

FORESEEING AND FORETELLING PROGNOSIS

Stephen Berns, MD FAAHPM
University of Vermont, Division of Palliative Medicine
Vermont Ethics Network Palliative Care Conference

FINANCIAL DISCLOSURES

- Stipend for coaching and teaching nationally for VitalTalk

LEARNING OBJECTIVES

- Discuss the benefits and challenges to prognosticating patients with serious illness
- Describe the models used to prognosticate patients for cancer, end-organ diseases, dementia, and frailty
- Name the skills used to share a prognosis with a patient and their family
- Apply prognostication models and communication skills to serious illness cases



INTRODUCTION

DEFINITION OF PROGNOSIS

- Prognosis is the science of estimating the likelihood of an outcome

TYPES OF PROGNOSTICATION



TIME



CURE



ABILITY

WHY IS SHARING PROGNOSIS IMPORTANT?



Provides context for medical decision making



Helps patients re-prioritize goals



Helps patients and their loved ones prepare for the future

Buton et al. JPM. 1995
Vandekieft. AFP. 2002

YET, WE STILL AVOID PROGNOSIS

Cancer Population

- 50% of oncologists reported that they “occasionally to always” withheld prognostic information from patients

Heart Failure

- Advanced heart failure patients reported that they received little or no information about the prognosis of their heart failure

Weeks et al. NEJM. 2012.
Lee et al. Cancer. 2017.
Helmsfors et al. Applied Nursing Research. 2018.

WHEN WE DO SAY IT, WE DON'T
ALWAYS DO A GOOD JOB



Confusing



Mixed messaging



Avoiding

CONFUSING
WORDS
FOR
PATIENTS

“So, if you had 100 people, the survival curve drops down because people die of one thing or another, including relapse. That tends to level off at about 2.5 years after transplant and stays level after that. It’s about 30% in your situation.”

“We have a few options for treatment. Let’s talk about the possibility of stem cell transplant and the possibility of cure...”

Back, A. VitalTalk. 2015

AVOIDING THE D WORD

Opinion

A PIECE OF MY
MIND

Say What You Mean, Mean What You Say

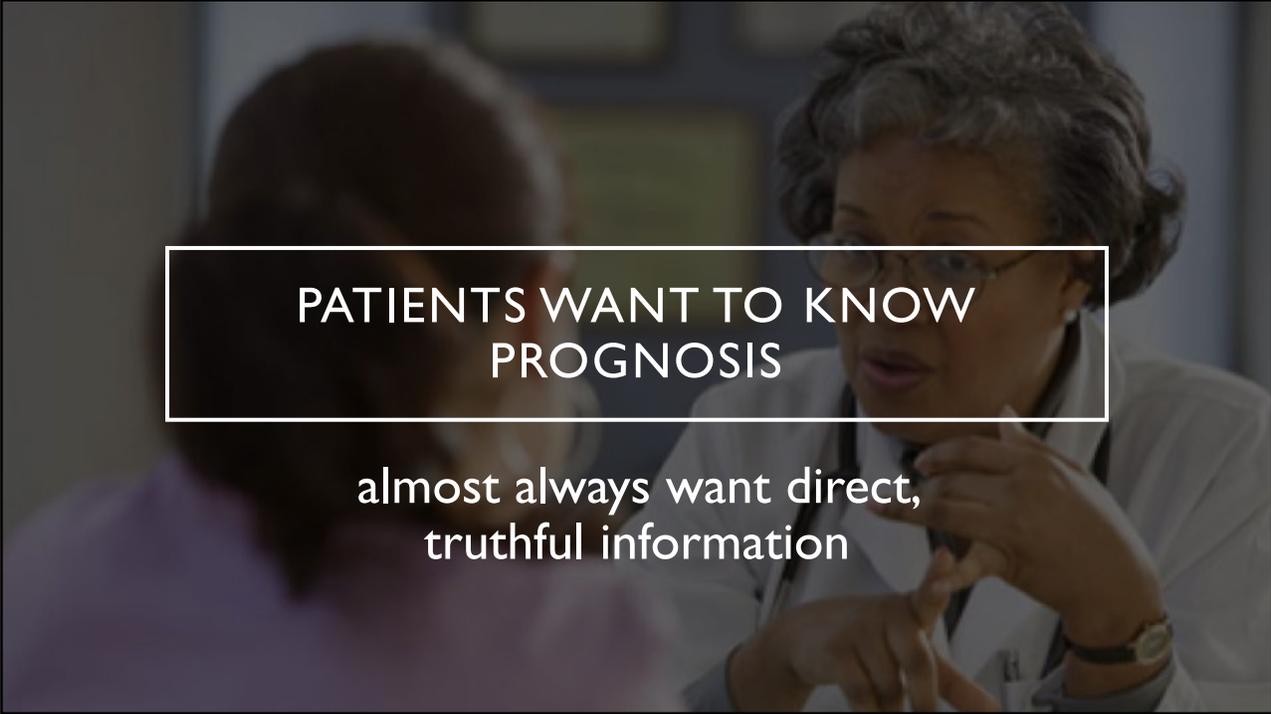
Amanda Fantry, MD
The Warren Alpert
Medical School of
Brown University,
Providence,
Rhode Island.

“And soon both the neurosurgeon and the nurse were adding some “ands” and “buts” in order to soften the harsh discussion”

WHAT IS HARD ABOUT
SHARING PROGNOSIS IN
SERIOUS ILLNESS
CONVERSATIONS?

REASONS WHY CLINICIANS DO NOT
SHARE PROGNOSIS

Baile et al. The Oncologist. 2000
Tesser et al. Psych Rep. 1971
Vermont Hospice Study. 2016.



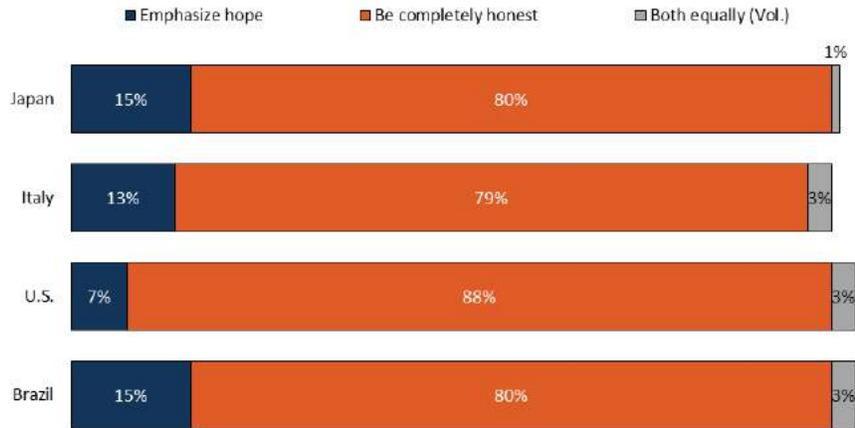
PATIENTS WANT TO KNOW
PROGNOSIS

almost always want direct,
truthful information

Figure 10

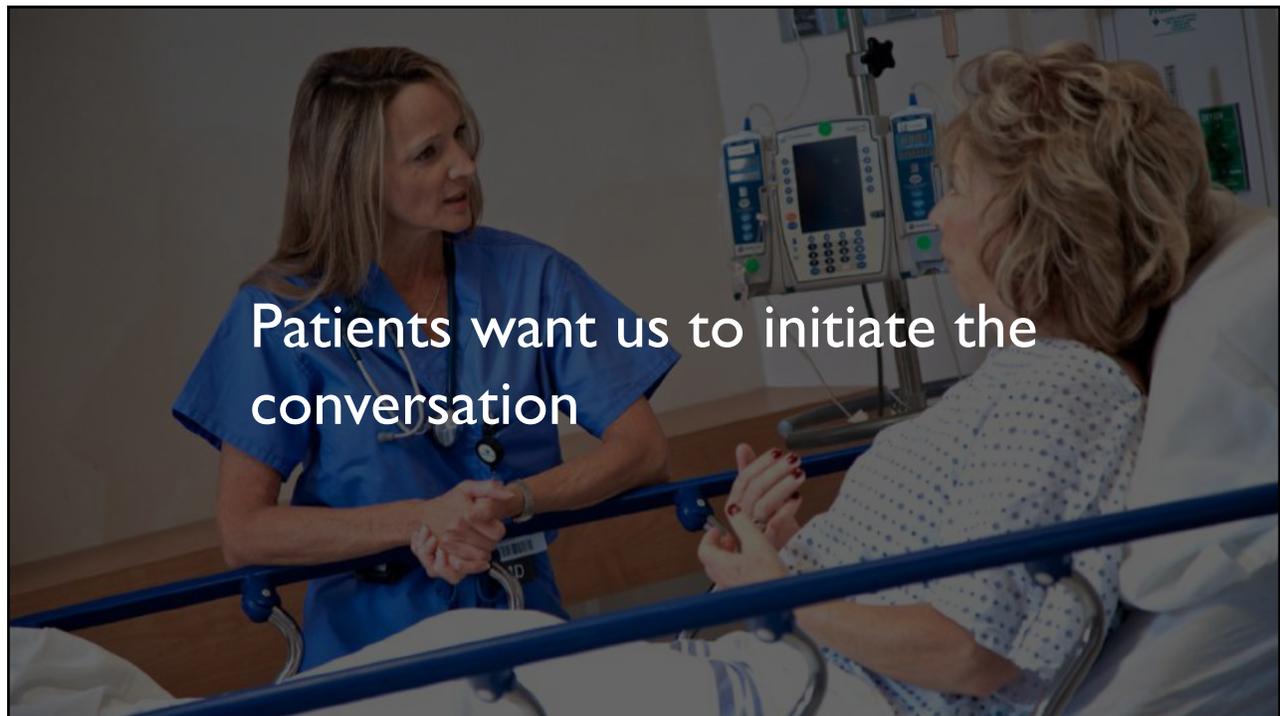
Across Countries, Most Want Doctors to Be Completely Honest Regardless of Prognosis

When a patient is seriously ill, do you think it is more important for their doctors to emphasize hope, or more important for doctors to be completely honest even if there is little chance of recovery?



NOTE: Neither (Vol.) and Not sure/No answer responses not shown.

SOURCE: Kaiser Family Foundation/The Economist Four-Country Survey of Aging and End-of-Life Medical Care (conducted March–November 2016)



California Man Learns He's Dying From Doctor on Robot Video

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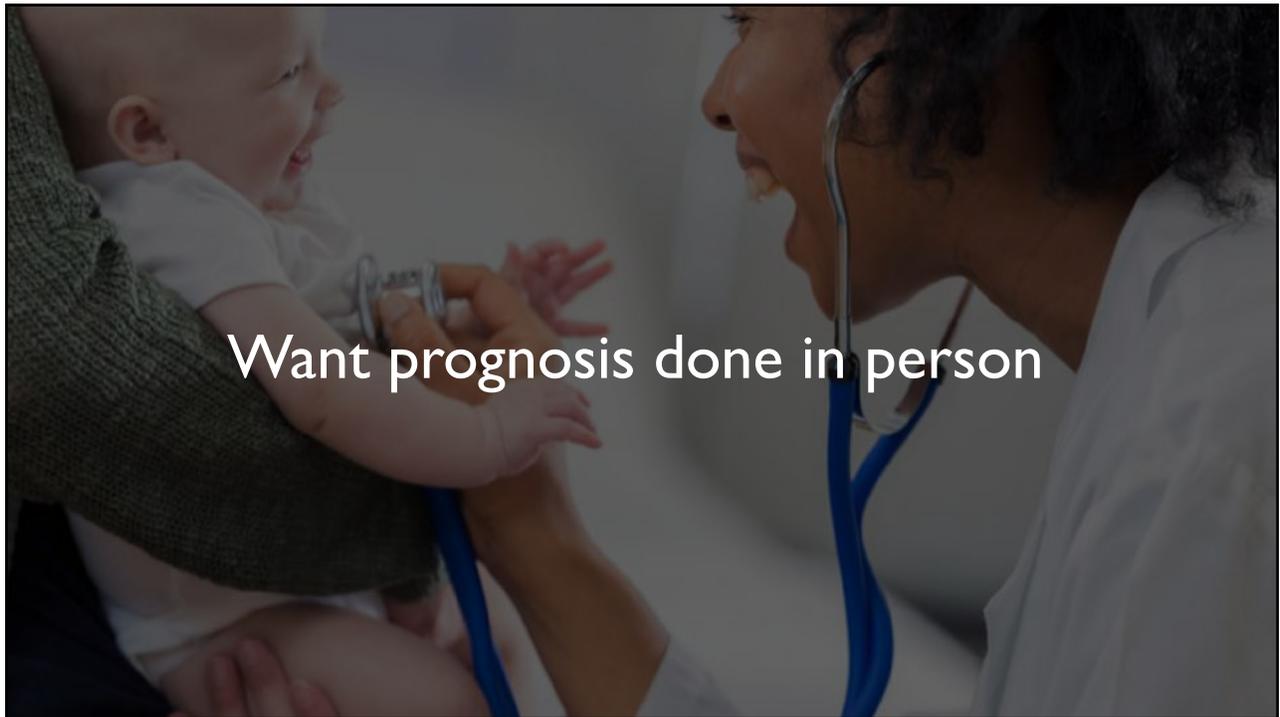
pat

"If

con



morphine drip until you die, it should be done by a human being and not a machine." his daughter Catherine Quintana said Friday



Want prognosis done in person

KNOWING
PROGNOSIS
IMPROVES PATIENT
CARE

Greater patient satisfaction

Lower anxiety and depression

Improved caregiver stress/anxiety

Improved goal-concordant care

Stronger therapeutic alliance

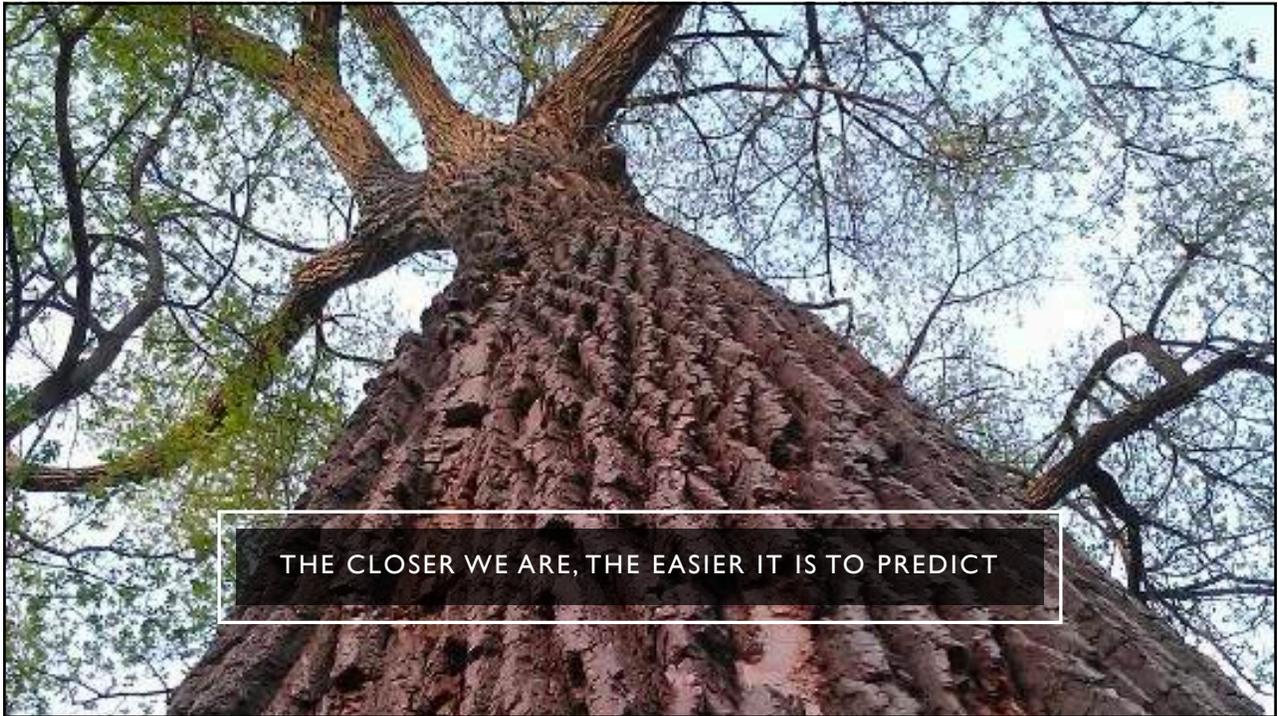


WHICH CASE IS EASIER TO
PROGNOSTICATE? WHICH IS HARDER?

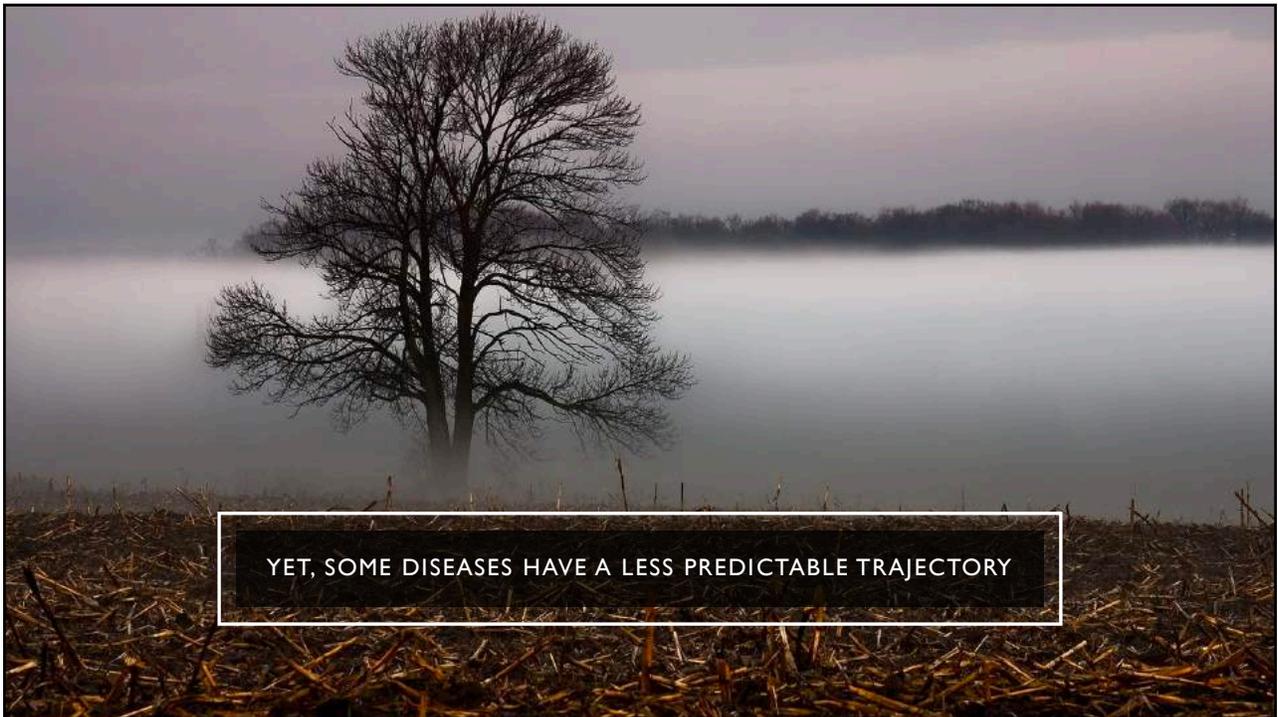
- A. 45 year old man with metastatic lung cancer to the bones on immunotherapy, walking into clinic today
- B. 65 year old woman with diabetes, heart failure recently hospitalized for heart failure exacerbation, taking ACE-I, beta-blocker, coming into outpatient clinic today.
- C. 60-year-old man with asthma, chronic kidney disease, who presents to the ICU with a new stroke in the setting of new onset atrial fibrillation and aspiration pneumonia. He is currently intubated, receiving antibiotics, and on pressors.
- D. 80-year-old woman with history of hypertension, diabetes, and chronic kidney disease, who you are seeing in the hospital for cellulitis.
- E. 75 year-old-man with history of hypertension, congestive heart failure, and stroke (right sided deficits) who was a stage 2 pressure ulcer. Now dependent on all ADLs and being admitted to a nursing home.

A major barrier to discussing prognosis is the lack of certainty in prognostic information

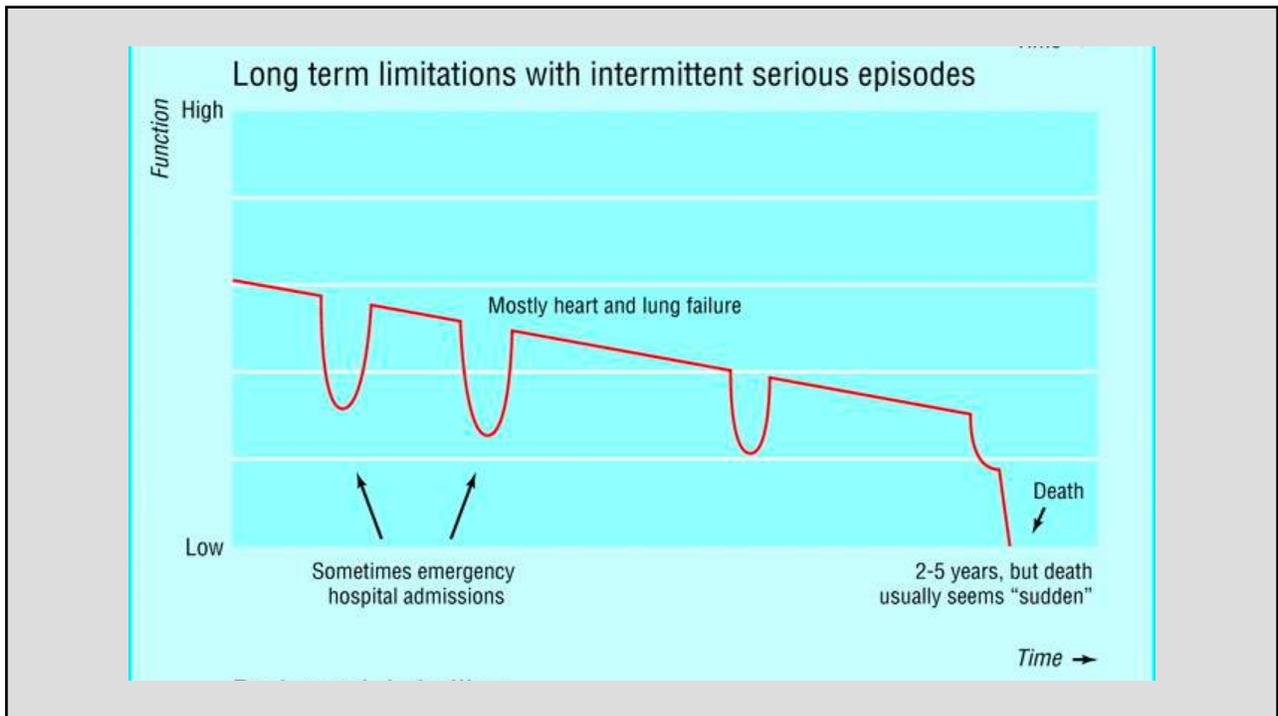
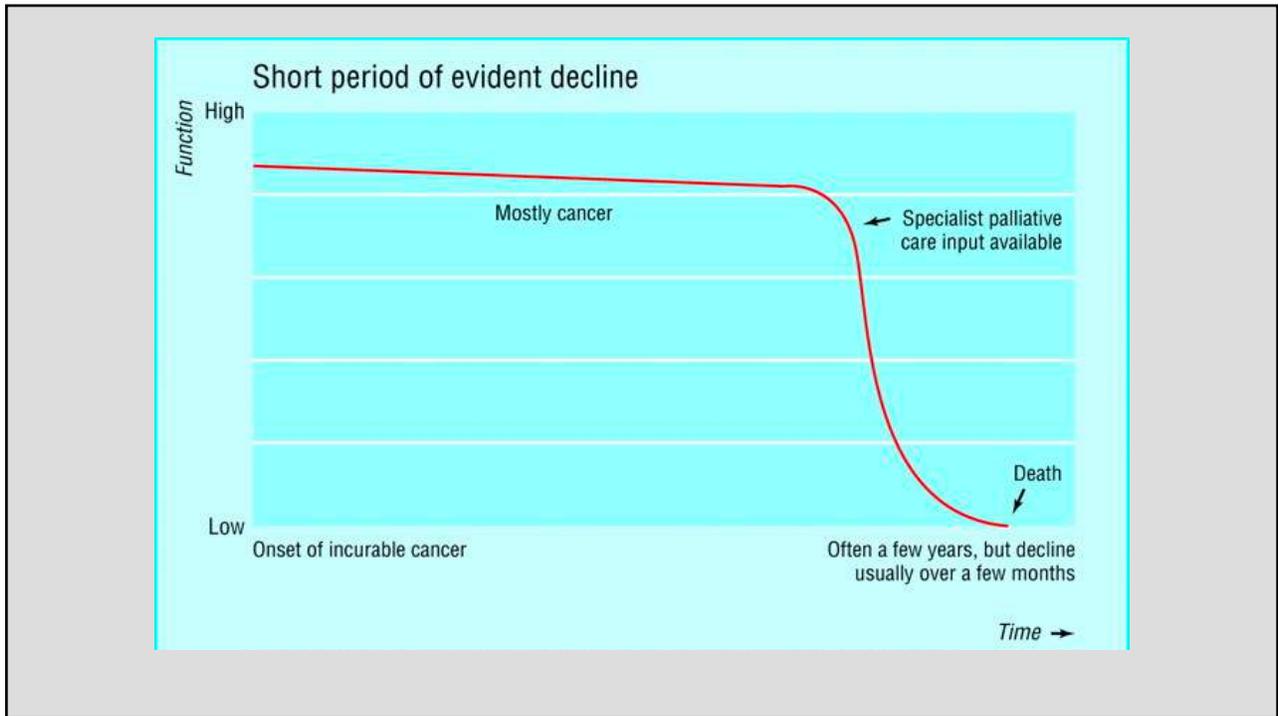


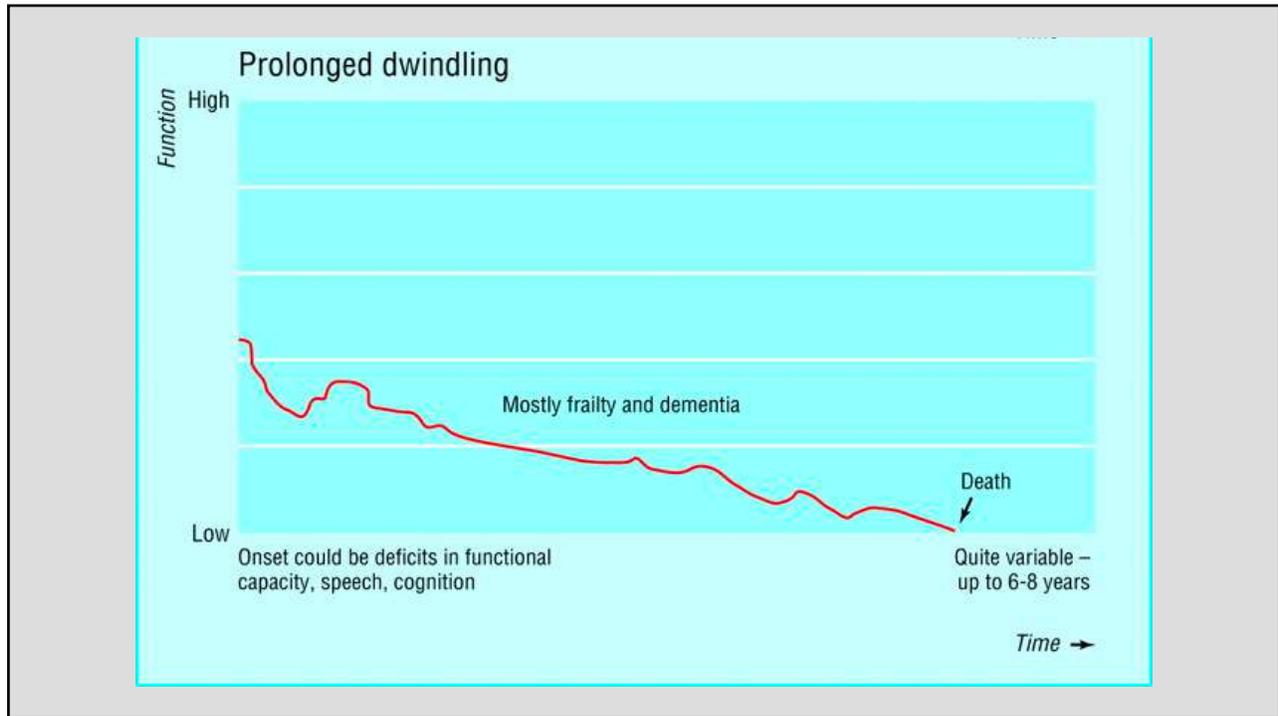


THE CLOSER WE ARE, THE EASIER IT IS TO PREDICT



YET, SOME DISEASES HAVE A LESS PREDICTABLE TRAJECTORY





PROGNOSTICATION TOOLS FOR CANCER

- Staging of cancer
- Functional status tools
- Risk factors for mortality: edema, dyspnea at rest, decreased oral intake, and delirium (Morita et al. Supp Care Cancer. 1999)

Performance Status categories*	
	Description
	Active, able to carry on all pre-disease performance without restriction
	Restricted in physically strenuous activity, but ambulatory and able to carry out work e.g., light house work, office work
	Unable to carry out any work activities, ambulatory and capable of all self care, but unable to carry out any work activities. Limited walking hours
	Unable to carry out any work activities, ambulatory and capable of all self care, but unable to carry out any work activities. Limited walking hours
	Unable to carry out any work activities, confined to bed or chair more than 50% of waking hours
	Totally disabled. Cannot carry on any self care. Totally confined to bed or chair

et al. 1982 ¹ Recursive Oncology Group	
0 Normal activity	100 Normal; no evidence of disease
1 Symptomatic and ambulatory, cares for self	90 Able to perform normal activities with only minor symptoms
	80 Normal activity with effort, some symptoms
2 Ambulatory >50% of time, occasional assistance	70 Able to care for self but unable to do normal activities
	60 Requires occasional assistance; cares for most needs
3 Ambulatory ≤50% of time, nursing care needed	50 Requires considerable assistance
	40 Disabled, requires special assistance
	30 Severely disabled
	20 Very sick, requires active palliative treatment

PROGNOSTICATION TOOLS FOR END ORGAN DISEASE

Liver disease= MELD-NA

- Estimates: 3-month survival without transplant

Heart failure= Seattle Heart Failure Model or MAGGIC Risk Calculator

- Estimates: 1-year survival, 5-year survival

Lung Disease= Staging (GOLD, Bode)

- Estimates: 4 year survival

PROGNOSTICATION TOOLS FOR CRITICAL ILLNESS

APACHE

- severity scores using the worst values measured within the first 24 hours of admission to the ICU
- Estimates= hospital survival, length of stay

SAPS or MPM

- severity score using the worst values measured within the first 24 hours of admission to the ICU
- Estimates= hospital mortality rate

SOFA

- assess the severity of organ dysfunction in patients who were critically ill from sepsis
- Estimates= hospital mortality rate

PROGNOSTICATION TOOLS FOR DEMENTIA

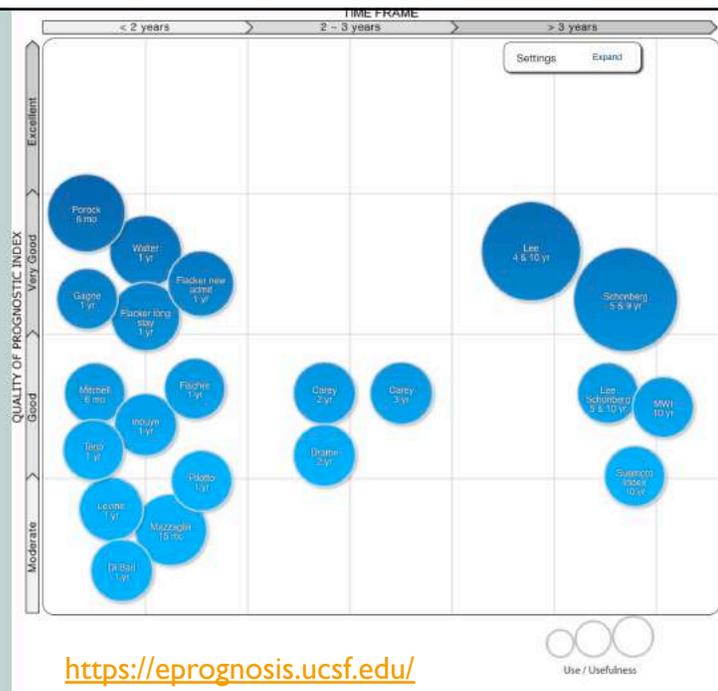
Advanced Dementia Prognostic Tool (ADEPT)

- 12-item additive score that includes information on patient age, gender, level of functional dependence, nutritional status, and presence or absence of various symptoms and medical conditions
- Estimates: 6-month survival

PROGNOSTICATION TOOLS FOR OLDER ADULT

4 types of patient populations

- Home
- Nursing Home
- Hospital
- Hospice



TOOL FOR
ALL
PATIENTS:
SIMPLY ASK
THE
QUESTION

Would you be surprised if they die
within the next year?

PROGNOSTICATE TIME FOR EACH OF
THE FOLLOWING PATIENTS

- A. 65 year old woman with diabetes, NYHA III heart failure recently hospitalized for heart failure exacerbation, taking ACE-I, beta-blocker, coming into outpatient clinic today.
- B. 80-year-old woman with history of hypertension, diabetes, and chronic kidney disease, who you are seeing in the hospital for cellulitis.
- C. 70 year old man with Alzheimer's dementia (able to speak, able to feed himself, occasional agitation), COPD, Atrial Fibrillation on anticoagulation, and recent weight loss and electrolyte changes. Presents to outpatient clinic.
- D. 75 year-old-man with history of hypertension, congestive heart failure, and stroke (right sided deficits) who was a stage 2 pressure ulcer. Now dependent on all ADLs and being admitted to a nursing home.

CAVEAT TO TOOLS



AVERAGES (BASED OFF OF POPULATION DATA)



DOES NOT INCLUDE ALL CO-MORBIDITIES

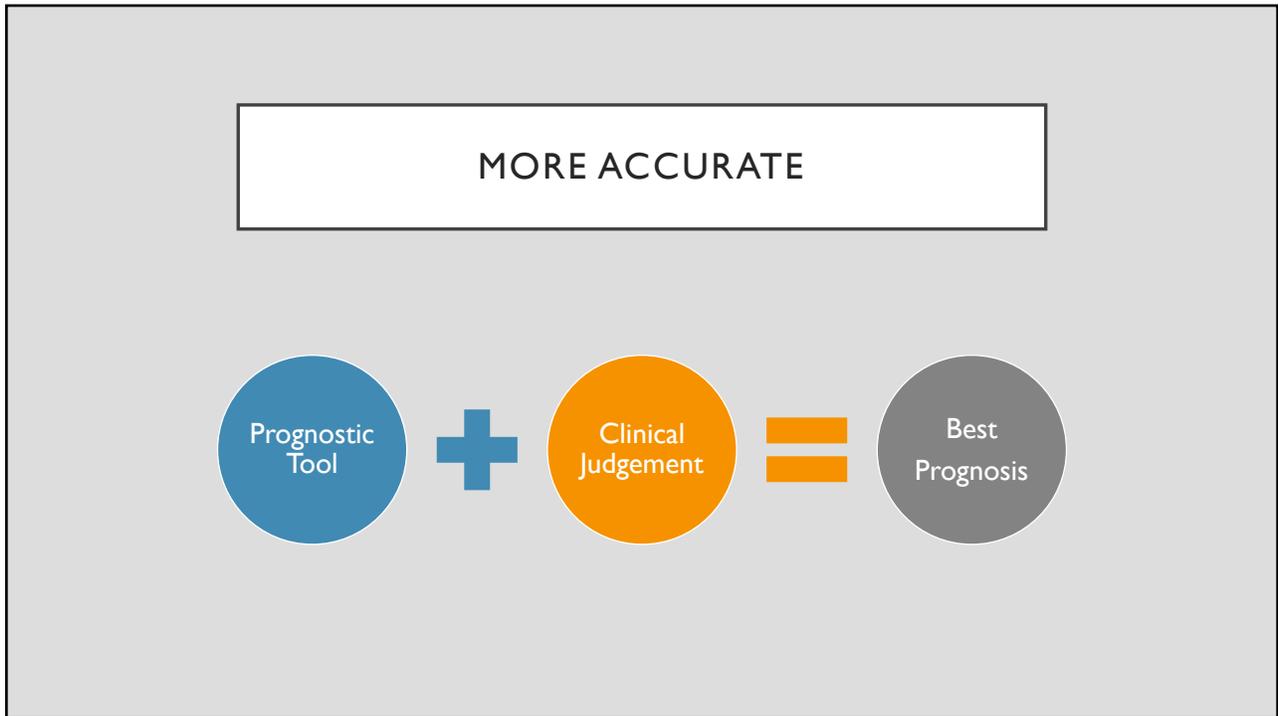


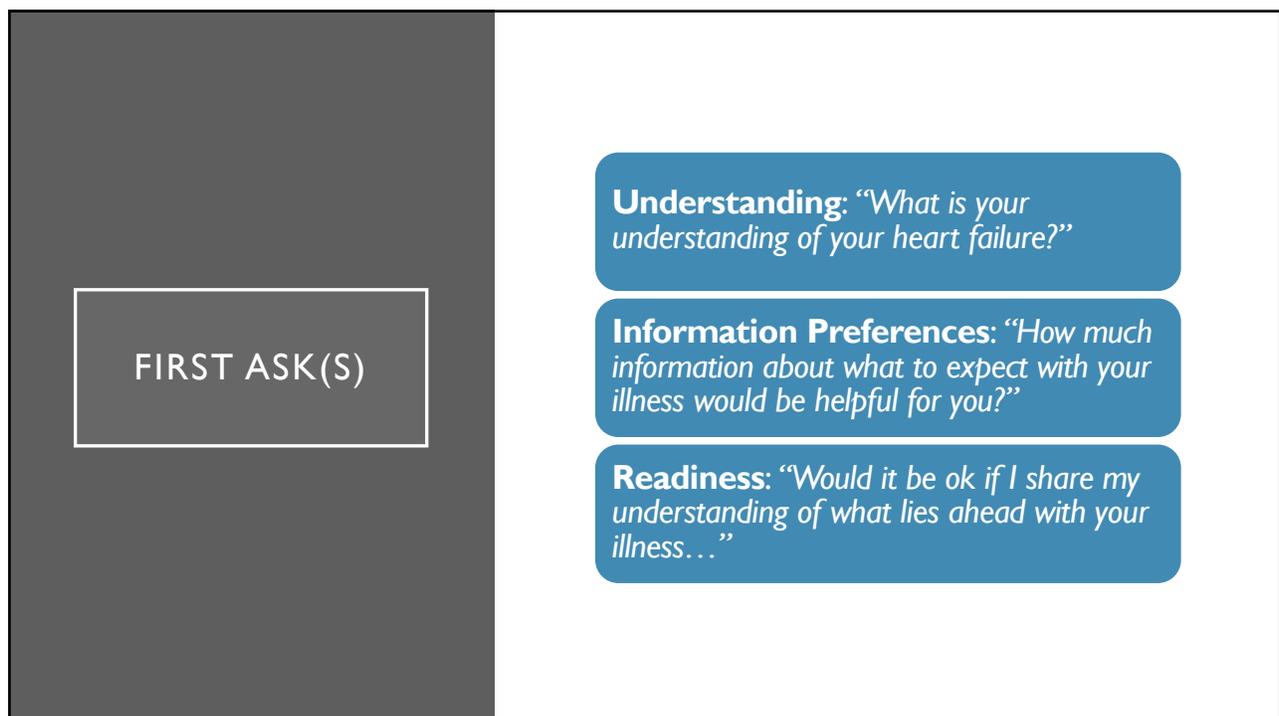
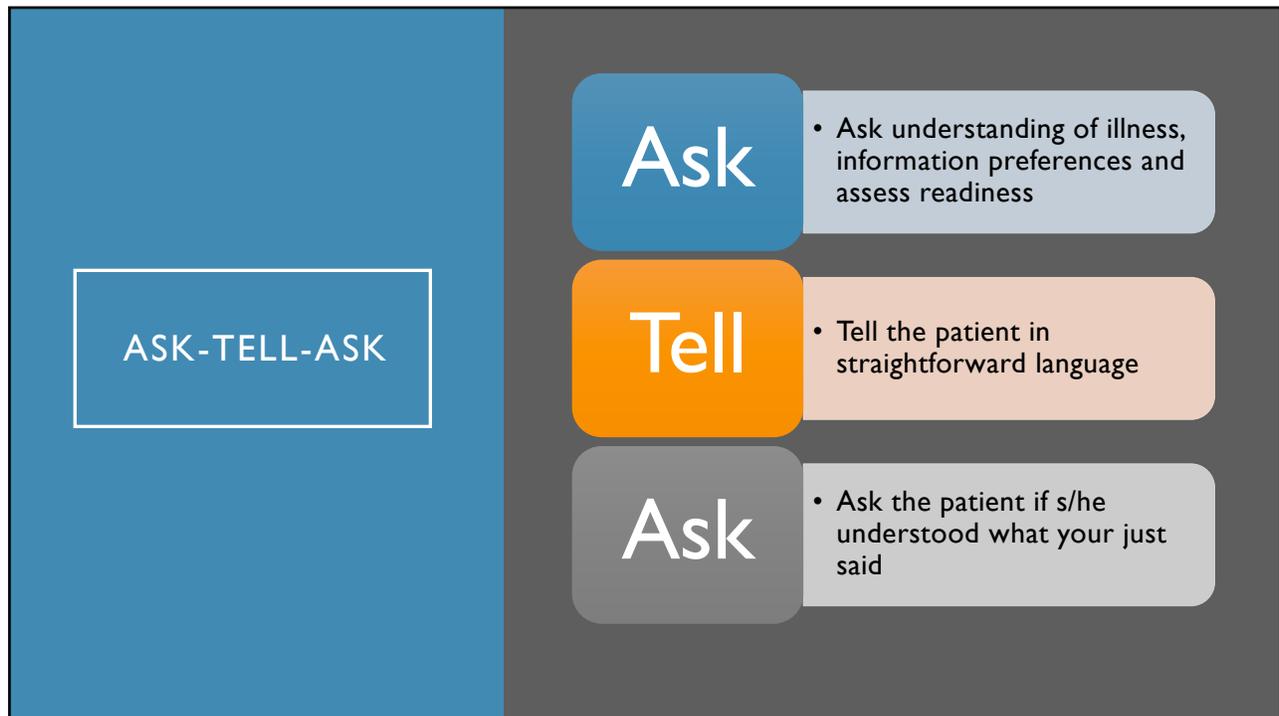
ACCURACY

HOW GOOD ARE CLINICIANS AT PREDICTING?

Overestimation

Bias





TELL THE PROGNOSIS

What's the "headline"?



TIPS FOR PROGNOSTIC HEADLINES

Be concise

1-2 phrases that give a take home message

Be clear

Understandable, 5th grade level
Avoid jargon

Be impactful

Message should include what this *means* for the patient

3 TYPES WAYS TO GIVE IMPACT

Time

“I hope this is not the case. I am worried that time could be as short as weeks to a few months”

Function

“I am concerned that this may be as strong as you feel and things are likely to get worse over time”

Unpredictable Events

“It can be difficult to predict what will happen to your illness. I hope you will continue to live well for a long time, and I am also worried that you could get sick quickly or even die from your illness”



BUT THIS IS
NOT MY
ROLE....

If you were in the room:

- “So it sounds like.... (prognosis insertion)”

If headline was delivered prior to your conversation:

- ASK + Permission
- “I heard that... (prognosis)”

PRACTICE: WHAT'S THE HEADLINE?

45 year old man with metastatic lung cancer to the bones on immunotherapy, walking into clinic today

- Surveillance CT scan shows new bone metastasis in lumbar and sacral spine, increased hilar lymphadenopathy, larger lung mass
- Oncologist says more chemotherapy will not likely benefit him

LABEL NEWS





OPTIONAL SECOND ASK

CHECK UNDERSTANDING

- *“To make sure I did a good job giving you the information, tell me what you will tell your spouse about our conversation.”*

EMOTIONAL CHECK

- *“How are you doing with that information?”*

HEADLINE PRACTICE

- A. 65 year old woman with diabetes, heart failure recently hospitalized for heart failure exacerbation, taking ACE-I, beta-blocker; coming into outpatient clinic today.
- B. 80-year-old woman with history of hypertension, diabetes, and chronic kidney disease, who you are seeing in the hospital for cellulitis.
- C. 70-year-old man with Alzheimer's dementia (able to speak, able to feed herself, occasional agitation), COPD, Atrial Fibrillation on anticoagulation, and recent weight loss and electrolyte changes. Presents to outpatient clinic.
- D. 60-year-old man with asthma, chronic kidney disease, who presents to the ICU with a new stroke in the setting of new onset atrial fibrillation and aspiration pneumonia. He is currently intubated, receiving antibiotics, and on pressors. His SOFA score=10 (50% mortality rate).

A glass sphere is centered on a newspaper page. The newspaper text is blurred but some words like "rolls over" and "ity cos" are visible. The sphere is highly reflective and sits on a dark shadow.

QUESTIONS?