JULIAN S. DAVIS MEMORIAL LECTURE

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JEWISH HOME

Overcoming Obstacles to Planning for End-of-Life Care

Julian S. Davis, M.D. Memorial Lecture

Some Definitions

- ACP = Advance Care Planning
  - Planning for medical decisions that will occur in the future.
- AD = Advance Directives
  - Living wills and health care proxies.
  - The way in which ACP is traditionally accomplished.
- Surrogate decision-making
  - One person making a decision on behalf of another.
  - Will sometimes refer to surrogate decision makers as caregivers.

Advance Care Planning

- Process by which individuals can plan for time of decisional incapacity for health care decisions.
- Many individuals reach a point in their illness when they are no longer able to participate in decision-making about their own care.
- Traditionally implemented through the completion of documents: living wills and health care proxies.

Why is ACP Necessary?

- Traditional view:
  - Individuals can identify in advance the care they want to receive.
  - The goal of ACP is to deliver this care.
  - Accomplished through the use of advance directives.
- Newer view.
  - End-of-life decisions are difficult, emotionally charged, and surrogates are burdened by them.
  - The goal of ACP is to decrease the burden of decision-making, for both patients and surrogates.

What is a Living Will?

- A document allowing you to specify what treatments you do or do not want to receive in the future.
- Not the same as a regular will.
- Does not need to be prepared by a lawyer.

Why Complete a Living Will?

- If no one to serve as a health care proxy, this is the only official way you have of making your wishes known.
- If you do have a health care proxy, it can serve as a guide to help that person make decisions.
- Doctors more likely to respect those wishes if Living Will in place.

Limitations of Living Wills

- Worded in terms of withholding treatment only most extreme circumstances known with certainty.
- Physicians have difficulty applying to specific clinical situations.
- If a family member disagrees with what is in a living will, the physician is more likely to listen to the family member than follow the living will.

California Advance Healthcare Directive Form

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

What is a Health Care Proxy?

- A person you choose to make medical decisions for you if you are not able.
- Not the same as a power of attorney.
- Does not need to be done by a lawyer.

Why Choose a Health Care Proxy?

- Can help to lower disagreements within the family.
- Can help to ensure that the person you trust the most is making decisions.
- Doctors are more likely to listen to someone holding an official piece of paper.

Limitations of Health Care Proxies

- Proxies frequently do not know patients' wishes.
- What proxies want on behalf of the patient may differ from what patient wants on behalf of him/herself.
- People struggle with being put in the role of making decisions for a loved one.

Summary: What Advance Directives Do

- Focuses on the individual patient and his/ her preferences.
- Focuses on surrogate decision making but does not involve the surrogate decision-maker.
- Focuses on treatment decisions.

- Is this what patients and their families need?

What do Patients and Caregivers (CGs) Need from ACP?

- Participants:
  - We started with 226 persons age ≥ 65 with advanced cancer, COPD, HF who participated in 2-year study examining their preferences for end-of-life care:
  - 125 died during the study period.
  - Of these 125, 104 had a caregiver enrolled as well.
  - Of 104 caregivers, 64 had a face-to-face post-death interview.
  - **64 caregivers with face-to-face post-death interviews**.

Fried, T.R. & O'Leary J.R. J Gen Intern Med. 2008;23:1602–7

Methods

- Open-ended interviews.
- Interviews audiotaped and transcribed.
- Transcripts reviewed by several investigators looking for common themes.
- Quantitative data obtained from interviews preceding the patient’s death.

Description of 64 Caregivers

Age (yr, mean ± SD)	61 ± 13
Female (%)	89
White (%)	95
Relationship to patient (%)	
Spouse	52
Child	24
Other	24

Description of 64 Patients

Age (yr, mean ± SD)	74 ± 7
White (%)	92
Diagnosis (%)	
Cancer	52
COPD	27
Heart Failure	21

Availability of Treatment Options and Effects on Decision-Making

- Traditional view: focus on treatments.
- Need to make intervention-based treatment decisions irrelevant for some patients:

  Dr. ____ had come in, and he came around and he said that he wasn't going to get any better. I knew that, but I think he had to hear that, and he asked us to decide what we wanted to do. If he wanted to go home with hospice or just what to do.

- In contrast, many CGs for patients with COPD and HF faced with specific treatment decisions:

  [The emergency room doctor] came out saying, "Do you want us to resuscitate her? If she doesn't stop with the seizures, do you want us to let her go?" I was shocked because I didn't know I had to come up with the answer right then.

- Little indication physicians knew patients' wishes.

Changes in Preferences at the End of Life

- Let’s take a little detour ….

- Think about the last time you went to the supermarket when you were hungry.
- What happened to the list you prepared in advance?

Changes in Healthcare Preferences

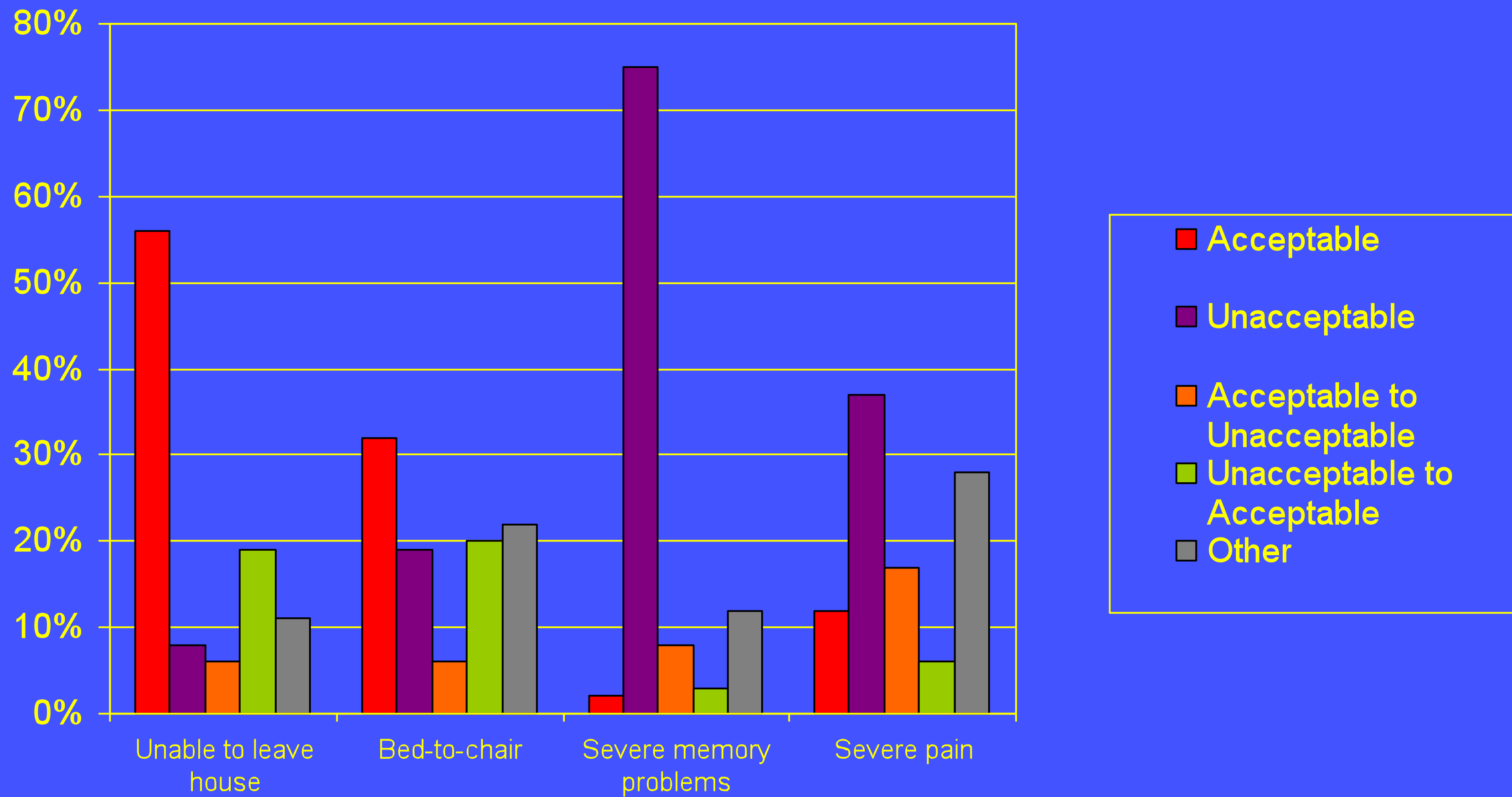
- People have a tremendous ability to adapt to declines in their health.
- What might seem unacceptable to someone looking down the road may become more acceptable the closer they get to that point.

Changes in Healthcare Preferences

- Serial interviews with the 226 older persons in the parent study to the one we are now looking at.
- Asked "would treatment be acceptable to you if it resulted in ____________ (an impaired state of health?"
- Interviewed at least every four months and more frequently if the person's own health declined.

Fried TR, et al. Arch Intern Med. 2006; 166:890-895

Changes in Healthcare Preferences



Changes in Preferences at the End-of-Life

- Traditional view: patients will want aggressive care at the end of life.
- Patients who had said they wanted aggressive treatment made a decision to forego therapy:

  By then the family arrived … and he said to the assembled family that he wanted to go home to die, and we kept asking him, "Are you sure that's what you want?" and he kept saying yes, that's what he wanted.

  I think she was tired. You know it was just a long grind, and she was just very tired, saying "I just don't want to do this any more."

Variability in Patient and Caregiver Desire for Prognostic Information

- Traditional view: patients and caregivers need prognostic information to do ACP.
- Many patients and caregivers are not ready/do not want to hear this information:
  - *I mean she had it for 4 years, and every doctor from the onset had told her this is not curable. The most we were looking at, after he got all the results back, he said 2 to 5 years, but my mother never heard that. She would come back from the doctors saying, "they are going to cure me, they will cure me.*
  - *If they told me, I don't know if it would have done any good because sometimes I had information overload. It would bounce off and I just couldn't absorb it. So, [the social worker] said to me that if I wanted to, I could ask the doctor how long she thought he had to live, but I didn't want to know that.*

Importance of Patient-Caregiver Communication

- Traditional view: focus on the patient alone
- Pt-CG communication a key component of EOL care:

(Interviewer: "He would say that he did not want to live this way?") Right, and of course I'd get annoyed at him. I'd say, "What are you talking about?" I kept trying to tell him he was going to be OK….See, what I didn't know was that he was praying to die, and I was praying that he would get better.

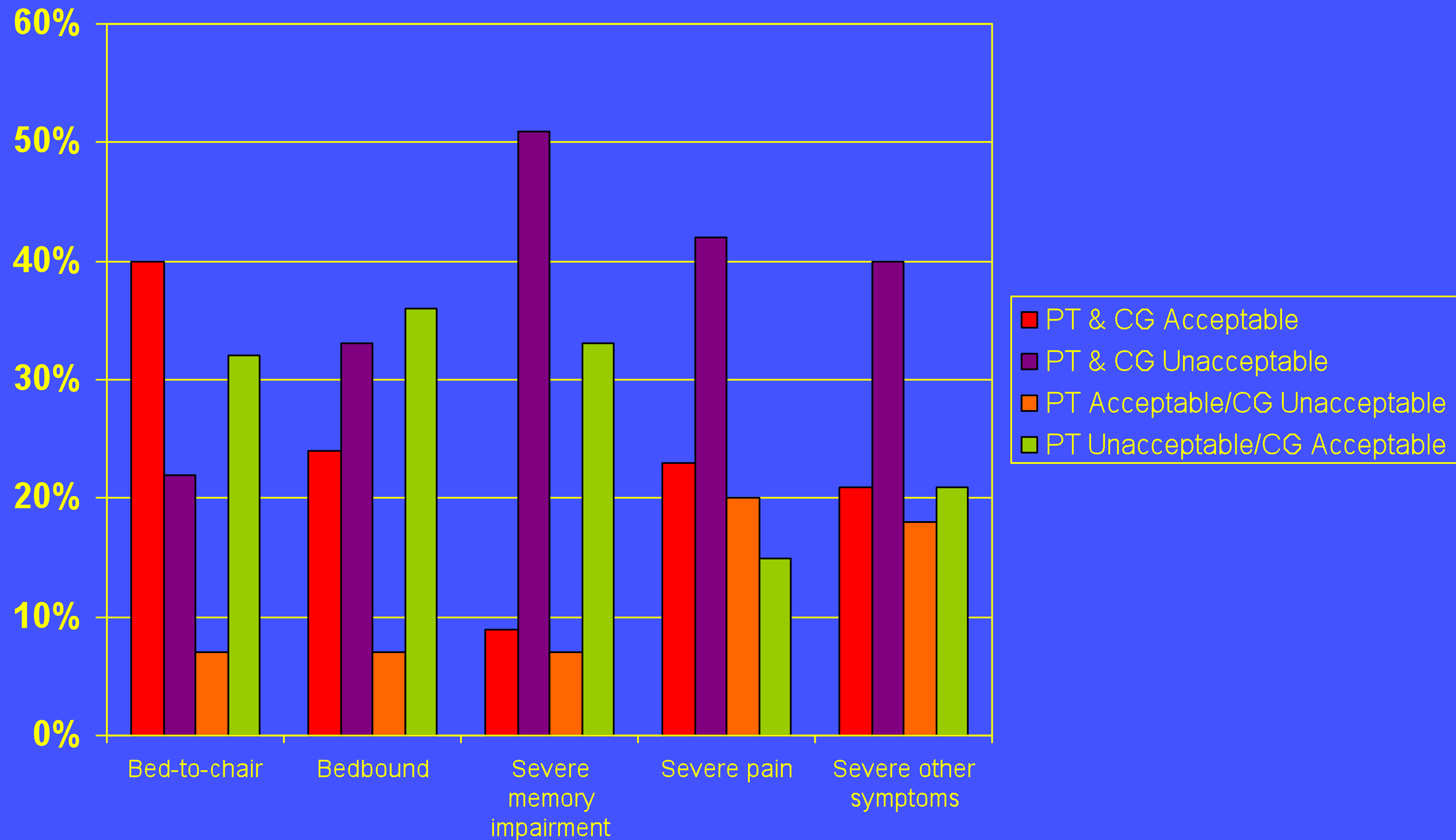
But what I didn't know until after he had died – 2 weeks before he died, he called my sister and told her he wasn't going to be around much longer. He knew he was going but he didn't want to tell me because I'd get mad at him….I just wanted him to fight, and he just wanted to tell her what he felt for me.

(CG of a patient who had reported he preferred to die in inpatient hospice): Well, there are only two things that stay in my mind constantly. The day we had to make the decision about hospice, that was the toughest day of my life.

I knew that she always did not want to have a respirator, but, because my sisters lived far away, she wanted them to know….So she left the burden off of me a little bit, saying, "This is what I want." And I felt good about that because the last couple days of her life it was so hard for me to communicate with them, knowing that this is what Mom wants and we have to give her wishes.

I was sitting by her side, and she said, "D., you've been good to me and I love you," and that was the last word she spoke to me. That was a gift.

PATIENT-FAMILY AGREEMENT REGARDING PREFERENCES



Fried TR, Bradley EH, Towle VR. Arch Intern Med. 2003;163:2073-2078.

A Patient and Caregiver-Centered View of ACP

- Patient-CG-clinician communication needs to be the cornerstone of ACP.
  - Challenge is how to do this when patients and caregivers may be at different stages of readiness.
- "Planning" needs to be for more than treatment alone; important component is giving caregivers permission and thinking about site of care.
- Rather than a focus on interventions, treatment decision-making can focus on notion of what might be "too much" – what are the outcomes that patients can't live with?

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  - The goal of ACP is to decrease the burden of decision making, for both patients and surrogates.
  - This goal depends upon facilitating communication among patients, caregivers, and clinicians.

A New Objective for ACP

- Current: making decisions consistent with the preferences of patients if they could speak for themselves.
  - Can't know preferences with certainty.
  - Ignores the caregiver.
- Proposed: making the best possible **in-the-moment** decision.
  - Based on all available information: clinical circumstances, caregiver understanding of patient preferences, caregiver needs and desires.

What is the New Objective for ACP Meant to Accomplish?

- Improve decisions not only when a surrogate is making them, but also when a patient is making them.
- Acknowledge the needs and desires of the surrogate.
- Decrease the burden on the surrogate decision maker.

ACP and Health Behavior Change

- Clinicians have believed that all you need to do to get people to engage in ACP is to give them information.
- But multiple studies have shown that giving information alone is not enough.
- Lots of reasons why people might not *want* to engage in ACP.
- Best to think about ACP like other difficult health behaviors: exercise, quitting smoking.

A Health Behavioral Approach to ACP

- Many health behavior models exist to try to explain why individuals participate or fail to participate in health promotion activities.
- Shared set of concepts:
  - People motivated by sense of susceptibility.
  - Barriers to and facilitators of behavior change.
  - Self-efficacy for behavior change.
  - Processes used to facilitate behavior change.

Stages of Behavior Change

- Precontemplation: not planning on changing behavior.
- Contemplation: thinking about changing behavior in the future.
- Preparation: planning on changing behavior soon.
- Action/Maintenance: having achieved the behavior change.
- The stages determine what specific activities a person ought to be doing.

Does the Health Behavior Model Fit ACP?

- Study of 63 older persons and 30 caregivers with experience as a surrogate decision-maker.
- Participants met in focus groups to discuss their experiences with ACP.

Fried, et al. J Am Geriatr Soc. 2009;57:1547-1555.

Description of 63 Older Persons

Characteristic	Value
Age, years, mean ± SD	76.2 ± 6.0
Female, %	68
Education, years, mean ± SD	13.0 ± 2.4
Race, %	
White	57
Black	37
Married, %	33
Lives alone, %	43
Number of chronic conditions, %	
1-3	33
≥ 4	67

Description of 30 Caregivers

Characteristic	Value
Age, years, mean ± SD	62.3 ± 11.7
Female, %	83
Education, years, mean ± SD	14.0 ± 2.1
Race, %	
White	90
Relationship to patient, %	
Spouse	53
Parent	27
Other	20
Daily contact with patient, (%)	90

Variable Readiness to Participate in ACP

You have to be ready. I don't know what makes you ready.

I'm going to tell you I don't want to talk about it. I don't want to discuss it. I don't want to hear that morbid talk.

After listening to you talk today, I think I will (participate in ACP). I got some good points just listening.

I have been thinking about it lately, that I need to get [a health care proxy]. I want it in black and white. I am going to take care of that.

Wide Range of Barriers

- Too difficult to think about dying.

  I don't want to think about [the end of life.] You know, it's "I'm going to live forever.

  It is just that [avoiding planning] goes with the feeling that you are going to go on forever.

- Inability to plan for the future.

  How can you plan when you don't know what is going to happen?

- Loved ones unable or unwilling to discuss ACP.

  I only have a daughter and …I couldn't talk to her anyway, because she would fall apart.

- No one available to be a surrogate decision maker.

  I would have to make the decision myself because I have no one.

Misconceptions and Religious Beliefs

- Putting things down in writing will result in premature withdrawal of care.

  I just didn't want somebody saying, "Hey, Charlie, pull the plug, this guy has signed this thing."

- Family/physician already knows what to do.

  I have no concern that somebody will make the right call.

- Future is in G-d's hands:

  I think it is in G-d's hands anyway because He sees what is best.

- Suffering is necessary.

  If G-d sees fit for me to suffer for some of my wrong deeds that I did, then that is in the Lord's hands.

Wide Range of Benefits

- Managing affairs while still able:

  I'm not getting any younger, and I wanted to be prepared and to get these things done now, while my head is still clear.

- Ensuring that wishes are met..

  Well, there are certain things I would like done or not done, so it's all there in the living will.

- Decreasing burden on loved ones.

  I don't think that it is fair to put the burden on anyone else anyway if you can avoid it. If the family or whoever knows what you want, then they say, "Well, this is the way it will be.".

- Keeping peace within the family.

  I have seen families where there were children, and it was always a lot of confusion and hard feelings about what the parent wanted, and it wasn't written down or anything. The children have broken up behind this kind of thing.

Wide Range of Processes

- Cognitive/Emotional
  - Thinking about recommendations made by physicians/loved ones.
  - Thinking about support available from loved ones.
  - Reflecting on experiences of others.
  - Reflecting on positive consequences.

- Behavioral:
  - Seeking out information regarding ACP.
  - Assessing loved ones’ readiness to communicate.
  - Individualizing communication with loved ones.

Precontemplation

- Think about why you might want to engage in ACP.
  - Helping loved ones? Keeping the peace? Exerting control?
- Think about how you can get support to do something that is hard.
- Convince yourself that this will help to improve the care you/your loved one receives.

Contemplation

- Continue to think about the positive aspects of ACP.
- Reflect on experiences of loved ones, and what helped to make things better or harder at the end of life.
- Gather materials you will need.
- Consider how to engage your loved ones.

Steps Needed To Prepare For In-the-Moment Decision Making

STEPS	SPECIFIC TASKS
Step 1: Choosing an Appropriate Surrogate	• Choosing an appropriate surrogate and accepting the role • Coming to a shared understanding about how much prognostic information patients and surrogates want to know
Step 2: Preparing for Informed Decision-Making (DM)	• Learning how to collect relevant information • Learning how to evaluate patients' evolving values

Gathering Relevant Information and Understanding Values

- What will happen to me if I undergo this treatment?
- What will happen to me if I *don't* undergo this treatment?
- What will this mean for my quality of life? My functioning?
- Do I still have the "fight?"
- Is the treatment risking too much?

Step 3: Coming to a Shared Understanding About the DM Process	• Coming to a shared understanding about what patients deem most important for surrogates to consider during surrogate decision-making
Step 4: Communicating with All Interested Parties	• Opening lines of communication with all interested parties to prevent conflict

A Shared Understanding of Decision-Making

- How do I want my surrogate to make decisions?
  - Do I want her to do what lowers her burden?
  - Are there things that are so important to me I want her to try to do no matter what?
  - Do I need to give her permission not to do them under certain circumstances?

Communicating with All Interested Parties

- Entire family/others need to meet to understand process of decision-making.
- Physician needs:
  - Understanding of decision-making process.
  - Understanding of patients' concerns.
  - Knowledge of patients' attitudes toward information.
  - Copies of all written documents.