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Prognostication II: Improving Accuracy to Support Care and Hospice Access

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Disclosure Slide

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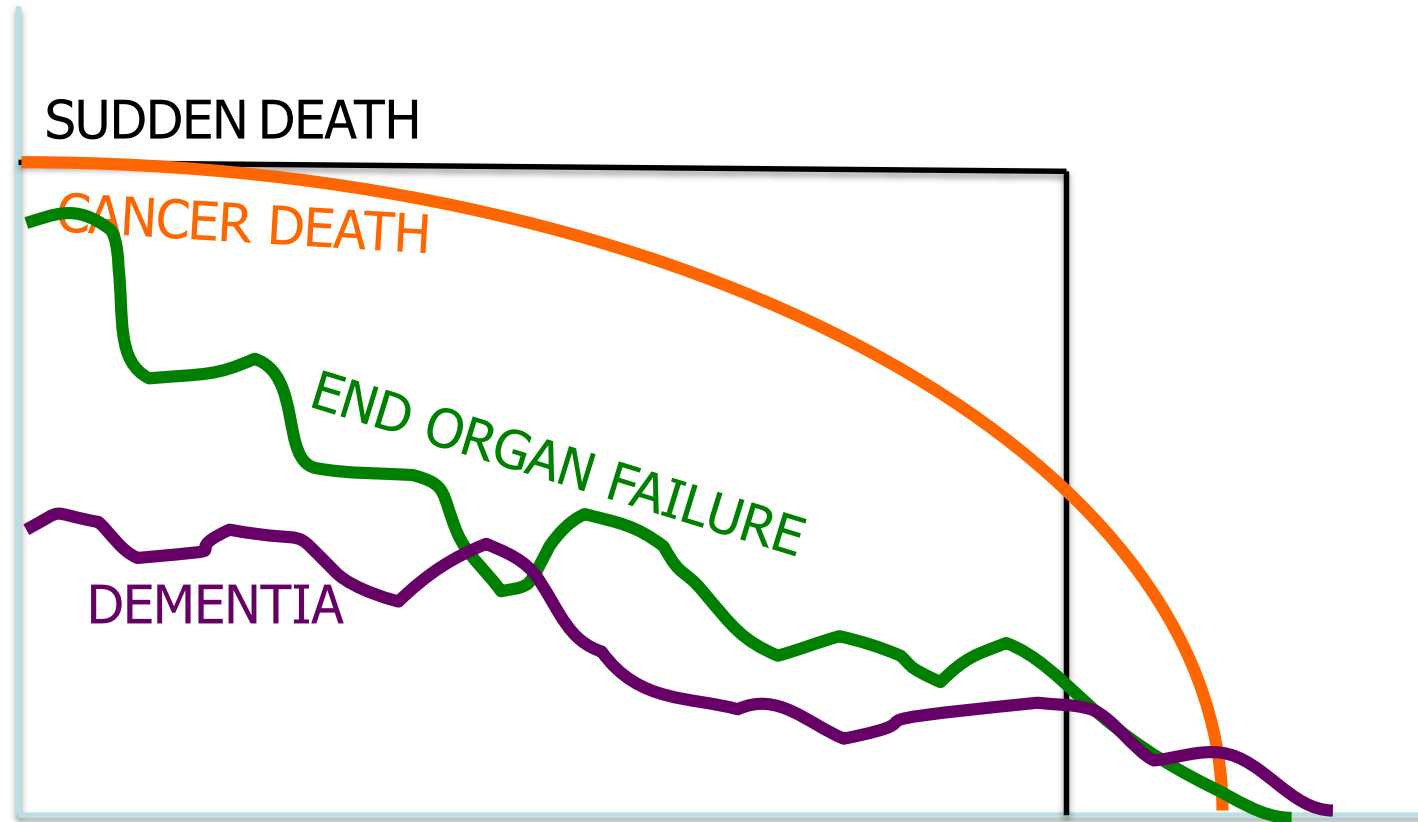
Prognostication in Advanced Illness

- Summary Lecture I
- General Indicators:
 - Karnofsky
 - Nutritional status (Alb. <2.5 gm/dl)
- Disease-specific indicators/hospice referral criteria:
 - Congestive heart failure (CHF)
 - Chronic pulmonary disease
 - Dementia
 - Renal disease
 - Liver disease
 - Acquired Immune Deficiency Syndrome
 - Cerebrovascular disease

Summary Prognostication I

- Various reasons of “Why” prognostication is necessary
- Patients/family want to know
- Health care professionals are not good at it (over optimism)
- Many death curves making some diseases harder to prognosticate
- On trajectory of illness, palliative care/disease-modifying therapy may interphase
- Prognostication is not an exact tool but more of an indicator

Illness Trajectories



Prognosis in Diseases Other than Cancer

- Prognosis is critical to formulating a care plan in chronic illness
- Formulating a prognosis in these illnesses is difficult due to the difference in death trajectory
- Formulating a prognosis includes:
 - Nondisease-specific indicators
 - Disease-specific indicators

Nondisease-Specific Indicators

- Performance status plays an essential prognostic role across all organ illness
- A global measure of a patient's functional capacity
- Most extensively studied
- Consistently found to predict survival in patients with advanced disease
- Karnofsky, PPS, ECOG

¹Lamont. Epidemiology and Prognostication in Advanced Cancer. Section II: Issues in Palliative Care. 469-474

Nonspecific Conditions Indicating Serious Illness and Decline

- Recurrent serious infections (urinary tract/lungs)
- Evidence of severe malnourishment
 - Disease-related weight loss of >10% in last 6 months
 - Albumin <2.5 gm/dl
 - Prolonged loss of appetite or limited oral intake
- Nonhealed pressure ulcers >2
- Decline in cognitive/physical function (Karnofsky/PPS <50%)
- Multiple comorbidities (CHF, COPD, renal insufficiency, etc.)

Disease-specific models for prediction of survival

CHF/Predictors of Survival

- Challenging prognostication, yet crucial:
HF prognosis similar or worse than that of many terminal cancers
 - Anticipatory management of end of life in CHF difficult, since course of illness more unpredictable
 - Following a new diagnosis of chronic heart failure (CHF), 40% of patients will survive less than 1 year
 - But 1-year mortality can vary from 5 to 75%

¹²Hogg. Prognostication or identification of palliative needs in advanced heart failure: where should the focus lie? *Heart* 2012 98: 523-524

CHF/Predictors of Survival

- Three examples of recognized models for prognostication in CHF:
 - Seattle Heart Failure (SHF)
 - Gold Standards Framework Prognostic Indicator Guide (GSF)
 - EFFECT cohort study

¹²Hogg. Prognostication or identification of palliative needs in advanced heart failure: where should the focus lie? *Heart* 2012 98: 523-524

The **EFFECT** Cohort Study

- Patients from community presenting to hospital with heart failure
 - *n* of over 4,000 patients
 - Predictors of mortality:
 - Age
 - Respiratory rate
 - Systolic blood pressure
 - BUN
 - Sodium
 - Hemoglobin
 - Comorbidities (CVA, dementia, COPD, cirrhosis, cancer)

¹⁵Lee, Douglas S., et al. Predicting mortality among patients hospitalized for heart failure. *JAMA: The Journal of the American Medical Association* 290.19 (2003): 2581-2587

The EFFECT Cohort Study

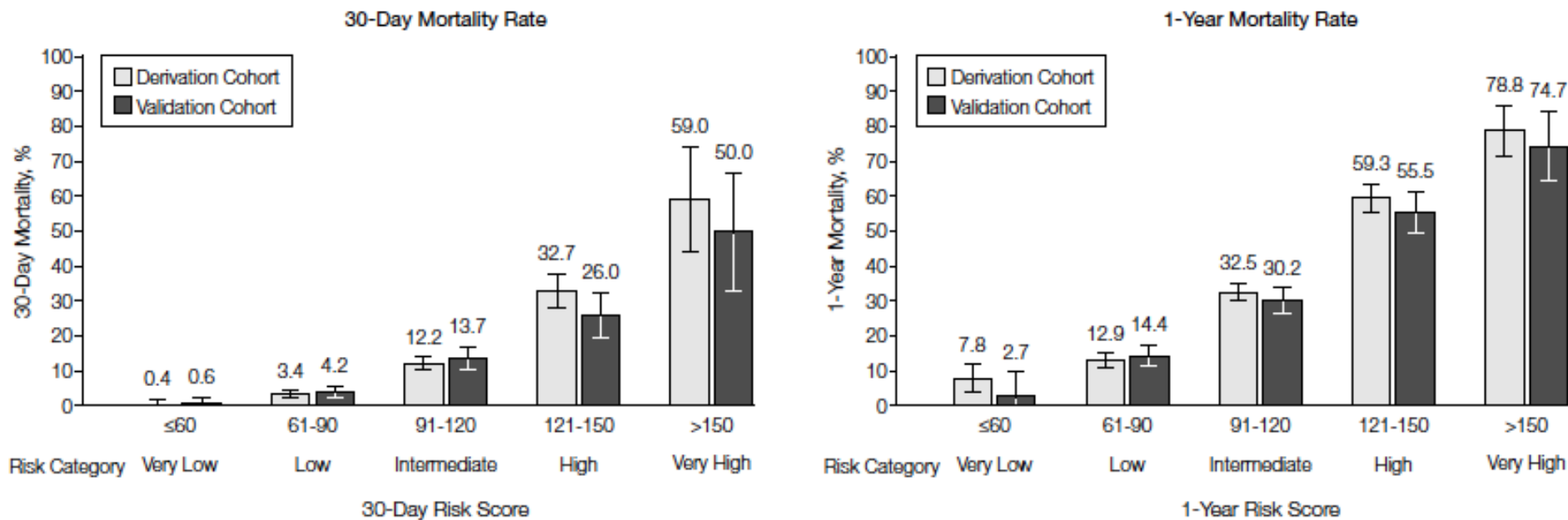
Table 4. Heart Failure Risk Scoring System*

Variable	No. of Points	
	30-Day Score†	1-Year Score‡
Age, y	+Age (in years)	+Age (in years)
Respiratory rate, min (minimal 20; maximum 45)§	+Rate (in breaths/min)	+Rate (in breaths/min)
Systolic blood pressure, mm Hg		
≥180	-60	-50
160-179	-55	-45
140-159	-50	-40
120-139	-45	-35
100-119	-40	-30
90-99	-35	-25
<90	-30	-20
Urea nitrogen (maximum, 60 mg/dL)§¶	+Level (in mg/dL)	+Level (in mg/dL)
Sodium concentration <136 mEq/L	+10	+10
Cerebrovascular disease	+10	+10
Dementia	+20	+15
Chronic obstructive pulmonary disease	+10	+10
Hepatic cirrhosis	+25	+35
Cancer	+15	+15
Hemoglobin <10.0 g/dL (<100 g/L)	NA	+10

¹⁵Lee, Douglas S., et al. Predicting mortality among patients hospitalized for heart failure. *JAMA: The Journal of the American Medical Association* 290.19 (2003): 2581-2587

The EFFECT Cohort Study

Figure. Mortality Rates Stratified by 30-Day and 1-Year Risk Scores



¹⁵Lee, Douglas S., et al. Predicting mortality among patients hospitalized for heart failure. *JAMA: The Journal of the American Medical Association* 290.19 (2003): 2581-2587

CHF/Hospice Guidelines

- NYHA Class 4 (serious cardiac symptoms at rest despite optimal treatment)
- Other relevant findings:
 - EF <20%
 - Refractory peripheral or pulmonary edema
 - Refractory arrhythmias
 - Comorbidities (COPD, renal insufficiency) or
 - Complications (stroke) or
 - Any nonspecific conditions

Noncancer Lung Disease Predictors of Survival

- COPD, Interstitial Lung Dz, Cystic Fibrosis
 - Chronic disease with a lot of symptom burden
 - Dichotomy of end-of-life approach **with lung transplantation** becoming increasingly used at end stage
 - Course characterized by infectious exacerbations on top of a progressive illness

¹⁶Bolan. Palliative care for people with non-malignant lung disease: Summary of current evidence and future direction. *Palliative Medicine* 27(9) 811–816

CODP/Predictors of Survival

- Prognosis in chronic condition: BODE score
- Prognosis in exacerbation: DECAF score

COPD / Predictors of Survival

Table 1 BODE index scoring

Variable	BODE Score			
	0	1	2	3
FEV ₁ , (% of predicted)	>65	50–65	35–49	<35
Dyspnea (MRC)	0–1	2	3	4
6MWD (m)	≥350	250–349	150–249	≤149
BMI	>21	≤21	—	—

BMI = body mass index; BODE = BMI (B), degree of airway obstruction (O), dyspnea as measured by the MRC scale (D), and exercise capacity as measured by the 6MWD test (E); FEV₁ = forced expiratory volume in 1 second; MRC = Medical Research Council dyspnea scale; 6MWD = 6-minute walk distance.

¹⁷Gote "Surrogates of Mortality in COPD". *American Journal of Medicine* 2006, Vol 119 10A, S54-S62

¹⁸Celli, Bartolome R., et al. "The body-mass index, airflow obstruction, dyspnea, and exercise capacity index in chronic obstructive pulmonary disease." *New England Journal of Medicine* 350.10 (2004): 1005-1012

COPD / Predictors of Survival

BODE Score	BODE quartile	Mortality at 4 years
0-2	1	20%
3-4	2	30%
5-6	3	40%
7-10	4	80%

¹⁷Gote "Surrogates of Mortality in COPD". *American Journal of Medicine* 2006, Vol 119 10A, S54-S62

¹⁸Celli, Bartolome R., et al. "The body-mass index, airflow obstruction, dyspnea, and exercise capacity index in chronic obstructive pulmonary disease." *New England Journal of Medicine* 350.10 (2004): 1005-1012

End-stage Pulmonary Disease Hospice Guidelines

- Breathlessness at rest despite treatments
- Dependent on oxygen
- Other relevant findings:
 - Recent pulmonary function tests (FEV1 < 30%)
 - Recent blood gases on room air (pO₂ < 55 mmHg, pCO₂ > 55 mmHg)
 - Recent O₂ saturation < 88%
- Comorbidities (CHF, renal insufficiency) or
- Complications (pulmonary bleeding) or
- Nonspecific conditions

Dementia/Predictors of Survival

- The Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life (CASCADE) study followed 323 nursing home residents with advanced dementia:
 - Over the 18-month study period, 55 percent of the cohort had died, and the median survival was 1.3 years
 - Infections and eating problems were associated with high mortality
 - Six-month mortality:
 - After a **PNA: 47%**
 - After a febrile episode: **45%**
 - After eating problems: **39%**

Dementia/Predictors of Survival

- Difficult to prognosticate in dementia
 - Hospice eligibility criteria and other prognostic tools have sensitivity of 20% for <6 months survival
 - The FAST scale
 - The ADEPT tool
 - Specificity of 89% and sensitivity of 27% for <6 month mortality

²¹Mitchell, Susan L., et al. The clinical course of advanced dementia. *New England Journal of Medicine* 361.16 (2009): 1529-1538

FAST Score

I. Functional Assessment Staging (FAST)		
Stage	Features	
1	No objective or subjective difficulties	
2	Subjective complaints of forgetting	
3	Decreased job functioning evident to co-workers. Difficulty traveling to new locations.	
4	Decreased ability performing complex tasks, eg, planning dinner for guests, handling finances	
5	Requires assistance to choose proper clothes for day, season, or occasion	
6a	Cannot dress without assistance; occasionally or more frequently	All of these features must be present for Stage 7c
6b	Cannot bathe without assistance; occasionally or more frequently	
6c	Cannot toilet without assistance; occasionally or more frequently	
6d	Incontinent of urine; occasionally or frequently	
6e	Incontinent of bowel; occasionally or frequently	
7a	Speech limited to less than 6 intelligible words during an average day	
7b	Speech limited to single intelligible word during an average day	
7c	Unable to ambulate independently	
7d	Cannot sit up independently	
7e	Cannot smile	
7f	Cannot hold head up independently	

²¹Mitchell, Susan L., et al. The clinical course of advanced dementia. *New England Journal of Medicine* 361.16 (2009): 1529-1538

Table 3

Final Multivariable Model of Characteristics Associated with Survival Among NH Residents with Advanced Dementia (n = 218,088)^a

Characteristics	Adjusted Hazard Ratio (95% Confidence Interval)	Regression Coefficient (Log Hazard Ratio) ^b	Points in Risk Score ^c
Recent NH admission	1.72 (1.69–1.75)	0.54207	3.3
Age (in years; per five-year increment)	1.18 (1.17–1.18)	0.16431	
65 < 70	—	—	1.0
70 < 75	—	—	2.0
75 < 80	—	—	3.0
80 < 85	—	—	4.0
85 < 90	—	—	5.0
90 < 95	—	—	6.0
95 < 100	—	—	7.0
≥100	—	—	8.0
Male	1.71 (1.68–1.74)	0.53623	3.3
Shortness of breath	1.57 (1.53–1.61)	0.44903	2.7
At least one pressure ulcers ≥Stage 2	1.44 (1.41–1.46)	0.36216	2.2
ADL score = 28 ^d	1.42 (1.40–1.44)	0.34929	2.1
Bedfast most of day	1.41 (1.38–1.44)	0.34024	2.1
Insufficient oral intake ^e	1.39 (1.37–1.41)	0.32837	2.0
Bowel incontinence ^f	1.37 (1.34–1.40)	0.31275	1.9
BMI <18.5 kg/m	1.35 (1.32–1.37)	0.29841	1.8
Weight loss ^g	1.30 (1.27–1.33)	0.26149	1.6
Congestive heart failure	1.28 (1.26–1.30)	0.24739	1.5

Mitchell SI, Miller SC, Teno JM, Davis RB, Shaffer ML. The Advanced Dementia Prognostic Tool: A Risk Score to Estimate Survival in Nursing Home Residents with Advanced Dementia. *J Pain Symptom Manage* 2010; 40:639-651.

Table 4

Number (%) of Subjects with Each Possible Total Risk Score and the Six- and 12-Month Probabilities of Death with Each Total Score (n = 218,088)

TION

Total Risk Score	Subjects with Each Score, n (%)	Observed Probability of Death Within	
		Six Months	12 Months
1 (minimum score)	84 (0.04)	0.01	0.06
>1-2	236 (0.11)	0.04	0.08
>2-3	1,232 (0.56)	0.05	0.11
>3-4	2,609 (1.20)	0.06	0.13
>4-5	5,859 (2.69)	0.06	0.15
>5-6	9,784 (4.49)	0.08	0.19
>6-7	14,700 (6.74)	0.10	0.23
>7-8	18,439 (8.45)	0.12	0.26
>8-9	21,634 (9.92)	0.15	0.30
>9-10	23,036 (10.56)	0.17	0.33
>10-11	22,509 (10.32)	0.21	0.37
>11-12	20,938 (9.60)	0.25	0.42
>12-13	18,632 (8.54)	0.29	0.47
>13-14	15,038 (6.90)	0.34	0.52
>14-15	111,691 (5.36)	0.40	0.57
>15-16	9,512 (4.36)	0.46	0.62
>16-17	6,721 (3.08)	0.52	0.67
>17-18	4,955 (2.27)	0.57	0.71
>18-19	3,585 (1.64)	0.64	0.76
>19-20	2,547 (1.17)	0.67	0.79
>20-21	1,777 (0.81)	0.73	0.84
>21-22	1,154 (0.53)	0.77	0.87
>22-23	648 (0.30)	0.83	0.90
>23-24	385 (0.18)	0.83	0.91
>24-25	188 (0.09)	0.88	0.94
>25-26	99 (0.05)	0.88	0.96
>26-27	58 (0.03)	0.83	0.90
>27-28	21 (0.01)	0.95	1.00
>28-32	17 (<0.01)	1.00	1.00

Mitchell SI, Miller SC, Teno JM, Davis RB, Shaffer ML. The Advanced Dementia Prognostic Tool: A Risk Score to Estimate Survival in Nursing Home Residents with Advanced Dementia. *J Pain Symptom Manage* 2010; 40:639-651.

Dementia Hospice Guidelines

- Inability to speak more than 6 words (FAST 7a)
- Inability to eat, walk, or sit up without assistance
- Urinary and bowel incontinence
- Other relevant findings:
 - Comorbidities (CHF, renal insufficiency)
 - Complications (repeated aspirations)
 - Any nonspecific conditions

ESRD/Predictors of Survival

- Over 75 year old: fastest growing HD group
 - 1-year survival: 59%
 - 5-year survival: 13%
- Only 20% die after decision to withdraw
- High percentage with comorbidities
- High in-hospital death (61% in one study)
- Unknown but low % die with hospice

²²Swidler, Mark A. Geriatric renal palliative care. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences* 67.12 (2012): 1400-1409

ESRD/Predictors of Survival

Charlson Comorbidity Index:

Comorbidity Points				
1 point each for coronary artery disease, congestive heart failure, peripheral vascular disease, cerebrovascular disease, dementia, chronic pulmonary disease, connective tissue disorder, peptic ulcer disease, mild liver disease, diabetes 1 point for every decade over 40 (e.g. a 65 year old would receive 3 points).				
2 points each for hemiplegia, moderate-to-severe renal disease (including being on dialysis), diabetes with end-organ damage, cancer (including leukemia or lymphoma)				
3 points for moderate-to-severe liver disease				
6 points each for metastatic solid tumor or AIDS				
Modified CCI Score Totals	Low score (≤3)	Moderate (4-5)	High (6-7)	Very High (≥8)
Annual mortality rate	0.03	0.13	0.27	0.49

²⁴Charlson et al. Validation of a Combined Comorbidity Index. *J Clin Epidemiol* 47, 11, 1245-1251

End-stage Renal Disease Guidelines

- Discontinuation of dialysis
- Creatinine >8.0 and BUN >100, with no dialysis planned
- Other relevant findings:
 - Comorbidities (CHF)
 - Complications (persistent confusion/delirium)
 - Any nonspecific conditions

End-stage Renal Disease Guidelines

- Prognostic tools:
 - Child-Pugh
 - MELD
- When ESRD is decompensating prognosis is poor
 - Even with moderate MELD or Child-Pugh score median survival is <6 months

Liver Disease/Predictors of Survival

- Child-Pugh classification

Parameter	Points assigned		
	1	2	3
Ascites	Absent	Slight	Moderate
Bilirubin	<2 mg/dL (<34.2 micromol/liter)	2 to 3 mg/dL (34.2 to 51.3 micromol/liter)	>3 mg/dL (>51.3 micromol/liter)
Albumin	>3.5 g/dL (35 g/liter)	2.8 to 3.5 g/dL (28 to 35 g/liter)	<2.8 g/dL (<28 g/liter)
Prothrombin time			
Seconds over control	<4	4 to 6	>6
INR	<1.7	1.7 to 2.3	>2.3
Encephalopathy	None	Grade 1 to 2	Grade 3 to 4

- Class 1 (score 5-6): 1-year **survival** 100%, 2-year 85%
- Class 2 (score 7-9): 1-year 80%, 2-year 60%
- Class 3 (score 10-15): **1-year 45%, 2-year 35%**

²⁵Infante-Rivard. Clinical and statistical validity of conventional prognostic factors in predicting short-term survival among cirrhotics. *Hepatology*. 1987;7(4):660

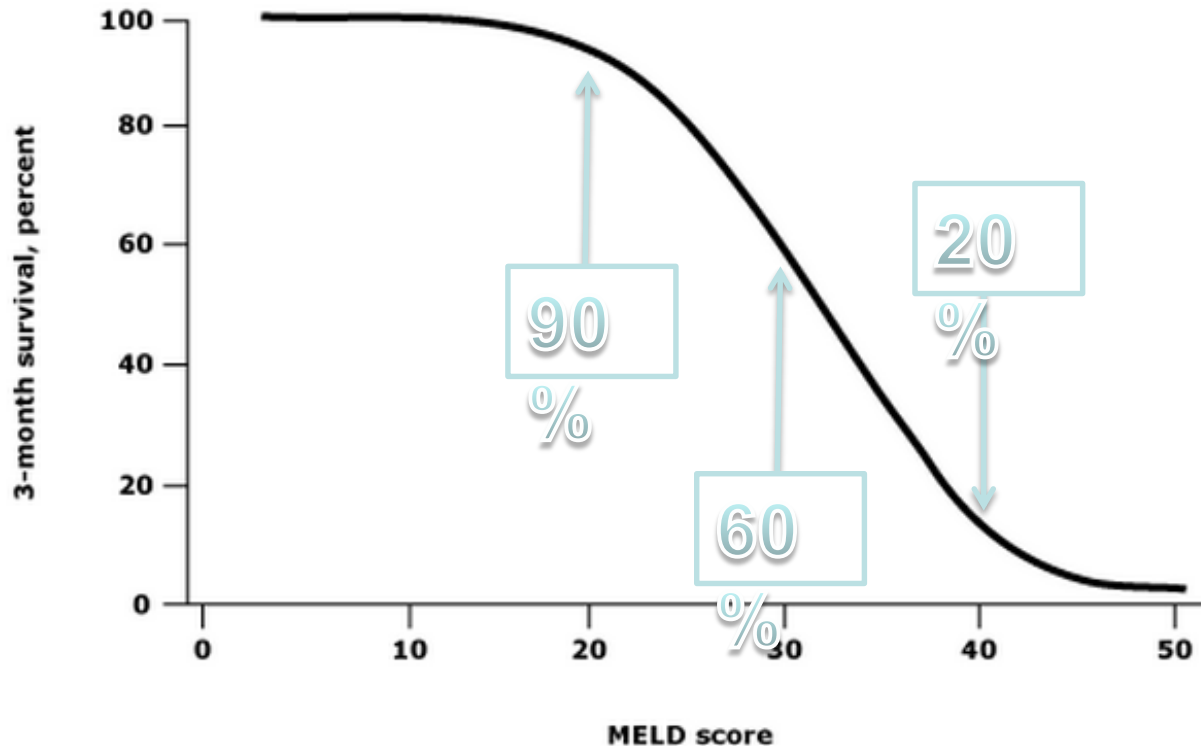
Liver Disease/Predictors of Survival

- MELD score
 - Better predictor of **short-term mortality**
 - Relies on few readily available and **objective** variables
 - Bilirubin
 - Creatinine
 - INR
 - **Scenarios** where MELD predicts **mortality**:
 - ESLD awaiting liver transplantation
 - Mortality of **alcoholic hepatitis**
 - **MELD score of 27 gives a 50% 90-day mortality**
 - Mortality on **hepatorenal** syndrome
 - **MELD score >20 gives a 3-month median survival**
 - Mortality in acute **variceal** hemorrhage
 - **Post-surgical** risk on patient with ESLD

²⁶Wiesner, Russell, et al. Model for end-stage liver disease (MELD) and allocation of donor livers. *Gastroenterology* 124.1 (2003): 91-96

Cirrhosis/Predictors of Survival

Estimated 3-month survival as a function of the MELD score in patients with cirrhosis



MELD: model for end-stage liver disease.

Adapted from: Wiesner, R, Edwards, E, Freeman, R, et al. Model for end-stage liver disease (MELD) and allocation of donor livers. *Gastroenterology* 2003; 124:91.

End-stage Liver Disease Hospice Guidelines

- Liver failure with clotting problems (INR>1.5), low albumin (<1.5)
- Persistent hepatic encephalopathy
- Persistent or recurrent ascites
- Renal failure related to liver failure (hepatorenal syndrome)
- Other relevant findings:
 - Comorbidities (CHF)
 - Complications (dementia)
 - Nonspecific conditions

AIDS/Predictors of Survival

- Despite advances in treatment, AIDS and its associated comorbidities remain important causes of death
 - HIV prognostic markers may be less useful in predicting death in current late-stage patients than in the era before highly active antiretroviral therapy
 - Factors affecting prognosis
 - Age (>65 years old)
 - Karnofsky score
 - Remaining on cART
 - Opportunistic infections response to therapy
 - Development of untreatable complications

²⁸Shen, Jennifer M., Arthur Blank, and Peter A. Selwyn. Predictors of mortality for patients with advanced disease in an HIV palliative care program. *JAIDS Journal of Acquired Immune Deficiency Syndromes* 40.4 (2005): 445-447.

EPERC Fast Facts and Concepts #213

AIDS Hospice Guidelines

- CD4 count <25; viral load >100,000
- History of repeated or persistent opportunistic infections (toxoplasmosis, MAC)
- History of AIDS-related cancer (Kaposi, lymphoma)
- Wasting (loss of 30% body mass)
- Other relevant findings:
 - Comorbidities (CHF)
 - Complications (dementia, PML)
 - Any nonspecific conditions

Cerebrovascular Disease Hospice Guidelines

- Stroke:
 - KPS <40%
 - Inability to maintain hydration (weight loss, ALB<2.5 gm/dl, aspiration, dysphagia, no artificial nutrition)
- Coma:
 - Absent verbal/response to pain withdrawal, abnormal brainstem
 - Medical complications: aspiration, infections, decubitus
 - Imaging: large volume or infarct

Conclusions

- Physicians' prognostic estimates are **a central element** of both patient and physician **decision-making**, especially at the end of life
- In chronic noncancer illness, prognostication is particularly difficult due to the irregular path of clinical deterioration in these patients' experience
- Need to prognosticate in two different scenarios:
 - The chronic medical condition
 - The acute exacerbation of the medical condition

Prognostication II: Improving Accuracy to Support Care and Hospice Access

Q/A

Bibliography

1. Lamont. Epidemiology and Prognostication in Advanced Cancer. Section II Issues in Palliative Care. 469-474
2. Hagerty. Communicating prognosis in cancer care: a systematic review of the literature. *Annals of Oncology* 16: 1005–1053, 2005
3. Lamont. Complexities in prognosticating in advanced cancer. *JAMA* 2003, Vol. 290, No. 1
4. Christakis. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *BMJ* 2000; 320:469-473
5. LaMont. Prognostic disclosure to Patients with Cancer Towards the End of Life. *Ann Intern Med* 2001 134:1096
6. Zanartu C. Matti-Orozco B. Use of prognostic tools in the hospital, assessment of factors behind their use or lack thereof through a physician-oriented survey. *Am J Hosp Palliat Care* 2013 Sep 26. [Epub ahead of print]
7. Gale & Christakis. Predicting Survival in Patients with Advanced Disease. *The Challenge of Palliative Medicine*
8. Karnofsky. The use of Nitrogen Mustard in the Palliative Treatment of Carcinoma. *Cancer*, 1, 1948, p 635
9. Reuben DB, Mor V, Hiris J. Clinical symptoms and length of survival in patients with terminal cancer. *Arch Intert Med* 1988; 148
10. Loprinzi. Prospective evaluation of prognostic variables from patient-completed questionnaires. *Clin Onc* 1994; 12:601-7
11. Evans. Prognostic uncertainty in terminal care: can the Karnofsky index help? *Lancet*. 1985;1(8439):1204
12. Hogg. Prognostication or identification of palliative needs in advanced heart failure: where should the focus lie? *Heart* 2012 98: 523-524

Bibliography

13. Levy. The Seattle Heart Failure Model. *Circulation* 2006 113: 1424-1433
14. Haga. Identifying community based chronic heart failure patients in the last year of life: a comparison of the Gold Standards Framework Prognostic Indicator Guide and the Seattle Heart Failure Model. *Heart* 2012 98: 579-583
15. Bolan. Palliative care for people with non-malignant lung disease: Summary of current evidence and future direction. *Palliative Medicine* 27(9) 811–816
16. Steer. The DECAF Score: predicting hospital mortality in exacerbations of chronic obstructive pulmonary disease. *Thorax* 2012;67:970–976
17. National Hospice and Palliative Care Organization
18. Mitchell, Susan L., et al. The clinical course of advanced dementia. *New England Journal of Medicine* 361.16 (2009): 1529-1538
19. Swidler, Mark A. Geriatric renal palliative care. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences* 67.12 (2012): 1400-1409
20. Cohen, Lewis M., et al. Predicting six-month mortality for patients who are on maintenance hemodialysis. *Clinical Journal of the American Society of Nephrology* 5.1 (2010): 72-79
21. Charlson et al. Validation of a Combined Comorbidity Index. *J Clin Epidemiol* 47, 11, 1245-1251
22. Infante-Rivard. Clinical and statistical validity of conventional prognostic factors in predicting short-term survival among cirrhotics. *Hepatology*. 1987;7(4):660
23. Wiesner, Russell, et al. Model for end-stage liver disease (MELD) and allocation of donor livers. *Gastroenterology* 124.1 (2003): 91-96
24. *Palliative and Supportive Care* 2005; 3; 265-272
25. Shen, Jennifer M., Arthur Blank, and Peter A. Selwyn. Predictors of mortality for patients with advanced disease in an HIV palliative care program. *JAIDS Journal of Acquired Immune Deficiency Syndromes* 40.4 (2005): 445-447