

Prognostication: Foreseeing and Foretelling

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Modified from lots of people

Session Outline

- Why prognostication is important
- Didactics on prognosis (foreseeing)
 - Malignant diseases
 - Non-malignant diseases
- How to talk about prognosis (foretelling)

Learning Goals for “Foreseeing”

- Describe the disease trajectory of advanced malignant disease.
- Describe the disease trajectory of advanced non-malignant diseases.
- Name two prognostic markers in advanced malignancy, and one in a non-malignant disease.

Foreseeing

- Doctors are not very good at this
 - Overestimate prognosis by 3-5x in terminal illness
 - Worse if the doctor knows the patient
 - Experienced physicians, academic oncologists better
 - Concordance with patients is poor

Why is prognosis important?

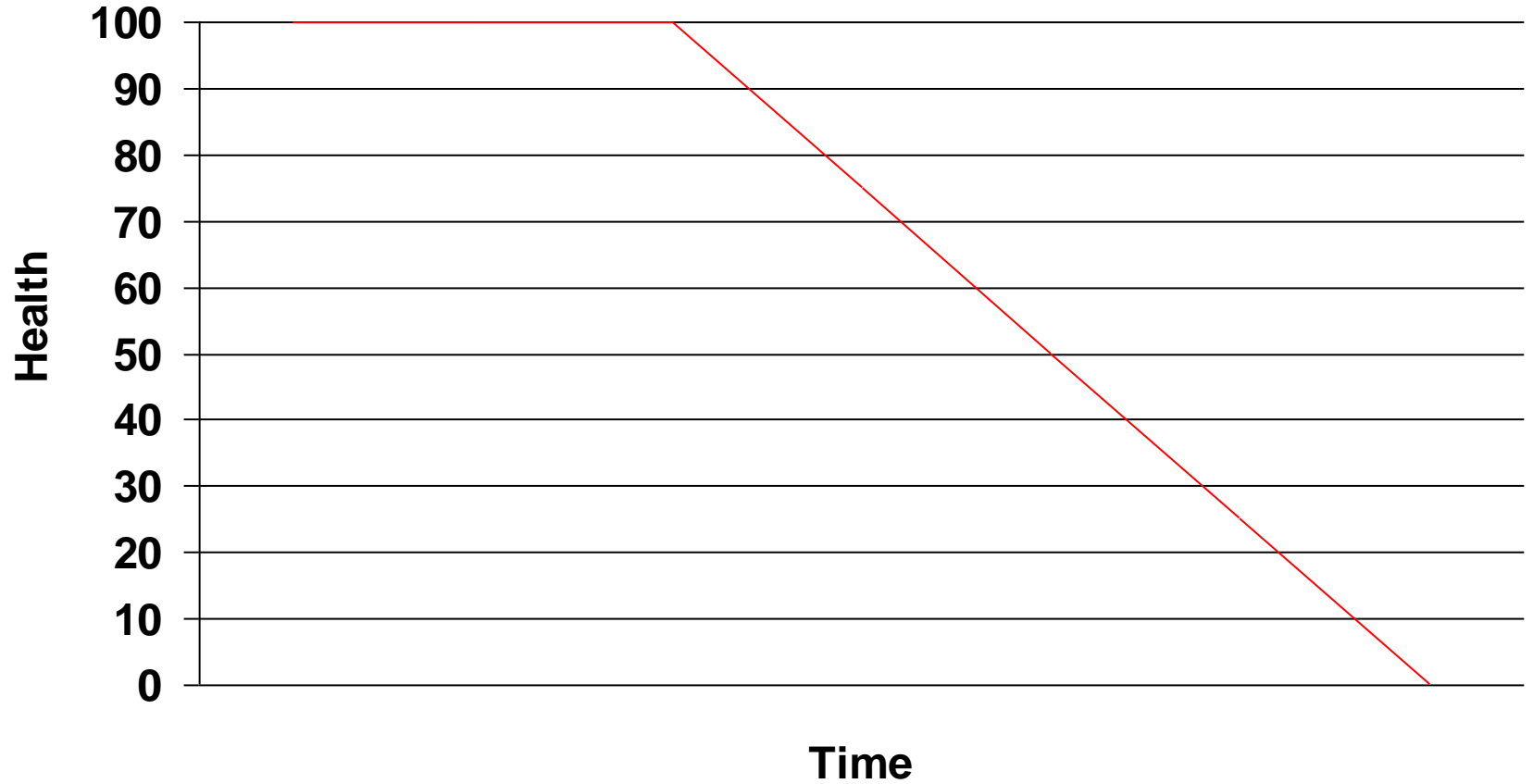
- Allows for planning
- Interviews of 287 geriatric clinic patients
 - 41% want CPR before learning survival to discharge
 - 22% want CPR after learning survival to discharge
 - 5% want CPR if overall prognosis < 1yr
- 917 hospitalized NSCLC and metastatic colon cancer patients
 - Patients who think they may live less than 6 months are more likely to favor comfort care

Malignant Diseases

A case

- 60yo M with colon cancer metastatic to the liver who is admitted with nausea and vomiting. He is found to have acute kidney injury secondary to decreased PO intake. While in the hospital he does not take much PO and he becomes delirious.

Malignant Diseases: Natural History



Malignant Diseases-

What are the indicators?

- Performance status
- Oral intake
- Edema
- Dyspnea
- Delirium
- WBC count
- %lymph
- Clinician's estimation

Malignant Diseases- Specific syndromes

- Malignant hypercalcemia
- Malignant pericardial effusion
- Carcinomatous meningitis
- Multiple brain metastases
- Malignant ascites, malignant pleural effusion, or malignant bowel obstruction

Malignant Diseases- Hospice eligibility

- <6 months: metastatic solid cancer, acute leukemia or high grade lymphoma not receiving systemic chemotherapy
 - Exceptions: metastatic breast or prostate cancer with good functional status

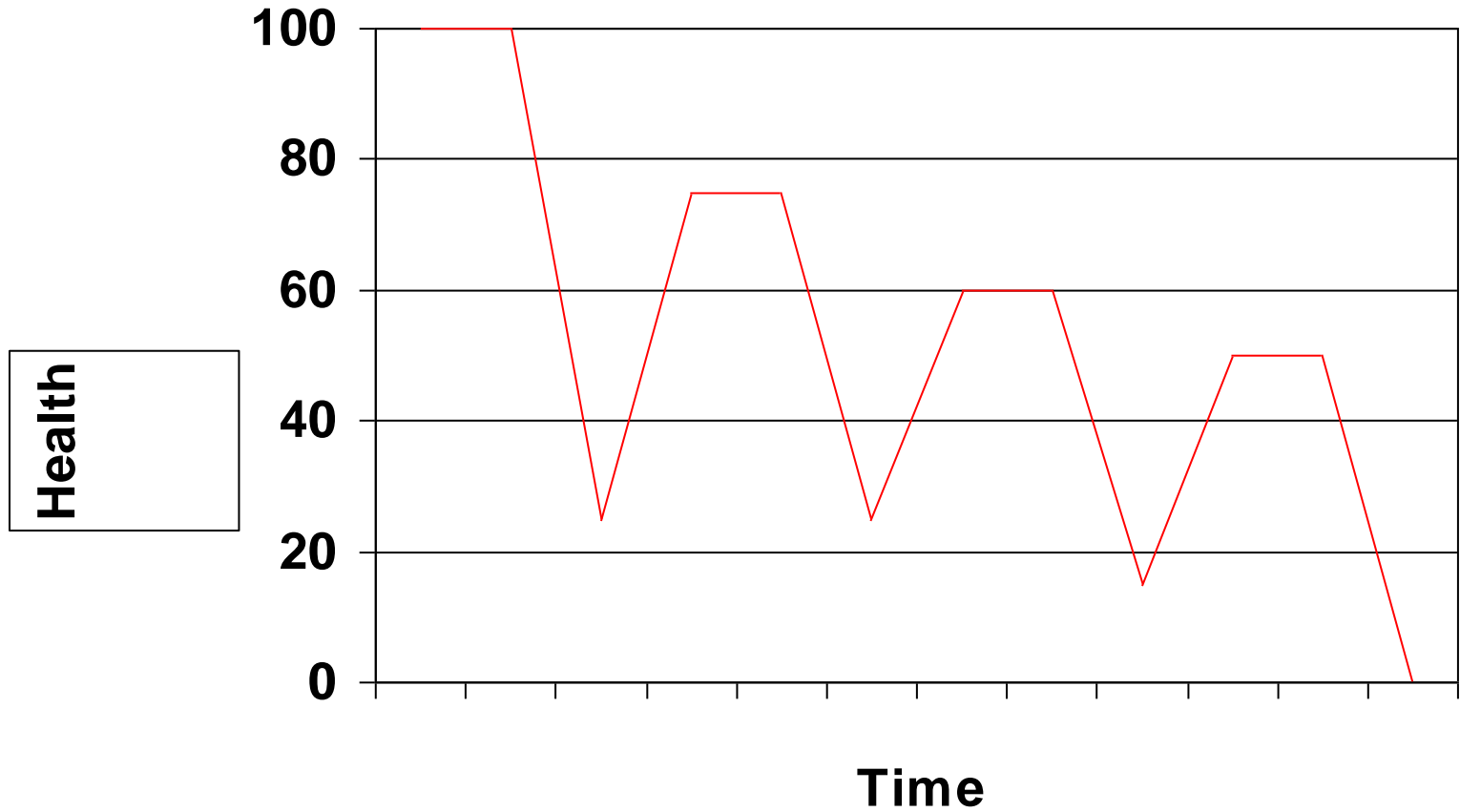
Malignant Diseases- Prognostic scales

- Palliative Prognostic (PaP) Score
- Palliative Performance Scale (PPS)
- Palliative Prognostic Index (PPI)

Malignant Diseases: The Case

- 60yo M with colon cancer metastatic to the liver, ARF, decreased PO intake, delirium.
- Using the PPI
 - PPS= 20
 - PO intake
 - Delirium
- PPI total= 10.5
 - Predicted survival <3 wks

Non-Malignant Diseases: Natural History



3 Non-Malignant Diseases

- Congestive heart failure
- Dementia
- ESLD

Heart Failure: A Case

- 60yo M with PMH significant for CAD and ICM, EF 15% who is admitted with increased SOB and LE edema. Pt reports SOB with minimal exertion. On exam pt's SBP is 90 and he appears volume overloaded. Labs are significant for Na 126, Cr 1.4, Hgb 10.

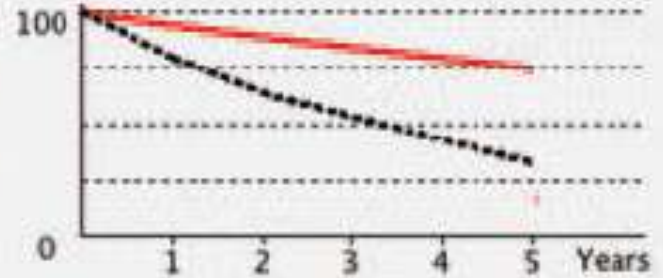
Heart Failure:

What are the indicators?

- Recent cardiac hospitalization (triples 1-year mortality)
- Elevated BUN/Cr, anemia, hyponatremia
- SBP<100, pulse >100
- Decreased LVEF
- Cachexia
- Reduced functional capacity

Seattle Heart Failure Model

	Baseline			Post-intervention		
	1 year	2 year	5 year	1 year	2 year	5 year
Survival	80%	64%	33%	84%	89%	75%
Mortality	20%	36%	67%	6%	11%	25%
Mean life expectancy	4.1 years			9.7 years		



Baseline Characteristics

Clinical

Age

Gender

NYHA Class

Weight (kg)

EF

Syst BP

Ischemic

Medications

ACE-I

Beta-blocker

ARB

Statin

Allopurinol

Aldosterone blocker

Diuretics

Lasix

Bumex

Demadex

Metolazone

HCTZ

Lab Data

Hgb

Lymphocytes

Uric Acid

Total Chol

Sodium

QRS >120 msec

Devices

None

BiV Pacer

ICD

BiV ICD

Defaults

Interventions

ACE-I ARB Beta-blocker

Statin Aldosterone Blocker

Devices

None

BiV Pacer BiV ICD

ICD LVAD

Heart Failure: The Case

- www.seattleheartfailuremodel.org
- Our patient: 24% 1 year mortality with mean life expectancy of 3.4 years

End-Stage Liver Disease: A Case

- 60yo M with ESLD secondary to ETOH, complicated by ascites, encephalopathy and thrombocytopenia who was admitted with hematemesis. Pt was found to have bleeding from esophageal varices. During the hospitalization pt had Cr 1.7, Bili 3, Albumin 1.8 and INR 1.5

End-Stage Liver Disease- What are the indicators?

- Child's class
 - ascites, bilirubin, albumin, PT and encephalopathy
- Child C = 55% one year mortality
- Child C admitted to ICU = 90% mortality
- Child C admitted to ICU and Cr>1.3 and ventilated >95% mortality

End-Stage Liver Disease- What are the indicators?

- MELD: $>40 = >95\%$ 3 month mortality
- Compensated vs decompensated cirrhosis
 - 10 vs 40% 1 year mortality
- Hepatorenal syndrome
 - Type 1: 8-10 weeks
 - Type 2: 6 months
- GI Bleed: 57% one year mortality
- Hyponatremia, age, HCC

End-Stage Liver Disease: The Case

- Decompensated cirrhosis ~40% 1 yr mort
- GI bleed ~57% 1 yr mortality
- Child's class C ~55% 1 yr mortality
- MELD 20 ~ 50% 3 month mortality

Dementia: A Case

- Pt is an 84yo M with Alzheimer's dementia who is admitted from a SNF with MS changes and found to have a UTI. At baseline pt is dependent for all ADLs. Exam is remarkable only for fever, tachycardia and dry mucous membranes.

Dementia:

What are the indicators?

- ADLs
- Functional capacity
- Comorbidities

Dementia: Prognostic Scales

- Functional Assessment Staging (FAST)
 - Studied in small number of pts
- Mortality Risk Index Score (MRI)
 - Studied in newly admitted to SNF

Dementia: The Case

- Using the MRI
 - 84yo- 1.4
 - Male- 1.9
 - Dependent for ADLs- 1.9
- MRI- 5.2= 23% 6 month mortality
- Prognosis very dependent on goals and levels of intervention

Miscellaneous Markers

- Stopping Dialysis = 7-14 days
- Not eating/no TF = weeks - months
- Not drinking/no IVFs = weeks

Objectives – How is prognosis discussed?

- To be able to describe how doctors talk about prognosis to patients with cancer
- To be able to describe the impact of having end of life conversations on patients with cancer and their family

What do patients want?

- 98% want doctor to be realistic, have opportunity to ask questions, acknowledge them as an individual
- Hope-giving characteristics:
 - Offering most up-to-date treatments
 - Appearing knowledgeable
 - Saying pain will be controlled
- Disliked: giving prognosis to family first and using euphemisms

What Do MDs Say They Do?

- 326 cancer patients referred to hospice
- Referring MDs (23% oncologists) asked:
 - “formulated survival” - what they thought
 - “communicated survival” - what they told
- MDs would communicate
 - No survival estimate (23%)
 - Same estimate they formulated (37%)
 - Discrepant estimate (40%) 70% optimistic

Oncologist and Patient Estimates of Cure: Predictors of Concordance

- Taped encounters between 51 oncologists and 141 advanced cancer patients

Communication variable	P
OPTIMISM	0.404
PESSIMISM	0.004
UNCERTAINTY	0.899

What Is Impact Of Discussion?

Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment.

Wright AA et al. JAMA. 2008;300:1665-1673.

Methods

- Prospective, longitudinal, multisite cohort study of cancer patients and caregivers
- Inclusion: metastatic cancer refractory to first-line chemotherapy, >20yo, caregiver, adequate stamina
- Exclusion: Dementia, delirium, non-English or Spanish speaking
- Setting: 7 outpatient sites
- Funding: NCI, NIMH

Methods

- Patients and caregivers interviewed at baseline
- After death, chart reviewed for care received at the end of life
- Caregiver interviewed a median of 6.5 months after the patient's death
- Main predictor variable
 - “Have you and your doctor discussed any particular wishes you have about the care you would want to receive if you were dying” Yes/No

Methods and Analysis

- Outcome measures for patients:
 - Use of life-sustaining treatments at EOL, mental health, hospice use
 - QOL at end of life as rated by caregiver
- Outcome measures for caregivers
 - Mental health
 - Bereavement adjustment
- Propensity score analysis

Results: Patients

- 123 of 332 (37%) had EOL discussions
- Baseline characteristic differences:
 - Site differences
 - Performance status
 - Symptom burden
 - Survival time

Results: Patients

- EOL discussions NOT associated with:
 - Worse patient emotional state
 - Meeting criteria for a mental disorder
- EOL discussions are associated with:
 - Accepting illness as terminal (53 vs 29%)
 - Preferring symptom control over life prolongation (85 vs 70%)
 - Having a DNR (63 vs 29%)

Results: Care Received

- EOL discussions - less likely to:
 - Receive mechanical ventilation (2 vs 11%)
 - Undergo resuscitation (1 vs 7%)
 - Be admitted to ICU (4 vs 12%)
- EOL discussions: more likely to be enrolled in hospice (67 vs 45%)

Results: Caregivers

- Direct relationship between patient QOL at end of life and caregiver QOL at follow-up
- Caregivers of patients with high QOL:
 - Better prepared for patient death
 - Less regret
 - Better physical and mental health

Results: Caregivers

- Caregivers of patients receiving aggressive care
 - Had higher risk of depression
 - Experienced more regret
 - Felt unprepared for the patient's death
 - Had worse QOL and self reported health

Clinical Bottom Line

- EOL discussions are associated with less aggressive medical care and improved perceived QOL near death
- They also improve bereavement outcomes for caregivers
- They are NOT associated with worse psychological outcomes for patients or caregivers

Non-oncological illness

- Silence predominates
 - Fewer studies
- Data suggests even less talk about prognosis
 - Collusion

In Summary, Physicians:

- De-emphasize prognosis
- Share an optimistic bias
- Talking about prognosis does not seem to lead to adverse outcomes

Objectives for how to talk about prognosis

- To describe a way to assess a patient's desire to discuss prognosis
- To describe phrases that one can use when discussing prognosis
- To describe how to balance cognitive information and emotional support when giving prognosis

Case: Mr P.

- 54M with Stage III adenocarcinoma of the esophagus
- Student A : “Aren’t you going to tell him his prognosis? It’s his right to know.”
- Student B: “Why ruin what time he has? I would not want to know how long I have.”
- What do you do?

A negotiation strategy

- Key question: “How much do you want to know about the future?”
- Three kinds of patient responses
 - Want explicit information
 - Do not want information
 - Ambivalent

For patients who **want** information

- Ask about understanding
- Ask why they ask
- Negotiate the content
- Provide the information
- Acknowledge the emotional reaction
- Check for understanding

Ask about understanding

Goals	What to ask
Find out what the person knows	What have others told you about what may happen in the future
Find out what the other person hopes	What do you think the future will bring

Ask why they ask

Goal	Question
Acknowledge the importance of this question	I am very happy to answer that, but do you mind telling me what made you ask that question?
Find out about what the concerns/question means	What are you concerned about? Is there something specific you are worried about?

Negotiate the content

- “Do you mean that you want me to talk about statistics about how long people live?”
- “Or is your question about how often the chemotherapy works to shrink the cancer?”

Giving the information

Goal	How to say it
Acknowledge the uncertainty in prognostication	Every person is different. I can only tell you what usually happens to people in your situation, not exactly what will happen to you
Give information without jargon	Doctors sometimes forget and use words that may not be understood. Please stop me if I am doing this
Give information in small chunks	Most people with your disease live only days to weeks
Check in frequently	Does it make sense so far

Attending to the information's emotional impact

Goal	How to say it
Attend to the emotional impact of the information	It seems like this is not what you expected?
	NURSE

When to go back to cognitive information

- The patient says “So...what next”
- You ask if it is ok “Do you want to talk about how we can work together to make your time as good as possible?”
- If emotions keep bubbling up, name it. “I see you want to talk about the future and yet it seems pretty emotional. What would be most useful.”

Cognitive questions about prognosis

Goal	How to say it
Assess understanding	What questions do you have?
Assess concerns?	What worries do you have about what I said?
	Given this information, do you want to talk about what you are thinking?
Assess hopes?	Given this limited time, what are you hoping for?
	What do you want to accomplish in the time you have remaining?

For patients who **do not** want information

- Elicit why the patient doesn't want the info
 - “Could you help me understand your thinking?”
- Acknowledge the patients concerns
 - Informational level: is there an underlying belief?
 - Emotional level: “These things can be difficult to talk about”
- Assess whether info would change decision making

For patients who are **ambivalent**

- Name the ambivalence
 - “It sounds like part of you wants to know and part of you might prefer not to know”
- Explore the pros and cons of knowing/not knowing
 - “Can you explain more about how you see this?”

When there are multiple people

Goal	Question
Acknowledge the importance of this question	I am very happy to answer that, but do you mind telling me what made you ask that question?
Check in with the other participants	Is this something that you want to hear about?
Normalize differences	It is pretty normal for some people to want to hear more than others
Negotiate differences	Given, your son wants to hear more about the future, would it be ok if I talk to him outside the room?

Conclusions

- Effective discussion about prognosis is not giving a pill of information—it's about
 - Assessing exactly what they want to know
 - Attending to their specific concerns
 - Attending to the emotions

Self Assessment Question #1

- Which of the following is the most important prognostication factor in patients with cancer?
 - a) WBC count
 - b) Functional status
 - c) Oral intake
 - d) Edema

Self Assessment Question #2

- What is the prognosis of a patient with metastatic non-small cell lung cancer and malignant hypercalcemia?
 - a) 8 days
 - b) 8 weeks
 - c) 8 months
 - d) 8 years

Self Assessment Question #3

- What is the impact of having end-of-life discussions with patients?
 - a) Increased patient depression
 - b) Increased patient anxiety
 - c) Decreased aggressive medical care near death
 - d) Decreased perceived patient quality of life near death

Self Assessment Question #4

- Which of the following would be the best response to the patient who says he does not want to know his prognosis?
 - a) “Could you help me understand your thinking”
 - b) “It is my obligation as a physician to tell you your prognosis”
 - c) “You are right, it is better to not know”
 - d) “I will need you to speak to our medical ethics consultants”

Self Assessment Question #5

- Which of the following is the best prognosticator in nursing home patients with dementia?
 - a) Functional Assessment Staging (FAST)
 - b) Mortality Risk Index (MRI)
 - c) Palliative Prognostic Index (PPI)
 - d) Palliative Performance Scale (PPS)