Working with the Family that Wants “Everything Done”

Matthew Gonzales, MD
Steven Pantilat, MD

Palliative Care Program
Division of Hospital Medicine
Department of Medicine
University of California, San Francisco
Disclosure

- We have no relevant disclosures to report
“Do Everything” Cases

- Think about patients you have cared for where the family asked you to “do everything”
  - What was the clinical situation?
  - What was the setting?
  - What about the case was difficult or challenging?
Mrs. M

- Mrs. M is a 73 year old woman s/p renal transplant 12 weeks ago admitted 6 weeks ago with MRSA pneumonia. She developed multisystem organ failure despite antibiotics and supportive care. She is intubated on high FiO2, hypotensive on 2 pressors with necrosis and gangrene of her toes and fingers, on CVVH for renal failure, has a large, deep sacral decubitus ulcer. She is confused and visibly in pain. Opioids make her comfortable and less responsive.
Mrs. M

Mrs. M’s family is very devoted and someone is always at her bedside. They insist that she responds to them and says she wants to live. Mrs. M’s family speaks English but Mrs. M speaks only Arabic. In-person interpreters say that Mrs. M cannot answer questions coherently. Mrs. M’s children understand that she is very sick and that all the doctors and nurses think she will die. They repeatedly state they want “everything done” with a goal of taking their mother home.
Challenges: Provider Perspective

- Prognostic uncertainty
- Information from many providers
- Patient suffering
- Distress of staff - nurses, RT
- Time consuming
- Poor utilization of resources
- Feeling of lack of efficacy
Prognostic Uncertainty

- The only certainty
- Many mortality prediction models exist
  - APACHE
  - Mortality probability model: MRM
  - Simplified Acute Physiology Score: SAPS3
  - eprognosis.org
  - Karnofsky Performance Status: KPS
  - Palliative Performance Scale: PPS

Vincent and Moreno *Critical Care* 2010;14:207
Prognostic Uncertainty

- What level of certainty is needed for decision making?
  - 0%
  - 100%
  - 99.9%
  - 1 in a million
- What about functional outcomes?
- Can people understand prognostic information?
Prognosis by Age

Life Expectancy for Men

- Top 25th Percentile
- 50th Percentile
- Lowest 25th Percentile
Challenges: Family Perspective

- Unrealistic expectations
- Lack of knowledge of patient wishes
- Multiple decision makers
- “She wants to live”
- Cultural issues
- Awaiting miracles
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?”
- 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”
- Resist religious debates

Sulmasy *JAMA* 2006;296:1385-1392
DeLisser *Chest* 2009;135;1643-1647
“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”

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 increases suffering
  - Everything that will prolong life, even if it increases suffering

Pantilat JAMA 2009;301:1279-81
When Families Want “Everything Done”

- Ensure good information from all clinicians
  - Provide consistent, clear information
- Focus on the patient
  - Avoid detailed discussions of medical management
- Demonstrate caring, concern, and understanding
  - Listen
  - Stay engaged and collaborative
Expressing Dismal Prognosis

- Be direct, but only as direct as you can
  - “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.”
  - “I am worried that even with everything we can do, it will only prolong her suffering.”
Invoking Futility

- Futility is rare and of little use at the bedside
- Alienates the family
- Seek constructive solutions
  - Focus on what you can do
  - Most conflicts resolve within days
  - Write Unilateral DNR order only if absolutely necessary

When Families Still Want “Everything Done” Despite Your Best Efforts

- Focus on harm reduction and collaboration
  - Stop regularly discussing limiting treatment
  - Acknowledge and adhere to the patient’s treatment philosophy
  - Address the medical team’s discomfort
  - Use clinical judgment to limit treatments that do not support the patient’s goals
- Ensure the best possible communication
  - Improves outcomes for patients and families

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
Family Meeting: Set up

- Arrange for a quiet, private place to meet
- Invite all invested parties
  - Patient, family, especially surrogate decision maker
  - Care team members: MDs, RNs, SWs, RTs, Chaplain
- Determine beforehand:
  - Goals of the meeting
  - Who will lead
Family Meeting: The Basics

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

Curtis and White *Chest* 2008;134:835-43
Family Meeting: Patient Preference

- Determine what the patient would want in this situation
  - Substituted judgment
  - The key role for the family

- Keep the focus on the patient
  - “If she could sit up in bed…”
  - “What would she think of this?”
  - “Not what you want for her, or what you’d want for yourself, but what she would want for herself”
Family Meeting: Summarize and Follow Up

- 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 contact
- Document the meeting
Maintain Perspective

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

- “Do everything” can have many meanings
- Elicit and establish overall goals and treatment plan
- Provide the best possible communication
- Practice harm reduction
- Provide support to patient, family, staff, and yourself