

## Prognostication Art & Science (or just another dirty word?)

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## Objectives

- The program says...
  - Discuss the use of prognostication when working with patients and families in need of a palliative care consult
- Suggesting...
  1. How do we use prognostication to identify patients/families in need of palliative care?
  2. What prognostic tools do we have available for that purpose?
  3. How do we talk prognosis with patients and families?

## Palliative Care (and hospice)

- Is the medical specialty focused on improving the quality of life of people facing serious illness. Emphasis is placed on pain and symptom management, communication and coordinated care.  
**Palliative care is appropriate from the time of diagnosis and can be provided along with curative treatment.**
- Different from Hospice
  - Terminal illness
  - 6 month prognosis
  - Forego curative
- Prognostic tools might be somewhat different

## Presumes Prognostication Important?

- |   |   |
|---|---|
| <ul style="list-style-type: none"><li>■ Goal setting</li><li>■ Decision making</li><li>■ Treatment options</li><li>■ Future planning</li><li>■ Resource utilization</li><li>■ Hospice referral<ul style="list-style-type: none"><li>■ Care-planning</li></ul></li><li>■ Hospice discharge</li></ul> | <ul style="list-style-type: none"><li>■ Done poorly<ul style="list-style-type: none"><li>■ Burdensome<ul style="list-style-type: none"><li>■ Futile care</li><li>■ Painful</li><li>■ Stressful</li></ul></li></ul></li><li>■ Done well<ul style="list-style-type: none"><li>■ Reduced stress</li><li>■ Dr/Pt alliance</li><li>■ Appropriate care</li><li>■ Resource utilization</li></ul></li></ul> |
|---|---|

## Prognostication

- Is it a word?
- Sounds bad, eh?
- **Prognosis**, n. (Greek – literally fore-knowing, foreseeing) is a medical term denoting the doctor's prediction of how a patient's disease will progress, and whether there is a chance of recovery. *Wictionary*
- **Prognostication**, n. 1 a forecast; prediction 2 the act of foretelling. *WB Dictionary*
- "A prognosis is more than a 'best guess' it is a prediction of the likelihood of a given outcome based on multiple sources of information." *Sinclair*

## Just another dirty word?

- Not to be said in public
- Doctors don't like to talk about it
- Patients don't want to hear it
- A classic, therapeutic dilemma
  - Like treating an asymptomatic condition (HBP)
  - With expensive medications that make you feel bad
- Lots of challenges

## Doctors

- Fear extinguishing hope
- Feel we lack accurate tools
- Time-consuming
- Lack Education
  - Prognostic tools
  - Communication
- "Prior knowledge of the future" may be very sad
- Hard place for lots of us to go
- We practice, "Realism, optimism, or avoidance".

## Do doctors want to tell?

- Christakis, NA. Attitude and self-reported practice regarding prognostication in a national sample of internists. *Archiv Intern Med.* 1998;158(21):2389-95.
- Survey of 1311 Internists / 697 respondents
  - "How long do I have to live?" 10X
  - Withdrew/Withheld 5X;
  - Hospice referral 5X
- "Terminal" = 13.5 +/- 11.8 weeks to live

## Majority Really Dislike Prognostication

Characteristic	Freq (%)
"Stressful" to make predictions	<b>60.4</b>
"Difficult"	<b>58.7</b>
Wait to be asked by patient	<b>43.7</b>
Believe patients expect too much certainty	<b>80.2</b>
Error will result in loss of patient confidence	<b>50.2</b>
Should avoid being specific	<b>89.9</b>
Inadequate training in prognostication	<b>56.8</b>

## How Good Are We?

- Christakis, NA. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *BMJ* 2000;320:469-473.
- At the time of hospice referral, MD asked for a Clinical Prediction of Survival (CPS)
- Only 20% accurate
- Overestimated survival by a factor of 5! (*but consistently*)
  - Experience helps; relationship hinders
- Implications
  - Late hospice referral, LOS 1 month (rather than 3), counterproductive choices (futile, aggressive, \$\$)
- Corrections
  - Disinterested, second opinion

## Prognostic Disclosure to Patients with Cancer near the End of Life.

Lamont EB, Christakes NA. *Ann Intern Med.* 2001;134:1096-1105.

- Compared "formulated" and "communicated" diagnosis
- How often MDs give frank survival estimates to patients who request them?
- Physician telephone survey (n=326)

## Results

- 23% would not communicate temporally specific prognosis
- 37% would
- 40% would communicate discrepant prognosis
- Median formulated Px 75 days
- Median communicated Px 90 days
- Median survival 26 days

## More...

- Pts with with optimistic or no Px communicated to them had shortest survival
- Pessimistic > the longest
- Older pt > franker
- Less functional > franker
- Older MDs favored (3X) no disclosure
- Less confident in Prognosis less disclosure
- More experience with hospice less frank
- Female MDs more pessimistic (maybe more accurate)

## 2<sup>nd</sup> Opinion?

## Authors Concluded

- Provided frank estimate only 37%
- Able and willing to formulate, but not communicate (even with insistent patients)
- Conscious and unconscious optimism
- Confident in Px, no more accurate, but if not confident less likely to be frank
- Most types of MDs avoid frank disclosure to most types of patients with cancer
- To be of real use to patients, the science of prognostication must be improved!
- Patients want accurate Px
- Tactful, respectful; not truth-dumping

## Patients' Views on Prognosis

- Communicating with realism and hope: Incurable cancer patients' views on the disclosure of prognosis. Hagerty et al. *J Clin Onc.* 2005;23:1278-1288.
- 218 consecutive metastatic cancer patients, 30 oncologists, Sydney, Australia
- A clear majority (*but not all*) of patients want:
  - Individualized and realistic disclosure
  - From a confident, collaborative, informed and supportive cancer specialist
  - Detailed information, checking for understanding, time for questions
  - Hope-giving approach favored

## Additional evidence suggests...

- Honest, ongoing communication of prognosis
  - Reinforces trust and hope
  - Enhances a mutually respectful doctor-patient relationship
  - Facilitates treatment decisions that are consistent with underlying values

## What Simple Tools Do We Have?

(Pessimistic, accurate female physician)

## How Good Are They?

## Good Evidence-Based Medicine?

### Tools...KISS (Keep It Simple... Stephenson)

- More complicated tools won't be generally useful
- Simple tools or indicators to suggest Palliative Care Consult or at least
- Turn our attention to a palliative plan of care
- Keeping PC definition in mind... "combined with all other medical care that is appropriate"
- What might suggest a significant shift in focus or PC consult?
- And then have more sophisticated tools available

### As I was thinking about it...

- Boom!
- Ahead-of-print alert from J Palliative Medicine
- Identifying patients in need of a PC assessment in the hospital setting. Weissman DE & Meier DE. *J Palliat Med.* 2011
  - A consensus report from CAPC
- Consultation Triggers Audio Conference
  - CAPC
- Checklist theory

### Criteria for a PC Assessment

At the time of Admission

A potential life-limiting condition *and...*

- Primary Criteria (global indicators)
  - The "surprise question" (SQ) – *You would not be surprised if the patient died within 12 months or before adulthood*
  - Frequent admissions
  - Admission prompted by difficult-to-control symptoms
  - Complex care requirements (home vent)
  - Failure to thrive (function, nutrition, cognition)
- Secondary criteria (more-specific indicators)
  - LTCF, chronic home O<sub>2</sub>, hospice enrollee
  - Elderly, cognitively impaired, acute hip fx
  - Metastatic or locally advanced CA, out-of-hospital arrest
  - Limited social support; absence of advance care plans

### Criteria for a PC Assessment

During each Hospital Day

A potentially life limiting condition *and...*

- Primary Criteria (global indicators)
  - The "surprise question"
  - Difficult-to-control symptoms
  - ICU LOS  $\geq$  7 days
  - Lack of goals clarity
  - Disagreements (Pt, staff, family RE Rx, CPR, PEG)
- Secondary criteria
  - Transplant (awaiting, not elig), **Pt/F distress or request**
  - Candidate/consult for: PEG, trach, dialysis, LVAD or AICD, LTAC discharge, BMTransplant

## (Focus on) KISS = SQ!

- Are these simple "Primary Criteria" accurate enough to:
  - Initiate PC Assessment and/or Consult
  - Begin a process with patient and family
  - Turn to more specific criteria and
  - Apply more sophisticated prognostic tools if necessary
- These indicators also apply to LTCF, office or home-care settings
- In a systems-based way, great tool for nursing
  - "Gee, Dr. S., I was doing the checklist on Mrs. Myra Bund in Rm 201, it really wouldn't surprise me if she died this year. We need to talk to her about what she really wants."

## SQ "The Surprise Question"

- Talked about it for years
- Hospices market physicians with 6-month SQ
  - Some apply "over-estimation" prognostic factor of 3X and say, "Would you be surprised if your patient died in the next 18 mos to 2 years?" (to get patients who die in 6 mos)
- Applied to PC settings as the 12-month SQ
- Seems so simple...soft science you say?
- Wouldn't it be nice if it was that simple?
- Is there hard science?

## Predicting 6-Month Mortality for Patients on Hemodialysis

Cohen, Moss, et al. *Cl J Am Soc Neph* 2010

- Despite specific guidelines, nephrologists rarely talk about prognosis – accuracy/hope
- This study of 512 hemodialysis patients
- Combined actuarial data from the record
  - Charlson Comorbidity Index (CCI)
- With SQ = 6-months
  - "Would I be surprised if this patient died in the next 6 months?"
- Came up with an integrated prognostic model
  - Integrating SQ with significant variables

## Charlson Comorbidity Index

Beddhu et al 2000

Comorbidity Score	Condition
1	CAD, CHF, PVD, CerebroVD, Dementia, COPD, PUD, CLD, DM
2	Hemiplegia, Mod-Sev Renal, DM with end-organ damage, any tumor, leukocytosis, lymphocytopenia
3	Mod or severe liver disease
6	Metastatic solid tumor, AIDS

**Add 1 for each decade > 40.**

**Score ≥ 8 had a 1-year survival of 50%**

**(Factor in alb and (Karnofsky) perf status would help)**

## Known Major Factors Influence Prognosis

- Older age
- Nutritional status
- Functional status
- Comorbid conditions
  - CHF, COPD, PVD, CVD, MI, DM, CA, dementia
- Serum albumin! In 133 studies!
  - < 3.0 g/dl vs > 4.0 g/dl = 4.4X risk of death
  - < 3.5 g/dl associated with 1 year mortality = 50%

## Results

- "No" response to SQ was a statistically significant marker for worse survival
- Also significant
  - Albumin, older age, presence of dementia, PVD
- All more significant than full CCI
- At the completion of the study (2 yrs)
  - 54.9% of "No" group was dead vs. just
  - 17.0% of "Yes" group
- Simpler was better, resulting in a 5-term integrated prognostic model
  - 4 factors + **Surprise Question**

## Prognostic Significance of the “Surprise” Question in CA Patients Moss et al JPM 2010

- Not previously studied in cancer patients
  - (well actually only in HD patients – work to do)
- 853 consecutive cancer patients in an academic cancer center with breast, lung or colon cancer
- Used SQ = 12 months
- “No” had a 7X greater hazard of death than “Yes”
- Simple, feasible, and effective tool to identify cancer patients at a greatly increased risk of 1-year mortality.

## Compare to Palliative Prognostic Score (PPS<sup>2</sup>) for cancer

Prognostic Factor	Partial Score
Dyspnea Absent	0
Present	1
Anorexia Absent	0
Present	1.5
Karnofsky Performance Status >= 50	0
30-40	0
10-20	2.5
Clinical Prediction of Survival > 12 wks	0
11-12 wks	2.0
9-10	2.5
7-8	2.5
5-6	4.5
3-4	6.0
1-2	8.5
Total WBC count: Normal 4.8-8.5K	0
High 8.5-11K	0.5
Very High > 11K	1.5
Lymphocyte percentage Normal 20-40%	0
Low 12-19.9%	1.0
Very low 0-11.9%	2.5

PPS =  
 dyspnea score +  
 anorexia score +  
 KPS score +  
 CPS score +  
 total WBC score +  
 lymph % score  
 Total score  
 0 – 5.5 = 70% of 30d  
 5.5 – 11 = 30-70%  
 11.1-17.5 = < 30%  
 (of surviving 30-days)

## Many General and Disease-Specific Tools/Indices Emerging

- Palliative Performance Scale (PPS)
- CHF
- COPD
- ESRD
- ALS
- Cancer
- Dementia
- Prognostication is no longer just another dirty word; there is science

## Palliative Performance Scale (PPS)

- Developed 1996 Victoria Hospice Society, BC, Canada
- Designed to measure functional performance and progressive decline to:
  - Communicate patient status
  - Evaluate home nursing care workloads
  - Study effects of treatment on the patient
  - Plan visits according to patient acuity and
  - Make discharge decisions
- Combines performance and extent of disease with nutritional and mental status
- Scores range from 0 (dead) to 100% in increments of 10
- Many hospices and PC Services use PPS

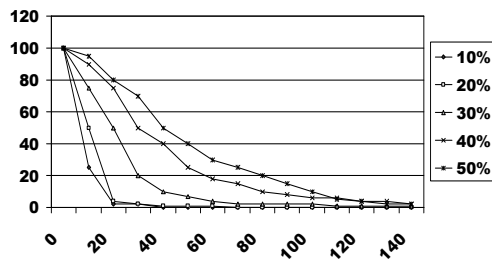
## Palliative Performance Scale (PPS)

% Score	Amb	Activity/Evi DZ	Self-care	Nutr Intake	Conscious
100	Full	Normal; NEDz	Full	Normal	Full
90	Full	NI; Some EDz	Full	Normal	Full
80	Full	NI w/ effort; Sig Dz	Full	NI or reduced	Full
70	Reduced	Unable to do NI work; Sig Dz	Full	NI or reduced	Full
60	Reduced	Unable to hobby; extensive Dz	Occ asst nec	NI or reduced	Full or confuse
50	Sit or lie	Unable any work; extensive Dz	Occ asst req	NI or reduced	Full or confuse
40	Mstly Bed	Unable to do most activities	Mainly asst	NI or reduced	Full, drowsy, +/- conf
30	Total Bed	As above	Total Care	Reduced	As above
20	As above	As above	Total Care	Minimal sips	As above
10	As above	As above	Total Care	Mouth care only	Drowsy or coma +/- conf
0	Death	-	-	-	-

## Validation of PPS

- ½ dozen studies
- Most recent PC Consults in Chapel Hill!
  - O. Olajide, Laura Hanson et al
  - PPS correlates well with length of survival
- Different numbers in different populations but correlates well
- Previous studies in Home, NH, Hospital, and Inpatient units
- Not widely used in this country
- Can also help validate admission, plan care, plan discharge

## PPS and Survival in Days Inpatient PC Unit adapted from Lau et al.



## CHF The Seattle Heart Failure Model (SHFM)

- A much more sophisticated tool
- Web-based  
<http://depts.washington.edu/shfm/app.php>
- Combines:
  - Clinical and lab values, HF meds, and devices
  - Age, sex, NYHA class, EF, BP, pacemaker, ICD, etc.
- Baseline data calculates 1-, 2-, 5-years survival and mortality rate and mean life expectancy
- Post-intervention can be input and re-calculated

**Seattle Heart Failure Model Calculator**

File Info

	Baseline	1 Year	2 Year	5 Year
Survival		80%	64%	33%
Mortality		20%	36%	67%
Mean life expectancy		4.1 years		

**Intervention**

	1 Year	2 Year	5 Year
Survival	94%	88%	74%
Mortality	6%	12%	26%
Mean life expectancy	9.4 years		

**Clinical**

Age: 65  
Gender: Male  
NYHA Class: 3A  
Weight (kg): 80  
EF: 30  
Syst BP: 120  
 Ischemic

**Medications**

ACE-I  
 Beta-blocker  
 ARB  
 Statin  
 Aldosterone blocker

**Diuretics**

Furosemide: 80  
Bumetanide: 0  
Torsemide: 0  
Metolazone: 0  
HCTZ: 0  
 QRS > 120 msec

**Lab Data**

Hgb (g/dL): 14  
Lymphocyte %: 25  
Uric Acid (mg/dL): 8  
Total Chol (mg/dL): 190  
Sodium: 137

**Devices**

None  
 BV Pacer  
 ICD  
 BV ICD  
 LVAD

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## James T et al. Increasing palliative consults for HF using the SHFM. *J Hosp Pall Nurs.* 2010;273-281.

- Applied tool retrospectively to 214 patients DC'd with Dx of CHF
- Divided into 3 groups based on life expectancy
  - $\leq 1.5$  yrs; 1.5-5 yrs;  $\geq 5$  yrs
  - 27 fit  $\leq 1.5$  yrs and 17 died within a year
    - On average 2.8 mos and 9.6 mos shorter than predicted
    - Most had postintervention scores that declined or did not improve
  - 75 with  $> 1.5$  yrs died in study period
- Now use SHFM  $\leq 1.5$  for automatic PC referral
- Patients are not informed of their score

## Mitchell SL, Miller DC, Teno JM et al. Prediction of 6-month survival of NH residents with advanced dementia using ADEPT... *JAMA.* 2010;304(17):1929-1935.

- Used minimum data set (MDS) data
- To create, retrospectively validate, then re-derive and prospectively validate a bedside score
  - a 12-item Advanced Dementia Prognostic Tool (ADEPT)
- Looked at 606 patients and compared with Hospice eligibility guidelines
- Ability to predict residents at high risk of death in 6 months was modest but better
- Potential for setting scores as triggers and doing further study... (or PC consult or compare to SQ)

Table 1. ADEPT Scoring in Nursing Home Residents With Advanced Dementia (N = 606).

Characteristic	No. (% of Nursing Home Residents)	Points in Risk Score
Nursing home stay <90 d	29 (4.78)	3.3
Age, y (per 5-y increment)		
65-69	7 (1.16)	1.0
70-74	34 (5.61)	2.0
75-79	61 (10.07)	3.0
80-84	136 (22.44)	4.0
85-89	171 (28.22)	5.0
90-94	129 (21.29)	6.0
95-99	56 (9.24)	7.0
$\geq 100$	12 (1.98)	8.0
Sex, male	110 (18.15)	3.3
Shortness of breath	35 (5.94)	2.7
$\geq 1$ Pressure ulcers at $\geq$ stage 2	33 (5.45)	2.2
Activity of daily living score $\geq 28^a$	256 (42.24)	2.1
Bedfast most of day	59 (9.74)	2.1
Insufficient oral intake <sup>b</sup>	252 (41.58)	2.0
Bowel incontinence <sup>c</sup>	537 (88.61)	1.9
BMI < 18.5 <sup>d</sup>	48 (8.26)	1.8
Recent weight loss <sup>d,e</sup>	68 (11.70)	1.8
Congestive heart failure	107 (17.66)	1.5

Abbreviations: ADEPT, Advanced Dementia Prognostic Tool; BMI, body mass index, calculated as weight in kilograms divided by height in meters squared.

<sup>a</sup>Activities of daily living score (range, 0-28) is the sum of scores in 7 domains of function, including bed mobility, dressing, toileting, transfer, eating, grooming, and locomotion. Each is scored on a 5-point scale (0-independent; 1-supervision; 2-limited assistance; 3-extensive assistance; and 4-total dependence). A score of 28 represents complete functional dependence.

<sup>b</sup>Not consuming almost all liquids in previous 3 days or at least 25% of food unswallowed at most meals.

<sup>c</sup>Occasionally, frequently, or always incontinent or never.

<sup>d</sup>BMI and recent weight loss are calculated with a sample size of 580 because a recent weight was not available for 26 nursing home residents.

<sup>e</sup>Recent weight loss is defined as more than 5% body weight in prior 30 days or more than 10% in prior 180 days.

Enough with tools!  
Or we'll look like this...

## The "Art" of prognostication Part of a therapeutic alliance

*Onc* 2005

### Principles

- Process of prognostication should not impose an additional burden ie time-consuming, too much detail
- Process, probabilistic, dramatically inaccurate for some. Never lose sight of patient or their individual patient trajectory. Deeply embedded in open, flexible, patient-centered dialogue
- Communicate when requested (?). Right to know or not know.
  - Ethical, religious, cultural, psychological considerations
  - Avoid inflicting additional harm
- Emphasize a holistic therapeutic approach beyond time limits

## Discussing Prognosis

from Back A, Arnold R, Tulsky J: *Mastering Communication with Seriously Ill Patients*

- "How much do you want to know?"
- Normalize a range of patient interest
  1. "Some people want details"
  2. "Some want to focus on the big picture"
  3. "Some would rather not discuss it at all"
- "What would be best for you?"
- The power of some, many, and most

## For Patients Who Want Information

1. Negotiate the content
  - "Different ways to answer" – statistics, worst & best case scenario, future events
  - "What would work best for you?"
2. Provide the information – pause & check in
3. Acknowledge patient/family reaction
  - "It looks like the information is not what you were expecting." "I wish it wasn't so...I wish that there was more...tell me what you're thinking"
4. Check for understanding
  - "Tell me what you are taking away from this discussion."
  - "Tell me what you will tell your spouse."

## Some Patients Maybe Relieved...

**Patients are often the best teachers...Mrs. B.**

## For Patients Who Don't...

1. Try to elicit and understand why
2. Acknowledge the patient's concerns
3. Ask for permission to revisit the topic
4. Make a private assessment about whether prognosis might change the patient's current decision-making
  - Negotiate for limited disclosure
  - Do they want someone else to know
  - "I understand you would rather not talk about it and respect that. I also think there are some important reasons to talk about it. I think it might influence some decisions..."



## How good are we? H & PC Specialist Doctors & Nurses

- Twomey F et al. Prediction of patient survival by healthcare professionals in a specialist PCU
- To compare accuracy of different professionals
  - MDs (PC and nonPC); RNs; CNAs; ward sisters
  - CPS in ranges (<24h;24-72h;72h-10d;10d-1m;1-3m;>3m)
- To identify helpful predictive variables
- Accurately predicted survival only ~50%
  - Nursing and junior medical more accurate
  - Assistants least accurate
  - Senior medical, when in error, tended to underestimate
  - (Ward sisters not noted in results)
- Independent mobility only predictive variable of LOS

## How Good Are We? Palliative Care Teams

- Higginson I, Constantini M. Accuracy of prognosis estimates by four palliative care teams: a prospective cohort study.
- To test the accuracy of giving an estimated range of prognosis rather than a specific time
- Mostly nurses, a few physicians and SWs
- Compared minimum and maximum estimated survival with actual
- 42% accurate; 36% optimistic; 22% pessimistic
- More accurate if minimum estimate < 14 days (closer to death)...horizon effect
- Concludes – discussion is more important and if appropriate consult more experienced clinicians

## Prognostication Competencies

- Are we testing ourselves?
  - Quality Assessment and Performance Improvement
  - Every hospice, PC Service, and unit
    - Every admission
    - CPS, SQ, and/or disease-specific tool
- Board questions – about tools and conversation
  - ACGME (Accreditation Council for Graduate Medical Education)
  - CHPN (Certified Hospice and Palliative Nurse)
- More research studies – it wouldn't take much to tip QAPI into research

## Well-trained PC Super Docs and Nurses!

Capable of using multiple scores & indices!

## Summary

- Prognostication
- Simple tools beget more sophisticated tools
- As Donald Berwick, now Administrator of CMS, said at ACP in 1999:
  - “If you would not be surprised that your patient died in the coming months...tell him.”
- But tell him in a patient-centered empathetic way with negotiated content
- Let's get good at it!
- Let's study our ourselves!

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