Ethical Issues: advance directives, nutrition and life support

December 12, 2013
Objectives

• Discuss parameters of consent for medical treatment and legal issues that arise

• Provide overview of advance planning
  – Health Care Proxies
  – Living Wills
  – DNRs
  – Family Health Care Decisions Act (“FHCDA”)
  – Powers of Attorney
**Case: Stanley**

- Stanley A. is an 82 year-old man who has diabetes. He recently scored 25 on a Mini-Mental Examination and has shown other signs of possible dementia. His only family is his brother Bert, who lives nearby. Stanley also has a very good friend, Barbara, who often comes with him to the clinic. Stanley has previously described his relationship with his brother as very difficult and has stated that he does not trust Bert.

- Stanley’s physician needs to do an invasive procedure and does not know who to get permission from.

- **What would you do to move forward in this case?**
Issues Raised by Stanley?

• Does Stanley have capacity to make his own health care decisions?
  – Who decides?

• Who can make health care decisions for Stanley if he does not have capacity?
  – His brother Bert?
  – His friend Barbara?
  – Any one else?
Does Stanley have capacity to make health care decisions?

- New York law presumes a person is competent and that a competent person has the right to *consent* to health care treatment and the right to *refuse* treatment.
Patient must be able to give informed consent

- Informed consent means the individual understands and appreciates:
  - the nature and consequences of the proposed treatment
  - the risks and benefits of the proposed treatment and alternative treatment
  - who will provide treatment

- Determination of ability to give informed consent for healthcare decisions is made by healthcare providers.

- Sylvia’s physician was uncertain and must discuss with a peer or review team.
Who may make health decisions for Stanley?

- Has Stanley executed advance directives?
- If not, can a surrogate make decisions?
- Any one else?
Advance Directives for Health Care

• Advance directives are documents executed in advance and effective upon incompetence to protect a person’s right to decide what medical care they should receive.

• Types of Advance Directives:
  – Health Care Proxy
  – Living Will (Medical Directive)
  – Do Not Resuscitate Order (DNR)
Health Care Proxy

• A document created by statute that allows an individual to appoint a health care agent (and substitute agent) to make health care decisions for them if they become incapacitated (as determined by two doctors)
  – A principal may indicate their wishes regarding organ donation on the proxy.
  – Any competent adult over 18 (younger if married or a parent) may complete one
  – A copy is as valid as the original
Health Care Proxy cont’d

• No hospital personnel may serve as agent in facility where individual is receiving treatment

• Two witnesses needed, but no lawyer or notary

• NYLAG’s Total Life Choices (TLC) program can put health care proxies and living wills on a free national registry run by the US Living Will Registry.
  – The TLC website provides advance planning forms and information about the national registry:
    www.nytlc.org
Capacity to execute a health care proxy

- The proper execution of a health care proxy requires that the person have sufficient mental capacity to understand the purpose and implications of the document.

- Capacity for executing a health care proxy may not be the same standard a physician would use in determining capacity.
  - A person’s capacity may change from day to day, or over the course of a day, depending on the nature of their illness, fatigue and the effects of medication.

- Err on the side of referral to LegalHealth
Role of Agent Named in Health Care Proxy

• Once authority commences and the doctors have determined that the principal is incapacitated, the agent steps into the shoes of the principal. Agent’s authority may be limited by language in the proxy or by the principal’s wishes as stated in a living will.

• An agent can:
  – Consult with doctors
  – Bring in a doctor for a second opinion
  – Examine the principal’s medical records
Artificial Hydration and Nutrition

Unless a healthcare agent knows the principal’s wishes regarding artificial hydration and nutrition, the agent cannot act on issues regarding artificial nutrition or hydration.

– The principal’s wishes may be stated in the proxy or in a living will

– The proxy form can simply state that the agent knows the principal’s wishes regarding artificial hydration or nutrition, without spelling out what those wishes are
Stanley’s Outcome

- Stanley’s physician determined he could not give informed consent for the invasive procedure, and could not find a health care proxy in the file.
- Stanley’s physician referred him to LegalHealth to see if he could execute a health care proxy.
- LegalHealth determined that Stanley could execute a health care proxy and he named Barbara as his agent.
- Now Barbara will be the only one authorized to make medical care decisions on his behalf.
Case: Ruth

• Ruth is a 60 year old woman with metastatic breast cancer. Ruth was admitted to the hospital 2 weeks ago with shortness of breath and would have died if she was not intubated. The only person with her at time of admission was her sister.

• While in ICU the hospital staff found out that Ruth has a living will that states she does not want any “heroic measures” to save her life. She also has a health care proxy, naming her friend Esther as agent.
Case: Ruth

- Over the years Ruth has had conversations with her agent and family stating she does not want to live like a “vegetable”.

- The family of the patient consists of orthodox Jews, who upon the advice of their rabbi, would not withdraw the ventilator from the patient even when it was determined that the patient was unable to be weaned from the ventilator. The health care agent, Esther, was too afraid to go against the wishes of the family. Ruth remained on life support and “living” the life she did not want.

- If the agent was willing to act in accordance with Ruth’s wishes would the outcome be different?
Ruth’s Medical Care

- Although Ruth had executed a health care proxy, her agent Esther was unwilling to disobey Ruth’s family. Ruth’s wishes were not honored.
  - Ruth was on life support for months “living” the life she did not want.
Case: Edna G.

- Edna G. is a 78 year-old woman in good health. She has no family members and her friends are older than her and in poor health. Several years ago, she appointed a friend as her health care agent, but that friend is now suffering from Alzheimer’s disease.
How can Edna protect herself with respect to end of life health care decisions?

- Execute a Living Will
- Execute a DNR
Living Will

• A statement of one’s wishes with respect to one or a number of potential medical care decisions.

• New York does not have a statute regulating living wills, but New York State courts have recognized living wills as a binding expression of a patient’s wishes.
  – Only valid for the medical situations it addresses
  – No lawyer needed to fill out form
  – Has to be witnessed by two adults

• Can be put on the free national registry through NYLAG’s Total Life Choices program (www.nytlc.org)
Do Not Resuscitate Orders

- Created by statute and law; covers both hospital and "non-hospital" DNR orders
- DNR orders affect only cardiopulmonary resuscitation (CPR)
- Every competent adult has the right to refuse life-sustaining treatment, such as CPR
• If there is a health care proxy, then the agent has authority to decide about all medical treatment, including CPR, unless the proxy form states otherwise.

• The healthcare agent must decide in accordance with the patient’s wishes or, if those wishes are not known, in accordance with patient’s best interests.
Edna’s Outcome

- LegalHealth assisted Edna to complete both a living will and a DNR order.

- Edna’s health care wishes have been clearly stated and will be honored if she becomes incapacitated.
Case: Stanley Returns

- A year later, Stanley was hospitalized with pneumonia. His brother Bert is the only person who is visiting him. You asked about Barbara, and Bert told you that she has passed away. Stanley’s mental condition has diminished even more and you are unable to discuss his health treatment.

- Can Bert make medical decisions for Stanley?
If there is no health care proxy, the FHCDA provides statutory authority for family members or close friends to consent to treatment for incapacitated relatives in a general hospital, nursing home or hospice care. The Surrogate must decide based on patient’s wishes and moral and religious beliefs, or, if unknown, patient’s best interests.
Considerations of Surrogate when making decisions

- Patient centered:
  - Based on expressions of wishes by patient to surrogate,
  - Consistent with the patient’s values, religious and moral beliefs to the extent reasonably possible

- Patient’s best interests:
  - Dignity and uniqueness of every person
  - Possibility and extent of preserving life
  - Preservation, improvement and restoration of health and functioning
  - Relief of suffering
  - Any medical condition and such other concerns and values as a reasonable person in the same circumstances would consider.
Who is a Surrogate?

Order of priority:
- Article 81 court-appointed guardian
- Spouse or domestic partner
- Adult child
- Parent
- Sibling
- Close friend
Domestic Partner

A person who is formally a party in a domestic partnership or similar relationship with the patient, entered into pursuant to the laws of the United States or any state, local or foreign jurisdiction; OR

Registered as the domestic partner with any registry by the employer of either party or any state, local or foreign jurisdiction; OR

Is formally recognized as a beneficiary or covered person under the either party’s employment benefits or health insurance; OR

Is dependent or mutually interdependent on the other person for support as evidenced by the totality of the circumstances indicating a mutual intent to be domestic partners including but not limited to:

- common ownership or joint leasing of real or personal property; OR
- common house-holding, shared income or shared expenses; OR
- children in common; OR
- signs of intent to marry or become domestic partners; OR
- the length of the personal relationship of the persons.
Close Friend

• Any person eighteen years of age or older:
  – Who is a close friend of the patient or a relative of the patient (not listed on the priority list), AND
  – Who has maintained regular contact with the patient as to be familiar with the patient’s activities, health, and religious or moral beliefs, AND
  – Who presents a signed statement to that effect to the attending physician.
When does FHCDA apply?

- Patient lacks capacity to give informed consent
- Patient has no health care proxy
- Patient is in hospital, nursing home or in hospice care (not ambulatory care clinics, homecare or specialty clinics)
- No known expression of patient’s wishes before two witnesses
Can Surrogate withhold life sustaining treatment?

- May only withhold life-sustaining treatment if the treatment:
  - would be an extraordinary burden to the patient and the patient is terminally or permanently unconscious, or
  - The patient has uncurable condition, and treatment would involve inhumane pain, suffering, or other burden under the circumstances.
Advancing Stanley’s Medical Care

- No expression of Stanley’s wishes known
- Bert can make decisions in Stanley’s best interest
Case: Jorge

- George is an undocumented immigrant who lacks health insurance has been hospitalized for the past month after brain surgery. He lacks capacity as a result of necrosis of the brain from radiation he received elsewhere. Before he could return to his home country where his family would provide the needed custodial care, he experienced medical complications and was put on a feeding tube. His medical team recommended surgery to place the feeding tube in his stomach. His surrogate, a niece, refused to consent for this procedure because she felt he was too weak to survive the surgery. His medical team disagreed with the surrogate’s decision.
What if there is disagreement between the providers and the patient’s surrogate?

- A bioethics consult or an ad-hoc bioethics meeting may be called whenever there is disagreement among or between providers and the patient’s surrogate.
- Bioethics review team will look at what is in the best interest of the patient.
- If continued disagreement, matter could go to court.
What if there are no surrogates?

• Hospital must identify, to the extent practical, the patient’s wishes about pending health care decisions
• Attending physician may decide about routine medical treatment
• Major medical treatments requires consultation with other health care professionals directly involved with patient’s care and concurrence of a second physician.
• Life-sustaining treatment decisions can be made by:
  – A court
  – Attending physician and a second physician determine patient will die imminently regardless of treatment, and providing treatment would violate accepted medical standards.
Minor Patients under the FHCDA

- Parent or guardian of a minor patient may decide about life-sustaining treatment in accord with the minor’s best interests. Minor’s wishes taken into account as appropriate under circumstances.
- If physician determines minor has decision-making capacity, minor’s consent is required to withhold or stop life-sustaining treatment.
- Attempt must be made to locate and inform other parent of a decision.
- Physician may accept emancipated minor’s life-sustaining treatment decisions without parental consent, subject to ethics review committee approval.
If I am satisfied with the FHCDA surrogacy process, why should I complete a health care proxy?

The FHCDA is no substitute for a health care proxy!

- Health care proxy encourages important discussion with agent about end-of-life wishes
- Health care proxy ensures that the proper person has authority to make decisions
- FHCDA only applies to inpatient general hospital, hospice and nursing home situations.
Healthcare Decision Making for Patients Who Lack Capacity

- Persons who need healthcare decisions made for them include:
  - Those who were never competent
  - Those who were once competent, but did not do advance directives
  - Minors (broad category of exceptions apply)
Court Appointed Guardians - Article 17A

• Adults who were mentally retarded or developmentally disabled as minors can have a court appoint a guardian under Article 17A.

• Article 17A guardian is allowed to:
  – Handle personal and property matters
  – Make health care decisions for that individual
  – Make end-of-life decisions for that individual
New Law for persons with Mental Retardation or Developmental Disabilities

Effective Dec. 2007, there is a law that authorizes “qualified family members” to withhold or withdraw life-sustaining treatment for persons with mental retardation or developmental disabilities even if they are not a guardian. A “qualified family member” is defined in the new law. The “qualified family member” is subject to the same extensive end-of-life procedural requirements that a guardian under 17A is required to fulfill under these circumstances.
Court Appointed Guardians - Article 81

- Adults who at one time had capacity but are no longer able to take care of themselves can have a guardian appointed for them by the court under Article 81 of New York’s Mental Hygiene Law.
- Article 81 guardian can handle individual’s
  - personal and property needs
  - routine or major medical decisions.

Note: Absent a health care proxy, an Article 81 guardian is “first in line” to make decisions regarding the withholding or withdrawing of life sustaining treatment under the FHCDA.
Palliative Care Access Act

- Requires that hospitals, nursing homes, home care agencies, special needs assisted living residences, and enhanced assisted living residences, provide access to information and counseling regarding options for palliative care appropriate to patients with advanced life limiting conditions and illnesses.

- Requires these providers and residences to facilitate access to appropriate palliative care consultation and services, including associated pain management consultation and services, consistent with the patient needs and preferences.

- Extends to surrogates where patient lacks capacity.
Case: Eric B.

- Eric B. is a 70 year old man with dementia and Parkinson's disease. He has 24/7 home care and has been living in a NYCHA apartment for 30 years, but recently told you he is facing an eviction proceeding. When he showed you the notice, you see that he failed to recertify his apartment.

- What options, if any, are available to Eric?
Surrogate Decision Making for Legal and Financial Matters

- Power of Attorney - a form that allows an individual to name an agent to handle the person’s personal affairs during their lifetime, including banking, selling of real or personal property and other financial matters.
  - The authority designated in a Durable Power of Attorney continues after a person becomes disabled or incompetent, but not after the person dies
  - The form needs to be notarized
  - A Power of Attorney does not cover healthcare issues
- If executed while someone is competent, a Power of Attorney can often avoid the need to have a guardian appointed once that person becomes disabled.
• Eric B. does not have capacity to execute a power of attorney.
  – LegalHealth explored with the home care attendant how Eric has been taking care of his day to day affairs and determined that he relies heavily on a community organization
  – LegalHealth negotiated with NYCHA to accept a statement from the community organization describing Eric’s income and the assistance they give him. The eviction proceeding was dropped.
For More Information About LegalHealth visit www.legalhealth.org