

# Thinking Differently about Advance Care Planning

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1. no solid evidence to support advance care planning
2. reasonable people might conclude that this is due to:
  - a. flawed concept
  - b. flawed implementation
  - c. flawed evaluation

# Toward Evidence-Based End-of-Life Care

Scott D. Halpern, M.D., Ph.D.

N ENGL J MED 373;21 NEJM.ORG NOVEMBER 19, 2015

Original Investigation | Health Policy

## Advance Care Planning Claims and Health Care Utilization Among Seriously Ill Patients Near the End of Life

*JAMA Network Open.* 2019;2(11):e1914471.

Deepshikha Charan Ashana, MD, MBA; Xiaoxue Chen, MPH; Abiy Agiro, PhD; Gayathri Sridhar, MBBS, MPH, PhD; Ann Nguyen, PharmD; John Barron, PharmD; Kevin Haynes, PharmD; Michael Fisch, MD; David Debono, MD; Scott D. Halpern, MD, PhD; Michael O. Harhay, PhD

Original Investigation | Critical Care Medicine

## Effect of Default Options in Advance Directives on Hospital-Free Days and Care Choices Among Seriously Ill Patients A Randomized Clinical Trial

*JAMA Network Open.* 2020;3(3):e201742.

Scott D. Halpern, MD, PhD; Dylan S. Small, PhD; Andrea B. Troxel, ScD; Elizabeth Cooney, MPH; Brian Bayes, MS; Marzana Chowdhury, PhD; Heather E. Tomko, BS; Derek C. Angus, MD, MPH; Robert M. Arnold, MD; George Loewenstein, PhD; Kevin G. Volpp, MD, PhD; Douglas B. White, MD, MAS; Cindy L. Bryce, PhD

# How ACP implementation/evaluation have been flawed

1. **Focusing** on treatments rather than goals and health states
2. **Targeting** patients too broadly (Goldilocks problem)
3. **Measuring** success with wrong outcomes
4. **Failing to consider** other processes, structures, and reimbursement models for supportive care that must be in place to prevent rushing to hospital in emergency

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# Intuitive vs Deliberative Approaches to Making Decisions About Life Support

## A Randomized Clinical Trial

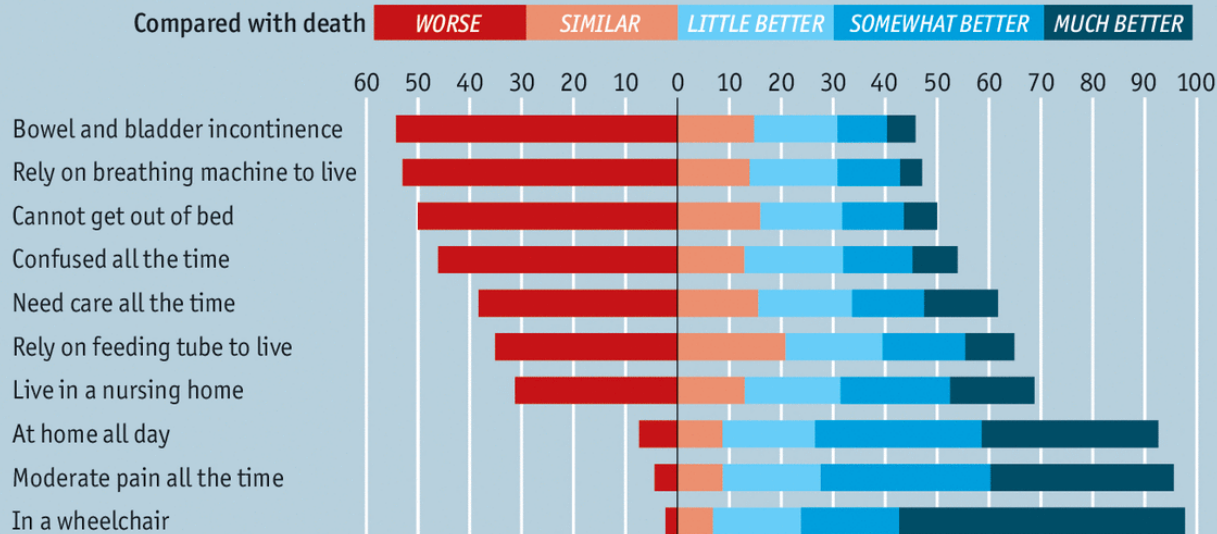
Emily B. Rubin, MD, JD; Anna E. Buehler, BA; Elizabeth Cooney, MPH; Nicole B. Gabler, PhD; Adjoa A. Mante, BA; Scott D. Halpern, MD, PhD

- Deliberating about life-support interventions did not change treatment acceptance rates compared with those arrived at intuitively
- Deliberation caused more patients to choose treatments that would result in health states they rated as similar to or worse than death

# Seriously ill patients identify many health states as being equal to or worse than death

## Where is thy sting?

Ratings of states of functional debility relative to death by patients in hospital with serious illnesses\*, %



Source: JAMA Internal Medicine

\*Survey conducted July 1st 2015 to March 7th 2016, Philadelphia, United States

Economist.com

# Semi-structured interviews with 30 seriously ill patients

Seriously ill patients can spontaneously identify health states worse than death

Patients consistently articulate 4 reasons WHY health states are worse than death

## Physical Function

Immobility  
Dependence on machines  
Constant pain  
Inability to bathe, toilet, eat

## Cognitive Function

Inability to recognize family members  
Inability to reason, to “think my thoughts”  
Inability to participate in decision making  
Inability to understand what’s happening

Burden on  
Others

Loss of Identity

Loss of Control

Inability to  
Connect



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# Not sick enough – affective forecasting

## Original Investigation

### Stability of End-of-Life Preferences A Systematic Review of the Evidence

Catherine L. Auriemma, MD; Christina A. Nguyen; Rachel Bronheim; Saida Kent, BS;  
Shrivatsa Nadiger, MD; Dustin Pardo, MD; Scott D. Halpern, MD, PhD

JAMA Internal Medicine Published online May 26, 2014

Figure 2. Percentage of Patients With Stable Preferences by Severity of Illness

#### Source

##### Older adults

Barrio-Cantalejo et al,<sup>12</sup> 2013

Carmel and Mutran,<sup>24</sup> 1999

Danis et al,<sup>32</sup> 1994

Weighted average

##### Outpatients

Janssen et al,<sup>13</sup> 2012

McKim et al,<sup>14</sup> 2012

Pruchno et al,<sup>16</sup> 2008

Golin et al,<sup>20</sup> 2000

Dales et al,<sup>23</sup> 1999

Weissman et al,<sup>22</sup> 1999

Weighted average

##### Inpatients

Eggar et al,<sup>19</sup> 2002

Krumholz et al,<sup>25</sup> 1998

Watson et al,<sup>26</sup> 1997

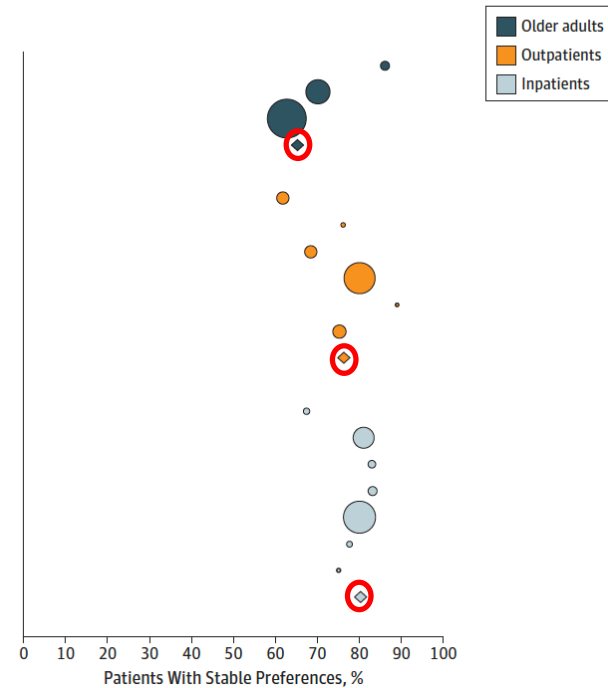
Bruce-Jones et al,<sup>28</sup> 1996

Rosenfeld et al,<sup>29</sup> 1996

Ganzini et al,<sup>31</sup> 1994

Everhart and Pearlman,<sup>33</sup> 1990

Weighted average



# Too sick – exclusion & outcome truncation

## The impact of advance care planning on end of life care in elderly patients: randomised controlled trial

BMJ 2010;340:c1345

Karen M Detering, respiratory physician and clinical leader,<sup>1</sup> Andrew D Hancock, project officer,<sup>1</sup> Michael C Reade, physician,<sup>2</sup> William Silvester, intensive care physician and director<sup>1</sup>

Like SUPPORT, recruited older inpatients who had survived until and were competent on 3<sup>rd</sup> hospital day → most excluded

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# Outcomes That Define Successful Advance Care Planning: A Delphi Panel Consensus



Rebecca L. Sudore, MD, Daren K. Heyland, MD, MS, Hillary D. Lum, MD, PhD, Judith A.C. Rietjens, PhD, Ida J. Korfage, MSc, PhD, Christine S. Ritchie, MD, MSPH, Laura C. Hanson, MD, MPH, Diane E. Meier, MD, FACP, Steven Z. Pantilat, MD, Karl Lorenz, MD, MSHS, Michelle Howard, PhD, Michael J. Green, MD, Jessica E. Simon, FRCPC, Mariko A. Feuz, BS, and John J. You, MD, MSc

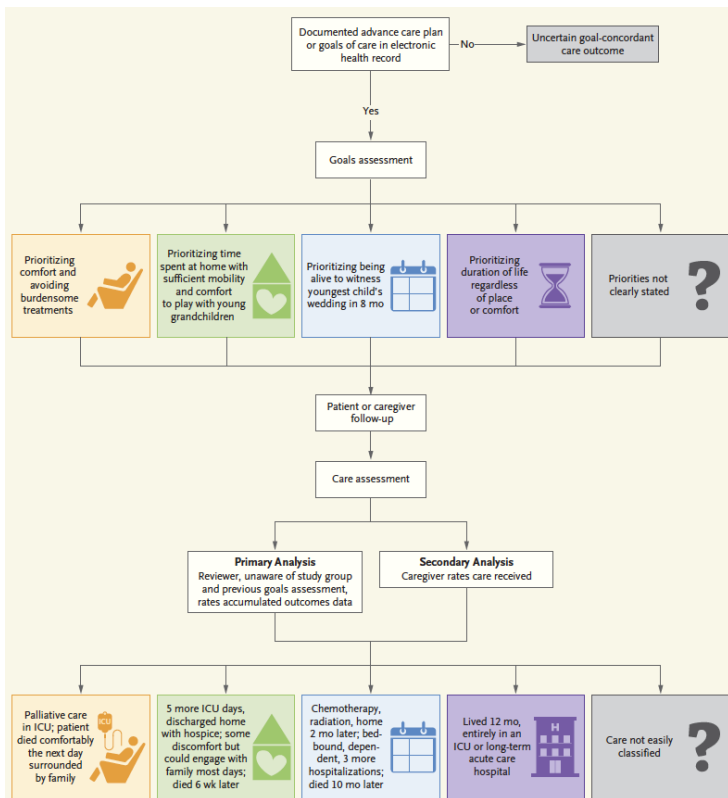
## Top 10 Advance Care Planning Patient-Centered Outcome Constructs Rated by Advance Care Planning Delphi Panel Experts

Outcome Constructs <sup>a</sup>	Domain <sup>b</sup>	Overall Ranking	Mean Rating (SD)
<u>Care received is consistent with goals</u>	Quality of care	1	6.71 (0.04)
Patient decides on a surrogate	Action	2	6.55 (0.45)
Document the surrogate decision maker	Action	3	6.50 (0.11)
Discuss values and care preferences with the surrogate	Action	4	6.40 (0.19)
Documents and recorded wishes accessible when needed	Action	5	6.27 (0.11)
Identify what brings value to patient's life	Action	6	6.20 (0.12)
Medical record contains physician treatment orders (e.g., POLST, code status) when it is clinically appropriate	Action	7	6.13 (0.17)
Discuss values and care preferences with clinicians	Action	8	6.08 (0.24)
Document values and care preferences	Action	9	6.02 (0.25)
Medical record contains advance directive or documentation patient refused	Action	10	6.01 (0.21)

# Goal-Concordant Care — Searching for the Holy Grail

Scott D. Halpern, M.D., Ph.D.

N ENGL J MED 381;17 NEJM.ORG OCTOBER 24, 2019



*Pilot study among 1,010 sepsis survivors*

Goal

Comfort (n=84)

Function (n=229)

Longevity (n=109)

Undoc/Undeterm (n=588)

Care received

Comfort

Function

Longevity

Undetermined

Goal-concordance: 34% (81% when goal identified)

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# Factorial thinking (and study design!)

	High fee-for-service penetration	High value-based payment penetration
Not motivating good ACP	<b>Worst</b>	<b>2nd or 3rd</b>
Motivating good ACP	<b>2nd or 3rd</b>	<b>Best</b>



# Take-home messages

- ✓ New ways to help patients articulate goals are emerging, as are methods to measure the concordance of care with these goals
- ✓ The (potential) benefits of (even ideal) ACP may not manifest in a vacuum; need residential monitoring and response systems
- ✓ Don't throw the baby out with the bathwater (yet)!