Advance Care Planning for Patients and Frailty

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Disclosure

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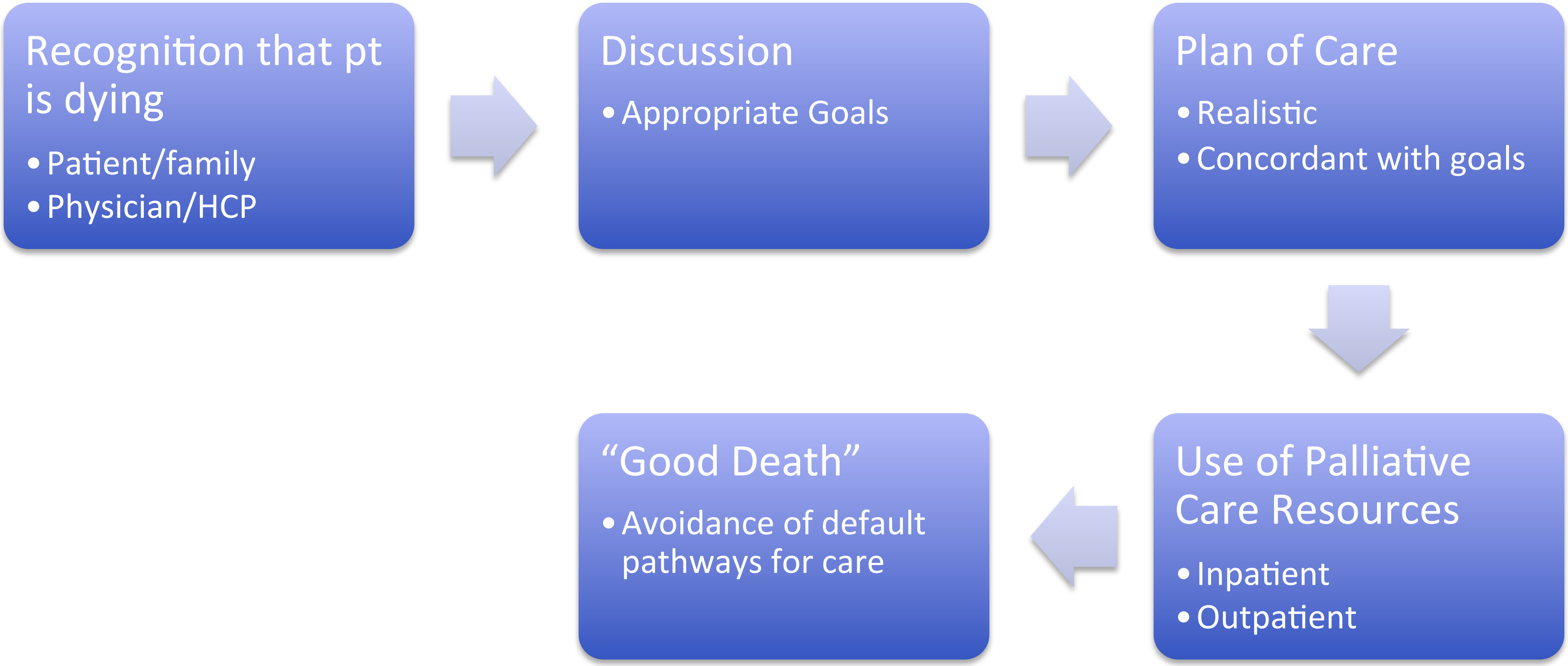
    - None
- Mitigating potential bias
    - Not applicable

Objectives

- Understand a framework for looking at Advance Care Planning and Goals of Care Discussions.
- Look at the current evidence for the effectiveness of Advance Care Planning.
- Appreciate the challenges involved in performing and studying Advance Care Planning in the Frail.

Why are you here?

How to get a “Good Death”



Recognition that pt is dying
- Patient/family
- Physician/HCP

Discussion
- Appropriate Goals

Plan of Care
- Realistic
- Concordant with goals

Use of Palliative Care Resources
- Inpatient
- Outpatient

“Good Death”
- Avoidance of default pathways for care

The Gaps

- Poor recognition of dying trajectory ✔✔
- Poor disclosure/communication ✔
- Goals do not reflect reality of advanced illness ✔
- Inadequate palliative resources ✔
- Pt excluded from palliative resources ✔✔✔
- No plans to deal with deterioration ✔

Survival Duration among Patients with a Noncancer Diagnosis Admitted to a Palliative Care Unit: A Retrospective Study

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- Review of 1000 pts admitted to 4 Toronto-area PCUs over 1yr
    - 79% Cancer, 21% Non-Cancer
- Compared with cancer, non-cancer patients more disabled, closer to death…
    - Lower mean PPS (40 vs 21)
    - Shorter mean survival (24d vs. 14d)
        - 90th percentile (66d vs. 25d)
    - BUT…shorter mean waiting time (3d vs. 9d)
- Many non-cancer patients rejected, never referred, or referred too late

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Closing the Gaps

- Better Prognostication*
- Better Communication
- Better Advance Care Planning
- More Palliative Care Resources
- Adapt PC to meet the needs of non-cancer patients
- Being ready for non-cancer EOL scenarios

ACP in Non-Cancer Illness

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ACP- A Tale of Two Cities

- Cancer
  - Discontinue curative/life-prolonging Rx when focus changes to palliation
  - Often clear transition point
  - Unidirectional trajectory, steady progression
  - Perception that disease is life limiting
  - Younger pt, younger caregivers
- Non-Cancer
  - Many curative/life-prolonging Rx continue when focus changes to palliation
  - No clear transition point
  - Exacerbations, or slow progression
  - Perception that disease is not life-limiting
  - Older patients, older caregivers

Thanks to Leah Steinberg

Observations - COPD

- COPD vs. Cancer in final 6 months
  - Fewer discussions of goals of care
  - More CPR/life support (no difference in preferences)
  - Greater symptom burden
  - Less patient understanding of disease, treatments
  - MDs less able to judge benefit of PC
  - Fewer die at home
- Disease course unpredictable
  - “Unexpected death”

Rocker et al. J Pall Med 2007:10:783-97.

Observations - COPD

- 14% of COPD pts entering pulmonary rehabilitation had ACP discussion with MD
    - 94% had opinion about intubation
    - 99% wanted to discuss ACP
- 1/3 of COPD pts on oxygen had discussed ACP
- COPD patients rate MD EOL communication skills as poor

Heffner et al. AJRCCM 1996;154:1735-40.
Knauft et al. Chest 2005;127:2188-96.
Curtis et al. Eur Respir J 2004;24:200-5.

Observations - CHF

- Pts with HF less involved in decision making than pts with cancer
- Pts don't associate symptoms with cardiac status
- History of recovery from exacerbations

BMJ 2002;325: 929–33
JAMA 1998;279:1709–14

Observations - Renal Failure

- ACP Rare (10%)
- Poor knowledge of PC options
    - Pts rely on nephrologist to address symptom issues
- Many regret decision to start HD
    - 52% started due to “doctor’s wish”
- Dialysis Deaths
    - Majority hospitalized
    - 1/3 “Unexpected”
        - Less use of PC
        - Poorer symptom control, QODD

Davison et al. Clin J Am Soc Nephrol 2010;5:195–204
McAdoo et al. Nephrol Dial Transplant 2012;27:1548-54.

Observations - Renal Failure

- Most patients have already considered EOL options
- Patients want greater discussion of quality of life and goals
    - Empowerment
    - Relationships with families
- Patients want MDs to initiate/facilitate this discussion (97%)
    - Major barrier

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Davison and Simpson. *BMJ* 2006;333:886.
Davison. *CJASN* 2006;1023-8.

Do we need ACP?

- Study of 3746 pts who died 2000-2006
- 42.5% required decision-making about CPR/ICU
    - 70% lacked capacity
    - 67.6% had advanced directives

Silveira et al. NEJM 2010;362:1211-8.

What does ACP do?

- Leave useful instructions to FMs/MDs?
- Ensures that EOL Care is in accordance with wishes?
- Reduces distress in patients/family members?
- Reduces aggressive care at EOL?
- Reduces costs at EOL?

Leaving useful instructions?

- Review of 688 ACP documents
  - 13% went beyond naming proxy, standard will
  - 5% gave specific instructions about use of LS
  - 3% gave instruction relevant for current situation
- Reasons ACP disregarded
  - "Not seen as hopelessly ill"
  - Family not available or overwhelmed
  - ACP document vague or inapplicable
  - Never disregarded unilaterally

Covinsky et al. J Am Geriatr Soc 2000;**48(5 Suppl): S187-193.**

Directing EOL Care?

- SUPPORT
    - Half of MDs unaware of patient preferences for CPR
    - Comprehensive intervention with facilitators
        - No improvements in communication with MD, timing of DNR orders, MD knowledge of pt preferences for DNR
        - Days spent in an ICU prior to death (>10d for 38%)
- Surrogate Decision-Maker Accuracy 68%
    - Not improved by ACP/Living Will
    - SDMs consider own hopes/needs, feel that decisions imply judgment about value of life

Shalowitz et al. Arch Int Med 2006;166:493-7.
SUPPORT. JAMA 1995;274:1591-8.

Directing EOL Care?

- Pts want us to ignore their advanced directives
  - 1159 pts from SUPPORT/HELP
  - 867 (75%) would prefer MD/family decision-making to advance directive
- Pts don't agree with own advanced directives
  - Telephone survey of 202 people >70 y.o.
  - Asked standard living will question, then 6 scenarios
  - Desire for LS explained 7-23% of answers

Puchalski et al. J Am Geriatr Soc 2000; **48(5 Suppl): S84-90**
Winter et al. J Palliat Med 2010;**13(5): 567-572**

Reducing Distress?

- Patients
  - Better QOL, higher satisfaction with care
  - No change in depression/"worry"
- Family Members
  - Lower rates of depression, distress, anxiety
  - Higher satisfaction with care

Wright et al. JAMA 2008;**300(14): 1665-1673.**
Detering et al. BMJ 2010;340:c1345

Reducing Aggressive Care?

- 332 pts with advanced cancer + SDMs
  - Pts with living wills underwent
    - Less mechanical ventilation (1.6% vs 11%)
    - Less resuscitation (0.8 vs 6.7%)
    - Less ICU admission (4.1% vs. 12.4%)
- RCT of 151 pts with metastatic lung Ca
  - Early PC vs "standard care"
    - Less aggressive care at EOL (33% vs. 54%)

Wright et al. JAMA 2008;**300(14): 1665-1673.**
Temel et al. N Engl J Med 2010;**363(8): 733-742.**

Reducing costs?

- ACP may reduce cost of care
    - Lower spending in final week ($1041)
    - Lower spending in final 6 months ($5585)
    - Higher costs associated with worse quality of death
    - Cost savings mostly in high-expenditure areas
- ACP Costs savings not universal

Zhang et al. Arch Int Med 2009;169:480-8.
Nicholas et al. JAMA 2011;306:1447-53.
Halpern and Emanuel. Arch Int Med 2012;172:

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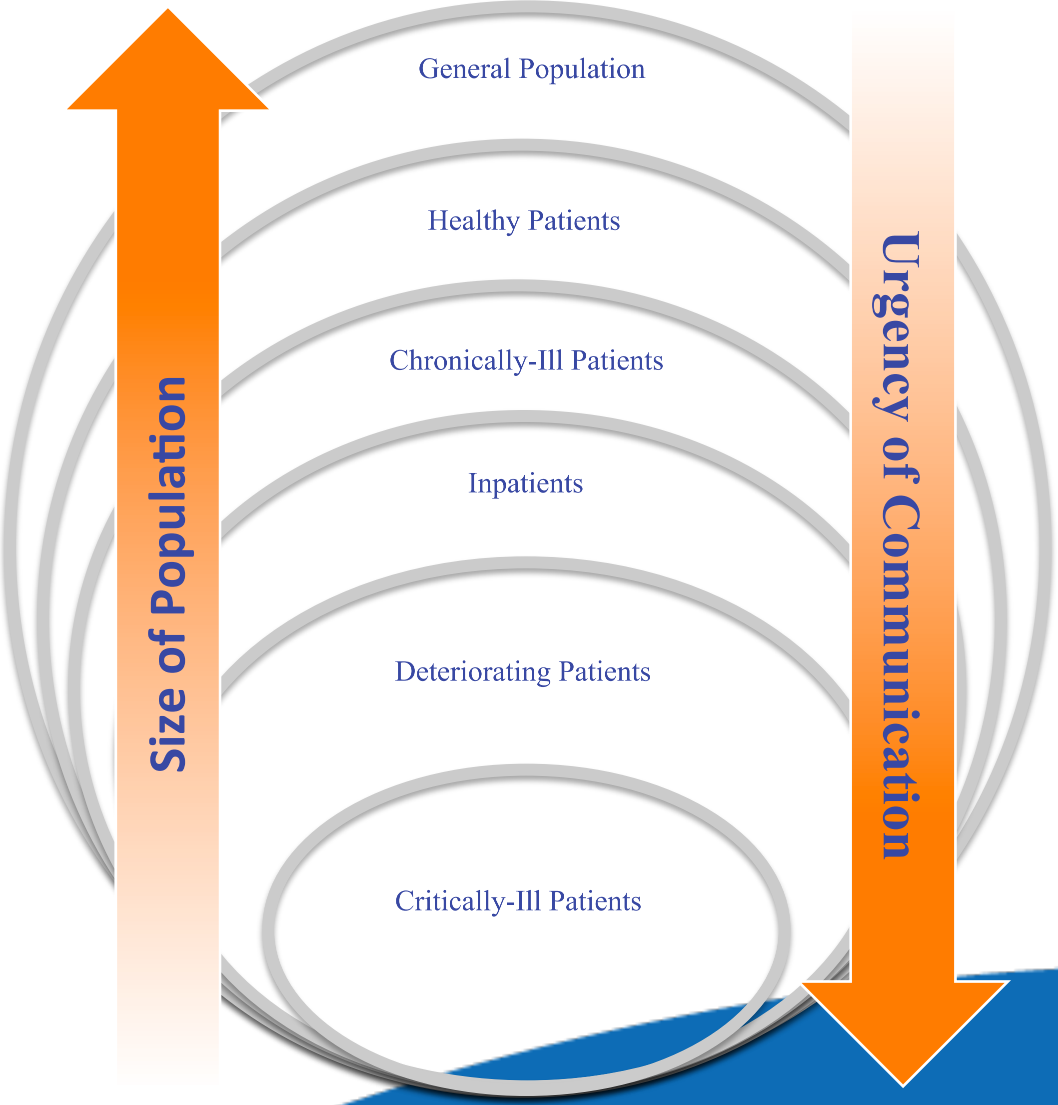
ACP Paradigms

- 1.0 – "Controlling death"
- 2.0 – Recording values
- 3.0 – Decisional readiness/coaching
    - Different goals in different settings
    - Preparing "the team"

Advance Care Planning 3.0

- "ACP Onion"
  - Public Awareness
  - Engagement in primary care
  - Outpatient chronic illness
  - Unscheduled admission
  - Outreach/Rapid Response
  - ICU



Advance Care Planning 3.0

- Change framework of ACP
    - Values, Outcome-based
        - “What outcome would I consider valuable?”
        - “What is important to me?”
    - Decisional preparation
    - Engagement at multiple levels.
  - Steps
    - Assess readiness
    - Choose a surrogate
    - Clarify values in real/hypothetical situations
    - Establish leeway in decision-making

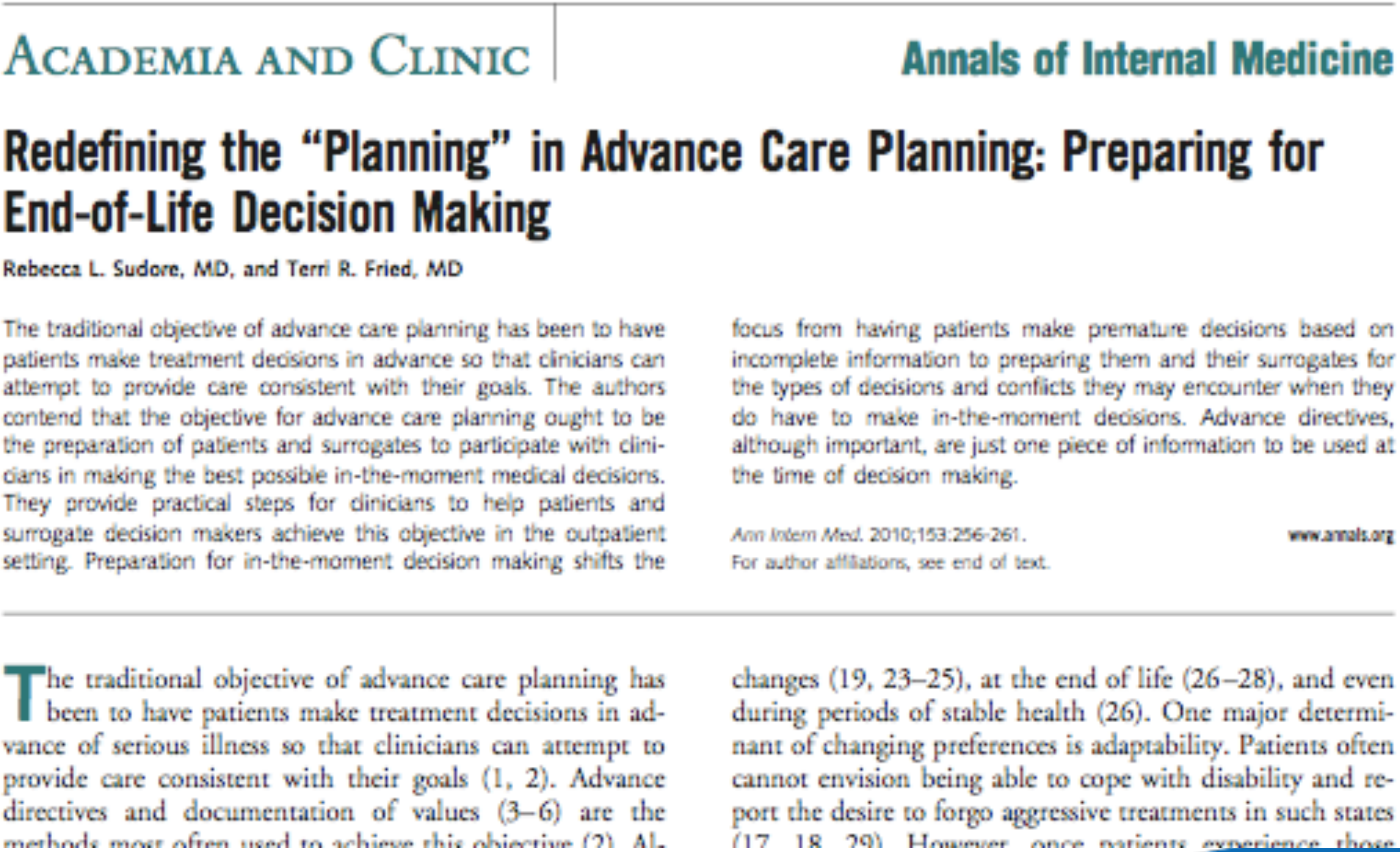
Sudore and Fried. Ann Int Med. 153(4): 256-U274.
Detering et al. BMJ 340: c1345.

Advance Care Planning 3.0

- Respecting Patient Choices
  - Facilitated Meetings/Decisional Coaching
  - Improved satisfaction with care
  - Reduced rates of death in ICU (0 vs. 15%)
  - 86% of pt wishes were “known and followed”
    - 30% in control group

Detering et al. BMJ 340: c1345.

Advance Care Planning 3.0



ACADEMIA AND CLINIC | Annals of Internal Medicine

Redefining the "Planning" in Advance Care Planning: Preparing for End-of-Life Decision Making

Rebecca L. Sudore, MD, and Terri R. Fried, MD

The traditional objective of advance care planning has been to have patients make treatment decisions in advance so that clinicians can attempt to provide care consistent with their goals. The authors contend that the objective for advance care planning ought to be the preparation of patients and surrogates to participate with clinicians in making the best possible in-the-moment medical decisions. They provide practical steps for clinicians to help patients and surrogate decision makers achieve this objective in the outpatient setting. Preparation for in-the-moment decision making shifts the focus from having patients make premature decisions based on incomplete information to preparing them and their surrogates for the types of decisions and conflicts they may encounter when they do have to make in-the-moment decisions. Advance directives, although important, are just one piece of information to be used at the time of decision making.

Ann Intern Med. 2010;153:256-261. www.annals.org
For author affiliations, see end of text.

The traditional objective of advance care planning has been to have patients make treatment decisions in advance of serious illness so that clinicians can attempt to provide care consistent with their goals (1, 2). Advance directives and documentation of values (3–6) are the methods most often used to achieve this objective (2). Al-

changes (19, 23–25), at the end of life (26–28), and even during periods of stable health (26). One major determinant of changing preferences is adaptability. Patients often cannot envision being able to cope with disability and report the desire to forgo aggressive treatments in such states (17, 18, 29). However, once patients experience those

Challenges in Non-Cancer

- Hard to translate goals into actions
  - "I want comfort care at home."
    - Is IV lasix "comfortable"?
    - Do you want to stay home no matter what?
- More limited access to supports that depend on prognosis
    - Home Care
    - Home Palliative Care
- Limited availability of advanced therapies outside acute hospital setting
    - Parenteral diuretics
    - Inotropes
    - Non-invasive ventilation

How to discuss EOL

- Normalize conversation
  - Plan A vs. Plan B
  - Wishing for something vs. planning for something
- "What is most important to you?"
  - Explore- fears, concerns
  - Acknowledge and validate
- Support
  - Separate message from messenger
  - What may happen if we don't discuss this
- Non-abandonment
  - Comanagement with specialist

How to discuss EOL

- Clarify unpredictable disease course
- Preview typical decisions
    - Assess tolerance of investigations and treatments
    - Sequential nature of disposition
        - “If things are not going well at home…”
- Start with the end…
    - “What would you consider to be a bad death?”

Determining Goals/Plan of Care – Communication Pearls

- Action plans for unforeseen events
    - "Things will not always go according to plan…"
- Ensure decision-making "team" is all present
    - Family member concerns can be a major barrier to discussion
- Refer to existing ACP resources
    - "Speak Up Campaign"
- Risk/benefit of discussing goals
    - Distress rare (<2%), but benefit common (~50%)

http://www.advancecareplanning.ca

Arch Intern Med 2004;164:1999–2004

ACP Resource

Speak Up

Start the conversation about end-of-life care.

Speak Up

Make your plan,
share your plan.

Imagine - one day, without warning, you find yourself in a hospital, unable to communicate. Who would speak for you and make health care decisions for you?

Learn more about Advance Care Planning.

Quick Links

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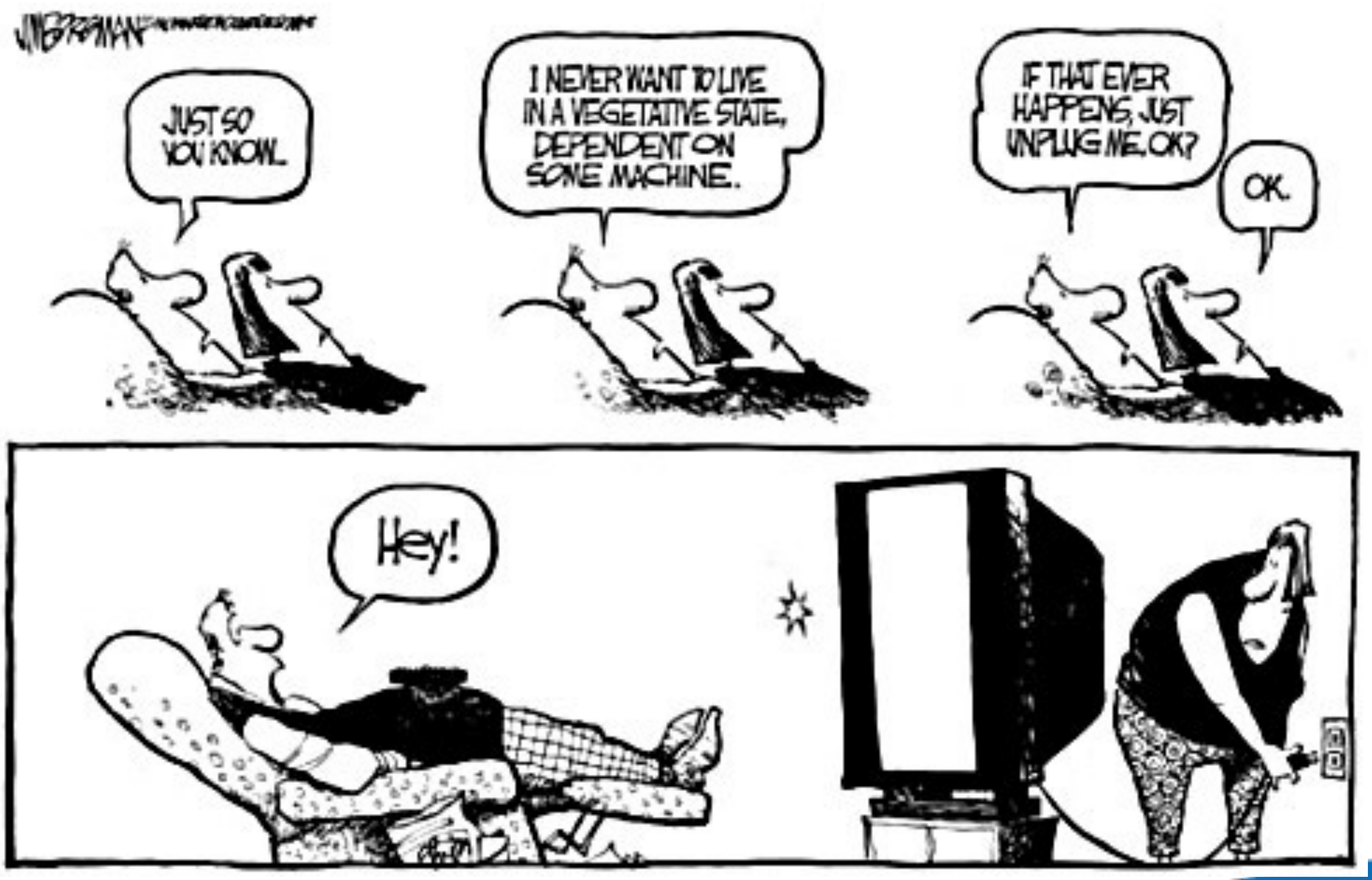
www.advancecareplanning.ca

Disease-specific considerations…



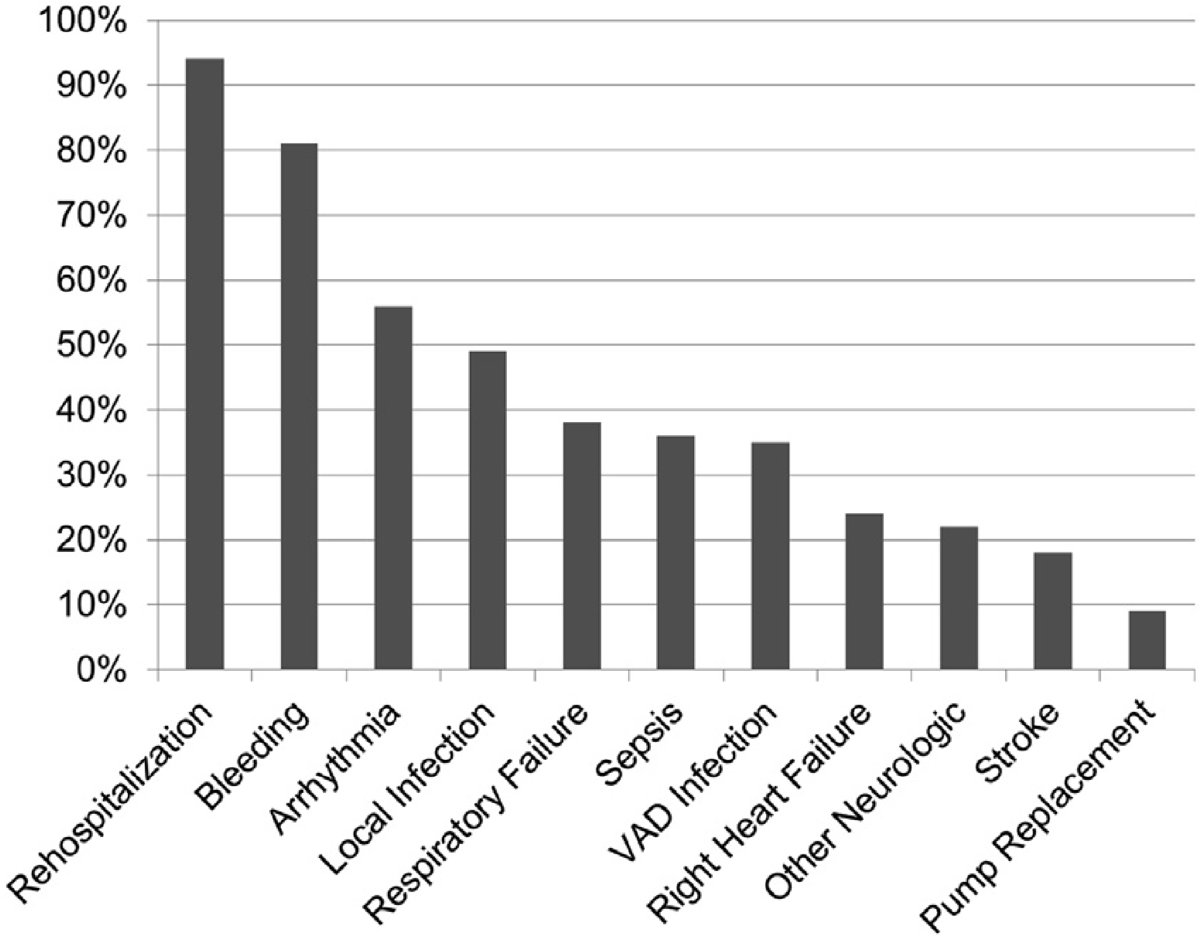
Respiratory Disease

- Antibiotics
- Non-invasive ventilation

Cardiac Disease

- Parenteral diuretics
- Inotropes
- ICD Deactivation
    - Rarely discussed with pt even after DNR order
    - Pacer vs. Defibrillator
    - Explain arrhythmic death vs “pump failure”
    - “I would recommend that…”
        - “People who benefit from ICDs are…”
        - “People who do NOT benefit from ICDs are…”
- Mechanical Cardiac Support (VAD)

Cardiac Disease- Complications of VAD



Swetz et al. *JPSM* 2014

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Renal Disease

- What would be the effect of dialysis (vs. conservative management)?
    - Mortality?
    - Quality of life?
- What would be involved in dialysis?
    - Hemodialysis
    - Peritoneal dialysis
- Trials of dialysis?
    - Acceptability of stopping HD?

Cirrhosis

- Transplant
- Concerns about PC medications causing encephalopathy, shortening life

A policeman walks down a street…

I want to make stuff better!

- Problem: People are dying from acute MI
- Potential Therapy: Thrombolysis
- Subjects: People with acute MI
- Setting: ER
- Design: Double-blinded RCT
- Endpoint: Mortality

I want to make stuff better!

- Problem: People are dying badly
- Potential Therapy: Living will? Communication? Palliative Care?
- Subjects: Patients? Physicians? Nurses? "The system"?
- Setting: Early? Late? Community? Clinic? Ward?
- Design: Retrospective? RCT? Before-after?
- Endpoint: Structure? Process? Outcome?

The problem…

- What is a “good death”?
  - “A decent or good death is one that is: free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards.”
    - » Institute of Medicine (1997)
  - Avoidable distress?
  - What are wishes? What is in general accord with them?
  - What are clinical, cultural and ethical standards for death?

Subjects

- Patient unavailable in up to 95% of cases
    - Endpoints rarely derived from subjects
    - Selection bias
        - Willingness to participate in “EOL” studies
- Staff
    - Who is targeted? Multidisciplinary…
- “System”
    - Take 2 aspirins and call me in the morning

Setting

- Early
    - Healthy, community-dwelling, clinic visits
    - Diluted? Conversation in earnest?
- Late
    - Chronic or Acute+Chronic illness, hospitalized
    - Too late to influence outcome?
- Selection bias

Design

- Retrospective
- RCT
    - Blinding
    - Crossover
- Before-After
    - Societal trends
    - Hawthorne
- Standardized Interventions
    - “Palliative Care Consultation”

Endpoints

- (Structure)
- Process
    - Steps that are taken or not taken
    - Easy to collect, hard to prove relevance
- Outcome
    - Demonstrable effect on subjects
    - Usually clearer importance to subjects, harder to collect

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Curtis and Engelberg. CCM 2006;34:s341-7.

ACP Quality Indicators- ACP

- Discussing preferences for LST with SDM
- Discussing prognosis with MD
- Discussing preferences for LST with MD, family
- Written ACP document
- Appointment for ACP discussion with MD
- (Discussing preferences for non-MD HCP)

Sinuff et al. J Pain Symptom Manage 2015; 10.1016/j.jpainsymman.2014.12.007

ACP Quality Indicators- GCD

- HCP discussing limited prognosis with patient
- HCP discussing risks/benefits of LST, palliation
- Arranged time with team to discuss plan
- HCP asked about prior ACP documentation
- HCP asked about values, goals

Sinuff et al. J Pain Symptom Manage 2015; 10.1016/j.jpainsymman.2014.12.007

ACP Quality Indicators- Documentation

- Documentation of GCD in record
- Documented goals consistent with preferences
- Documentation of conversations
- HCP helps pt access legal documents for ACP

Sinuff et al. J Pain Symptom Manage 2015; 10.1016/j.jpainsymman.2014.12.007

Ask yourself the following

- What problem are the investigators looking at?
- Who are the subjects? Are they appropriate?
    - Any chance of a selection bias? What effect would this have?
- What intervention are they investigating?
    - If there is a "control" group, what did they get?
- What is the setting for this study?
    - Would you get the same findings in another setting?
- What is the design? What do you need to watch for?
- What are the outcomes? Are they relevant?

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