



# *Decisional Capacity: Legal, Ethical & Clinical Considerations*

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*Honoring Patient Preferences, The Role Of MOLST, November 11-12, 2005*

# 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 patients 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

# ***HEALTH CARE PROXY IN NEW YORK (Cont.)***

- 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***

- “Clear and convincing” evidence (*Eichner v. Dillon*, 1981)
- 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?*