How to make sense of it all: Prognosis and surrogate decision making in the ICU

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Providence St. Vincent Medical Center

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Providence Portland Medical Center

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HOW TO MAKE SENSE OF IT ALL: PROGNOSIS AND SURROGATE DECISION MAKING IN THE ICU

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Objectives

❖ To explore the causes of misperceptions about prognosis among surrogate decision makers in ICUs.
❖ To summarize the consequences of misperceptions about prognosis in ICUs.
❖ To suggest strategies to disclose news of a poor prognosis to surrogates.
Background

- One in five deaths in the US occurs in an ICU.
- Most patients with advanced illness lack decision making capacity.
- Family members or others act as surrogates regarding decisions about use of life support.

Surrogates & Physicians Often Have Discordant Expectations about Prognosis

- White DB. JAMA. 2016
- Cox CE. Crit Care Med. 2012
- Mitchell SL. NEJM. 2009
- Mack JW. J Clin Onc. 2007
- Azoulay E. Crit Care Med. 2004
- Lee SJ. JAMA. 2001
- SUPPORT. JAMA. 1995
What do you think are the chances that the patient will survive this hospitalization?

- No chance of survival
- 1% chance of survival
- 5% chance of survival
- 10% chance of survival
- 15% chance of survival
- 25% chance of survival

<table>
<thead>
<tr>
<th>MD’s</th>
<th>Surrogate’s</th>
</tr>
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<tbody>
<tr>
<td>43%</td>
<td>57%</td>
</tr>
</tbody>
</table>

43% of surrogates held significantly more optimistic expectations about prognosis compared to the attending physician.

White DB. JAMA. 2016

Physicians are Reasonably Accurate at Predicting Hospital Mortality

Mortality predictions in the intensive care unit: Comparing physicians with scoring systems

The area under the summary ROC curve was 0.85 for physicians' predictions, with good discrimination between survivors and nonsurvivors.

Sinuff T. CCM. 2006

What About the Uncertainty?

Surrogate Decision-Makers’ Perspectives on Discussing Prognosis in the Face of Uncertainty

Most surrogates see prognostic uncertainty as unavoidable and acceptable and desire a discussion of uncertain prognosis.

Evans L. AJRCCM 2009
Should we care that surrogates frequently have inaccurate expectations about patients’ prognoses in ICUs?

Ethical Concern: Misperceptions May Lead to Decisions that Do Not Reflect Patients’ Values

- Misperceptions May Lead to Decisions that Do Not Reflect Patients’ Values
- Most patients’ preferences are sensitive to the likely outcomes of treatment. (Fried T. NEJM. 2002)
- Surrogates with unduly optimistic expectations may choose more invasive treatment than patient would choose.

Economic Concern: Optimism about Prognosis May Lead to Costly Overtreatment at the End of Life

- Optimism about Prognosis May Lead to Costly Overtreatment at the End of Life
- RCTs
  - Murphy DJ. NEJM 1994
  - Volandes AE. BMJ 2009
- Observational studies:
  - Fried TR. NEJM. 2002
  - Silveira MJ. NEJM, 2010
  - Lloyd CB. Crit Care Med. 2004
Unanswered Questions about Causes

- It is not clear why the frequent discordance about prognosis exists.
- Interventions developed without a clear understanding of the causes risk being misguided.

Why the Disconnect?
A Simple Conceptual Model

- No disclosure about prognosis
- Discordance about prognosis

Newsweek Columnists

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...
Do Physicians Discuss Prognosis in ICUs?

Prognostic information was defined as “statements of expected course of illness, prospect of survival or recovery, or statements of uncertainty about the future.”

TIME TO FIRST DISCUSSION ABOUT PROGNOSIS

LeClaire M. Chest 2005

Why the Disconnect?

Another Simple Conceptual Model

Surrogates can’t comprehend the information (anxious, overwhelmed, too complex) → Discordance about prognosis

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**

**QUANTITATIVE VERSION**:

“...chance of surviving. Saying it another way, that means there’s about a 90% chance that he’s going to die.”

**QUALITATIVE VERSION**:

“...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></th>
<th>Group 1 Quantitative Language (10% chance of survival)</th>
<th>Group 2 Qualitative Language (very unlikely to survive)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>17% ± 22</td>
<td>16% ± 27</td>
<td>p=0.62</td>
</tr>
</tbody>
</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”

![Graph showing substantial physician-family disagreement about prognosis]

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.”

Hypotheses

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</th>
<th>Outcome measure</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>What surrogate heard</td>
<td>What surrogate believed</td>
<td>p &lt; .0001</td>
</tr>
<tr>
<td>Mean chance of survival</td>
<td>16% ± 19</td>
<td>23% ± 22</td>
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Original Research

Surrogate Decision Makers' Interpretation of Prognostic Information

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?”

“Interpret the surge”

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

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

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

Limitations of the Studies

- Hypothetical cases

- Perhaps the strength of real relationships with clinicians will overcome whatever inclinations surrogates' feel to disbelieve prognostications.
Mechanisms of Physician-Family Discordance about Prognosis

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

Similar Prevalence and Causes of Discordance in Actual Surrogate Decision Making

<table>
<thead>
<tr>
<th>Proportion (N = 239)</th>
<th>(95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence of Discordance about Prognosis</td>
<td>43%</td>
</tr>
<tr>
<td>Cause</td>
<td></td>
</tr>
<tr>
<td>Combination of misunderstanding and difference in belief</td>
<td>24%</td>
</tr>
<tr>
<td>Misunderstanding alone</td>
<td>15%</td>
</tr>
<tr>
<td>Different beliefs alone</td>
<td>4%</td>
</tr>
</tbody>
</table>
Main Findings

- 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.

Clinical Implication

We Need to Change our Mental Model

“The family just doesn’t get it…”

A Better Mental Model

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

- Have I not addressed prognosis?
- Have they misunderstood?
- Are they emotionally overwhelmed?
- Do they have a different belief system?
Key Stakeholders’ Perspectives on Interventions to Improve Communication about Prognosis

Goal: To determine the perspectives of key stakeholders regarding important elements of effective communication about prognosis in ICUs.

Study Design: In-depth semi-structured interviews with 114 participants at 3 US academic medical centers.
- Surrogates (n=47)
- ICU clinicians (MDs, nurses, SW, chaplains) (n=45)
- National experts (n=22)

Main theme:
- Improving communication about prognosis should be embedded in a more comprehensive intervention to support surrogates.
  - Focus on building relationships and trust
  - Provide intensive emotional support and frequent communication
  - Focus on gist of prognosis rather than overly precise estimates
  - Facilitate consideration of patient’s values/preferences

Anderson WG. Ann Am Thorac Soc. 2014
Emotional Arousal Changes How We Deliberate

- **'Hot' State**
  - Fight or flight
  - Non-deliberative
  - Black and white

- **'Cool' State**
  - Rational processing
  - Deliberative
  - Appreciate trade-offs

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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.


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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)

Leveraging Principles of Behavioral Economics

Focusing Effects

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

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
Conclusions

- The conventional explanation that discordance about prognosis is due to 'simple misunderstandings' is incomplete.
- There are emotional and psychological mechanisms that contribute to the discordance.
- Interventions that do not attend to these mechanisms are unlikely to fully address the problem.

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