# PALLIATIVE CARE

## FOR THE PRIMARY CARE PROVIDER

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60TH ANNUAL NMAFP FAMILY MEDICINE SEMINAR

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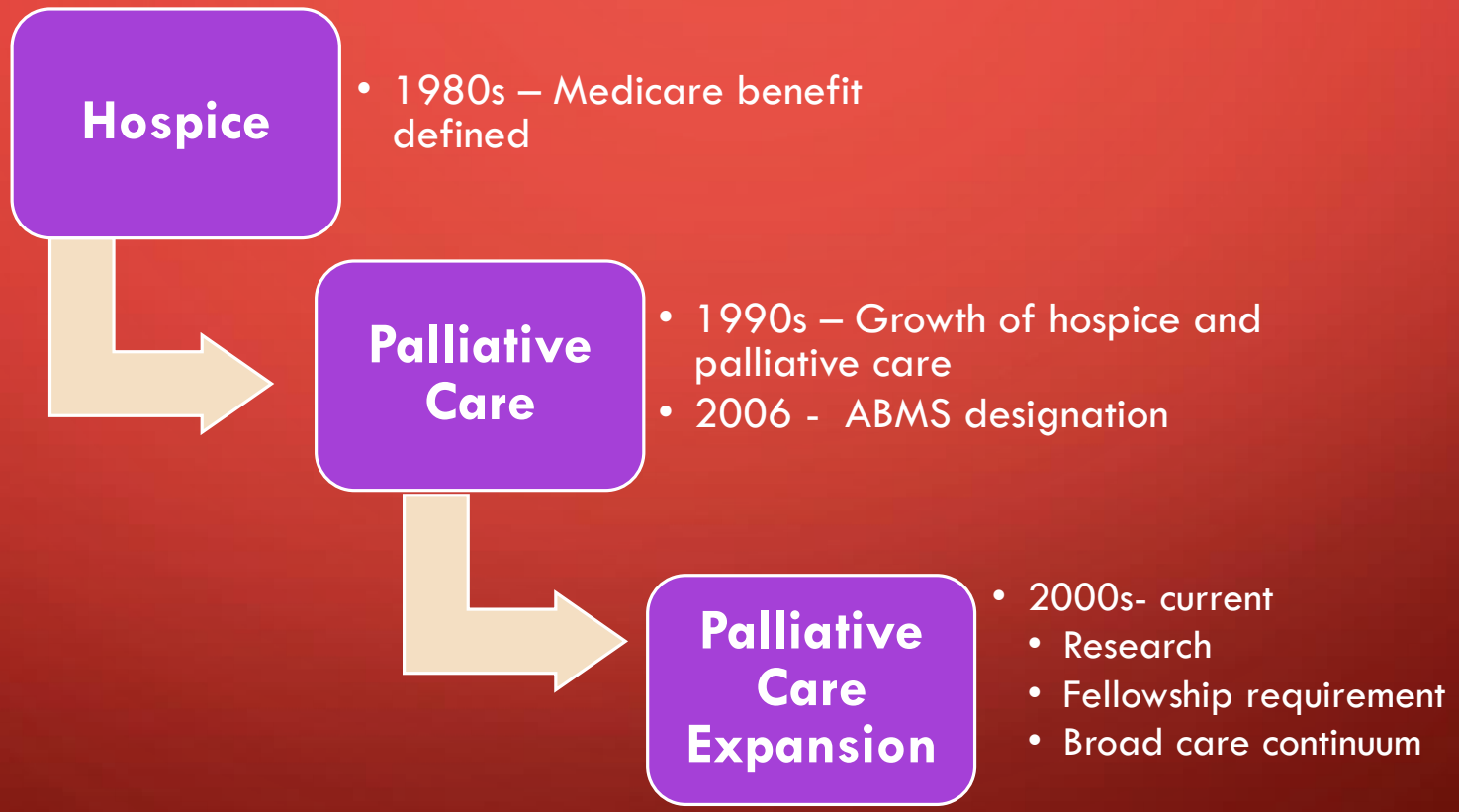
# DISCLOSURES

- I have none

# OBJECTIVES

- Define and differentiate hospice and palliative care and review when to consider referrals
- Differentiate primary and specialty palliative care skills
- Focus on primary palliative care skills:
  - Outline surrogacy for decision making in New Mexico
  - Review framework for discussing serious news and goal setting
  - Review prognostication tools for common chronic serious illnesses
- Reflect on one new skill or resource you'll use in practice

# GROWTH OF HOSPICE AND PALLIATIVE CARE



# HOSPICE

- Hospice: A health care benefit
  - Medicare benefit (Part A) since 1983; many private insurances have a “hospice benefit”
  - Two MDs or DOs certify prognosis $\leq$ 6 months if “disease runs its usual course”
  - Focus is on comfort and relief of suffering, not life prolongation
  - Interdisciplinary team provides care
  - It is not a place; primarily home-based

# HOSPICE
## (AND COMFORT CARE)

- "Comfort Only Care" is a type of care in which the sole goal is to provide comfort. All treatment options are framed as "does this provide comfort?"
  - This typically refers to hospice-like care within the hospital
  - Like hospice, it is patient dependent and is not "one size fits all"

# HOSPICE

- A note on cultural humility and awareness:
  - The Spanish word for hospice, hospicio, can signify a place for orphans, a place for migrants, a place where elderly people go when they have no loved ones to care for them, or “a place for the destitute”
  - Instead we recommend using “servicios de hospice” or “cuidado paliativo en casa”

# DO PHYSICIANS KNOW WHAT PALLIATIVE CARE IS?

- "Physicians tend to either equate palliative care with "hospice" or "end of life" care, and **they are very resistant to believing otherwise.**"
  - Public Opinion Research on Palliative Care 2011

- Why?

# PALLIATIVE CARE: WHO DEFINITION

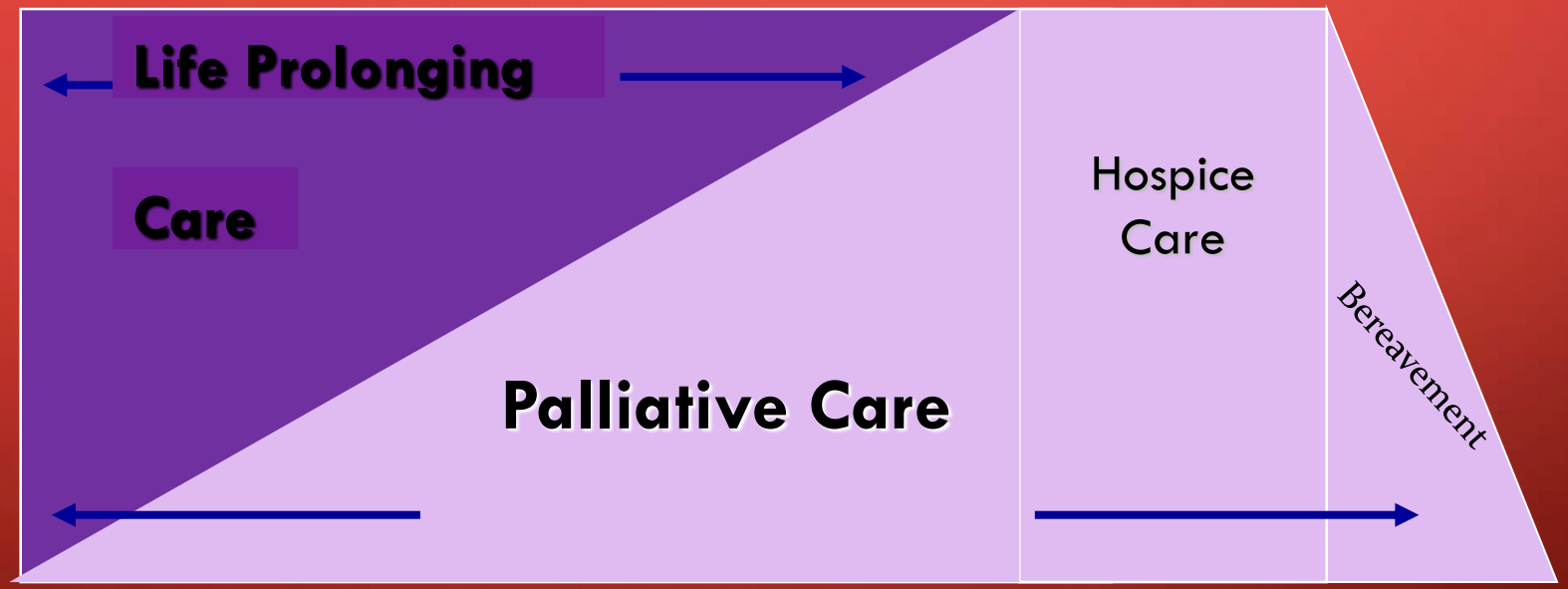
- "An approach that improves the **quality of life** of patients and their families facing the problems associated with life threatening illness, through **prevention of and relief of suffering** by means of early identification and impeccable assessment and **treatment of pain and other problems, physical, psychological and spiritual**"

# WHO DEFINITION CONTINUED

- Palliative Care:
  - will **ENHANCE QUALITY OF LIFE,** and may also positively influence the course of illness
  - is applicable early in the course of illness, in **CONJUNCTION WITH OTHER THERAPIES THAT ARE INTENDED TO PROLONG LIFE,** such as chemotherapy or radiation therapy.
  - intends **NEITHER TO HASTEN NOR POSTPONE DEATH**

# CONCEPTUAL SHIFT IN PALLIATIVE CARE

# CONCEPTUAL SHIFT IN PALLIATIVE CARE



# PALLIATIVE CARE

*All hospice care IS palliative care*

(type of care to alleviate suffering),

*BUT*

*Not all palliative care is hospice care*

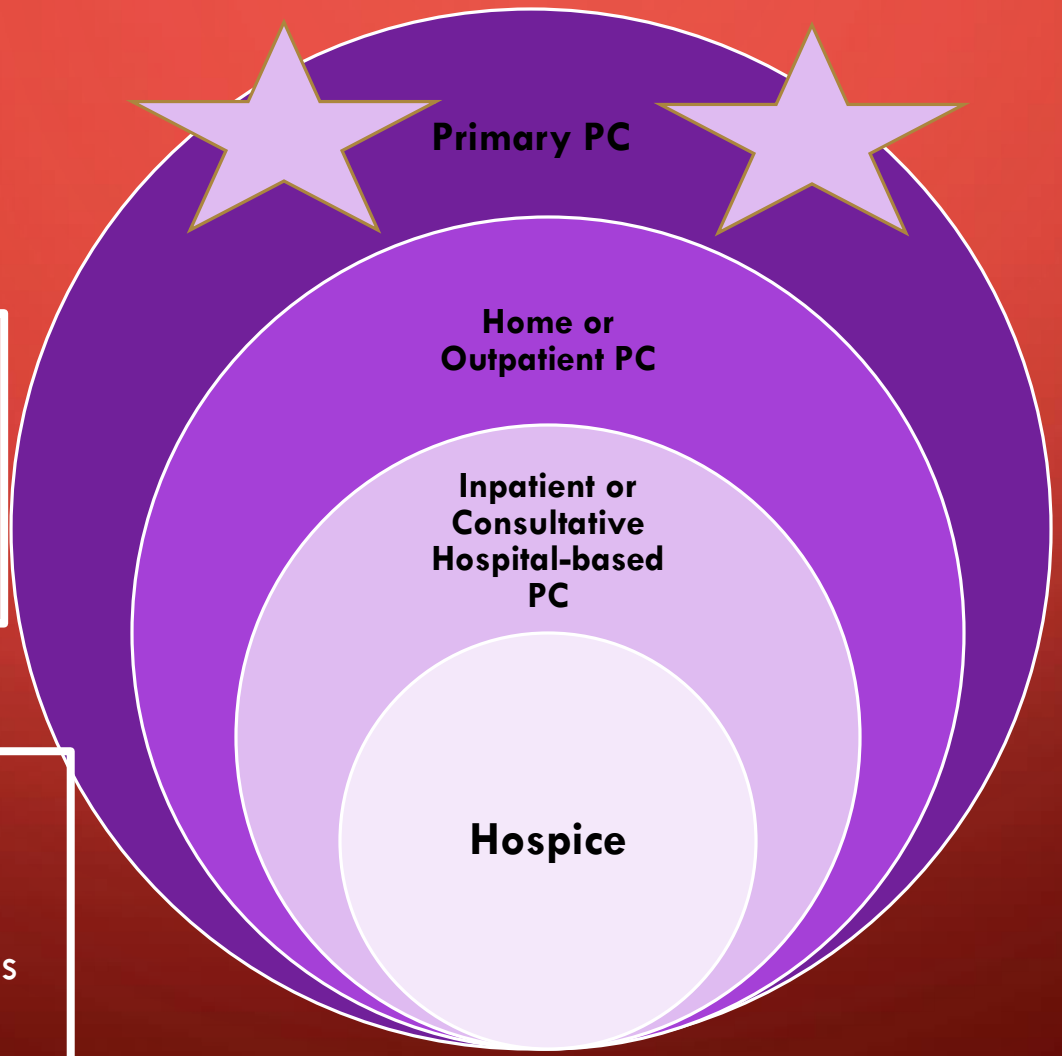
(you can still get curative care and

have any prognosis)

# WHY DO WE DO WHAT WE DO?

- Focus on the “illness”, not just the “disease”
  - What is *this* patient’s and family’s experience of the disease, and how can we help them all live as fully as they can in whatever time they have?
- People who have conversations with their health care providers about what type of care they want, their goals and priorities when they are very ill:
  - Less suffering and improved QOL
  - Less pain
  - Fewer days in hospital
  - More likely to die with hospice care
  - Less likely to die in an ICU
  - Live longer (NEJM Non-small cell lung cancer)

# WHO SHOULD GET PALLIATIVE CARE AND HOSPICE?




Most patients with chronic, serious, or terminal illness

Chronically or seriously Ill, or early stage of terminal illness (non-crisis)

Seriously ill patients, in medical crisis

Terminally ill, < 6 months to live, choosing QOL/symptom focus

# Generalist plus Specialist Palliative Care — Creating a More Sustainable Model

Timothy E. Quill, M.D., and Amy P. Abernethy, M.D.

N ENGL J MED 368;13 NEJM.ORG MARCH 28, 2013

## PRIMARY PC

- Basic discussions about:
  - Prognosis
  - Goals of treatment
  - Suffering
  - Code status
  - Hospice
- Basic pain and symptom management
- Basic management of depression and anxiety

## SPECIALIST PC

- Advanced communication skills
  - Conflict about goals or treatments
  - Conflict between people
- Complex pain and symptom management
- Management of more complex psychosocial distress:
  - Suffering and “total pain”
  - Existential distress

# PRIMARY PALLIATIVE CARE—COMMUNICATION AND DECISION MAKING: SURROGACY IN NM

- If someone is decisional, make decisions with that person
  - "But the POAHC wants us to do x, y, z…."!
- Who makes decisions for non-decisional patients?
  - Guardian, POAHC
  - What if there is no guardian or POAHC?
    - Uniform health Care Decisions Act
      - http://law.justia.com/newmexico/codes/nmrc/jd_ch24art7a-acff.html

# UNIFORM HEALTH CARE DECISIONS ACT

- **24-7A-5. Decisions by surrogate.**

  B… In the absence of a designation or if the designee is not reasonably available, any member of the following classes of the patient's family who is reasonably available, in descending order of priority, may act as surrogate:

  - (1) the **spouse**, unless legally separated or unless there is a pending petition for annulment, divorce, dissolution of marriage or legal separation;
  - (2) ***an individual in a long-term relationship*** *of indefinite duration with the patient in which the individual has demonstrated an actual commitment to the patient similar to the commitment of a spouse and in which the individual and the patient consider themselves to be responsible for each other's well-being;*
  - (3) an adult child;
  - (4) a parent;
  - (5) an adult brother or sister; or
  - (6) a grandparent.

# UNIFORM HEALTHCARE DECISIONS ACT

- If none of the individuals eligible to act as surrogate is reasonably available,

an adult who has exhibited **special care and concern** for the patient, who is familiar with the **patient's personal values** and who is reasonably **available** may act as surrogate

# ROLE OF A DECISION MAKER

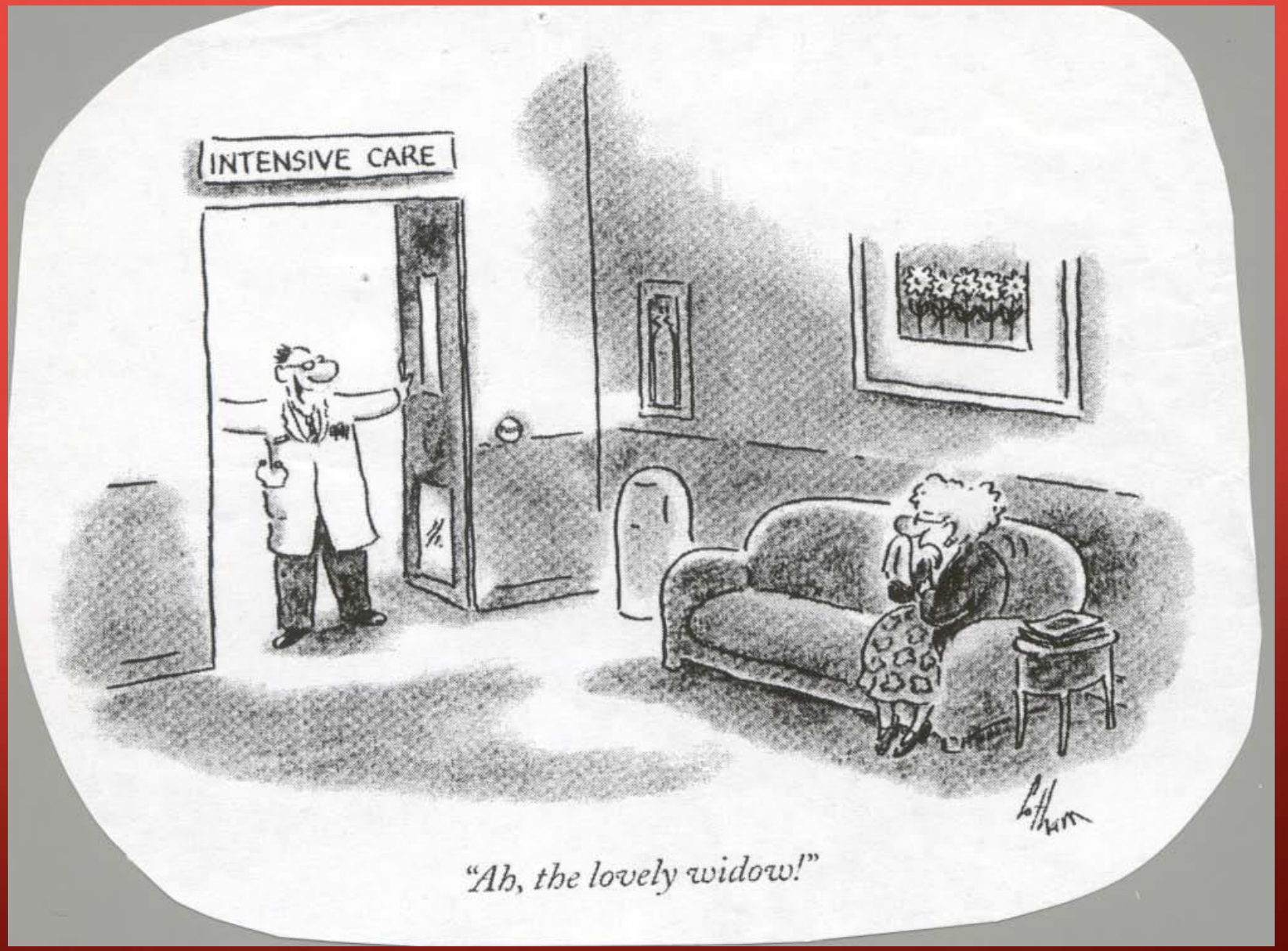
- To reflect the wishes of the patient, NOT what the decision-maker would want if in that situation
  - Never ask “what do you want us to do?”
  - Ask “Have you ever had conversations with your father about his wishes if he were in this situation?”
  - Ask “What would your father want if he heard this information that you just heard, and could talk with us?”

- Make sure you have explained the *diagnosis, treatment options, and prognosis* to the best of your ability before you ask someone to make a decision (informed consent).

# PRIMARY PALLIATIVE CARE—COMMUNICATION SKILLS

## TALKING ABOUT DIFFICULT THINGS

## (BREAKING BAD NEWS)



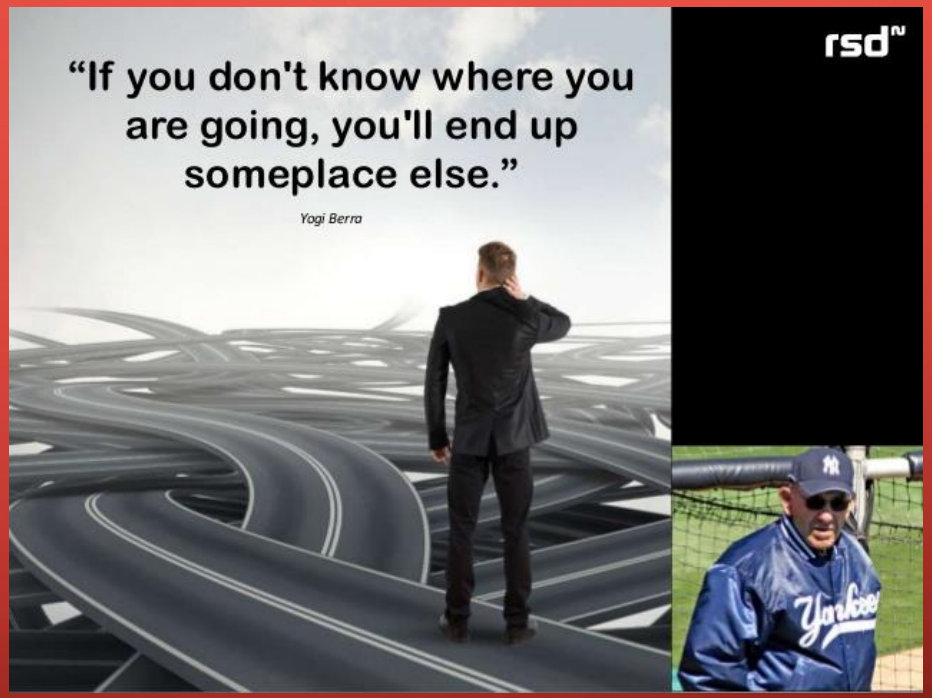

*"Ah, the lovely widow!"*

# POTENTIAL TRIGGERS FOR COMMUNICATION

- Cancer:
  - Surprise question
  - >2 lines of chemo with metastatic disease
- COPD:
  - Functional decline
  - Increased symptoms
  - Hospitalizations
- ESLD:
  - Decompensated liver disease
  - Hospitalizations
  - Rising MELD
- CHF:
  - Functional decline
  - Hospitalization
  - Increased symptoms
  - Inotropes
- ESRD:
  - Surprise question
  - Low albumin
  - Dementia
  - PVD

JAMA Dec 2014 174 (12)

# **SPIKES:** A COGNITIVE ROAD MAP FOR A COMMUNICATION SKILL



# INFORMATION AND EMPATHY

- "In medical consultations, patients experience a double-need: *to know and understand* and *to feel known and understood*."
  - JCO 32(31): Nov 2014.

# INFORMATION SHARING AND EMPATHIC ENGAGEMENT

## SPIKES

- Set-up/Setting
- Perception
- Invitation
- Knowledge
- Emotion/Empathy
- Summarize

## NURSE

- Name the emotion
- Statements of Understanding
- Respect
- Support
- Explore emotion

# SPIKES: SET-UP

- Review the chart
- Invite the right people
  - Textbook vs Reality
- Emotionally prepare yourself
  - What do I expect in this encounter?
- Make time
- Private room, chairs and tissues
- Introductions
- Sit down
- Appropriate eye and physical contact

# SPIKES: ASSESS PERCEPTION

- Inquire about patient's knowledge of the disease

- "What is your understanding about …
  - your cancer at this stage?"
  - the reason we ordered the CT scan?"
  - the events of your hospitalization so far?"
  - why we arranged this family meeting today?"
  - your prognosis?"

# SPIKES: INFORMATION/INVITATION

- ASK: What does your patient want to know?
  - Don't make assumptions
    - About culture
    - About information preferences
  - Use official interpreters
- "I want to talk to you about your prognosis, but I am not sure what you want to know. Are you the sort of person who likes to know details or general information about your illness?"

# SPI**K**ES: K**K**NOWLEDGE

- Fire the "**warning shot**"

- "I am afraid the situation is more serious than we thought."

- "I have some serious news to share."

# SPIKES: KNOWLEDGE

- Use jargon-free language
- Know your audience
- Silence is helpful
- Tell the truth
- Repeat as necessary
- Stop and check for understanding

- Pitfalls:
  - Lecturing, blocking (avoidance, changing the subject), collusion

# ACTIVE LISTENING

- Repeat family/patient's words to ask questions:
  - "You said she would never want to "be a vegetable." What does that mean to you?"
- Silence
- Non-verbal communication
- When you hear or see expressions of emotion, acknowledge them

# RESPONDING TO EMOTIONS: NURSE

- N = Naming
- U = Understanding
- R = Respecting
- S = Supporting
- E = Exploring

- I can tell you are really frustrated.
- This helps me understand what you are thinking.
- You've done an amazing job coping with your situation
- I'm going to help you through the next steps.
- Tell me more…

# KNOW YOURSELF

- What are your triggers?
- What emotions do you avoid?
- Remember – *You are not responsible for the disease*
- What's your technique for in-the-moment "re-orienting"
  - Ex. Three deep breaths

# SPIKE**S**: **S**UMMARIZE

- Non-abandonment:
  - "We will work together on this."
- Check understanding:
  - "When you go home today, how will you explain what I told you to your family?"
- Invite questions
  - "What questions do you have?"

# SPIKES: SUMMARIZE/ FOLLOW UP

- Make sure the patient knows:
  - Next steps
  - How to reach you
- Repetition as necessary
- What are the patient's goals?
  - Identify specific problems (pain, symptoms, financial, psychosocial)
  - Can you connect prognosis, patient goals and service needs to resources you offer?

# GOAL SETTING

- Allow patient to state their goals: *Knowing that time is short, what is important to you in the time that is left?*
- Non-decisional patient: *What would your mother choose if she was with us in this room and heard this information? Would she want to look into options for further chemotherapy or would she want to focus on her comfort and be at home?"*
- Summarize all decisions made and plan of action

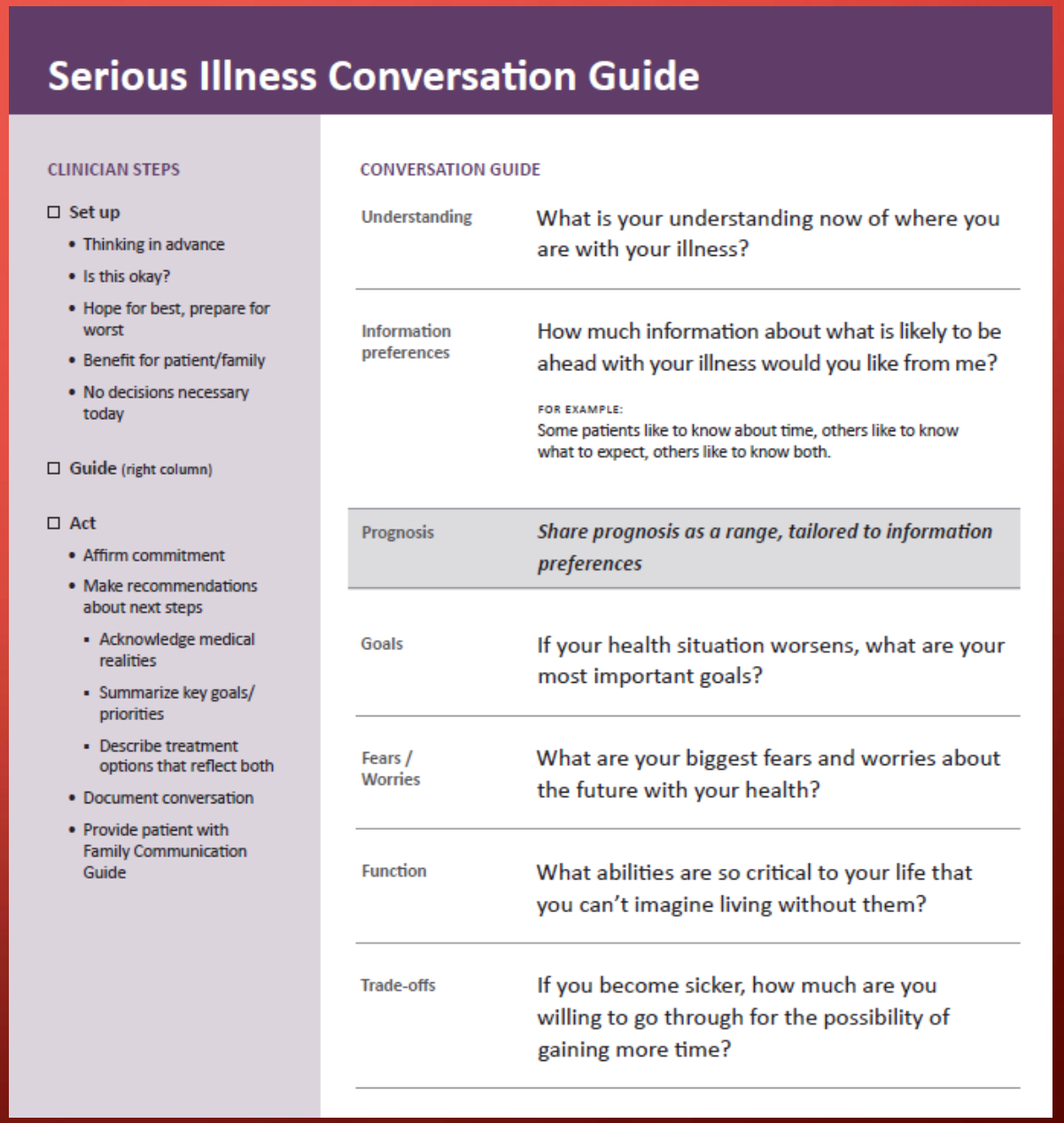
# REMEMBER…

- These are not YOUR decisions.
- Your role is to give the decision-maker the pertinent medical information, to clarify the goals and to help guide them. They use this information and their knowledge of the patient to make an informed decision.
- Don’t make assumptions about goals: “They wouldn’t have come into the ED if they didn’t want aggressive treatment.”

# SERIOUS ILLNESS CONVERSATION GUIDE

Bernacki et al, BMJ Open. 2015.

(https://qxmd.com – under the oncology tab)



## Serious Illness Conversation Guide

**CLINICIAN STEPS**

☐ **Set up**
- Thinking in advance
- Is this okay?
- Hope for best, prepare for worst
- Benefit for patient/family
- No decisions necessary today

☐ **Guide** (right column)

☐ **Act**
- Affirm commitment
- Make recommendations about next steps
  - Acknowledge medical realities
  - Summarize key goals/ priorities
  - Describe treatment options that reflect both
- Document conversation
- Provide patient with Family Communication Guide

**CONVERSATION GUIDE**

| | |
|---|---|
| Understanding | What is your understanding now of where you are with your illness? |
| Information preferences | How much information about what is likely to be ahead with your illness would you like from me?<br>FOR EXAMPLE:<br>Some patients like to know about time, others like to know what to expect, others like to know both. |
| Prognosis | ***Share prognosis as a range, tailored to information preferences*** |
| Goals | If your health situation worsens, what are your most important goals? |
| Fears / Worries | What are your biggest fears and worries about the future with your health? |
| Function | What abilities are so critical to your life that you can't imagine living without them? |
| Trade-offs | If you become sicker, how much are you willing to go through for the possibility of gaining more time? |

# BILLING FOR ADVANCE CARE PLANNING

- 99497 – Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health professional; *first 30 minutes*, face-to-face with the patient, family member(s) and/or surrogate.
- 99498 – Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health professional; *each additional 30 minutes*. (List separately in addition to code for primary procedure.)

# BILLING FOR ADVANCE CARE PLANNING

| When Advance Care Planning services occur **at the same time** as the Annual Wellness Visit (AWV): | When Advance Care Planning services occur during another visit (such as E&M, CCM, or TCM): |
|---|---|
| • Bill using modifier -33<br>• No Part B coinsurance or deductible (consistent with the AWV) | • Cost sharing (copay/deductible) applies as for other physicians' services |

# THREE CARDINAL SKILLS OF MEDICINE

1. Diagnosis 2. Treatment 3. Prognostication

- Prognostication is a lost art in the *cure vs. care* culture of medicine
  - BUT….With renewed focus on value and quality in medical care, do we need to be more comfortable asking ***SHOULD we do XXX, not CAN we do XXX***.
  - *Prognostication is a core skill* in primary care medicine


"You've got six months, but with aggressive treatment we can help make that seem much longer."

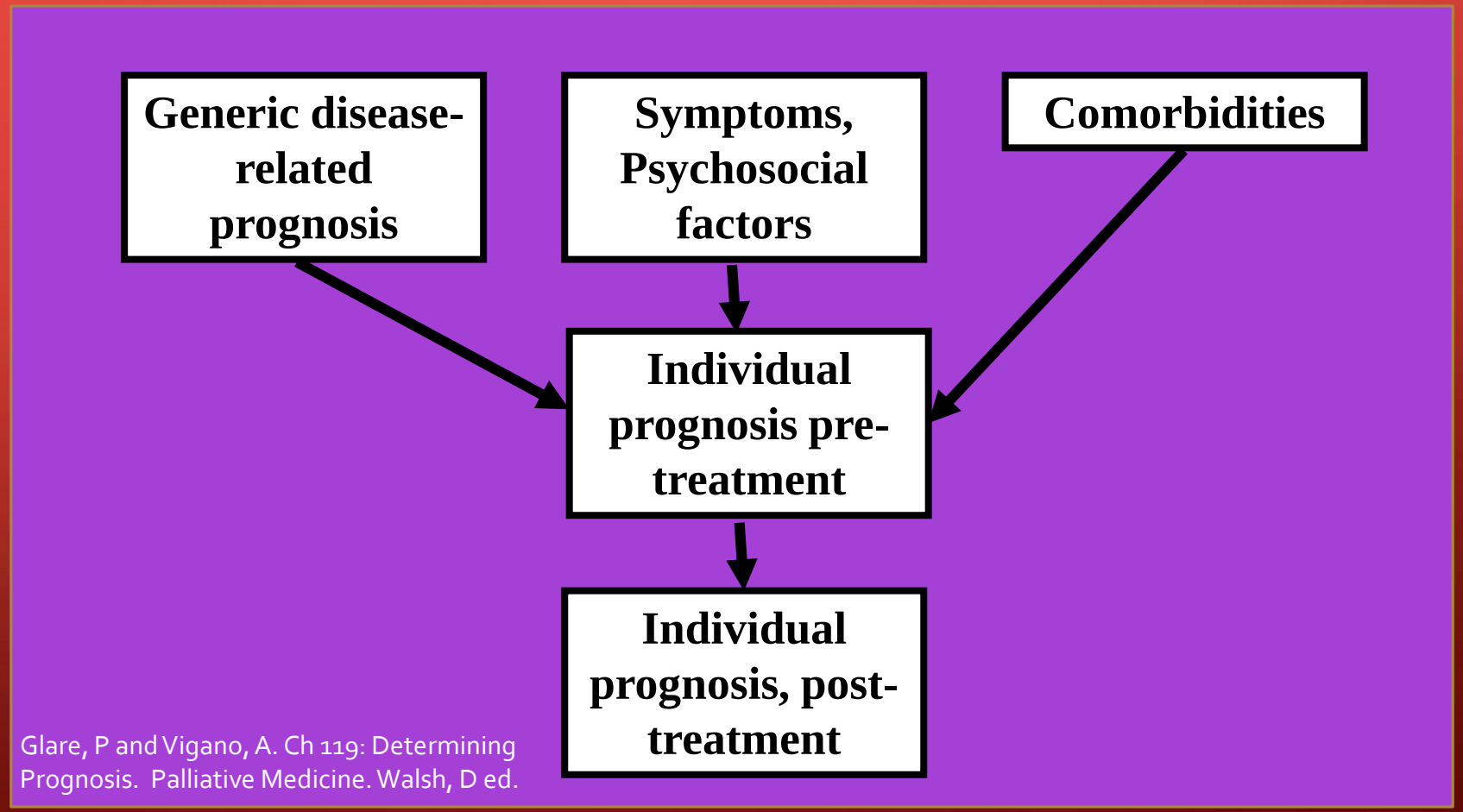
# PRIMARY PALLIATIVE CARE—PROGNOSTICATION WHY BOTHER?

- What do patients with serious and terminal illness want?
  - Comfort
  - A sense of control / dignity
  - To relieve burden on loved ones
  - To strengthen relationships
  - To avoid prolongation of dying process
  - To die at home, not in hospital
  - Participation in funeral/legacy planning

Singer, Martin, & Kelner (1999).*JAMA*, 28(2), 163-168.
Steinhauser, KE, et al (2000). *JAMA*, 284(19), 2476-2483

- Patients who understand their prognosis make different decisions
  - CPR – Murphy et al. NEJM. 1994.
  - Oncology treatments – Weeks et al. JAMA. 1998; Temel et al. JCO 2011

# THE ART OF PROGNOSTICATION




Glare, P and Vigano, A. Ch 119: Determining Prognosis. Palliative Medicine. Walsh, D ed.

# GENERAL PREDICTORS OF POOR PROGNOSIS

- Declining functional status
- Markers of poor nutritional status
- Multiple comorbid disease processes
- Evidence of acceleration of disease process

# PATTERNS OF FUNCTIONAL DECLINE

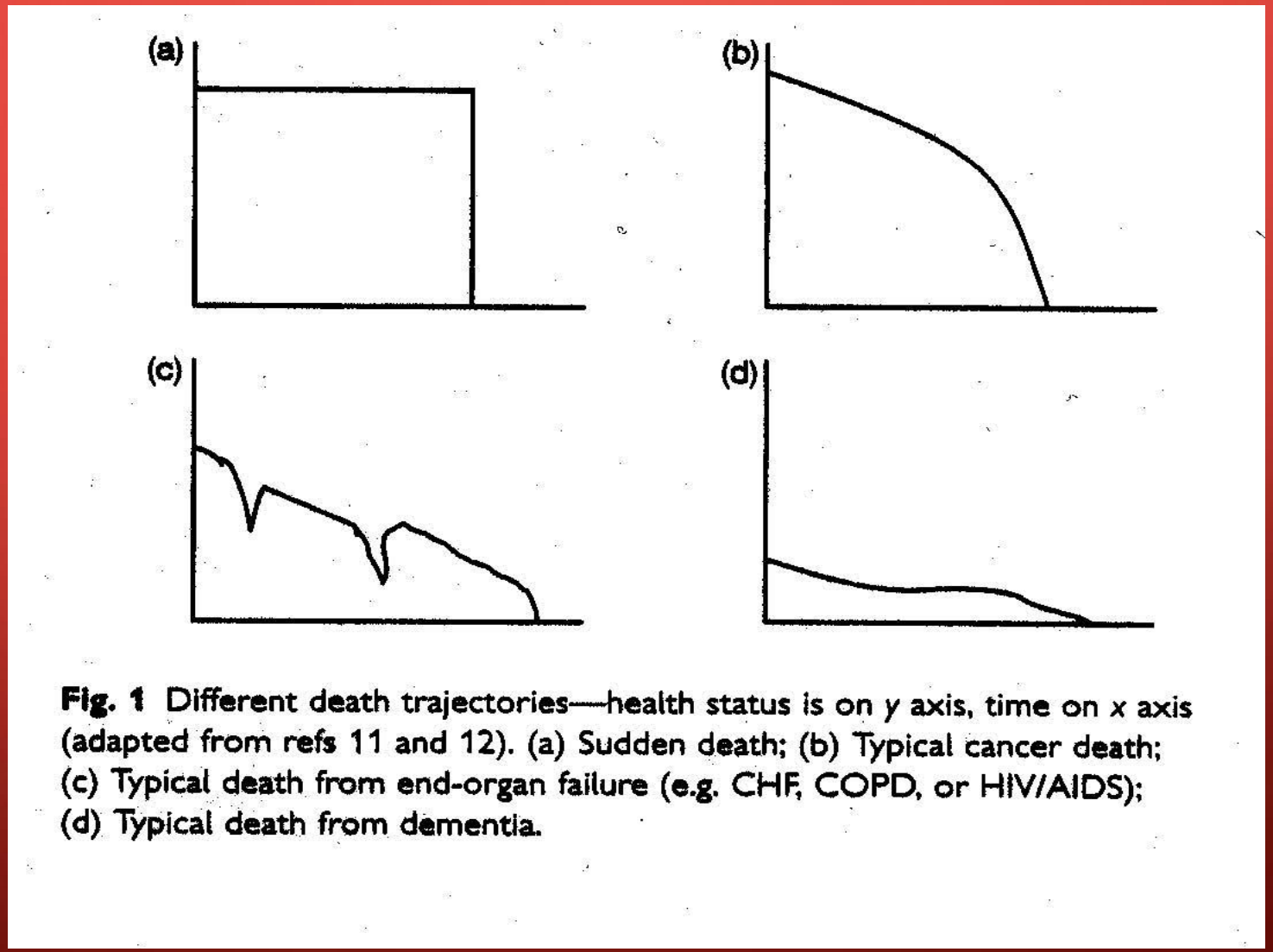



**Fig. 1** Different death trajectories—health status is on *y* axis, time on *x* axis (adapted from refs 11 and 12). (a) Sudden death; (b) Typical cancer death; (c) Typical death from end-organ failure (e.g. CHF, COPD, or HIV/AIDS); (d) Typical death from dementia.

# SUBJECTIVE SURVIVAL PREDICTIONS: SURPRISE QUESTION

- Surprise Question: "Would I be surprised if this patient died in the next year?"
  - 826 of 853 consecutive pts with lung, breast, or colon cancer at WVU cancer center
  - 16% = no, 84% yes
  - Pts in the "no" category had a HR of death = 7.787, $p<0.001$
    - Moss, AH, et al. JPM. 2010
  - Also validated in renal, outpatient medicine settings
- If the answer is "No,"
  - Have you discussed advance care planning?
  - Is a palliative care consult appropriate?

# TOOLS FOR PROGNOSTICATION

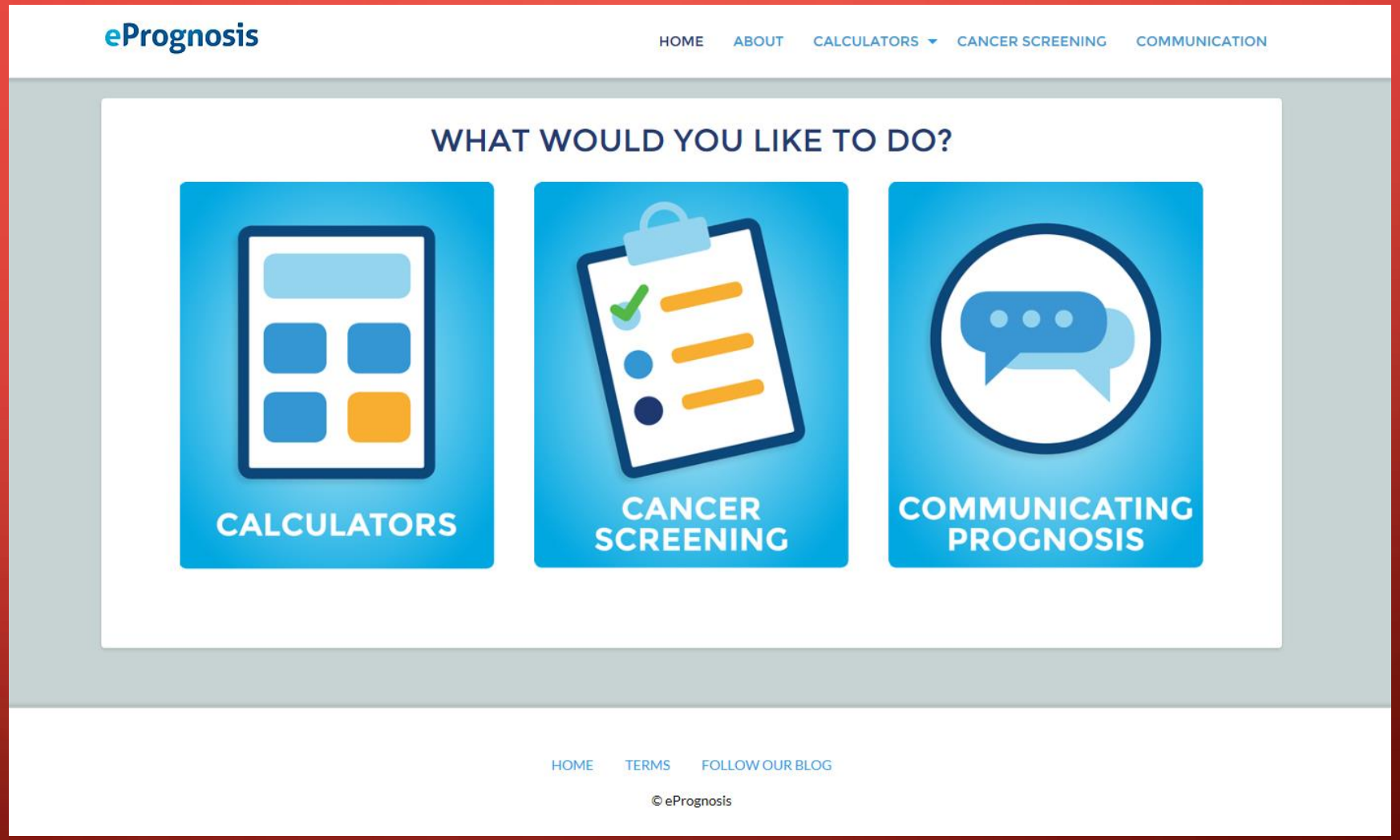
- Surprise question (outpatient medicine, renal disease, cancer)
- Measures of functional decline
  - Palliative performance scale, ECOG score
- www.eprognosis.org
- www.mypcnow.org – Fast Facts
  - Prognosis in COPD: BODE Index
  - Prognosis in patient on dialysis:  Modified Charlson Comorbidity Index, touchcalc HD mortality predictor
  - Mortality Risk Index in dementia

# TOOLS FOR PROGNOSTICATION

Victoria Hospice

## Palliative Performance Scale (PPSv2) version 2

| PPS Level | Ambulation | Activity & Evidence of Disease | Self-Care | Intake | Conscious Level |
|---|---|---|---|---|---|
| 100% | Full | Normal activity & work<br>No evidence of disease | Full | Normal | Full |
| 90% | Full | Normal activity & work<br>Some evidence of disease | Full | Normal | Full |
| 80% | Full | Normal activity with Effort<br>Some evidence of disease | Full | Normal or reduced | Full |
| 70% | Reduced | Unable Normal Job/Work<br>Significant disease | Full | Normal or reduced | Full |
| 60% | Reduced | Unable hobby/house work<br>Significant disease | Occasional assistance necessary | Normal or reduced | Full<br>or Confusion |
| 50% | Mainly Sit/Lie | Unable to do any work<br>Extensive disease | Considerable assistance required | Normal or reduced | Full<br>or Confusion |
| 40% | Mainly in Bed | Unable to do most activity<br>Extensive disease | Mainly assistance | Normal or reduced | Full or Drowsy<br>+/- Confusion |
| 30% | Totally Bed Bound | Unable to do any activity<br>Extensive disease | Total Care | Normal or reduced | Full or Drowsy<br>+/- Confusion |
| 20% | Totally Bed Bound | Unable to do any activity<br>Extensive disease | Total Care | Minimal to<br>sips | Full or Drowsy<br>+/- Confusion |
| 10% | Totally Bed Bound | Unable to do any activity<br>Extensive disease | Total Care | Mouth care<br>only | Drowsy or Coma<br>+/- Confusion |
| 0% | Death | - | - | - | - |


ePrognosis
HOME
ABOUT
CALCULATORS
CANCER SCREENING
COMMUNICATION
WHAT WOULD YOU LIKE TO DO?
CALCULATORS
CANCER SCREENING
COMMUNICATING PROGNOSIS
HOME
TERMS
FOLLOW OUR BLOG
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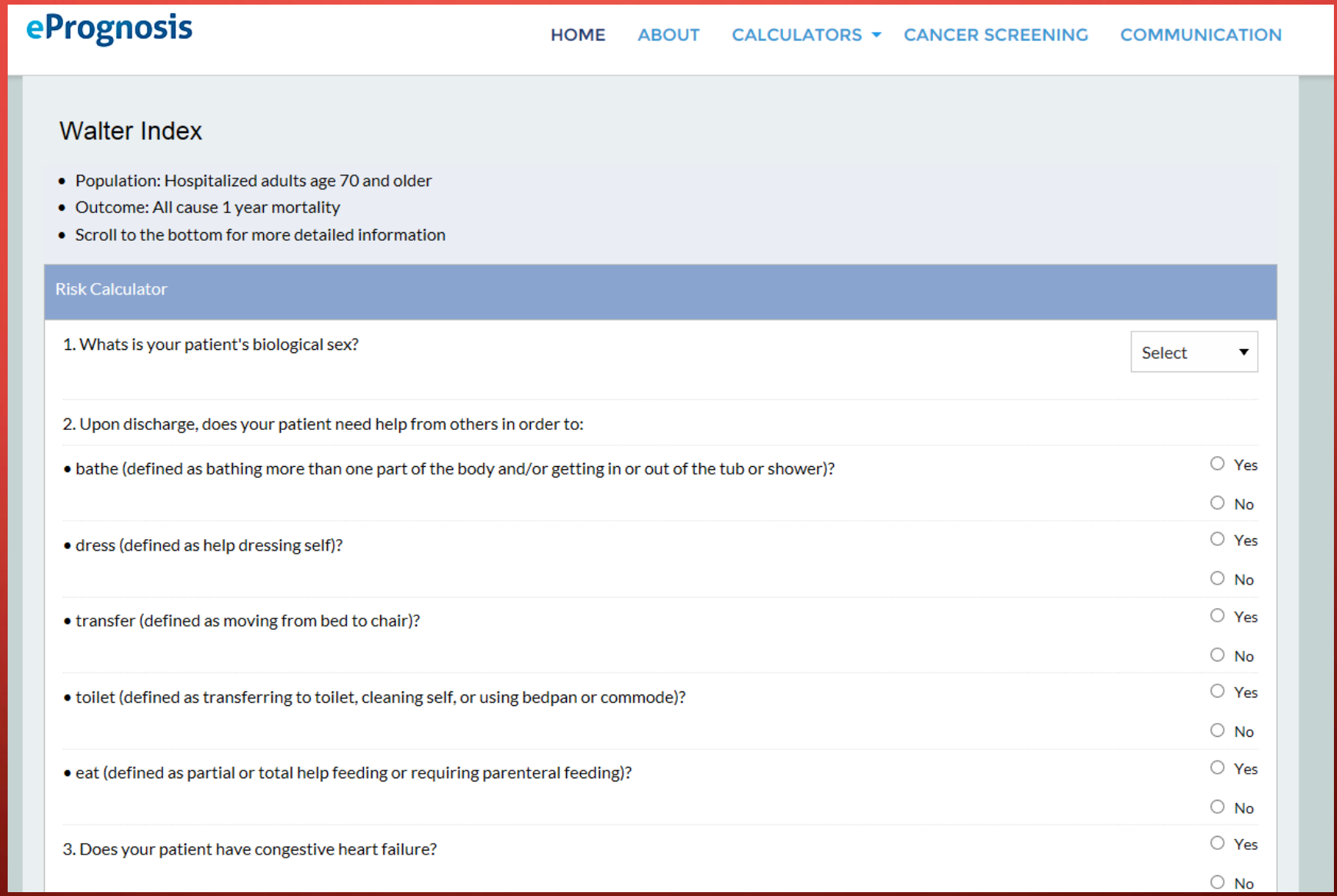
# WHERE IS YOUR PATIENT?



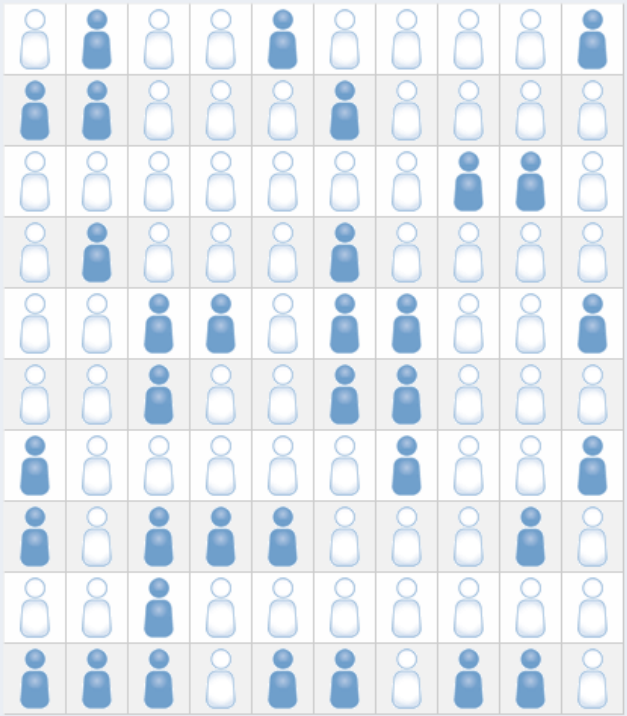


ePrognosis
HOME
ABOUT
CALCULATORS
CANCER SCREENING
COMMUNICATION
Walter Index
Population: Hospitalized adults age 70 and older
Outcome: All cause 1 year mortality
Scroll to the bottom for more detailed information
Risk Calculator
1. Whats is your patient's biological sex?
Select
2. Upon discharge, does your patient need help from others in order to:
bathe (defined as bathing more than one part of the body and/or getting in or out of the tub or shower)?
Yes
No
dress (defined as help dressing self)?
Yes
No
transfer (defined as moving from bed to chair)?
Yes
No
toilet (defined as transferring to toilet, cleaning self, or using bedpan or commode)?
Yes
No
eat (defined as partial or total help feeding or requiring parenteral feeding)?
Yes
No
3. Does your patient have congestive heart failure?
Yes
No

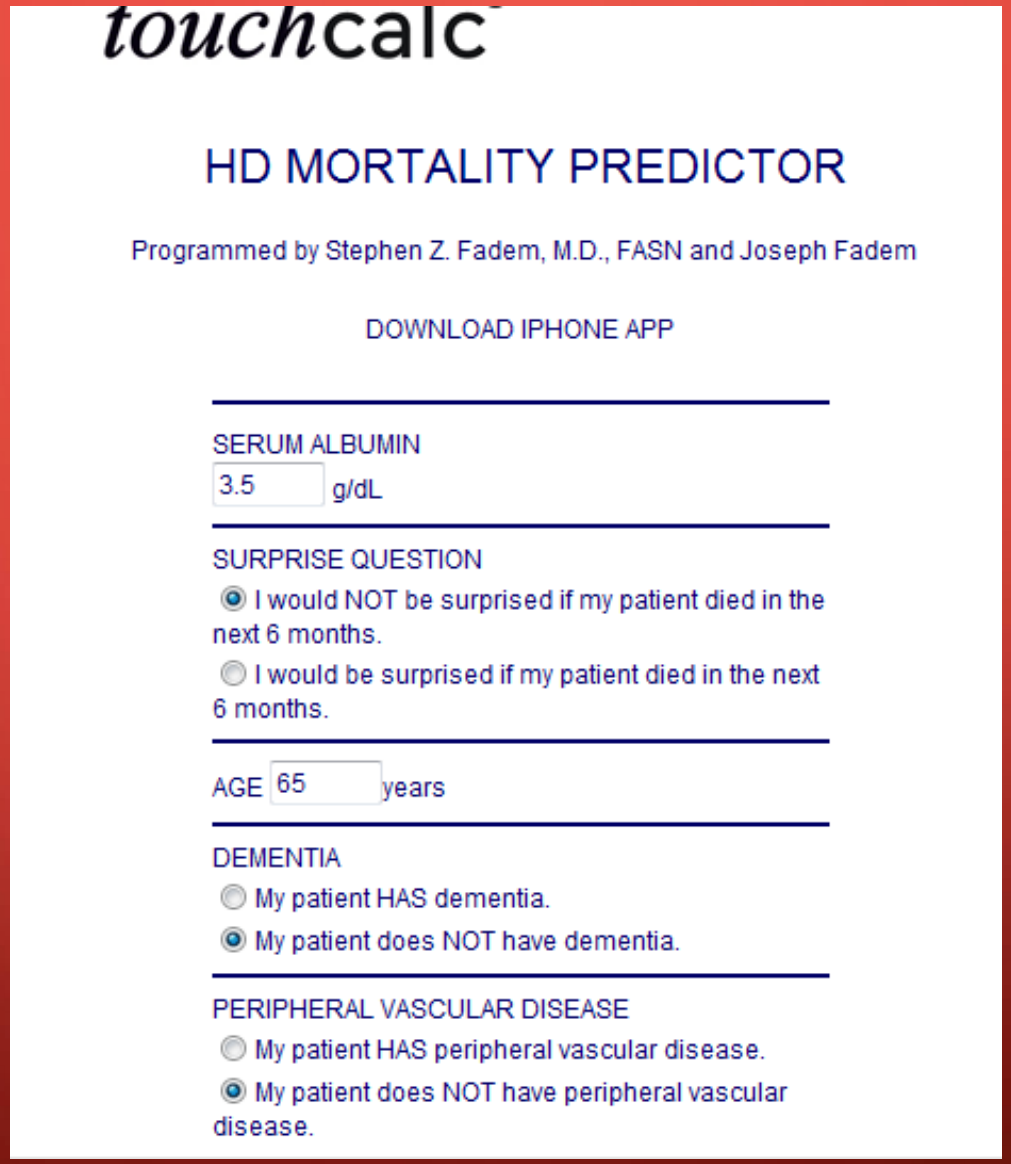
# Walter Index

- Population: Hospitalized adults age 70 and older
- Outcome: All cause 1 year mortality
- Scroll to the bottom for more detailed information

As illustrated by the graphic below, out of 100 hospitalized adults age 70 and older with similar answers, 34 will die (shaded) and 66 will survive (un-shaded) over the next year.

Risk calculators cannot predict the future for any one individual. Risk calculators give an estimate of **how many** people with similar risk factors will live and die, but they cannot identify **who** will live and who will die.




touchcalc
HD MORTALITY PREDICTOR
Programmed by Stephen Z. Fadem, M.D., FASN and Joseph Fadem
DOWNLOAD IPHONE APP
SERUM ALBUMIN
3.5 g/dL
SURPRISE QUESTION
I would NOT be surprised if my patient died in the next 6 months.
I would be surprised if my patient died in the next 6 months.
AGE 65 years
DEMENTIA
My patient HAS dementia.
My patient does NOT have dementia.
PERIPHERAL VASCULAR DISEASE
My patient HAS peripheral vascular disease.
My patient does NOT have peripheral vascular disease.

# PROGNOSIS COMMUNICATION

## Example Discussions

**DIABETES DISCUSSION**

**CANCER SCREENING**

**GOALS OF CARE & CODE STATUS**

## Communication Skills

| | | |
|---|---|---|
| Addressing Emotions | Discussing Lag Time to Benefit | Making a Recommendation |
| Asking Permission | Ask-Tell-Ask | Addressing Uncertainty |
| Care Consistent with Goals | Discussing Next Steps | Discussing Trade-offs |

# RESOURCES

- PALS line UNMH for palliative care physician assistance—505-272-2000 Monday through Friday 8-5
  - Erin FitzGerald, erfitzgerald@salud.unm.edu
- American Academy of Hospice and Palliative Medicine: www.**aahpm**.org
  - *PC-Facts (critical summaries of articles related to PC)*
- Palliative Care Fast Facts: http://www.mypcnow.org/fast-facts
  - (concise, practical, evidence based summaries on key palliative care topics—pain management, prognostication, vent withdrawal, etc)
- Center to Advance Palliative Care: www.capc.org
- American College of Physicans: https://www.acponline.org/system/files/documents/practice-resources/business-resources/payment/advance_care_planning_toolkit.pdf
- EPEC
  - Education in Palliative and End-of-life Care
  - http://www.epec.net
- Specializing in Palliative Medicine:
  - Fellowship: www.**aahpm**.org

# PRIMARY PALLIATIVE CARE ECHO CLINIC

- Palliative Care ECHO Grand Rounds: November 14, 2017
  - Introduction of new Palliative Care clinic for NON specialists
  - Will cover Palliative Care skills and knowledge such as:
    - Pain and symptom management
    - Prognostication and determining hospice eligibility
    - Advance Care Planning
    - Addressing suffering
    - Psychological and spiritual needs of patients and their familes
- Tuesdays 12-1 starting January 2018 will have didactic and cases
- Interdisciplinary participants encouraged
- echo.unm.edu

# RESOURCES


- Back, A et al. *Approaching Difficult Communication Tasks in Oncology*. CA: A Cancer Journal for Clinicians. 55(3): May/June 2005.
- Back A, Arnold R, and Tulsky J. Mastering Communication with Seriously Ill Patients: Balancing Honesty with Empathy and Hope. Cambridge University Press. 2009.
- Bernacki, RE et al. "Communicating about Serious Illness Care Goals: a Review and Synthesis of Best Practices." JAMA Internal Medicine. 2014 Dec; 174(12): 1994-2003.
- Clayton, J et al. "Clinical Practice Guidelines for Communicating Prognosis and End-of-Life Issues with Adults in the Advanced Stages of a Life-Limiting Illness, and their Caregivers." MJA. 2007: 186(12) S77-S108.
- VITALtalk.org
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# REFLECT

- Share with you neighbor:
  - Which prognostication tool or communication skill from this lecture will you use this week?
  - Which resource are you most likely to use in clinical practice?

# MANY THANKS!