Key Health Care Decision Making Processes

Steven Levenson, MD, CMD

Always Tough Decisions

Key Steps: Challenges
- Time
- Complexity
- Staff
  - Availability
  - Knowledge
  - Skills
- Lawyers
- Surveyors
- Too many forms to complete

Key Steps: Why Bother
- Organizes a complex topic
- Helps optimize results for patients
- Needed to address rights effectively
- Efficient use of time
- Helps match tasks to appropriate skills
- Helps ensure legal, regulatory compliance
- Prevents expensive complications
- Helps teach important principles

Key Steps in Making Ethics Decisions
1. Identify
   - Individuals who wish to discuss LSTs
   - Situations where discussion of LSTs is indicated
2. Obtain existing care instructions
   - Clarify individual’s values, goals, wishes
3. Clarify relevant medical issues
   - Including physical condition, prognosis, and decision-making capacity
4. Define decision-making capacity
   - Try to optimize capacity
5. Identify primary decision maker
6. Certify qualifying conditions

Key Steps in Making Ethics Decisions (continued)
7. Define and discuss treatment options with patient or authorized decision maker
   - Match medical findings with individual’s values, goals, wishes
8. Implement treatment options
   - Document medical orders (MOLST form) about life-sustaining treatments
9. Review situation periodically and continue or modify approaches, as appropriate
1-Identify Need For Discussion
- Individuals who want to discuss or review further
- Situations where life-sustaining treatment options are, or are likely to be, pertinent in the short-term
  - During the individual’s stay
  - Within the next 4-6 months
- CPR

2-Identify and Obtain Existing Care Instructions
- Some individuals have already participated in advance care planning
- Some decisions already made and documented
- A key step to help identify values and wishes (explicit and implicit)
- Federal and state laws/regulations identify individual rights to
  - Advance care planning
  - Input into medical treatment decisions

2-Identify and Obtain Existing Care Instructions
- Identify and obtain existing information and documents
  - Regarding health care decisions and other evidence of patient values and wishes
  - Explain rights to advance care planning and to have input into medical treatment decisions
  - Transfer copies of documents to those needing them, place in medical record

2-Identify and Obtain Existing Care Instructions
- Review and clarify existing documents
  - People may not know what their documents say or what they don’t cover
  - Written documents may be general, vague, or place conditions on implementation of specific choices
- MOLST form will need review
  - On admission
  - Under other circumstances

2-Identify and Obtain Existing Care Instructions
- Offer general guidance/support about MOLST and advance care planning
  - Laws and regulations require this
  - Many individuals need information and assistance
  - General advice and help is not the same as discussing and choosing specific treatment options
    - Beware of mixing the two

3-Clarify Relevant Medical Issues
- Clarify the individual’s current medical situation (what are active illnesses, problems, conditions?)
  - Understanding problems and prospects is a key starting point for identifying benefits, risks, and pertinence of potential interventions
  - Vital participants: physicians and others
3-Clarify Relevant Medical Issues

- Establish prognosis
  - How likely is the individual to stabilize, improve, decline, die, etc.?
  - Often possible to establish a most likely course or outcome
    - Helps clarify relevance of potential treatments
  - Prognosis is based on likelihood, not on certainty
  - Evidence about factors that predict poorer outcomes

4-Define Decision Making Capacity

- Define or confirm an individual's decision-making capacity
  - Essential to optimize patient participation in healthcare decisions
  - Decision making capacity is not the same as legal competence or mental status
  - Adjudication of incompetence is not routinely necessary and is harder to reverse if condition changes

- As appropriate, inquire about prior decision making capacity
  - Decision making capacity is three dimensional, and should be evaluated across time, not just at one moment
  - Factors that have affected decision making capacity may still be pertinent
    - Delirium, recent illness, medication effects

- Assess or confirm decision making capacity initially (for example, upon admission) and periodically thereafter
  - Decision making capacity
    - Can fluctuate
    - May change with time or as new factors or conditions arise

- Reconcile diverse opinions about decision making capacity
  - It is important to have one single operating perspective about decision making capacity
  - Certify decision making capacity or incapacity
    - HCDA requires physicians to certify lack of decision making capacity
    - This information will be relevant to many situations, not just end-of-life

- Document basis for conclusions about decision making capacity
  - Various individuals will need to refer to this information to understand how these conclusions were reached
  - Reassess or confirm periodically, as needed
    - Decision making capacity may change with time
4-Optimizing Decision-Making Capacity

- Identify and address factors affecting decision making capacity
  - Underlying causes of lethargy, confusion, delirium, etc. often affect decision making capacity; some can be addressed
  - Medications, medications, medications
  - Medical conditions such as hypothyroidism and fluid and electrolyte imbalance

4-Define Decision Making Capacity

- Define the individual’s role in making health care decisions, based in part on decision making capacity determinations
  - The patient will play a more or less substantial role, depending on the scope of decision making capacity and extent and causes of incapacity

5-Identify Primary Decision Maker

- Identify appropriate primary decision maker
  - The patient or someone else
    - Patient may still participate despite not being primary decision maker
  - Beware of claims to be authorized decision maker despite lack of documents or of legally valid succession

5-Identify Primary Decision Maker: Challenges

- Unavailable, unwilling, or unable
- Conflicts within a category
- Conflicts among different categories
- Multiple claims to be authorized decision maker
- No authorized decision maker
- Attempted bypass of explicit patient wishes

5-Identify Primary Decision Maker

- Guide substitute decision makers regarding roles and responsibilities
  - The primary decision maker will need to communicate with other family members
  - Substitute decision maker should
    - Take into account
      - Patient’s explicit and implicit wishes and best interest
      - Discuss and consider relevant medical information
    - Not impose personal values or choices

5-Identify Primary Decision Maker

- Follow succession identified in HCDA
- Document primary decision maker and basis for his/her designation
  - When decision making succession is unclear, it is important to be able to show (now and subsequently) that someone was chosen by making best effort to follow a legally valid sequence
- Prepare for challenges in doing this
6-Certify Qualifying Conditions

- Identify terminal, end-stage, or persistent vegetative state (PVS)
  - Important to follow HCDA definitions
  - Terminal or end-stage relate to individual's overall condition, aggregate of their burdens of age and illness
  - Not necessary to have specific fatal condition in order to be terminal or end-stage

6-Certify Qualifying Conditions

- Purposes
  - To provide overview of patient condition and prognosis
  - Some advance directives only triggered by presence of qualifying condition
  - To permit certain decisions about life-sustaining treatments
    - For example, surrogate decisions to withhold or withdraw treatment

6-Certify Qualifying Conditions

- HCDA requires certain physician certifications
  - Practitioners should be guided by HCDA definitions
    - May confuse meanings of these terms or apply personal interpretations
    - Relates to medical information about condition and prognosis

6-Certify Qualifying Conditions

- Based on probability, not certainty
  - That is true of all ethics decision making
  - Document basis for conclusions about qualifying conditions
    - Others may need to understand the basis for such determinations

7-Define and Present Health Care Issues & Options

- Convergence of
  - Patient values, wishes, goals
  - Medical considerations
    - Condition and prognosis
    - Treatment indications, availability, effectiveness

7-Define and Present Relevant Health Care Issues

- Identify the pertinence of various treatment options
  - Should be done in context of
    - medical condition
    - prognosis
    - available treatment options
    - qualifying conditions
    - patient goals, wishes, and values
7-Define and Present Health Care Issues & Options

- Offer support for current treatment orders and advance care planning
  - Should be more than just presenting treatment options
  - People often need time and support from various sources to make decisions
  - Support from staff, practitioners, family, friends, clergy, etc.
- Clarify the individual’s goals, wishes, and values as much as possible

7-Define and Present Relevant Health Care Issues

- Define relevant issues needing discussion or decisions; for example
  - Scope of individual’s decision-making capacity
  - Options to address inadequate food intake
  - Potential benefits and limits of CPR
  - Capacity to consent to procedures
- Important to define problem concisely and accurately

7-Define and Present Relevant Health Care Issues

- Present information to patient or authorized decision maker
  - Review relevance of various treatment options
  - Literature identifies more and less successful ways to do so
  - How information is presented may influence how primary decision maker understands issues and makes decisions

7-Define and Present Relevant Health Care Issues

- For many individuals, potential treatments will not change the course or materially improve the outcome
- Health care practitioner not obliged to provide a treatment that he/she considers medically ineffective or not in patient’s best interest
  - Should explain basis for conclusions
  - Must follow procedures identified in HCDA

7-Define and Present Relevant Health Care Issues

- Medical literature contains considerable evidence about interventions that are more or less likely to affect outcomes in various situations; for example
  - CPR not effective in people where cardiopulmonary arrest is
  - Limited impact on function and quality of life of tube feedings in end-stage dementia
    - Related to end of life
    - Caused by advanced, irreversible medical conditions
- Patients or authorized decision makers may need repeated efforts to make relevant decisions
- Document relevant information that clarifies basis for various decisions
  - Important risk management measure
  - Minimal risk of legal complications when proper process is followed
8-Implement Treatment Decisions
- Write specific orders regarding withholding or withdrawing life-sustaining treatments
- Use MOLST form or give verbal orders
- Orders should cover CPR and other relevant situations where choices have been made

MOLST Orders Represent Convergence
- Convergence of
  - What the patient/ADM authorizes
  - The medical issues
    - Patient condition and prognosis
    - Treatment indications, availability, pertinence, and potential effectiveness

8-Implement Treatment Decisions
- Don’t confuse CPR status with treatment prior to arrest
  - Wanting other interventions prior to arrest does not automatically mean someone wants CPR
  - "Code status" does not automatically equate with scope of treatment warranted prior to arrest, or the need to hospitalize for illness

9-Review Periodically / Update as Indicated
- Individuals have right to change or revoke choices about treatment
  - Current orders or advance directives
  - Review/confirm decision making capacity prior to accepting changes or revocation
  - Sometimes, new or revised care instructions are needed in order to implement treatment choices

9-Review Periodically / Update as Indicated
- Reevaluate situation periodically
  - Including medical condition and prognosis
  - Reaffirm patient goals, wishes, and values
  - Revisit the process outlined herein
    - To greatest possible extent, given the various challenges
  - Follow legally required procedures for making changes

Implementation Challenges
- Obtain consultative support
  - For example, PCAC
    - PCACs advise and support, but don’t make or impose decisions on behalf of practitioners, facilities, or patients
  - Various individuals (clergy, patient advocates, etc.) may be able to help explain situations and obtain effective decisions
Implementation Challenges

- Facilities and programs (hospitals, nursing homes, dialysis centers, etc.) or residential care settings can establish organizational policies and procedures
- Effective if policies are promoted and performance overseen and improved over time

Other settings

- Attaining systematic approach is more challenging, but still feasible
- Some details that are relevant to institutional settings (for example, PCAC) may not apply in community settings
- In any setting
- Assign responsibilities such as obtaining copies of advance directives or documenting decision making capacity

Implementation Challenges

Helpful to establish a performance improvement activity related to the entire process and its components

- Are legal requirements followed?
- Are decision-making capacity determinations done properly?
- Are specific individuals fulfilling their roles consistently?
- Is MOLST being used correctly?

References