ETHICAL DECISION MAKING: A HOW TO

INTRODUCTION

AGENDA

- Ethical principles in medical decision making
- Who makes the decision?
  - Patient with capacity
  - Patient without capacity
    - Priority of surrogates
- How do you decide for another?
- Special circumstances
  - A role for the bioethicist
  - Quality of life/implicit bias
- Case studies
- Q & A

WHY BIOETHICS?

- Health Care Decisions Act
  SCPA §1750-b(5)(d) Dispute mediation.
- Family Health Care Act
  Public Health Law §2994-m Ethics review committees.

ETHICAL PRINCIPLES

Patient autonomy
Beneficence
Nonmaleficence
Justice

PATIENT AUTONOMY

Patient autonomy Patients can make informed and voluntary decisions. The right of patients to make decisions regarding their healthcare without duress or influence.

Patients with capacity can accept, refuse or terminate treatment.

BENEFICENCE AND NONMALEFICENCE

Beneficence: Requires that there be a benefit to the patient, a procedure to be provided is to have the intent of benefiting the patient, 'do good.'

Nonmaleficence: Requires that there be no intentional harm to a patient. It is understood that some procedures may cause immediate harm to a patient (chemotherapy), but the overall intent is to benefit the patient.

JUSTICE

Justice requires that people are afforded the same treatment opportunities as other patients. Requires a fair distribution of services and burdens and benefits of treatment are available equally to all.

PATIENT WITH CAPACITY

Every person has the right to make his or her own treatment decisions, as well as the right to accept or decline life sustaining treatment.

Presumption of capacity

- Agree to treatment
- Refuse treatment
- Refuse tests
- Discontinue treatment

PATIENT WITH CAPACITY

Ability to understand their diagnosis.

Appreciate the information provided regarding treatment options and outcome.

Ability to reason when making treatment choices.

Ability to communicate treatment decisions.

UCSD HRPP

http://irb.ucsd.edu/decisional.shtml

INFORMED CONSENT

- Person provided sufficient information to make a decision regarding diagnosis and treatment options.
- Decision free from coercion and duress.
- Have necessary capacity to give consent.

PATIENT WITHOUT CAPACITY

All patients:

- Health care agent
- Court appointed Guardian
- Actively involved family member

Patients with ID/DD

- Consumer Advisory Board
- Surrogate Decision Making Committee

- Court Order

PATIENT WITHOUT CAPACITY

PROXY OR SURROGATE

- Can consent to recommended treatment
- Can make choices between medically appropriate options

Proxy may refuse instituting or continuing life sustaining treatment with knowledge of patient's prior wishes.

Surrogate may refuse life sustaining treatment when legal processes are followed.

PATIENT WHO LOST CAPACITY

- How does the proxy know?

While it is always preferable that the proxy have a conversation with the patient, the conversations may not cover every scenario.

COMMUNICATION

DETERMINING PATIENT WISHES

Five wishes

Organization for advanced planning, including forms and discussion questions.

NYS does not recognize a living will but does recognize written declarations of intent.

https://www.fivewishes.org/

The five wishes:

1. The person I want to make care decisions for me when I can't.
2. The kind of medical treatment I want or don't want.
3. How comfortable I want to be.
4. How I want people to treat me.
5. What I want my loved ones to know.

https://www.fivewishes.org/five-wishes-sample.pdf

DETERMINING PATIENT WISHES

Atul Gwande, MD, a physician ethicist, suggests having a conversation with the patient in advance and asking five questions.

Gawande, Atul. Being Mortal : Medicine and What Matters in the End. New York :Metropolitan Books, Henry Holt and Company, 2014.

https://www.pbs.org/video/frontline-being-mortal/

Questions:

- What is your understanding of where you are and of your illness?
- What are your fears or worries for the future?
- What are your goals and priorities?
- What outcomes are unacceptable to you? What are you willing to sacrifice and what are you not?
- What would a good day look like?

- https://www.nextavenue.org/atul-gawandes-5-questions-ask-lifes-end/
- https://www.pbs.org/video/frontline-being-mortal/

PATIENT WITHOUT CAPACITY

MHL Art 81 or SCPA Art. 17-A

The court order (or decree) appointing the Guardian should state whether the Guardian has the authority to make medical decisions for the person.

SURROGATE AUTHORITY

Surrogate

Authorized to make medical decisions, including end of life decisions, for someone else, even if their wishes are not known.

The law establishes a process for making these medical decisions for the person with intellectual or other developmental disabilities.

SURROGATE FOR THE PERSON WITH AN INTELLECTUAL OR OTHER DEVELOPMENTAL DISABILITY

Advocate for treatment

Treatment decisions based on person's best interests,* and when known, the person's wishes including moral and religious beliefs.

SCPA §1750-b(2) and (4)

*Best Interest

-dignity and uniqueness of the person
-preserve, improve or restore health
-relief of suffering
-unique nature of artificial nutrition/hydration
-entire medical condition of the person

SCPA §1750-b(2)(b)

END OF LIFE DECISION MAKING

Deciding whether to start treatment, continue treatment, stop treatment or refuse treatment.

Life sustaining treatment is medical treatment, including cardiopulmonary resuscitation and nutrition and hydration, provided by means of medical treatment, which is sustaining life functions and without which, according to reasonable medical judgment, the patient will die within a relatively short time period.

SCPA §1750-b(1)

HOW TO DECIDE

Decision-making process

Step 1: Identify the decision.

Step 2: Gather relevant information.

Step 3: Identify the alternatives.

Step 4: Weigh the evidence.

Step 5: Choose among alternatives.

Step 6: Take action.

Step 7: Review your decision & its consequences.

- UMASS/ DARTMOUTH, https://www.umassd.edu/fycm/decision-making/process/

*If an Arc of New York Chapter's guardianship committee is being asked to make a decision about life sustaining treatment for someone the Chapter is primary guardian for, also refer to

The Arc New York §1750-b Process: A Step-By-Step Guide.

Step 1:

Identify the decision.

What is the decision you are being asked to make?

The physician completes the MOLST Checklist, often in consultation with the surrogate, including

What treatment decisions are requested
Confirm patient's lack of capacity to make medical decisions

Certify the patient
- has a terminal condition; OR
- is permanently unconscious; OR
- the medical condition which requires life sustaining treatment is irreversible and which will continue indefinitely

AND the proposed treatment would impose an extraordinary burden on the patient

SCPA §1750-b(4)(b)

Step 2:

Gather relevant information.

Talk to the physician
Talk with the nurse
Talk with the family
Talk with house staff
Talk with the house nurse
Review the record (medical history, ISP, notes)
Review the medical record
Request a family meeting

Step 3:

Identify the alternatives.

What treatment options are available to patient?

Step 4:

Weigh the evidence/information gathered.

Weigh the risks/benefits of each treatment option in light of the best interest of the person and the statutory mandates.

Best Interest

- dignity and uniqueness of the person
- preserve, improve or restore health
- relief of suffering
- unique nature of artificial nutrition/hydration
- entire medical condition of the person

Artificial Nutrition and Hydration:

When there is no reasonable hope of maintaining life, the artificial nutrition and hydration poses an extraordinary burden on the patient.

SCPA §1750-b(4)(b)

Extraordinary burden

- The person's overall medical condition
- The expected outcome of treatment

Matter of Elizabeth M., 30 AD3d 780 (3rd Dept. 2006)
Matter of Joseph P., App. Div, 4th Dept., May 24, 2013
SCPA §1750-b(4)(b)

Step 5

Choose among treatment options.

Step 6

Take action.

Sign the consent for treatment/MOLST form after any administrative processes are completed.
Advise the physician/team of decision.
Advise others

Physician responsibilities:

- Complete MOLST form and include checklist.
- Provide notice to (if not already received):
  - The patient
  - CEO of the facility
  - Mental Hygiene Legal Service (if living in a facility)
  - Commissioner of OPWDD (if not living in a facility)

SCPA §1750-b(d)

Who can object?

- Patient
- Parent
- Adult sibling
- Other health care providers
- Director of the facility
- Mental Hygiene Legal Service
- Commissioner of OPWDD

SCPA §1750-b(5)

Step 7

- Review the decision & its consequences if no objections.

SPECIAL CIRCUMSTANCES

Beyond filing legal objections in court, little attention has been paid to the options available to family members, surrogates, and supporters

ROLE OF THE BIOETHICIST VERSUS ADVOCACY

- Bioethicist are trained to identify areas of conflict, recognize competing values among patients, surrogates and healthcare providers that might be present, and mediate disputes. In the community, they work to identify disparities, ensure justice in treatment and seek to obtain equitable care for patients.
- Advocates can take on the patient's role, arguing on their behalf, even litigating if necessary. The bioethicist can call upon an advocate in appropriate cases.

If an objection is made, a request can be made to have the ethics committee [or similar entity for medication disputes] for non-binding mediation.

SCPA 1750-b(5)(d)

PHYSICIAN ATTITUDES TOWARD PEOPLE WITH DISABILITIES

In 2021, 714 physicians were surveyed* regarding their attitudes towards providing care to people with disabilities

- 82.4% of the respondents agreed that people with significant disabilities had a worse quality of life than nondisabled people
- 40.7 % of the respondents were 'very confident' about being able to provide the same care to disabled patients and nondisabled patients
- 56.5% of the respondents would welcome patients with a disability into their practice

*Iezzoni, Lisa, Sowmya R. Rao, Julie Ressalam, Dragana Bolcic-Jankovic, Nicole D. Agaronnik, Karen Donelan, Tara Lagu, and Eric G. Campbell. Physicians' Perceptions of People With Disability and Their Health Care. Health Affairs. February 2021. 40:2, 297.

RED FLAGS AT BEDSIDE

Language used

unfortunate

Your child has cerebral palsy; she will ***never*** be able to walk and will ***always be dependent***

These people with an intellectual disability

Attitude/behavior toward patient

Not addressing the patient

Not including the patient

Hey there buddy/sweetheart, I am going to explain the treatment plan to your caregiver…

Find the champion!

Bioethicist
Social Worker
Patient Advocate
Physician
Staff nurse, house manager, care coordinator

Stress the humanity and abilities of the patient

CASE EXAMPLES

- Loretta L. is a 65 year old woman with Down Syndrome and moderate developmental disabilities. She has lived in residential settings since she was five years old. Her sister is her primary advocate. For the last two years, Loretta has been having significant seizure activity of unknown etiology. She has been hospitalized seven times. Six months ago, she took a sharp decline in functioning and her physician diagnosed her with end stage Alzheimer's disease, congestive heart failure, osteoporosis, recurrent pneumonia, seizure disorder, and aspiration. After the most recent hospitalization, her sister requested a MOLST form be completed to implement do not resuscitate and do not intubate orders and refer Loretta to hospice services.

- Patrick P. was a 72 year old man residing in a community residence certified by OPWDD. He had no known family. He was diagnosed with profound intellectual disabilities and beginning in 2010 experienced a physical decline. In the fall of 2012, he was diagnosed with dementia. He was subsequently diagnosed with dysphagia and a feeding tube was placed in November of that year. The following spring, he dislodged the PEG tube and he had to be hospitalized to have it replaced. A month later, it again became dislodged and the question was raised as to whether or not it should be replaced.

Going forward

Communicate early and often about our wishes
Mindful of attitudes towards people with disabilities- ours and other providers
Mindful of the language used describing people
Reach out to others with expertise
Use bioethicists to assist in conflict resolution at bedside
Training of healthcare professionals in the unique abilities of people with disabilities

Thank you

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