Making Recommendations to Surrogates about Life Support Decisions in ICUs

Douglas B. White, MD, MAS
Associate Professor of Critical Care Medicine
Director, Program on Ethics and Critical Care

The CRISMA Laboratory
Department of Critical Care Medicine
School of Medicine
Center for Bioethics and Health Law
University of Pittsburgh

©University of Pittsburgh 2009
Disclosures

Research Funding
- NHLBI- R01
- NIA- Beeson Award
- Greenwall Foundation Faculty Scholars Program
- UPMC Innovation Fund

No other financial conflicts relevant to this talk
Why are life support decisions difficult?

The nature of the decision is different from most decisions that arise in ICUs.

- Physicians’ technical expertise cannot identify the right answer.
- “Correctness” of decision driven by the individual patient’s values.
- Clinicians often have no prior knowledge of the patient.

www.dartmouthatlas.org/topics/preference_sensitive.pdf
## The Anatomy of a Medical Decision

Giving recommendations different from providing information

<table>
<thead>
<tr>
<th>Dimensions of Decision-Making</th>
<th>Informed</th>
<th>Shared</th>
<th>Paternalistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information Exchange</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MD provides Medical Information</td>
<td>x</td>
<td>x</td>
<td>x (minimal)</td>
</tr>
<tr>
<td>MD elicits patient values</td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Who deliberates?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td></td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>Physician &amp; family</td>
<td></td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>Who decides?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td></td>
<td></td>
<td>Physician</td>
</tr>
<tr>
<td>Physician &amp; family</td>
<td></td>
<td></td>
<td>Physician</td>
</tr>
</tbody>
</table>

Charles C. BMJ. 1999
Physicians’ Attitudes about Recommendations for EOL Care

- 45% of US generalists do not routinely provide recommendations about EOL care decisions, and instead only provide information.

- Patients significantly more likely to want a recommendation than physician was to provide one (p<0.0001)

Johnston SC. JGIM 1998
Question: What role do physicians take in life support decisions for patients at high risk of death or debilitation?

Design: Prospective, multicenter qualitative study of audiotaped physician-family discussions.

Subjects: 495 family members and 414 clinicians of incapacitated critically ill patients involved in 162 life support decisions.

White. Crit Care Med. 2010
Do physicians provide recommendations during deliberations about whether to limit life support?

Analysis:

For each decision, coded presence/absence of:

- Treatment recommendations from physicians
  • Excellent inter-rater reliability (kappa= 0.91)

<table>
<thead>
<tr>
<th>Recommendation from clinician</th>
<th>N=163 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>52%</td>
</tr>
</tbody>
</table>
Responding to Requests for Recommendations

- For 33% decisions, families requested recommendation.
- In half the cases, physicians refused or avoided.

FAMILY: Doctor, can I ask your professional opinion, please, don't hesitate, I'm really ready for this. What would you recommend, strongly recommend? Please don't think about, you know, hurting my feelings. I'm trying to listen to you as much as I can.

PHYSICIAN: Sure. That's a tough question for me to answer.

FAMILY: I'm not asking your personal, just your professional opinion.

PHYSICIAN: Well, even as a professional, it's tough for me to answer...What I like to do is, is kind of give you the facts as, as I know from my experience and what we can expect from her having this large injury... (CN 11; line 120)
Potential Concerns about Giving Recommendations
Physicians in ICUs Don’t Know Their Patients

- For highly value-laden decisions, how can a physician be sufficiently informed to make a recommendation?
- Is it possible to gain sufficient clarity about patient values through brief conversations with surrogates?
Variability in Physician Values May Lead to Unwarranted Variability in Care

Cook DJ. JAMA 1995;273:703-08
The Role of Physicians’ Recommendations in Medical Treatment Decisions

ANDREA D. GURMANKIN, MA, JONATHAN BARON, PhD, JOHN C. HERSHEY, PhD, PETER A. UBEL, MD

- **Design:** Online experiment; n=102 participants presented hypothetical medical treatment scenarios in which the treatment choice that maximized health was obvious. Physicians’ recommendations were varied in 3 ways:
  1. Physicians’ recommendations supporting what maximized health,
  2. Physicians’ recommendations against what maximized health,
  3. No physicians’ recommendation.
Imagine that you were recently diagnosed with a serious arrhythmia (an irregularity in the heart beat)

There is a small chance—a 2% (2 out of 100) chance—of sudden death in the next year from this type of arrhythmia, but there are no other risks to having this arrhythmia. There is an antiarrhythmic medication that completely eliminates this arrhythmia, which would completely eliminate the 2% chance of death from the arrhythmia. However, this medication carries with it a moderate sized chance—a 7% (7 out of 100) chance per year—of an allergic reaction that always result in sudden death. The chance of death from the medication is greater than the chance of death from the arrhythmia. There are no other risks or side effects of this medication.

Would you take the antiarrhythmia medication?

Physicians’ Recommendations Can Be Unduly Persuasive

Most subjects did not follow the physicians’ recommendation when it went against the decision that maximized health, but a small proportion did.

Ubel P. Med Decis Making 2002
Potential for Undue Influence

When the physician recommended that you get the [treatment], you said you would, and when the physician recommended that you do not get the [treatment], you said you would not.

<table>
<thead>
<tr>
<th>Response Frequency</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>41%</td>
<td>I believe the physician had important additional information that should influence my decision</td>
</tr>
<tr>
<td>17%</td>
<td>The physician had information about my risk that went beyond the data given in the question</td>
</tr>
<tr>
<td>13%</td>
<td>Physicians know best</td>
</tr>
<tr>
<td>9%</td>
<td>I don’t like having the responsibility of making my own medical decisions</td>
</tr>
<tr>
<td>9%</td>
<td>Other</td>
</tr>
<tr>
<td>6%</td>
<td>I don’t trust myself to make the right decision</td>
</tr>
<tr>
<td>6%</td>
<td>I didn’t notice that the scenarios were the same</td>
</tr>
<tr>
<td>1%</td>
<td>No response</td>
</tr>
</tbody>
</table>

Ubel P. Med Decis Making 2002
Potential benefits of giving recommendations.
Pro: Most Surrogates Want a Recommendation

Value laden decision: “Imagine that your loved one’s illness worsened considerably and there was only a very small chance he would survive with continued use of life support and ICU treatment. If he survived, he would have physical and cognitive disabilities that made it so that he/she was dependent on others for basic tasks such as bathing, paying bills and preparing meals, but would be able to communicate.”

Johnson S. AJRCCM. 2011
Most Surrogates Want a Recommendation

Johnson S. AJRCCM. 2011
To Overcome Emotional and Psychological Factors That Negatively Affect Decision Quality

The Vortex: Families’ Experiences with Death in the Intensive Care Unit

By Karin T. Kirchhoff, RN, PhD, Lee Walker, RN, PhD, Ann Hutton, RN, PhD, Vicki Spuhler, RN, MSN, Beth Vaughan Cole, RN, PhD, and Terry Clemmer, MD. From University of Utah College of Nursing (LW, AH, BVC) and LDS Hospital (VS, TC), Salt Lake City, Utah, and University of Wisconsin School of Nursing, Madison, Wis (KTK).

Letting go: Family willingness to forgo life support

Valerie Swigart, RN, PhD, Charles Lidz, PhD, Victoria Butterworth, PhD, and Robert Arnold, MD, Pittsburgh, Pa.

Decisions About Life-Sustaining Treatment

Impact of Physicians’ Behaviors on the Family

Virginia P. Tilden, RN, DNSc, FAAN; Susan W. Tolle, MD; Michael J. Garland, DScRel; Christine A. Nelson, RN, MS
High rates of long-term psychological symptom burden among surrogates.

“stress, guilt over the decisions they made, and doubt regarding whether they had made the right decisions.”

Association between role discordance and worse bereavement outcomes. (Gries. Chest 2008)

Wendler D. Ann Intern Med. 2011
A Dilemma

Giving recommendations:
- Potential for paternalism and abuse of power

Withholding recommendations:
- Potential for decisions driven by fear and insecurity
- Adverse bereavement outcomes

Pros outweigh cons IF
- Physicians take seriously the ethical obligation to focus on patient’s values when making recommendations.
A Few Suggestions

- Create context in which surrogates can disagree with you.
- Talk about the patient’s values before providing a recommendation.
- Consider allowing family to deliberate for a time before giving a recommendation.
- Ground your recommendation in the patient’s values.
  - “Based on what you’ve told be about your father, it sounds like the plan that would be most consistent with his values is....”
- Conceptualize recommendation as part of the deliberations, not the final word.
  - “Does this seem like it fits with his values?”
Giving a recommendation

Ask-Tell-Ask

- **Ask**: “Would you like to hear my opinion?”
- **Tell**: give patient-centered recommendation

“Based on what you’ve told me about your father, it sounds like….”

- **Ask**: “What do you think about that?”