Case #1

AUTONOMY CHALLENGE

Case #1
Autonomy

- Patient: 93 yo AA female
- Out patient clinic
- Requested by: PMD
- Patient religion: Baptist
- **Reason for consult**: Patient refusing replacement of pacemaker; PMD believes this is low risk beneficial treatment and feels he would be complicit in her suicide if he honors her refusal.

Case #1
Autonomy

- Clinical status of patient: 93 yo living at home with son and daughter-in-law; decrease in eating, increase in sleeping; found to have non-working pacemaker and bradycardia. PMH of moderate CHF and anemia. PMD recommends low risk procedure to replace pacemaker.
- Patient's decision making capacity: She has always been "sharp as a tack" and remains cognitively aware and appropriate. She reads the paper and watches old movies most of the day. She does not lack decision-making capacity.
- Patient's wishes: Adamantly refuses procedure. States she has lived long, fruitful life but it's her "time to go". She is tired.
- Ethical analysis? What would you want to know? Does her autonomy automatically rule? Benefits vs. burdens?

Case #2
Balancing Principles

- Autonomy vs. Beneficence vs. Non-Maleficence
  - 76 yo male – chronic Afib – chose to refuse blood thinning meds after doctors told him to give up biking
  - Patient had Living Will stating “if I cannot recover to a meaningful quality of life” I wish to forgo all life-sustaining treatments”.
  - Patient named his wife as his health care proxy and son as alternate
  - Patient suffered large MCA embolic stroke
  - Day three after failed embolectomy – wife demands removal from vent and comfort care
  - Neuro team gives prognosis: Patient has good potential to recover; but will have significant disabilities

Case #3
Culture, Race and Ethnicity in Health Care

- 84 yo Pilipino male visiting his daughter in America is brought to hospital and diagnosed with stage IV lung cancer with liver mets; no benefit from any “curative” attempts; but doctors recommend palliative care and d/c to hospice care
- Wife and daughter request the medical/nursing staff “not to tell the patient he has cancer” because it will take away all hope and happiness and our belief is that the family should carry the burden
- Doctor calls for ethics consult stating “I cannot send patient home on hospice w/o his knowledge about prognosis and diagnosis”

Case #4
Decision-making capacity

- 88 yo female resident of long term care
- Medical history of CVA's, CHF and moderate dementia
- Routine physical discovered breast lump; biopsy showing breast cancer
- Patient given full disclosure of finds; patient refuses any surgical procedure stating her reasons "I've lived a long and good life; I prefer to avoid any hospitalizations and procedures regardless of the outcome; if I suffer pain/discomfort I prefer medications to relieve
- 30 minutes after discussion, patient forgot she had breast lump; when told again, she repeated the above refusal and rationale.

Case #5
Informed consent and refusal

- 62 yo male w/ schizoaffective disorder x 42 years; currently compliant with meds, but institutionalized in previous years when non-compliant. Has DM with charcot foot* and non-healing wound from procedure on foot
- Lives alone in apartment; unemployed on disability
- Mother, age 83, involved in his life and care
- No advance directive; no guardian; patient has been making his own decisions
- Medical team strongly recommends amputation of charcot foot
- Patient adamantly refuses

Case #6
Surrogate Decision Making

- 57 yo female w/ end stage COPD on ventilator; unable to wean – prognosis poor for survival
- 30 year common law* marriage to spouse at bedside; spouse wants to withdraw vent and allow her to die peacefully (based upon his knowledge of her wishes)
- Patient originally from Cuba – brother in Florida arrives at hospital and demands to be decision-maker and wants "everything done" – trach/PEG/LTAC

**No legal recognition of common law in NJ*

Shared Decision-Making
Case #7

- Impact of decision-making on family members
- Autonomy model

Quotes

- “I think all the time that I made the wrong decision to withdraw the ventilator. I question whether I did the right think. It was only three weeks and maybe I should have tried longer. Maybe the doctors were wrong. Maybe she could have lived. Maybe she could have gotten better. I think about it all the time.”

Quotes

- “I just wish that I had not been forced to make a life and death decision for my dad. You never forget that. It was a horrible thing to have to do. I often wonder if I was right or wrong and I’ll never know.”

Quotes

- "I felt like I had to know everything about my wife's illness in order to make these decisions. I went on the internet and asked all of my friends who knew anything about medicine. It was a terrible burden."

Quotes

- “I did what I thought was best, but my sister now makes me feel guilty and I am angry that she couldn’t support me in my decision to put in the feeding tube for mom.”
- “Well, my sister is still part of the family, but we don’t communicate anymore because of our decision to enroll dad in hospice. No birthday cards, no nothing.”

What is an Advance Directive? Case #8

- Written expression of patient's preferences about medical interventions under given circumstances and/or appointment of health care proxy
- Can be completed by persons who have decision-making capacity and are =>age 18 (adults)
- Is for "future" medical situations – is operative only:
  - ***When hospital/MD receives AD***
  - ***When patient determined to have lost decisional capacity***
  - ***When diagnosis and prognosis determined***
  - ***When time to evaluate patient's wishes***

Advance Directives
Language Matters - #8

- “meaningful quality of life”
- “reasonable chance of recovery”
- “terminal illness”
- “irreversible”
- “if I am brain dead”….
- “if burdens outweigh benefits”
- “if I am a vegetable….”

How can we make these documents more effective

How is POLST different than an advance directive?

- Targeted EOL population – limited life expectancy (< 1 year)
- Does not require loss of decision-making capacity to be acted upon
- Does not require interpretation, diagnosis, prognosis first
- Not limited to adults
- Applies immediately at point of contact – Actionable Orders
- Is a ***medical order*** to be filled out by the practitioner (Physician or Nurse Practitioner in NJ)
- Can be created by the practitioner ***with*** the patient or the patient's surrogate if the patient lacks capacity

Case #9
Maternal-Fetal Issues

- 43 yo female, 24 weeks pregnant s/p IVF with twins, suffers large ICH, now comatose with no chance for meaningful recovery
- Patient has Living Will requesting no artificial life supports (including ventilator) in event of no reasonable chance for recovery to cognitive state
- Husband devastated; requests removal of ventilator in keeping with her wishes
- Neonatal MD states babies are “well” and could survive; much better prognosis for babies if patient maintained on ventilator as long as possible

Case #10
Elderly patients

- Request for ethics consultation for 92 yo male with severe aortic stenosis, CHF and failure to thrive; daughter demanding “everything be done” including PEG tube feedings to improve nutrition
- Upon visit with patient (daughter not present), patient appeared to be confused; discovery that patient was very hard of hearing;
- With personal hearing aid device, patient able to understand and communicate with team; patient expressly requesting to go back to nursing home on comfort care with no PEG feeding tube.
- Daughter counseled on patient’s rights to be self determined

Case #11
VSED (Options of Last Resort)

- 30 yo quadriplegic
- Diving accident age 24
- Hope for stem cell research finding a “cure”
- Given up hope; wants to know how to die
- Only legal option in NJ – VSED
- Literature states “peaceful way to die” – very little studies on young patients w/o cancer or dementia
- Barriers to a good death