Goals of Care and Advance Directives

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Advance Directives

- **Two Kinds**
  - Living Will
    - A Piece of paper
  - Power of Attorney for Healthcare
    - A Human Person
- **One Intent**
  - To preserve the self-determination of the patient.
    - This is most commonly identified as the principle of "autonomy."

Living Will

- Generally designates 3 trajectories of care:
  - Give me everything.
  - Give me some things.
  - Give me very little.
- Only becomes legally valid when the patient is *imminently dying.*
- It is *always* overridden by a patient who changes his or her mind (as long as the patient has decisional-capacity).

Health Care Power of Attorney

- Rather than expressing wishes in writing like a Living Will, designates a person with whom you should speak.
  - Preferable to Living Will
    - Easier to talk to a person than to try to discern a document that speaks in generalities.
    - Legally active when the patient either (a) *cannot* or (b) *chooses not* to participate in care decisions.
    - Gives broad authority to POA to participate in and steer decisions about care.

Illinois Health Care Surrogate Act

- Patient's Guardian of the person
- Patient's spouse
- Adult son or daughter
- Either parent of the patient
- Any adult brother or sister
- Any adult grandchild
- Close friend
- Patient's Guardian of the estate

  - *Conflicts* between members of a particular group are resolved by:
    - majority vote (if a majority exists)
    - Consensus
    - One seeking guardianship rights over the other

The Failure of Advance Directives

- Promote an intervention-based methodology of decision-making.
- Completion rate remains below 25% in the United States.
- Over a 2 year period, 1/3 of all people have changed their preferences about life-sustaining treatments.
- Only accurately recorded and followed 26% of the time in hospitals in the United States.

Tentative Conclusion #1

- The question that precedes all others in the clinical context is, To whom should I be speaking?
  - Don’t forget that the patient is your first choice.
  - Rely on advance directives when they are there but remember that for all of our obsession with them they still remain a significantly limited and, more often than not, absent tool.
  - In the absence of advance directives, use the Illinois Health Care Surrogate Act but remember that people are not as clear as law.

Goals of Care

- Kaldjian et al. “Goals of Care Toward the End of Life: A Structured Literature Review,” *American Journal of Hospice and Palliative Medicine* 25(6) 501-11.

- Identified Six Goals
  - Be cured.
  - Live Longer.
  - Improve or maintain function or QOL.
  - Be comfortable.
  - Achieve life goals.
  - Provide support for family/caregiver.

Two Different Conversations

- **Interventions**
  - Informed consent for concrete, “snap-shot” events:
  - (a) Risks,
  - (b) Benefits,
  - (c) “Any questions?”
  - (d) “Do you want it?”
  - One-and-Done Model that isolates interventions from larger clinical realities.
- **Goals of Care**
  - Conversation about the experience of illness.
  - Conversation about values, hopes, fears.
  - Relate particular interventions to values, hopes, fears.
  - Ambiguous, personal, painful, shifting, and played out over time.
  - Often times one more conversation makes a difference.

Talk to Patients While You Can

- Tell me what you're hoping for and I'll tell you what I think we can reasonably do for you.
- If you get unexpectedly sicker or if I have to give you something that will make you drowsy, who would you like me to talk to about your care?
- Can that person meet with you and me to discuss where we are so they know me and we make sure they know what you want?
- I'm thinking that as 'x' progresses, you may find it more difficult to breathe. If that happens here are some things I could do. Would you want, 'a', 'b' or 'c'?

Tentative Conclusion #2

- There is little point in our obsession with informed consent for particular interventions if we don't consider the larger goals of care in cases of chronic or terminal illness and complex care.

Goals of Care and Futility

- **Lantos JD, Singer PA, Walker RM, et al. The illusion of futility in clinical practice. *American Journal of Medicine* 1989;87:81–4.**
- **2 elements to any futility determination:**
  - (a) establishing goals of care—determined by the patient or family.
  - (b) Probability of success in meeting those goals—determined by physicians.
- **Cannot discuss whether care is futile unless we know what the goals of care are.**
  - If keeping the person alive is the goal while the family hopes and prays for a miracle, then intervention ‘x’ is not futile in their eyes.
  - Then you know where you stand and have some hints as to how to proceed.

Tentative Conclusion #3

- You have a very difficult job. Many would not want to do it; some simply cannot do it.
- Like most difficult work, it is rewarding in meaningful and profound ways.
- You have the privilege of being with people as they face the most important questions of human existence: questions of meaning and purpose, love and loss, death and the possibility of eternal life. Take advantage of such an opportunity. Learn about the human condition. Work to become familiar with the ambiguity and life that these questions hold. You'll be a better person for it: a better spouse, a better sibling, a better parent, a better child, a better friend, and a better doctor.