



# ADVANCE CARE PLANNING: HOW DO WE MAKE SENSE OF THE EVIDENCE?





#### THE PROBLEM



Original Article

Admission of the very elderly to the intensive care unit: Family members' perspectives on clinical decision-making from a multicenter cohort study

- Of 80+ aged patients in ICU on lifesupports, 25% families stated preference was for 'comfort measures'
- Spent on average 10 days in ICU before death

Daren K Heyland<sup>1</sup>, Peter Dodek<sup>2</sup>, Sangeeta Mehta<sup>3</sup>, Deborah Cook<sup>4</sup>, **ORIGINAL RESEARCH** 

> The prevalence of medical error related to end-of-life communication in Canadian hospitals: results of a multicentre observational study

Daren K Heyland, <sup>1</sup> Roy Ilan, <sup>2</sup> Xuran Jiang, <sup>3</sup> John J You, <sup>4</sup> Peter Dodek <sup>5</sup>

BMJ Qual Saf. 2016

JAMA Internal Medicine | Original Investigation

#### Clinician-Family Communication About Patients' Values and Preferences in Intensive Care Units

Leslie P. Scheunemann, MD, MPH; Natalie C. Ernecoff, MPH; Praewpannarai Buddadhumaruk, RN, MS; Shannon S. Carson, MD; Catherine L. Hough, MD; J. Randall Curtis, MD, MPH; Wendy G. Anderson, MD; Jay Steingrub, MD; Bernard Lo, MD; Michael Matthay, MD; Robert M. Arnold, MD; Douglas B. White, MD, MAS 26% of family conferences didn't

address patient values and preferences Only 8% of decisions grounded on patient values and preferences

Of patients who preferred not to have CPR, 174 (35%) had orders to receive it.

Considerable variability in overtreatment rates across sites (range: 14-82%).

JAMA IM 2019

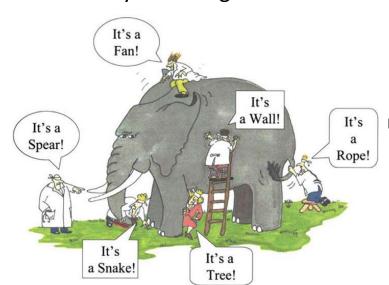


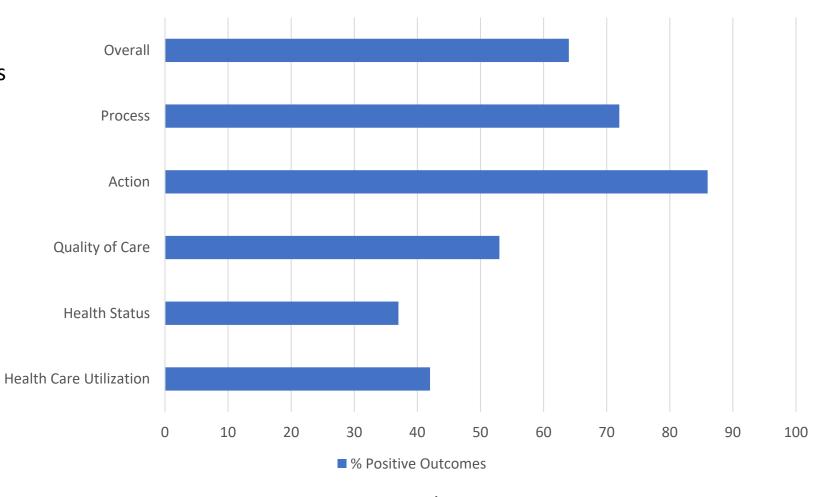
# THE SOLUTION: THE EVIDENCE SUPPORTING ACP



#### From 69 RCTs in the last decade

- 41% focused on process
- 28% making EOL treatment plans
- 7% focus on communicating GOC
- 4% ordering life-sustaining treatments
- 4% focus on completion of ADs
- 16% 'undefined'
- Studied in
  - variety of patient populations
  - Variety of settings





% Positive Outcomes

McMahan RD J Am Geriatr Soc 2020 In press





# **KEY POINTS**

- Too much heterogeneity in evidence supporting ACP
- Need to strive for more 'homogeneity' and standardization
- New approach (terminology and tools) needed?
- Definition/Conceptualization of ACP is problematic
  - Planning for death (certainty) is not the same as planning for serious illness (uncertainty)
  - Decontextualized 'conversation' not the same as in the moment clinical decisionmaking
  - Current approach that relies on open-ended values and preference questions lead to medical error
  - Consideration of people/patients are informed, autonomous consumers illfounded



### FRAMING AROUND EOL CARE IS PROBLEMATIC



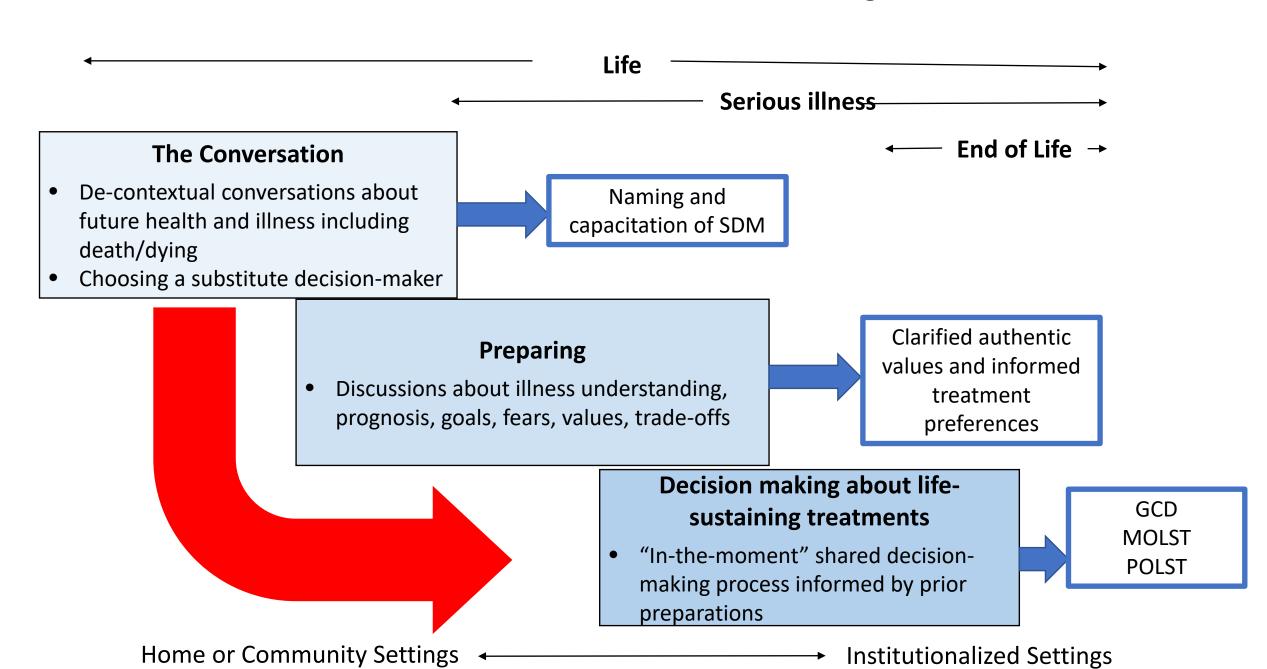
Death is not a certainty at the point that an ICU Doctor has to decide about the application (or not) of lifesustaining treatments



Patients with chronic, life-limiting illness and POLST receive significant amount of goal DIS-concordant care involving ICU admission in last 6 months.

Heyland Health Care 2020

#### The Continuum of Communication and Decision-making in Serious Illness







#### WHAT ACP SHOULD AND SHOULD NOT BE



- Should not be about developing and promoting 'de-contextualized' Instructional Directives
  - These have limited validity and clinical utility.1
  - 4% of ACP interventions were Ads in recent systematic review of RCTs in the last 10 years.<sup>2</sup>
- Should focus on activities that better prepare patients and SDMs for future 'in the moment' decision-making.<sup>3</sup>
  - 1. Heyland Health Care 2020
  - McMahan RD J Am Geriatr Soc
    2020 In press
  - 3. Sudore Ann Intern Med 2010





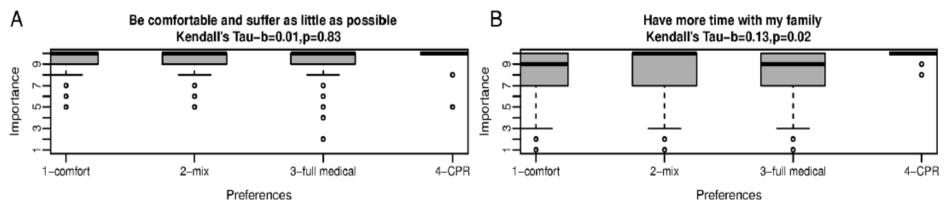
# Discordance between patients' stated values and treatment preferences for end-of-life care: results of a multicentre survey



Daren K Heyland, Rebecca Heyland, Peter Dodek, John J You, Tasnim Sinuff, Tim Hiebert, Xuran Jiang and Andrew G Day

BMJ Support Palliat Care published online October 6, 2016

- There were inconsistencies in participants' expressed value statements.
- For example, we expected that 'living as long as possible' would be negatively correlated with
  - 'be comfortable and suffer as little as possible',
  - 'avoid being attached to machines and tubes',
  - 'death is not prolonged' and the
  - However, we did not find a significant negative correlation in any of these instances.
- In fact, "live as long as possible" was positively correlated with "be comfortable and suffer as little as possible" (correlation coefficient, 0.14, p=0.03).



No/little relationship between measured values and elicited preferences



# PROBLEMS WITH CURRENT ACP/GOC APPROACH

- People are unclear on their authentic values
  - Not as simple as asking them "What's important to you?"
- People are 'ill-informed' about risks, benefits, and possible outcomes of life-sustaining treatments
  - Not as simple as asking them their preference "What do you want us to do?"
  - Wishes should not be equated with a medical order!



Need greater support in <a href="mailto:shared-decision making">shared- decision making</a> related to serious illness in <a href="mailto:advance">advance</a>

PS. Patient (and Family) lack of preparedness is a major barrier to Physician engagement You JAMA Int Med 2015

## **PLAN WELL GUIDE:**

#### A NOVEL DECISION AID TO SUPPORT DECISION-MAKING IN SERIOUS ILLNESS

Compared to other ACP tools, Plan Well Guide offers the following features or attributes:

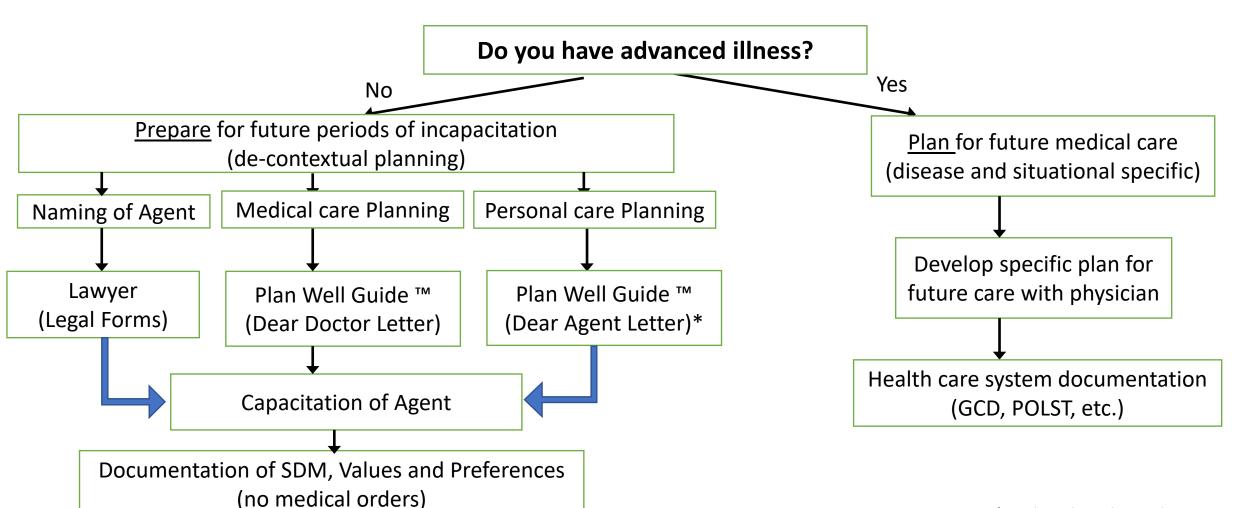
- 1) Discriminates between planning for terminal care vs. planning for serious illness
- 2) Explains how we make medical decisions under conditions of uncertainty
- 3) Utilizes a 'constrained' values clarification tool where respondents have to pick between competing values
- 4) Uses 'Grids' to transparently connect states values to respondent preferences for medical treatments during serious illness
- 5) provides a 'first in class' decision aid on the different levels of care

#### RCT showed<sup>1</sup>

- Increased likelihood that patients will receive the care that is right for them
- Reduced decision conflict (more knowledgeable, more clarity, more sure)
- Majority very satisfied with the experience and would recommend it to others
- Physicians considered intervention patients to have lower decisional conflict
- Physicians spent less time with patients finalizing goals of care for intervention patients compared to usual care patients.
   1. Heyland CMAJ Open 2020



# **Advanced Serious Illness Preparation and Planning (ASIPP)**



\*To be developed