Prognosticating - Understanding and Overcoming Misconceptions

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Overview

- Examine the causes of the high prevalence of physician-surrogate discordance about prognosis in ICUs.
- Describe an ongoing multi-center trial of an intervention to improve surrogate decision making for patients with advanced critical illness.
Surrogates & Physicians Often Have Discordant Expectations about Prognosis

Continuing Medical Education Article

Expectations and outcomes of prolonged mechanical ventilation*

Christopher E. Cox, MD, MPH; Tereza Martinu, MD; Shailaja J. Sathy, MD; Alison S. Clay, MD; Jessica Chia, MD; Alice L. Gray, MD; Maren K. Olsen, PhD; Joseph A. Govert, MD; Shannon S. Carson, MD; James A. Tulsky, MD

- Cox CE. Crit Care Med. 2012
- Azoulay E. Crit Care Med. 2004
- SUPPORT. JAMA. 1995
- Lee SJ. JAMA. 2001
- Mack JW. J Clin Onc. 2007

“Most surrogates reported high baseline expectations for 1-yr patient survival, functional status, and quality of life. Surrogate-physician pair concordance in expectations was poor (all K<0.08)…”
Methods

- 80 surrogates of critically ill patients from 3 UCSF ICUs
- Assessed surrogates’ interpretations of 16 different prognostic statements.
- Surrogates whose estimates differed from actual meaning were invited to participate in a semi-structured interview

“If the doctor says X, what does that mean to you?”

He will definitely survive.
He has a 90% chance of surviving.
It is very likely he will survive.
I think he will survive.
It is very unlikely he will die.
I am optimistic he will survive.
He has a 50% chance of surviving.
I am concerned he will not survive.
It is possible he will not survive.
He probably will not survive.
I don’t think he will survive.
It is very unlikely he will survive.
It is very likely he will die.
It is unlikely he will survive. That means he will likely die.
He has a 5% chance of surviving.
He will definitely not survive.

Chance of Survival, %

- Interquartile range
- Median response
- Mean response
- Minimum and maximum values
Table 1. Surrogates’ Explanations for Overly Optimistic Interpretations of Grim Prognostic Statements

<table>
<thead>
<tr>
<th>Need to express optimism</th>
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<tr>
<td>“I always hope for the best outcome for my husband. Even with [a] five percent chance of survival there is still hope. I hold onto hope strongly.”</td>
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<td>“I guess I understand that [the patient] may eventually die...I guess I just have to hope more.”</td>
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<tr>
<th>Belief that patients’ fortitude will lead to better-than-predicted outcomes</th>
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<tr>
<td>“I do think that a person’s will to live and their ability to survive very stressful situations can have an impact on whether they are going to survive or not. And we are talking about my father in this case, not just any patient. I know that my father could do better than what the doctor is saying...and I think he will.”</td>
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<tr>
<th>Disbelief of physicians’ ability to prognosticate</th>
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<tr>
<td>“Ultimately I don’t think [doctors] can really know the percent chance of survival unless someone comes in dead.”</td>
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<tr>
<td>“Whenever you get into a percentage, that’s always an iffy proposition. I think any physician would probably tell you that if they say '5%' to you that they’re not really giving you a real figure because they really couldn’t say...exactly.”</td>
</tr>
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Optimism Bias
Psychology of Risk Perception

A cognitive bias that leads people to overestimate, in relation to others, their likelihood of experiencing positive outcomes and avoiding negative outcomes.

“Where all the women are strong, all the men are good looking, and all the children are above average.”
“It’s not just what the doctor tells me:” Factors that influence surrogate decision-makers’ perceptions of prognosis*

Elizabeth A. Boyd, PhD; Bernard Lo, MD; Leah R. Evans, Med; Grace Malvar, BA; Latifat Apatira, BA; John M. Luce, MD; Douglas B. White, MD, MAS

Objective: Physicians often underestimate the worst-case scenarios ill patients often cited to them by surrogates. We sought to investigate whether surrogates rely on what they learn from the physician’s assessments. Surrogate decision-making and illness perceptions are informed by the patient’s will to live, the patient’s history of survival, the surrogate’s bedside observations of the patient, the surrogate’s faith and optimism, and the surrogate’s belief that their presence at the bedside will improve prognosis.

Main Results: Less than 2% of surrogates reported that their prognostic estimate was informed solely by the physician’s prognostications.

“Less than 2% of surrogates reported that their prognostic estimate was informed solely by the physician’s prognostications.”

Boyd E. Crit Care Med. 2010
Surrogate Decision Makers’ Responses to Physicians’ Predictions of Medical Futility

Lucas S. Zier, MS; Jeffrey H. Burack, MD, MPP, BPhil; Guy Micco, MD; Anne K. Chipman, MS; James A. Frank, MD; and Douglas B. White, MD, MAS
Hope, Truth, and Preparing for Death: Perspectives of Surrogate Decision Makers

Latifat Apatira, BA; Elizabeth A. Boyd, PhD; Grace Malvar, BA; Leah R. Evans, MEd; John M. Luce, MD; Bernard Lo, MD; and Douglas B. White, MD, MAS

**Design:** semi-structured interviews with 180 surrogates of ICU patients at high risk of death.

- "Do you think physicians should avoid discussing prognosis in order to maintain hope?"

**Results:**
- 95% felt that avoiding such discussions was unacceptable.
- Physicians’ prognostications allow families time:
  - to prepare emotionally for the patient's death.
  - To prepare practically (making funeral arrangements, notifying relatives)

**Implications:** Surrogates value discussions about prognosis because they facilitate emotional and psychological preparation for death.

Apatira L. Ann Internal Med. 2008
Gist of Problems to Address:

- Families are often overwhelmed
- Insufficient clinician-family communication
- Distrust
- Ineffective/incomplete discussion of prognosis, patient values, treatment options.
Emotional Arousal Changes How We Deliberate

‘Hot’ State
• Fight or flight
• Non-deliberative
• Black and white’

‘Cool’ State
• Rational processing
• Deliberative
• Appreciate trade-offs
Four Supports Intervention: adding to the ICU team a specially trained nurse interventionist to:

- maintain a longitudinal relationship with surrogates
- provide emotional support, communication support, decision support, and anticipatory grief support.

The Four Supports Intervention

- **Emotional Support**
  - Longitudinal relationship, empathy, daily check-ins.

- **Communication Support**
  - Scheduled family conferences

- **Decision Support**
  - Values clarification exercise; “nudges” clinicians to address prognosis, values, options

- **Anticipatory Grief Support**
  - Opportunity for life review and closure
Leveraging Principles of Behavioral Economics
The Power of Defaults

📍 Default: “the events or actions that will be set in place if no alternatives are actively chosen.”

📍 Intervention: Flipping the default for family meetings

“On-demand” family meetings (opt-in, MD-driven) → “Prescheduled” family meetings (opt-out, protocol-driven)
Focusing effect: the psychological tendency to place more importance on a factor that a person is prompted to consider.

Intervention: Focusing clinicians on surrogates’ misperceptions about prognosis before a family meeting.
RCT of Family Support Intervention

N=400 surrogates of ICU patients at high risk of death/disability in 6 UPMC ICUs

Four Supports Intervention  
3 & 6 month follow-up

Brief Educational Intervention  
3 & 6 month follow-up

Outcome measures:  
**Surrogate DM:** Surrogates’ 6 month symptoms of depression & anxiety  
**Patient:** hospital and 6 month mortality/functional status,  
**Health system:** hospital costs and 6 month healthcare costs  
**Decision quality:** perception of prognosis; pt-centeredness of care, decisional conflict
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UNC
Shannon Carson, MD, MS

UAB
C. Seth Landefeld, MD
Surrogates’ Optimism is Associated with More Use of Life Support Before Death

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Outcome measure</th>
<th>β (95% CI)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>If surrogate is optimistic*†</td>
<td>Hospital LOS</td>
<td>44.0% (1.6% – 86.5%)</td>
<td>0.042</td>
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<tr>
<td></td>
<td>ICU LOS</td>
<td>48.9% (7.4% – 90.4%)</td>
<td>0.021</td>
</tr>
<tr>
<td></td>
<td>Duration of mechanical ventilation</td>
<td>44.3% (1.6% – 87.1%)</td>
<td>0.042</td>
</tr>
</tbody>
</table>

* Optimistic discordant is defined as: (surrogate’s estimate – MD’s estimate) > +20%

† Adjusted for patient’s age, race (non-Hispanic black vs. other), APACHE II score, surrogate’s religion (affiliated vs. none), and surrogate’s relationship with the patient (spouse/child/other)

We modeled the association using linear regression

Due to the skewness of LOS data, they are log-transformed in the model
Surrogates’ Optimism is Not Associated with Higher Survival to Discharge

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Odds Ratio</th>
<th>P value</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>If surrogate is optimistic* (adjusted)†</td>
<td>1.20</td>
<td>0.56</td>
<td>0.65 – 2.20</td>
</tr>
</tbody>
</table>

* Optimistic discordant is defined as: (surrogate’s estimate – MD’s estimate) > +20%
† Adjusted for patient’s age, race (non-Hispanic black vs. other), APACHE II score, surrogate’s religion (affiliated vs. none), and surrogate’s relationship with the patient (spouse/child/other)

The outcome variable is binary: whether the patient died (y=0) or did not die (y=1) in the hospital

We modeled the association using logistic regression

Funding: NIH-NHLBI- R01HL094553
Thinking about Mental Models

Definition of mental model: A psychological representation of a situation that informs how individuals reason and behave.
The Usual Mental Model

"The family does not understand what's going on..."

- Repeat yourself
- Say it louder.
Why the Disconnect?
A Simple Conceptual Model

No disclosure about prognosis  \rightarrow  Discordance about prognosis
I Shouldn't Have Had To Beg for a Prognosis

Aug. 22, 2005 issue - I was once a stalker. My victims—yes, there were several—were high on the social scale, but they were not celebrities. They were doctors....
Question: How frequently do physicians discuss prognosis in GOC talks?
Design: Audiotaped 51 physician-family discussions re: limiting life support; 80% mortality.
Setting: 4 Seattle-area hospitals
Method: Coding of clinicians’ prognostic statements.

Table 3. Prognostic statements by category in the 51 intensive care unit family conferences

<table>
<thead>
<tr>
<th>Type of Prognostic Information</th>
<th>Proportion of Conferences in Which Category Was Addressed (n = 51) No. (%)</th>
<th>No. of Prognostic Statements (n = 477) No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Survival</td>
<td>32 (63)</td>
<td>78 (16.4)</td>
</tr>
<tr>
<td>Short-term</td>
<td>31 (61)</td>
<td>68 (14.3)</td>
</tr>
<tr>
<td>Long-term</td>
<td>6 (12)</td>
<td>10 (2.1)</td>
</tr>
<tr>
<td>Functional outcomes</td>
<td>44 (86)</td>
<td>272 (57.0)</td>
</tr>
<tr>
<td>Status/quality of life</td>
<td>39 (77)</td>
<td>163 (34.2)</td>
</tr>
<tr>
<td>Anticipated disposition</td>
<td>18 (35)</td>
<td>35 (7.3)</td>
</tr>
<tr>
<td>Freedom from ventilator</td>
<td>15 (29)</td>
<td>36 (7.5)</td>
</tr>
<tr>
<td>Intermediate outcome</td>
<td>19 (37)</td>
<td>38 (8.0)</td>
</tr>
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</table>

Why the Disconnect?
Another Simple Conceptual Model

Surrogates can’t comprehend the information
(anxious, overwhelmed, too complex)

Discordance about prognosis
Understanding of Prognosis Among Parents of Children With Cancer: Parental Optimism and the Parent-Physician Interaction
Jennifer W. Mack, E. Francis Cook, Joanne Wolfe, Holcombe E. Grier, Paul D. Cleary, and Jane C. Weeks

Understanding of Prognosis and Goals of Care Among Couples Whose Child Died of Cancer
Kelly E. Edwards, Bridget A. Neville, Earl F. Cook Jr, Sarah H. Aldridge, Veronica Dussel, and Joanne Wolfe

Understanding of Prognosis Among Parents of Children Who Died of Cancer
Impact on Treatment Goals and Integration of Palliative Care
Hypotheses:

- **H1**: Surrogates in ICUs can comprehend physicians’ prognostications embedded in a “typical” family meeting.
- **H2**: Quantitative prognostic statements will be better understood than qualitative statements.

**Design**: RCT; 169 surrogates of incapacitated ICU patients.

**Intervention**: Randomized to view 1 of 2 versions of simulated ICU family conference; varied only by qualitative vs quantitative prognostic statement.
Methods - Content of Simulated Family Conference

Introductions

Explanation of medical situation

Empathy, Conversation about patients as person

Disclosure of prognostic estimates

Deliberation & agreement on time limited trial

QUANTITATIVE VERSION:
“I would say he has about a 10% chance of surviving. Saying it another way, that means there’s about a 90% chance that he’s going to die.”

QUALITATIVE VERSION:
“I would say it’s very unlikely that he will survive. Saying it another way, that means it’s very likely he’s going to die.”

N=35 physicians
Chance of survival: 9% ± 4%
Simulated Family Meeting
Outcome Measure 1: Surrogates’ Understanding of Physician’s Prognostications

What do you think the doctor thinks are the chances that the patient will survive this hospitalization?

No chance of survival

Will definitely survive

Surrogate’s understanding of MD’s estimate
## Results

What do you think the doctor thinks are the chances that the patient will survive this hospitalization?

<table>
<thead>
<tr>
<th>Group 1</th>
<th>Group 2</th>
<th>p-value</th>
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</thead>
<tbody>
<tr>
<td><strong>Quantitative Language</strong>&lt;br&gt;(10% chance of survival)</td>
<td><strong>Qualitative Language</strong>&lt;br&gt;(very unlikely to survive)</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>17% ± 22</td>
<td>16% ± 27</td>
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</table>

- Only 52% of subjects in quantitative group estimated the prognosis to be exactly 10% chance of survival.
- 1 in 5 subjects estimated a > 40% chance survival
Physician-surrogate Discordance about Prognosis is “Non-random”

Substantial Physician-Family Disagreement About Prognosis

Physician's Estimate of Prognosis for Survival

Family's Estimate of Prognosis for Survival
Hypothesis 3: There will be discrepancies between surrogates’ understanding of the physician’s prognostications and their belief about the patient’s prognosis, in the direction of optimism.
Mechanisms of Physician-Family Discordance about Prognosis

1. What do you think the doctor thinks are the chances that the patient will survive this hospitalization?

2. What do you think are the chances that the patient will survive this hospitalization?
## Differences Between What Surrogates Hear and Believe

<table>
<thead>
<tr>
<th>Outcome measure What surrogate heard</th>
<th>Outcome measure What surrogate believed</th>
<th>p-value</th>
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<tbody>
<tr>
<td>Mean chance of survival</td>
<td>16% ± 19</td>
<td>23% ± 22</td>
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</table>
### Similar Prevalence and Causes of Discordance in Actual Surrogate Decision Making

<table>
<thead>
<tr>
<th>Prevalence of Discordance about Prognosis</th>
<th>Proportion (N = 459)</th>
<th>(95% CI)</th>
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<tr>
<td></td>
<td>51.4%</td>
<td>47%-56%</td>
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#### Cause

- Combination of misunderstanding and difference in belief: 21.8% (18%-26%)
- Misunderstanding alone: 25.5% (22%-30%)
- Disbelief alone: 3.7% (2%-5%)

**Funding:** NIH-NHLBI- R01HL094553
The frequent disconnect about prognosis between clinicians and surrogates has multiple causes:

- Absent or incomplete disclosure by clinicians
- Misunderstandings by surrogates
- Optimism bias and other psychological processes causing disbelief of physicians’ prognostications.
A Better Mental Model

“What’s keeping us from being on the same page?”

Have I not addressed prognosis?

Have they misunderstood?

Are they unable to accept what I’ve said?

Do they have a different belief system?