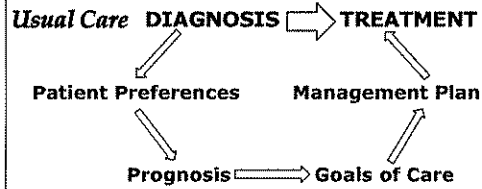


Four step process for Patient-Centered Care



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Four step process for Patient-Centered Care

- Identifying patient preferences
- Communication about medical prognosis
- Defining goals of care
- Implementing a management plan consistent with those goals

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Questions

- What if the patient lacks capacity to decide?
- Who is the right person to help with that decision?

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Terms used in Advance Care Planning

- **Advance care planning:** the process (rather than a single consultation or signing of a statutory document) of discussing end-of-life care with the patient and developing a valid expression of the patient's wishes regarding future medical care.
- **Advance directive:** a person's oral and written instructions about his or her future medical care, in the event he or she becomes unable to communicate. Two types: living will and health care proxy.

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Terms (cont.)

- **Advance Care Directives**
 - **Living will** - a written form of advance directive in which a patient's wishes regarding the administration of medical treatment are described if the patient becomes unable to communicate at the end-of-life.
 - **Health care proxy** - a document in which the patient appoints someone to make decisions about his or her medical care if he or she cannot make those decisions. In Missouri called, durable power of attorney for health care.

Scripts on asking about Advance Directives

- Have you given any thought to what kind of treatment you would want (and not want) if you become unable to speak for yourself in the future? (living will)
- If you are unable to speak for yourself, who would be best able to represent your views and values? (health care surrogate)

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Definition of Prognosis

- Prognosis is the future course of disease following its onset.
 - General course
 - Course in this particular case
 - How the disease will affect lives of persons
 - how illness impacts work, function, relationships, symptoms

Types of Prognosis

- Clinical course – evolution of the prognosis of disease that has come under medical care and is treated in a variety of ways
- Natural history of disease – how patients fare if nothing is done for their disease

Studies in Prognosis (1)

- Cohort study of 343 physicians and 468 patients at University of Chicago
- On average physicians predicted patients would live 5.3 times longer than they did.
- Predictions were accurate 20% of the time
- The better the doctor knew the patient, the more likely error was likely.
 - *BMJ* 2000;320:469-473

Studies in Prognosis (2)

- SUPPORT trial showed that 3 days before death from CHF, 80% were given prognosis of 6 or more months
- 2 days before death, patients with COPD predicted to have 50% 6 month survival
- 4 days before death, patients with colon cancer given 40% chance of 6 month survival
 - *New Horiz* 1997;5:56-61

Physicians and Prognosis

- Physicians feel torn by three competing needs:
 - They want to communicate honestly so that patients can make decisions.
 - They want to avoid harming patients and fear that truthful communication about limited prognosis may destroy hope.
 - They want to avoid discussions about poor prognosis due to their own discomforts.

Problems with Prognosis

- We tend to overestimate prognosis due to:
 - Optimism in the beneficial effects of our treatments.
 - Underestimating the impact of complex or advanced medical problems on life expectancy.
 - Collaborative denial of death.

Resurgent Relevance of Prognosis

- Increased number of patients with chronic disease
- Federal regulations regarding hospice referral
- Emergence of randomized, controlled clinical trials and outcomes evaluations
- Need for evaluations of cost-effectiveness
- Need to guide ethical decision making

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Scripts on describing Goals

- Given the severity of your illness, what is most important for you to achieve?
- How do you think about balancing quality of life with length of life in terms of your treatment?
- What are your most important hopes?
- What are your biggest fears?
 - "Scripts" from Quill *JAMA* 2000;284:2502-2507

When should end-of-life discussions be initiated?

Urgent Indications

- Imminent death
- Talk about wanting to die
- Inquiries about hospice or palliative care
- Recently hospitalized for severe progressive illness
- Severe suffering and poor prognosis

Routine Indications

- Discussing prognosis
- Discussing treatment with a low probability of success
- Discussing hopes and fears
- Physician would not be surprised if patient died in 6-12 months

Quill, *JAMA* 2000;284:2502-7

Physician's Fears

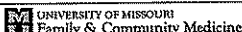
- Fear of being changed
- Fear of expressing emotion
- Fear of eliciting an emotional reaction
- Fear of doing harm
- Fear of illness or death
- Fear of ignorance or lack of knowledge

Physician Fear's

- Fear of blame
 - Blame by patients when a diagnosis is bad (shoot the messenger)
 - Blame by family members (when illness or death occurs, someone must be at fault)
 - Blame by colleagues when a patient dies (medical training reinforces the notion that death is a failure)

Family/Patient Meeting


- Determine appropriate setting for discussion
- Ask the patient and family what they understand
- Discuss specific patient preferences
- Review the course of illness, prognosis, and treatment options
- Discuss general goals of care
- Respond to emotions
- Establish a plan

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Goals of treatment

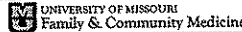
- Relative emphasis on life prolongation
- Relative emphasis on maintenance of physical and cognitive function
- Relative emphasis on comfort

- Prioritization of these goals helps in the development of a therapeutic plan

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Scripts on asking about wish for attempted CPR

- If you were to die suddenly, that is, you stopped breathing or your heart stopped, we could try to revive you by using cardiopulmonary resuscitation (CPR). Are you familiar with CPR? Have you given thought as to whether you would want it?
- Given the severity of your illness, CPR would likely be ineffective. I would recommend that you choose not to have it, but that we continue all potentially effective treatments. What do you think?

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Pathways (1)

- **Intensive pathway:**
 - Prime goal is life prolongation, then
 - maintenance of physical and cognitive function, and then
 - maximization of comfort

This translates into all medically indicated procedures, including cardiopulmonary resuscitation, intubation, and ICU care.

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Pathways (2)

- **Comprehensive pathway:**
 - Prime goal is maintenance of physical and cognitive function
 - prolongation of life
 - maximization of comfort
- Attempted CPR would be excluded as would ICU care, because both of these interventions have a low probability of success, and when they do not result in death, commonly result in functional decline.

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Pathways (3)

• **Basic pathway:**

- Prime goal is maintenance of physical and cognitive function
- maximization of comfort
- life prolongation
- Nursing facility or home based care for all medical conditions and substitution of medical treatment for surgical treatment whenever possible.

Pathways (4)

• **Palliative pathway:**

- Prime goal is comfort
- maintenance of physical and cognitive function
- life prolongation
- Facility or home based care exclusively, keeping diagnostic tests to a minimum. May be hospice candidate.

Pathways (5)

• **Comfort pathway:**

- Only goal is comfort
- Treatment is exclusively to relieve symptoms, e.g. pneumonia would be treated with oxygen, acetaminophen, and morphine, not antibiotics.
- From the Hebrew Rehabilitation Center for Aged, Boston MA. Gillick, et al, *J Am Geriatr Soc* 1999;47(2):227-230

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Keep in Mind

- Prioritizing goals of care will affect the interventions offered and recommended.
- Goals and therefore management plan may change as prognosis and patient wishes change.
