Shared Decision Making at the Moment of Critical Illness

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Conflict of Interest

- Karl Thomas: royalty payments from UpToDate (online textbook)

Objectives

- Describe a **framework** for approaching ethical dilemmas that arise in the setting of critical illness.
- Explain how eliciting a patient's **goals and values** assists patient and surrogate decision-making.
- Define a concept of **authenticity** and how it applies to surrogate decision making.
- Recognize how **moral distress** may arise in the context of critical illness and can overlap with medical futility.

The Moment of Critical Illness

- Sudden acute illness that:
  - Is life threatening
  - Has only transient opportunities for intervention
- Critical care treatments are:
  - Dependent on a high degree of medical expertise
  - Complex
  - Expensive
  - May be painful
  - High risk

- Case: 72 year old man transferred to ICU
  - 2 years ago: Stroke and unable to walk
  - 1.5 years ago: Advanced stage lung cancer
  - 4 months ago:
    - Second stroke, could only communicate "yes" and "no"
    - Recurrent cancer in lymph nodes
    - Moved to residential care facility

Day of admission: found unresponsive and he was brought in for evaluation of stroke or seizure or metastatic disease

Case Continued

- On arrival: ineffective coughing with mucus and saliva, not "protecting airway"
- Advanced directive included in transfer paperwork: Iowa Bar Association Form-Living Will and Medical Power of Attorney (wife)
  - Completed after first stroke
  - If I should have an incurable or irreversible condition that will result either in death within a relatively short period of time…

Sudden Acute Illness Case

- Family en route, but immediate decisions:
  - Intubation and mechanical ventilation?
  - Treat for seizure (also would likely require intubation and mech. vent)?
- Nurse, respiratory therapist and medical resident all skeptical about aggressive intervention: "Why are we doing this?
  - Viewpoint not shared by all, however

- The patient's family and wife arrive.
- Before we can describe intubation and mechanical ventilation family tells ICU team: "Do everything you can, he's always been a fighter."

Case Summary

- Diagnostic and prognostic uncertainty
- Loss of capacity
- Need for decisions to be made immediately
- Medical staff did not agree on best course of action
- High risk for misinterpretation of statements and making inaccurate assumptions

Sources of Difficulty

- Patients and surrogates
  - Do not anticipate specific types of critical illness
  - Advanced directives not complete or not specific
- Medical staff
  - Do not know patient as a "whole person"
  - Need to take action
  - Often want more testing and time to estimate prognosis
- Communication and teamwork
  - Multiple medical personnel, family members / surrogates
  - Lack of established working relationships
    - Patients often do not have established relationship with critical care staff
    - Patient and surrogates may have not worked together on high risk medical decisions

Projection Bias

- Both surrogates as well as medical staff can project their own personal values and preferences onto the patient and treatment choices.
  - Spiritual practices and religious beliefs
  - Optimism, pessimism, realism
  - Unrealistic expectations common (both extremes)
  - Understanding and preferences based on individual prior experiences and healthcare

Patients, Physicians and the Most Important Goal of Care

- 100 patients or surrogates asked about their most important goal of care.
- Faculty and fellow physicians asked same question.
- "In 67.7% (63/92) of cases, the most important goal of care identified by patients/surrogates differed from the one identified by physicians."

Gehlbach TG, *et al.* Code Status Orders and Goals of Care in the Medical ICU. Chest, 2011; 139:802-9

Accuracy of Surrogate Decision Makers

- 2595 surrogate-patient pairs using end-of-life scenarios:
  - CPR
  - Intubation
  - Artificial nutrition and hydration
- 68% accuracy for whether the surrogate's treatment choice predicted the actual patient's choice

Shalowitz DI, et.al. The Accuracy of Surrogate Decision Makers. Arch Intern Med, 2006; 166:493-7

Autonomy and Critical Illness

- Patients frequently
  - Lack capacity – medications, organ failure
  - Face extreme pressure - fear, pain
  - Do not have time to – prepare, deliberate, decide
- Surrogate conflicts
  - Their own interests, spirituality, obligations, emotions, family role, new role, secondary gain
- For patients and surrogates with sudden acute illness, exercise of strictly-defined autonomy may not be possible within the context of these knowledge gaps, emotions, conflicts of interest, medical uncertainty and many other strong competing influences.

Other Resources and Influences for Decision Making Needs at the Time of Critical Illness

- The patient's lifetime of decisions, actions, priorities, loves and spirituality
- The provider's knowledge and experience
- Communication and teamwork based on active discussion and shared, deliberate planning

An Expanded View of Decision Process

- **Shared decision** making occurs when the provider and patient share all stages of the decision making process simultaneously.
- **"Shared decision making is a collaborative process** that allows patients / surrogates and clinicians to make healthcare decisions together, taking into account the best scientific evidence available, as well as the patient's values, goals and preferences."

- Robinson A, Thomson R. Variability in Patient Preferences for Participating in Medical Decision Making. Qual Health Care. 2001; 10:i34-38.
- Kon AA, et.al. Shared Decision Making in Intensive Care Units. Am J Respir Crit Care Med. First published online 20 Apr 2016 as DOI: 10.1164/rccm.201602-0269ED.

Shared Decision-Making and Autonomy

- "At its core, shared decision making rests on accepting that individual self-determination is a desirable goal and that clinicians need to support the patient to achieve this goal whenever feasible… Shared decision making recognizes the need to support autonomy by building good relationships, respecting both the individual competence and interdependence on others."

Elwyn, G, et. al. Shared Decision Making. J Gen Intern Med. 2012; 27:1361-7

Ethical Justification for Shared Decision Making in the ICU

- Direct involvement of patients/surrogates
  - Respect for persons, autonomy
- Role justification for clinicians
  - Expertise and knowledge of medical interventions
  - Ability to view options within reference frames of beneficence, nonmaleficence
  - Professionalism and core values

Kon AA, et.al. Shared Decision Making in Intensive Care Units. Am J Respir Crit Care Med. First published online 20 Apr 2016 as DOI: 10.1164/rccm.201602-0269ED.

Authenticity

- Authentic definition: “faithful to an original”, “reliable, accurate representation.”
- Authentic: The moral agent follows reasons and motives that reflect and express self-identity and vision. An authentic choice is one that makes sense within the framework of the beliefs and values that the individual affirms.

http://plato.stanford.edu/entries/authenticity/

Shared Decision Making, Authenticity and Autonomy

- Shared decision includes discussion and evaluation of present choices within the context of previous, value-laden choices
- Decisions based on understanding prior expressions of values and goals of the patient may be viewed as authentic to the patient and aligned with respect for their autonomy.

Shared Decision Making in the ICU

- Focus on essential elements
  1. Information Exchange
  2. Deliberation
  3. Making a treatment decision

Information Exchange

- Minimize barriers
  - Establish trust
  - Openly acknowledge emotions
  - Demonstrate empathy
  - Explain medical situation
    - Assess and reassess at the patient’s/surrogate’s level of understanding
- Understand decision-making preferences
  - State that there are choices and options to select
  - Explain surrogate decision making, substituted judgment
  - Check on level of comfort in making decision
  - State medical timeframe and assess readiness of patient or surrogate to decide

Deliberation

- Review treatment choices
  - List and describe options
  - Offer decision-support tools if available
  - Check understanding
- Discuss and elicit patient’s values, goals and preferences
  - Previously written statements
  - Identify/describe values about health
  - Recognize when values may be in conflict
  - Draw relationships between values, goals, preferences

Make a Treatment Decision

- Identify preferences
  - “What is most important for you/her/him?”
- Restate options within context of achieving goals and honoring preferences
- Give permission to talk about and make decisions that are distressing, raise moral concerns, or which create new conflicts
- Make a decision – agree on a treatment plan and time frame

Pitfalls and Strategies

- As soon as possible request family / surrogates come to bedside
  - Key stakeholders present (but maybe not all)
    - Patient, surrogates, RN, spiritual advisors and other medical staff
  - Accept that conditions may not be ideal
    - Telephone, not all family can be present
- Uncertain prognosis
  - Follow medical guidelines when possible
  - Time-limited trials
    - Agree on endpoint and when next decision will be made
- No consensus or antagonism between surrogates
  - "What would she/he tell us to do if they were listening to us now?"
  - Openly state medical team support for the DPOA or NOK and ask that the other family/stakeholders do the same
  - Hospital attorney
- Inability to make decision or achieve consensus
  - Ethics consultation

Moral Distress in Critical Illness

- Moral distress and professional distress
  - knowing what to do in an ethical situation, but not being allowed to do it (Savel RH, Am J Crit Care 2015; 24:276-78)
  - Violations of values or sense of justice
  - Providing treatments that do not agree with
  - Not being able to say everything that could be said
  - Not participating in decision making
  - Not re-evaluating decisions in light of new information
- Perception of medical futility: treatments are unlikely to provide any significant benefit to the patient, may become source of distress
- Who is susceptible?
  - Medical staff as well as surrogates and family

Shared Decision Making, Moral Distress and Medical Futility

- The shared decision process offers the possibility to reduce the risk of moral distress and perceptions of medical futility by:
  - Providing a mechanism for open communication
  - Places treatment considerations within the context of specific patient values, goals and preferences: humanizes both the right to make a decision and the actual course of treatment selected
  - Fundamentally concerned with respect for the patient as a whole person rather than their physiologic disease state

Conclusion: Return to Case

- Decision-making discussion
  - Patient was comfortable and enjoyed life while in the residential care facility
  - The uncertainty of diagnosis prevented clear understanding of prognosis
  - Decision – time limited trial (3 – 5 days on ventilator).
- Discharged from ICU with new advanced directive and DNR/DNI selection on treatment preferences, would return to hospital if necessary, but not to ICU