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

Richard Stephenson MD
It's About How You Live
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Dick.Stephenson@hospicecarecenter.org

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?
- Goal setting
- Decision making
- Treatment options
- Future planning
- Resource utilization
- Hospice referral
- Care-planning
- Hospice discharge
- Done poorly
  - Burdensome
  - Futile care
  - Painful
  - Stressful
- Done well
  - Reduced stress
  - Dr/Pt alliance
  - Appropriate care
  - Resource utilization

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?

- 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

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

How Good Are We?

- 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.


- 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)

2nd 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
- 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 potentially 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 O2, 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 ≥ 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

- 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

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

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 that 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

- 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.

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)

<table>
<thead>
<tr>
<th>% score</th>
<th>Amb</th>
<th>Activity/Ev/Dz</th>
<th>Self care</th>
<th>Nut Intake</th>
<th>Conscious</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>Full</td>
<td>Normal; NEDx</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>90</td>
<td>Full</td>
<td>Nil; Some Edx</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>80</td>
<td>Full</td>
<td>Nil or seldom</td>
<td>Full</td>
<td>Nil or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>70</td>
<td>Reduced</td>
<td>Unable to do all work, nil Edx</td>
<td>Full</td>
<td>Nil or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>60</td>
<td>Reduced</td>
<td>Unable to do any work, extreme Edx</td>
<td>Gcu asst or req</td>
<td>Nil or reduced</td>
<td>Full or continuel</td>
</tr>
<tr>
<td>50</td>
<td>Silt or Silt</td>
<td>Unable to do any work, extreme Edx</td>
<td>Gcu asst or req</td>
<td>Nil or reduced</td>
<td>Full or continuel</td>
</tr>
<tr>
<td>40</td>
<td>Maln Bed</td>
<td>Unable to do most activities</td>
<td>Mostly asst</td>
<td>Nil or reduced</td>
<td>Full, N Std, Very had</td>
</tr>
<tr>
<td>30</td>
<td>Total Bed</td>
<td>As above</td>
<td>Total Care</td>
<td>Reduced</td>
<td>As above</td>
</tr>
<tr>
<td>20</td>
<td>As above</td>
<td>As above</td>
<td>Total Care</td>
<td>Minimal risp</td>
<td>As above</td>
</tr>
<tr>
<td>10</td>
<td>As above</td>
<td>As above</td>
<td>Total Care</td>
<td>N Intel care only</td>
<td>As above</td>
</tr>
<tr>
<td>0</td>
<td>Death</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Compare to Palliative Prognostic Score (PPS²) for cancer

- 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)

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, pacer, 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

James Y et al.
- Applied tool retrospectively to 214 patients DC’d with Dx of CHF
- Divided into 3 groups based on life expectancy
  - < 1.5 yrs; 1.5-5 yrs; > 5 yrs
  - 27 fit ≤ 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 < 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).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No. of Points</th>
<th>Risk Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, year 65+</td>
<td>0</td>
<td>1.0</td>
</tr>
<tr>
<td>Creatinine (mg/dl)</td>
<td>0.5</td>
<td>0.5</td>
</tr>
<tr>
<td>Incontinence</td>
<td>0</td>
<td>1.0</td>
</tr>
<tr>
<td>Activity of daily living score</td>
<td>0.5</td>
<td>0.5</td>
</tr>
<tr>
<td>Weight loss score #</td>
<td>0.5</td>
<td>0.5</td>
</tr>
<tr>
<td>BPI pain score</td>
<td>0</td>
<td>1.0</td>
</tr>
<tr>
<td>BPI distress #</td>
<td>0</td>
<td>1.0</td>
</tr>
<tr>
<td>MIBS</td>
<td>0</td>
<td>1.0</td>
</tr>
<tr>
<td>ADL score</td>
<td>0</td>
<td>1.0</td>
</tr>
<tr>
<td>Dementia severity</td>
<td>0</td>
<td>1.0</td>
</tr>
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<td>0</td>
<td>1.0</td>
</tr>
<tr>
<td>Plasma creatinine (mg/dl)</td>
<td>0.5</td>
<td>0.5</td>
</tr>
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<td>Activity of daily living score</td>
<td>0.5</td>
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<td>Dementia severity</td>
<td>0</td>
<td>1.0</td>
</tr>
</tbody>
</table>

James Y et al.
Enough with tools!
Or we’ll look like this…

The “Art” of prognostication
Part of a therapeutic alliance
Maltoni et al. J Clin
Dec 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 own selves!

References