Communication in Serious Illness: Ethical Values, Empirical Evidence, and Clinical Experience

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Objectives

- To explore ethical theory framing best practices for serious illness communication
- To review evidence linking high quality communication to outcomes in serious illness
  - Prognosis
  - POLST
  - Interpersonal communication
  - Decision aids
- To discuss application of communication skills in decision-making in serious illness

Mrs. BC

76 yo woman admitted to hospital from a nursing home with sacral decubitus ulcer and osteomyelitis with uncontrolled pain; past depression with suicide attempt; early dementia

Ethical communication challenges?

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Mrs. BC

76 yo woman admitted to hospital from a nursing home with sacral decubitus ulcer and osteomyelitis with uncontrolled pain; past depression with suicide attempt; early dementia

Ethical communication challenges:

- Decisional capacity / surrogate role
- Prognosis – treatable but incurable infection
- Goals of care
- Preference for site of care

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Mr. ML

A 53 year old man with COPD is admitted for progressive leg weakness, severe hypoxia. X-rays suggest lung CA metastatic to brain.

Ethical communication challenges?

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Mr. ML

A 53 year old man with COPD is admitted for progressive leg weakness, severe hypoxia. X-rays suggest lung CA metastatic to brain.

Ethical communication challenges:

- Delivering bad news (prognosis)
- Preferences for CPR / vent decision
- Goals of care

Mrs. LS

A 95 year old woman, previously healthy, is admitted with a small MI and non-sustained VT. She has a living will, but wants life support if it will “help”.

Ethical communication challenges?

Mrs. LS

A 95 year old woman, previously healthy, is admitted with a small MI and non-sustained VT. She has a living will, but wants life support if it will “help”.

Ethical communication challenges:

- Defining “help” (goals of care)

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Ethical Framework

Communication is valued by people with serious illness

- Serious illness threatens communication
- Family caregivers want more information than they receive
- Most persons with serious illness value control (*autonomy)*
- Communication affects outcomes – satisfaction, treatment choices, resource use, family bereavement (*beneficence, non-malfeasance, justice)*

Singer 1999; Steinhauser 2000; Hanson 1997; Teno 2004

Decision-making in the ICU

Audiotaped 51 ICU family meetings

- Clinicians spoke 71% of the time; family 29%
- Greater time for family to talk → more family satisfaction
- More empathetic statements → more family satisfaction
- 2% met criteria for shared decision-making

Selph, JGIM 2007; White, Arch IM 2007; McDonagh CCM 2004

Shared decision-making

Shared decision-making ensures treatment in serious illness is guided by patient values rather than medical norms or economic pressures

Shared decision-making used in only 9% of outpatient encounters

1. Role in decision-making
2. Clinical circumstances
3. **Treatment options**
4. Pros and cons
5. Clinical uncertainties
6. Assess patient / family understanding
7. Explore patient / family preferences

Braddock 1997

When to use shared decision-making

High risk, high certainty ▪ Intermediate discussion	High risk, low certainty ▪ Shared decision-making
Low risk, high certainty ▪ Simple consent ▪ Minimal discussion	Low risk, low certainty ▪ Simple consent ▪ Some elements of shared decision-making

Whitney SN, Ann Intern Med 2004

Goals of care framework

"To cure sometimes, to relieve often, to comfort always"

- Curing disease & restoring health
- Prolonging survival
- Restoring or maintaining function
- Promoting comfort
- Patient goals ("quality of life") –
  - Staying home
  - Maintaining awareness
  - Living to see a grandchild born
  - Spiritual goals
- Providing support for family

Kaldjian, Am J Hosp Pall Med 2009

Evidence and Clinical Application: Prognosis

Defining prognosis

Knowledge beforehand – prediction of future outcomes of a disease based on medical evidence and clinical experience.

- Time: life expectancy or probability of survival
- Experience of illness: trajectory, function, symptoms
- *Historically, emphasis diminished as therapies emerged*

Christakis NA, Soc Sci Med 1997

Prognosis allows preparation

"What tormented Ivan Illych most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and that he only need keep quiet and undergo a treatment and then something very good would result."

-- Leo Tolstoy, 1886

"Being honest is a big deal. She never had a clue that she was that close to the end. I think doctors should have told her that death was close. She never had the chance to say good-bye."

-- bereaved family member in NC, 1991

Patients frame prognosis with optimism

Patients with Stage III, IV lung and colon cancer (n=917) – 55% died within 6 months

- 96% gave themselves >50% chance of living 6 months or more
- Understanding of prognosis correlated with treatment choices

Weeks JC, JAMA 2000

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Patients frame prognosis with optimism

Patients with Stage IV lung, colorectal cancer (CANCors n=1193) who discussed chemotherapy with MD

- 94% elected chemotherapy
- 69-81% expected potential cure
  - » Nearly all expected life prolongation
  - » Over 90% expected some symptom relief
- Minority race / ethnicity groups, poor quality MD communication → more likely to expect benefit

Weeks J, NEJM 2012

Family members frame prognosis with optimism

N=126 patients with prolonged ventilator use

- Family expected 1-yr survival 93% (MD 43%)
- Family expected 1-yr function 71% (MD 6%)
- *Actual 1-yr survival + high function: 9%*

Little research on facilitating patient / family understanding of prognosis

Glare JPM 2008; Glare BMJ 2003; Cox AIM 2009

Physicians frame prognosis with optimism

MD asked prognosis for 468 terminally ill patients enrolling in hospice

- Actual median survival 24 days
- 20% accurate, 63% overestimated, 17% underestimated
- Physicians told patients to expect better survival than they believed was true
- Accuracy increased with experience and shorter MD-patient relationship

Physicians able to discriminate high from low risk patients, but prognosis poorly calibrated

Glare BMJ 2003;Christakis, BMJ 2000

Do patients want to know prognosis?

Survey of 126 patients with Stage IV cancers

- 80-85% want survival rates
  - 59% want to discuss survival when metastatic disease first discovered

Interviews with 179 family for ventilated ICU patients with 40% risk of death

- 93% felt that avoiding prognostic information is an unacceptable way to sustain hope
- Needed for practical and emotional preparation

Apatira & White, AIM 2008; Hagerty, JCO 2004

Communication improves prognostic awareness

Audio-recording of 51 oncologists with 151 advanced cancer patients

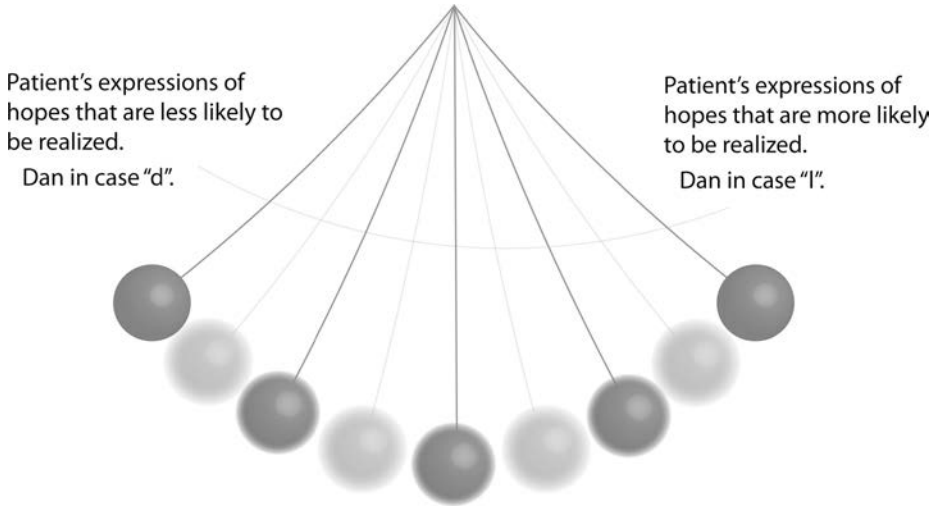
- 3.3 optimistic statements / visit
- 1.2 pessimistic statements / visit
- ~ 50% patients - oncologist concordance on probability for cure
  - » If oncologist made at least one pessimistic statement, increased concordance with prognosis (OR 2.59)

Robinson TM, Support Care Cancer 2008

Prognosis for geriatric patients

Prognostic awareness

- *What is your understanding of how you are doing now?*
- *What do you think the future holds?*
  - » *What else do you want to know?*
  - » *Can we think together about a way to talk about this?*
  - » *I hope . . . and I worry . . .*



Try this – prognosis in practice

e-Prognosis and other tools

Communication skills for prognostic awareness

- Explore how much a patient wants to know

Communicate time frames –

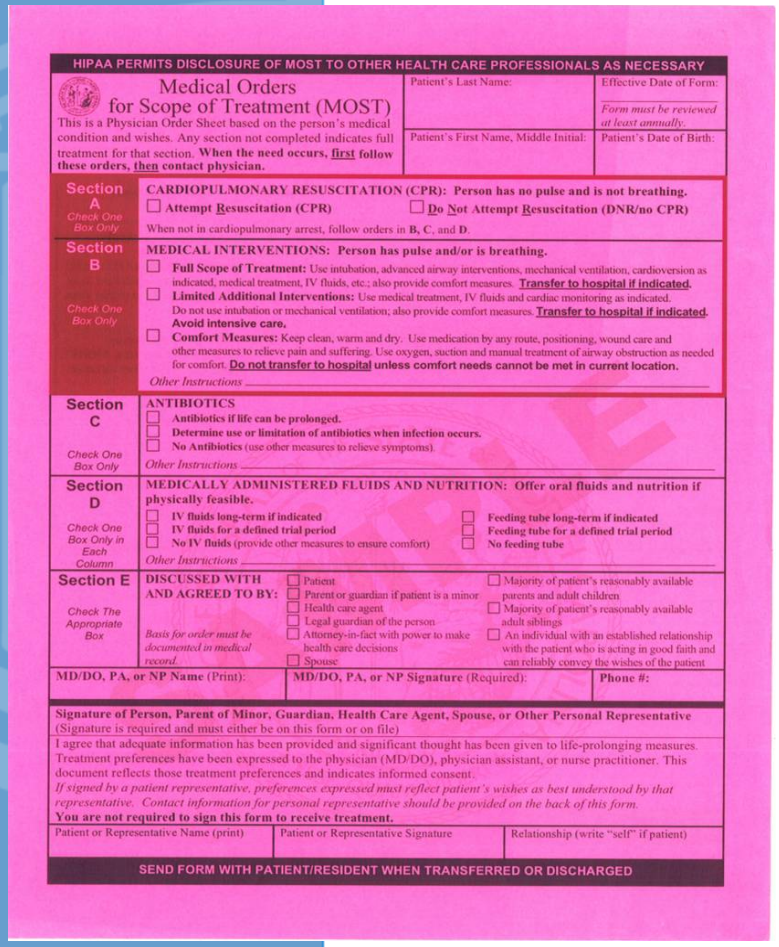
- *Hours to a few days*
- *Days to weeks*
- *Weeks to months*
- *Several months, but a year is unlikely*
- *Many years*

Talk about illness trajectory –

- Dementia -- *She is likely to live for years, . . . but she will slowly worsen in ability . . .*
- Systolic ischemic heart failure – *. . . these symptoms will come off and on for the rest of your life. . . you may have months of time*

Evidence and Clinical Application: POLST Paradigm

POLST advance directive



HIPAA PERMITS DISCLOSURE OF MOST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

Medical Orders for Scope of Treatment (MOST)

This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed indicates full treatment for that section. **When the need occurs, first follow these orders, then contact physician.**

Patient's Last Name: | Effective Date of Form: *Form must be reviewed at least annually.*

Patient's First Name, Middle Initial: | Patient's Date of Birth:

Section A *Check One Box Only*

CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.

☐ **Attempt Resuscitation (CPR)** ☐ **Do Not Attempt Resuscitation (DNR/no CPR)**

When not in cardiopulmonary arrest, follow orders in **B, C**, and **D**.

Section B *Check One Box Only*

MEDICAL INTERVENTIONS: Person has pulse and/or is breathing.

☐ **Full Scope of Treatment:** Use intubation, advanced airway interventions, mechanical ventilation, cardioversion as indicated, medical treatment, IV fluids, etc.; also provide comfort measures. **Transfer to hospital if indicated.**

☐ **Limited Additional Interventions:** Use medical treatment, IV fluids and cardiac monitoring as indicated. Do not use intubation or mechanical ventilation; also provide comfort measures. **Transfer to hospital if indicated. Avoid intensive care.**

☐ **Comfort Measures:** Keep clean, warm and dry. Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. **Do not transfer to hospital unless comfort needs cannot be met in current location.**

Other Instructions _____

Section C *Check One Box Only*

ANTIBIOTICS

☐ **Antibiotics if life can be prolonged.**
☐ **Determine use or limitation of antibiotics when infection occurs.**
☐ **No Antibiotics** (use other measures to relieve symptoms).

Other Instructions _____

Section D *Check One Box Only in Each Column*

MEDICALLY ADMINISTERED FLUIDS AND NUTRITION: Offer oral fluids and nutrition if physically feasible.

☐ **IV fluids long-term if indicated** ☐ **Feeding tube long-term if indicated**
☐ **IV fluids for a defined trial period** ☐ **Feeding tube for a defined trial period**
☐ **No IV fluids** (provide other measures to ensure comfort) ☐ **No feeding tube**

Other Instructions _____

Section E *Check The Appropriate Box*

DISCUSSED WITH AND AGREED TO BY: *Basis for order must be documented in medical record.*

☐ Patient
☐ Parent or guardian if patient is a minor
☐ Health care agent
☐ Legal guardian of the person
☐ Attorney-in-fact with power to make health care decisions
☐ Spouse
☐ Majority of patient's reasonably available parents and adult children
☐ Majority of patient's reasonably available adult siblings
☐ An individual with an established relationship with the patient who is acting in good faith and can reliably convey the wishes of the patient

MD/DO, PA, or NP Name (Print): | **MD/DO, PA, or NP Signature** (Required): | **Phone #:**

Signature of Person, Parent of Minor, Guardian, Health Care Agent, Spouse, or Other Personal Representative
(Signature is required and must either be on this form or on file)

I agree that adequate information has been provided and significant thought has been given to life-prolonging measures. Treatment preferences have been expressed to the physician (MD/DO), physician assistant, or nurse practitioner. This document reflects those treatment preferences and indicates informed consent.

If signed by a patient representative, preferences expressed must reflect patient's wishes as best understood by that representative. Contact information for personal representative should be provided on the back of this form.

You are not required to sign this form to receive treatment.

Patient or Representative Name (print) | Patient or Representative Signature | Relationship (write "self" if patient)

SEND FORM WITH PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED

- Pragmatic policy + practice change
  - 27 states
  - Orders for current care – *putting your living will into action*
  - Patient or surrogate shared decision-making – with MD / APP
  - Portable across settings

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POLST changes treatment

Used for nursing home / PACE residents:

- Comfort goal – 13% hospitalized; only 2% hospitalized to extend life
- PACE residents who died received care consistent with preferences 46% of the time
- Residents with POLST more likely to have orders “beyond DNR” (98% vs 16%)
  - » Reduced use of other life-sustaining treatments when comfort primary goal (14% vs 23%)
  - » No improvement in symptom management

Tolle 1998; Lee 2000; Hickman 2011

Try this – POLST in practice

Use POLST to "put living will into action"

- Guide treatment in current health state

Use POLST to guide a discussion

- Serious illness
- Multiple chronic conditions + acute exacerbations
- "Frequent flyers"

Use POLST to improve transitional care

- LTC – hospital transfers
- LTC cross-cover communication
- Palliative care patients leaving hospital

✓ ***DO NOT rely on POLST for symptoms***

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Evidence and Clinical Application: Interpersonal communication

Communication is a procedure

Training to enhance MD skills

Oncotalk: intensive communication training for oncology fellows (n=115)

- 5.4 new skills in sharing bad news
- 4.4 new skills in facilitating palliative care transition
- 16% vs 54% used term “cancer” in communication

Back AL, Arch Intern Med 200; Fallowfield L, Lancet 2002

Structured ICU family meetings

- 16 trials in ICU settings (5 RCTs)
  - Printed information + VALUE family meeting
  - Ethics consultation
  - Palliative care consultation
  - ICU clinicians OR palliative care OR ethics
- Results:
  - Reduced family emotional distress
  - Improved family understanding
  - Reduced intensity / cost of medical care
  - No increase in mortality
  - No benefits in symptom control, QOL

Scheunemann LP, Chest 2011; Fawole OA JGIM 2012

ICU Communication: SIT Trial

SIT: Support & Information Team intervention

- Brochure on chronic critical illness
- 2+ family meetings with SIT clinicians
  - » Prognostic information
  - » Guided discussion of goals of care
  - » Feedback to ICU clinicians

N=365 family decision-makers for 256 adult patients ventilated for 7+ days

- NSD in anxiety / depression
- Increased PTSD symptoms (25.9 vs 21.3)
- NSD family perception of communication
- NSD treatment, hospital LOS, survival

Carson SS JAMA 2016

ICU Communication: PARTNER Trial

PARTNER intervention

- Nurses with added communication skills
- Family support pathway / ICU team meetings
- QI coaching

N=1420 ICU patients with poor prognosis

- NSD in anxiety / depression
- NSD in PTSD symptoms
- Improved quality of communication (69 vs 63)
- Shorter ICU LOS (6.7 vs 7.2 days)
- Increased hospital mortality; NSD 6 month mortality

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White DA NEJM 2018

Palliative Care Communication

- 43 clinical trials of primary or specialty PC
  - 2+ domains of PC
  - Cancer, CHF most common serious illnesses
  - 42% home, 33% outpatient, 26% hospital
- Results:
  - Improved patient QOL
  - Reduced symptom burden
  - Increased advance care planning
  - Improved patient / caregiver satisfaction
  - Reduced health care utilization
  - No effect on mortality

Kavalieratos D JAMA 2016

Try this – communication skills

Create teaching sessions for learning and practicing communication skills as a procedure

- Vitaltalk tools
- Teach, observe, then mentored practice to competency

ICU patient / family meetings

- Extended discussion of goals of care
- Early in illness trajectory
- Engage ICU team

Palliative care communication

- Strong evidence for cancer, outpatient settings
- Effect on patient-centered outcomes

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Evidence and Clinical Application: Decision aids

Decision aids

- Structured, balanced information
- Promotes shared decision-making
  - » Precedes but does not replace clinical communication
- Extensive evidence (>30 RCTs) improving efficiency, knowledge, quality of decision
  - » Few decision aids for seriously ill patients
  - » Few decision aids for proxy decision-makers

Graham 2007; O'Connor AM Cochrane Review 2009

Tools to support shared decision-making

17 RCTs of decision tools for serious illness

- ACP tools
  - Prepare for Your Care (Sudore)
  - ACP videos (Volandes)
- Decision-making for treatment
  - “Question prompt list” advanced CA (Clayton)
  - Chemotherapy with limited benefit (Peele)
  - Goals of care for malignant glioma (El-Jawhari)
  - CF lung transplant (Vandemheen)
  - Feeding options in dementia (Hanson)

Austin CA JAMA Intern Med 2015

ACP Decision aids

Videos on CPR decision and goals of care

- Glioma outpatients; new NH admissions; older outpatients – increased choice for comfort care
- Reduced disparities in preferences by race / health literacy among outpatients
  - » Advanced cancer patients less likely to want CPR but no change in overall level of care
- Reduced use of destination LVAD with improved decision quality

El-Jawahri A, JCO 2010; Volandes AE JPM 2008; 2011; 2012; McCannon JB JPM 2012; Volandes AE Cancer 2012; Volandes AE BMJ 2009; Allen LA JAMA IM 2018

Making Choices

Feeding Options for Patients with Dementia

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Improving Decision-Making RCT

DA on tube feeding vs assisted feeding for advanced dementia

N=256 surrogates for residents 65+ with advanced dementia and feeding problem

- Reduced decisional conflict
  1.65 vs 1.97, p<0.001
- Increased discussions (MD / NP / PA)
  46% vs 33%, p=0.04
- Increased assisted feeding interventions
- Reduced weight loss (6% vs. 16%, p=0.01)
- NSD mortality (27% vs. 29%)

Hanson LC, JAGS 2011

A Decision Aid about Goals of Care for Patients with Dementia

Goals of Care RCT

R01 – NIA: *Goals of Care: A Nursing Home Trial of Decision Support for Advanced Dementia*

Cluster randomized trial

- 20 nursing home sites
- 300 surrogates for residents with late-stage to advanced dementia (GDS 5-7)

Decision aid + care planning vs. attention control

- Primary outcome: communication quality
- Secondary outcomes: goals of care and treatments

Goals of Care Study: Main Findings

Primary goal comfort for most family caregivers

- **65% at enrollment**
- **79% at 9 months or death**

<u>GOC Decision aid + staff discussion resulted in</u>

- Better quality of communication
- Improved concordance on goals
- Increased palliative care in treatment plans
- Doubled use of MOST / POLST
- Reduced hospital transfers by half, without harming survival

Hanson LC, JAMA Internal Medicine 2016

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Try this – use a decision aid to augment communication

Volandes videos:

http://www.acpdecisions.org/

Dementia decision aids:

https://www.med.unc.edu/pcare/resources/feedingoptions/

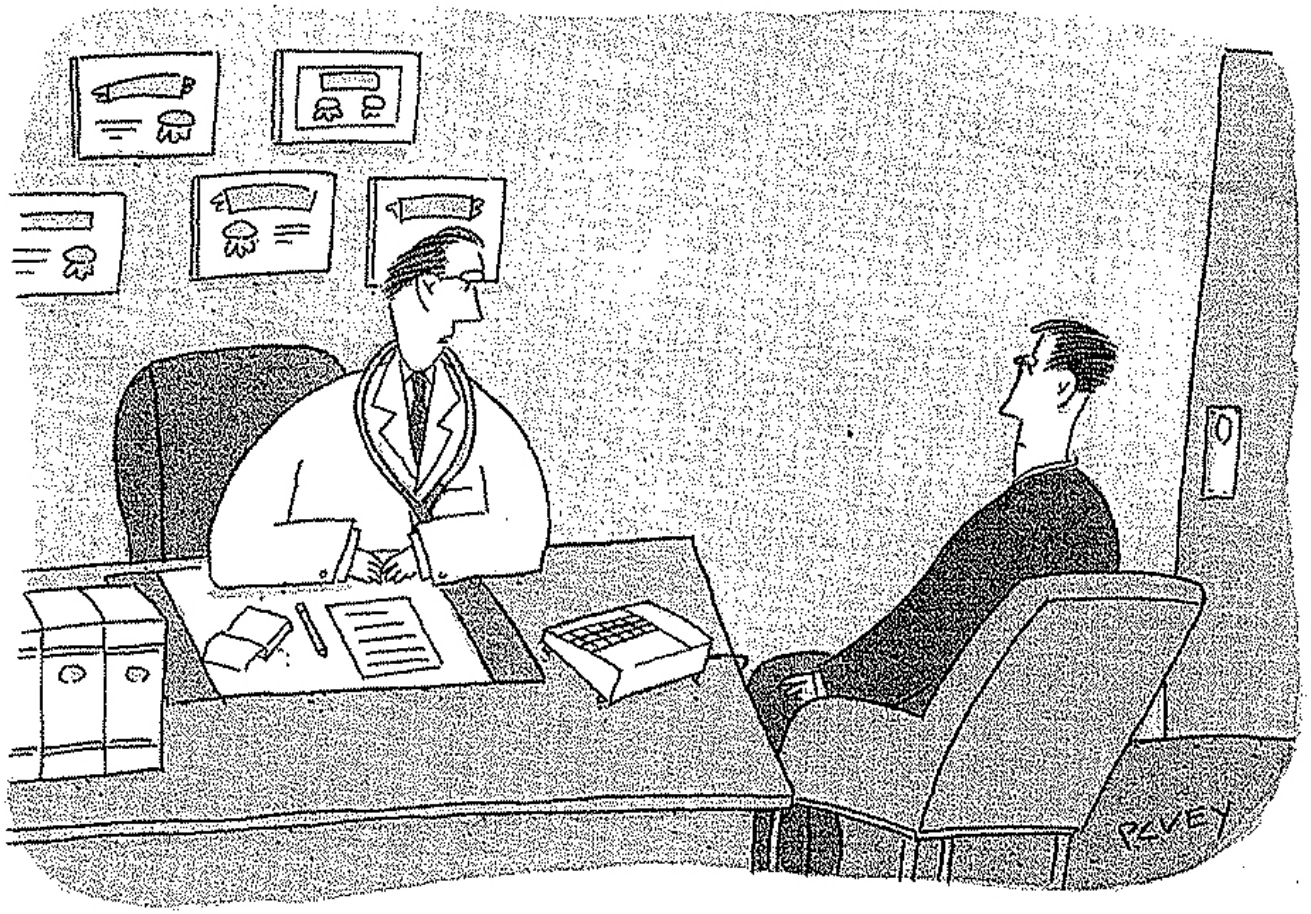
https://www.med.unc.edu/pcare/resources/goals-of-care/

Print decision aids:

http://decisionaid.ohri.ca/

Summing up

- Recognize when shared decision-making is the ethical “procedure”
- Quality communication impacts patient outcomes
- Speak about the things to come . . . prognosis frames goals of care choices
- Use evidence to enhance communication – decision aids, clinician training, and structured interpersonal communication



"There's no easy way I can tell you this, so I'm sending you to someone who can."