to reconcile any differences in perception about the patient's condition. We believe that this strategy will prompt family members to detail how they are assessing the patient's condition and promote a visual dialogue where physicians and family members should better be able to understand each other's perspective about the patient's condition. Furthermore, discussions at the bedside should improve joint decision-making about treatment and should decrease the need to progress through further stages of the fair process model because of conflicts. Thus, by engaging in discussion at the bedside, futility communication can serve as a source of trust rather than conflict for families and physicians as differences in perception of the patient's condition can be actively reconciled.

This study has several limitations. The scenario that was explained to participants in order to calculate the likelihood of ICU surrogates continuing treatment when communicated varying survival estimates was specific and not representative of all medical cases associated with decisions to withhold treatment. Therefore the data may not be generalizable beyond the scenario from which it was gathered. By defining doubt in futility as any statement which indicated concern or uncertainty about physician's ability to accurately prognosticate about futility and belief in futility as any statement which indicated confidence in the ability of physicians to accurately futility we may have arbitrarily grouped participants into distinct categories: those who doubted the accuracy of physicians ability to predict futility, and those who believed in physician futility prognostications. Our experience analyzing this data suggests that belief and doubt in the ability of physician's to accurately predict futility is not so easily categorized. There are levels of doubt and levels of belief and given that this study is the first exploration into this area of futility, our analysis did not capture these intricacies. Finally, while our model offers clarification as to how ICU family members evaluate the accuracy of physician' futility predictions and use these predictions to inform treatment choices, we did not determine if there were areas other than decision-making in which participants used statements of futility.

We strongly believe that communicating futility at the bedside will prove effective in increasing the clarity of surrogate-physician futility communication and decreasing conflict. Future studies should evaluate the effectiveness of this strategy and develop specific guidelines for such communication. Other research should present ICU family members with medical scenarios different than the one employed in this study to determine the threshold of withholding treatment. The utility of such a study would be to determine how surrogates interpret different medical scenarios as related to different survival estimates when deciding to limit treatment. As stated previously, our data did not indicate if surrogates use futility for reasons other than decision-making . Future studies should address this critically important aspect of medical futility and end of life care as it may inform future communication strategies.

Medical futility has for some time been a source of conflict between physicians and surrogates of critically ill patients. Yet by engaging in discussions at the bedside about both *what* constitutes futile care and *why* a prediction of futility is being made, understanding can be improved and conflict surrounding medical futility can be decreased. Physicians should understand that communication about futility can be a source of trust and understanding, rather than disagreement and conflict, in decision-making when effectively communicated

Part III

Conclusion

In the last decade there has emerged in the medical literature qualitative and quantitative analyses of medical prognostication and its role in clinical practice and decision-making. Christakis' investigations have contributed most significantly to the current understanding of this area of research. These studies have uncovered both the difficulties that physician's face when attempting to accurately prognosticate, as well as the current barriers in communicating survival predications to patients and surrogate decision-makers [15, 41]. Examination of this area has also demonstrated the importance of formulating and communicating such predictions to patients and surrogates because of their importance in medical decision-making [12, 13].

While this body of research has extensively investigated prognostication from the perspective of the physician, there has been limited research attempting to understand prognostication from the perspective of surrogate decision-makers. The afore-described studies for this thesis have examined both prognosis and futility in an attempt to understand the attitudes of surrogate decision-makers towards the ability of physician's to make accurate medical predictions about a patient's chances of survival, and how surrogates use survival estimates when making decisions about treatment. As prognosis and futility are closely related areas of medical prophecy, this research has demonstrated important similarities in the attitudes of surrogate decision-makers towards statements of prognosis and futility. However, important differences have also emerged indicating that prognostic estimates and futility predictions are not viewed nor interpreted in the same manner. Accordingly different strategies must be employed during communication of these estimates for shared decision-making.

For physicians, prognostic and futility estimates in critical illness are fundamentally related because they are both an attempt to foretell the illness course of a patient.[3] Futility estimates are a specific type of prognostic survival prediction where the physician prophesizes unequivocally that a patient will die and therefore offers a survival estimate of zero. In this sense futility predictions are very similar to low prognostic estimates in that they represent an extremely low estimate of patient survival.

Beyond these similarities prognosis and futility are very different. While low prognostic estimates indicate that there is a very small chance of survival, they still predict that treatment may be effective. For physicians who communicate low prognostic estimates, the option remains for continued therapeutic intervention. In contrast a prediction of futility implies that future therapeutic interventions will be ineffective and that if curative interventions are provided to the patient, they will only at best serve to prolong the final stages of the dying process. Unlike prognostic predictions, futility predictions are very much a self-fulfilling prophecy. The estimation that a patient is imminently dying and that further medical interventions will be ineffective is followed by withdrawal or withholding of treatment that often leads to the death of the patient [15]. Thus prognostic

---

[3] Prognostic estimates can arise in almost any medical situation and can address a variety of attributes of a patient's illness course including the likelihood of developing morbidities, the predicted efficacy of a therapeutic interventions, and a host of other characteristics related to the illness. This thesis has examined the role of quantitative prognostic and futility survival estimates in critical illness and therefore further discussion will be limited to prognostic estimates in such circumstances. However, it should be noted that one major difference between these different types of predictions is the ubiquity and variety of prognostic estimates in medical decision-making. In other words futility is used only to communicate that certain interventions are useless and while futility predictions do not always arise in cases of life-threatening it is most often encountered in such circumstances.

estimates, even very low prognostic estimates, do not carry as explicit a recommendation that interventions should be discontinued.

Therefore futility predictions are much more value-laden than prognostic estimates. Indeed, a futility prediction by its very nature implies that given the patient's current state, the physician believes it no longer appropriate to continue curative therapy. Yet evaluation of what is appropriate is a very subjective assessment. Indeed the futility literature, as has been explained in part II of this thesis, has included years of debate about what is considered appropriate in critical illness and the most recent guidelines about futility have concluded that the definition of futile care, or the determination of medical appropriateness, is best made on an *individual* basis between the physician and surrogate or physician and patient [71]. Examination of the prognosis literature has yielded no such debate because while research has demonstrated that physicians are not particularly accurate when formulating prognostic predictions [15], these predictions do not generally carry explicit recommendations about treatment.

Moreover, the circumstances in which physicians communicate these estimates are different. Prognostic estimates can change over time depending on a variety of patient and medical factors and thus these predictions are communicated at multiple points upon the illness trajectory of the patient. But prognostic estimates are also central to shared-decision making and often guide curative treatment options [10]. In contrast, futility predictions occur at the perceived endpoint of an illness. While futility estimations do represent a prognostic estimate and are therefore important for shared decision-making, such predictions usually guide palliative treatment options and decisions to limit treatment [46].

These differences between futility and prognosis are reflected in both surrogate attitudes towards these medical prophecies and the manner in which these estimates are used for decision-making. From the studies in this thesis it is possible to conclude that ICU surrogates doubt the ability of physicians to make survival predictions about individual patients. Indeed, using the previously described definitions of doubt and belief, 89% (34/38) participants doubted the ability of physicians to accurately prognosticate for individual ICU patients and 61% (23/38) doubted the ability of physician's to accurately predict medical futility. There is a significant difference ($p < 0.0001$)[4] in the number of participants who doubted the accuracy of prognostic estimates versus the number of participants who doubted futility estimates. While doubt about the ability of physicians to make survival predictions is common, surrogates are more likely to believe in the accuracy of a futility prediction than a prognostic estimate.

The reason for this difference is likely multifactorial. Prognostic survival estimates are essentially predictions about a patient's risk of death. Literature on risk communication has demonstrated that interpretation of quantitative risk is not rational but rather subject to systematic biases. Among these are heuristics, optimism bias, and categorical perception of risk as either dangerous or safe [72]. These biases can affect how risk is

---

[4] This value was calculated using a Chi-square test. With one degree of freedom the Chi-squared value was equal to 33.809 and thus the resultant two-tailed p value was less than 0.0001 indicating statistical significance.

interpreted and lead to doubt about the accuracy of the statistics [72, 73]. Futility predictions are not framed as estimations about a patient's *risk* of death, rather they are predictions that a patient *will* die. Thus futility predictions are not as susceptible to the aforementioned interpretative biases because they are not framed as risk.

Data from these studies may also indicate that surrogates are more likely to interpret definitive statements as more accurate than statistical statements because even low statistical statements still offer a degree of hope that a patient will improve. One participant explained the difference between futility predictions and prognostic survival estimates in the following way:

> INT: Do you think family members are more likely to believe a doctor who says, "Look, there's absolutely no chance for survival," as opposed to a doctor who says, "I think it's unlikely that your family member is going to survive." Do you think family members interpret those two [statements] differently?
>
> SUB: Oh, there is a huge difference...Everyone's always gonna leap for hope, even a small amount of hope. You know, that's kind of a human reaction. I mean that's like a night'n'day kind of a response to tell a family member because...you provide 'em with a little bit of leeway [in the second statement].

Prognostic predictions provide family members with a chance of hope, however slight, that a patient will recover. This seems to provide surrogates with interpretive leeway necessary to doubt prognostic estimates.

Data analysis also yielded a variety of reasons why surrogates doubted the ability of physician's to prognosticate. These included systems of belief about prognosis, formative experiences with prognosis, and alternative interpretations of prognostic estimates. Often participants cited more than one reason as to why they doubted the ability of physicians to accurately prognosticate. In contrast, analysis of the futility data demonstrated that the accuracy of a futility prediction was based upon comparison of the prediction to the surrogate's assessment of the patient's condition. With so many different factors affecting the accuracy of prognostic statements, as compared to the specific manner that family members interpreted futility statements, there were more reasons to doubt the accuracy of prognostic estimates.

There were however striking parallels between the way that participants formed an assessment of the patient's condition and the formative experiences that led surrogates to doubt or believe prognostic estimates. In both cases prior experiences with critically ill patients influenced assessment of the patient's condition and interpretation of prognostic estimates. Visual observation of the patient's current state and illness trajectory was also an important factor.

Yet even among these similarities there were important differences. Visual observation in futility interpretation was based on specific severity of illness indicators. In prognosis interpretation, visual observation was described as much more general. Moreover, during futility interpretation visual observation and prior experiences were used to inform an *assessment* of the patient's condition. This was then compared to the futility prediction. In prognosis interpretation these observations were used to *directly* evaluate the survival prediction.

Perhaps most importantly, there were differences in the manner that participants used statement of futility and prognosis. The prognosis data suggests that while some surrogates do use prognosis for decision-making, most do not. Yet almost half of participants stated that prognosis was important for preparatory reasons. The model that was developed for futility interpretation suggests that futility statements are used extensively for decision-making. This is supported by the fact that there is less doubt about the accuracy of such predictions and that futility estimations in many ways force decisions about limiting treatment by their very nature.

Thus while there are similarities between prognosis and futility communications there are most certainly differences. Physicians should understand the power of a futility prediction in that it seems to force decisions to limit treatment and is generally interpreted as more accurate than prognostic estimates. Prognostic statements are not believed to be as accurate, however, surrogates expect uncertainty in these predictions yet require them for decision-making and preparation. In cases of critical illness, where physicians may communicate predictions of both prognosis and futility, it is important to be aware of these differences.

Communication of survival estimates, be it in the context of futility or prognosis, need not be an area of distrust and conflict. Clear and effective communication based on the strategies outlined in this thesis may improve communication, promote understanding and help physicians, surrogates, and patients to achieve desired outcomes.

Appendix 1: Interview guide

READ ALOUD TO SUBJECT: "I'd like you to imagine the following situation: Your loved one is admitted to the intensive care unit with a life-threatening illness. He or she is on a breathing machine and can't 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. "

RQ1: Do family members believe physicians' predictions about whether a patient will survive, especially when the prediction is that the patient is unlikely to survive?

SEMI-STRUCTURED INTERVIEW QUESTIONS:

1. When someone is very sick in an intensive care unit, what do you think determines whether they will live or die?
2. Do you think doctors can accurately predict whether a particular patient will live or die? Why or why not?
3. Should family members of ICU patients believe doctors' predictions when the doctor says that a patient will probably not survive? Why or why not?
4. If a doctor told you he thought there was absolutely no chance for your loved one to survive the hospitalization, would you believe him? Why or why not?

RQ2: Is prognostic information important to family members of critically ill patients? Does prognostic information play a role in whether to limit life sustaining treatment?

SEMI-STRUCTURED INTERVIEW QUESTIONS:

1. If a doctor thinks the patient has very little chance of surviving, do you think he should tell the family? Why or why not?
    a. Probe: Why do you think this information is important?
2. Would information about your loved one's chances for surviving affect how you make decisions about whether to continue full life support? How?
3. Imagine that you are making decisions for your loved one who is too sick to participate. If the doctor told you he felt there was very little chance that your loved one would survive, would this affect the decisions you would make about life support?"

Appendix 2: Consent Form

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO BE A RESEARCH SUBJECT

Communicating Prognosis: Family Member and Physician Agreement about the Meaning of Prognostic Statements

A. PURPOSE AND BACKGROUND

Douglas B. White, MD, and Lucas Zier, from the Department of Medicine, are conducting a study to learn about how physicians and family members interpret various ways that physicians sometimes communicate about a patient's chances for surviving his/her illness. You are being asked to participate in this study because your family member is currently hospitalized in the ICU.

B. PROCEDURES

If you agree to be in this study, you will be asked to complete a written questionnaire and participate in a short interview. The questionnaire will ask questions about communication in the intensive care unit. It also contains questions about your beliefs about how physicians and patients' families should communicate in this setting. Finally, it will ask questions about your experience with physicians while your loved one has been in the intensive care unit. The questionnaire should take between 10-20 minutes to complete.

The interview will last 10 minutes and will address your attitudes about prognostic information, as well as what role prognostic information should play when making decisions with doctors. The researcher will make a sound recording of the interview. After the interview, someone will type into a computer a transcription of what's on the tape and will remove any mention of names. The original sound recording with the names will then be destroyed. The sound recording that has had the names removed will be kept for 6 years after completion of the study and then will be destroyed. You have the right to request that the audiotape be stopped at any time during the recording.

C. RISKS/DISCOMFORTS

Thinking about your family member's medical conditions, treatments and prognosis during the questionnaire may cause you emotional discomfort.

Participation in research may involve a loss of privacy, but information about you and your family member will be handled as confidentially as possible. Your name and your family member's name will not be used on the questionnaire or in any published reports about this study. We will use a coding system to link the study information gathered from you and your family member. The code will be kept in a password-protected computer in a locked office.

D. BENEFITS

There will be no direct benefit to you or your family member for participating in this study. The study may benefit future ICU patients and their family members by helping to shape interventions that might improve physician-family communication in the ICU.

E. ALTERNATIVES

You may refuse to participate in this study. You may change your mind about participation in the study at any point and you may skip any questions you do not wish to answer.

F. COSTS

There will be no cost to you for participating in this study.

G. PAYMENT

You will not be reimbursed for participating in this study.

H. QUESTIONS

This study has been explained to you by Mr. Zier, Dr. White, or by the person who signed below and your questions were answered. If you have any other questions about the study, you may call Dr. White at (415) 502-8275 or Lucas Zier at (415) 710-3478.

I. CONSENT

You have been given copies of this consent form and the Experimental Subject's Bill of Rights to keep. PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to participate or to withdraw at any point in this study without penalty or loss of benefits to which you are otherwise entitled.

If you wish to participate in this study, you should sign below.

____________ Date	______________________________ Subject's Signature for Consent
____________ Date	______________________________ Person Obtaining Consent

References

1. Yellen SB, Burton L.A. and Elpern E.: Communication about advance directives: Are patients sharing information with physicians? Camb Q Healthc Ethics 1992;4:377-387.

2. In the Matter of Karen Quinlan, An Alleged Incompetent, Supreme Court of New Jersey, 1976.

3. Barber v Superior Court, California Court of Appeals, 1983, vol 147 Cal. App. 3d 1006.

4. Arnold RM, Kellum J: Moral justifications for surrogate decision making in the intensive care unit: Implications and limitations. Crit Care Med 2003;31:S347-353.

5. Jonsen AR: The Birth of Bioethics, Oxford University Press, 1998.

6. Emanuel EJ, Emanuel LL: Proxy decision making for incompetent patients. An ethical and empirical analysis. Jama 1992;267:2067-2071.

7. 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.

8. High DM: Surrogate decision-making: Who will make decisions for me when I can't? Clin Geriatr Med 1994;10:445-461.

9. Charles C, Whelan T, Gafni A: What do we mean by partnership in making decisions about treatment? Bmj 1999;319:780-782.

10. Carlet J, Thijs LG, Antonelli M, Cassell J, Cox P, Hill N, Hinds C, Pimentel JM, Reinhart K, Thompson BT: Challenges in end-of-life care in the ICU. Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003. Intensive Care Med 2004;30:770-784.

11. Charles C, Gafni A, Whelan T: Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Soc Sci Med 1997;44:681-692.

12. Lloyd CB, Nietert PJ, Silvestri GA: Intensive care decision making in the seriously ill and elderly. Crit Care Med 2004;32:649-654.

13. Murphy DJ, Burrows D, Santilli S, Kemp AW, Tenner S, Kreling B, Teno J: The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation. N Engl J Med 1994;330:545-549.

14. Christakis NA, Iwashyna TJ: Attitude and self-reported practice regarding prognostication in a national sample of internists. Arch Intern Med 1998;158:2389-2395.

15. Christakis NA: Death Foretold: Prophecy and Prognosis in Medical Care, The University of Chicago Press, 1999.

16. Ptacek JT, Eberhardt TL: Breaking bad news. A review of the literature. Jama 1996;276:496-502.

17. Rabow MW, McPhee SJ: Beyond breaking bad news: how to help patients who suffer. West J Med 1999;171:260-263.

18. von Gunten CF, Ferris FD, Emanuel LL: The patient-physician relationship. Ensuring competency in end-of-life care: communication and relational skills. Jama 2000;284:3051-3057.

19. Markowitz AJ, McPhee SJ: Complexities in prognostication in advanced cancer: "to help them live their lives the way they want to". Jama 2003;290:2056.

20. Azoulay E, Chevret S, Leleu G, Pochard F, Barboteu M, Adrie C, Canoui P, Le Gall JR, Schlemmer B: Half the families of intensive care unit patients experience inadequate communication with physicians. Crit Care Med 2000;28:3044-3049.

21. 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.

22. Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulsky JA: Families looking back: One year after discussion of withdrawal or withholding of life-sustaining support. Crit Care Med 2001;29:197-201.

23. Youngner S: Applying futility: saying no is not enough. J Am Geriatr Soc 1994:887-889.

24. Goold SD, Williams B, Arnold RM: Conflicts regarding decisions to limit treatment: a differential diagnosis. Jama 2000;283:909-914.

25. Charmaz KC: Constructing Grounded Theory: A Practical Guide through Qualitative Analysis, Sage Publications, 2006.

26. Sackett DL RBH, Guyatt GH, Tugwell P: Clinical Epidemiology: A Basic Science for Clinical Medicine, 2nd ed. Boston, Little, Brown and Company, 1991.

27. Azoulay E, Pochard F, Chevret S, Adrie C, Annane D, Bleichner G, Bornstain C, Bouffard Y, Cohen Y, Feissel M, Goldgran-Toledano D, Guitton C, Hayon J, Iglesias E, Joly LM, Jourdain M, Laplace C, Lebert C, Pingat J, Poisson C, Renault A, Sanchez O, Selcer D, Timsit JF, Le Gall JR, Schlemmer B: 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.

28. Diem SJ, Lantos JD, Tulsky JA: Cardiopulmonary resuscitation on television. Miracles and misinformation. N Engl J Med 1996;334:1578-1582.

29. Casarett D, Fishman JM, MacMoran HJ, Pickard A, Asch DA: Epidemiology and prognosis of coma in daytime television dramas. Bmj 2005;331:1537-1539.

30. Paling J: Strategies to help patients understand risks. Bmj 2003;327:745-748.

31. Edwards A, Elwyn G, Mulley A: Explaining risks: turning numerical data into meaningful pictures. Bmj 2002;324:827-830.

32. Carrese JA, Rhodes LA: Bridging cultural differences in medical practice. The case of discussing negative information with Navajo patients. J Gen Intern Med 2000;15:92-96.

33. Carrese JA, Rhodes LA: Western bioethics on the Navajo reservation. Benefit or harm? Jama 1995;274:826-829.

34. Back AL, Arnold RM, Baile WF, Tulsky JA, Fryer-Edwards K: Approaching difficult communication tasks in oncology. CA Cancer J Clin 2005;55:164-177.

35. Jecker NS: Knowing when to stop: the limits of medicine. Hastings Cent Rep 1991;21:5-8.

36. Fine RL, Mayo TW: Resolution of futility by due process: early experience with the Texas Advance Directives Act. Ann Intern Med 2003;138:743-746.

37. Tweed WA, Bristow G, Donen N, Kirk BW: Evaluation of hospital-based cardiac resuscitation, 1973--77. Can Med Assoc J 1980;122:301-304.

38. DeBard ML: Cardiopulmonary resuscitation: analysis of six years' experience and review of the literature. Ann Emerg Med 1981;10:408-416.

39. Bedell SE, Delbanco TL, Cook EF, Epstein FH: Survival after cardiopulmonary resuscitation in the hospital. N Engl J Med 1983;309:569-576.

40. Schneiderman LJ, Faber-Langendoen, K., Jecker N.S.: Beyond futility to an ethic of care. Am J Med 1994;86:110-114.

41. Christakis NA, Lamont EB: Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. Bmj 2000;320:469-472.

42. Cantor MD, Braddock CH, 3rd, Derse AR, Edwards DM, Logue GL, Nelson W, Prudhomme AM, Pearlman RA, Reagan JE, Wlody GS, Fox E: Do-not-resuscitate orders and medical futility. Arch Intern Med 2003;163:2689-2694.

43. Rodriguez RM, Wang, N.E., Pearl, R.G.: Prediction of poor outcome of intensive care unit patients admitted from the emergency department. Crit Care Med 1997;25:1801-1806.

44. Chang RW: Individual outcome prediction models for intensive care units. Lancet 1989:143-146.

45. Rapoport J, Teres D, Lemeshow S: Can futility be defined numerically? Crit Care Med 1998;26:1781-1782.

46. Consensus statement of the Society of Critical Care Medicine's Ethics Committee regarding futile and other possibly inadvisable treatments. Crit Care Med 1997;25:887-891.

47. Rubin SB: When Doctors Say No: The Battleground of Medical Futility, Indiana University Press, 1998.

48. Brody BA, Halevy, A.: Is futility a futile concept? J Med Phil 1995;20:123-144.

49. In re: Conservatorship of Wanglie: Findings of Fact, Conclusions of Law and Order, Minnesota District Court, Probate Court, Fourth Judicial District, 1991.

50. In the matter of Baby K, 16 F3d 590 (4th Cir), 1994.

51. Gilgunn v Massachusetts General Hospital, Mass Super Ct, 1995, vol No. 92-4820, verdict 21.

52. Johnson SH, Gibbons V.P., Goldner J.A., Winer R.L., Eton, D.: Legal and institutional policy responses to medical futility. J Health Hosp Law 1997;30:571-574.

53. Cal Prob Code: 4736 (West 2000).

54. Tex Health and Safety Code: 166.

55. Berger JT: Advance directives, due process, and medical futility. Ann Intern Med 2004;140:402-403; author reply 404.

56. Casarett D, Siegler M.: Unilateral do-not-attempt-resuscitation orders and ethics consultations: a case series. Crit Care Med 1999;27:1116-1120.

57. Halevy A, Neal R.C., Brody, B.A.: The low frequency of futility in an adult intensive care unit setting. Arch Intern Med 1996;156:100-104.

58. Hoffmann DE: Does legislating hospital ethics committees make a difference? A study of hospital ethics committees in Maryland, the District of Columbia, and Virginia. Law Med Health Care 1991;19:105-119.

59. Lappetito J, Thompson P: Today's ethics committees face varied issues. A CHA survey reveals committees' functions, authority, and structure. Health Prog 1993;74:34-39, 52.

60. Sox H, Blatt, M, Higgins M, et al.: Medical Decision Making. Boston, Butterworth, 1988.

61. Read JL, Quinn RJ, Berwick DM, Fineberg HV, Weinstein MC: Preferences for health outcomes. Comparison of assessment methods. Med Decis Making 1984;4:315-329.

62. Nord E: Methods for quality adjustment of life years. Soc Sci Med 1992;34:559-569.

63. Stiggelbout AM, Kiebert GM, Kievit J, Leer JW, Stoter G, de Haes JC: Utility assessment in cancer patients: adjustment of time tradeoff scores for the utility of life years and comparison with standard gamble scores. Med Decis Making 1994;14:82-90.

64. Yellen SB, Cella DF, Leslie WT: Age and clinical decision making in oncology patients. J Natl Cancer Inst 1994;86:1766-1770.

65. McQuellon RP, Muss HB, Hoffman SL, Russell G, Craven B, Yellen SB: Patient preferences for treatment of metastatic breast cancer: a study of women with early-stage breast cancer. J Clin Oncol 1995;13:858-868.

66. Silvestri G, Pritchard R, Welch HG: Preferences for chemotherapy in patients with advanced non-small cell lung cancer: descriptive study based on scripted interviews. Bmj 1998;317:771-775.

67. Edwards A, Elwyn G., Mulley, A.: Explaining risks: turning numerical data into meaningful pictures. Bmj 2002;324:827-830.

68. Emanuel LL, Emanuel EJ: Decisions at the end of life. Guided by communities of patients. Hastings Cent Rep 1993;23:6-14.

69. Churchill LR: The ethical issues of futility from a community perspective. N C Med J 1995;56:424-426.

70. Sugarman J: A community policy on futility? A conversation of the North Carolina community. N C Med J 1995;56:415-417.

71. Medical futility in end-of-life care: report of the Council on Ethical and Judicial Affairs. Jama 1999;281:937-941.

72. Lloyd AJ: The extent of patients' understanding of the risk of treatments. Qual Health Care 2001;10 Suppl 1:i14-18.

73. Edwards A, Elwyn G: Understanding risk and lessons for clinical risk communication about treatment preferences. Qual Health Care 2001;10 Suppl 1:i9-13.

Bibliography

1. Cal Prob Code. In: 4736 (West 2000).

2. Tex Health and Safety Code. In: 166.

3. In the Matter of Karen Quinlan, An Alleged Incompetent. In: Supreme Court of New Jersey; 1976.

4. Barber v Superior Court. In: California Court of Appeals; 1983.

5. Cruzan v. Missouri Department of Health. In: Supreme Court of the United States; 1990.

6. Federal Patient Self Determination Act 1990. In: 42 USC 1395 cc (a); 1990.

7. In re: Conservatorship of Wanglie: Findings of Fact, Conclusions of Law and Order. In: Minnesota District Court, Probate Court, Fourth Judicial District; 1991.

8. Surrogate decisions come under scrutiny. Hosp Ethics 1993;9(1):8-10.

9. In the matter of Baby K. In: 16 F3d 590 (4th Cir); 1994.

10. 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(20):1591-8.

11. Gilgunn v Massachusetts General Hospital. In: Mass Super Ct; 1995.

12. Consensus statement of the Society of Critical Care Medicine's Ethics Committee regarding futile and other possibly inadvisable treatments. Crit Care Med 1997;25(5):887-91.

13. Vacco v. Quill. In: Supreme Court of the United States; 1997.

14. Washington v. Glucksberg. In: Supreme Court of the United States; 1997.

15. Medical futility in end-of-life care: report of the Council on Ethical and Judicial Affairs. Jama 1999;281(10):937-41.

16. Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulsky JA. Families looking back: One year after discussion of withdrawal or withholding of life-sustaining support. Crit Care Med 2001;29(1):197-201.

17. Addington-Hall J, McPherson C. After-Death Interviews with Surrogates/Bereaved Family Members: Some Issues of Validity. J Pain Symptom Manage 2001;22(3):784-90.

18. 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(3):638-43.

19. Annas GJ. The health care proxy and the living will. N Engl J Med 1991;324(17):1210-3.

20. Arnold RM, Kellum J. Moral justifications for surrogate decision making in the intensive care unit: Implications and limitations. Crit Care Med 2003;31(5 Suppl):S347-53.

21. Azoulay E, Chevret S, Leleu G, et al. Half the families of intensive care unit patients experience inadequate communication with physicians. Crit Care Med 2000;28(8):3044-9.

22. 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(9):1832-8.

23. Azoulay E, Pochard F, Chevret S, et al. Opinions about surrogate designation: a population survey in France. Crit Care Med 2003;31(6):1711-4.

24. Back AL, Arnold RM, Baile WF, Tulsky JA, Fryer-Edwards K. Approaching difficult communication tasks in oncology. CA Cancer J Clin 2005;55(3):164-77.

25. Baergen R. Revising the substituted judgment standard. J Clin Ethics 1995;6(1):30-8.

26. Bedell SE, Delbanco TL, Cook EF, Epstein FH. Survival after cardiopulmonary resuscitation in the hospital. N Engl J Med 1983;309(10):569-76.

27. Berger JT. Advance directives, due process, and medical futility. Ann Intern Med 2004;140(5):402-3; author reply 4.

28. Booth MG, Doherty P, Fairgrieve R, Kinsella J. Relatives' Knowledge of Decision Making in Intensive Care. J Medical Ethics 2004(30):459-61.

29. Bramstedt KA. Questioning the decision-making capacity of surroagtes. Internal Medicine Journal 2003;33:257-9.

30. Brock DW. Patient Self-Determination Act. Trumping advance directives. Hastings Cent Rep 1991;21(5):S5-6.

31. Brock DW. What is the moral authority of family members to act as surrogates for incompetent patients? Milbank Q 1996;74(4):599-618.

32. Brody BA, Halevy, A. Is futility a futile concept? J Med Phil 1995;20:123-44.

33. Cantor MD, Braddock CH, 3rd, Derse AR, et al. Do-not-resuscitate orders and medical futility. Arch Intern Med 2003;163(22):2689-94.

34. Cantor NL. Can healthcare providers obtain judicial intervention against surrogates who demand "medically inappropriate" life support for incompetent patients? Crit Care Med 1996;24(5):883-7.

35. Carlet J, Thijs LG, Antonelli M, et al. Challenges in end-of-life care in the ICU. Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003. Intensive Care Med 2004;30(5):770-84.

36. Carrese JA, Rhodes LA. Western bioethics on the Navajo reservation. Benefit or harm? Jama 1995;274(10):826-9.

37. Carrese JA, Rhodes LA. Bridging cultural differences in medical practice. The case of discussing negative information with Navajo patients. J Gen Intern Med 2000;15(2):92-6.

38. Casarett D, Siegler M. Unilateral do-not-attempt-resuscitation orders and ethics consultations: a case series. Crit Care Med 1999;27:1116-20.

39. Casarett D, Fishman JM, MacMoran HJ, Pickard A, Asch DA. Epidemiology and prognosis of coma in daytime television dramas. Bmj 2005;331(7531):1537-9.

40. Chang RW. Individual outcome prediction models for intensive care units. Lancet 1989:143-6.

41. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Soc Sci Med 1997;44(5):681-92.

42. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. Soc Sci Med 1999;49(5):651-61.

43. Charles C, Whelan T, Gafni A. What do we mean by partnership in making decisions about treatment? Bmj 1999;319(7212):780-2.

44. Charmaz KC. Constructing Grounded Theory: A Practical Guide through Qualitative Analysis: Sage Publications; 2006.

45. Christakis NA. Death Foretold: Prophecy and Prognosis in Medical Care: The University of Chicago Press; 1999.

46. Christakis NA. Prognostication and bioethics. Daedalus 1999;128(4):197-214.

47. Christakis NA, Iwashyna TJ. Attitude and self-reported practice regarding

prognostication in a national sample of internists. Arch Intern Med 1998;158(21):2389-95.

48. Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. Bmj 2000;320(7233):469-72.

49. Churchill LR. The ethical issues of futility from a community perspective. N C Med J 1995;56(9):424-6.

50. Cogen R, Patterson B, Chavin S, Cogen J, Landsberg L, Posner J. Surrogate decision-maker preferences for medical care of severely demented nursing home patients. Arch Intern Med 1992;152(9):1885-8.

51. Cohen S, Sprung C, Sjokvist P, et al. Communication of end-of-life decisions in European intensive care units. Intensive Care Med 2005;31(9):1215-21.

52. Cook KF, Ashton CM, Byrne MM, et al. A psychometric analysis of the measurement level of the rating scale, time trade-off, and standard gamble. Soc Sci Med 2001;53(10):1275-85.

53. Coppola KM, Ditto PH, Danks JH, Smucker WD. Accuracy of Primary Care and Hospital-Based Physicians' Predictions of Elderly Outpatients' Treatment Preferences With and Without Advance Directives. Arch Intern Med 2001;161:421-40.

54. Coppolino M, Ackerson L. Do Surrogate Decision Makers Provide Accurate Consent for Intensive Care Research? CHEST 2001;119(2):603-12.

55. Coverdale JH, McCullough LB, Chervenak FA. Assisted and surrogate decision making for pregnant patients who have schizophrenia. Schizophr Bull 2004;30(3):659-64.

56. Covinsky KE, Fuller JD, Yaffe K, et al. Communication and decision-making in seriously ill patients: findings of the SUPPORT project. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. J Am Geriatr Soc 2000;48(5 Suppl):S187-93.

57. Curtis JR, Patrick, D. L., Shannon, S. E., Treece, P. D., Engelberg, R. A., Rubenfeld, G. D. The family conference as a focus to improve communication about end-of-life care in the intensive care unit: Opporunities for improvement. Crit Care Med 2001;29(2 Suppl).

58. Curtis JR, Patrick DL, Shannon SE, Treece PD, Engelberg RA, Rubenfeld GD. The family conference as a focus to improve communication about end-of-life care in the intensive care unit: opportunities for improvement. Crit Care Med 2001;29(2 Suppl):N26-33.

59. Danis M, Federman D, Fins JJ, et al. Incorporating palliative care into critical care education: principles, challenges, and opportunities. Crit Care Med 1999;27(9):2005-13.

60. Danis M, Southerland LI, Garrett JM, et al. A prospective study of advance directives for life-sustaining care. N Engl J Med 1991;324(13):882-8.

61. DeBard ML. Cardiopulmonary resuscitation: analysis of six years' experience and review of the literature. Ann Emerg Med 1981;10(8):408-16.

62. Diem SJ, Lantos JD, Tulsky JA. Cardiopulmonary resuscitation on television. Miracles and misinformation. N Engl J Med 1996;334(24):1578-82.

63. Ditto PH, Danks JH, Smucker WD, et al. Advance Directives as Acts of Communication: A Randomized Controlled Trial. Arch Intern Med 2001;161(3):421-30.

64. Drane JF, Roth RB. Medical decision making for the incompetent patient. Health Prog 1987;68(10):37-42.

65. Drought TS, Koenig BA. "Choice" in End-of-Life Decision Making: Researching Fact or Fiction? The Gerontologist 2002;42(Special Issue III):114-28.

66. Edwards A, Elwyn G., Mulley, A. Explaining risks: turning numerical data into meaningful pictures. Bmj 2002;324:827-30.

67. Edwards A, Elwyn G. Understanding risk and lessons for clinical risk communication about treatment preferences. Qual Health Care 2001;10 Suppl 1:i9-13.

68. Edwards A, Elwyn G, Mulley A. Explaining risks: turning numerical data into meaningful pictures. Bmj 2002;324(7341):827-30.

69. Edwards D. A philosophical discussion of end-of-life decision-making methods for incompetent patients. Int J Palliat Nurs 2002;8(3):146-51.

70. Elliott C. Meaning what you say. J Clin Ethics 1993;4(1):61-2.

71. Emanuel EJ, Emanuel LL. Proxy decision making for incompetent patients. An ethical and empirical analysis. Jama 1992;267(15):2067-71.

72. Emanuel EJ, Weinberg DS, Gonin R, Hummel LR, Emanuel LL. How well is the Patient Self-Determination Act working? an early assessment. Am J Med 1993;95(6):619-28.

73. Emanuel LL, Emanuel EJ. Decisions at the end of life. Guided by communities of patients. Hastings Cent Rep 1993;23(5):6-14.

74. Emanuel LL, Emanuel EJ, Stoeckle JD, Hummel LR, Barry MJ. Advance directives. Stability of patients' treatment choices. Arch Intern Med 1994;154(2):209-17.

75. Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. J Gen Intern Med 1989;4(1):23-30.

76. Evans C, McCarthy M. Prognostic uncertainty in terminal care: can the Karnofsky index help? Lancet 1985;1(8439):1204-6.

77. Fagerlin A, Ditto PH, Danks JH, Houts RM, Smucker WD. Projection in surrogate decisions about life-sustaining medical treatments. Health Psychol 2001;20(3):166-75.

78. Fine RL, Mayo TW. Resolution of futility by due process: early experience with the Texas Advance Directives Act. Ann Intern Med 2003;138(9):743-6.

79. Fischer GS, Tulsky JA, Rose MR, Siminoff LA, Arnold RM. Patient Knowledge and Physician Predictions of Treatment Preferences After Discussion of Advance Directives. J Gen Intern Med 1998;13:447-54.

80. Forster LE, Lynn J. Predicting life span for applicants to inpatient hospice. Arch Intern Med 1988;148(12):2540-3.

81. Fried TR, Bradley EH, Towle VR. Valuing the outcomes of treatment: do patients and their caregivers agree? Arch Intern Med 2003;163(17):2073-8.

82. Gerety MB, Chiodo LK, Kanten DN, Tuley MR, Cornell JE. Medical treatment preferences of nursing home residents: relationship to function and concordance with surrogate decision-makers. J Am Geriatr Soc 1993;41(9):953-60.

83. Gigliotti GA, Rubin J. The right to refuse treatment: an application of the economic principles of decision-making under uncertainty. Int J Law Psychiatry 1991;14(4):405-16.

84. Glaser BG, Strauss A. L. Discovery of Grounded Theory. Chicago: Adeline; 1967.

85. Goold SD, Williams B, Arnold RM. Conflicts regarding decisions to limit treatment: a differential diagnosis. Jama 2000;283(7):909-14.

86. Gregory DR. VA nettwork futility guidelines: a resource for decisions about withholding and withdrawing treatment. Camb Q Healthc Ethics 1995;4:546-8.

87. Hagerty RG, Butow PN, Ellis PM, et al. Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. J Clin Oncol

2005;23(6):1278-88.

88. Halevy A, Neal R.C., Brody, B.A. The low frequency of futility in an adult intensive care unit setting. Arch Intern Med 1996;156:100-4.

89. 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(11):1339-44.

90. Hanson LC, Danis M, Mutran E, Keenan NL. Impact of patient incompetence on decisions to use or withhold life-sustaining treatment. Am J Med 1994;97(3):235-41.

91. Hanson LC, Tulsky JA, Danis M. Can clinical interventions change care at the end of life? Ann Intern Med 1997;126(5):381-8.

92. Hare J, Pratt C, Nelson C. Agreement between patients and their self-selected surrogates on difficult medical decisions. Arch Intern Med 1992;152(5):1049-54.

93. Heyland DK, Rocker GM, Dodek PM, et al. Family satisfaction with care in the intensive care unit: results of a multiple center study. Crit Care Med 2002;30(7):1413-8.

94. Heyland DK, Tranmer J, O'Callaghan CJ, Gafni A. The seriously ill hospitalized patient: preferred role in end-of-life decision making? J Crit Care 2003;18(1):3-10.

95. Hickey M. What are the needs of families of critically ill patients? A review of the literature since 1976. Heart Lung 1990;19(4):401-15.

96. High DM. Who will make health care decisions for me when I can't? J Aging Health 1990;2(3):291-309.

97. High DM. Surrogate decision making. Who will make decisions for me when I can't? Clin Geriatr Med 1994;10(3):445-62.

98. High DM. Surrogate decision-making: Who will make decisions for me when I can't? Clin Geriatr Med 1994;10:445-61.

99. Hines SC, Glover JJ, Babrow AS, Holley JL, Badzek LA, Moss AH. Improving advance care planning by accommodating family preferences. J Palliat Med 2001;4(4):481-9.

100. Hines SC, Glover JJ, Holley JL, Babrow AS, Badzek LA, Moss AH. Dialysis Patients' Preferences for Family-Based Advance Care Planning. Ann Intern Med 1999;130(10):825-8.

101. Hoffmann DE. Does legislating hospital ethics committees make a difference? A

study of hospital ethics committees in Maryland, the District of Columbia, and Virginia. Law Med Health Care 1991;19(1-2):105-19.

102. Houts RM, Smucker WD, Jacobson JA, Ditto PH, Danks JH. Predicting elderly outpatients' life-sustaining treatment preferences over time: the majority rules. Med Decis Making 2002;22(1):39-52.

103. Jacob DA. Family members' experiences with decision making for incompetent patients in the ICU: a qualitative study. Am J Crit Care 1998;7(1):30-6.

104. Jecker NS. Knowing when to stop: the limits of medicine. Hastings Cent Rep 1991;21:5-8.

105. Johnson D, Wilson M, Cavanaugh B, Bryden C, Gudmundson D, Moodley O. Measuring the ability to meet family needs in an intensive care unit. Crit Care Med 1998;26(2):266-71.

106. Johnson SH, Gibbons V.P., Goldner J.A., Winer R.L., Eton, D. Legal and institutional policy responses to medical futility. J Health Hosp Law 1997;30:571-4.

107. Jonsen AR. The Birth of Bioethics: Oxford University Press; 1998.

108. Justice AC, Covinsky KE, Berlin JA. Assessing the generalizability of prognostic information. Ann Intern Med 1999;130(6):515-24.

109. Karlawish JHT, Quill T, Meier DE. A Consensus-Based Approach to Providing Palliatiev Care to Patients who Lack Decision-Making Capacity. Ann Intern Med 1999(130):835-40.

110. Kaufman S.And a Time to Die: How American Hospitals Shape the End of Life. New York, New York: Scribner; 2005.

111. Keenan SP, Mawdsley C, Plotkin D, Webster GK, Priestap F. Withdrawal of life support: how the family feels, and why. J Palliat Care 2000;16 Suppl:S40-4.

112. Lamont EB, Christakis NA. Prognostic disclosure to patients with cancer near the end of life. Ann Intern Med 2001;134(12):1096-105.

113. Lappetito J, Thompson P. Today's ethics committees face varied issues. A CHA survey reveals committees' functions, authority, and structure. Health Prog 1993;74(9):34-9, 52.

114. Layde PM, Beam CA, Broste SK, et al. Surrogates' predictions of seriously ill patients' resuscitation preferences. Arch Fam Med 1995;4(6):518-23.

115. Lelie A, Verweij M. Futility without a dichotomy: towards an ideal physician-

patient relationship. Bioethics 2003;17(1):21-31.

116. Levine C, Zuckerman C. The Trouble with Families: Toward and Ethic of Accommodation. Ann Intern Med 1999;130(2):148-52.

117. Libbus MK, Russell C. Congruence of decisions between patients and their potential surrogates about life-sustaining therapies. Image J Nurs Sch 1995;27(2):135-40.

118. Lilly CM, De Meo DL, Sonna LA, et al. An Intensive Communication Intervention for the Critically Ill. Am J Med 2000;109(6):469-75.

119. Lloyd AJ. The extent of patients' understanding of the risk of treatments. Qual Health Care 2001;10 Suppl 1:i14-8.

120. Lloyd CB, Nietert PJ, Silvestri GA. Intensive care decision making in the seriously ill and elderly. Crit Care Med 2004;32(3):649-54.

121. Lo B. Futile Interventions. In: Resolving Ethical Dilemmas: A Guide for Clinicians. Baltimore: Williams & Wilkins; 1995.

122. Lo B, Steinbrook R. Resuscitating Advance Directives. Arch Intern Med 2004;164(14):1501-6.

123. Lowy C. The doctrine of substituted judgment in medical decision making. Bioethics 1988;2(1):15-21.

124. Luce JM, Alpers A. End-of-life care: What do the American courts say? Crit Care Med 2001;29(2 Supplement):N40-5.

125. Maltoni M, Nanni O, Derni S, et al. Clinical prediction of survival is more accurate than the Karnofsky performance status in estimating life span of terminally ill cancer patients. Eur J Cancer 1994;30A(6):764-6.

126. Marbella AM, Desbiens NA, Mueller-Rizner N, Layde PM. Surrogates' agreement with patients' resuscitation preferences: effect of age, relationship, and SUPPORT intervention. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. J Crit Care 1998;13(3):140-5.

127. Markowitz AJ, McPhee SJ. Complexities in prognostication in advanced cancer: "to help them live their lives the way they want to". Jama 2003;290(15):2056.

128. Martin DK, Thiel EC, Singer PA. A New Model of Advance Care Planning. Arch Intern Med 1999;159:86-92.

129. McQuellon RP, Muss HB, Hoffman SL, Russell G, Craven B, Yellen SB. Patient preferences for treatment of metastatic breast cancer: a study of women with

early-stage breast cancer. J Clin Oncol 1995;13(4):858-68.

130. Meeker MA. Family Surrogate Decision Making at the End of Life: Seeing them through with Care and Respect. Qual Health Res 2004;14(2):204-25.

131. Meeker MA, Jezewski, M. A. A Voice for the Dying. Clin Nurs Res 2004;13(4):326-42.

132. Meier DE, Morrison RS. Autonomy Reconsidered. N Engl J Med 2002;346(14):1087-9.

133. Menikoff JA, Sachs GA, Siegler M. Beyond advance directives--health care surrogate laws. N Engl J Med 1992;327(16):1165-9.

134. Mezey M, Kluger M, Maislin G, Mittelman M. Life-sustaining treatment decisions by spouses of patients with Alzheimer's disease. J Am Geriatr Soc 1996;44(2):144-50.

135. Miles SH, Koepp R, Weber EP. Advance end-of-life treatment planning. A research review. Arch Intern Med 1996;156(10):1062-8.

136. Miller TE, Coleman CH, Cugliari AM. Treatment decisions for patients without surrogates: rethinking policies for a vulnerable population. J Am Geriatr Soc 1997;45(3):369-74.

137. Moore CD, Sparr J, Sherman S, Avery L. Surrogate decision-making: judgment standard preferences of older adults. Soc Work Health Care 2003;37(2):1-16.

138. Murphy DJ, Burrows D, Santilli S, et al. The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation. N Engl J Med 1994;330(8):545-9.

139. Nord E. Methods for quality adjustment of life years. Soc Sci Med 1992;34(5):559-69.

140. O'Brien LA, Grisso JA, Maislin G, et al. Nursing home residents' preferences for life-sustaining treatments. Jama 1995;274(22):1775-9.

141. Ouslander JG, Tymchuk AJ, Rahbar B. Health care decisions among elderly long-term care residents and their potential proxies. Arch Intern Med 1989;149(6):1367-72.

142. Paling J. Strategies to help patients understand risks. Bmj 2003;327:745-8.

143. Parkes CM. Accuracy of predictions of survival in later stages of cancer. Br Med J 1972;2(5804):29-31.

144. Pearlman RA, Uhlmann RF, Jecker NS. Spousal understanding of patient quality of life: implications for surrogate decisions. J Clin Ethics 1992;3(2):114-21; discussion 21-3.

145. Perez-San Gregario M, Blanco-Picabia A, Murillo-Cabezas F. Psychological problems in the family members of gravely traumatised patients admitted into an ICU. Intensive Care Med 1992;18:278-81.

146. Phipps E, True G, Harris D, et al. Approaching the End of Life: Attitudes, Preferences, and Behaviors of African-American and White Patients and Their Family Caregivers. J Clin Oncol 2003;21(3):549-54.

147. Pochard F, Azoulay E, Chevret S, et al. Symptoms of anxiety and depression in family members of intensive care unit patients: ethical hypothesis regarding decision-making capacity. Crit Care Med 2001;29(10):1893-7.

148. Powell T. Extubating Mrs. K: Psychological Aspects of Surrogate Decision Making. J Law Med Ethics 1999;27(1):81-6.

149. Prendergast TJ. Resolving conflicts surrounding end-of-life care. New Horiz 1997;5(1):62-71.

150. Prendergast TJ. Withholding or withdrawal of life-sustaining therapy. Hosp Pract (Off Ed) 2000;35(6):91-2, 5-100,2.

151. 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(4):1163-7.

152. Prendergast TJ, Puntillo KA. Withdrawal of Life Support: Intensive Caring at the End of Life. JAMA 2002;288(21):2732-40.

153. Principe-Rodriguez K, Rodriguez-Cintron W, Torres-Palacios A, Casal-Hidalgo J. Substituted judgement: should life-support decisions be made by a surrogate? P R Health Sci J 1999;18(4):405-9.

154. Ptacek JT, Eberhardt TL. Breaking bad news. A review of the literature. Jama 1996;276(6):496-502.

155. Puchalski CM, Zhong Z, Jacobs MM, et al. Patients Who Want Their Family and Physician to Make Resuscitation Decisions for Them: Observations from SUPPORT and HELP. J Am Geriatr Soc 2000;48(5 Suppl):S84-90.

156. Rabow MW, Hauser JM, Adams J. Supporting Family Caregivers at the End of Life: "They Don't Know What They Don't Know". JAMA 2004;291(4):483-91

.

157. Rabow MW, McPhee SJ. Beyond breaking bad news: how to help patients who

suffer. West J Med 1999;171(4):260-3.

158. Rapoport J, Teres D, Lemeshow S. Can futility be defined numerically? Crit Care Med 1998;26(11):1781-2.

159. Read JL, Quinn RJ, Berwick DM, Fineberg HV, Weinstein MC. Preferences for health outcomes. Comparison of assessment methods. Med Decis Making 1984;4(3):315-29.

160. Rhodes R, Holzman IR. The not unreasonable standard for assessment of surrogates and surrogate decisions. Theor Med Bioeth 2004;25(4):367-85.

161. Rodriguez RM, Wang, N.E., Pearl, R.G. Prediction of poor outcome of intensive care unit patients admitted from the emergency department. Crit Care Med 1997;25:1801-6.

162. Rubin SB. When Doctors Say No: The Battleground of Medical Futility: Indiana University Press; 1998.

163. Ryan CJ. Betting your life: an argument against certain advance directives. J Med Ethics 1996;22(2):95-9.

164. Sackett DL RBH, Guyatt GH, Tugwell P. Clinical Epidemiology: A Basic Science for Clinical Medicine, 2nd ed. Boston: Little, Brown and Company; 1991.

165. Sayers GM, Beckett N, Waters H, Turner C. Surrogates' decisions regarding CPR, and the fallacy of substituted judgment. J Clin Ethics 2004;15(4):334-45.

166. Schneiderman LJ, Faber-Langendoen, K., Jecker N.S. Beyond futility to an ethic of care. Am J Med 1994;86:110-4.

167. Schneiderman LJ, Pearlman RA, Kaplan RM, Anderson JP, Rosenberg EM. Relationship of general advance directive instructions to specific life-sustaining treatment preferences in patients with serious illness. Arch Intern Med 1992;152(10):2114-22.

168. Schonwetter RS, Teasdale TA, Taffet G, Robinson BE, Luchi RJ. Educating the elderly: cardiopulmonary resuscitation decisions before and after intervention. J Am Geriatr Soc 1991;39(4):372-7.

169. Schonwetter RS, Walker RM, Solomon M, Indurkhya A, Robinson BE. Life values, resuscitation preferences, and the applicability of living wills in an older population. J Am Geriatr Soc 1996;44(8):954-8.

170. Seckler AB, Meier DE, Mulvihill M, Paris BE. Substituted judgment: how accurate are proxy predictions? Ann Intern Med 1991;115(2):92-8.

171. Sehgal A, Galbraith A, Chesney M, Schoenfeld P, Charles G, Lo B. How strictly do dialysis patients want their advance directives followed? Jama 1992;267(1):59-63.

172. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. Arch Intern Med 2006;166(5):493-7.

173. Silverman HJ, Tuma P, Schaeffer MH, Singh B. Implementation of the patient self-determination act in a hospital setting. An initial evaluation. Arch Intern Med 1995;155(5):502-10.

174. Silverstein MD, Stocking CB, Antel JP, Beckwith J, Roos RP, Siegler M. Amyotrophic lateral sclerosis and life-sustaining therapy: patients' desires for information, participation in decision making, and life-sustaining therapy. Mayo Clin Proc 1991;66(9):906-13.

175. Silvestri G, Pritchard R, Welch HG. Preferences for chemotherapy in patients with advanced non-small cell lung cancer: descriptive study based on scripted interviews. Bmj 1998;317(7161):771-5.

176. Singer PA, Martin DK, Lavery JV, Thiel EC, Kelner M, Mendelssohn DC. Reconceptualizing advance care planning from the patient's perspective. Arch Intern Med 1998;158(8):879-84.

177. Smucker WD, Houts RM, Danks JH, Ditto PH, Fagerlin A, Coppola KM. Modal preferences predict elderly patients' life-sustaining treatment choices as well as patients' chosen surrogates do. Med Decis Making 2000;20(3):271-80.

178. Sonnenblick M, Friedlander Y, Steinberg A. Dissociation between the wishes of terminally ill parents and decisions by their offspring. J Am Geriatr Soc 1993;41(6):599-604.

179. Sox H, Blatt, M, Higgins M, et al. Medical Decision Making. Boston: Butterworth; 1988.

180. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. Jama 2000;284(19):2476-82.

181. Stiggelbout AM, Kiebert GM, Kievit J, Leer JW, Stoter G, de Haes JC. Utility assessment in cancer patients: adjustment of time tradeoff scores for the utility of life years and comparison with standard gamble scores. Med Decis Making 1994;14(1):82-90.

182. Strauss AL, Corbin J. Basics of qualitative research: Techniques and procedures for developing grounded theory. Thousand Oaks, CA: Sage; 1998.

183. Sugarman J. A community policy on futility? A conversation of the North Carolina community. N C Med J 1995;56(9):415-7.

184. Suhl J, Simons P, Reedy T, Garrick T. Myth of substituted judgment. Surrogate decision making regarding life support is unreliable. Arch Intern Med 1994;154(1):90-6.

185. Sulmasy DP, Haller K, Terry PB. More talk, less paper: predicting the accuracy of substituted judgments. Am J Med 1994;96(5):432-8.

186. Sulmasy DP, Terry PB, Weisman CS, et al. The accuracy of substituted judgments in patients with terminal diagnoses. Ann Intern Med 1998;128(8):621-9.

187. Teno J, Lynn J, Connors AF, Jr., et al. The illusion of end-of-life resource savings with advance directives. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. J Am Geriatr Soc 1997;45(4):513-8.

188. Teno J, Lynn J, Wenger N, et al. Advance directives for seriously ill hospitalized patients: effectiveness with the patient self-determination act and the SUPPORT intervention. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. J Am Geriatr Soc 1997;45(4):500-7.

189. Teno JM, Licks S, Lynn J, et al. Do advance directives provide instructions that direct care? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. J Am Geriatr Soc 1997;45(4):508-12.

190. Teno JM, Stevens M, Spernak S, Lynn J. Role of written advance directives in decision making: insights from qualitative and quantitative data. J Gen Intern Med 1998;13(7):439-46.

191. Terry PB, Vettese M, Song J, et al. End-of-life decision making: when patients and surrogates disagree. J Clin Ethics 1999;10(4):286-93.

192. Tomlinson T, Howe K, Notman M, Rossmiller D. An empirical study of proxy consent for elderly persons. Gerontologist 1990;30(1):54-64.

193. Tonelli MR. Waking the Dying: Must We Always Attempt to Involve Critically Ill Patients in End-of-Life Decisions? CHEST 2005;127(2):637-42.

194. Truog RD, Brett AS, Frader J. The problem with futility. N Engl J Med 1992;326(23):1560-4.

195. Tulsky JA. Beyond advance directives: importance of communication skills at the

end of life. Jama 2005;294(3):359-65.

196. Tulsky JA, Chesney MA, Lo B. How do medical residents discuss resuscitation with patients? J Gen Intern Med 1995;10(8):436-42.

197. Tweed WA, Bristow G, Donen N, Kirk BW. Evaluation of hospital-based cardiac resuscitation, 1973--77. Can Med Assoc J 1980;122(3):301-4.

198. Uhlmann RF, Pearlman RA, Cain KC. Physicians' and spouses' predictions of elderly patients' resuscitation preferences. J Gerontol 1988;43(5):M115-21.

199. Veatch RM. Inactivating a total artificial heart: special moral problems. Death Stud 2003;27(4):305-15.

200. Vigano A, Dorgan M, Bruera E, Suarez-Almazor ME. The relative accuracy of the clinical estimation of the duration of life for patients with end of life cancer. Cancer 1999;86(1):170-6.

201. von Gunten CF, Ferris FD, Emanuel LL. The patient-physician relationship. Ensuring competency in end-of-life care: communication and relational skills. Jama 2000;284(23):3051-7.

202. Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. Jama 1998;279(21):1709-14.

203. Weissman JS, Haas JS, Fowler FJ, Jr., et al. The stability of preferences for life-sustaining care among persons with AIDS in the Boston Health Study. Med Decis Making 1999;19(1):16-26.

204. Whelan T, Levine M, Willan A, et al. Effect of a decision aid on knowledge and treatment decision making for breast cancer surgery: a randomized trial. Jama 2004;292(4):435-41.

205. White DB, Curtis JR. Care near the end-of-life in critically ill patients: a North American perspective. Curr Opin Crit Care 2005;11(6):610-5.

206. White DB, Engelberg RA, Wenrich MD, Lo B, Curtis JR. Prognostication during physician-family discussions about limiting life support in intensive care units. Crit Care Med 2007;35(2):442-8.

207. Wolf SM, Boyle P, Callahan D, et al. Sources of concern about the Patient Self-Determination Act. N Engl J Med 1991;325(23):1666-71.

208. Wu AW, Young Y, Dawson NV, et al. Estimates of future physical functioning by seriously ill hospitalized patients, their families, and their physicians. J Am Geriatr Soc 2002;50(2):230-7.

209. Yellen SB, Burton L.A. and Elpern E. Communication about advance directives: Are patients sharing information with physicians? Camb Q Healthc Ethics 1992;4:377-87.

210. Yellen SB, Cella DF, Leslie WT. Age and clinical decision making in oncology patients. J Natl Cancer Inst 1994;86(23):1766-70.

211. Youngner S. Applying futility: saying no is not enough. J Am Geriatr Soc 1994(42):887-9.

212. Zweibel NR, Cassel CK. Treatment choices at the end of life: a comparison of decisions by older patients and their physician-selected proxies. Gerontologist 1989;29(5):615-21.