Advance Directives: The good, the bad, and the questionable

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Context

- Death denying society
- Death = taboo
- Death is institutionalized

- Rise of Technology – public has high expectations of medicine
- Potential for the Technological Imperative

Context: Decision making

- Patient Choice and Wishes
  - Many patients do not want to die in hospital
  - Many patients do die in hospital
  - Expensive EOL treatments and care
  - Patients might choose differently if they know what their options are

Context: Decision making

- What about Surrogate Decision Makers?
  - Surrogates may not know what the patient would want
    - Difficult to say “no”, refuse interventions or withdraw without knowing explicit views of patient
  - Surrogates feel burden of choosing for a loved one
    - Emotional burden for surrogates (Wendler and Rid, 2011)
    - 40 studies (29 qualitative, 11 quantitative), n=2832 SDMs
    - 11 = 1/3 SDMs experienced a negative emotional burden due to making treatment decisions for patient
    - 29 = many/most SDMs experienced negative emotional burden
    - Burden lasted months or years = stress, guilt, doubt

Advance Care Planning

- Why is it important?
- Respect for Autonomy
  - Self-determination, to self-govern
- Patient wishes = gold standard
  - Informed consent/refusal
  - Capacitated patient's express wishes, choices throughout healthcare
  - End-of-Life – especially important

Advance Care Planning

- 37% Americans have an Advance Directive (most do not)
- Advance Directives = formal legal document specifically authorized by state laws that individuals complete to be invoked if they become seriously ill and unable to make decisions.
  - Living Wills
  - Physician Order for Life Sustaining Treatment (POLST)
- Can designate a Health Care Power of Attorney (HCPOA) = designates a specific surrogate or proxy to make decisions for the patient (as if she were the patient)

Yadav et al, Health Affairs 2017

Advance Care Planning: Pros

- Documents capture capacitated patient's wishes and choices about EOL (at least broadly)
- Patients can indicate type of person they are and their values
  - Full court press, let me go, weigh benefits/burdens
- Patients can appoint a person to make decisions if unable
- Patients can change them at any time
  - Non-decisional patient can change mind about HCPOA or refuse treatments – check state laws
- May begin a discussion about patient's values and choices with surrogates and providers

Advance Care Planning: patient groups

- ACP particularly useful for certain groups of patients
  - Diagnoses – cancer, renal or other, neurological diseases*
  - Chronic conditions
  - Severe genetic conditions
- Diseases or conditions where the outcomes can be foreseen

- *Studies show this group is most likely to have ADs (~40-55%)

Yadav et al, Health Affairs 2017

Advance Care Planning: Cons

- Capture patient wishes *at the time of writing*
- Difficult to predict the likely scenarios for end-of-life if not terminal or chronic condition
  - What would I want if….
  - I don’t want to be on a ventilator, but…
  - Myriad of unforeseen decisions and options
- May be challenging to communicate the nuances of wishes to surrogates or HCPOA
- May change mind and not update ADs

Advance Directives: Critique

- Henry Perkins (2017) – *The False Promise of Advance Directives*
- ADs are fundamentally flawed
- Some argue they are flawed in ***use***
  - Due to gaps in patient understanding, communication, application

Advance Directives: Critique

- He argues they have ***flawed assumptions***
  - People think about their EOL care – No, they resist and avoid it
  - ADs can control future medical care – No, it's too complex and unpredictable
  - Even if ADs do not facilitate critical care, they do not complicate it – No, disagreements can arise about their application
  - Perception is that ADs can set "too exacting a standard for care, implying a good death fulfills a patient's every instruction, however impractical." (p 54)

Perkins, 2007, Annals of Internal Medicine

Surrogates and Patient Wishes

- How well do surrogates predict patient wishes?

- Shalowitz et al (2006):
  - Systematic Review of 16 studies, 151 hypothetical scenarios and 2595 surrogate-patient pairs
  - Surrogates predicted patients' treatment preferences w/ 68% accuracy
  - Patient designated surrogate (69%) vs legally assigned surrogates (68%)

Surrogates and Patient Wishes

- Shalowitz et al (2006):
  - Most accurate in scenarios about patient's current health (79%) or antibiotics 72%
  - Least accurate in scenarios involving dementia (58%) or stroke (58%)
  - Neither patient designation of surrogates nor prior discussion of patient's treatment preferences improved predictive accuracy

When might you not honor an AD?

- Rare and need robust reasons not to honor AD
- What type:
  - POLST = legally an order, need clear and robust reasons not to honor it
  - Living Will – how specific are the wishes? Is the surrogate advocating to follow them or not? Why?
- Capacitated patient changes her mind (document it)
- A more recent document is provided (updated AD, POLST)

When might you not honor an AD?

- What about HCPOA contradicting AD wishes?
  - Specific reasons why she is not following the patient's expressed wishes
  - Are the wishes vague or specific?
  - Does the decision contradict the patient's known wishes?
  - Does the HCPOA have capacity? Are they "fit" to decide?
  - Who determines Best Interests for the patient? On what basis?
  - Is there a clear secondary gain for the HCPOA?
  - Is there harm to the patient?

Case: Mr. Garcia

- 80 y/o man w/ CHF, Type 2 diabetes, declining kidney function, UTI with sepsis
- Admitted from nursing home 1 week ago
- When admitted Mr. Garcia said he wanted to be no CPR
  - DNR order placed in his chart
- Dr. Simpson estimates life expectancy = days/weeks

Addressing patient-centered ethical issues in health care, ASBH 2017, pp. 43-51

Case: Mr. Garcia

- Social circumstances
  - Mr. Garcia has 4 adult children, all visit
  - Maria states she is his POAHC – no paperwork yet
  - Disagreement among the family about patient's wishes and values
- Mr. Garcia lost capacity two days ago
- Maria tells Dr. Simpson to rescind the DNR order
- Dr. Simpson call an ethics consultation

Addressing patient-centered ethical issues in health care, ASBH 2017, pp. 43-51

Case: Mr. Garcia

- What are the ethical issues?
- What should the ethics consultant do?
- What might the different legal vs. ethical considerations be?

Case: Ms. Johnson

- 48 y/o female
- Huntingtons Disease
- Diabetes, hyper-tension, dementia
- Develops kidney failure, needs dialysis 3x per week
- Resides in a nursing home, but now in hospital
- Refuses intermittently
- Advance Directive names sister as HCPOA

Case 2

- Discussion about whether to restrain the patient when she refuses
- Sister gives consent to restrain the patient for dialysis treatment
- Nephrologists are divided
- Nurses are against it

- What are the ethical issues?
- What should the ethics consultant do?

Advance Directive Clinic

- Paul Hutchinson, MD, MA
  - Advance Care Planning Clinic
  - 40 minute appointments to help patients w/ ACP
    - Medicare reimbursement
  - Bring loved one with them
  - Discuss EOL wishes, preferences, choices, values
  - Fill out forms if ready

Nguyen and Hutchison, J Pain Symptom Mgmt, 2018

Key Questions:

- Tell me about the things in your life that are important to you.
- What abilities/experiences are so critical to your life that you cannot imagine living without them?
- Are you a spiritual person? If so, tell me about the role spirituality plays in your life. How does it affect your beliefs about death?
- What are your greatest fears about becoming sick? Dying?
- If you became very sick, how much are you willing to go through for the possibility of more time?
- If you became very sick, do you have goals you doctors should be aware of?
- Is there anything you'd like your healthcare agent to know about how you would like them to make decisions for you if you have a life-threatening condition?

Advance Directive Clinic

- What are the pros/cons of such a clinic?
- Would it be able to be implemented in your setting?
- What efforts do you make at your institution to have patients complete ADs or bring them in?
- What has worked or not worked?

Advance Directives

- Best we have a present
- Flawed but not without use
- Should begin and continue a conversation, means of talking about wishes near the EOL
- Should look for better alternatives
- Perhaps they work best when focused on higher level decisions, e.g. no CPR, no artificial food/hydration, no ventilator (long term), or all aggressive measures.
- Trying to fine tune decisions is less realistic unless person has a specific condition where the outcomes may be easier to foresee.

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