

The Complexities of Advance Care Planning:

What Are We Even Talking About?

Rebecca Sudore, MD

Professor of Medicine, Division of Geriatrics, UCSF

Director, Vulnerable Aging Research Core of the NIA-funded Pepper Center

Director, Innovation & Implementation Center of Aging & Palliative Care Research

rebecca.sudore@ucsf.edu

[@prepareforcare](#)



University of California, San Francisco
Division of Geriatrics



Objectives



- What is ACP? → It's complex
- Why do ACP?
- What is known and yet unknown?

Consensus Definition of ACP

- **OLD Definition:** Treatment decisions (e.g., CPR)
- However...
 - Issues related to prediction, adaptation, extrapolation ~ context
 - What matters most is the **outcome of treatment**
- **NEW Definition:** “ACP is a **process** that supports adults at any age or stage of health in understanding and sharing their personal **values**, life goals, and preferences regarding **future** medical care.”

...more complex

Sudore et al., Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. J Pain Symptom Manage. 2017 May;53(5):821-832

Fried TR, et. al., N Engl J Med. 2002; Quill TE. JAMA. 2000; McMahan. J of Pain & Symptom Manage. 2013; Lockhart LK, et. al., Death Stud. 2001, Pearlman RA, et. al., Arch Intern Med. 2005; Halpern J, et. al., J Gen Intern Med. 2008; Loewenstein G. Med Decis Making. 2005; Ubel PA. Med Decis Making. 2005; Fried TR, et. al., Arch Intern Med. 2006; Gillick MR. N Engl J Med. 2004; Perkins HS. Ann Intern Med. 2007; Ubel PA, et. al., Health Psychol. 2005; Fried et. al., Arch Intern Med. 2006; Winter L, et. al., Int J Aging Hum Dev. 2003

Complexity: Readiness & Life Course



Readiness to Engage



First Steps

Next Steps

**Advanced
Steps**

Life Course

Complexity: Context, Setting

Advance Care Planning

- Conversations about values, wishes & preferences
- Appointment of a Substitute Decision Maker
- Development of Advance Care Plans and Instructional directive (where applicable)

Documentation

- Advance care planning documents
- Goals of care documents (MOST, POLST, other level of care forms, etc.)
- Care Plans

Decisions about Goals of Care or consent* for treatment

- Clarification of previous ACP conversations; values; preferences
- Information re Diagnosis; Prognosis; Risks/benefits of treatment
- Options for care & treatment

Organizational and System Aspects (context specific)

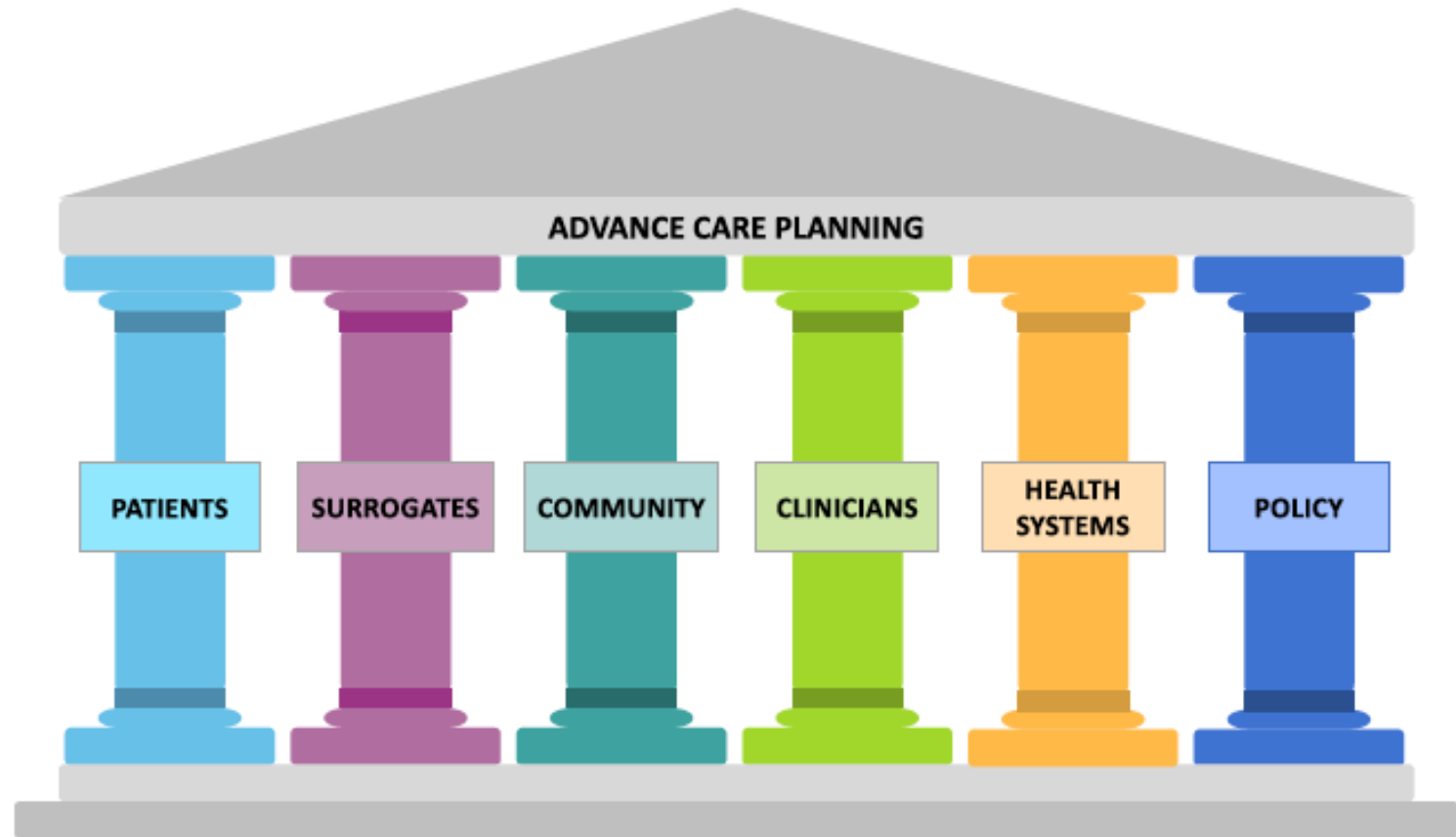
Home or Community Settings



Institutionalized Settings

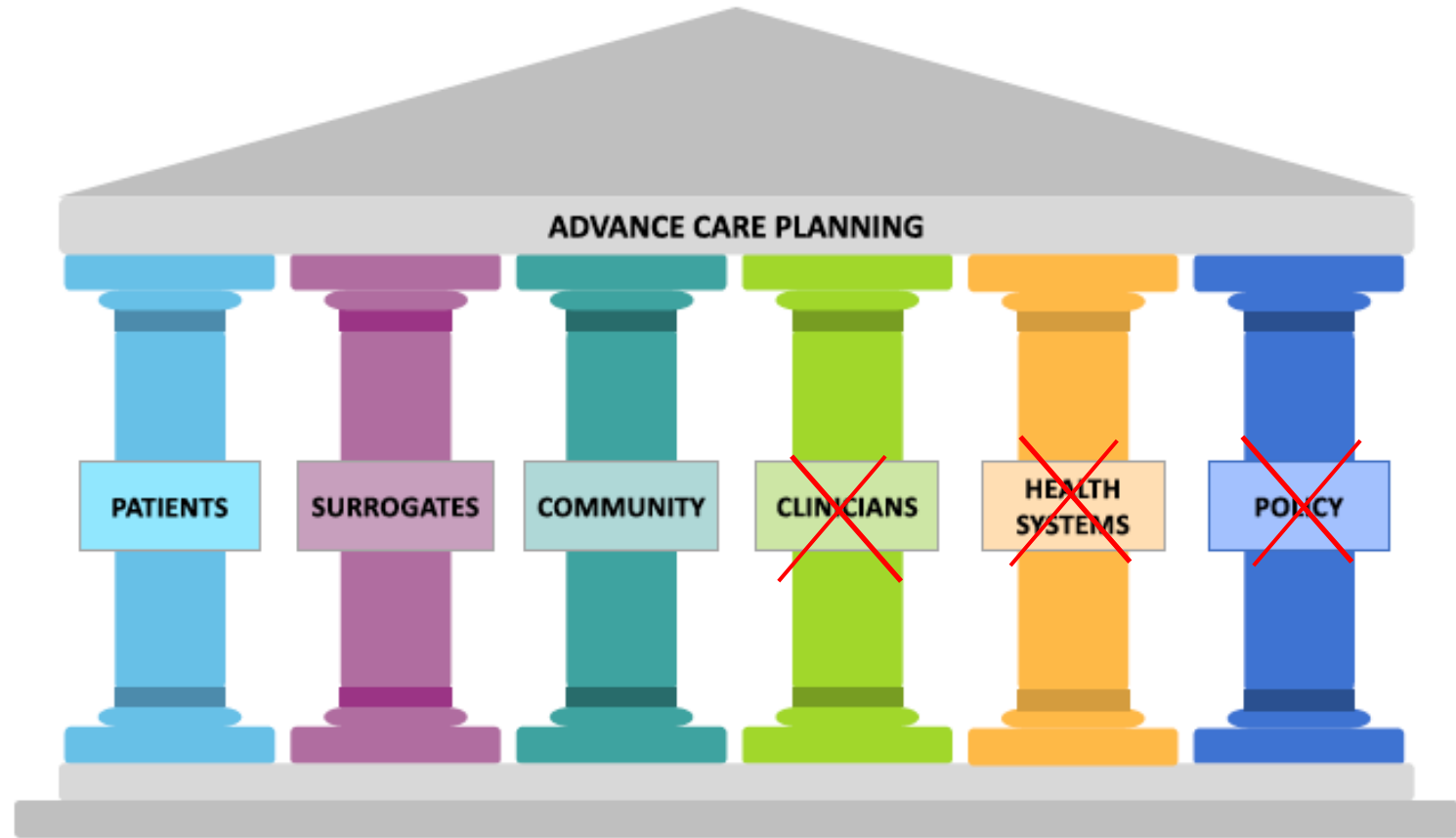
Complex Interplay of Many Stakeholders

...yet no one "owns" ACP



McMahan, Tellez, Sudore: Deconstructing the Complexities of ACP Outcomes: What Do We Know and Where Do We Go? A Scoping Review, *J Am Geriatr Soc.* Sept. 2020

Complexity of Injustice and Disparities



McMahan, Tellez, Sudore: Deconstructing the Complexities of ACP Outcomes: What Do We Know and Where Do We Go? A Scoping Review, *J Am Geriatr Soc.* Sept. 2020

Why Do ACP?

- **Patients, Surrogates, Clinicians want ACP**
 - Especially if they have experience making serious medical decisions



McMahan, Sudore et al.
J Am Geriatr Soc. 2020 Sep 7

Why Prepare Patients & Surrogates?

- Clinicians cannot make recs or guide in decision making w/o patients' values and needs.
 - Highly individual
 - Can ONLY be provided by patient/surrogate
- Without **preparation**, patients and surrogates not able to communicate values effectively
 - Stress & no prior relationship with clinicians



Redefining the “Planning” in Advance Care Planning: Preparing for End-of-Life Decision Making

Rebecca L. Sudore, MD, and Terri R. Fried, MD



Life
sustaining
treatments



Preparation for
communication &
decision making

Sudore RL, et al. Redefining the Planning in ACP. *Ann Intern Med.* 2010 Aug 17;153(4):256-61

Sudore RL, et al. Engaging Diverse English- and Spanish-Speaking Older Adults in ACP: The PREPARE Trial. *JAMA Intern Med.* 2018 Dec 1;178(12):1616-1625

What is Known? ACP is Wanted

- Patients want to talk to clinicians about ACP
- Expect providers to initiate ACP
- Patients view as way to prepare surrogates, decrease burden
- Clinicians view as an important part of job to help patients and families prepare for decision-making.

McMahan, Sudore et al. *J Am Geriatr Soc.* 2020 Sep 7;

What is Known? Mixed Results

What are the right outcomes?
-AD, QOL, GCC?
What is reasonable to expect of ACP?

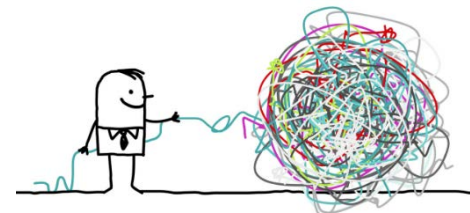
- In *some* studies...improves:
 - AD completion
 - Patient satisfaction w/ care, QOL
 - Goal concordant care (GCC)
 - Surrogate-clinician communication
 - **Decreased stress for the surrogate decision maker**
- Mixed results in review of 80 systematic reviews (observational, qualitative, feasibility and pilot RCTs)
 - Studies and reviews were deemed of low quality



Detering KM et al. *BMJ*. 2010; Silveira MJ, et al. *N Engl J Med*. 2010;362(13):1211-1218; Houben CH, et al. *J Am Med Dir Assoc*. 2014; Bischoff et al. *J Am Geriatr Soc*. 2013; Bond WF, et al. *J Palliat Med*. 2018; Teno MJ et al. *JAGS* 2007

Jimenez G, Tan WS, Virk AK, Low CK, Car J, Ho AHY. Overview of systematic reviews of advance care planning: summary of evidence and global lessons. *J Pain Symptom Manage*. 2018;56(3):436-459.e25

Sudore RL, Heyland DK, et al. Outcomes that Define Successful ACP. *J Pain Symptom Manage*. 2018 Feb;55(2):245-255

Deconstructing the Complexities of Advance Care Planning Outcomes: What Do We Know and Where Do We Go? A Scoping Review

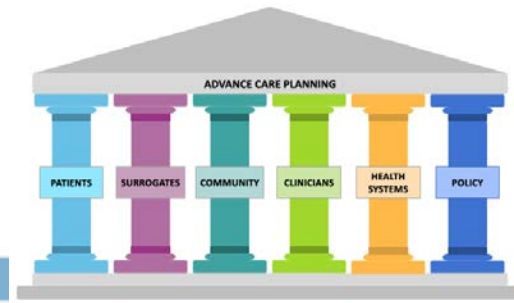


Ryan D. McMahan, MD, MAS, *[†]   Ismael Tellez, BA, *[†] and Rebecca L. Sudore, MD *[†]

- Scoping Review of 69 high quality ACP RCTs from 2010-20, none in prior reviews
- Primary outcomes for all interventions predominantly positive
- Mixed results:
 - Health Status (QOL) and Quality of Care (GCC)
- Consistently positive results:
 - Incr. pt/surrogate satisfaction w/ communication & care
 - Decreased surrogate & clinician distress

What is Yet Unknown?

More Research is Needed



- ACP is complex and can be many different things
 - When we say ACP, what do we mean?
 - Do we need new definition(s) by context, timing, stakeholders
- ACP is but one piece in a broken healthcare system
 - What outcomes are reasonable to expect?
 - AD? Is QOL & goal concordant care realistic?
 - Should we focus on **pt/surrogate preparation & surrogate outcomes?**
- ACP is not “owned” by one specialty/program
 - Challenge and an opportunity ~ normalize
- Should programs take a broader, holistic approach?
 - Implementation science: stakeholders, context, culture, workflows

