Responding to Patients and Families that Want “Everything Done”

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Mrs. M

- Mrs. M is a 73 year old woman s/p renal transplant 3 months 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 and is altered. She is minimally responsive on opioids.
Mrs. M

Mrs. M’s family are very devoted and always at her bedside. They insist that she responds to them and says she wants to live. Mrs. M’s children speak English but Mrs. M speaks only Arabic. You have had in-person interpreters at the bedside who 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.
“Do Everything”

- Does not always mean “do everything you possibly can to keep our loved one alive at all costs”
  - Request can have many meanings
- “Everything” has different meanings to families and medical staff
- Ask a better question
  - “How were you hoping we could help?”

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

- Explore what “doing everything” means
  - “I want every possible treatment to let me live as long as possible”
  - “Don’t abandon me”
  - “I’m scared of dying”
  - “I can’t bear the thought of leaving my children”

- Recommend 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

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
- 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 increase her suffering.”
When Families Want “Everything Done”

- Demonstrate caring, concern, and understanding
  - Listen
  - Stay engaged and collaborative
- Futility is rare and of little use at the bedside
  - Focus on what you can do
  - Write Unilateral DNR order only when necessary
- Most conflicts resolve within days

Smedira et al. NEJM 1990;322:309-15
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 conferences
  - 30 min vs 20 min
- Family talked more (physician talked the same)
  - 14 min vs 5 min
- Lower prevalence of PTSD-like symptoms, anxiety, and depression 90 days 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
- Determine beforehand:
  - Goals of the meeting
  - Who will lead
Family Meeting: Conduct

- Introductions
- Assess the family’s understanding of the patient’s situation
  - “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
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

- Most conflicts are resolved within 4 days
  - Although the really difficult cases are rare, they are stressful
- Having a sick loved one is very stressful
- Conflicting and contradictory information from providers can be very distressing
- Avoid overwhelming or badgering families
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