Prognostication

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I have nothing to disclose

Objectives

- Understand why the skill of prognostication is necessary
- Identify tools available to assist in developing prognostication skills
- Identify physical, biological and psycho-social parameters that may influence prognosis



Basically we are not good at this...

Studies

- > 2000 BMJ Article:
- 343 Physicians provided survival estimates for 468 patients
- Median survival was 24 days
- > 20% of predictions were accurate
- 63% were overly optimistic
- > 17% were overly pessimistic
- Studies over the years have had similar results
- Recent study showed the closer the doctor is to the patient the less likely they were to predict prognosis accurately (over optimistic)

History

In the 19th century diagnosis, treatment and prognosis recognized as the three great clinical skills in medicine.

Over the past 100 years, prognosis gradually gave way to treatment as the core clinical skill next to diagnosis.



Why do we need to reclaim this skill?

- To provide patients and their families with information so they can set goals, priorities, and expectations of care
- To help patients develop insight into their dying
- To assist clinicians in their decision-making
- To establish patients' eligibility for care programs, including timely referral to hospice

Definition

 Prognosis is defined as the 'relative probabilities of the various outcomes of the natural history of the disease'

Be aware of probabilities vs possibilities

5 Ds of Prognostication

- Disease progression/recurrence
- Death
- Disability/Discomfort
- Drug Toxicity
- Dollars



Disease Progression

- How quickly will the ascites reaccumulate?
- With or without treatment what will happen?
- Is the treatment for "cure" or "control" (Many heart failure patients will say I "had" heart failure last year...)

Death

How long have I got?



Disability/Discomfort

- Will I walk again?
- Will I be in pain?
- Will I be able to go back to work?
- Will I be able to care for myself/my family

Drug Toxicity

- Will I get addicted to morphine?
- What are the side effects of the medications for the disease?
- Are the side-effects worse than the disease
- Response rates to the treatment

Dollars

- What is the overall expense to the patient?
- To the system?
- Choosing Wisely: right treatment, right patient at the right time?
- Are we doing it because we do not know how not to do it?

Prognostication Norms

- Do not make predictions
- Keep what predictions you do make to yourself
- Do not communicate predictions to the patient unless asked
- Do not be specific
- Do not be extreme
- Be optimistic

Four Basic Trajectories

- Sudden Death (trauma, accidents, Cardiac Arrest, PE)
- Progressive decline with accelerated end (Cancer)
- Progressive decline punctuated with exacerbations (CHF, ESRD, COPD)
- Long gradual decline (Dementia/Stroke/Parkinson's)
 Common pathway: anorexia/cachexia and eventual coma



Illness trajectories

Four Basic Paths

Two Skills of Prognostication

Formulating the prediction (i.e.Foreseeing)

- Communicating the prediction to the patient, family or other medical professionals (i.e.Foretelling)
- These skills are largely ignored in medical education. Usually covered in "Breaking Bad News" session.

Clinical Prediction of Survival Problems

- One relies on experience of similar cases and having a reliable memory
- Subject to cognitive biases: framing effect (selecting a different prognosis depending on how the information is obtained) Anchoring (too much weight on one piece of information, Confirmation Bias (seeking information that only reinforces the initial choice, Selective Recall (remembering only significant and outlier cases)

CPS consistently overestimates survival by 45%

Interesting

- The greater the experience of the doctor the greater their prognostic accuracy
- The stronger the doctor-patient relationship, the lower the prognostic accuracy



What should I do now?



Factors associated with survival

- Age, Gender, Marital Status
- Tumor Factors: primary site, histology, stage
- Psychological well being
- Performance status: has been the most studied and consistently shows an association with survival duration.

Tools

Eastern Cooperative Oncology Group-ECOG PS
 Karnofsky Performance Status Scale-KPS
 Palliative Performance Scale-PPS

Performance Status	Definition	
0	No symptoms; normal activity level	
1	Symptomatic, but able to carry out normal daily activities	
2	Symptomatic; in bed less than half of the day; needs some assistance with daily activities	
3	Symptomatic; in bed more than half of the day	
4	Bedridden	

ECOG-PS

Used for Cancer patients

ECOG-PS

 Has been shown to be predictive of survival in advanced cancer

KPS

KARNOFSKY PERFORMANCE STATUS SCALE KPS scale

Able to carry on normal activity and to work: no	100	Normal no complaints; no evidence of disease.		
special care needed.	90	Able to carry on normal activity; minor signs or symptoms of disease.		
	80	Normal activity with effort; some signs or symptoms of disease.		
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active wo		
	60	Requires occasional assistance, but is able to care for most of his personal needs.		
	50	Requires considerable assistance and frequent medical care.		
Unable to care for self; requires equivalent of	40	Disabled; requires special care and assistance.		
institutional or hospital care; disease may be progressing	30	Severely disabled; hospital admission is indicated although death not imminent.		
rapidly.	20	Very sick; hospital admission necessary; active supportive treatmen necessary.		
	10	Moribund; fatal processes progressing rapidly.		
	0	Dead		

KPS vs ECOG





- Developed in the '40s
- Used to measure effects of chemotherapy on performance status
- Predictor of oncological outcomes
- KPS <50% was associated with shorter survival</p>

KPS

National Hospice Study in the early 80's involved 1000 patients

- Each increase in KPS level (eg 10-20) accounted for approximately 2 weeks of remaining life span.
- > 10-20: 2 weeks
- > 30-40: 7 weeks
- 50: 12 weeks
- Problems: wording of the scale. Lower scores indicate when hospitalization is necessary. Something that was common in the 50's

Palliative Performance Scale (PPS)

%	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Level of Conscious
100	Full	Normal activity, no evidence of disease	Full	Normal	Full
90	Full	Normal activity, some evidence of disease	Full	Normal	Full
80	Full	Normal activity with effort, some evidence of disease	Full	Normal or reduced	Full
70	Reduced	Unable to do normal work, some evidence of disease	Full	Normal or reduced	Full
60	Reduced	Unable to do hobby or some housework, significant disease	Occasional assist necessary	Normal or reduced	Full or confusion
50	Mainly sit/lie	Unable to do any work, extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
40	Mainly in bed	Unable to do any work, extensive disease	Mainly assistance	Normal or reduced	Full, drowsy, or confusion
30	Totally bed bound	Unable to do any work, extensive disease	Total care	Reduced	Full, drowsy, or confusion
20	Totally bed bound	Unable to do any work, extensive disease	Total care	Minimal sips	Full, drowsy, or confusion
10	Totally bed bound	Unable to do any work, extensive disease	Total care	Mouth care only	Drowsy or coma
0	Death	—	-		-

PPS

- Developed in Canada to address the limitations of the KPS
- Added categories for oral intake and conscious levels
- PPS 10-20%-median survival 6 days
- > PPS 30-50%-41 days
- PPS performs well as a predictor of prognosis in heterogeneous hospice population and performs well for NH residents and patients with non-cancer dx.

Symptoms

- Onset and severity of certain symptoms is associated with poor survival
- Anorexia, weight loss, xerostomia, dysphagia, dyspnea

Patients with KPS >50% and non of the 5 key symptoms had a median survival of 6 months and 10% had survival of 1.5 years

Symptoms

- Patients with similar performance status and all 5 of the symptoms had a median survival of 2 months and a 10% chance of living for 9 months
- In patients with a poor performance status, symptoms had less of an absolute impact on survival
- KPS of 10-20% with symptoms 2 weeks and without symptoms 8 weeks
- Strongest association between symptoms and survival is for anorexiacachexia
- Unfortunately, this leads the uninformed to the discussion about feeding tubes

QOL

- Physical Symptoms
- Function
- Psychological State
 Family/Social Relationships
 Socio-economic Status

Quality of Life (QOL)

- Fatigue, Insomnia, frequent pain, "outlook"
- Most commonly attributed to high distress
- Low symptom distress did not guarantee long-term survival but patients with high symptom distress virtually all had short survival times

QOL

Does the patient's QOL actively influence the natural history of the disease and therefore survival or is the QOL merely a reflection of the severity of the illness progressing towards death?

Controversial

Prognosis in Non-Cancer Diagnoses

Difficult because of the variable nature of the illnesses, less predictable decline

 Barrier for such patients to access appropriate end of life care

Non-Cancer Pts 4 Things

- Pathology, clinical and environmental factors are relevant
- Performance status is still a useful measure of survival
- Emotional and mental status of pt and family influence the length of survival
- Rate of disease progression, rate of hospitalizations, development of new complications are important

Nutritional Status

>10% weight loss over 6 months
 Decreased serum albumin <2.5
 Associated with poor performance status
 Highly predictive of short-term mortality

COPD

- Dyspnea at rest, poor activity tolerance
- > FEV1 <30% predicted</p>
- Right heart failure/phtn
- Hypoxemia at rest on O2
- Hypercapnia pCO2>50mmHg
- Weight Loss >10% over 6 months
- Resting tachycardia



Heart Failure

- Age >64
- NYHA Class IV
- » EF 20%
- Systolic hypotension
- Low Na, high BUN
- Nutritional status (Albumin)
- Uncontrolled arrhythmias
- Optimally treated with diuretics and vasodilators
- LVAD use, defibrillators etc, make prognostication challenging

ALS

- Median survival 3-5 years (range 6 mo-20 yrs)
- 50% in 2.5 yrs-89% in 7 yrs
- Lower limb onset=longer survival
- > Upper limb or bulbar=shorter survival
- Younger onset-longer
- Area of residence=mountainous, shorter
- » Vital Capacity <50% of predicted</p>
- Survival worse with poor nutritional status
- After PEG insertion=6-7mo survival



ALS use of BiPap

- Study of 122 patients. All patients offers BiPap at VC <50%
- Group 1: BiPap used more that 4 hours/d (14 mo)
- Group 2: Did not tolerate BiPap and used it <4h/d(7 mo)</p>
- Group 3: Refused BiPap (4.6 mo)
- Study suggests that all ALS pt be offered BiPap
- Riluzole 100mg/d prolongs survival by about 2 months

ESRD

Despite advances, ESRD patients have a mortality rate of apprx 10%-23% per year. Mainly due to the high co-morbid conditions of cardiovascular and peripheral vascular disease

Dementia

Functional Assessment Scale (FAST)

1	No difficulty either subjectively or objectively.
2	Complains of forgetting location of objects. Subjective work difficulties.
3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity. *
4	Decreased ability to perform complex task, (e.g., planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc.)
5	Requires assistance in choosing proper clothing to wear for the day, season or occasion, (e.g. pt may wear the same clothing repeatedly, unless super- vised.*
6	Occasionally or more frequently over the past weeks. * for the following A) Improperly putting on clothes without assistance or cueing . B) Unable to bathe properly (not able to choose proper water temp) C) Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue) D) Urinary incontinence E) Fecal incontinence
7	 A) Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview. B) Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview C) Ambulatory ability is lost (cannot walk without personal assistance.) D) Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.) E) Loss of ability to smile. F) Loss of ability to hold up head independently.
*Scon Psych	ed primarily on information obtained from a knowledgeable informant. opharmacology Bulletin, 1988 24:653-659.

Domino Effect

Sentinel Events

- Bacteremia
- ⇒ MI
- ▷ PE
- Amputation
- Aspiration PNA
- > Dysphagia
- Pressure ulcers

Communicating Prognosis

Difficult and evidence suggest we are not good at this type of communication

 Clinicians tend to underestimate patients' information needs and overestimate how much they understood about they illness and its likely outcome.

Patients are twice removed form reality. Prognosis is not formulated accurately and it is communicated even more optimistically.

Why Communicate

- Patient may want to make the most of the time remaining, finish uncompleted tasks and prepare for their own death.
- Studies found that giving an explicit terminal diagnosis reduced admission rates to the hospital and increased the chance of dying at home.

How to Communicate

- Play it straight (be honest and direct)
- Make it Clear (information that is understandable)
- Show you Care (empathetic words and non-verbal communication)
- Give Time (pt shouldn't feel rushed)
- Pacing (provide info at a rate that is appropriate to the individual)
- Stay the Course (convey that you will not abandon the pt as the illness progresses)

Communicate

Prepare for the discussion (check the facts, environment)

- Relate to the Person (develop rapport)
- Elicit pt and care-giver preferences (what do they know, what and who to they want to know)
- Provide info
- Acknowledge Emotions and Concerns
- Foster Realistic Hope (not a binary concept)
- Encourage questions
- Document

ALWAYS

 Discuss code status in a realistic and understandable way and express your concerns.
 Make it a dialogue, not "what do you want?"

Make it a dialogue, not "what do you want?"

References

- Oxford Textbook of Palliative Medicine 5th Ed.
 Oxford University Press Pg 81-104, 2015
- National Institute of Neurological Disorders and Stroke 2016. <u>NINDS.NIH.Gov</u>
- Palliative Care Network of Wisconsin, Fast Facts 2016. <u>mypcnow.org</u>