FORESEEING AND FORETELLING PROGNOSIS

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

- Confusing
- Mixed messaging
- Avoiding

“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

Say What You Mean, Mean What You Say

“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

PATIENTS WANT TO KNOW PROGNOSIS

almost always want direct, truthful information

Baile et al. The Oncologist. 2000
Vermont Hospice Study. 2016.
Patients want us to initiate the conversation
California Man Learns He’s Dying From Doctor on Robot Video

By Tessa Gerlach

March 15, 2019

SALEM, OR — Being of chronic, terminal, undiagnosed condition, but was unable to understand the terminal prognosis from the robotic doctor. "If you continue with the 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

FORESEEING

Prognostication tools for your patients
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
Short period of evident decline

- Mostly cancer
- Specialist palliative care input available
- Onset of incurable cancer
- Often a few years, but decline usually over a few months
- Death

Time

Long term limitations with intermittent serious episodes

- Mostly heart and lung failure
- Sometimes emergency hospital admissions
- 2-5 years, but death usually seems “sudden”

Time
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)
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

- Home
- Nursing Home
- Hospital
- Hospice

https://eprognosis.ucsf.edu/
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
MORE ACCURATE

Prognostic Tool + Clinical Judgement = Best Prognosis

FORETELLING
ASK-TELL-ASK

**Ask**
- Ask understanding of illness, information preferences and assess readiness

**Tell**
- Tell the patient in straightforward language

**Ask**
- Ask the patient if s/he understood what you just said

**FIRST ASK(S)**

**Understanding**: “What is your understanding of your heart failure?”

**Information Preferences**: “How much information about what to expect with your illness would be helpful for you?”

**Readiness**: “Would it be ok if I share my understanding of what lies ahead with your illness…”
TELL THE PROGNOSIS

What’s the “headline”?

[News headlines shown]
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 a 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”
IDENTIFYING THE FOREST... FROM THE TREES

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)”
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
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?”
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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).