Prognostication at the End of Life: Replacing Guesses with Answers

Mark V. Blum, MD, FAAHPM
Medical Director
Bristol Hospice, Sacramento

Dawn Lambie, RN, MSN
Director of Patient Care Services
Bristol Hospice, Sacramento

Mark Blum has no unresolved conflicting affiliations to disclose.
Dawn Lambie has no unresolved conflicting affiliations to disclose.

Objectives

- Know why is it important to prognosticate
- Consequences of not doing so
- Advantages of doing so?
- Explore role of hope in prognosis
- Explore typical error patterns
- Be able to use disease-specific data

Why Bother?

- Patient/family decision-making near end of life
- Further therapy
  - Emphasize cure/remission vs. comfort
  - Avoid painful/expensive therapy if unlikely to be beneficial
- Family visits
- Work, travel
- Care-giving, FMLA, avoid financial ruin
- Conclude business and financial affairs
- Repair or bring closure to relationships

Why Bother?

- Appropriate use of resources
- Referrals to palliative care or hospice

Prognosis Can Guide Clinical Decisions


Our worries

- Inflicting pain
- Being blamed
- Uncertainty
- Sense of failure
- Expressing emotions
- Own mortality
- Self-fulfilling prophecy
Patients’ Misunderstandings

- 1/3 of patients with metastatic disease believe it’s localized
- 1/3 patients receiving palliative CTX believe its curative

Patients’ Want...

- Information about prognosis and optimism
- 55% of patients referred for Palliative Care want information on a dire prognosis
- Tend to want physician to overestimate
- Older, less educated want less information
- May not want to know they are dying

...Patients’ Want

- Depressed patients want more information
- Anxious patients want less information
- Realism with compassion
- Lessening of uncertainty
- Family members present for the discussion but want to control which members

Hope

- Previously unacceptable options may become OK
- Self-ratings of QOL remain high, even in advanced disease
- Possible definitions of hope
  - A belief that cure is possible
  - Alternatives
    - Absence of suffering
    - Meaningful time spent with family
    - Repair of relationships

Consequences Of Failure To Prognosticate

- Death in institutional setting more likely
- Symptom management secondary to other interventions
- Loss of time with family
- Financial and emotional consequences
- Late referral (or none) to Hospice

Cancer Trajectory: Diagnosis to Death

Joanne Lynne
The Washington Home Center for Palliative Care Studies. 2003

Terminally Ill Cancer Patients
- 468 patients in Hospice
- Actual median survival 24 days
- Accurate prognosis (within 33% AS) 20%
- Optimistic 63%
  - Overestimated survival by 5.3X
- Pessimistic 17%
- Clinical experience increased accuracy
- Long relation with patient decreased accuracy


Palliative Prognostic Score (PaP)

Survival of Medicare Hospice Patients

- 6451 Hospice patients
- Mean age 76 years
- 80% had cancer
- Median survival after enrollment = 36 days
- 16% died within 7 days
- 15% lived longer than 6 months


Prognosis With Advanced Solid Tumors...

- 177 French patients
- Patients hospitalized with metastatic or inoperable solid tumors
  - breast 13.6% lung 10.7%
  - pancreas 10.2% colon/rectum 9.6%
  - head/neck 7.9% prostate 7.3%
- Estimated survival of several days-6 months by their physicians


Prognosis With Advanced Solid Tumors...

- 5 factors had negative influence on survival
  - 2 or more metastatic sites
  - median survival 32 days vs. 119 days
  - cerebral metastases
  - 23 days vs. 70 days
  - LDH ≥600 IU
  - 28 days vs. 102 days

... Prognosis With Advanced Solid Tumors...

- Low KPS
  - ≤30% 14 days
  - 40-60% 39 days
  - ≥70% 146 days
- Low serum albumin
  - <2.4 g/dL 30 days
  - 2.4-3.3 g/dL 55 days
  - >3.3 g/dL 126 days


Response And Survival Data For Chemotherapy

- For metastatic or locally advanced cancer
- First line CTX
  - expect poorer response for 2nd.... line CTX
- Response =>50% reduction in tumor volume
- Patients w/good enough performance to participate in clinical trials
- Median survival represents both responders and non-responders

Response to CTX

Cancer Syndromes With Short Median Survival Times

- Hypercalcemia 8 weeks (except newly diagnosed breast cancer or myeloma)
- Pericardial effusion 8 weeks
- Meningitis 8-12 weeks
- Spinal cord compression
- Multiple brain metastases
- No Tx 1-2 months
- Steroids 2-3 months
- Whole brain XRT 3-6 months

Malignant Pleural Effusion

- Prognosis especially poor if due to
  - GI
  - Lung
  - Ovary
- Survival
  - Average 3-6 months
  - Median 4 months
  - 3 month mortality 65%
  - 6 month mortality 80%

Organ System Failure Trajectory

- Joanne Lynn. The Washington Home Center for Palliative Care Studies. 2003

Physicians' Survival Predictions

- Median predicted chance of surviving 2 months
  - 1 week prior to death 51%
  - 1 day prior to death 17%
  - CHF 62%
  - Lung cancer 17%
  - Coma 11%

Prognostic Accuracy By A Hospital-based Palliative Care Service...

- 429 patients seen by OHSU PCS
- 46% had cancer
- 50/50 male/female
- Patients assigned to 1 of 4 survival categories
... Prognostic Accuracy By A Hospital-based Palliative Care Service...

- 58% assigned to correct survival category
- 27% too optimistic
- 16% too pessimistic
- Neither cancer diagnosis nor length of hospital stay before consultation were associated with accuracy
- If team was consulted to address prognosis and goals of care they were less likely to be accurate

ESRD - Survival On Dialysis

- 1 year: 75%
- 5 years: 40%
- Independent predictors:
  - Albumin <3.5 g/dl
  - Functional status
  - Age
  - 20% elect to D/C dialysis

Modified Charlson Comorbidity Index for ESRD...

- 1 point each for:
  - CAD, CHF, PVD, cerebrovascular disease, dementia, COPD, connective tissue disease, PUD, mild liver disease, DM
  - 1 point for every decade over 40
  - (e.g. 3 points at age 65)

... Modified Charlson Comorbidity Index...

- 2 points each for:
  - hemiplegia
  - moderate to severe renal disease (including dialysis)
  - DM w/end-organ damage
  - cancer
  - 3 points for moderate-severe liver disease
  - 6 points for metastatic solid tumor or AIDS

End Stage Liver Disease...

- MELD (Model for End stage Liver Disease)
- 3 factors
  - Total bilirubin
  - INR
  - Cr
- Online: www.unos.org/resources/meld/PeldCalculator.asp
- iPhone: MedCalc

Survival in ESLD


Predictive value loses accuracy after 1 year so repeat yearly

Other Prognostic Factors In ESLD...

- Adverse Factors
  - Hyponatremia (<135)
  - Spontaneous bacterial peritonitis
    - 30% 1-year survival
  - Hepatoma
  - Hepatic encephalopathy
  - Continued EtOH use in alcoholic liver disease

...Other Prognostic Factors In ESLD

- Refractory ascites
- 50% 6-month survival
- Tobacco use (continuing)
- Age
- Male gender
- No affect on survival
- Variceal bleeding


Medical guidelines for determining prognosis in selected non-cancer diseases: National Hospice and Palliative Care Organization; 1995.


Hepato-Renal Syndrome

- Type I: Acute with ARF over days
  - Median survival <2 weeks
  - 100% mortality in 8-10 weeks
- Type II: ARF occurring over weeks-months
  - Median survival 6 months


COPD-BODE Index

- B: BMI
- O: Airflow obstruction (FEV1 as % of predicted)
- D: Dyspnea (mMRC dyspnea scale)
  - 0 SOB only with strenuous exercise
  - 1 SOB hurrying on level or walking up slight hill
  - 2 Walk slower than others my age or have to stop when walking on level ground
  - 3 Have to stop at about 100 yds or after a few minutes on level ground
  - 4 Too breathless to leave house or SOB when dressing
- E: Exercise capacity (6-minute walk test)
Prognosis In Heart Failure

- 1991: 6847 patients admitted to a Scottish hospital for first episode of HF
- 5-year survival 25% for men or women
- Compared to men admitted with cancer of lung, colon, prostate, or bladder or to women with cancer of lung, breast, ovary, or colon
- Prognosis in HF worse for all except lung cancer


Heart Failure With Preserved LV Function...

- HF with LV dysfunction (EF <50%) compared to HFPEF (diastolic dysfunction)
- 662 patients (France)
- 95% NYHA class III or IV
- HFPEF group significantly
  - Older
  - More likely female
  - More likely hypertensive
  - Etiology of HF less likely to be ischemic heart disease
  - Co-morbidities same except less likely to have PAD


Seattle Heart Failure Model

http://depts.washington.edu/shfm/app.php

Survival After Cardiac Arrest

- Pre-hospital
  - 2-33%
- Inpatient
  - 0-29%
- Comatose after recovery
  - 80%
- Meaningful neurological recovery
  - 10-30% of survivors

Variables Associated With Failure To Survive To Discharge S/P CPR


- “It’s OK if Dad dies from (cancer) but I wouldn’t want him to die just because his heart stopped”
- “People die (experience cardiac arrest) for a reason”
- The terminal event is (almost) always cardiac arrest, irrespective of underlying diagnosis
- If we can’t fix the underlying problem, CPR is ineffective

Anoxic-ischemic Encephalopathy After Cardiac Arrest

- Poor neurologic outcome defined by death
- persistent unconsciousness (e.g. PVS)
- severe disability requiring full care after 6 months


Strong Predictors Of Poor Outcome (False + Rate Of 0%)

- Absent pupillary light reflex 24 hrs S/P CPR or 72 hrs S/P CPR (if reflex initially intact)
- Absent corneal reflex 72 hours S/P CPR
- Absence of N20 somatosensory evoked potential of bilateral median nerves >24 hours S/P CPR

Moderate Predictors Of Poor Outcome

- PE findings (72 hours S/P CPR)
- no spontaneous eye movements or absent oculocephalic reflexes
- No or extensor only motor response to pain
- EEG findings within 1 day of CPR
- Myoclonic status epilepticus


Traumatic Brain Injury

- http://www.crash2.lshtm.ac.uk/Risk%20calculator/index.html
- Risk of 14-day mortality
- Risk of poor outcome at 6 months
  - high vs low-moderate income nation
  - age
  - Glasgow coma score
  - Pupillary reaction to light
  - Major extra-cranial head injury
  - CT scan findings

Interventions After CVA

- PEG
  - 6 month mortality 50%
  - 3 year mortality 80%
  - 78% of 6 month survivors had severe disability
- Tracheostomy
  - 1 year survivors: 56% severely disabled

Holloway et al. Prognosis and decision making in severe stroke. JAMA. 2005;294(6):725-33

Mortality Risk For NH Residents With Advanced Dementia

- 222,000 NH patients with advanced dementia
- 6 & 12 month survival after MDS obtained
- NHPCO dementia criteria simulated with MDS data
  - 53% 6-month mortality


Causes Of Death In Dementia And Other Neurogenerative Diseases

- Infections
- Pneumonia
- UTI
- Cutaneous
- Malnutrition
- Not starvation

Predictors Of Death In End-stage Dementia

- Hospitalization for pneumonia
  - 53% 6-month mortality
- New hip fracture
  - 55% 6-month mortality

PPSv2

- Read horizontally at each level for best fit
- Left side dominance
- Score in 10% increments only using best fit

PPS In Prognostication


www.ePrognosis.org

Division of Geriatrics, University of California, San Francisco. 2012.

The IDT and Prognosis

- Patient and Family
- Nursing
- CHHA’s
- Social Work
- Chaplains
- Volunteers
- Physicians
  - Primary MD
  - Hospice MD
  - Specialists
- Other (e.g. RD, PT, OT, ST)

Certification/Recertification Tool

- Chronological view of decline
- Initiated upon admission
- Case Managers complete
- Facilitates discussion during IDT
- Improves awareness of indicators of prognosis

Categories

- PPS, FAST
- ADL’s
- Weight, MAC, BMI, visual changes
- Oral intake (type and amount)
- Presence of new or poor healing pressure ulcers
- History of falls
Categories, con’t

- Medication changes
- Mental status changes
- Fatigue and sleep
- ED visits or hospitalizations
- Other

Just When You Think You’ve Got It!

- Mr. K: 82 yr old male
- History: COPD, CAD, CHF, HTN, Dementia
- Week history of dyspnea worsening 2 days prior to hospitalization.
- After trial of BIPAP mechanical ventilation initiated.
- Multiple diagnostic studies completed throughout July 2011.

Mr. K

- Referred to Hospice for terminal extubation at home
- Goals of care: peaceful death at home
- Coordination of care:
  - Hospital MD’s
  - Hospital Staff
  - Hospice Respiratory Therapist
  - Critical Care Transport Team

Mr. K

- Care conference at hospital
- Upon arrival home
  - Initiation of Morphine and Midazolam SQ infusions
  - Extubation by RT
  - Initiation of BIPAP with transition to oxygen mask

Mr. K

- Next 8 Weeks:
  - Oxygen use intermittent
  - Ambulating with cane
  - Eating small meals
  - Morphine Sulfate liquid as needed
  - Engaging interactions with Hospice CM
  - October 10, 2011
  - Mr. K passed peacefully in his sleep

Mr. K

- 2 Hours Later:
  - Transitioned to nasal cannula
  - Oxygen saturation 95%
  - Patient arousable, resting comfortably
  - Prognosis discussion by Hospice MD
- Next Day:
  - Midazolam discontinued
  - Morphine rate reduced
  - Taking bites of oatmeal
What tormented Ivan Illych most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and that he only need keep quiet and undergo a treatment and then something very good would result."

The Death of Ivan Illych*  Leo Tolstoy, 1886.

Conclusions

- Clinician has a duty to prognosticate
- accurately
- openly
- Can be evidence-based
- We tend to be optimistic
- Data exists to guide process
- HOWEVER: occasionally we are not right!

Mark Blum  
marktpmg@yahoo.com  
(916) 425-1794

Dawn Lambie  
dlambie@bristolhospice.com  
(916) 782-5511