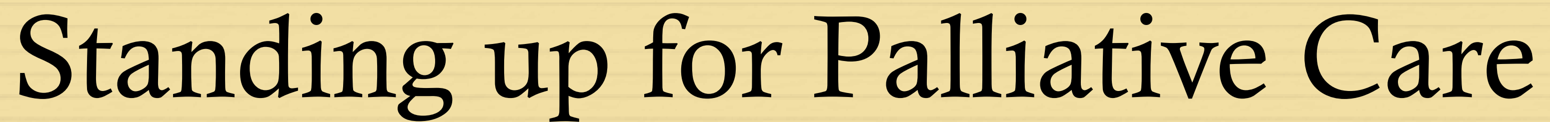
Standing up for Palliative Care



Jennifer Philip

How do we die?

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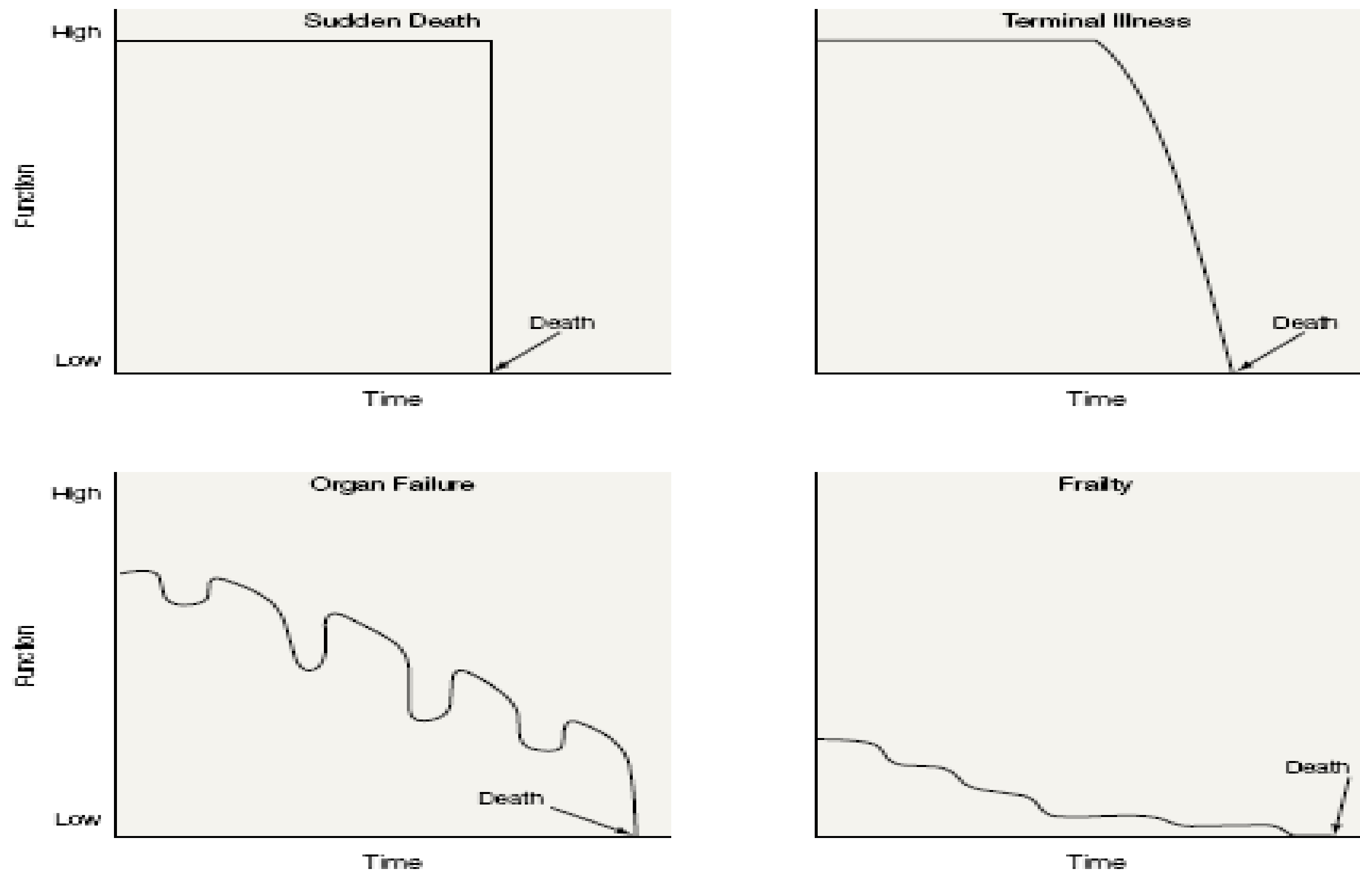
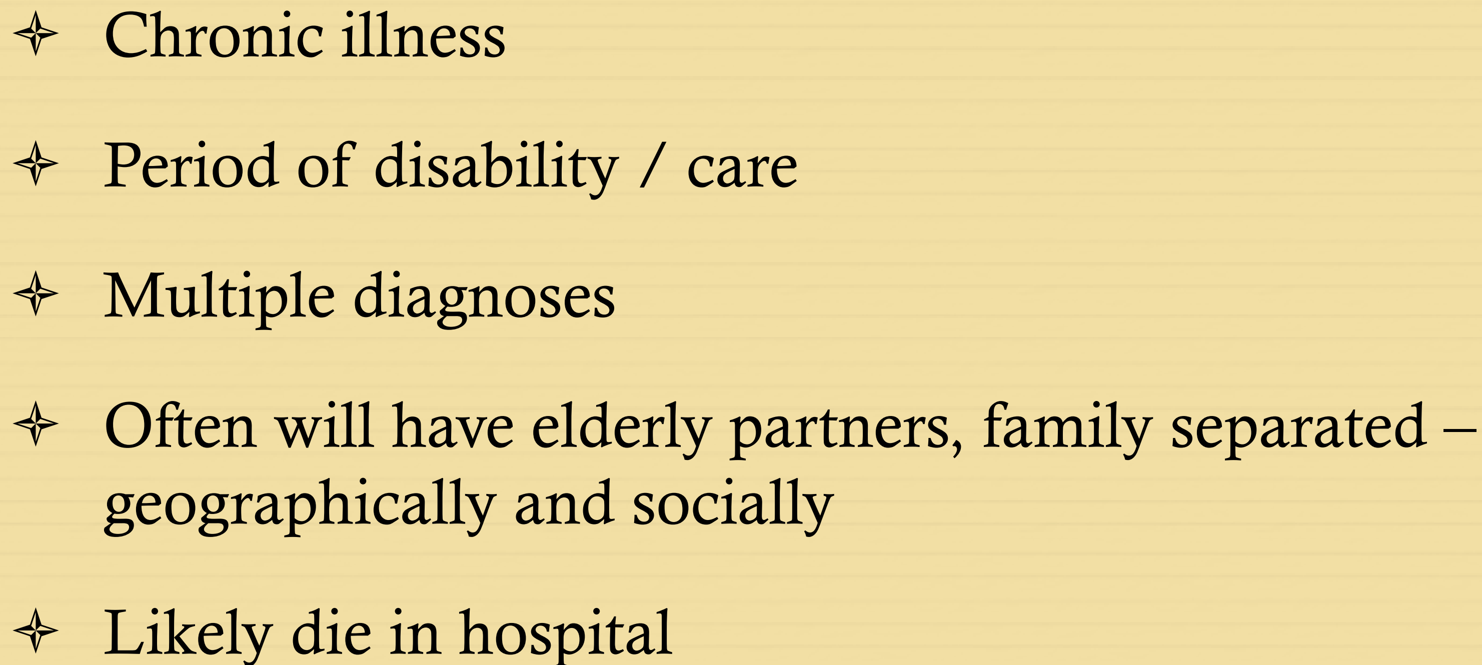
Lynn, JAMA 2003




Chronic illness
Period of disability / care
Multiple diagnoses
Often will have elderly partners, family separated – geographically and socially
Likely die in hospital

Has anyone noticed dying is becoming more complex?

Complexity of Dying

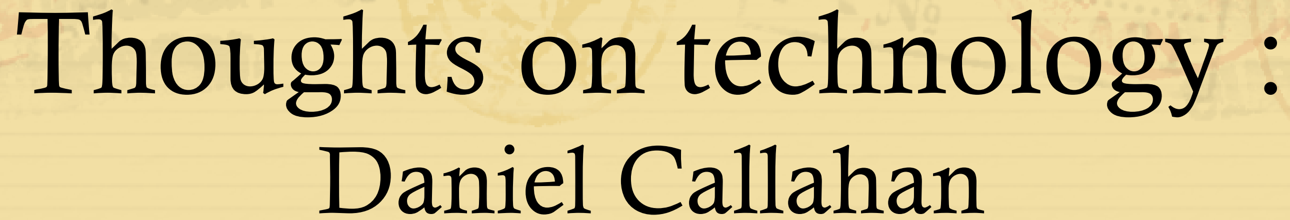
- Interventions possible, complexity and cost
- Difficulty prognosticating
- Expectations of the success of treatments by patients and families
- Multiple health care teams involved as patients navigate multiple diagnoses

Complexity of Dying

- Psychosocial issues of patients and families which impact upon care – often heightened at this time.
  - Split families
  - Substance abuse
  - Distrust of health systems
- Complexity of caring at home

Why?..

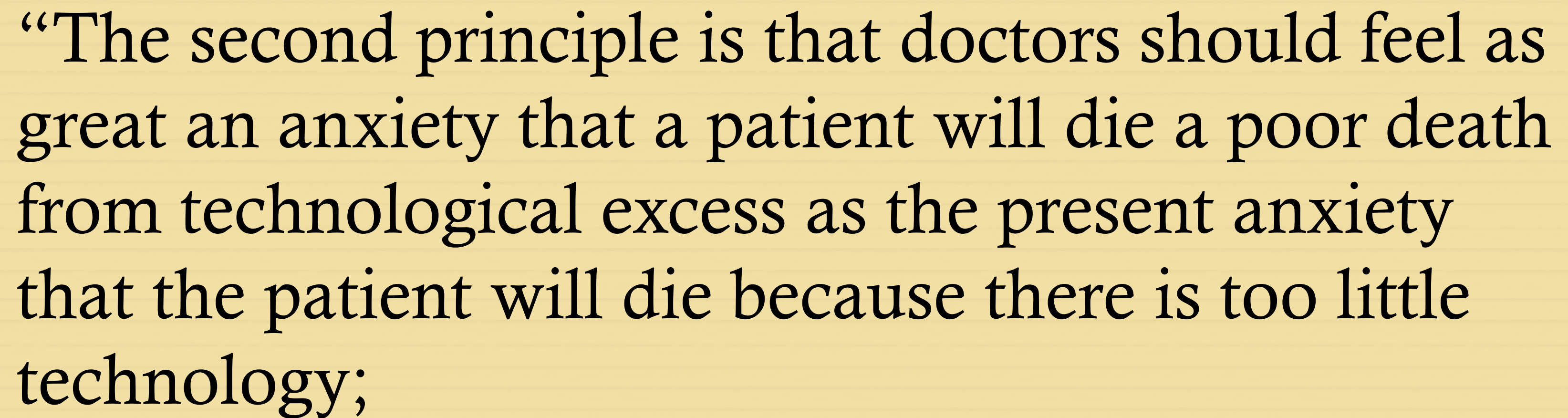
- Heightened value attributed to technology
- Always something more that can be done
- Default position of treatment in hospitals
- No treatment not presented as a viable choice
- Lack of recognition of harm of technological death



Thoughts on technology : Daniel Callahan

"The first principle is that no one should have to die a worse death as a result of medical technology than would have been the case prior to the invention of that technology.

If technology threatens to leave us worse off, and we nonetheless feel obliged to use it, we have then indeed become its slaves."



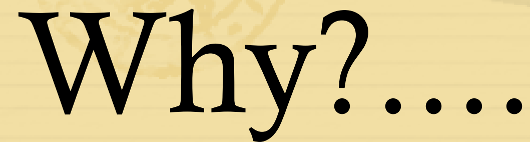
"The second principle is that doctors should feel as great an anxiety that a patient will die a poor death from technological excess as the present anxiety that the patient will die because there is too little technology;

… these dual anxieties should remain in tension with each other, neither the one nor the other being allowed to gain the upper hand."

- Subspecialisation – not confident to make a decision that covers another's area of specialisation.

"A kind of classic story… of the primary care physician they say they know the patient's dying, the patient is old, many organs are failing at the same time, this patient is dying. But along comes the cardiologist and says, "well, I'm not sure, we can still do something about the heart. And the liver guy says, well, I'm not ready to give up".

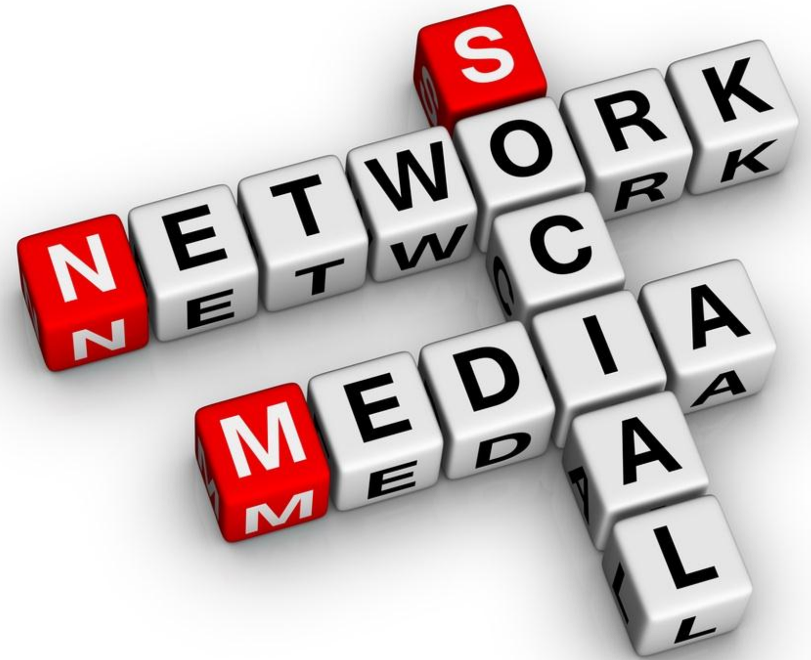
Why?....

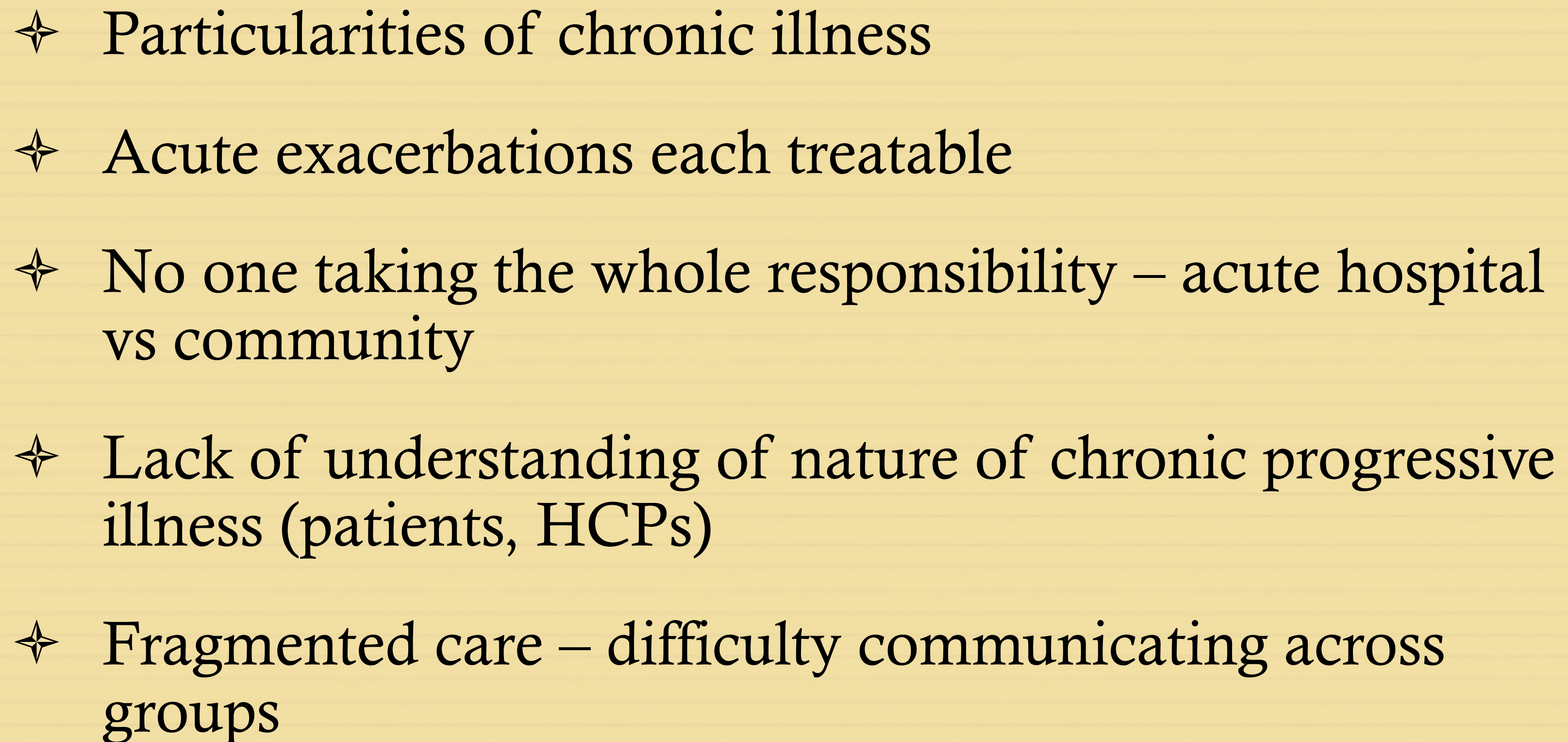


- No community discourse of end of life concerns
- Doctors and HCP reluctant, not well trained in communication , fearful will cause harm / distress.
- Lack of recognition that final phase may be important phase of life.

Why?

- Impact of media
  - Social media – literacy /perspective
  - Traditional media – marketing of science
  - Language in media and common parlance - battles to be fought.





- Particularities of chronic illness
- Acute exacerbations each treatable
- No one taking the whole responsibility – acute hospital vs community
- Lack of understanding of nature of chronic progressive illness (patients, HCPs)
- Fragmented care – difficulty communicating across groups

Glaser and Strauss

"The appropriate place of death has become firmly located outside of the community and within the hospital. Set here, it is no longer the occasion of a ritual ceremony over which the dying person presides while surrounded by friends and relatives. Instead, death has become a technical phenomenon. Dying is …seen as a medical condition. The central character at the scene of death is now not the dying person, but the doctor"

Palliative care is…

- an approach that improves the quality of life of patients and their families facing the problems associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.

  World Health Organisation 2012

What is different?

- WHO recommends embedding in health care systems
- In Australia, evolved initially in inpatient units, then community services, hospital consultancy services.

- Social development
- Regards dying as normal, and part of life
- Care goals are not disease parameters, rather are defined by the patient
- Inclusion of family in unit of care

Palliative care strengths…

- Symptom relief
- Holistic assessment of needs and potential disease responses
- Experts in Communication (patients, families, colleagues)
- Negotiation through collegiate and ethical domains
- Shared decision-making , planning and goal setting
- Improved quality of life …. Through achievement of negotiated goals

High quality evidence of benefit

- Improved symptom relief
- Improved psychological status
- Improved carer psychological status
- Reduced hospitalisation, ED presentations, LOS and death in acute hospital system
- Improved survival
- Improved well being and survival of surviving spouses.

(Higginson 2009, Temel 2010, Hudson 2011, Christakis 1998, Philip 2013, Temel 2013, Rosenwax 2006)

Yet palliative care not fully used…

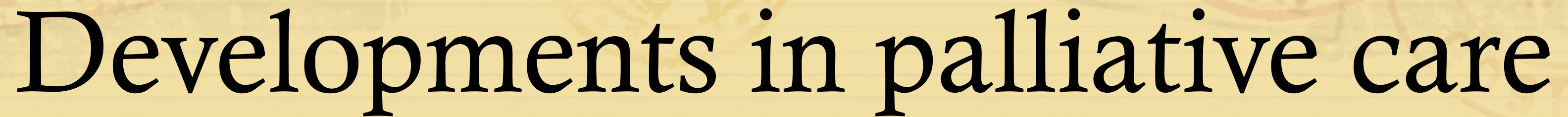
Yet not fully utilised.

- Seen as EOL only – bed based model
- PC seen as elective (parallel faith in possibilities of technology)
- Difficult decision making – often uncertainty or not confident, and, potential threat of family anger

Yet not fully utilised..

- Substantial disquiet broaching need : doctors, fearful of patient and family reactions (vs what patients and families say)
- Communication task – takes time effort and skills
- Easier to continue treatment rather than have difficult conversation

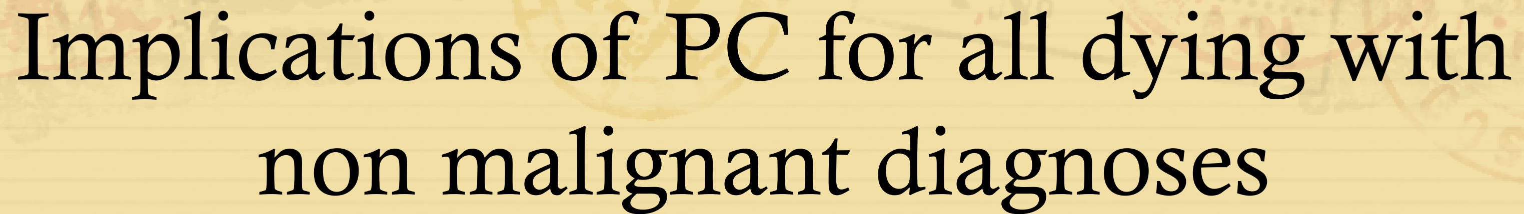
Developments in palliative care



- Expansion of consult models of care
  - Outpatient care
  - Chronic disease models of palliative care
- Earlier engagement
- Enhancement of communication training and skills – marketing
- Training in palliative care approach (PC4U)

Challenges

- Huge demand
- Growing cohort of people with non-malignant disease



Implications of PC for all dying with non malignant diagnoses

- UK: secondary analysis of data from the Regional Study of Care for the Dying
- 1/3 (243/720) of cancer patients SPC referral scored > median on three symptom measures.
    - No. of symptoms (eight or more),
    - No. of distressing symptoms (three or more)
    - No. symptoms lasting > 6/12 (three or more).
- 269/1605 noncancer patients (16.8%) fulfilled these criteria.

Addington-Hall 2008

Implications….. Cont'd

- Therefore: estimated that 71 744 people dying from nonmalignant disease in England and Wales each year may require SPC
- Represent an increase of 79% in caseload
- Conservative as matched to just 1/3 of Ca SPC referred Addington-Hall 2008
- A different model of palliative care required to be sustainable

Further challenges

- Funding
  - ABF model : no model for funding consult services
  - ABF – funds direct clinical time only, no teaching / research etc
  - Difficulty with private insurance funding for PC
- Community models of care provision
- Planning and discussing care in advanced illness (ACPs) and willingness to engage.
- Advocacy – thinking through public education strategies

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