Advance Care Planning: What is the evidence and why does it matter?

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The Quest for Goal Concordant Care

Conflict of Interest Disclosure

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Advance Care Planning: A Definition*

- *Advance* care planning (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.***
- The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.
- For many people, this process may include choosing and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her own decisions.

As distinguished from real-time or in the moment goals of care discussions with patients or proxies

*Sudore et al, Defining Advance Care Planning for Adults: A Consensus Definition from a Multidisciplinary Delphi Panel, J Pain Symptom Manage, 2017

A Truncated History of ACP

Problem	Solution
Patients receive unwanted treatments at end-of-life →	Living Will (1967)
Not all decisions and treatments can be predicted →	Health Care Proxy, DPAH (1983)
Physicians don’t engage in ACP discussions →	Lay ACP programs (1993)
Preferences are not acted upon →	Medical Orders for Life Sustaining Treatments (MOLST) (1995)
Doctors don’t have time to engage in MOLST/ACP discussions →	Reimbursement for ACP (2016)
Patients are not aware that they have a MOLST form or what it contains →	??? (2020)

The Evidence Base of ACP

- 1994-2017: 80 published systematic reviews of ACP that include over 1660 mixed quality research studies
  - 1.5 times the number of delirium treatment studies
  - 8 times the number of breathlessness treatment studies
  - 15 times the number of cancer pain treatment studies for children
- 2017-2020: 7 additional high quality RCT's (16,555 total patients [15,120 in one study]), 1 additional scoping review (69 studies)
- 1990-2020: $30 million in NIH funding to ACP research
- 1993-2016: Advance directive prevalence increased from 26%-37%

What has been studied?

- Populations
  - Adults of all ages; healthy adults; hospitalized adults; adults in critical care; community dwelling adults; nursing home residents; persons with cancer, heart disease, neurological disease, dementia, frailty
- Attitudes/Beliefs/Prevalence
- Interventions
  - Patient education and decision support (print, web, video)
  - Physician, nurse, social worker education and reminders
  - Nurse, social worker, and physician led group/individual counseling
  - Trained ACP facilitator led group/individual counseling

Strong body of evidence demonstrates that a number of interventions can increase:

- Knowledge of advance directives and advance care planning
  - Patients, surrogates, health care professionals
- Completion of an advance directive
- Documentation of advance directive in the medical record
- Rate of advance care planning discussions with physicians
  - Measured immediately following the ACP intervention

There is minimal-no consistent evidence from high quality studies that ACP can:

- Influence medical care at end-of-life for patients lacking decisional capacity
- Enhance quality of death and dying
- Increase the likelihood that end-of-life care is consistent with patient preferences
- Improve patient/surrogate satisfaction
- Improve surrogate quality of life or bereavement outcomes

The premise and process of ACP

- Patients can articulate their values and goals and identify what treatments would align with those goals in hypothetical future scenarios
- Wishes are documented or shared with a trusted surrogate
- Surrogates will invoke substituted judgement to make treatment decisions when needed
- Clinicians will honour preferences and decisions
- Health systems/society will support goal-concordant care
- And thus, patients will receive goal-concordant care

The Problem

- Treatment choices near end of life are not simple, logical, linear, autonomous, nor predictable but complex, uncertain, socially determined, emotionally laden, and changing over time
- Substituted judgement presumes that surrogates can:
  - Extrapolate specific treatment decisions from distant general ACP discussions
  - Piece together what their loved one would have wanted
  - Disentangle their own preferences, emotions, and feelings of guilt from the decision at hand
- Treatment decisions do not occur in a vacuum but are driven by:
  - Financial incentives and the marketplace (supply and demand)
  - Societal capacity to support patient needs
  - Institutional/regional cultures and practice patterns

Continuing to invest in ACP is not benign

- Poor communication skills that characterize current ACP practice lead to goal discordant and sub-optimal care (Heyland, Healthcare, 2020)
  - Varying the language used in ACP changes treatment decisions (Halpern et al, JAMA Network Open, 2020)
  - Surrogate's decisions are influenced by how the choices are framed to them (Barnato et al, CCM 2013)
  - Lack of quality control around MOLST discussions can lead to withholding of beneficial treatments
  - Presence of MOLST form may discourage complex discussions with surrogates or patients
- Efforts devoted to ACP (research and clinical dollars, resources, workforce) come at the expense of addressing other important needs of the seriously ill

The ACP Paradox…

- Why is there such strong faith in the promise ACP despite thirty years of evidence to the contrary?
  - Respect for persons
  - Uniquely western need to believe that we can control what happens to us
  - Commitment bias
  - Confirmation bias
  - Financial incentives
  - Lack of alternate approaches
- What does it mean if we narrow our focus to appointment of a proxy?
  - Grief over loss of our raison d'etre after years of effort
  - Coming to terms with the limits of autonomy as determinative of life's course
    - Rugged individualism is *the* core US value