

An Ethical Perspective of End of Life Resources & Issues

Mary E. Homan, MA, MSHCE
Director, Ethics
Mercy West Communities

5 November 2015

Oklahoma Society for Quality & Risk Management
Oklahoma Hospital Association Convention & Trade Show



The Case

- Mrs. F. is an 80-year-old woman, with nonresectable lung cancer, diabetes, hypertension, chronic renal insufficiency, and severe degenerative joint disease.
- Complained of extreme shortness of breath. She was diagnosed with lobar pneumonia.
- No living will or advance care planning document.
- Quite religious.
- Develops high fevers and septicemia. Develops worsening hypoxemia.
- Physician lays out a range of treatment options. Family wants “everything done.”
- Staff believes further aggressive treatments are futile.
- Mrs. F. lingers in the ICU

Objectives

- Identify possible conflict situations that can divide patients, families, physicians, and other caregivers, compromise patient care, and lead to moral distress.
- Provide communication techniques to assist patients, loved ones, physicians and other caregivers.
- Improve the coordination of patient care across disciplines and different settings.

The Evolution of Futility

1. First generation: Definitions

A. Clinical futility was determined by physician.

2. Second Generation: Procedural

A. Futile care guidelines and policies

B. Rise of patient autonomy & decision-making

3. Third Generation: Communication & Negotiation

A. Patient/family engagement

B. Support for caregivers

The Prevalence and Cost of Care Perceived to be “Futile”

- 98 (8.6%) were perceived as receiving probably futile treatment
- 123 (11%) were perceived as receiving futile treatment
- 11 (1%) were perceived as receiving futile treatment only on the day they transitioned to palliative care
- Patients with futile treatment assessments
 - Received 464 days of perceived futile critical care treatment
 - 6.7% of all assessed patient days in the 5 ICUs studied
 - 84 of the 123 patients perceived as receiving futile treatment died before hospital discharge
 - 20 died within 6 months of ICU care
 - 6-month mortality rate of 85%
- The cost of futile treatment in critical care was estimated at \$2.6mil

Morally Problematic Language

- Futility

- What counts as futility?
- “By summarily dismissing the treatments as futile, the clinicians fail to articulate the source of conflict.”
- “[d]oes not promote understanding when people disagree about whether means to an agreed-upon end are reasonable, or about the worthiness of the ends themselves.”

Morally Problematic Language

- Quality of life
 - According to whom?
 - “If for example some people were given life-saving treatment in preference to others because they had a better quality of life than those others, or more dependants and friends, or because they were considered more useful, this would amount to regarding such people as more valuable than others on that account”(Harris, 121).
 - Unable to distinguish the treatment *from* the person

A Caution to the Huynh et al Study

- Data were derived from the *perceptions of a single physician* making a single assessment about futility on each day the patient was in the ICU.
- This mode of assessment stands in sharp contrast to current recommendations that futility assessments be based on an inclusive process that *incorporates the perspectives of all stakeholders*.

Reasons for Conducting an Ethics Consultation

**The 3 Cs: Clarification,
Confusion, Conflict**



Ethics consults convey respect for persons by creating a space for voices and concerns to be shared in the pursuit of quality patient care and building an ethical culture.



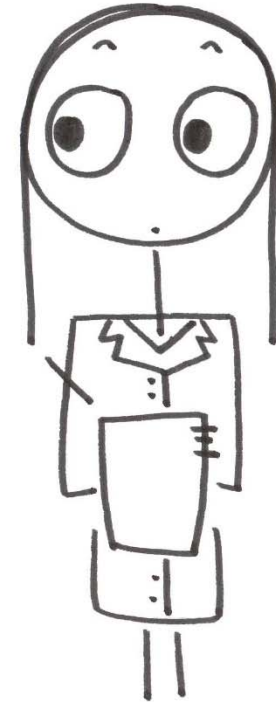
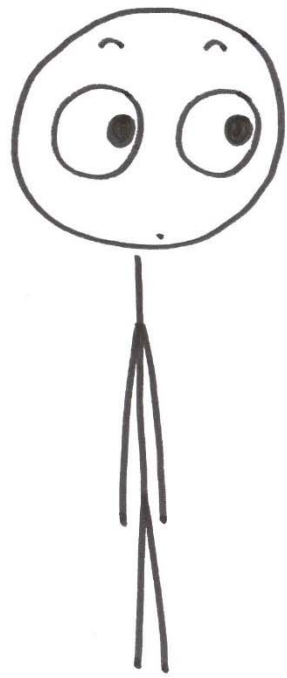
Clarification

- Clarification about ethics questions, the meaning of terms, the application of ethical principles
- Clarification regarding treatment options, including no treatment at all
- Clarification regarding benefit/burden, forgoing/withholding/withdrawing treatment
- Clarifying if the presented material is an “ethics issue”
 - Complicated by overlap with other areas, i.e. risk, compliance, palliative care, pain management

Confusion

- Confusion about appropriate treatment goals and their purpose(s)
- Confusion about the course(s) of treatment
- Confusion about the ethics of an action or inaction
- Confusion about health status of the patient – diagnosis and prognosis
- Confusion about the appropriate decision-maker

What
problem?



Conflict

- Between and among patient and/or family members about healthcare decisions and treatment goals
- Between and among health care team members about authority, power, treatment goals, and coordinating care
- Conflict between patient/family and health care team about healthcare decisions and goals
- Between guiding values and principles
 - i.e., respect for autonomy in tension with justice

Sources of Confusion & Conflict

Appointed agent who cannot follow patient's wishes.

Family & interpersonal dynamics

Physicians who will only stop treatment when they think further treatment is useless.

Grief

Difficulty of value laden decisions under uncertain conditions.

Loss of meaning

Important issues sometimes go unaddressed.

Physicians who believe advance directives and DNR orders are only for dying patients.

Providers/caregivers fail to communicate & coordinate care.

No single physician is designated as the primary contact.

Physicians tend to present all treatment options as though they are equal.

Avoidance of difficult conversations.

Failure to address unreasonable requests.

Lack of advance directives or instructions for care.

Mistrust of medical team.

Discontinuity among specialists, consultants, and attending.

Enhancing Communication and Coordination of Care: A “Third Generation” Approach



Guidelines for Communication and Care Coordination

- Communicate early and often with patients and families
 - Be clear about realistic options & patient status
- Communicate early and often with members of the care team
 - Designate single physician to *routinely* communicate/coordinate
- Determine comprehensive goals of care and evaluate routinely
 - Inform patient/family about “best available appropriate care”



Guidelines for Communication and Care Coordination

- Make time for and participate in care conferences
 - “Same page conversations”
- Exercise care in offering/discussing treatment options
- Address unreasonable requests up-front and candidly
- Ensure non-abandonment and quality end of life care

Best Available Appropriate Care

Care is clinically indicated and clinically appropriate in advancing patient treatment in the current context.

Care has demonstrable benefit to the patient.

Care does not result in excessive burden.

The proposed care is actually available with qualified staff.

Attending to Conflict Situations

- Establish a comfortable, respectful private setting
 - "I'd like to talk to you about the treatment you are requesting and the possible implications of this."
- Determine level of understanding
 - "What do you understand about your loved one's health situation?"
- Clarify hopes and expectations
 - "What do you think your loved one would want in this situation?"
 - "What are your hopes and expectations if we provide the treatment you are requesting?"
 - Address unreasonable expectations & requests *at this time*



Attending to Conflict Situations

- Discuss withholding or withdrawing treatment.
 - Compassionately address benefit and burden of treatment (ERD 32)
 - Share further care options, i.e. palliative care, hospice
- Respond to deeper needs.
 - What else is going on behind the conflict?
- Devise a care plan that is appropriately patient-centered.



Table 2. Potential Underlying Meanings of "Everything"

Domain	Concept	What "Everything" Might Mean	Questions to Ask
Affective	Abandonment	"Don't give up on me."	"What worries you the most?"
	Fear	"Keep trying for me."	"What are you most afraid of?"
	Anxiety	"I don't want to leave my family."	"What does your doctor say about your prospects?"
	Depression	"I'm scared of dying."	"What is the hardest part for you?"
Cognitive		"I would feel like I'm giving up."	"What are you hoping for?"
	Incomplete understanding	"I do not really understand how sick I am."	"What are your most important goals?"
	Wanting reassurance that best medical care has been given	"Do everything you think as a doctor is worthwhile."	"What is your understanding of your condition/prognosis?"
	Wanting reassurance that all possible life-prolonging treatment is given	"Don't leave any stone unturned." "I really want every possible treatment that has a chance of helping me live longer." "I will go through anything, regardless of how hard it is."	"What have others told you about what is going on with your illness?" "What have they said the impact of these treatments would be?" "Tell me more about what you mean by 'everything.'"
Spiritual	Vitalism	"I value every moment of life, regardless of the pain and suffering (which has important meaning for me)."	"Does your religion (faith) provide any guidance in these matters?"
	Faith in God's will	"I will leave my fate in God's hands; I am hoping for a miracle; only He can decide when it is time to stop."	"How might we know when God thinks it is your time?"
Family	Differing perceptions	"I cannot bear the thought of leaving my children (wife/husband)."	"How is your family handling this?"
	Family conflict	"My husband will never let me go."	"What do your children know?"
	Children or dependents	"My family is only after my money." "I don't want to bother my children with all this."	"Have you made plans for your children (other dependents)?" "Have you discussed who will make decisions for you if you cannot?"



Lack of Agreement

- Call for ethics consult
- Focus on restricting treatment options in light of the patient's best interests
- ***Offer no treatment options that will cause or extend suffering with no possibility of benefit or are not clinically indicated***
- Offer time-limited trial for a clinically appropriate treatment
- Discuss alternate care options – “Best available appropriate care”



Communicating in Conflict

- Learn the patient's and family's story
 - Gender, Culture, Values
- Attend to emotions
 - Patient/family emotions
 - Care team member emotions
- Power of language
 - Share-check-share; timing & pacing; **LISTEN**
 - Critical empathy
- Be fully present
- Poisoning the well
 - How am I contributing to the conflict?



Next Steps

- **Documentation**
 - It is imperative that all discussions and decisions with family/surrogate be thoroughly documented in the patient's chart.
- **Debrief with Caregivers**
 - Since these situations are often stressful and difficult for physicians and other caregivers, a formal debriefing meeting should be conducted during and after the stay of the patient so the physicians and other caregivers can express their feelings and be supported in their roles.



Returning to Mrs. F.

- Mrs. F. is an 80-year-old woman, with nonresectable lung cancer, diabetes, hypertension, chronic renal insufficiency, and severe degenerative joint disease.
- Complained of extreme shortness of breath. She was diagnosed with lobar pneumonia.
- No living will or advance care planning document.
- Quite religious.
- Develops high fevers and septicemia. Develops worsening hypoxemia.
- Physician lays out a range of treatment options. Family wants “everything done.”
- Staff believes further aggressive treatments are futile.
- Mrs. F. lingers in the ICU

Questions?

- Mary E. Homan, MA, MSHCE
- Director, Ethics, Mercy West Communities
- mary.homan@mercy.net | 405.936.5408

References

- American Medical Association. *Code of Medical Ethics: Current Opinions with Annotations, 2010-2011*. American Medical Association; 2010.
- Brett AS. Futility revisited: reflections on the perspectives of families, physicians, and institutions. *HEC Forum*. 2005;17:276–293.
- Burns JP, Truog RD. Futility: A concept in evolution. *Chest*. 2007;132(6):1987-1993. doi:10.1378/chest.07-1441.
- Harris J. QALYfying the value of life. *J Med Ethics*. 1987;13(3):117–123.
- Huynh TN, Kleerup EC, Wiley JF, et al. The frequency and cost of treatment perceived to be futile in critical care. *JAMA Intern Med*. 2013;173(20):1887-1894. doi:10.1001/jamainternmed.2013.10261.
- Panicola MD, Hamel R. Enhancing communication and coordination of care: a “third generation” approach to medical futility. *Health Care Ethics USA*. 2012;20(1):9–21.
- Truog RD, White DB. Futile treatments in intensive care units. *JAMA Intern Med*. 2013;173(20):1894-1895. doi:10.1001/jamainternmed.2013.7098.
- United States Conference of Catholic Bishops. *Ethical and Religious Directives for Catholic Health Care Services, Fifth Edition*. 2009. Available at: <http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf>.