Surrogate Decision Making: Standards and Pitfalls

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Disclosures

- Grace Oei
  - No financial disclosures
- Kathy McMillan
  - No financial disclosures
- Carl Ricketts
  - No financial disclosures

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Objectives

- Define surrogate decision making and describe the ethical standards of surrogate decision making
- Examine the practical aspects of surrogate decision making at the bedside
- Analyze common ethical questions around surrogate decision making through clinical ethics consult analysis

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Mr. S

72 year old male diagnosed with colon cancer 6 years ago

- Treated on initial diagnosis with surgery and chemotherapy, remission achieved
- 1 year ago, diagnosed with recurrent colon cancer with metastatic disease
- Not a surgical candidate, poor long term prognosis
- Trial of chemotherapy attempted but suffered severe side effects

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Mr. S

72 year old male diagnosed with colon cancer 6 years ago

- Loving and intact family – wife of 42 years, 3 adult children, 5 grandchildren
  - 2 of 3 children live close to the patient and his wife
- Great insurance
- Established relationship with his PMD

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Mr. S

72 year old male diagnosed with colon cancer 6 years ago

- After discussion with family, declined further chemotherapy due to toxicity to focus on quality of life
- Transitioned to palliative care with additional therapies based on burden / benefit analysis
- Advance directive naming his wife as his durable power of attorney (DPOA)
  - Request to not prolong life

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National Hospice and Palliative Care Organization

CaringInfo

www.nhpco.org

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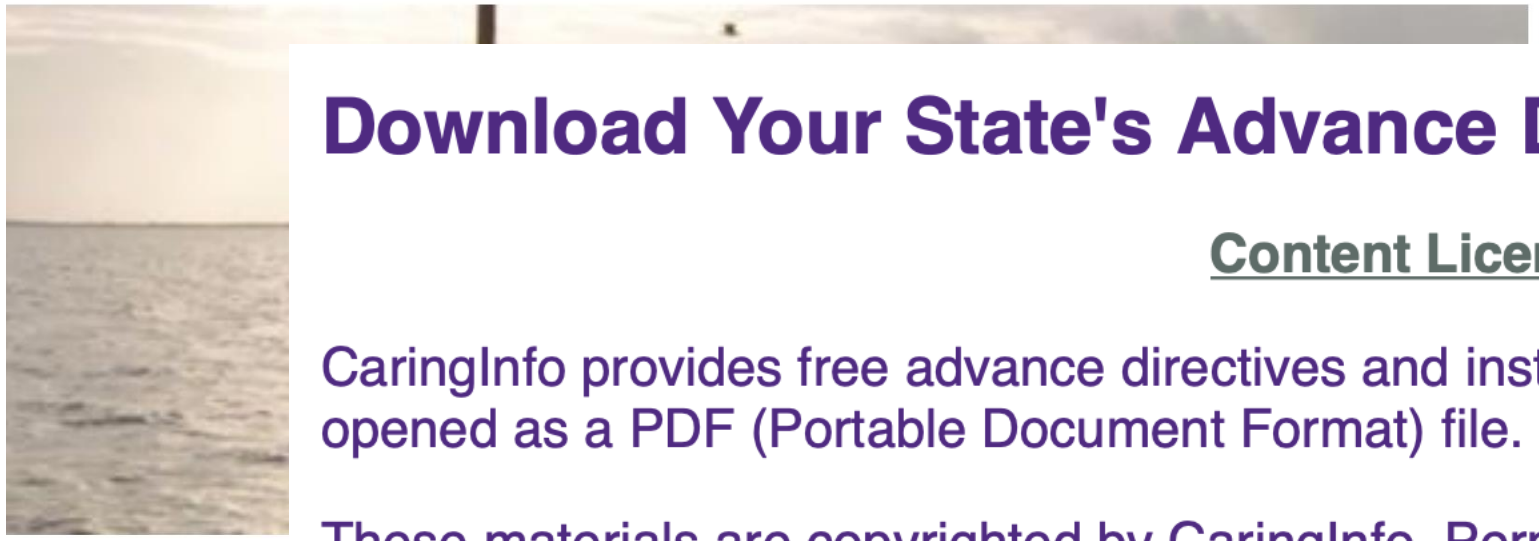

Advance Care Plan

Download Your State's Advance Directives

Content Licensing and Co-branding Opportunities

CaringInfo provides free advance directives and instructions for each state that can be opened as a PDF (Portable Document Format) file.

- HIPAA Privacy Rule Summary
- Appendix A: Glossary of Terms

www.aarp.org or www.caringinfo.org or https://www.nia.nih.gov/health/advance-care-planning-healthcare-directives

ADVANCE HEALTH CARE DIRECTIVE FORM

Print Form Reset Form

CALIFORNIA PROBATE CODE SECTION 4700-4701

4700. The form provided in Section 4701 may, but need not, be used to create an advance health care directive. The other sections of this division govern the effect of the form or any other writing used to create an advance health care directive. An individual may complete or modify all or any part of the form in Section 4701.

4701. The statutory advance health care directive form is as follows:
ADVANCE HEALTH CARE DIRECTIVE (California Probate Section 4701) Explanation

☐ (a) Choice Not to Prolong Life

I do not want my life to be prolonged if (1) I have an incurable and irreversible condition that will result in my death within a relatively short time, (2) I become unconscious and, to a reasonable degree of medical certainty, I will not regain consciousness, or (3) the likely risks and burdens of treatment would outweigh the expected benefits, OR

https://oag.ca.gov/sites/all/files/agweb/pdfs/consumers/ProbateCodeAdvancedHealthCareDirectiveForm-fillable.pdf

Mr. S

72 year old male diagnosed with colon cancer 6 years ago

- After discussion with family, declined further chemotherapy due to toxicity to focus on quality of life
- Transitioned to palliative care with additional therapies based on burden / benefit analysis
- Advance directive naming his wife as his durable power of attorney (DPOA)
  - Request to not prolong life
- Physician Order for Life Sustaining Treatment (POLST) form filled out to request Do Not Attempt Resuscitation (DNAR), limited additional intervention, no artificial nutrition and hydration

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National POLST Paradigm

CLICK HERE
I'M A PATIENT / CAREGIVER

CONTACT US

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NAVIGATION

Advance Care Planning Resources

Guidance for Healt
Professionals to Id
Patients for POLST

What is "POLS

"POLST" is a national move
patient autonomy regardin
emergency. The "P" used to mean "Physician" but it means so much more than
that:

National Healthcare Decisions Day is April 16!

https://polst.org

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HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B
(Effective 4/1/2017)*

First follow these o… Physician/NP/PA. A co… form is a legally valid phys… not completed implies full tr… **POLST complements an … is not intended to replace …**

Patient Last Name: | Date Form Prepared:

A — Cardiopulmonary Resus… *If patient is …*

Check One

- ☐ **Attempt Resuscitation/CPI…**
- ☐ **Do Not Attempt Resuscitat…**

B — Medical Interventions:

Check One

- ☐ **Full Treatment – primary go…**
  In addition to treatment describ… advanced airway interventions, …
  ☐ ***Trial Per…***
- ☐ **Selective Treatment – goal …**
  In addition to treatment describ… IV fluids as indicated. Do not in… intensive care.
  ☐ ***Request …***
- ☐ **Comfort-Focused Treatme…**
  Relieve pain and suffering with … treatment of airway obstruction… with comfort goal. ***Request tra…***

Additional Orders: _____

C — Artificially Administered Nutrition: *Offer food by mouth if feasible and desired.*

Check One

- ☐ Long-term artificial nutrition, including feeding tubes.
- ☐ Trial period of artificial nutrition, including feeding tubes.
- ☐ No artificial means of nutrition, including feeding tubes.

Additional Orders: _____

D — Information and Signatures:

Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker

☐ Advance Directive dated _____, available and reviewed →
☐ Advance Directive not available
☐ No Advance Directive

Health Care Agent if named in Advance Directive:
Name: _____
Phone: _____

Signature of Physician / Nurse Practitioner / Physician Assistant (Physician/NP/PA)
My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.

Print Physician/NP/PA Name:	Physician/NP/PA Phone #:	Physician/PA License #, NP Cert. #:
Physician/NP/PA Signature: *(required)*		Date:

Signature of Patient or Legally Recognized Decisionmaker
I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Print Name:		Relationship: *(write self if patient)*
Signature: *(required)*	Date:	Your POLST may be added to a secure electronic registry to be accessible by health providers, as permitted by HIPAA.
Mailing Address (street/city/state/zip):	Phone Number:	

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

*Form versions with effective dates of 1/1/2009, 4/1/2011, 10/1/2014 or 01/01/2016 are also valid.

https://capolst.org/wp-content/uploads/2017/09/POLST_2017_Final.pdf

Mr. S

72 year old male diagnosed with colon cancer 6 years ago

- Still enjoying a satisfactory quality of life with good functional status
- Sudden onset of severe abdominal pain, distention, nausea, and emesis
- Brought to the ED for evaluation and diagnosed with complete large bowel obstruction from a tumor
- Palliative surgical management recommended
  - Decompression of the bowel
  - Colostomy placement

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Mr. S

- Confused mental status
  - Administration of opioid pain medications
  - Acute illness
- Mrs. S and a daughter at bedside
  - Physicians ask Mrs. S to make decision regarding whether to perform the surgical intervention

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Clinical and Ethical Considerations

- As a named DPOA, when should Mrs. S start making decisions on behalf of Mr. S?
- Should Mrs. S decide to pursue surgery when Mr. S's code status is DNAR?
- If Mr. S is started on IVF is this considered artificial nutrition and hydration?

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Clinical and Ethical Considerations

- If Mrs. S decides to pursue surgery and IVF can a clinician decline to provide this type of medical care because it may appear to contradict Mr. S's stated wishes on his POLST and AD?
- If Mrs. S decides to pursue surgery is she fulfilling her duty as Mr. S's surrogate or making decisions based on her own wishes for her husband?

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Standards of Surrogate Decision Making

- Stated wishes
  - Written
  - Oral statements
- Substituted Judgement
  - Make the decision the patient would have made based on knowledge of the patient's goals and values
- Best interests
  - Decide for the patient taking into account information specific to the situation based on commonly held societal values

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Stated Wishes Standard

- Direct information from the patient
- Can be formal (AD, POLST, etc.) or informal (conversations with family / friends)
- Written vs oral
  - Courts give legal document more weight than oral statements
  - Written documents inherently are more accountable than oral statements
- **All advance directives will need some degree of interpretation to ensure that the current situation fulfills the intent of the patient's stated wishes**

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Stated Wishes Standard

- Problems
  - Patients are not as informed as they should be
  - Patients change their mind and forget to tell their family / friends or forget to write it down
  - Wording of the AD is vague and requires a great deal of interpretation
  - Stated request may conflict with the patient's best interest
  - Not very many people have AD or POLST
- **The most reliable AD, POLST or stated wishes are consistent over time and with the patient's lived and stated values**

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Stated Wishes Standard – Avoiding Problems

- Talk about goals of treatment first, then talk about specific interventions
  - Technology is value neutral
  - E.g – “I value my ability to be independent and do not want to live if I had to permanently live with the aid of a machine” NOT “never intubate me” or “never start me on dialysis”
- Discuss mostly likely scenarios in depth
  - Goals of treatment then specific interventions
- Have serial conversations over time
- Encourage written documentation of goals, values, wishes

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Substituted Judgement Standard

- Indirect information
  - Extrapolated from current knowledge about the patient
- Problems
  - Little to enforce consistency
  - May not accurately reflect the patient's wishes
  - Really hard to do
  - Can conflict the patient's best interests

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Substituted Interests and Best Judgments

An Integrated Model of Surrogate Decision Making

Daniel P. Sulmasy, MD, PhD

Lois Snyder, JD

How Should Decisions Be Made?

Decision making should honor the wide variability in patient beliefs about how decisions ought to be made. Some value au-

Table. The Substituted Interests Model of Surrogate Decision Making

Step	Sample Conversation Starters and Points
Empathy and connection: Acknowledge stresses of the situation and difficulty of the task and attend to needs of the surrogate	"It must be very difficult to see your loved one so sick."
Authentic values: Understand the patient as a person Values: interpersonal, moral, religious, familial, psychological Directives: substantive treatment preferences and process considerations, such as who should decide and how	"Tell us about your loved one." "Has anyone else in the family ever experienced a situation like this?"
Clinical data: Share understanding of the patient's clinical circumstances and prognosis	"All of that is important for us to know as we face the current situation." "Here is what is wrong. . ." "This is what is likely to happen. . ."
Substituted interests: Determine what the patient's real interests are, given the patient's values and these circumstances	"Knowing your loved one, what do you think would be the most important for him/her right now? Avoiding pain? Having family members here?"
Clinical judgment: Share understanding of the options and offer recommendation based on clinical experience, tailored to the particular patient's real interests.	"Here's what could be done." "This is what we would recommend, based on what we know and what you've told us about your loved one."
Best judgment for the patient: Best path to promote the good of this patient as a unique person, in the context of his or her relationships, authentic values, known wishes, and real interests, given the circumstances and options	"Knowing your loved one, does our recommendation seem right for him or her? Do you think another plan would be better, given his or her values, preferences, relationships?"

Sulmasy, JAMA, 2010

Substituted Judgement Standard - Avoiding Problems

- Get the know the patient
  - Elicit the patient's goals and values from the surrogate
  - Obtain multiple viewpoints
  - Evaluates fitness of the surrogate to serve
- Keep the focus on the patient
  - Avoid putting the focus on the surrogate
  - Avoid "You don't want your loved one to suffer, do you?"
- Establish (and re-establish) common ground with the surrogate
  - This is not a "war" to win with the surrogate
- Make a medical recommendation for treatment

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Best Interest Judgement Standard

- Best interest based on medical judgement and commonly held societal values
  - Free from pain
  - Quality of life over quantity
- Problems
  - Subject to clinician bias
  - Uncomfortable to be the “decider”

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Best Interest Judgement Standard – Avoiding Problems

- Obtain a clear medical picture
  - Accurate information regarding prognosis and reversibility
- Elicit multiple viewpoints
- Addresses biases
- Trial of therapy to allow time to clarify the situation

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Who Can Be A Surrogate?

- Moral Qualifications
  - Willing to serve
  - Able to interact with the medical team
  - Best to have direct knowledge of the patient's goals, values, and wishes
    - "Knows the patient the best and loves the patient the most"
- Legal Qualifications
  - "Agent" – named in legal document
  - "Surrogate" – presumed to be in a position to serve
  - Hierarchy, if any, determined by state law

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Surrogate Decision Making for Mr. S

- Moral qualification
  - Wife of 42 years
- Legal qualification
  - Named as Mr. S's agent
- Standard to be used
  - Stated wishes
  - Substituted judgement

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Surrogate Decision Making for Mr. S

- Start with goals and values
  - Define quality of life
  - What are the most important values?
- Prognosis and reversibility
- How to best get the patient to his treatment goal given the medical reality?
- Consistent with previously expressed wishes?

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Surrogate Decision Making for Mr. S

- Start with goals and values
  - Define quality of life – able to recognize family and friends, able to live at home, able to live without aid of technology, no long term artificial nutrition / hydration
  - What are the most important values? Time with family and friends
- Prognosis and reversibility
- How to best get the patient to his treatment goal given the medical reality?
- Consistent with previously expressed wishes?

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Surrogate Decision Making for Mr. S

- Start with goals and values
  - Define quality of life
  - What are the most important values? Time with family and friends
- Prognosis and reversibility
  - Adequate pre-surgical functional status, will need to be intubated for surgical intervention → likely will get extubated
  - Will likely need a nasogastric tube until bowel function returns
  - May need TPN for nutritional support if bowel dysfunction is prolonged
  - Will live with a colostomy bag until death
  - After hospitalization anticipate recovery for additional time before death
  - Likely acceptable functional status (not dependent on ventilator, tube feeds)

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Surrogate Decision Making for Mr. S

- Start with goals and values
  - Define quality of life
  - What are the most important values?
- Prognosis and reversibility
- How to best get the patient to his treatment goal given the medical reality?
  - Goal – time with family with intact cognition
  - Discuss willingness to accept short term invasive technology for long term gain
  - Discuss acceptability of quality of life with a colostomy bag
  - Discuss worst case scenario → complications in OR or in the ICU
  - Discuss other treatment options
- Consistent with previously expressed wishes?

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Surrogate Decision Making for Mr. S

- Start with goals and values
  - Define quality of life
  - What are the most important values?
- Prognosis and reversibility
- How to best get the patient to his treatment goal given the medical reality?
- Consistent with previously expressed wishes?
  - All AD and POLST need interpretation
  - Focus on treatment goals, not individual technology
  - Absolute resistance to a certain technology as the primary treatment goal may be at the expense of other goals

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Summary Points

- Standards of surrogate decision making
  - Stated wishes
  - Substituted judgement
  - Best interest
- Surrogate decision making is hard
  - All stated wishes need some degree of interpretation
  - Focus on getting to know the patient
  - Focus on patient's goals and values to guide treatment goals
- Requires best medical recommendation given medical reality
- Focus on treatment goals, not individual technology
- Reassess and adjust as needed → individualized road for the patient

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Topics NOT Addressed

- Ethical nature of surrogate decision maker's actions
- How to select the surrogate decision maker
- Conflict between family members of the patient
- Conflict between the clinical team and the patient's family
- Decision making for unrepresented patients
- Shared medical decision making

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Surrogate Decision Making: Standards and Pitfalls

Kathy McMillan, BSN, MA

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Three Roles of Nurses in End of Life Care

1. Information Broker
   - Giving Information to Physicians
     - Clinical status
     - Family's emotional state
     - Expressed wishes
   - Giving Information to Family Members
     - Explaining equipment
     - Clinical Status
     - Translating medical terms to lay language
     - Educating
   - Mediation
     - Bringing physicians and family members together
     - Involving other disciplines

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Three Roles of Nurses in End of Life Care

2. Supporter
   - Building trust
     - Introducing family to other staff members
     - Allowing family to participate in care
     - Finding out what is important to family
     - Helping maintain hope
     - Accepting their decisions
     - Preparing them for bad news
   - Showing Empathy
     - Attempting to understand how the family sees situation
     - Being present
     - Acknowledging feelings

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Three Roles of Nurses in End of Life Care

3. Advocate
   - Advocating for patient to physicians
     - Questioning plan of care
     - “Planting seeds” to physician that palliative care may be best
     - Timing discussions so best physician will be present
   - Advocating for patient to family
     - Clarifying goals of care
     - Explaining implications of decisions
     - Presenting realistic picture of situation
     - Coaching families to make decisions consistent with patient’s goals
     - Helping accept the inevitability of death

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Surrogate Decision Making: Standards and Pitfalls

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Religion/Spirituality & End of Life Decisions

- Reliance on R/S to cope with diagnosis
  - Potentially positive and negative consequences
- Relationship between Clergy and Care Recipients
  - Clergy uniquely positioned to help patients consider medical decisions at or near EOL within a R/S framework.
- Clergy's knowledge of EOL is poor
  - Uncertain and passive approach to counseling congregants about decision making

Sanders, Justin J. "Seeking and Accepting: U.S. Clergy Theological and Moral Perspectives Informing Decision Making at the End of Life." Journal of Palliative Medicine, Vol. 20, No. 10, 2017. https://doi.org/10.1089/jpm.2016.0545. Accessed 16, Jan. 2019

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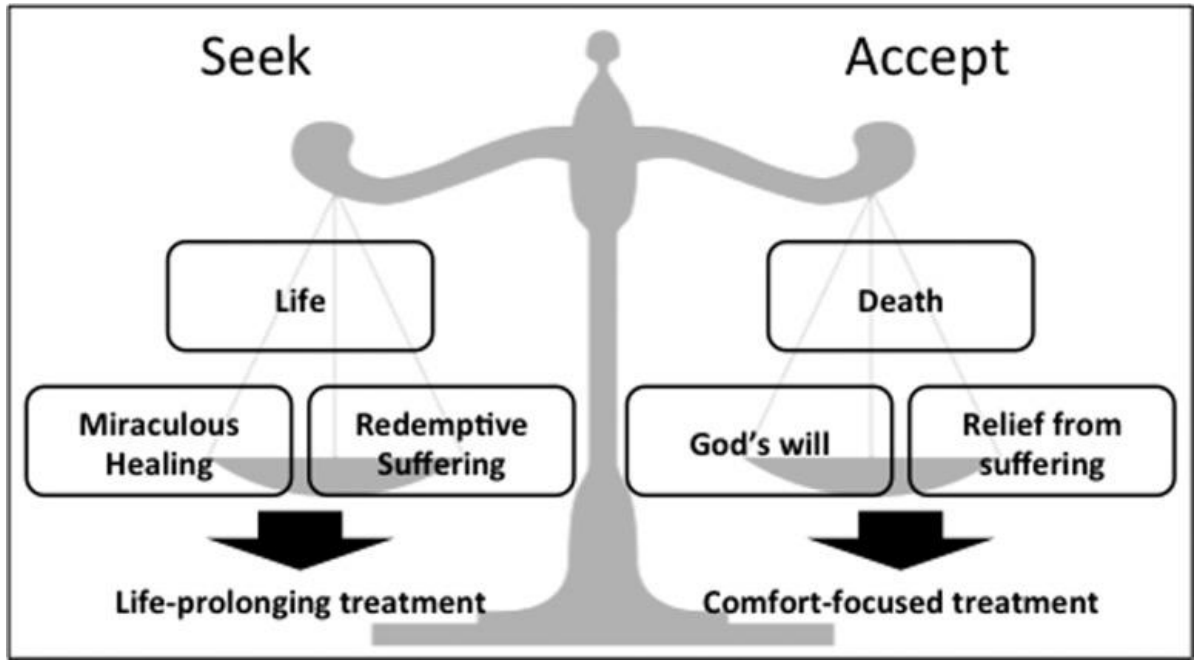
Religion/Spirituality & End of Life Decisions

- Theological Framework for end-of-life decision making

- Age, Family, and community responsibility
- Prognosis and treatment burden
- Free Will



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Religion/Spirituality & End of Life Decisions

- Patient Preferences for intensive EOL care
  - Optimistic prognostic perceptions, more intensive cancer care, and less frequent and shorter hospice use

True G, Phipps EJ, Braitman LE, et al. : Treatment preferences and advance care planning at end of life: The role of ethnicity and spiritual coping in cancer patients. Ann Behav Med 2005;30:174–179

Boyd EA, Lo B, Evans LR, et al. : “It's not just what the doctor tells me:” factors that influence surrogate decision-makers' perceptions of prognosis. Crit Care Med 2010;38:1270–1275

Zier LS, Burack JH, Micco G, et al. : Surrogate decision makers' responses to physicians' predictions of medical futility. Chest 2009;136:110–117

- Seeking Life & Accepting Death- axis point

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Spiritual Care & Surrogates: Mrs. M

- Chaplain's spiritual support can serve as the bridge
  - Mrs. M has experienced brain death and the family has been approached by the organ donation procurement team. The family does not understand brain death and have many questions regarding the theological implications, specifically eschatologically; for Mrs. M if her organs are donated.

  - Futility Disputes
  - Eschatology
  - Faith
  - Medical Decision

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Religion & Spirituality Takeaway

- Surrogate-Care Provider Relationship
  - Collaborative vs. Unilateral decision-making
    - Patients who have strong religious beliefs underlying their rationale will benefit from acknowledgment of their beliefs.

Pope TM. Surrogate selection: an increasingly viable, but limited, solution to intractable futility disputes. Saint Louis University Journal of Health Law and Policy. 2010;3:183–252.

Quill TE, Arnold R, Back AL. Discussing treatment preferences with patients who want “everything” Ann Intern Med. 2009;151:345–349.

Balboni TA, Paulk ME, Balboni MJ, et al. Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. J Clin Oncol. 2010;28:445–452.

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