Definition of ACP

- More than advance directives
- More than assignment of a medical POA
- More than MOST forms

ACP is preparing patients and family to participate with clinicians in making the best possible in-the-moment medical decisions

Sudore, RL and Fried TR. Ann Intern Med 2010

Definition of ACP

- Values clarification
  - Attitudes toward life-sustaining treatment
  - Trade-offs between quality and quantity of life
- Communication
  - Between patients and decision-makers
  - Between patients and clinicians
- Completion of Advance Directives (AD)
  - Living will
  - Medical power of attorney
  - CPR directive/MOST forms

Fried TR et al. JAGS 2010
Objectives

• Contemporary Trends in Advance Care Planning (ACP) among Older Adults
• ACP Process as Behavior Change
• A novel ACP Group Visit Model

Methods

• Design: Observational cohort study of the Health and Retirement Study and linked Medicare data
• Setting: National survey
• Participants: 4394 decedents (1993 – 2007)
  Mean age 82.6 at death, 55% women

1. Does ACP increase quality of care at end-of-life?

Advance Care Planning and the Quality of End-of-Life Care in Older Adults


Funding: National Center for Research Resources and the Greenwall Foundation

Methods

• Predictors - From proxy interviews:
  – Advance directive
  – Medical power of attorney
  – Discussion of EOL care preferences with next of kin
• Outcomes:
  – Hospital admission in last month of life
  – In-hospital death
  – >14 d in the hospital
  – ICU admission
  – >1 ED visit in last month
  – Hospice admission
  – Length of hospice ≤ 3 days
Prevalence of ACP

- 76% had engaged in ACP
- None, 24%
- AD only, 3%
- POA only, 9%
- AD + POA, 9%
- AD + discussion, 6%
- POA + discussion, 9%
- Discussion only, 14%
- All ACP parts, 26%

ACP is associated with quality EOL care

Any ACP:
- Reduced in-hospital deaths
- Increased hospice use, and early hospice admission

Key Findings

- AD completed about 5 years (61 months) before death
- AD associated with 69% less risk of long hospitalization
- ACP did not impact rate of EOL hospitalization in the last month of life

Clinical Bottom Line

1. Does ACP increase quality of care at EOL?

In this national, population-based survey of broad ACP actions in older adults:

76% of older adults engaged in ACP, which was associated with fewer in-hospital deaths and more hospice use at EOL.
2. How often are decision-makers needed at end-of-life?

**Advance Directives and Outcomes of Surrogate Decision Making before Death**

Silveira, MJ, Kim, SYH, Langa, KM.

Funding: VA, University of Michican, NIA, and the Greenwall Foundation

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**Methods**

- Design: Observational cohort study of the Health and Retirement Study, age >60
- Setting: National survey, represent 12 million U.S. deaths
- Participants: 3746 decedents (2000-2006)
  Mean age 80.5 at death, 53% women

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**Methods**

- Predictors – From proxy interviews:
  - Advance directive or medical power of attorney
  - Have an EOL decision to make?
  - Have capacity to make that decision or used a surrogate?
- Outcomes – From proxy interviews:
  - All care possible
  - Limited care - “Limited care in certain situations”
  - Comfort care - “Comfortable and pain-free while forgoing extensive measures to prolong life”

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**Results: Circumstances of Death**
Results: Decision Making

Of 100 people:
43 of 100 people who died had an EOL decision to make
30 of 100 had a decision, and used a surrogate
10 of 100 had a decision, used a surrogate, and did not have an AD or POA
43% made an EOL decision
70% lacked capacity
34% No AD/POA
46% Had AD
61% Had POA

Key Findings

• Goal-concordant care associated with AD:
  • 83% who wanted limited care received it
  • 97% who wanted comfort care received it

Clinical Bottom Line

2. How often are decision-makers needed at end-of-life?

In this national, population-based survey of the need for decision-makers in older adults:

About 30% of older adults will need a surrogate to help make a decision at the end of life.
3. What is end-of-life care for Medicare beneficiaries?

Teno JM, Gozalo PL, Bynum JP, Leland NE, Miller SC, Morden NE, Scupp T, Goodman DC, Mor V.


Funding: NIA and Robert Wood Johnson Foundation

Methods

• Design: Retrospective study of 20% of Medicare beneficiaries
• Participants:
  – 270K (died in 2000); 292K (died in 2005); 286K (died in 2009)
  – Mean age 82.3 at death, 58% women
• Main Outcomes:
  – Site of death
  – Place of care (Acute hospital; ICU use; hospice use)
  – Burdensome transitions (within last 3 days of life)

Key Results

Clinical Bottom Line

3. What is end-of-life care for Medicare beneficiaries?
Of older Medicare beneficiaries,
More individuals are dying at home, but aggressive EOL has increased, including
• ICU utilization
• Overall healthcare transitions
• Late transitions in the last 3 days of life
Summary: ACP for the Elderly

- High-quality ACP requires moving beyond Advance Directives
- How can we prepare older adults and their families for complex medical decisions in the setting of multiple illnesses, especially in primary care?

Objectives

- Contemporary Trends in ACP among Older Adults
- ACP Process as Behavior Change
- A novel ACP Group Visit Model

Main objective of ACP:
Prepare patients/surrogates for best possible in-the-moment decisions
- Help patients identify and articulate values to guide decisions
- Requires behavior change and multiple steps

Multiple Steps of ACP Process

<table>
<thead>
<tr>
<th>Key Domains</th>
<th>Decision Makers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Life</td>
<td>Flexibility for Surrogates</td>
</tr>
<tr>
<td>Ask Doctors Questions</td>
<td></td>
</tr>
</tbody>
</table>

ACP as a Health Behavior Change

Model of ACP Engagement

What are Patient Barriers to Engaging in ACP?

Objectives

- Contemporary Trends in Advance Care Planning (ACP) among Older Adults
- ACP Process as Behavior Change
- A novel ACP Group Visit Model

Fried et al. JAGS 2009. 57:1547-1555.
Building on CU expertise...

Science of ACP Group Visit Model

- **Purpose:**
  Develop an ACP Group Visit Model to engage patients in the ACP process via behavior change

- **Theory:**
  Group dynamic impacts attitudes, norms, and behavior control to influence behavior intentions (Stages of Change), leading to ACP actions

Conversation Group Medical Visits

- Two-session group
- One month apart
- Patients 65 years and up
- Groups of 8-10 patients
- Referred by PCPs
- Co-facilitated by MD and LCSW

4 clinics
5 groups in each clinic:
- Seniors (Primary Care grant)
- Anschutz Internal Medicine
- Lowry Internal Medicine
- A.F. Williams Family Medicine

Pilot: ACP Group Medical Visit

- **Core components of the facilitated discussion:**
  - Rapport building
  - Participants share personal experiences, concerns and opinions, ask questions
  - Facilitators guide the discussion of ACP knowledge
    - Identifying values/preferences
    - Choosing a surrogate decision maker
    - Common medical options
  - Peer learning
ACP Group Visit Structure

Session A
- Introductions
- Video
- ACP Discussion
  - Values
  - Decision Maker

Session B
- Follow up
  - Decision Maker flexibility
  - Talking with PCP
- ACP Discussion
  - Common Medical Options

2 hour visit includes: Check in by medical assistant, medical update form, group discussion, evaluations and After Visit Summary.
Optional: Individual 10 minute provider visit

ACP Tool: The Conversation Project

ACP Group Visit Evaluation

Session A
- Evaluations
- Phone Interview

Session B
- Evaluations
- Phone Interview
- 1 month
- 3 Month
- 6 Month
- 1 Year

1 month

Pilot Project Goals

- Assess patient-centered ACP outcomes
  - How the group impacts ACP
- Determine ACP actions at 3 months:
  - Contemplation of preferences
  - Communication w/ decision maker or PCP
  - Completion of Advance Directives, including POA
- Review PCP documentation in EPIC
- Evaluate clinic and UCH feasibility
- Implement in 4 UCH primary care clinics
Recruitment

73 Referrals
- Group 1: 8
- Group 2: 4
- Group 3: 8
- Group 4: 4
- 11 Pending
- 10 No shows

45 Scheduled
- 22 Declined

Participant Characteristics (N=24)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (range)</td>
<td>77 (70-88)</td>
</tr>
<tr>
<td>Female</td>
<td>14 (58%)</td>
</tr>
<tr>
<td>White</td>
<td>19 (79%)</td>
</tr>
<tr>
<td>Attended as a couple</td>
<td>6 (25%)</td>
</tr>
<tr>
<td>Relationship Status</td>
<td></td>
</tr>
<tr>
<td>Married/Partnered</td>
<td>10 (42%)</td>
</tr>
<tr>
<td>Widowed</td>
<td>7 (29%)</td>
</tr>
<tr>
<td>Referred by Provider</td>
<td>18 (75%)</td>
</tr>
</tbody>
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Pilot: Why Did You Come?

I just came because my children thought maybe I should get some help!

My doctor suggested I try this. I didn’t know anything about it, but there are so many

classes about this. It started to interest me.

I haven’t talked about it, and that is the reason that I wanted to take this class... I

needed some way to introduce the conversation to my husband who was in
denial.

Pilot: Addresses Barriers to ACP

<table>
<thead>
<tr>
<th>Fried, 2009</th>
<th>Group Participant Quote:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Too hard to think about dying</td>
<td>&quot;Talking about it in the group like this, it makes you feel a lot more comfortable thinking about it.&quot;</td>
</tr>
<tr>
<td>Lack of knowledge</td>
<td>&quot;I’m a little more sure now what I want and so by having this discussion group, it solved a lot of my concerns, a lot of my wondering about different things. I just feel more confident in what I want now.&quot;</td>
</tr>
<tr>
<td>Inability to plan for the future</td>
<td>&quot;I’ve taught the 5 Wishes in churches and I still haven’t filled in my form. I’m one of those that talk about it a lot but don’t do it.&quot;</td>
</tr>
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</table>
Pilot: Addresses Barriers to ACP

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<tr>
<td>Loved ones are unwilling to discuss</td>
<td>“I’ve had that experience with trying to have the conversation at the kitchen table and the next thing I know, everyone is getting up to wash the dishes or fine-tuning the TV. And I was like, Oh, lost them!”</td>
</tr>
<tr>
<td>Not planning because “family knows what to do”</td>
<td>“That’s why you have to know, first of all, what you want.”</td>
</tr>
</tbody>
</table>

Pilot: Supports ACP Behavior Change

Fried, 2009

Group Participant Quote:

Physician will make decisions

“I want to have a say in every decision, if I am competent to do that.”

No medical choices to make

“In terms of types of care that I am interested in, I would like to have medical input because I don’t know about ... the considerations about whether or not you want to be on life support and how that can influence the quality of your life.”

No surrogate available

“If your family can’t, just simply can’t engage in that conversation, maybe you could do the one side of the conversation in writing for them.”


Pre-Contemplation

Contemplation

Preparation

Action

Maintenance

“I’m here primarily concerning the notifications of people in case of any type of emergency.”

“How do you get there though? You may have all these preconceived ideas about I just want to go when I’m ready, and then at the last minute, it is sort of like, hmmm…”

“At this point, it seems like the next step is really on me, on us.”

Pre-Contemplation

Contemplation

Preparation

Action

Maintenance

“Advance Directives are not something that are done once in your lifetime and you are done with that. Your health changes. Your circumstances. You age. They don’t have to be something that is done only once.”

Pilot: Group Promotes Benefits of ACP

“Well, the different experiences that each one expressed. They expressed their experiences and it put me at ease to realize that there are people out there who have the same thoughts as I do, and they are in the same situations that I am in where their loved ones cannot bear talking about the subject. ... It gave me more encouragement to find a way to encourage my loved ones to listen to what I have to say.”

Pilot: Group Promotes Benefits of ACP

“I thought, this is something that I’ve spent time thinking about, trying to discuss with my kids. ... They seem to have a problem with me talking about it... I would be interested in any suggestions that could help me with that because I want to have as many decisions made and things in place before I become disabled or before I die so that they are not left with so many questions and hard things to deal with.”

Pilot: Triggers PCP Discussions

- From a PCP note:
  “We talked about AD and her recent participation in the Conversation Group. She did find it very helpful. She is leaning towards being full COR with initial efforts, but makes it very clear that she would not wish to be left on life-support or have long-term feeding tubes if she is not going to return to as close as she is currently in terms of overall quality of life and wellness level.”
- Plans to meet with an attorney for a living will
- Plans to appoint her son as the medical durable power of attorney

Discussion

- What are your thoughts on this Advance Care Planning Group Visit Model?
Challenges to the ACP Group

• High risk, high reward?
• Recruitment and last minute cancellations?
• Responsiveness to participant needs?
• Meeting a variety of participant expectations?
• Cognitive impairment?

Summary

• ACP for older adults is more than POA, AD, CPR vs DNR, MOST forms
• Quality ACP involves a process with multiple steps and behavior change
• ACP Group Visits are Complex, Diverse, Desired and Appreciated

Thank you!

The Conversation Project is a national conversation with the modern U.S. family about what each of us wants toward the end of our years.

The Conversation is about preparing family members for an emotional journey beyond end-of-life directives and insurance policies. It’s estate planning for the soul.