End-of-Life Care in the ICU

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Disclosure

- I have no relevant disclosures to report
End of Life in the ICU

- Nearly 2.5 million deaths/year
- 1 in 5 deaths include ICU stay
- For people who die in the hospital, ICU stay associated with:
  - Longer LOS: 12.9 vs 8.9 days
  - Higher costs: $24,541 vs $8,548

National Center for Health Statistics, 2006
http://www.cdc.gov/nchs/fastats/deaths.htm
End of Life in the ICU

- Uncontrolled symptoms in up to 80% of patients
- Conflict and misunderstandings reported by
  - 70% of providers
  - 40% of family members
- Anxiety, PTSD, complicated grief in 1/3 of families
- PTSD found in 1/3 of providers

Myhren et al Crit Care 2010
Puntillo et al Crit Care Med 2010
Azoulay et al Am J Respir Crit Care Med 2009
Anderson et al J Gen Intern Med 2008
Merlani Am J Respir Crit Care Med 2011
ICU Cases

“Do everything”

Typical cases
Needs of Seriously Ill Patients and Their Families in the ICU

- Comfort and dignity
- Communication
- Psychosocial support

Singer et al. *JAMA* 1999;281:163-8
Needs of Seriously Ill Patients and Families in the ICU

- Comfort and dignity
  - Symptom control
    - Relief of patient suffering should not be a reason to withdraw life-sustaining interventions
  - Treat patient like a person
    - Have family bring in photos
    - Address patient by name and talk to them
    - Attend to privacy

Singer et al. *JAMA* 1999;281:163-8
Needs of Seriously Ill Patients and Families in the ICU

- Comfort and dignity
- Communication
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Singer et al. *JAMA* 1999;281:163-8
Needs of Seriously Ill Patients and Families in the ICU

- **Communication**
  - Clear, timely, compassionate
  - Elicit patient values and treatment preferences

- **Family meetings**
  - Early and often as necessary
  - Plan and practice

Nelson et al. *J Crit Care* 2009;24:626.e7-14
Curtis and White *Chest* 2008;134:835-43
The VALUE of Good Communication

- 22 ICUs in France
- 108 family members randomly assigned
- VALUE communication and brochure about bereavement vs usual care
- All patients had life-sustaining interventions withdrawn
  - 90% had mechanical ventilation
  - 72% had vasopressors
  - 76% sedated

Lautrette A et al. NEJM 2007;356:469-78
VALUE Intervention

- Value and appreciate what the family members said
- Acknowledge the family members’ emotions
- Listen
- Ask questions that would allow the caregiver to understand who the patient was as a person
- Elicit questions from the family members
VALUE Intervention Results

- Longer family conferences
  - 30 min vs 20 min
  - Family talked more: 14 min vs 5 min
  - Physician talked the same

- Lower prevalence of PTSD-like symptoms, anxiety, and depression in family members 3 months later
Talking with Patients and Families

- “Thank you for coming to talk with us”
- Introductions
- Elicit understanding
  - “I was wondering if you could tell me what you understand about what is going on with you (your father)”
- Provide a summary of the patient’s condition
  - Begin from where the family is
  - Avoid jargon: mechanical ventilation, pressors
  - Check for understanding

Curtis and White Chest 2008;134:835-43
Talking with Patients and Families

- Determine what the patient wants or would want
- Eliciting patient values and preferences
  - “What was she like?”
  - “If she could sit up in bed…”
  - “Not what you want for her, or what you’d want for yourself, but what she would want for herself”
Talking with Patients and Families

- Assume responsibility for the decision
  - “Based on what I know about your mother and the medical situation… I recommend”
  - Don’t force the family to decide
  - Check for agreement and leave room for disagreement

- Summarize
- Arrange follow up
- Document the meeting
Needs of Seriously Ill Patients and Families in the ICU

- Psychosocial support
  - Open access and proximity to patient
  - Hope and empathy
    - “What do you hope will happen?”
    - “I can see how much you love her”
    - “This must be very stressful”
    - “We will take good care of her”
“Do Everything” Cases

Think about patients you have cared for where the family asked you to “do everything” when you were sure the patient would die

- What was the clinical situation?
- What was the setting?
- What about the case was difficult or challenging?
“Do Everything”

- Request can have many meanings
  - “Do everything you possibly can to keep our loved one alive at all costs”
  - “Don’t abandon her/us”
  - “She is scared to die”
  - “I can’t bear the thought of him dying”
  - “I don’t believe that she’s really dying”

Different Perspectives

How we see it | How families see it
---|---
LOS | Length of life
Date of discharge | Date of death
68 yo AML, MSOF | Mom
Dying | Alive
Maintain Perspective

- The family is suffering
  - Having a sick loved one is very stressful
  - Conflicting and contradictory information from providers can be very distressing
- Really difficult cases are stressful, but rare
  - All cases will resolve
  - Occasionally the patient will surprise you
Accuracy of Clinician Prognostication

- 560 medical ICU patients
- Daily survival estimates by attending physicians, fellows, residents, nurses
  - “Do you think this patient will die in the hospital or survive to be discharged?”
- 50% of patients predicted to die survived to discharge
- 15% of patients who all providers predicted would die survived

Meadow et al. Crit Care Med 2011
Accuracy: Long-Term Outcomes

- 1-year outcomes of prolonged mechanical ventilation: Predictions vs. Actual

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Family</th>
<th>MD</th>
<th>Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Survival</td>
<td>93%</td>
<td>44%</td>
<td>56%</td>
</tr>
<tr>
<td>Fxnl independence</td>
<td>71%</td>
<td>6%</td>
<td>9%</td>
</tr>
<tr>
<td>Good QOL</td>
<td>83%</td>
<td>4%</td>
<td>33%</td>
</tr>
</tbody>
</table>

- MD accuracy = 36-74%
- Family accuracy = 41-62%

Cox et al. *Crit Care Med* 2009
Responding to Families

- “She’s a fighter”
  
  “Yes, she has been very strong. I worry that this time the illness is stronger”

- “She wants to live”
  
  “Of course she does. But would she want to live like this?”

- “We are waiting for a miracle”
Understanding “Miracles”

- By definition, miracles are:
  - Rare
  - Not brought about by medical professionals
- Meaning of miracles:
  - Divine intervention bringing about recovery
  - “Don’t give up on him”
  - “I’m not giving up on my loved one”
  - “I’m not ready for her to die”
  - “I’m not giving up on God”
  - “I don’t believe what you say about prognosis”
Responding to Hope for a Miracle

- Probe the meaning of miracle
  - “What do you mean by miracle?”
  - “What would that look like?”
- Resist religious debates
- Explain
  - “As a physician I have to practice medicine as we understand it”
  - “I, too, hope for that miracle. That’s what it would take”

Sulmasy JAMA 2006;296:1385-1392
DeLisser Chest 2009;135:1643-1647
Widera et al. JPSM 2011;42:119-25
Responding to “Do Everything”

- “Everything” has different meanings to families and medical staff
- Ask a better question
  - “How were you hoping we could help?”
- Try to establish a philosophy of treatment
  - Everything that will prolong life, but not if it is invasive
  - Everything that will prolong life, even if it is invasive
When Families Want “Everything Done”

- Ensure good information from all clinicians
  - Provide consistent, clear information
- Avoid detailed discussions of medical management
- Demonstrate caring, concern, and understanding
  - Listen
  - Stay engaged and collaborative
When Prognosis is Very Poor

- Be direct, but only as direct as you can
  - “I am worried that even with everything we can do, it will not change the outcome.”
  - “Even with all the advances of modern medicine, there are still limitations.”
  - “Your mother is dying and unfortunately nothing we can do will change that.”
  - “The question is not whether your mother will die, but how, when, and where.”
Harm Reduction and Collaboration

- Attempt small steps
  - DNR: “We’ll do everything to help, but if he dies suddenly, we will let him go in peace”
  - No intensification of treatments
- Stop discussing withdrawal of interventions
- Address clinician discomfort
  - Empathy as the antidote for moral distress
  - Discuss as a team
  - Acknowledge concerns, correct misperceptions

Conclusion

- Most ICU cases resolve with good communication and care
- The rare “Do everything” case can be very stressful to everyone involved
- Elicit and establish overall goals and treatment plan
- Provide the best possible communication
- Practice harm reduction
- Provide support to patient, family, staff, and yourself