Prognostication: balancing certainty, science and experience

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Objectives

• Identify three barriers to effective prognostication

• Practice effective prognosis communication with peers, patients & families

• Examine how to improve prognostication
Outline

• Formulating a prognosis
• The research
• Is now the right time to tell?
• Identifying implicit and explicit requests
• Techniques for sharing prognostic information
• Phew! Glad that is done!
• Improving your communication
What is a Prognosis?

An estimation of possible future outcomes of a treatment or a disease process founded upon a combination of experience, statistics and validated models.
Two Parts to Prognostication

• Formulation (Foreseeing)
  – Clinician estimates vs models
  – Rarely done explicitly
  – Rarely documented
  – Not just predicting death

• Communication (Foretelling)
  – Permission first
  – Empathetic
What Can be Predicted?

• Time to discharge
  – Case management/Utilization Review
  – Hospital throughput

• Functional outcome after therapy
  – Surgical outcomes

• Risk of medical outcome
  – Stroke, heart attack, cancer
  – 30-day re-hospitalization
And Death...
Predicting Risk of Death

- Medicare Hospice Benefit
- Withdrawal or withholding of life-sustaining treatments
- Activating a living will
- Choosing to go home
- Distant relatives
- Talking about important issues
- Providing care
The Research Problem

• Minimal research funding
• Minimal publications
• Mostly looking at genetic risk factors
• No revenue to be made (?)
• Mystery of prognosis
Who Can We Learn From?

- Weather forecasting
- Predictive analytics
- Clinical decision support systems
- CRM/advertising
- Fraud detection
- Underwriting
- Sports statistics - Moneyball
Estimated Individualized Prognosis

- Primary Disease
- Co-morbidities
- Functional Status
- Signs & Symptoms
- Goals of Care
- Trajectory of Illness
- Medications & Interventions
- Social Determinants
- Psychologic factors
- Element of Uncertainty
SUPPORT Study

- Doctors provided formulated prognoses
- 59% of physicians acknowledged receiving
- 15% of physicians reported discussing w/ patients/families
Comparison of SUPPORT and MD survival estimates

Kaplan-Meier 180-Day Survival

Predicted 180 Day Survival

n=4028  d=1889
<table>
<thead>
<tr>
<th>Situation</th>
<th>Median No. of Such Experiences</th>
<th>% Reporting This Experience at Least Once</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient asking “How long do I have to live?” in last year</td>
<td>10</td>
<td>89.5</td>
</tr>
<tr>
<td>Patient cared for in intensive care units in last year</td>
<td>30</td>
<td>87.4</td>
</tr>
<tr>
<td>Patient from whom life support had been withdrawn or withheld in last year</td>
<td>5</td>
<td>82.2</td>
</tr>
<tr>
<td>Patient referred to hospice in last year</td>
<td>5</td>
<td>84.1</td>
</tr>
<tr>
<td>Variable</td>
<td>Prognostication Is Stressful (n = 381)</td>
<td>Prognostication Is Not Stressful (n = 250)</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>--------------------------------------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td>Age, mean, y</td>
<td>45.3</td>
<td>46.2</td>
</tr>
<tr>
<td>Sex, % male</td>
<td>79.5</td>
<td>82.0</td>
</tr>
<tr>
<td>Specialty, % generalists</td>
<td>48.0</td>
<td>47.6</td>
</tr>
<tr>
<td>Board certification, % certified</td>
<td>79.8</td>
<td>79.2</td>
</tr>
<tr>
<td>Time spent in patient care, %</td>
<td>90.1</td>
<td>86.5</td>
</tr>
<tr>
<td>Prognostic queries, mean No. of patients</td>
<td>23.8</td>
<td>21.1</td>
</tr>
<tr>
<td>Life support withdrawal, mean No. of patients</td>
<td>16.1</td>
<td>18.3</td>
</tr>
<tr>
<td>Difficulty, % finding prognostication difficult</td>
<td>68.0</td>
<td>44.1</td>
</tr>
<tr>
<td>Patient expectations, % thinking that their patients expect too much certainty</td>
<td>85.2</td>
<td>72.1</td>
</tr>
<tr>
<td>Training, % with inadequate training in prognostication</td>
<td>61.4</td>
<td>49.8</td>
</tr>
<tr>
<td>Patient confidence, % feeling that patients would lose confidence after a prognostic error</td>
<td>55.6</td>
<td>42.3</td>
</tr>
</tbody>
</table>
Table 3. Internists’ Perceptions About How Prognostic Errors Would Be Regarded by Patients and Colleagues

<table>
<thead>
<tr>
<th>Statement</th>
<th>% Agreeing</th>
</tr>
</thead>
<tbody>
<tr>
<td>If I were to make an error in <em>diagnosis</em>, my <em>patients</em> might lose confidence in me</td>
<td>88.0</td>
</tr>
<tr>
<td>If I were to make an error in <em>prognosis</em>, my <em>patients</em> might lose confidence in me</td>
<td>50.2</td>
</tr>
<tr>
<td>If I were to make an error in <em>diagnosis</em>, my <em>colleagues</em> might lose confidence in me</td>
<td>81.3</td>
</tr>
<tr>
<td>If I were to make an error in <em>prognosis</em>, my <em>colleagues</em> might lose confidence in me</td>
<td>28.7</td>
</tr>
<tr>
<td>If a physician colleague made an error in prognostication, I would probably lose some confidence in the colleague</td>
<td>17.2</td>
</tr>
</tbody>
</table>
Discordance

- 236 patients and 38 community oncologists
- Compared 2-year survival estimates
- 161 (68%) discordant
  - More common among non-white (95% vs 65%)
  - 144 (89%) of discordant patients did not know they were discordant
  - 155 (96%) were more optimistic
Figure 2. Receiver Operating Characteristic Curves for Accuracy of Prognostic Estimates of Patient Survival to Hospital Discharge

- Physicians: C statistic = 0.829; 95% CI, 0.77-0.88
- Surrogates: C statistic = 0.735; 95% CI, 0.66-0.80
Not Just in Cancer

• 90% of people on HD didn’t recall prognostic discussion
  – Annual mortality 22%
• 89% of people with HF didn’t recall discussion
• 82% of patients and 45% of caregivers in HF population figured out independently, death was imminent

Davison, CJASN, 2010; Strachan 2009; McCarthy 1997
Pediatric Considerations

- Prognostic discussions more likely with PC
  - 97% vs 83%
- Prognostic discussions earlier with PC
  - Median 8 days vs 2 days
- Context is important, many patients want some information
- Parents consider both difficult & necessary

Ullrich 2016; Brand 2017; Nyborn 2016
Nurse Perceived Barriers

• Logistics
• Discomfort with discussion
• Perceived lack of skill or training
• Fear of conflict

Aslakson et al, JPM 2012
<table>
<thead>
<tr>
<th>Domain</th>
<th>Practical Advice</th>
<th>Possible Solutions</th>
</tr>
</thead>
</table>
| Knowledge, skills, and attitudes| Primary care team builds knowledge, skills, and attitudes to conduct conversations about goals and values with patients with serious illnesses | Build training into medical school and primary care-track training programs  
Generate postgraduate training programs aimed at learning and practicing communication skills about serious illness  
Incentivize training time with professional requirement credits (eg, CME, CEU) and reimbursement (eg, RVU) for time spent in training |
| Prognostication                | Primary care team identifies appropriate patients for discussions                   | Develop predictive analytic algorithms that identify high-risk patients  
Combine analytic approaches with clinician judgment to generate clinician buy-in  
Creation of registries, such as those driven by patient-centered medical homes, to track patients eligible for conversation |
| Timing and initiation of conversations | Primary care team create systems to prompt high-quality discussions with patients at the right time | Use integrated systems (eg, patient preparation, reminders) to facilitate the conversation  
Train nonclinician members of the primary care team (eg, social workers, nurses) to lead and follow up on these conversations  
Create care models and policies that incentivize primary care teams to have conversations |
| Lack of coordination           | Primary care team takes responsibility for coordination with specialists and interdisciplinary services needed to follow up on conversations | Delineate explicit responsibilities for elements of conversation among clinicians  
Build care models that incentivize coordination of care between clinicians in a fragmented care delivery system  
Use policy to ensure follow-up and management of needs generated by conversations about patients' wishes |
| Documentation                  | Documentation of all information relevant to advance care planning is placed in a single location in the medical record | Create a single documentation site in the electronic medical record for all advance care planning, information, including MOLST or POLST forms  
Create standards and audit adherence to ensure use of the single chosen site |
| Feedback and quality improvement| Primary care team respond to appropriate metrics measuring quality, timing, and proportion of documentation for high-risk patients | Build practice metrics on timing, quality, and quantity of conversations completed for selected patients  
Develop national consensus and promulgation of key metrics for timing, quality, and number of conversations for different patient populations |

Abbreviations: CEU, continuing education unit; CME, continuing medical education; MOLST, Medical Orders for Life-Sustaining Treatment; POLST, Physician Orders for Life-Sustaining Treatment; RVU, relative value unit.
**Table 2. Documentation of Prognostic Information by Reason for Consultation**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>All patients (n=412)</th>
<th>Symptom management consults (n=181)</th>
<th>Goals of care consults (n=108)</th>
<th>Both (n=123)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Documentation of functional status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ECOG only</td>
<td>12</td>
<td>3</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>KPS only</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>ECOG and KPS</td>
<td>8</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Palliative Performance Scale</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>ADLs</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td><strong>Documentation of EBP</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palliative Prognostic Score</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Palliative Prognostic Index</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>MELD score</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Walter Index(^1)</td>
<td>1(^1)</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Lee Index(^1)</td>
<td>1(^1)</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

\(^1\)The Walter Index and the Lee Index were documented for the same patient.

ADLs, Activities of Daily Living; ECOG, Eastern Cooperative Oncology Group; KPS, Karnofsky Performance Scale; MELD, Model for End Stage Liver Disease.
**Table 3: Association between patient overall satisfaction with EOL care and other variables: results from ordinary least squares multiple linear regression**

<table>
<thead>
<tr>
<th>Variable</th>
<th>$\beta$ (95% CI)</th>
<th>$t$</th>
<th>$p$ value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussion of prognosis</td>
<td>3.57 (0.78 to 6.36)</td>
<td>2.51</td>
<td>0.012</td>
</tr>
<tr>
<td>Age</td>
<td>0.15 (0.02 to 0.28)</td>
<td>2.25</td>
<td>0.025</td>
</tr>
<tr>
<td>Rural</td>
<td>2.57 (0.15 to 4.98)</td>
<td>2.09</td>
<td>0.037</td>
</tr>
<tr>
<td>Female</td>
<td>−1.55 (−3.69 to 0.59)</td>
<td>−1.42</td>
<td>0.156</td>
</tr>
<tr>
<td>Retired</td>
<td>−0.59 (−3.09 to 1.90)</td>
<td>−0.47</td>
<td>0.640</td>
</tr>
<tr>
<td>Married or common-law status</td>
<td>−1.48 (−3.64 to 0.69)</td>
<td>−1.34</td>
<td>0.181</td>
</tr>
<tr>
<td>Has post-secondary education</td>
<td>−0.39 (−2.71 to 2.14)</td>
<td>−0.23</td>
<td>0.815</td>
</tr>
<tr>
<td>Religion stated</td>
<td>1.72 (−1.26 to 4.70)</td>
<td>1.14</td>
<td>0.257</td>
</tr>
<tr>
<td>Caregiver present</td>
<td>0.00 (−2.12 to 2.12)</td>
<td>0.00</td>
<td>0.998</td>
</tr>
<tr>
<td>Functional ability</td>
<td>0.04 (−0.05 to 0.13)</td>
<td>0.83</td>
<td>0.405</td>
</tr>
<tr>
<td>Cancer diagnosis</td>
<td>2.50 (0.37 to 4.62)</td>
<td>2.31</td>
<td>0.022</td>
</tr>
</tbody>
</table>

*F = 2.21 (p = 0.014); df$_1$ = 11, df$_2$ = 346; adj. $R^2$ = 0.036

EOL = end of life, CI = confidence interval.

Note: The $\beta$ estimates the increase in the dependent variables (satisfaction scores) per unit increase of continuous predictors or in the yes versus no group for binary predictors.
Techniques

• Review case information
• Clarify the question
• Affirm the question
• Raise the question
• Elicit patient knowledge/emotions
• Seek permission
Techniques

• Find humility
• Use ranges, not numbers
• Pause...(yes, even longer than that)
• Manage expectations
• Address emotions
• Find the difficult words
Follow Up

• Phew! Glad that is done!
• Readdress goals of care
• Affirm openness
• Ensure follow-up
• Demonstrate commitment to care
Get Feedback

• Before you start a family meeting
  – Ask colleagues for feedback

• During discussion
  – Observe and note things that work well (or didn’t)
  – Assess emotions in the room

• After the meeting
  – Elicit feedback
  – Give feedback
Survived to Hospital Discharge, N = 2607

- Narrow Inclusion Criteria, n = 19
- Intermediate Inclusion Criteria, n = 300
- Broad Inclusion Criteria, n = 923
Curate Trusted Tools

• See Appendix slide deck
• Pallimed prognosis links
• GeriPal ePrognosis (Site and App)
• Pubmed search and alerts
• SEER database (cancer)
Study Your Own Efforts

<table>
<thead>
<tr>
<th>Prognosis:</th>
<th>Min: □ Min. □ Hrs □ Dys □ Wks □ Mos.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Avg: □ Min. □ Hrs □ Dys □ Wks □ Mos.</td>
</tr>
<tr>
<td>Disc. w/</td>
<td>Max: □ Min. □ Hrs □ Dys □ Wks □ Mos.</td>
</tr>
<tr>
<td>□ Pt □ Fam</td>
<td></td>
</tr>
</tbody>
</table>
Summary

• Formulate first!
• Listen for implicit cues to discuss prognosis
• Define the context
• Seek permission
• Re-address as information changes
• Document, document, document
• Ask for feedback, give others feedback
References


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