It's my Choice: Navigating Patient/Family Conflict

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Learning Objectives

- Define decision making capacity
- Describe the process for determining capacity
- Discuss the role of surrogates in decision making
- Identify two approaches to resolving family/patient conflict

Challenges in Patient/Family Communication

- The chronically ill teen who refuses further treatment
- The grandmother who wants to discontinue dialysis
- The distraught family that refuses to bring in the advance directive
- The previously healthy 90 y/o with GI bleed who refuses surgery
- The demanding son who threatens to sue despite a clearly executed AD
- The daughter/surrogate who waits until mom is incapacitated to "save" her
- The wife of 50 years that cannot carry out her husband's wishes

Patient Self-Determination Act

Part of the Omnibus Reconciliation Act of 1990, it became effective in Dec, 1991

- Requirements:
  - Written notice of rights & policies
    - Right of patients to make decisions regarding care
    - Right to accept of refuse medical treatment
    - Right to make an advance directive
  - Inquire about the existence of AD and document
  - Education of staff
  - Must admit and treat patients regardless of presence or absence of AD

The Patient's Right to Self-Determination in Health Care Decision Making

Consensus Principles

- All patients with decision making capacity have the right to consent to – or to decline – any and all presented (i.e., medically indicated) treatment options;
- Incapacity does not, of itself, cause patients to lose that right;
- If the incapacitated patient's wishes are known--e.g., through a written advance directive or equally through oral discussions, those wishes must be honored;
- The above principles apply whether or not the patient is "terminal," and they apply to all forms of medical treatment including, e.g., medically assisted nutrition and hydration (MANH)

Advance Directives (AD)

Definition

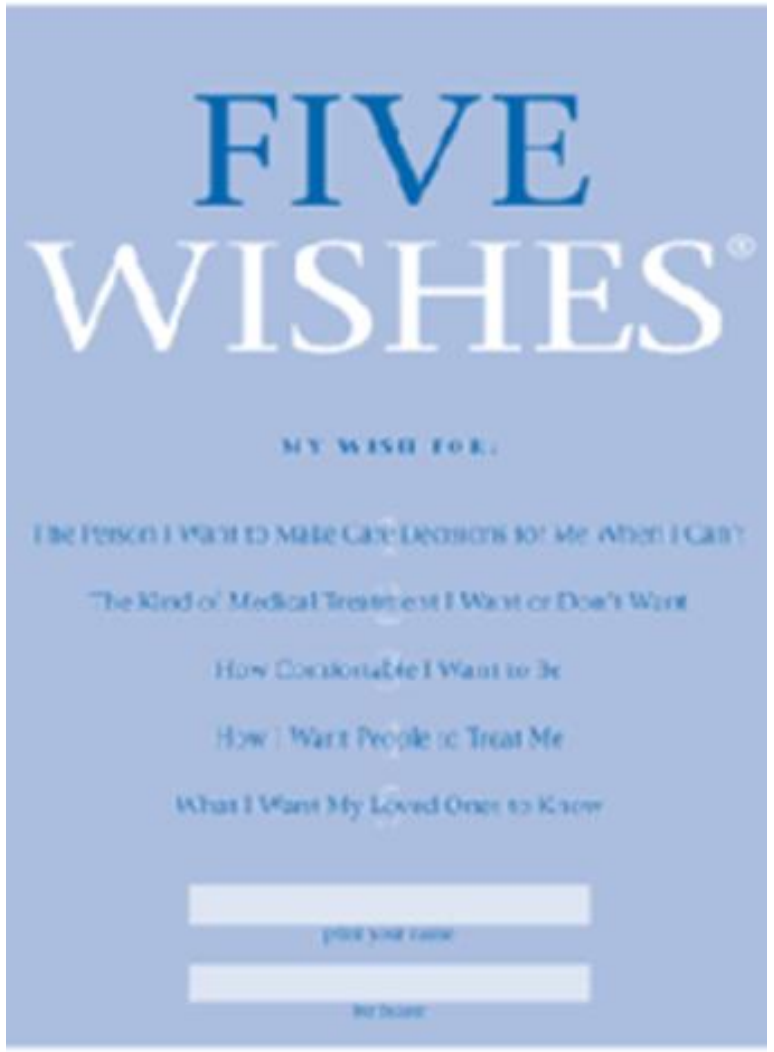
- Healthcare proxy or living will
  - Capable person states medical care wishes and treatment preferences
  - Implemented in lapsed capacity
- Patient Self Determination Act (PSDA)
  - Gives patients right of healthcare decisions

Types of Advance Directives

- Durable Power of Attorney for Healthcare
- Living Will
- Five Wishes Document
- Physician Orders for Life-Sustaining Treatment (POLST)
  - Comfort Measures
  - Antibiotics
  - Artificial Nutrition & Hydration
  - CPR

Five Wishes

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



Components of Informed Consent

- "An individual's autonomous authorization of a medical intervention"
  - Disclosure
  - Comprehension
  - Voluntariness
  - Consistency
  - Communicating a choice

- Beauchamp & Childress, 2001

Decisional Capacity Elements

- Understand and process information about diagnosis, prognosis, and treatment options
- Weigh benefits, burdens, and risks of care options
- Apply personal values to the analysis
- Arrive at decision that is consistent over time
- Communicate decision

- The threshold for determination of decisional capacity is an assessment of an individual's ability to make decisions about healthcare and treatment

Jones & Holden (2004)

Jones & Holden's Algorithm

- 1. Do the history and physical examination confirm that the patient can communicate a choice?
- 2. Can the patient understand the essential elements of informed consent?
- 3. Can the patient assign personal values to the risks and benefits of intervention?
- 4. Can the patient manipulate the information rationally and logically?
- 5. Is the patient's decision-making capacity stable over time?

Decisional Capacity Definitions: Capacity vs. Competence

Clinical Determination - Determining if a person can understand, make, and be responsible for the consequences of healthcare decisions

Competence - Legal presumption that an adult has the mental ability to negotiate legal tasks (entering into contract, making a will, standing for trial)

Incompetence - Judicial determination that because a person lacks this ability, he or she should be prevented from doing certain things

When the patient lacks capacity

Who speaks for the patient?

IF there is no durable power of attorney AND the patient is determined to lack capacity

We use what is considered a "substituted decision maker" (legal) or "surrogate decision maker" (ethics)

Key Areas of State Provisions

1. The priority of surrogates who may legally act in the absence of an appointed agent or guardian with health care powers;

2. Limitations on the types of decisions the surrogate is empowered to make;

3. The standards for decision-making; and

4. The process for resolving disputes among equal priority surrogates.

There are 7 states without laws: MA, MN, MO, NE, NH, RI, VT

(Winn, 2018)

Surrogate Consent Statutes

Regulated by state law

- 44 states have surrogate consent laws
  - 19 states have same-sex marriage laws
- Designate order of family decision makers for incapacitated patients without appointed proxy
  - Spouse, adult children, parents, and then distant relatives
- Family decisions restricted in a majority of states
  - Persistent vegetative state, comatose, or terminal
- Disputes between family members are common
  - Healthcare workers are in a position to mitigate effects of poor or delayed treatment decisions
  - Help patient and family/proxy think about alternative treatments and goals

Standards for Decision Making

Substituted Judgment

- Decisions are made based on how the patient would decide

Best Interests

- No knowledge of patient wishes
- Standard for children
- For those who have never been competent

Obligations of Surrogates

Substituted Judgment Considerations

- Current diagnosis
- Prognosis (the likely outcome or course of a disease or condition)
- Preference the person has expressed about the treatment
- Religious or personal beliefs
- Knowledge of patient views and opinions
- Expressed concerns about the effects of illness and treatment on family or friends

Best Interest Standard

- Protection for the incapacitated from medical paternalism
- Do no harm
- Relief of suffering
- Preservation and restoration of function
- Quality and extent of life

Rights of a Surrogate

- To be fully informed
- To review the medical record
- To make any and all health care decisions
- To ask for a second opinion

Cultural Perspectives

- Race and ethnicity may influence treatment preferences and decision making
- Advance care planning and written directives are not universally acceptable
- Value systems of patients and healthcare professions from different ethnic backgrounds may conflict during decision making
- Cultural influences include:
  - Deference to physician decision making
  - Family's role in protecting patient from burdens associated with life and death decision making
  - Spiritual obligations or beliefs

Cultural Perspectives

- In non-traditional family settings, decisions may be driven by communitarian concerns rather than individual preferences
- Family structure may not reflect closest confidant and supporter
- Hierarchical model vs. consensus model
- Same-sex spouses as decision makers

Treatment Goals

- Restoration and cure
- Stabilization of functioning
- Preparation for a comfortable and dignified death

Communication Barriers:

- Family's exclusion of patient or the patient's wishes
- Designation of a decision maker and/or reaching consensus
- Family tensions
- Parental values vs. child's best interests
- Difference in culture or values from providers
- Patient / family inability to comprehend and appreciate discussions
- Poor timing which raises anxiety or alienates patients & families
- Durability of DNR decisions
  - Change in patient situation and attitude

Communication Considerations & Strategies

- Family meeting
- Clarify team goals
- Determine patient & family values and wishes
- Respect both patient autonomy and well-intentioned family
- Consider the family
- Allow time for decisions
- Consider an ethics consult

Questions?

How might we approach these situations now?

- The chronically ill teen who refuses further treatment
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