"They just don't get it": Evidenced-based approach to understanding and resolving conflict between health care providers and surrogate-decision makers in end-of-life care

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Disclosure Information

- No relevant financial relationships to disclose

The Case of Mr. M

- 58-year-old African-American man
- Strong Baptist faith
- ESLD secondary to EtOH and hepatitis C, not a candidate for transplant
- ESRD on dialysis
- Hx of prior cardiac arrest with return of circulation
- 6 wk hospitalization, multiple ICU admissions with profound hypotension during dialysis
- Patient and his wife want "everything" done

Strategy

- Understand what "doing everything" means to the patient and family
- Propose a philosophy of treatment
- Recommend a plan of treatment
- Support Emotional Responses

Quill et al, Ann Intern Med, 2009;151:345-349.

Family Meeting

- Understand that his liver disease is getting worse and cannot be fixed. They have been told that Mr. M would not be able to do outpatient dialysis.
- Prognosis of days to weeks is discussed.
- States that his main goal is to get home.
- Discuss the option of focusing on comfort and getting him home as the top priority.
- Discuss hospice care as the best support for that approach.

Family Meeting

- He does not want to stop dialysis and prefers to continue all of the treatments he is getting in the ICU.
- Agree to continue all current treatments, but if he gets sicker, recommend against CPR or intubation.
- It would not get him to his goal of going home and it would likely result in dying on machines in the ICU.

The Case of Mr. M

"I want to stay full code. It's in God's hands. We are hoping for a miracle."

The Medical Team

- "They just don't get it."
- "CPR or intubation would be futile."
- "We have discussed the poor prognosis many times, but they don't seem to hear it."
- "What is wrong with them?"

Conflict

- The patient and his wife are requesting treatment that the medical team thinks is unlikely to be helpful
- Frustration for the patient/family and the medical team

Objectives

- Describe the prevalence and characteristics of conflict between patients/families and ICU staff.
- Describe the reasons why physicians and surrogate decision-makers often have different interpretations of a patient's prognosis.
- Explain how faith and belief in miracles can influence prognostication and preferences for end-of-life care.
- Describe strategies that can be used to reduce disagreement between physicians and patients/surrogates regarding end-of-life care.

Conflict between patient/family and ICU clinicians is common

- Cross sectional survey of 7,498 ICU staff
  - 26% of respondents reported a patient relative/ICU staff conflict occurring in the past week.
- 48 family members of ICU patients who had been considered for withdrawal or withholding of life-sustaining treatment
  - 40% reported conflict between staff and family
  - Communication and staff unprofessional behavior were most common

Azouley et al. Am J Respir Crit Care Med. 2009;180(9):853-60
Abbot et al. Crit Care Med. 2001; 29(1):197-201

Conflict Negotiation

- Develop curiosity about the other person's story
- Ask **"Why would a reasonable, rational, and decent person do that?"**
- Instead of "What is wrong with them?"

Paterson K et al. Crucial Confrontations. 2005

How do surrogates estimate prognosis?

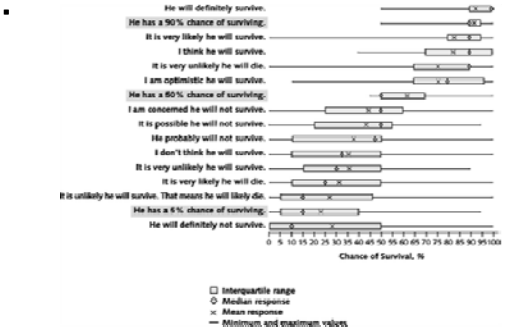
Boyd et al. Crit Care Med, 2010; 38: 1270-1275

How do surrogates estimate prognosis?

- Surrogates knowledge of the intrinsic qualities and will to live of the patient
- Surrogates observations of the patient
- Patient's History of Illness and/or Survival
- Surrogates belief in the power of their support and presence
- Surrogates optimism, intuition, and faith

Boyd et al. Crit Care Med, 2010; 38: 1270-1275

80 ICU Surrogates



Zier et al. Ann Intern Med. 2012;156(5):360-366

What were the reasons for the optimistic bias?

- Need to express optimism
- Belief that patient's fortitude will lead to better than predicted outcomes
- Disbelief of physicians' ability to prognosticate
- Interpretation of prognosis as a "gist" estimate rather than a precise estimate

Zier et al. Ann Intern Med. 2012;156(5):360-366

Back to the case

- Mr. and Mrs. M did mention using other factors to determine prognosis
  - History of surviving many serious set-backs, including a prior code
  - Faith and belief in miracles
- What does the literature say about belief in miracles?

Palliative Care Rounds: Towards Evidence-Based Practice
Edited by Erik K. Fromme, MD, and Robert M. Arnold, MD, on behalf of Society of General Internal Medicine End-of-Life Interest Group

Approaching Patients and Family Members Who Hope for a Miracle

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Widera et al. J Pain Symptom Managment, 2011 Jul;42(1):119-25

How common is belief in miracles?

- 79% of US population believe that "miracles still occur as in ancient times"
- Little difference based on age
- Majority of respondents from every major religion and those unaffiliated with any religion agreed

Religion among the millennials. Pew Research Center, 2010

How common is belief in miracles in health care?

- Survey of 1006 adult Americans and 774 trauma professionals
- A patient in PVS could be saved by a miracle
  - 61% of public respondents
  - 20% of trauma professionals
- Divine intervention from God could save a person even if the physician told them "futility had been reached".
  - 57% of public respondents

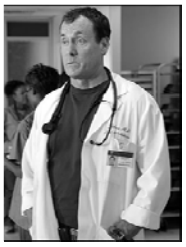
Jacobs LM, et al. Arch Surg 2008

What is meant by the hope for a miracle?

- A belief in a divine supernatural intervention that supersedes the laws of nature
- A manifestation of denial of impending loss
- An expression of hope or optimism about the possibility of unexpected recovery
- An expression of anger, frustration, or disappointment over certain aspects of medical care

Sulmasy DP. South Med J 2007
Delisser HM. Chest 2009
Lo B, et al. JAMA 2002

What is the role of health care providers in the hope for miracles?



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What is the role of health care providers in the hope for miracles?

- 1997 telephone survey of 1033 individuals living in the southeastern United States
- 88% respondents believed in religious miracles
  - 63% responding "definitely" in their belief.
- 80% said that they believed God acts through medical doctors to cure sickness
  - 49% reporting that they definitely believed

Mansfield CJ, et al. Soc Sci Med 2002

How does faith and belief in miracles influence medical decision making?

- 68 African American and white patients with an advanced stage of lung or colon cancer
- "To what extent do you believe in divine intervention or the possibility of a miracle that might change the course of your illness?"
- Belief in miracles or divine intervention was associated with preference for CPR

Ann Behav Med 2005;30: 174-179

How does faith and belief in miracles influence medical decision making?

- 345 outpatients with advanced cancer followed from baseline interview until death
- 78.8% reported that religion helps them cope "to a moderate extent" or more
- High level of positive religious coping at baseline was significantly associated with the receipt of:
  - Mechanical ventilation during the last week of life (11.4% vs 3.6%)
  - Intensive life-prolonging care (13.6% vs 4.2%)
  - Less advanced-care planning in all forms, including DNR orders, living wills, and DPOA-HCs

Phelps. JAMA. 2009;301:1140-1147.

Back to our case

- Mr. and Mrs. M may not believe our assessment of prognosis and may be using other factors, including their faith, to determine prognosis.
- Belief in miracles is common
- May even believe that God acts through the medical team and the care we are providing
- Faith and belief in miracles influence decision making
- What can we do about it?

Does medical team support of spiritual needs make a difference?

- Coping with Cancer Study
- 343 outpatients with advanced cancer followed from baseline interview until death
- Are they getting support?
  - 60% reported spiritual needs were minimally or not at all supported by the medical system
  - 54% reporting that they had not received pastoral care visits

Balboni TA et al. J Clin Oncology. 2010;28:445-452

Does medical team support of spiritual needs make a difference?

- Full Sample
  - Three-fold greater odds of receiving hospice care
  - No association with receipt of aggressive end-of-life care
- High Religious Coping:
  - More likely to receive hospice
  - Less likely to receive aggressive end-of-life care

Balboni TA et al. J Clin Oncology. 2010;28:445-452

What else can we do to reduce disagreement between surrogates and the medical team?

Proactive Communication and Bereavement Brochure

- Family members of 126 dying patients in 22 French ICU's
- Intervention
  - Proactive end-of-life conference
  - A Bereavement Brochure

Lautrette et al. N Engl J Med 2007

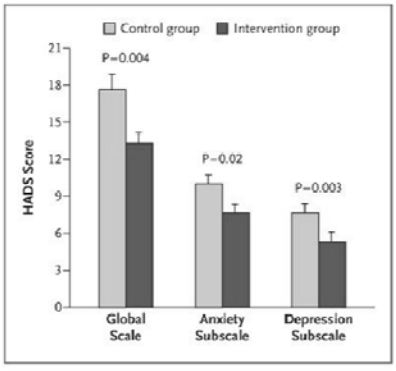
VALUE communication system

- **V**alue and appreciate what surrogates communicate
- **A**cknowledge their emotions with reflective summary statements
- **L**isten carefully
- **U**nderstand who the patient is as a person by asking open-ended questions
- **E**licit Questions

Proactive Communication and Bereavement Brochure

- Conflict:
  - Increase in the number of relatives who eventually agreed with physicians after an initial disagreement regarding decisions to forgo life-sustaining treatments.
- Bereavement (90-day postmortem follow-up)
  - Decrease in symptoms of posttraumatic stress, anxiety, and depression.

Lautrette et al. N Engl J Med 2007



Back to the case

- Palliative medicine team, including chaplaincy continued to visit daily
- Transferred out of the ICU, remained full code
- One day later, developed hypotension, AMS and respiratory distress in dialysis
- Mrs. M says she still thinks he would want intubation and ICU transfer

What do we do now?

- The medical team feels that intubation will not benefit Mr. M and he will likely experience significant burden
- No good evidence for how to proceed

What do we know?

- Multiple studies have shown that there is variability in decision-making preferences, but the majority of patients and surrogates prefer a shared decision-making approach.
- Some evidence suggests that ICU surrogates are at higher risk of PTSD and depression if there is discordance between their preferred and actual role in decision making.
- Can we find a middle ground?

Johnson et al. Am J Respir Crit Care Med, 2011;183(7):915-21
Gries et al. Chest, 2010;137(2):280-7

Time-Limited Trials

- Agreement between clinicians and a patient/family.
- Use certain medical therapies over a defined period to see if the patient improves or deteriorates according to agreed-on clinical outcomes.
- If the patient improves, disease-directed therapy continues.
- If deteriorates, the therapies in the trial are withdrawn, often shifting to purely palliative measures.
- Recommended by many experts in the field, but not evidence-based.

Quill and Holloway. JAMA, 2011;306(13):1483-1484

What if no agreement is reached?

- Impartial third part involvement
- Ethics consultation
- Ethics consult is a service provided by an individual consultant, team, or committee to address the ethical issues involved in a specific clinical case. Its central purpose is to improve the process and outcomes of patient care by helping to identify, analyze and resolve ethical problems.

Schneiderman et al. JAMA, 2003;290(9):1166-72

What is the evidence?

- 551 ICU patients in whom value-laden treatment conflicts arose during the course of care were randomized to receive ethics consult or usual care.
- Ethics consultations:
  - Reduced hospital and ICU days, reduced life-sustaining measures with mechanical ventilation in patients who did not survive to discharge
  - No mortality difference
  - 87% of doctors, nurses, and surrogates felt consult was helpful

Schneiderman et al. JAMA, 2003;290(9):1166-72

Mr. M

- A formal time-limited trial was not discussed. He was intubated and transferred to the ICU.
- Limitations of time-limited trials:
  - Hard to institute in the context of rapid clinical deterioration.
  - Require excellent communication and agreement between all providers caring for the patient

Mr. M

- 3 days later his mental status still had not improved and he remained ventilator dependent.
- For his wife, the fact that he was no longer responding to her was a huge change.
- She was in agreement with withdrawing life-sustaining measures and enrolling in hospice.

CONCLUSIONS

- Conflicts between ICU staff and patient's family members are common.
- First step in conflict negotiation is to develop curiosity about the other person's perspective.
- Recognize that patients/surrogates use multiple factors other than the physician's estimate to determine prognosis, including faith.
- Faith and belief in miracles affect decision-making.

CONCLUSIONS

- Supporting spiritual needs and the VALUE proactive communication strategy can help reduce disagreement.
- Time-limited trials are another tool that can be used to find middle ground.
- Ethics consultations can be helpful when disagreement persists.

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Thank you!

Questions?