Objectives

- Discuss the role of clinicians in providing realistic prognoses for patients with advanced illness.
- Identify sources of information that can assist clinicians in the prognostic estimates they formulate about patients.
- Identify information needed by terminally ill patients and their families to make informed decisions about accepting, declining, or withdrawing life-sustaining treatments once prognosis has been given.
- Examine effective and compassionate communication strategies for patients and families coping with advanced illness.

Outline

- What is prognostication?
- Attitudes to prognostication important?
- Challenges to prognostication?
- Tools for prognostication?
- Trajectories of illness?
- How to prognosticate with patients and families?

What is prognostication?

- Arthur C. Clarke's three laws of prediction:
  - When a distinguished but elderly scientist states that something is possible, he is almost certainly right. When he states that something is impossible, he is very probably wrong.
  - The only way of discovering the limits of the possible is to venture a little way past them into the impossible.
  - Any sufficiently advanced technology is indistinguishable from magic.

What is prognostication?

tasseography
What is prognostication?

- Prognosis = knowing before
- The act of prophecy
- Future oriented
- Who is the prophet?
- A normative, behavior-oriented, and ethical practice
- Comprised of knowledge, skill, and attitude
- Two elements for physicians:
  - Foreseeing: estimating the probability of an individual developing a particular outcome over a specific period of time (prognosis)
  - Foretelling: communicating the prognosis with the patient and family.

What is prognostication?

- A global picture that includes “natural” lifespan, illness, and social determinants of health
- It is not the same as predicting survival from a discrete intervention
- It is not just a specialized skill limited to end-of-life care—all of our patients have life spans

Why is prognosis important?

- “Doc, should I…”
  - Be worried? Tell my family?
  - Start hemodialysis?
  - Try another round of chemotherapy?
  - Undergo surgery?
  - Transfer to an LTAC?
  - Take a vacation?
  - Enroll in hospice?
- An opportunity for:
  - Trust and respect
  - Empathy and hope
  - Honesty and Integrity
  - Empowerment

Why is prognosis important?

- diagnosis
- prognosis
- therapy
Why is prognosis important?

- Identifies patients most likely to benefit from different strategies:
  - Preventative care
  - Acute care
  - Chronic care
  - Palliative care

- Patients with poor prognosis are:
  - Unlikely to survive to benefit for interventions that have delayed benefits
  - Exposed to immediate risks
  - Sometimes will to take greater risks

- Interventions should be targeted to patients whose life expectancy affords time for them to benefit.

Colorectal cancer screening

USPSTF Guidelines

- Age 50-75: Routine screening
- Age 75-85: Small or Marginal Benefit, recommend against routine screening
- Age 85+: Recommend against screening

- These are guidelines, which should be filtered through clinical judgment
- In general, target screening to healthier patients with good prognosis

Guidelines and prognosis

- "One-size-fits-all" approach to medical care based on age does not work in diverse elderly population
  - Great variation in life expectancy
  - Patient, family, and community expectations for longevity also vary

- More guidelines now base recommendations on prognosis rather than age alone
  - E.g. cancer screening (stop if limited life expectancy)
  - E.g. diabetes care (tolerate higher A1c if limited life expectancy)

Challenges to prognostication

- Younger patients with trauma or cancer have a clearer trajectory: hanging on until they fall off
- A poor prognosis is difficult to hear
- Older adults are not straightforward:
  - May have absence of dominant terminal condition
  - Age + functional + cognitive + multi-morbidity

Challenges to prognostication

Prognostic information is hard to find:

- Generally, less than 30% of medical textbook chapters discuss prognosis (instead focus on etiology, diagnostic criteria and treatment)
- Tools developed for mortality prediction in older people may be difficult for busy clinicians to remember or use
Inaccuracy of prognostication

<table>
<thead>
<tr>
<th>Study</th>
<th># Patients</th>
<th>Median CPG (Years)</th>
<th>Median A5 (Years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prames et al</td>
<td>71</td>
<td>24 (18-33)</td>
<td>28 (23-35)</td>
</tr>
<tr>
<td>Evans et al</td>
<td>42</td>
<td>26 (20-30)</td>
<td>30 (23-37)</td>
</tr>
<tr>
<td>House-Moore et al</td>
<td>62</td>
<td>20 (13-34)</td>
<td>24 (19-34)</td>
</tr>
<tr>
<td>Mikaeli et al</td>
<td>103</td>
<td>22 (10-40)</td>
<td>26 (13-65)</td>
</tr>
<tr>
<td>Mikaeli et al</td>
<td>533</td>
<td>23 (9-70)</td>
<td>25 (10-45)</td>
</tr>
<tr>
<td>Doehner et al</td>
<td>21</td>
<td>21 (14-38)</td>
<td>25 (19-62)</td>
</tr>
<tr>
<td>Nystrom et al</td>
<td>88</td>
<td>22 (13-50)</td>
<td>25 (14-65)</td>
</tr>
<tr>
<td>Orkiszewski et al</td>
<td>325</td>
<td>17 (3-130)</td>
<td>20 (13-65)</td>
</tr>
<tr>
<td>Overall</td>
<td>1,081</td>
<td>20 (15-46)</td>
<td>23 (15-62)</td>
</tr>
</tbody>
</table>

Shortcomings of clinical predictions

- Tend to overestimate patient survival by a factor of between 3-5x.
- Tend to be more accurate for very short-term prognosis than long-term prognosis.
- Influenced by relationships
  - The length of doctor patient relationships increases the odds of making an erroneous prediction.
  - A family’s optimism may be contagious

Tools for prognostication

- Clinical judgment
- Prognostic indices
- Illness trajectories
- Communication toolset

US Life Tables

- Life expectancy increases as age increases
- But note that not all octogenarians are created equal

Great Variation in Life Expectancy for People of Similar Ages

<table>
<thead>
<tr>
<th>Age</th>
<th>Independent</th>
<th>Mobility disabled</th>
<th>ADL disabled</th>
</tr>
</thead>
<tbody>
<tr>
<td>70</td>
<td>16.7</td>
<td>15.7</td>
<td>11.5</td>
</tr>
<tr>
<td>75</td>
<td>13.2</td>
<td>12</td>
<td>8.2</td>
</tr>
<tr>
<td>80</td>
<td>10.3</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>85</td>
<td>8</td>
<td>6.9</td>
<td>4.6</td>
</tr>
</tbody>
</table>

Use Functional Status

Walter LC. JAMA 2001;285:2750-56

Determining prognosis

- Performance status
  - Karnofsky
  - ECOG/WHO
- Symptoms
  - Weight loss/anorexia
  - Cognitive factors
  - Dysphagia
  - Dyspnea

ECOG/WHO

<table>
<thead>
<tr>
<th>Grade</th>
<th>Criteria</th>
<th>Median Prognosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Fully active, able to carry on all predisease performance without restriction</td>
<td>—</td>
</tr>
<tr>
<td>1</td>
<td>Restricted in physically strenuous activity but able to carry out routine work of a light or sedentary nature (e.g., light house work, office work)</td>
<td>3 months</td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of all self-care but unable to carry out any work activities, up and about more than 50% of waking hours</td>
<td>1 month</td>
</tr>
<tr>
<td>3</td>
<td>Capable of any limited self-care, confined to bed or chair more than 50% of waking hours</td>
<td>&lt;3 months</td>
</tr>
<tr>
<td>4</td>
<td>Completely disabled, cannot carry on any self-care; totally confined to bed or chair</td>
<td>—</td>
</tr>
<tr>
<td>5</td>
<td>Dead</td>
<td>—</td>
</tr>
</tbody>
</table>

Karnofsky Performance Scale

- Reliable
- Valid (especially when KPS < 50)
- Simple
- Reproducible measure of patient function
- Independent predictor of survival

Use comorbid conditions

- CHF (Class III, IV)
- ESRD
- Dementia
- Severe COPD (oxygen dependent)
- Cancer
- Severe depression
- Stroke

Disease Specific Prognosis

Lunney, J. D. et al. JAMA 2003;289:2387-2392

http://www.aipr.ucw.edu/EPERC/FASTFACTS_INDEX/I_1/20.htm
Prognostic indices

• Physicians can use prognostic indices to lend confidence to their judgments about prognosis
  - National survey of 697 physicians: 57% felt inadequately trained in prognostication
• Prognostic indices provide an objective measure to support clinical intuition
• Combining clinical estimates with prognostic indices results in more accurate estimates than either alone.

Christakis & Iwashyna, Arch Intern Med 1998

What is a prognostic index?

• Definition:
  - A clinical tool that quantifies the contributions that various components of the history, physical exam, and laboratory findings make towards a diagnosis, prognosis, or likely response to treatment.

McGinn, JAMA, 2000

What is a prognostic index?

• Examples of disease or context-based indices:
  - Charlson comorbidity index
  - CHADS2 for atrial fibrillation stroke risk
  - Dukes staging system for colorectal cancer
  - Manchester score for small-cell lung cancer
  - International Prognostic Index for non-Hodgkin’s lymphoma
  - NYHA CHF classification scheme

McGinn, JAMA, 2000

Predicting outcomes: tools

• CARING Criteria
  - Cancer
  - Recent Hospital Admissions
  - Resident of a Nursing Home, LTAC or SNF
  - ICU with MOF
  - Non-Cancer Hospice and Palliative Care Guidelines
• Retrospective cohort study 5 prognostic indicators demonstrated high specificity (79%) and sensitivity (75%) for mortality at 1 year


CARING Criteria

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>None</th>
<th>Multiple Admissions within last year</th>
<th>Nursing Home Residence/LTAC/SNF</th>
<th>CARING</th>
<th>ICU with MOF</th>
<th>CHF Non-Cancer Hospice Guidelines/Life Expectancy ≤6 mos</th>
<th>Meet criteria in 2 columns</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;65</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>&lt;13</td>
</tr>
<tr>
<td>65-75</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>≥13</td>
</tr>
<tr>
<td>&gt;75</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>≥13</td>
</tr>
</tbody>
</table>

RISK Category (For Mortality at 1 year):
- Low <5—Consult not needed
- Mod 5-12—Consider consult at admission; if no consult placed—recommend consideration in note
- High ≥13—ALL patients with high risk should receive palliative consult upon admission, LIFE Support Consult needs ordered

Adapted from A Practical Tool to Identify Patients Who May Benefit from a Palliative Approach: The CARING Criteria (Fischer, et al., 2006, JPSM)
Prognostic Indices for Older Adults: A Systematic Review

- **Systematic review**
- No Pubmed MeSH term
- Identified 16 validated non-disease specific prognostic indices for older adults
- Evaluated quality: accuracy and generalizability

**Prognostic indices: analysis**

- **Accuracy: discrimination**
  - Sorts dead from living
  - Most no better than 70%
  - Coin flip is 50%
- **Accuracy: calibration**
  - How well does predicted risk match observed risk?
  - Example:
    - Prediction is 15% 1 year mortality in lowest risk group
    - Observed a 17% 1 year mortality
  - But most indices had >10% difference in predicted:observed mortality at some level of risk
- **Generalizability: transportability**
  - An index may perform well in a research dataset
  - What about geographic regions? Severity of illness? Time?
- **Impact on outcomes**
  - No indices were evaluated for clinical impact

**Prognostic indices: findings**

- A few indices: accurate, developed and tested in large and diverse settings
- Recommended:
  - Cautious use of highest quality indices
  - In conjunction with
    - Clinical factors not captured in index
    - Patient preferences
  - Prognostic indices + clinical judgment better than clinical judgment alone

**Illness trajectories**

- Dementia
- Heart disease
- Lung disease

**Medicare Hospice Benefit Guidelines for Determining Prognosis in Dementia**

To be eligible for hospice, patients must meet both of the following criteria:

- Functional Assessment Staging (FAST): Patient must be at or beyond stage 7c and show all of the features of stages 6a-7c.
- Medical conditions: Patients must have had at least 1 of the listed medical conditions over the prior year.
Functional Assessment Staging (FAST)

- Stage 6a: Cannot dress without assistance
- Stage 6b: Cannot bathe without assistance
- Stage 6c: Cannot toilet without assistance
- Stage 6d: Incontinent of urine occasionally or frequently
- Stage 6e: Incontinent of bowel occasionally or frequently
- Stage 7a: Speech limited to fewer than 6 intelligible words during an average day
- Stage 7b: Speech limited to a single intelligible word during an average day
- Stage 7c: Unable to ambulate independently
- Stage 7d: Cannot sit up independently
- Stage 7e: Cannot smile
- Stage 7f: Cannot hold head up independently

Hospice Criteria: At least 1 of these medical conditions over the prior year

- Aspiration pneumonia
- Pyelonephritis or other upper urinary tract infection
- Sepsis
- Decubitis ulcer, multiple, stage 3-4
- Recurrent fever after treatment with antibiotics
- Eating problems such that fluid or food intake is insufficient to sustain life (or, if tube fed, weight loss 10% over prior 6 months or serum albumin 2.5 g/dL)

Advanced Dementia, Complications, and Prognosis

- 6-month mortality rates after the development of
  - pneumonia – 47%
  - a febrile episode – 45%
  - eating problems – 39%
- After hospitalization for PNA or hip fracture
  - 55% 6-month mortality rate

Prognostication in heart disease

- Demographic factors (i.e. age)
- Heart failure severity
  - LVEF <20%
  - New York Heart Assn. Classification
    - Class IV: Symptoms of CHF at rest despite optimal treatment
- Comorbid diseases
- Physical examination findings
- Laboratory (i.e. Na)
Rehospitalization for heart failure

- 11,855,702 Medicare beneficiaries discharged with Heart Failure
  - One in four (19.6%) were re-hospitalized at 30 days
  - One third (34%) were re-hospitalized at 90 days

- OPTOMIZE-HF Registry
  - Older than 65 & hospitalized for new or worsening heart failure
  - Almost two-thirds (64%) are readmitted at one year

Hospitalization predicts mortality

- Communitywide study of a large northeast metropolitan area
- Mean age was 76
- All-cause death rates
  - 37.3% at 1 year after hospital discharge
  - 52.9% at 2 years
  - 78.5% at 5 years

Repeated hospitalizations predict mortality

- REMATCH trial
  - Chronic end stage heart failure patients with contraindications for cardiac transplant
  - Average age – mid-late 60’s
  - Medical management arm
    - Spent 83 days in the hospital during the last 2 years of life
    - In the last 6 months of life - 1 out of every 4 days spent as inpatients

Lung disease

- Very difficult to predict terminal events
- FEV1 ≤ 30%
- Repeated episodes of respiratory failure
- Presence of cor pulmonale
- Hypoxemia
- Dyspnea at rest
- Low functional status

BODE INDEX

<table>
<thead>
<tr>
<th>Variable</th>
<th>Points on BODE Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>FEV1 (% of predicted)‡</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>Distance walked in 6 min (m)</td>
<td>≥350 250-349 150-249 ≤149</td>
</tr>
<tr>
<td>MMRC dyspnea scale♂</td>
<td>0-1 2 3 4</td>
</tr>
<tr>
<td>Body-mass index♂</td>
<td>≥21 ≤21</td>
</tr>
</tbody>
</table>
Cancer terminology

- Tumor grade
- Tumor size
- Tumor staging
- Cancer specific survival
- Relative survival
- Overall survival
- Disease-free survival
- Progression-free survival rate
- Response rate

Small cell lung cancer: survival rates
Small cell lung cancer: stage at diagnosis

Percent of Cases & 5-Year Relative Survival by Stage at Diagnosis: Lung and Bronchus Cancer

- 15% Unspecified
- 3% Limited
- 57% Extensive
- 32% 21% 20% 19%

**Lung cancer prognosis: quality of life and functional status**

- 566 patients age ≥70 with NSCLC stage IV or IIIB
- Assessed:
  - Quality of life
  - Comorbidities
  - Functional status
- Quality of life and IADLs were highly associated with prognosis while ADLs and comorbidities were not
- Low performance status and high number of metastasis also correlated with shorter survival


Dying is a predictor of death.

**Impact of effective prognosis delivery**

- Improve patient/family’s ability to
  - Cope
  - Plan
  - Grieve
- Your delivery may be what they remember most (especially if they saw it coming)
- Encourages realistic goals and autonomy
- Strengthens physician-patient relationship
- Fosters collaboration among patient, family, medical team
- Environment of honesty

**Impact of effective prognosis delivery**

Examples
- If we don’t start dialysis, does that mean we’re letting mom die?
- If we don’t place the PEG tube, will daddy starve?
- But that’s not what my pastor told me...
- This is all my fault...
How to prognosticate with patients and families

- Confess your finitude
- Let your patient know you will share prognosis on the their terms, to the degree that they want
- Endure the silences
- Inquire about reasons for asking
  - “What are you expecting to happen?”
  - “How specific do you want me to be?”
  - “What experiences have you had with:
    - others with same illness?
    - others who have died?”

How to prognosticate with patients and families

- “The road to recovering looks like…”
- “The road to not recovering looks like…”

How to prognosticate with patients and families

- Limits of prediction
  - “Hope for the best, plan for the worst”
  - better sense over time
  - can’t predict surprises, get affairs in order
- Reassure availability, whatever happens
- Patients vary
  - “planners” want more details
  - those seeking reassurance want less
- Avoid too much precision and caginess
  - hours to days …days to weeks… months to years
  - average

How to prognosticate with patients and families

- Consider cultural variances
  - Consult or involve an interpreter, chaplain, or another professional
  - Show an interest
- Anticipatory grief
  - Anger, guilt, denial, sadness
  - “It may come in waves…”
  - “Give yourself permission to grieve…”

How to prognosticate with patients and families

- What if the family wants to withhold information?
  - Ask the patient what he/she wants to know
  - Compromise
  - Balance respect for culture, personal autonomy, and professional integrity
- Be direct
- Be compassionate
- Avoid medical jargon
- Maintain hope, but don’t give false hope
  - “I wish…”
- Ask/tell/ask
- Moral reassurance:
  - Clarify patient’s values and goals
  - Spiritual and cultural beliefs
  - Double effect
How to prognosticate with patients and families

• Buckman’s six-step protocol
  1. Getting started
  2. What does the patient know?
  3. How much does the patient want to know?
  4. Sharing the information
  5. Responding to patient, family feelings
  6. Planning and follow-up

• Give milestones and time-limited trials

• Don’t just do something… sit there.

• You are a guide on a journey:
  o Patients, families
  o Students, residents