Advance Care Planning research in Canada: “state of the nation”

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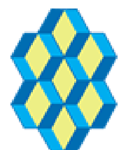
CARENET
Canadian Researchers at the End of Life Network



TVN Improving care for the frail elderly

Outline

- Where have we been?
- Where are we now?
- Where do we need to go?

My perspective …

- Hospital based general internist
- Clinician-researcher
- Improvement of end-of-life communication and decision-making for seriously ill hospitalized patients and their families
- TVN Theme Lead for Advance Care Planning / End-of-Life Care

Support for EOL research in Canada

- CIHR Palliative and End-of-life Care committee
- CIHR: 10 New Emerging Team (NET) grants (2004-2009)
  - Family caregiving
  - Cancer-associated cachexia and anorexia
  - Vulnerable populations
  - Improving communication and decision-making at the end-of-life
- CARENET (Canadian Researchers at End of Life Network)

RESEARCH

What matters most in end-of-life care: perceptions of seriously ill patients and their family members

Daren K. Heyland, Peter Dodek, Graeme Rocker, Dianne Groll, Amiram Gafni, Deb Pichora, Sam Shortt, Joan Tranmer, Neil Lazar, Jim Kutsogiannis, Miu Lam, for the Canadian Researchers, End-of-Life Network (CARENET)

How important is it …	% “Extremely Important”
To have trust and confidence in the Doctor looking after you	55.8

Good end-of-life communication and decision-making

How important is it …	% “Extremely Important”
To have an adequate plan of care & services available at home upon discharge	41.8
To not be a physical or emotional burden	41.8

Heyland DK et al. CMAJ. 2006.

CMAJ RESEARCH

Defining priorities for improving end-of-life care in Canada

Daren K. Heyland MD MSc, Deborah J. Cook MD MSc, Graeme M. Rocker DM MHSc, Peter M. Dodek MD MHSc, Demetrios J. Kutsogiannis MD MHS, Yoanna Skrobik MD, Xuran Jiang MD MSc, Andrew G. Day MSc, S. Robin Cohen PhD, for the Canadian Researchers at the End of Life Network (CARENET)

“End-of-life care in Canada may be improved for patients and their families by providing better psychological and spiritual support, better planning of care and enhanced relationships with physicians, **especially in aspects related to communication and decision-making**.”

Conceptual framework of end-of-life communication and decision making

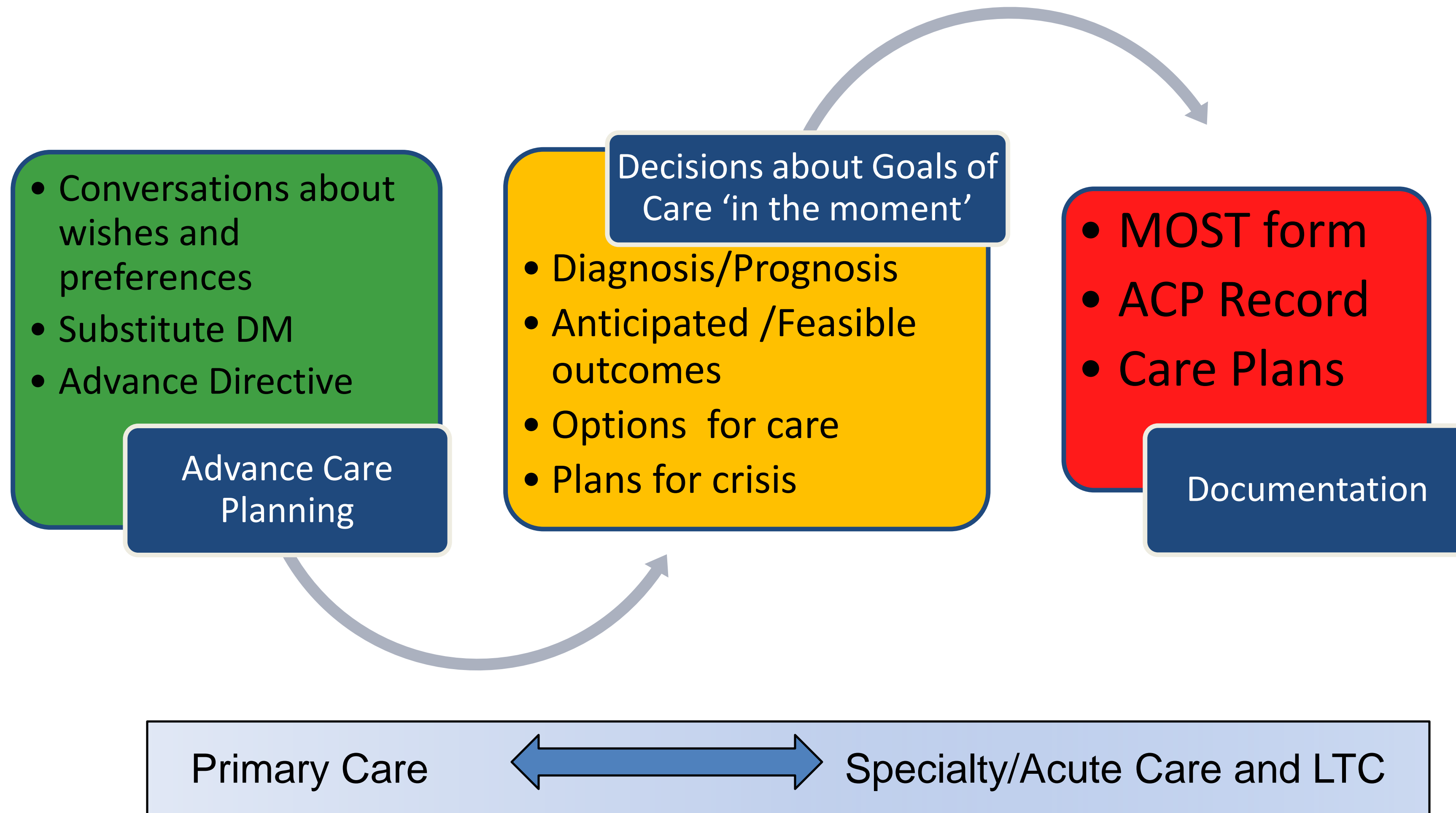
Vol. ■ No. ■ ■ 2015 Journal of Pain and Symptom Management 1

Original Article

Improving End-of-Life Communication and Decision Making: The Development of Conceptual Framework and Quality Indicators

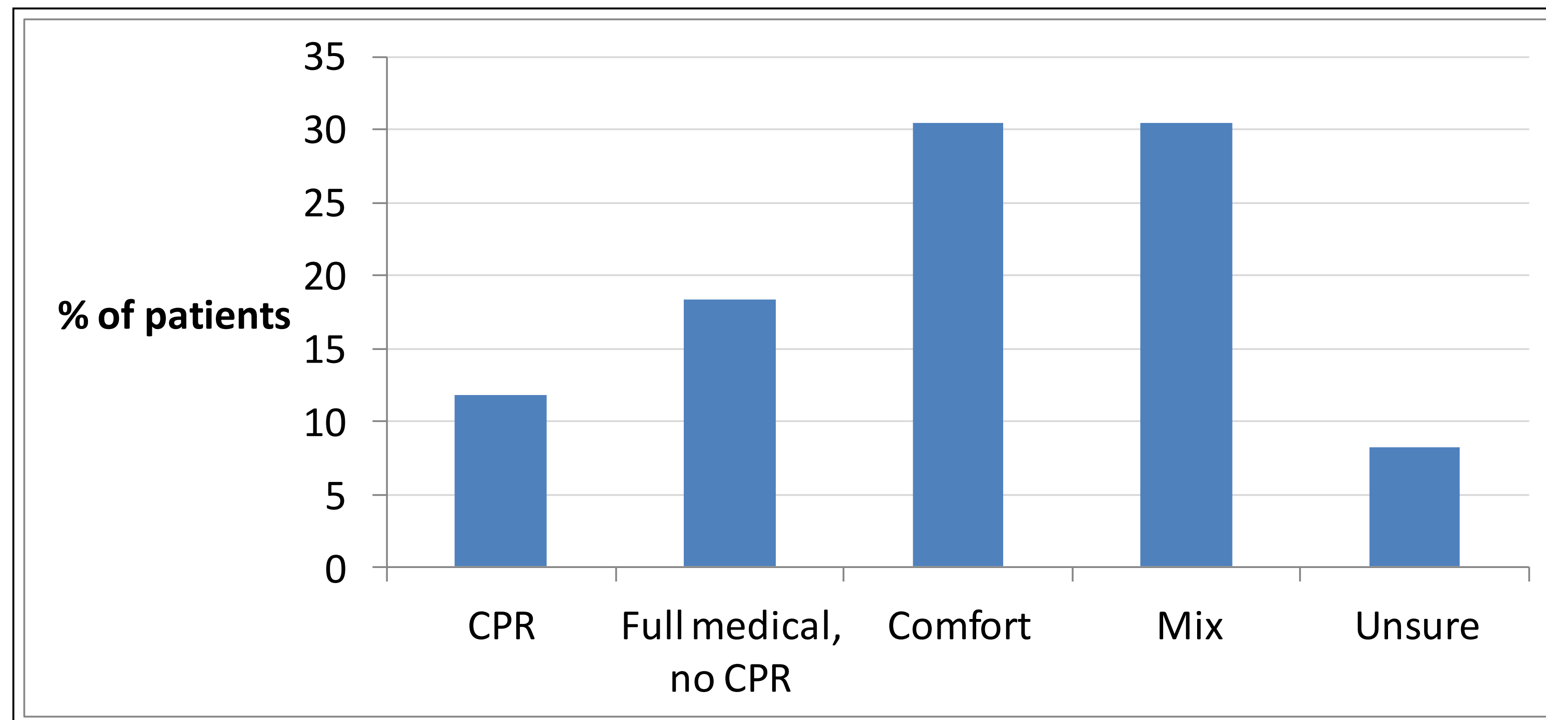
Tasnim Sinuff, MD, PhD, Peter Dodek, MD, MHSc, John J. You, MD, MSc, FRCPC, Doris Barwich, MD, CCFP, Carolyn Tayler, RN, BN, MSA, CON (C), James Downar, MDCM, MHSc, FRCPC, Michael Hartwick, MD, MEd, FRCPC, Christopher Frank, MD, FCFP, Henry T. Stelfox, MD, FRCPC, PhD, and Daren K. Heyland, MD, FRCPC, MSc

EOL communication & decision-making

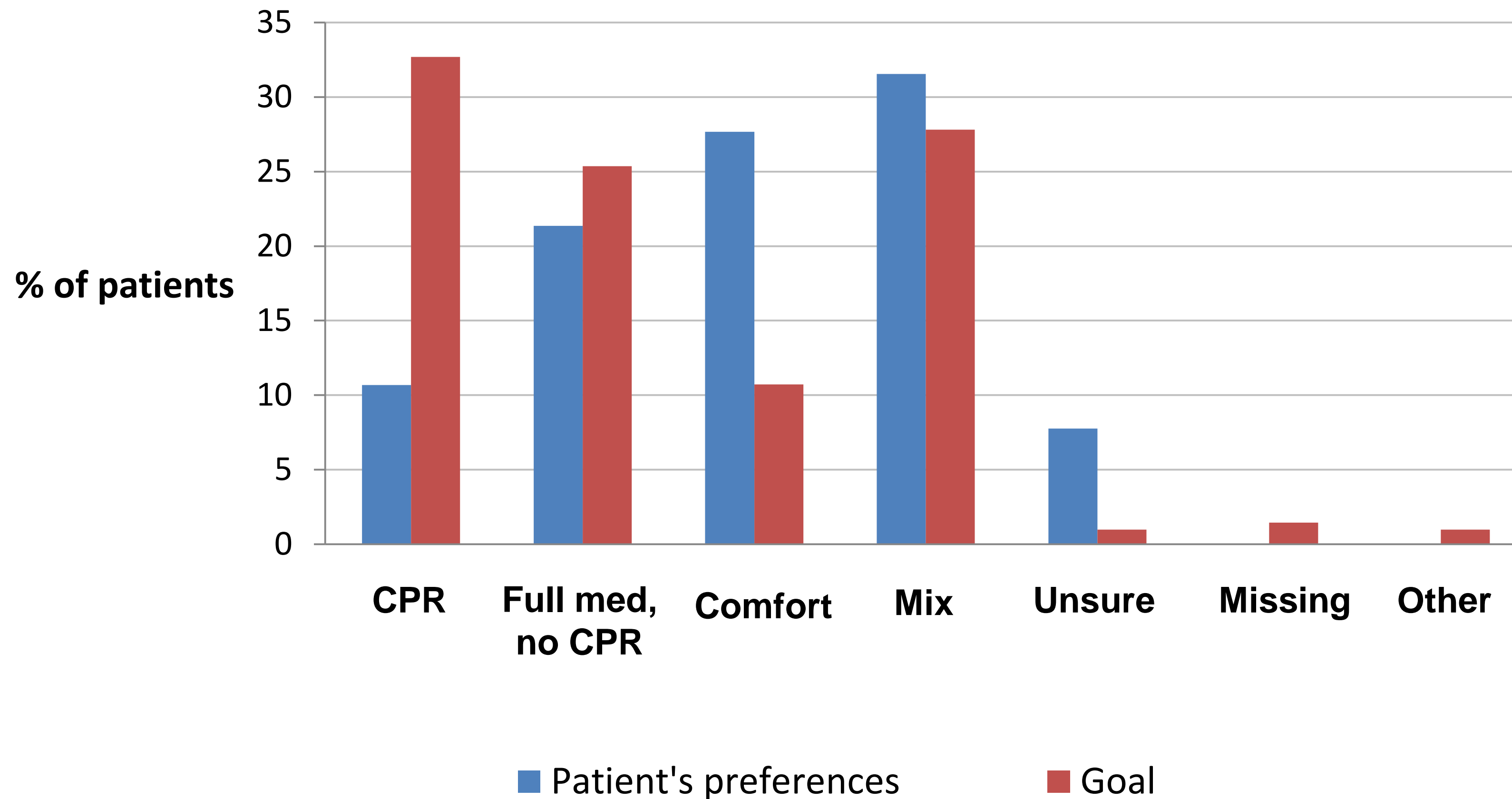


Seriously ill frail elderly: preferences for EOL care

- 76% of patients have thought about the kinds of life-sustaining treatments they would want
- 89% of these patients have discussed with someone



Prescribed orders for life sustaining treatment are discordant with patient preferences 70% of the time



Where do we need to go?

- *"End of Life Care: The Last 100 days"*, CAHS Forum, Ottawa, Sept 2012

- Narrowing gaps between EOL care that patients prefer and what they actually receive should be a national priority
- The quantity and quality of advance care planning needs to be improved
- Burdens to family caregivers must be acknowledged and addressed
- Physicians in training need more and better education about palliative care

Cook D, Rocker G, Heyland D. CMAJ Nov 5, 2013.

TVN: a unique opportunity for ACP research in Canada

- TVN research themes:
  - **Advance care planning** / end-of-life care
  - Acute care/critical care
  - Community and residential care
  - Transitions of care

TVN research: advance care planning

- Identifying patients for advance care planning
  - Identifying seriously ill frail elderly in primary care (Urquhart)

- Advance care planning tools:
  - Knowledge synthesis EOL communication tools (Chung/Oczkowski)
  - Evaluation of ACP tools with seriously ill elderly patients (Cunningham)
  - iGAP: ACP tool testing in primary care (Howard)
  - iDECIDE: testing decision support tools in hospital setting (You)

- Access to advance care planning:
  - EOL conversations for LGBT older adults (deBries/Gutman)
  - Cross cultural issues in ACP (Neyfeh)

Annals of Internal Medicine

REVIEW

Decision Aids for Advance Care Planning: An Overview of the State of the Science

Mary Butler, PhD, MBA; Edward Ratner, MD; Ellen McCreedy, MPH; Nathan Shippee, PhD; and Robert L. Kane, MD

Advance care planning honors patients' goals and preferences for future care by creating a plan for when illness or injury impedes the ability to think or communicate about health decisions. Fewer than 50% of severely or terminally ill patients have an advance directive in their medical record, and physicians are accurate only about 65% of the time when predicting patient preferences for intensive care. Decision aids can support the advance care planning process by providing a structured approach to informing patients about care options and prompting them to document and communicate their preferences. This review, commissioned as a technical brief by the Agency for Healthcare Research and Quality Effective Health Care Program, provides a broad overview of current use of and research related to decision aids for adult advance care planning. Using interviews of key informants and a search of the gray and published literature from January 1990 to May 2014, the authors found that many decision aids are widely available but are not assessed in the empirical literature. The 16 published studies testing decision aids as interventions for adult advance care planning found that most are proprietary or not publicly available. Some are constructed for the general population, whereas others address disease-specific conditions that have more predictable end-of-life scenarios and, therefore, more discrete choices. New decision aids should be designed that are responsive to diverse philosophical perspectives and flexible enough to change as patients gain experience with their personal illness courses. Future efforts should include further research, training of advance care planning facilitators, dissemination and access, and tapping the potential opportunities that lie in social media or other technologies.

Ann Intern Med. doi:10.7326/M14-0644 www.annals.org
For author affiliations, see end of text.
This article was published online first at www.annals.org on 29 July 2014.

Key findings

- Many decision aids widely available but not evaluated
- Most of those tested are proprietary or not publicly available
- Future efforts should focus upon:
  - Development of more validated tools appropriate for patients across various settings
  - Broad array of tools for use at various stages of life/illness trajectory
  - Who should facilitate EOL communication and how
  - Tapping potential opportunities in social media or other technologies

Where do we need to go?

- Patients & family members: ACP tools
- Clinicians: better training in EOL communication
- Health system: how to embed and implement ACP (tools) in practice
- Social change: normalize conversations about death & dying

“If we needed a cause to unite us all, improving end of life care should be that cause.”

-- Deborah Cook & Graeme Rocker, 2013

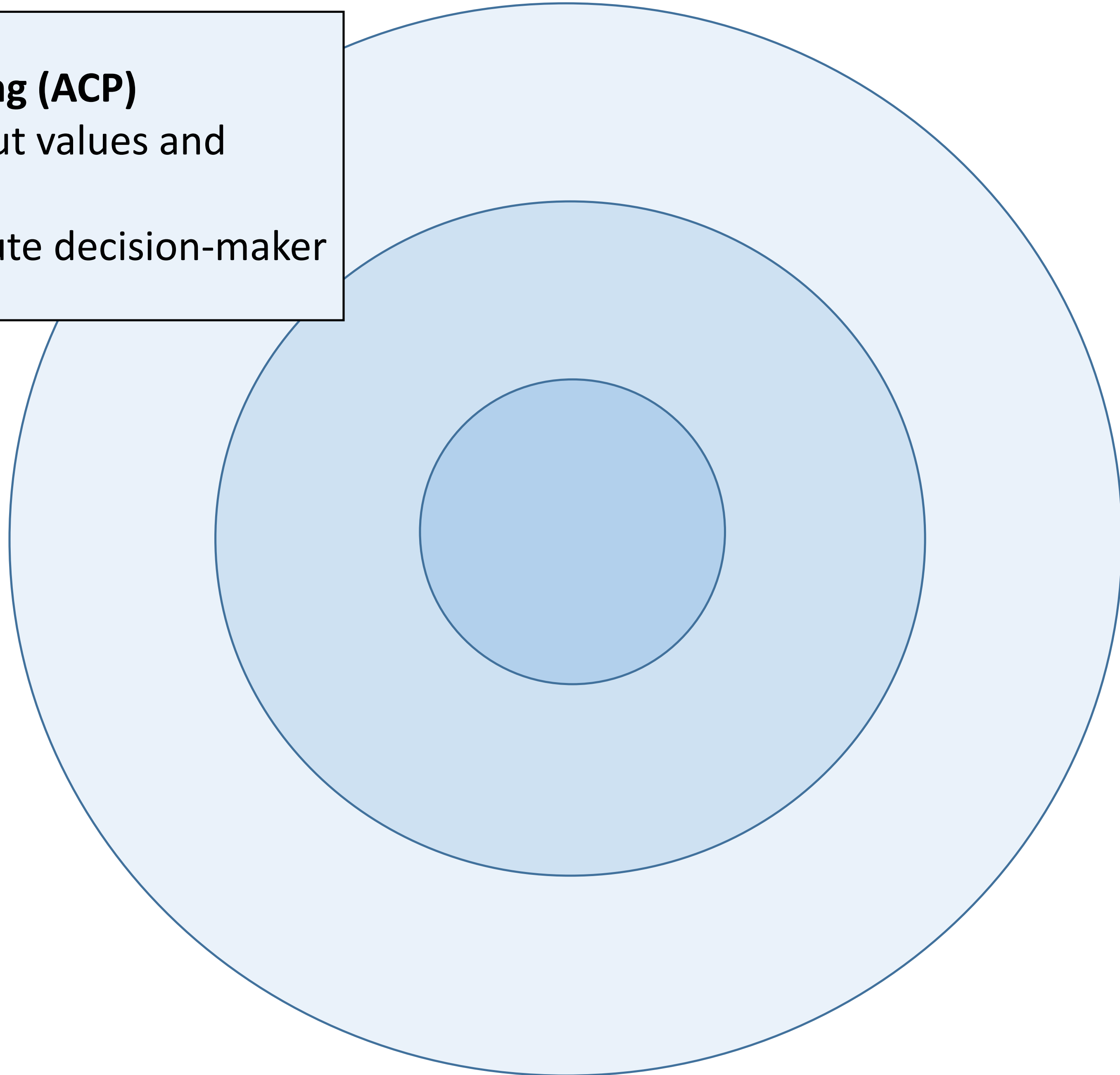
Advance Care Planning (ACP)

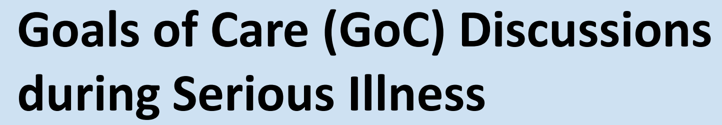
Goals of Care (GoC) Discussions during Serious Illness

Decision making about life-supporting treatment

Advance Care Planning (ACP)

- Conversations about values and preferences
- Choosing a substitute decision-maker



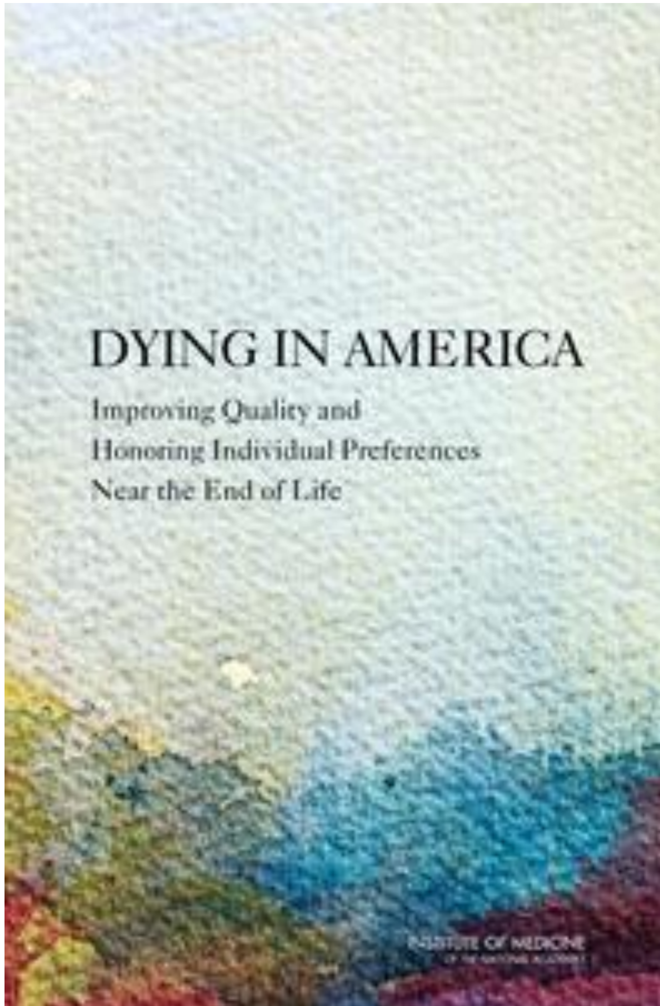


Goals of Care (GoC) Discussions during Serious Illness

- Discussions about illness understanding, prognosis, goals, fears, values, trade-offs

Decision making about life supporting treatment

- “in the moment” shared decision making process informed by ACP and GoC discussions



Recommendations

1. Delivery of care
2. Clinician-patient communication and advance care planning
3. Professional education and development
4. Policies and payment systems
5. Public education and engagement

Institute of Medicine. Sept 17, 2014.