Evidence-based and Resident Centered End of Life Care

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Objectives

- Framing the imperative for advance care planning: Alice's story
- Why don't we talk about it?
- How should we talk about it?
  - Shared decision making and decision aids
  - Tailoring conversations
- Elements of a "whole system" approach to advance care planning
- Alice's story (How could it be different next time?)

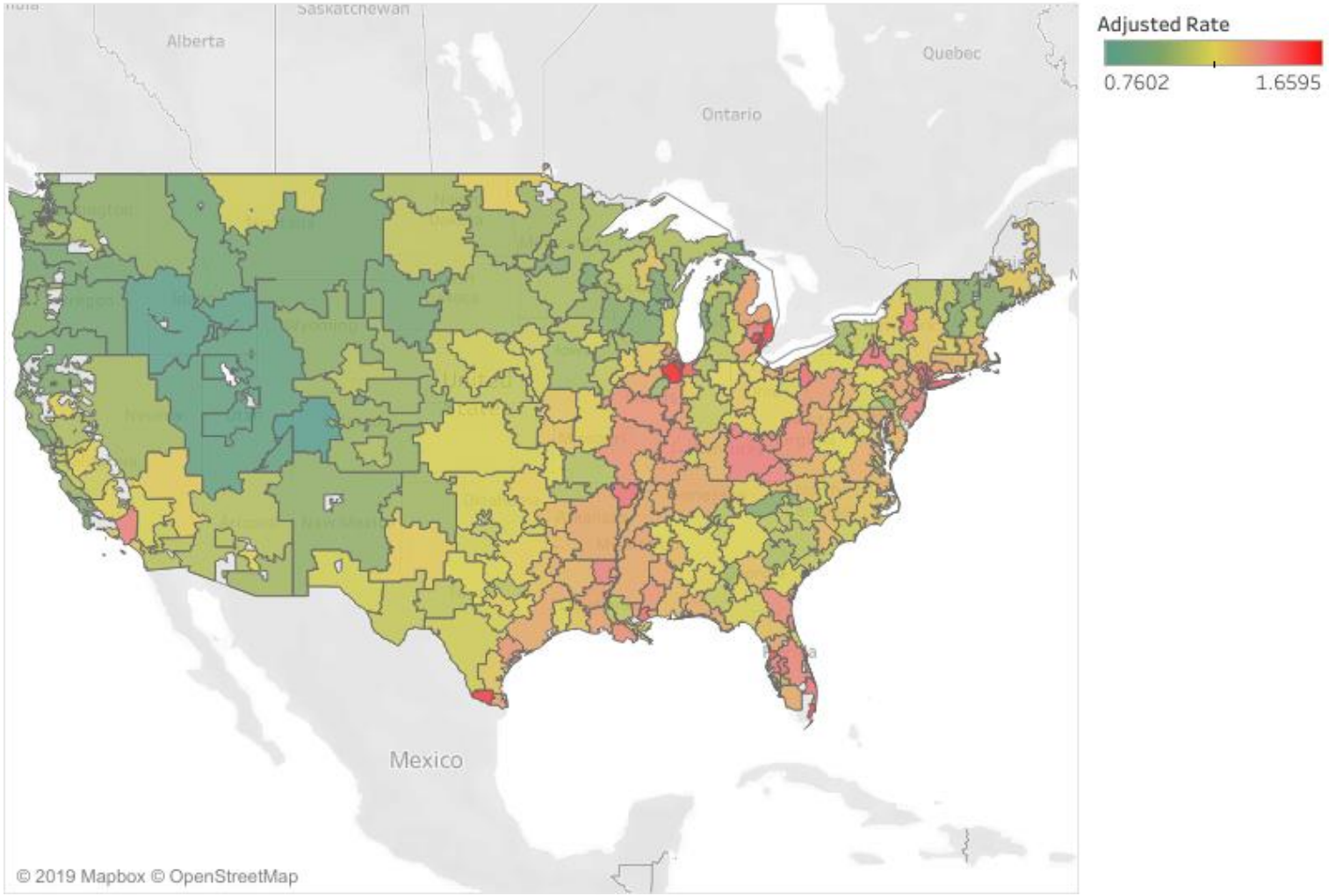
Alice’s death

- As described by Atul Gawande, Mortal Lessons (Metropolitan Books, 2014) p. 77.

Alice’s death

- What would you change if you could?
- Would Alice’s death have been different at your institution? In what ways?

Map: Hospital Admissions per 1,000 Decedents During the Last Six Months of Life, by HRR



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Advance Care Planning*

- ACP is the process of planning for future medical care with the goal of helping patients receive care that is aligned with their preferences
- ACP involves more than completing an advance directive in isolation, not just an individual's preference for a certain medical procedure (e.g. CPR)
- There is a poor correlation between wishes expressed in AD, documentation in the medical record and the end of life care individuals receive

- *From Lum et al. Med Clin N Am 99 (2015) 391-403.

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ACP – Essential components*

- Different types of ACP may be appropriate at different life and illness stages, but should include the following 3 components:
  - Education
  - A structured approach to thinking about the choices a patient faces
  - A reliable method for documenting and communicating these choices

- *Butler M, et al. Ann Intern Med. 2014;161:408-418

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The ACP imperative – when absent or delayed

- Poor quality of life, anxiety and family distress
- Prolongation of the dying process
- Undesired hospitalizations
- Patient mistrust of the health care system
- Clinician burnout
- High costs

ACP – when present

- Ability to identify, respect and implement an individual's wishes for medical care → Increased "concordance" goals and treatments
- Ability for an individual to manage personal affairs while still able
- Peace of mind, less burden on loved ones and peace within the family
- Reduction in stress, anxiety and depression in surviving family members
- Improved patient satisfaction and quality of life
- Fewer hospital deaths; more hospice use

- *Brighton and Bristowe. Postgrad Med 2016;92:466-470.

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ACP – why don't we talk about it?*

- Patient factors
  - Anxiety, denial, desire to protect family
- Clinician factors
  - Lack of training, comfort and time
  - Difficulties with prognostication
- System factors
  - Life sustaining care is the default (i.e. inertia)
  - No system for end of life care
  - Poor systems for recording patient wishes; ambiguity about who is responsible

*Bernacki RE, et al. JAMA Intern Med. 2014;174(12):1994-2003.

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ACP – Key facts about “the conversation”*

- Patient is not more likely to experience anxiety, depression and loss of hope by having an ACP conversation
- Patient is more likely to experience goal concordant care
- Reduction in surrogate distress

  - *Bernacki RE, et al. JAMA Intern Med. 2014;174(12):1994-2003.

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ACP conversations: Information for clinicians*

- Patients want the truth about prognosis
- You will not harm your patient by talking about end of life issues
- Anxiety is normal for both patient and clinician during such conversations
- Patients have goals and priorities besides living longer
- Learning about patient goals and priorities empowers you to provide better care

  - *Bernacki RE, et al. JAMA Intern Med. 2014;174(12):1994-2003.

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Evidence-based communication: Shared decision making

- Shared decision making (SDM)
  - A form of informed decision-making that takes place in a clinical context and is explicitly interactive; it balances evidence with values
  - Patient and clinician relate to and influence each other as they work together to make a decision about the patient's health
  - Takes into account medical evidence; clinician expertise; patient values and preferences, and unique attributes of the patient and her or his family, such as cultural or linguistic affinity and mutual trust
  - Focuses on choice, rather than change

    - Blair and Legare. Patient (2015) 8:471-476

Robust evidence supports the effectiveness of SDM

- Shared decision-making*:
  - Improves patient knowledge about their health condition and possible outcomes of care
  - Improves patient confidence in their decisions
  - Improves patient satisfaction, health outcomes and appropriateness of care
- Shared decision-making significantly improves outcomes for disadvantaged patients (minority ethnic groups; low literacy/low education populations; low income; medically underserved)
  - SDM may be more beneficial to disadvantaged groups than higher literacy/SEC status patients**
    - * http://www.breecollaborative.org/wp-content/uploads/EOL-Care-Final-Report.pdf, Accessed May 31, 2019
    - **Durand MA, et al. PLOS ONE. 2014;9(4):e94670

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Shared decision making – we think we do it, but…

- 2014 study of patients scheduled for elective cardiac catherization found 88% of patients held fundamentally mistaken beliefs about the procedures, despite having signed informed consent
- Only 19% of patients with colorectal cancer understood that chemotherapy was not likely to cure their cancer
- Only 5% of advanced cancer patients understood essential aspects of their diagnosis

SDM: The role of patient decision aids (PDAs)

- PDA: Evidence-based educational tools designed to assist patients with evaluating health care options
  - Provide relevant information
  - Help patients clarify and communicate values and preferences
  - Facilitate communication and collaboration between provider and patient
- Meant to supplement and facilitate, not replace, conversations and counseling with provider or care team
- PDAs may include written material, decision grids, videos, and web-based or other electronic interactive programs

Patient decision aids: The evidence

- Over 130 randomized controlled trials demonstrate PDAs lead to patients:
  - Gaining knowledge
  - Having more accurate understanding of risks, harms and benefits
  - Feeling less conflicted about decisions
  - Rating themselves as less passive and less often undecided

Patient decision aids: Evaluating quality

- Not all PDAs are “created equal” – need to assure that evidence-based criteria are met; presentation is balanced; and conflicts of interest are mitigated
  - International Patient Decision Aid Standards (IPDAS) provides criteria to assess the quality of PDAs (http://dx.doi.org/10.1371/journal.pone0004705)
  - Ottawa Hospital Research Institute: https://decisionaid.ohri.ca/ evaluates decision aids relative to IPDAS criteria
  - Washington State Health Care Authority certification process describes criteria and lists “certified” aids: https://www.hca.wa.gov/about-hca/healthier-Washington/patient-decision-aids-pdas

Patient decision aide quality criteria: A sampling from Washington State

- Explicitly state the decision under consideration
- Identify the target audience
- Describe the available options including non-treatment
- Describe the positive features of each option
- Describe the negative features of each option
- Help patients clarify their values for outcomes of options
- Show positive and negative features of options with balanced detail

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ACP decision aid: An example

https://www.healthwise.net/ohridecisionaid/Content/StdDocument.aspx?DOCHWID=tu2951

“It’s always too early until it’s too late”: Barriers to effective ACP in nursing homes

- Diminished capacity of residents
- Communication difficulty with residents
- Staff training, confidence, availability and ownership
- Time
- Non-recognition of ACD documentation by allied health professionals
- Lack of strong commitment on part of organizational leadership

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“Whole system” approach to ACP in nursing homes*

- Necessary but insufficient:
  - In service training
  - Teams (multi-disciplinary awareness; role definition; formalized communication)
  - Standardized documentation
- Institutional engagement: An imperative
  - Management engagement and support (LEADERSHIP)
  - Policy development
  - Quality improvement processes → especially measurement

*Flo et al. BMC Geriatrics (2016) 16:24 and Gilissen et al. BMC Geriatrics (2018) 18:47.

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Elements of successful ACP system in LTC

- Deploy evidence-based advance planning tools and programs
  - SDM framework –
    - Train inter-professional teams that include a primary treating clinician (physician; ARNP)
  - Evidence-based decision aids
- Standardize tools and training across your institution
- Recognize that different types of ACP may be appropriate at different life and illness stages, but should include the following 3 components:
  - Education
  - A structured approach to thinking about the choices a patient faces
  - A reliable method for communicating these choices

Define a process that assures effective ACP for each client

- Address readiness and identify barriers
- Identify surrogate decision makers
- Ask about the patient's values related to quality of life
- Document ACP preferences
- Monitor and update preferences
- Translate preferences into medical care plans (e.g. CPR directive; POLST)
- Assure effective communication of plans across the care continuum

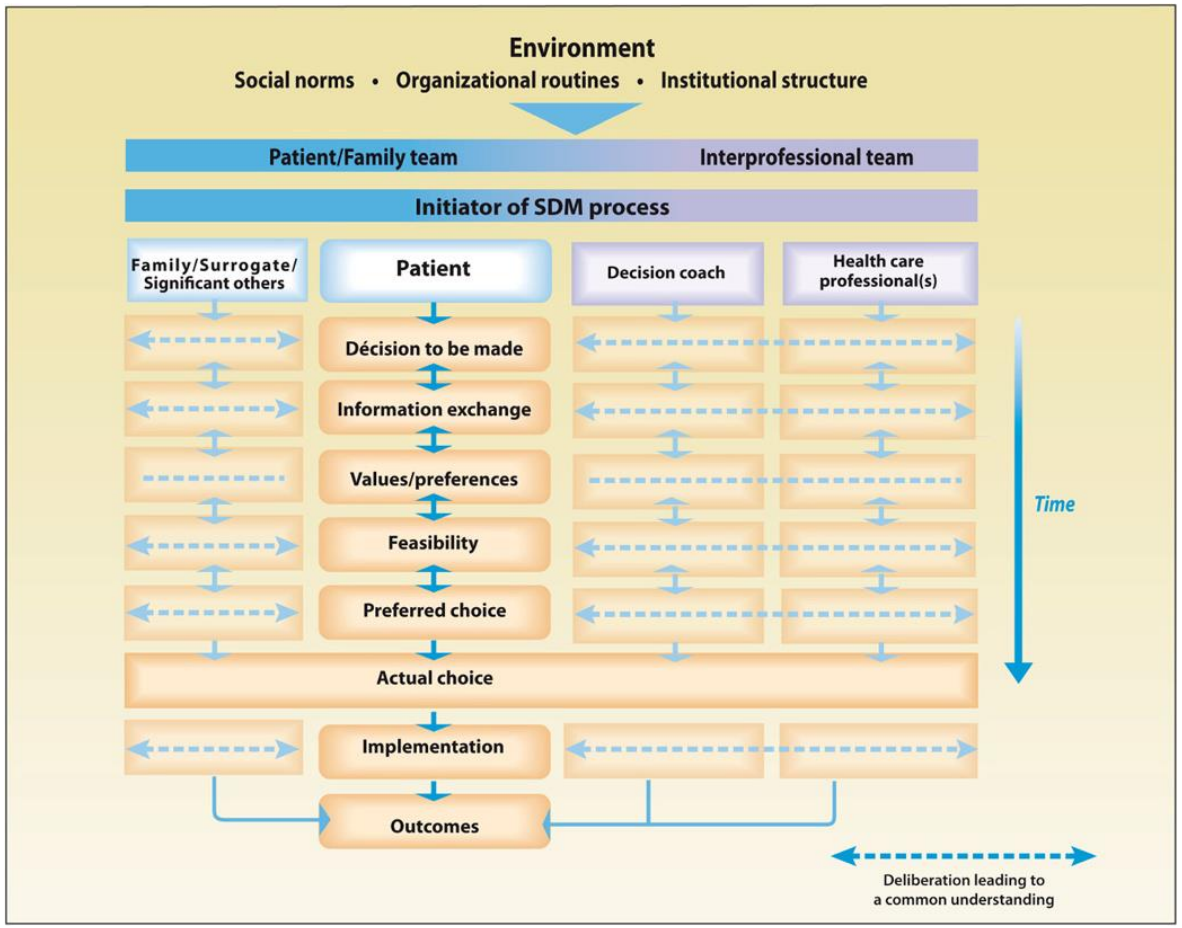
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ACP – It takes a team

- Who is on the team?
- What are there roles?
- How are they trained?

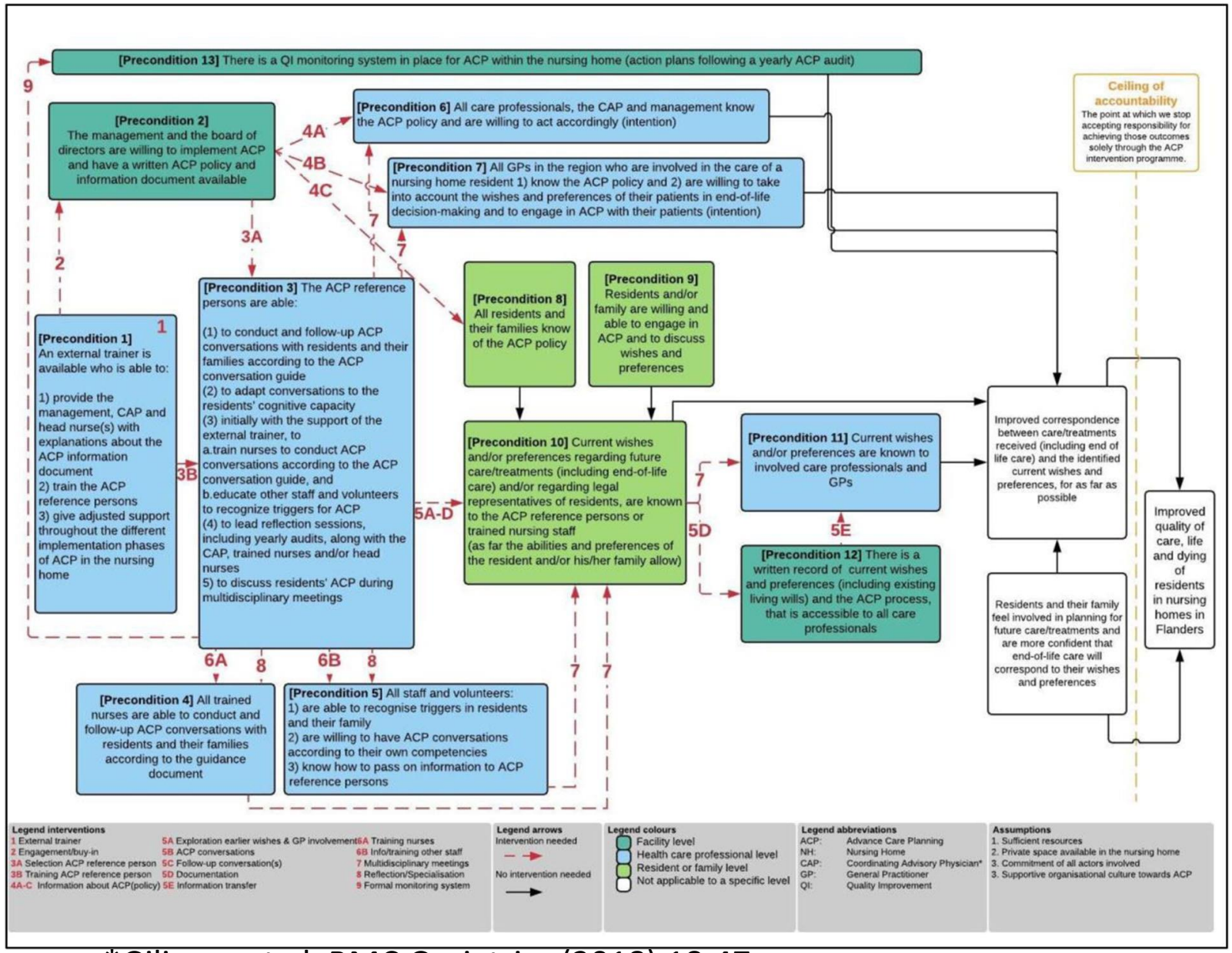
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A Model for Inter-Professional Shared Decision Making



From: Legare F, et al. Patient Educ Couns. 2012.

Theory of Change: A Systems Approach to ACP in Nursing Homes*



*Gilissen et al. BMC Geriatrics (2018) 18:47.

Measures

- Process measures
  - Staff training
  - ACP documentation
  - Goal concordant care
- Outcome measure
  - Measure family and friend satisfaction with end-of-life care by widespread use of an after-death survey tool similar to that used by hospice agencies (www.hospicecahpssurvey.org/content/SurveyInstruments.aspx)

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