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Evolutions in Advance Care Planning

Karin Porter-Williamson MD FAAHPM

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Session Description

With the passage in 1990 of the Patient Self Determination Act (PDSA), institutions were called on to address advance care planning at a system level. Since that time, there has been much evolution in the concepts of Advance Care planning (ACP), serious illness care planning (SICP), recognition of the infrastructure necessary for patient care preferences to be honored across time and across the continuum of care.

This session will focus on key elements of advance care planning, and how that work can provide a foundation for more in depth shared decision making when the need for serious illness care planning arises. We will also discuss recent debate in the Palliative Medicine professional community on the utility of advance care planning, and how we work to assure that ACP, in conjunction with SICP, has the desired impact of empowering patients in decision making, as was the original intent of the PSDA.

LEARNING OBJECTIVES

- Describe the evolution of Advance Care Planning terminology, from the days of the Patient Self Determination Act to now
- Understand advanced care planning and serious illness care planning as a spectrum across lifespan and health status
- Realize the ultimate goal of high quality Advance Care Planning: Delivery of Goal Concordant Care

Case Example- Rev. James and his wife Louise

- 88 year old preacher, I met him in the neuro ICU after he had suffered a bad stroke.
  - The stroke was “survivable”
  - Prognosis for him to recover to go back to preaching was very poor.
  - Upon hearing her husband would not be able to preach again, she knew what to do.

They had spoken on the matter as part of his advance care planning. He had told her “if there ever comes a time I can no longer preach, I don’t want to hang around. Let me go then.”

Case Example – Mr. Olson

- 88 year old male with a 6.3 cm abdominal aortic aneurysm visits his geriatrician at a health system ambulatory site
- She asks him what his wishes would be if it were to burst, knowing that would be catastrophic
- He says "If it blows, comfort please. No surgery. No ICU or tubes."
- She documents it in an ACP note, viewable with 2 clicks in his chart
- 6 weeks later….. It blows.
- ED nurse sees the acp note and they institute comfort plan in the ED, they get him admitted to inpatient hospice at a unit close by

Case Example – Ms. May and her Daughter Marie

- 88 year old female with dementia, dysphagia, recurrent infections
- Family wishing aggressive care for any condition that could be reversible
- They did not want her to be put through a code blue if she were to go into cardiopulmonary arrest but wanted everything up to that point
- Daughter too afraid to sign a classic out of hospital DNR form for fear it would be overinterpreted
- Once she saw the detail in the TPOPP form, she was agreeable to sign

Revisiting the Patient Self Determination Act of 1990

- Passage of law whereby institutions must ask patients if they have an Advance Directive, and if not if would they like to complete one

- Goal: Assure patient voice is heard with regard to treatments they would or would not want as part of their medical care

- **Beginning step** in evolution of the Shared Decision Making Model, moving away from paternalism in medical decision making

Consensus Definition, 52 experts

"Advance care planning 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 advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness."

Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, Matlock DD, Rietjens JAC, Korfage IJ, Ritchie CS, Kutner JS, Teno JM, Thomas J, McMahan RD, Heyland DK. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. J Pain Symptom Manage. 2017 May;53(5):821-832.e1. doi: 10.1016/j.jpainsymman.2016.12.331.

Epub 2017 Jan 3. PMID: 28062339; PMCID: PMC5728651.

Does Advance Care Planning work?

- **MEH…**
- AD completion rates remain low
- Presence of AD is NOT sufficient to ensure goal concordant care
- There is a gap between hypothetical future scenarios and in the moment decision making
- Surrogates/clinicians choose treatments different from what is on the AD
  - Care preferences change over time
- **CLEARLY a check box on the admissions form is not enough**

- **YEAH…**
- ACP is complex, dependent on internal and external factors, settings, workflows, etc.
- When oversimplified to a check box, that is not the answer.
- ACP is reported valuable by those who have done it
- High quality ACP results in decreased anxiety, grief, posttraumatic stress, and burden for surrogate decision makers
- Need outcome measures to capture the benefits

ACP is one critical part of the Shared Decision Making Model

- The dominant model for communication between providers and patients/surrogates facing decisions about management of complex/serious illness
  - "Interpersonal, interdependent process where health care provider and patient relate to and influence each other as they collaborate in making decisions about the patient's health care."
  - Clinician influences patient with medical knowledge and facts re: benefits/burdens of various treatment options
  - Patient influences clinician by providing the values and goals relevant to the treatment decision at hand.

Shared Decision Making Model

- **Advance Care Planning**
- **Serious Illness Care planning**
- **Artifacts of ACP/SICP**
  - Conversation amongst person/ loved ones
  - Documentation of conversation in EMR
  - Durable Power of Attorney HC
  - Advance Directive
  - POLST type documents

ACP, SICP and the associated artifacts are prework for

"In the Moment" medical Decision making

When the time comes

Advanced Care Planning

- For Healthy people
- Educational and reflective
- Values related to a future reality of illness
- People do on their own

- For Rev. James and Louise... Discussion of his values assured she knew what he would say when she was asked to speak for him some years after the conversation.
- ACP worked here.

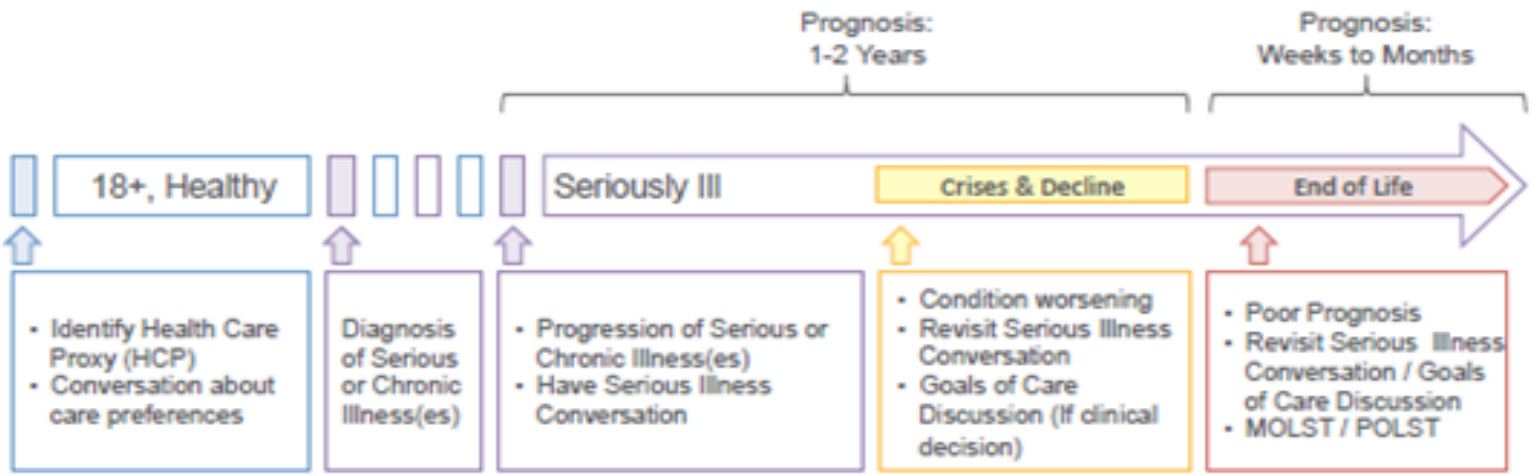
Serious Illness Care Planning

- Planning in the context of serious illness
- The future state of ill health has arrived
- Moderated discussion between trusted medical providers and patient/family
- Requires the skill of the medical provider in discussion of the condition, trajectory of illness, prognosis
- Requires an understanding of the values of the patient/family, about what matters to them in the living

"ACP" has evolved into a field of study and implementation science:

- System workflows to identify those needing communication around their health and decision making
- Expert communication skills in complex decision making
- Electronic records which capture that communication efficiently for providers to see across time and space
  - The conversation documentation itself
  - The "artifacts" of the communication
- System workflows which promote goal concordant care
  - Code status Ontology which is clear and specific for providers at the bedside in an emergency
  - Tracking of concordance between patient goals and care received over time

Advance Care Planning Terminology



Advance Care Planning = Planning in Advance of Serious Illness

Serious Illness Care Conversation = Planning in the context of progression of serious illness

Goals of Care Discussion = Decision making in context of clinical progression / crisis / poor prognosis

Timing and importance of Advance Care Planning Interventions

- We know that we need to talk with our patients about their wishes, but this is hard

- Patients and families must be willing to talk about it
  - 60-70% of people affirm that speaking with their doctor/family about their wishes is important
    - Only 15-20% actually do
    - Waiting for the provider to bring it up
    - Don't want to talk about it too early

- Many Providers have not had training in this complex communication or feel uncomfortable with these conversations

Conversations are Key

Earlier conversations about patient goals and priorities for living with serious illness are associated with:

- Enhanced goal-concordant care Mack JCO 2010
- Improved quality of life
- Reduced suffering
- Better patient and family coping
- Higher patient satisfaction Detering BMJ 2010
- Less non-beneficial care and costs Wright 2008, Zhang 2009

It's Time to Rename and Reframe

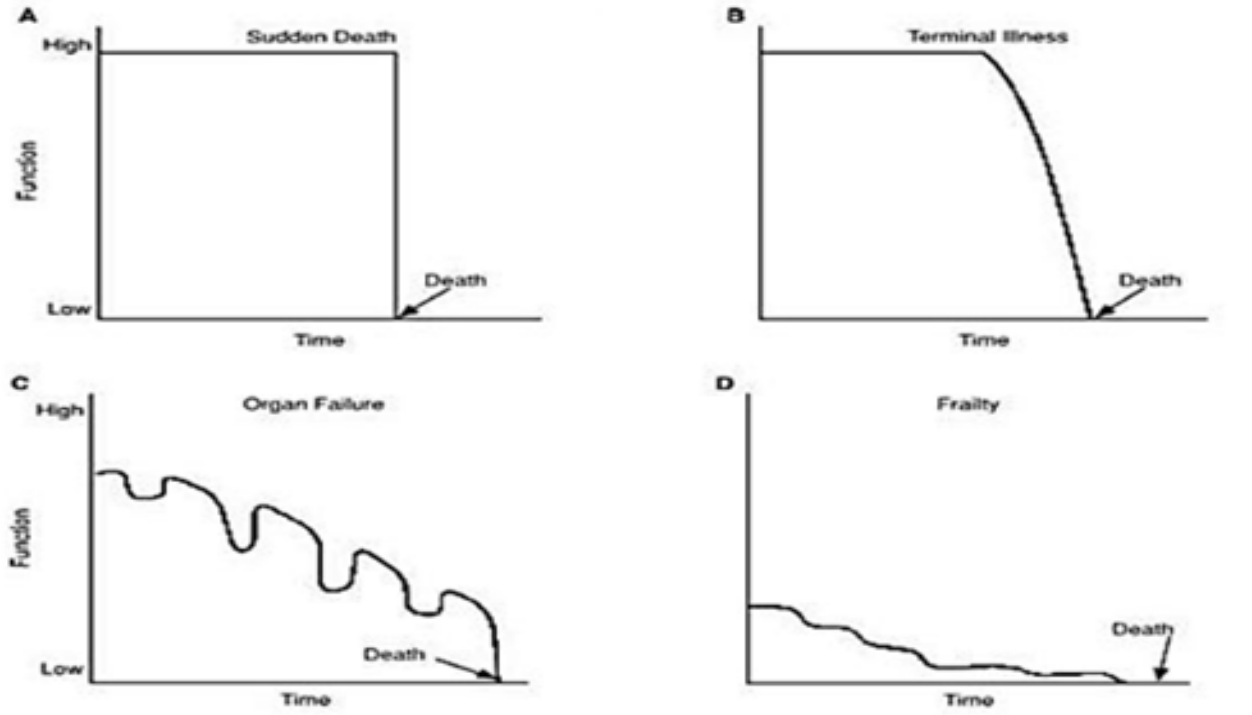
- Need to get away from "End of Life" discussions
  - These conversations are about a person's priorities for how they want to LIVE
  - This is about people considering their values in life while they are healthy, or while they are living with serious illness, or while they are representing a loved on in that situation
  - The last thing on Marie May's mind was her mom dying. She wanted her mom to live, while recognizing specific limits if it got bad enough, but NOT before…..

So, when is it time to start Serious Illness Care Planning?

- Asking the "surprise question" can help
  - Would it **surprise** me if this person were to die in the next year? (answer of "no" means it's time)
  - NOTE: **NOT** the same as saying someone has a prognosis of a year or less

- Recognizing functional trajectories can help

Illness Trajectories



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How Does One build skill in communication for Serious Illness Care Planning?

- Best done as skills practice, combining didactics and experiential learning to have the best retention of information

- Serious Illness Care Planning Program
  - www.ariadnelabs.org
  - Conversation guide with structure around a serious illness conversation, using patient tested language

- Vital Talk training program
  - www.vitaltalk.org
  - Train the trainer courses, e-learning options, mentoring solutions

Goal concordant care as the Holy Grail

- Must establish what the patient's goals are
- Must maintain clarity of those goals as they change over time
  - Must have process infrastructure in and across systems to check in periodically and at change in condition
- Must have a measure of the nature of care received proximate to the most recent goals
  - Process measures
  - Outcome measures

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Receipt of goal concordant care… or not

- Analysis of enrollment surveys from a multicenter cluster-randomized trial of outpatients with serious illness. Patients reported their prioritized health care goal and the focus of their current medical care; these items were matched to define receipt of goal-concordant care.
- 405 patients with a prioritized health care goal, 58% reported receipt of goal-concordant care, 17% goal-discordant care, and 25% were uncertain of the focus of their care. Patient-reported receipt of goal concordance differed by patient goal. For patients who prioritized extending life, 86% reported goal-concordant care, 2% goal-discordant care, and 12% were uncertain of the focus of their care. For patients who prioritized relief of pain and discomfort, 51% reported goal-concordant care, 21% goal-discordant care, and 28% were uncertain of the focus of their care. Patients who prioritized a goal of relief of pain and discomfort were more likely to report goal-discordant care than patients who prioritized a goal of extending life (relative risk ratio 22.20; 95% CI 4.59, 107.38).

Modes ME, Heckbert SR, Engelberg RA, Nielsen EL, Curtis JR, Kross EK. Patient-Reported Receipt of Goal-Concordant Care Among Seriously Ill Outpatients-Prevalence and Associated Factors. J Pain Symptom Manage. 2020 Oct;60(4):765-773. doi: 10.1016/j.jpainsymman.2020.04.026. Epub 2020 May 7. PMID: 32389606; PMCID: PMC7508896.

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