Foreseeing and Foretelling-

Can we improve our skills in formulating and giving a prognosis in Palliative Care?

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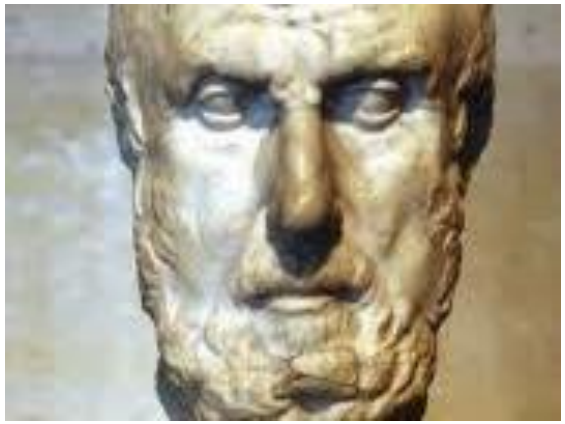
Objectives

- To define prognosis and its spheres
- To review the history of medical prognosis
- To consider the reasons for giving a prognosis in Palliative Care
- To understand the obstacles to giving a prognosis
- To evaluate the current prognostic tools
- To consider the future for prognostication.



It seems to be highly desirable that a physician should pay much attention to prognosis. If he is able to tell his patients when he visits them not only about their past and present symptoms, but also tell them what is going to happen, as well as to fill in the details they have omitted, he will increase his reputation as a medical practitioner and people will have no qualms in putting themselves under his care.

The Book of Prognostics : Hippocrates 4th Century BC

History of prognosis in medicine

- Traditionally one of 3 cardinal skills.
- “Mantic” and “Semiotic”(Magic vs Clinical signs)
- Inverse relationship with therapeutics
- The “renaissance” of prognosis

Definition of prognosis

Prognosis is an epidemiological term defined as the relative probabilities of the various outcomes of the natural history of a disease and can be made about any outcome of an illness.

The Domains of Prognosis

- Disease progression/recurrence
- Disability/discomfort
- Drug toxicity
- Dollars
- Death

Fries JF, Erlich GE(eds) Prognosis. Contemporary outcomes of disease, 1981.

Typical examples of the domains in practice

- **Disease progression-**It is likely that the cancer will slowly progress within the next year
- **Disability**-Not everyone with cancer gets pain
- **Drug toxicity**-30-60% of people taking opiates will develop nausea but this will usually subside within 10 days
- **Dollars**-It is likely that this patient has more than 2 but less than 9 weeks to live, and so qualifies for CMI funding
- Time to **Death.** Pancreatic cancer has a 5 year survival of 5 %. Median survival is 4-6 mths.

Some of the reasons for formulating a prognosis in palliative care

- Patients' and families' needs, goals and priorities, ACP
- Facing dying, preparing
- Clinical decision-making
- Eligibility for care, programmes, policies
- Communication between health professionals

Physicians' 'norms of prognostication'

- Avoid if possible ("structured silence")
- Don't discuss unless asked
- Be vague
- Don't be extreme
- Be optimistic!

Christakis N and Glare P "Predicting survival in patients with advanced disease" in the Oxford Textbook of Palliative Medicine 2004.

Reasons why HPs may not give an accurate prognosis

- Lack of training

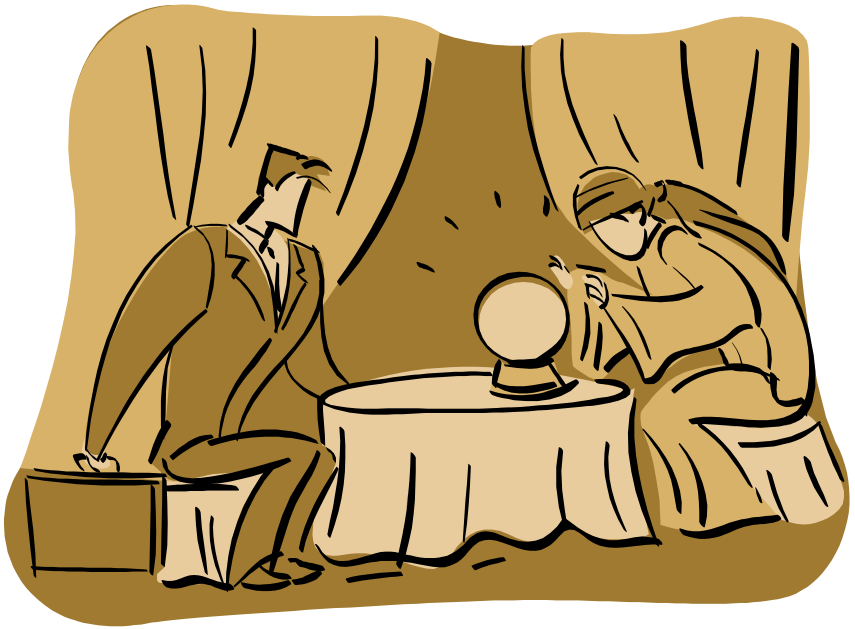
Stress

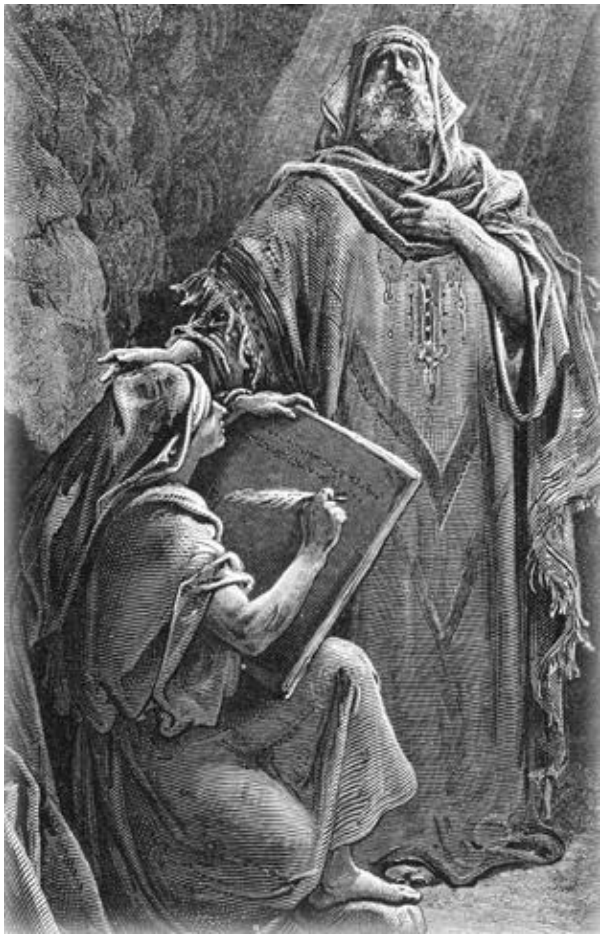
- No time to attend to patient's emotional needs
- Fear of a negative impact on the patient: the self-fulfilling prophecy
- Uncertainty
- Requests from family to withhold information
- Feelings of inadequacy about lack of treatments
- Hope that another (e.g.Haematology) drug might work better
- Fear of being judged by colleagues/patients/families
- The difficulty of balancing accuracy, honesty,& hope simultaneously

Hancock K et al; Truth telling in discussing prognosis in advanced life-limiting illness: a systematic review. Palliat Med Sept 2007 21:507-17

Prognostic anecdotes

- He said “I can’t possibly say. I’m not God”
- “Only 2 people can give you a prognosis: the executioner and a doctor in an American soap.”
- “Just go home and make the most of your remaining time.”(And other variations)
- “Mate, you’re on the cliff face, hanging on by your fingernails and you could fall off at any time.”
- “But the surgeon said he’d got it all (the cancer) and that I’d have about 18mths of quality time before it came back” (2 mths later he was dying.)
- “Doctor am I dying?” “Not on my watch!” (patient died).





2 components to prognosis- Foreseeing and Foretelling

How to formulate a prognosis

- Refuse/guess
- Get an ‘expert’ opinion- specialist or textbook
- Use population data
- Use Evidence Based Medicine(internet search for systematic review or clinical trial)
- Use clinical experience: subjective judgement
- Use a prognostic scoring tool, based on actuarial judgement and clinical experience

Prognosis in early stage cancer

- Disease- based, type of tumour, histology, T N M, tumour markers, receptor status,
- Likely responsiveness to treatment
- 5 year survival with or without treatment
- Oncologists/Physicians tend to be over-optimistic in their formulating and communicating a prognosis.
- Patients can generally accept long term forecasts.

  Steinhauser K, Christakis NA-Factors considered important by patients, family, physicians and other caregivers. JAMA 2000 284(19):2476-82

Prognosis in advanced cancer

- Median survival by major primary sites. *Christakis N, Glare P. Prognosis in Advanced Cancer. 2008. Oxford.*
- A dynamic process
- As disease progresses primary diagnosis less important.
- Disease-specific factors less important
- Clinical signs and patient factors (e.g. performance status) become more important
- Rate of progression of cancer important

Validated Prognostic tools

- Palliative Prognostic score (PaP) -1999
- Palliative Performance Scale (PPS)-1999
- Palliative Prognostic Index (PPI)-1999
- Glasgow Prognostic score (GPS)-2005
- Feliu prognostic nomogram -2011
- Prognosis in Palliative Care study (PiPS)-2011

Palliative Prognostic score (PaP)

Criterion	Assessment	Partial Score
Dyspnoea	Yes No	0 1
Anorexia	Yes No	0 1.5
Karnofsky status	>30 <20	0 2.5
Clinical Prediction Survival	12 wks. 1-2	0 8.5 and several in between
Total WBC	<8.5 8.6-11	0 8.5
% Lymphocytes	20-40 <12	0 2.5
Risk Group A,B,C	Low, Med High >70%,30-70%,<30% 1 mth	Total 0-5.5, 5.6-11 >11

An example: Mrs P

- 72, oesophageal cancer , non resectable, diagnosed 6 mths previously, had radiotherapy.
- Admitted to hospice with dysphagia, anorexia, shortness of breath, carer fatigue
- PaP- Dyspnoea= 1; Anorexia= 1.5; Karnofsky= 2.5; CPS(3-4w)=6;Total WBC, high=0.5, % lymphs <11.9%= 2.5. Total score = 14 ; Therefore high risk i.e <30% chance of 1 mth.
- Family utterly shocked but had time to come to terms with her rapid deterioration and death within 3 weeks.

Factor X?

- *Phillips D, Smith D. Postponement of death until symbolically meaningful occasions ;JAMA 263, 1990; 1947-1951*

2 ethnic groups in California- Chinese and Jews

2 special holidays- Harvest Moon celebration and Passover.

In each group there was a significant dip in mortality before, and a peak in mortality after the festival period, suggesting psychological factors involved. Not reproduced subsequently.

The question about prognosis

Talking about prognosis

Clinical Practice Guidelines for communicating prognosis and end-of-life issues… Clayton et al. MJA 2007 ;186(12) 77.

PREPARED acronym

Different ways of presenting information- words, numbers, graphs. Some patients find pie charts and graphs more impersonal, clinical, cold. A time range is better than specific endpoints.

It's not what you say, it's the way that you say it!

TALKING ABOUT SEX DOESN'T MAKE YOU PREGNANT.

TALKING ABOUT DEATH DOESN'T MAKE YOU DEAD.

Non cancer conditions

- CCF- NYHA class, age>64, chest pain, breathlessness at rest, LVEF<20%,Dilated cardiomyopathy, LVF, maximal Rx
- COPD –Advanced age, dyspnoea at rest, FEV1<30%, pulm hypertension, cor pulmonale BODE index
- Alzheimer's- unable to walk unaided, hold a conversation, onset of medical complications

What is the future for prognosis?

- Targeted therapies are changing the goalposts
- New scoring systems?
- Computerized tools and APPs?
- The role of physicians?

In conclusion

- Giving a prognosis is often important
- It is difficult for good reasons, and it has limitations
- Many doctors try to avoid it or are over-optimistic
- Patients and families want prognoses with compassionate honesty
- The language we use is important
- There are many validated tools, and guidelines.
- Prognostication is a crucial skill which can be learned and taught. I think it should reclaim a place in medical curricula

References

- Christakis N, Glare P. *Prognosis in Advanced Cancer.* 2008 Oxford university Press
- Fries JF, Erlich GE(eds). *Prognosis. Contemporary Outcomes of Disease.* Bowie MD. The Charles Press 1981
- Christakis N,Glare P. *Predicting survival in patients with advanced disease* in the Oxford Textbook of Palliative Medicine 2004.
- Hancock K et al. *Truth-telling in discussing prognosis in advanced life-limiting illness: a systematic review.* Palliat Med 2007; 21:501-517
- Lund S, Stone P. *Predicting survival in advanced cancer patients.* EJPC 2013 (20):2

References contd.

- Steinhauser K, Christakis NA. *Factors considered important by patients, family, physicians and other caregivers.* JAMA 2000(19):2476-82
- Phillips D, Smith D. *Postponement of death until symbolically meaningful occasions.* JAMA 1990:263;14
- Young D,Hade E. *Holidays, Birthdays and Postponement of Cancer Death.* JAMA 2004:292(24);3012-3016
- Clayton et al *Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers.* Med J Aust 186(12):77