ADVANCE DIRECTIVES

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Case Study

Mrs. A, a 76 y/o widow with Alzheimer's disease, resides in a nursing home. Often she does not recognize relatives and friends or respond when asked questions. She requires assistance with dressing, bathing, and eating. When still lucid, she told her children and her friends many times that she wanted "no heroics" if she became senile. After visiting a neighbor after a severe stroke, she told her son, "That is not living. I don't want to die plugged into a machine, unable to recognize my family and having to depend on others to take care of me. If I'm like that, just let me die in peace."

Mrs. A develops pneumonia and sepsis. Her son and daughter remind the physician of these conversations and ask him not to administer antibiotics for the infection or transfer her to an acute care hospital. However, her brother strongly believes that life-sustaining treatment should be provided regardless of her previous statements or the expected quality of life. He asserts, "Life is sacred; you can't just let her die." The brother ads, "She's a totally different person. She was so afraid of being senile. But look at her now. She's not suffering."

Barriers to Advance Care Planning

Table 3. Barriers, Grouped According to Theme, to the Advance Care Planning (ACP) Steps of Contemplation, Discussion, and Documentation

Barrier Theme	Individual Participant-Identified Barriers	Overall* n = 143	Not Contemplated ACP Wishes n = 59	Not Discussed ACP with Family n = 67	Not Discussed ACP with Doctor n = 98	Not Documented ACP Wishes n = 131
			%			
ACP perceived to be irrelevant	I am too healthy.[C]		41	33	36	32
	I prefer to leave my health in God's hands.[C]		43	35	28	29
	I have not given it much thought.[O]		21	—	21	35
	I prefer to leave my health to fate.[O]		—	15	—	—
	My doctor, family, and friends already know my decisions.[O]		5	1	2	3
	Any perceived as irrelevant barriers.	84	75	64	67	77
Personal barriers	It makes me nervous or sad.[C]		28	19	19	13
	I don't want to think about death. I'd rather leave the choice to others.[O]		16	—	4	—
	I am too busy with work and family.[O]		40	7	4	18
	Any personal barriers.	53	59	27	27	28
Relationship concerns	I have a poor relationship with my family and friends.[C]		—	36	—	2
	I have poor a relationship with my doctor.[C]		—	—	29	—
	I don't want my family involved.[C]		—	25	—	—
	I don't have family or friends.[C]		—	22	—	—
	I don't want to worry or burden my family or friends.[C]		—	43	—	—
	Any relationship barriers.	46		76	30	2
Information needs	I need more information about my health and healthcare choices.[C]		29	18	26	22
	I don't know what an advance directive is.[C]		—	—	—	15
	Any informational barriers.	36	29	18	26	31
Health encounter time constraints	I have too many other medical problems.[C]		—	—	30	—
	My doctor is too busy.[C]		—	—	18	—
	Any time constraint barrier.	29	—	—	39	—
Problems with advance directive form	I need help understanding the forms.[O]		5	—	5	28
	I do not like to fill out forms in general.[O]		—	—	—	2
	The advance directive form was not helpful.[O]		—	—	—	2
	Any problems with advance directives.	29	5	—	5	30

The barrier domains are presented in descending order of prevalence across all of the ACP steps. The total n for each step differs as varying numbers of participants reported not completing individual ACP steps. Participants could endorse multiple barriers for each ACP step.

* The Overall column represents all participants (n = 143). For each barrier theme, the proportion of participants who endorsed any of the individual barriers at any of the four ACP steps is presented.

[C] = closed-ended responses participants could choose from a predefined list; [O] = responses to the open-ended question, "Are there any other reasons?"

Patient Perceived Barriers:

- I am too healthy.
- I prefer to leave my health in God's hands.
- I have not given it much thought.
- I am too busy with work and family.
- I don't want to worry or burden my family or friends.

Schickedanz, Adam et al., "A Clinical Framework for Improving the Advance Care Planning Process: Start with Patients' Self-Identified Barriers." *JAGS* 57, no. 1 (2009): 31–39.

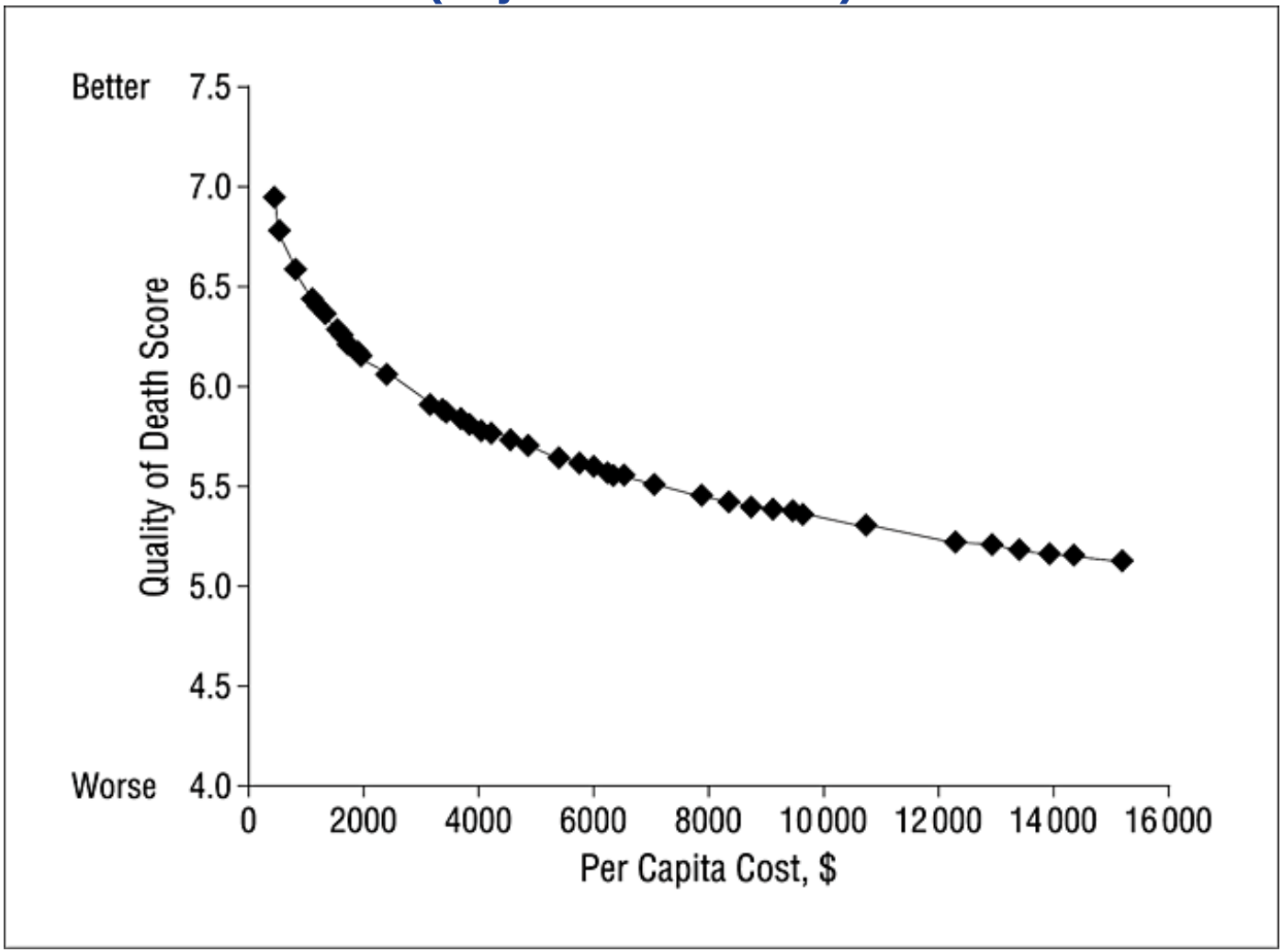
Moving End of Life Decisions *Away* from the End-of-Life

Why is it important to plan **NOW** for later healthcare decisions?

- Almost 1 out of every 2 adults have at least one chronic disease,[1] for example: diabetes, COPD, CHF, or dementia
- The majority of deaths occur in a hospital, nursing home, or other institutional setting instead of at home[2]
- When it comes time to make important end-of-life decisions, 50% of people are unable to make them for themselves[3]
- 30% of Medicare dollars are spent during the last year of life[4]

1. Wu SY, Green A. "Projection of Chronic Illness Prevalence and Cost Inflation," *RAND Health*: Santa Monica, CA, 2000.
2. Teno, Joan M. et. al., "Family Perspectives on End-of-Life Care at the Last Place of Care," *JAMA* 291:1 (2004): 89.
3. U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging, and Long-Term Care Policy, *Advance Directives and Advance Care Planning: Report to Congress* (August 2008).
4. Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group, "2006 National Health Care Expenditures Data," Baltimore, MD, January 2008.

Association between cost and quality of death in the final week of life (adjusted P = .006)



Zhang, B. et al. Arch Intern Med 2009;169:480-488.

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Moving End of Life Decisions *Away* from the End-of-Life

Yet, for the most part, patients and their families have not taken the time to begin a process of Advance Care Planning:

- Nationally, just 5-15% of individuals have advance directives[1]
- When health professionals are unaware of a patient's wishes, decisions to forgo medical interventions are often delayed[2]
- Making end-of-life decisions can be overwhelming and devastating for family members, especially if their loved one has not communicated his or her wishes [3]

1. Kirschner, Kristi L., "When Written Advance Directives are not Enough." Clin Geriatric Med 21 (2005): 193-9.
2. Thelen, Mary, "End-of-Life Decision Making in Intensive Care," *Critical Care Nurse* 25:6 (2005): 34.
3. Ibid.

Advance Care Planning

What is advance care planning?

- Process of planning for future medical care
- Values and goals are explored and documented
- Determine agent or chosen decision-maker
- Professional, legal responsibility

Advance Care Planning

What is advance care planning?

- Trust building
- Uncertainty reduced
- Helps to avoid confusion and conflict
- Permits peace of mind among family members

What is an Advance Directive?

Is a statement a patient makes, while still of decision-making capacity, about how treatment decisions should be made at some future time if he or she loses the capacity to make such decisions

- Simply *provide instructions* about the choices you would prefer for future healthcare

- Appoint *another person* or persons who would make your healthcare decisions *if you were unable* to make them yourself.

Ought to have been discussed and understood by all involved parties

Examples of Advance Directives

Durable Power of Attorney for Health Care	Living Will
You designate an agent to make health care decisions on your behalf	You make a statement to physicians about three specific healthcare decisions
Activated if you become incapable of making your own healthcare decisions	Activated only if you are diagnosed with a terminal condition or are in a persistent vegetative state
You can give permission to your agent to make decisions on your behalf about nursing homes, feeding tubes, treatment during pregnancy, pain and symptom control, CPR, other medical interventions, organ donation and autopsy	You make decisions about whether you would want tube feeding or life-sustaining procedures in “yes/no” language
You have space to make spiritual and/or religious wishes known and communicate comforting thoughts to loved ones	

Choosing a Healthcare Agent-DPAHC

The CSM Advance Care Planning Packet provides a mechanism for choosing a healthcare agent:

Is the person willing to accept the responsibility?

Is the person able to make difficult decisions under stress?

Does the person know your values and choices?

Is this person able to deal with tough issues in a crisis?

Can the person speak your wishes even if they do not agree with them?

Spiritual or Religious Dimensions

A very personal dimension of one's life…may include a religion

An appreciation of how ***your*** personal faith fits into the discussion on end-of-life care is important

An understanding of how ***your*** faith community stands on these issues may be beneficial

- Contact your clergy or spiritual advisor and access other resources to answer these questions

Introducing the Concept

How do I get my family to begin to talk about end-of-life care?

- You are important, and so are your wishes…
- We want to make sure we take good care of you…
- There may be a point in time when you cannot talk about your wishes, so let's talk about this…
- I don't know all about you that I need to know to take care of you as you would like…
- We do not know your preferences and goals. If you cannot tell us in advance, we could do too little or too much, and that is not *necessarily* doing what you would want to do…

Document Placement

What do I do once my AD has been completed?

- Give a copy to:
  - Primary physician
  - Hospital upon admission
  - Agents
  - Lawyer
  - Any health care facility, or agency that you use
  - Car when traveling
- Communicate placement of document in own home

Recommendations

Review the document yearly with your agent

Update copies

Let your family know who your agents are

- Be firm
- Does not preclude discussion

Discuss the AD with all of those appropriate

Thank you!

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