Decisional Capacity: Legal, Ethical & Clinical Considerations

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Background Data

• Patients living longer

• Compression of morbidity theory

• Complex reality
  – Live healthy a little longer
  – Long periods of increasing debility / dependence
  – Likelihood of losing mental capacity before death
  – Likelihood of explicit end of life decisions
Some Challenges of Interviewing Patients with Suspected Dementia

- Separation from normal aging memory loss
- Early detection of questionable benefit
- Challenge of remembering diagnosis or Rx
- Need to involve family
- Patient/ family may not acknowledge
Diagnostic Interviewing Strategies

• General interview
  – Organize time relationships
  – Recall facts
  – Reason abstractly

• Folstein Mini-Mental Status Test

• Geriatric Depression Scale
Some Challenges of Interviewing Patients with Suspected Dementia

• Patient may hide or minimize deficits
• Diagnostic interview may seem invasive
  – Clearly demonstrate deficits
  – May be confirming biggest fears
• The diagnosis of dementia is “bad news”
  – Emotional impact
  – Practical impact (live alone; drive, checkbook)
Pressure to Address Difficult Issues While the Patient has Capacity

- Values history
  - *What makes life most worth living?*
  - *Are there circumstances when life would not be worth living?*

- Advance directives
  - *Who should make decisions if you can’t?*
  - *What ideas/values do you have to guide them?*

- Specific treatments
  - *Do-not-resuscitate*
  - *Feeding tube*
The Challenge of "Partial Capacity"

- Capacity in a medical context
  - Medical assessment (narrow definition)
  - Consult only when uncertainty persists
- Easy when fully present or severely impaired
- Many cases with partial capacity and insight
  - Need to meet with patient and family together
  - Try to achieve consensus
Who Decides When a Patient is Cognitively Impaired?

Some Practical Strategies

- Meet with the patient and key caregivers
- Allow each person to tell their story
- Integrate quantitative cognitive assessments
- Be honest and direct about the diagnosis
- Respond to emotions elicited
- Identify areas of agreement and disagreement
What decisions might be made if patients lose capacity?

• Medical decisions about life-prolonging Rx
  – Cardiopulmonary resuscitation
  – Mechanical ventilation
  – Dialysis
  – Feeding tube
• Medical decisions about ordinary treatment
  – Antibiotics
• Medical decisions about palliative care
  – Pain and symptom management
REMINDERS ABOUT TUBE FEEDING

- It can be refused, like any other medical treatment
- In New York, Missouri, and Florida, surrogate decision requires evidence of patient preference
- It can prevent malnutrition, but is not the same as eating
- It is sometimes life prolonging
- It is intrusive
- It can cause complications
What do people want if they lose mental capacity?

- To be respected and understood as people.
- To have their goals and values honored
- To struggle on their behalf about each medical decision
- To lessen suffering and enhance quality of life
How to make decisions if patient cannot speak for himself?

Hierarchy of Surrogate Decision-Makers

- Surrogate designated by patient
- Close family member(s) or friend(s)
- Court-appointed surrogate
How to make decisions if patient cannot speak for herself?

Hierarchy of Decision-Making Strategies

• Substituted judgement
  – Making decisions as the patient would
  – Using the patient's values and statements

• Best interests
  – Balancing of benefits and burdens
  – Using our values and beliefs
Three Kinds of Advance Directives

- Health Care Proxy
- Living Will
- Organ Donation
Elements of Health Care
Proxy

- Formally designated person to make decisions on your behalf if you are unable (Agent)

- Job is to make decisions as you would, using what is known about your values and wishes (substituted judgement)

- Empowered to represent you for virtually all medical decisions (in NY and Missouri, legal restrictions apply to feeding tube decisions)
Elements of Living Will

- Statement of values, goals, and wishes made while competent to guide treatment if competence lost

- May include circumstances (terminal illness, dementia, PVS) as well as specific treatments

- May be as general or as specific as you wish
Elements of Organ Donation

• Permission to donate organs
  – In setting of irreversible brain damage
  – In the setting of treatment withdrawal if it results in death

• Can specify which organs are permissible
Advance Directives
General Challenges

• Few completed (20% nationally despite Patient Self-Determination Act)

• Clinical uncertainty
  – 1% chance of “improvement”
  – 99% chance of no response

• Physician power
  – Bias toward disease-based treatment
  – Relative lack of skill / comfort in palliation
Advance Directives: Challenges of Capacity

- Presumed in adults
- Capacity vs competence
- Limited to relevant medical decisions
- Assessed by physicians involved in care
- Potential role for psychiatric consultation
- “Catch 22” rationality
Advance Directives
Challenges of Health Care Proxy

• Uninformed about patient values and wishes

• Whose philosophy? Proxy bias

• Proxy / patient agreement is far less than 100% in hypothetical scenarios

• Proxy assertiveness an essential quality
Advance Directives
Challenges of Living Wills

- Can’t possibly anticipate all circumstances
- Easy to create doubt about specific circumstance
- May refuse treatments that would meet goals and request treatment that would not
- May limit flexibility of health care agent
Advance Directives

Challenges of Organ Donation

- Criteria for brain death is clear, but excludes some potential donors
- Family may object in the face of clear patient desire to be a donor
- Some with severe brain damage who do not meet criteria would want to donate
- Live heart-beating donors
NEW YORK LAW

• *In Re Eichner* (NY Ct. of Appeals, 1981): When there is clear and convincing evidence of the patient’s wishes, they may be followed without fear of civil or criminal liability

• Court urges legislature to act

• No legislation until 1990, after US Supreme Court rules in Cruzan
HEALTH CARE PROXY IN NEW YORK

• No special form necessary

• Lawyer or notary not necessary

• Permits an adult to name one adult, also alternate(s)

• Dated and signed by 2 adult witnesses with attestation clause
Authority of agent is triggered by loss of capacity

Agent stands in shoes of patient

Agent is presumed to know patient wishes (no need for evidence of knowledge)

Decision about nutrition and hydration must be based upon “reasonable knowledge” of patient wishes

Written instructions, separate or included, are guidance for agent
IS A HEALTH CARE PROXY PREFERABLE TO A LIVING WILL?

• Actual person to speak with in “real time”

• Not necessary to rely solely on interpretation of patient’s written directive (if there is one)

• No evidence burden

• Great moral comfort, because agent was selected by the patient
FILLING OUT A HEALTH CARE PROXY

- Picking the person (available, informed, assertive)
- Communication with intended agent / others
- Written instructions?
- Witnessing requirements
- Distribute copies (PCP, agent, others)
In New York, Level of Evidence of the Patient’s Preferences Needed to Forego Artificial Hydration and Nutrition

• Health Care Agent
  – Reasonable evidence

• Other Surrogate Decision-Maker
  – Clear and convincing evidence
LIVING WILL IN NEW YORK


• No specific statutory provision (not needed with existing case law)

• Guidance to Health Care Agent
Advance Directives

Summary of Challenges to Patients with Capacity

- Develop and articulate a philosophy
- Discuss philosophy with family and friends
- Complete an advance directive
- Encourage patients / family members to do the same
Advance Directives

Summary of Challenges for Patients without Capacity

- Substituted judgement
- Empower designated agents; families
- Give both choice and guidance
- Always consider the patients goals
- Consider quality of life and personhood for patients who cannot speak for themselves
Who Decides When a Patient is Cognitively Impaired?

Concluding Thoughts

- Many patients face cognitive impairment late in life
- Patients and their families become the focus of care
- Knowing what a patient would want is imprecise
- Quality-of-life concerns must be addressed
Who Decides When a Patient is Cognitively Impaired?

Concluding Thoughts

• A consensus-based process based on what is known about the patient’s values and wishes as interpreted by the family is the best approach.

• Many challenging decisions will be needed over time, so the commitment not to abandon is critical.
Food for Thought

• What are your biggest fears about completing an advance directive?

• What are your biggest fears about not completing such a document?

• Would there be any circumstances where you would want life-sustaining therapy stopped?