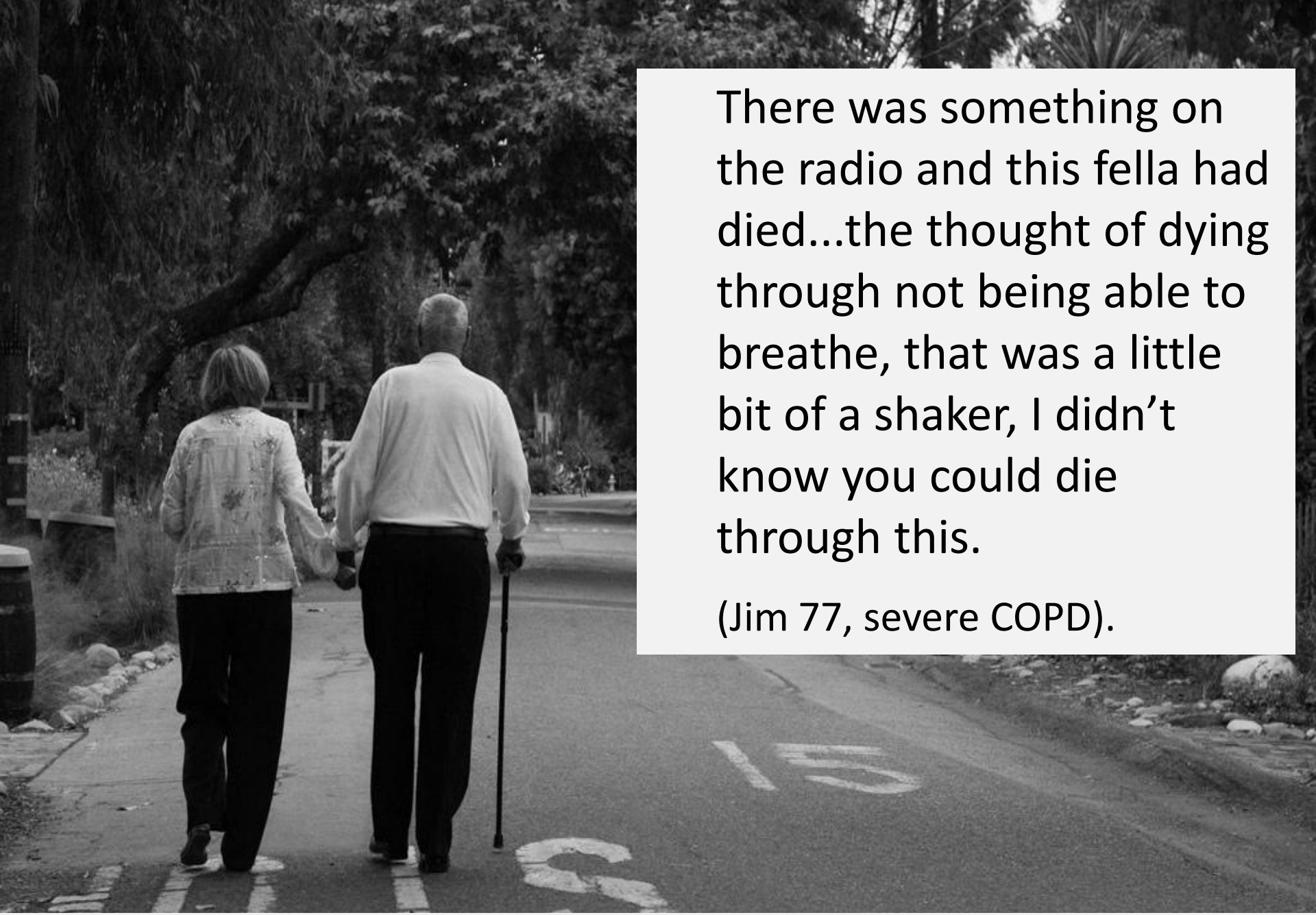

Palliative care beyond cancer:
where to from here?

The worst part I think is getting up in the morning. It takes me ages…I think it's the tiredness that affects me most. I sit on the edge of the bed and I put my slippers on. I've to sit on the bed a bit while I trot off to the bathroom…I just brush my teeth, wash my hands and then I've to sit on the toilet seat to get my breath back to pull the curtains back in the bedroom. And then after I've pulled the curtains back then I've got to sit down again on the bed….I just dread the mornings really (Mary, 85, HF)



Barnes S, Gott M, et al. Prevalence of symptoms in a community-based sample of heart failure patients. *J Pain Symptom Manage* 2006 Sep;32(3):208-16.



There was something on the radio and this fella had died...the thought of dying through not being able to breathe, that was a little bit of a shaker, I didn't know you could die through this.

(Jim 77, severe COPD).

Gardiner C, Gott M et al. Living with advanced COPD: patients concerns regarding death and dying. *Palliative Medicine* 2009. 23(8) 691-697

*The doctor decided he needed a stomach x-ray because his stomach was very bloated....**so less than an hour before he died poor man there were three of us trying to lift him onto an x-ray plate**. ..He was talking to me and I knew that he knew he was dying, there was no two ways about it (Heather, carer of HF patient).*



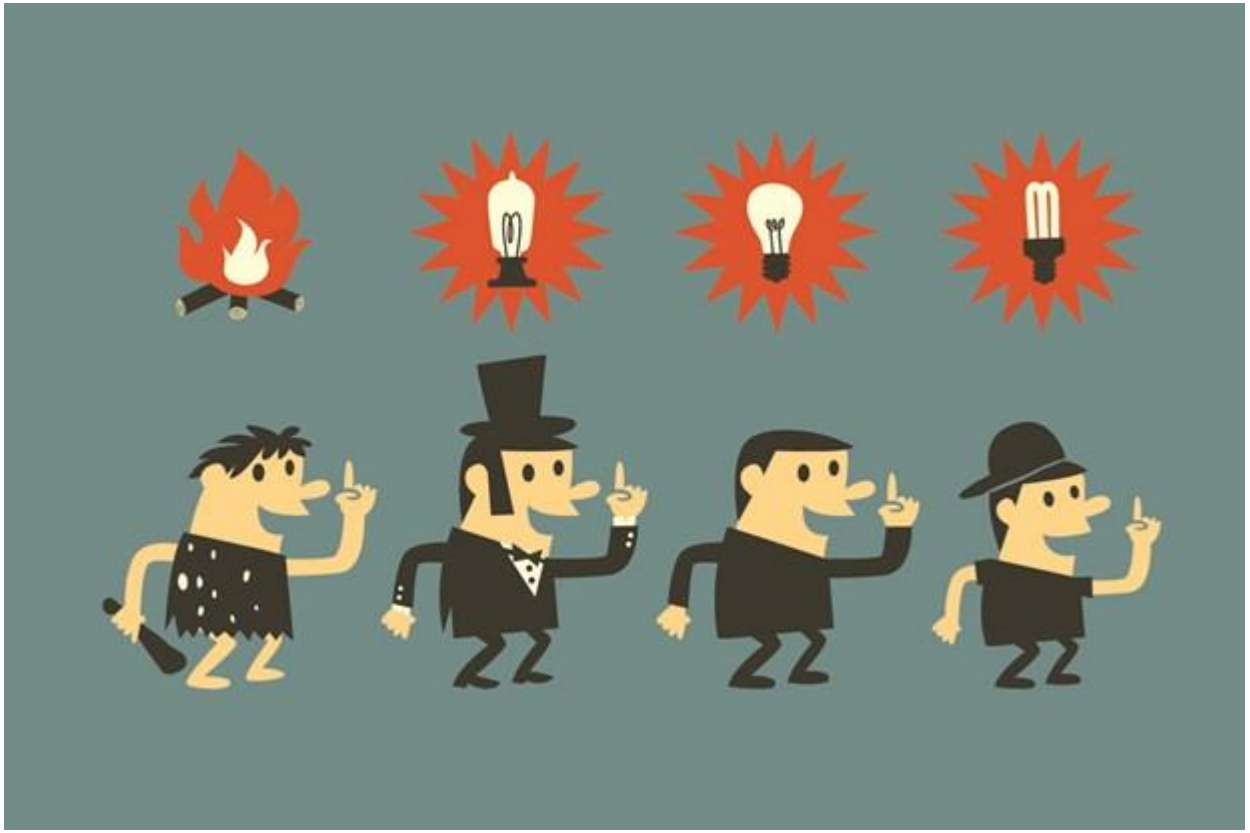
Small N, Barnes S, Gott M, Payne S, Parker C, Seamark D, Gariballa S. Dying, death and bereavement: a qualitative study of the views of carers of people with heart failure in the UK. *BMC Palliative Care* 2009, 8:6.



We know that people with conditions other than cancer die with comparable levels of palliative care need, but receive lower levels of palliative care.


The question is: what do we do about it?


KEEP
CALM
AND
SHOW YOUR
WORKING OUT

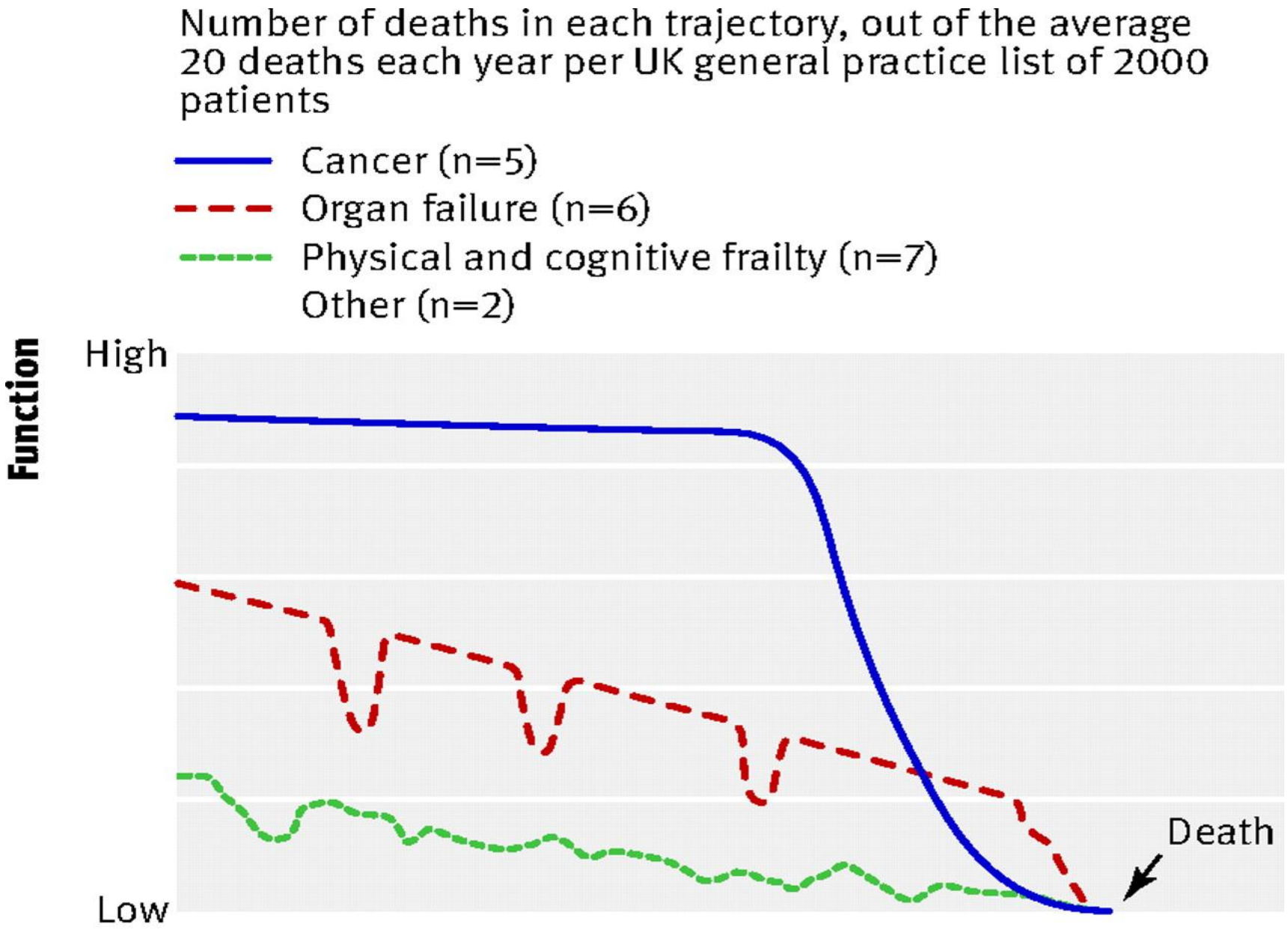


1. Identify when in the disease trajectory specialist and ‘generalist’ palliative care should intervene

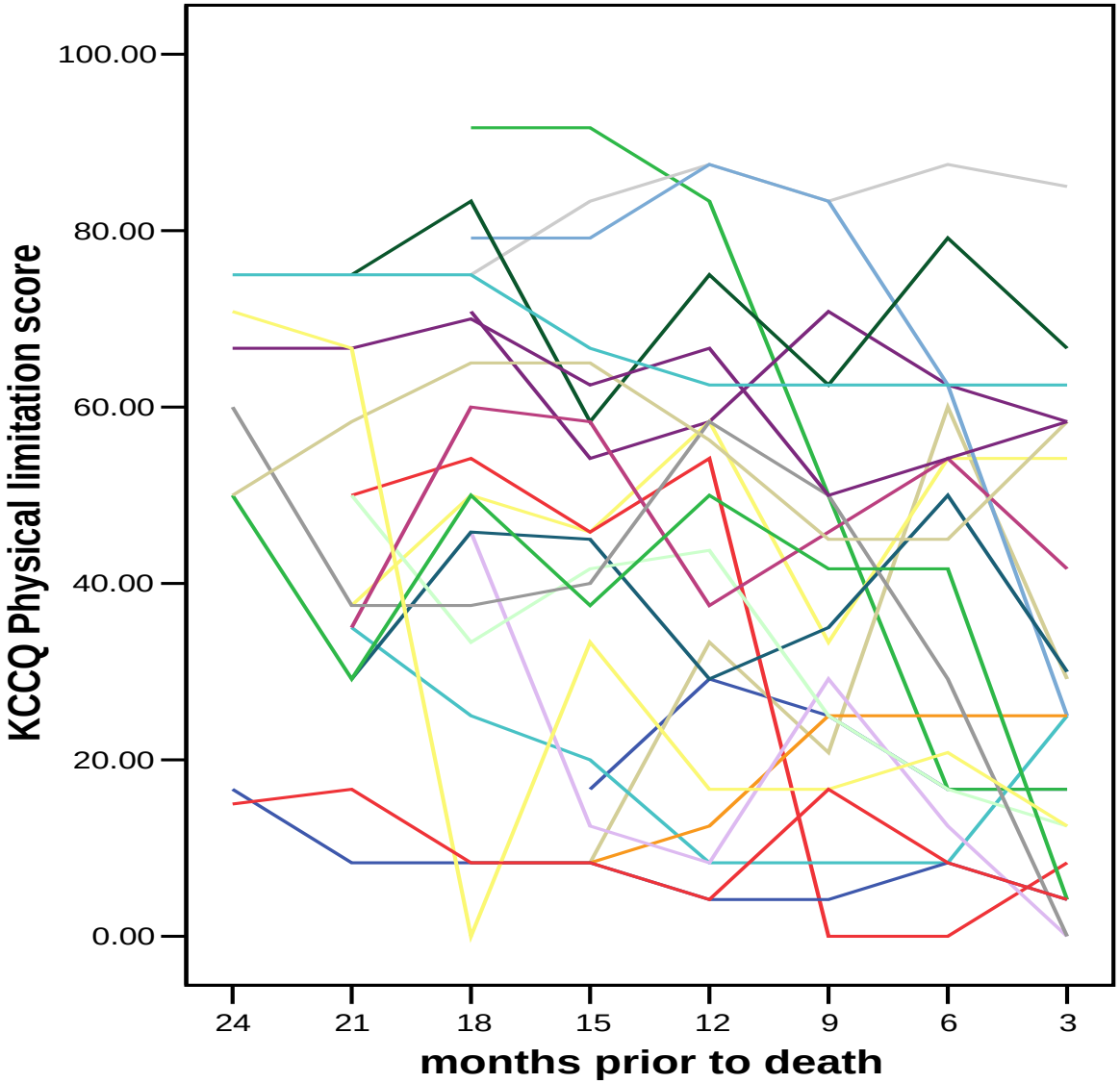
A longitudinal study to identify the palliative care needs of older people with heart failure and their family carers

Gott M, Barnes S, Payne S, Parker C, Small N, Seamark D, Gariballa D.

- 542 people with heart failure (New York Heart Association (NYHA) stages II-IV) and 213 of their informal carers were recruited from primary care practices in four areas of the UK completed Qol and service use questionnaires every 3 months for 2 years or until death
- A subset of 43 patients participated in semi-structured interviews
- Interviews with bereaved carers were arranged 3 months after the death of participants.
- Phase II involved gathering qualitative data from nine focus group discussions with healthcare professionals working in primary care.



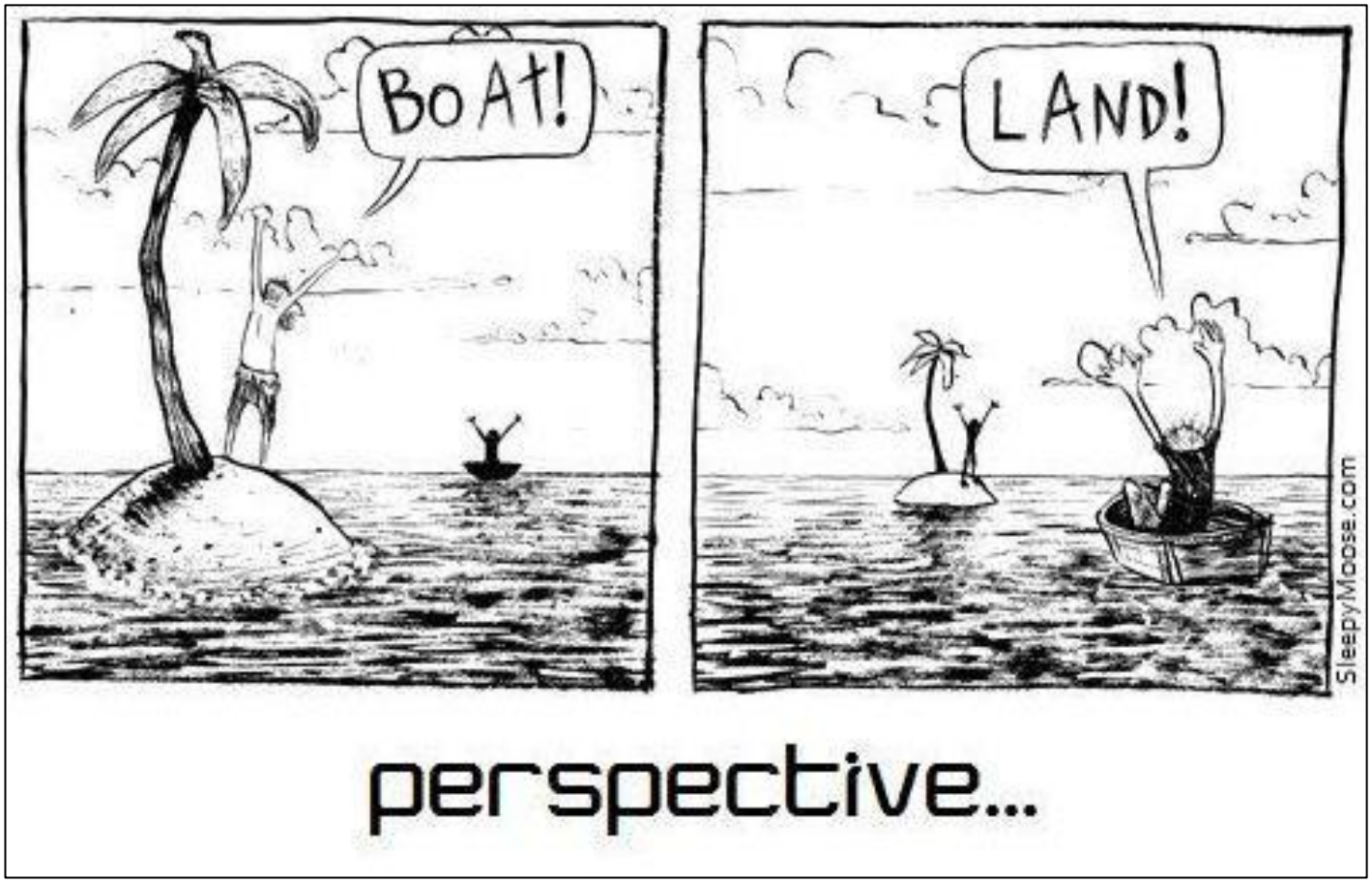
Murray, Scott A., et al. "Illness trajectories and palliative care." *International Perspectives on Public Health and Palliative Care* (2013): 30.



Gott, M., et al. Dying trajectories in heart failure. *Palliative Medicine* 21.2 (2007): 95-99.

Additional barriers to palliative care provision (& to living/dying well with Heart Failure)

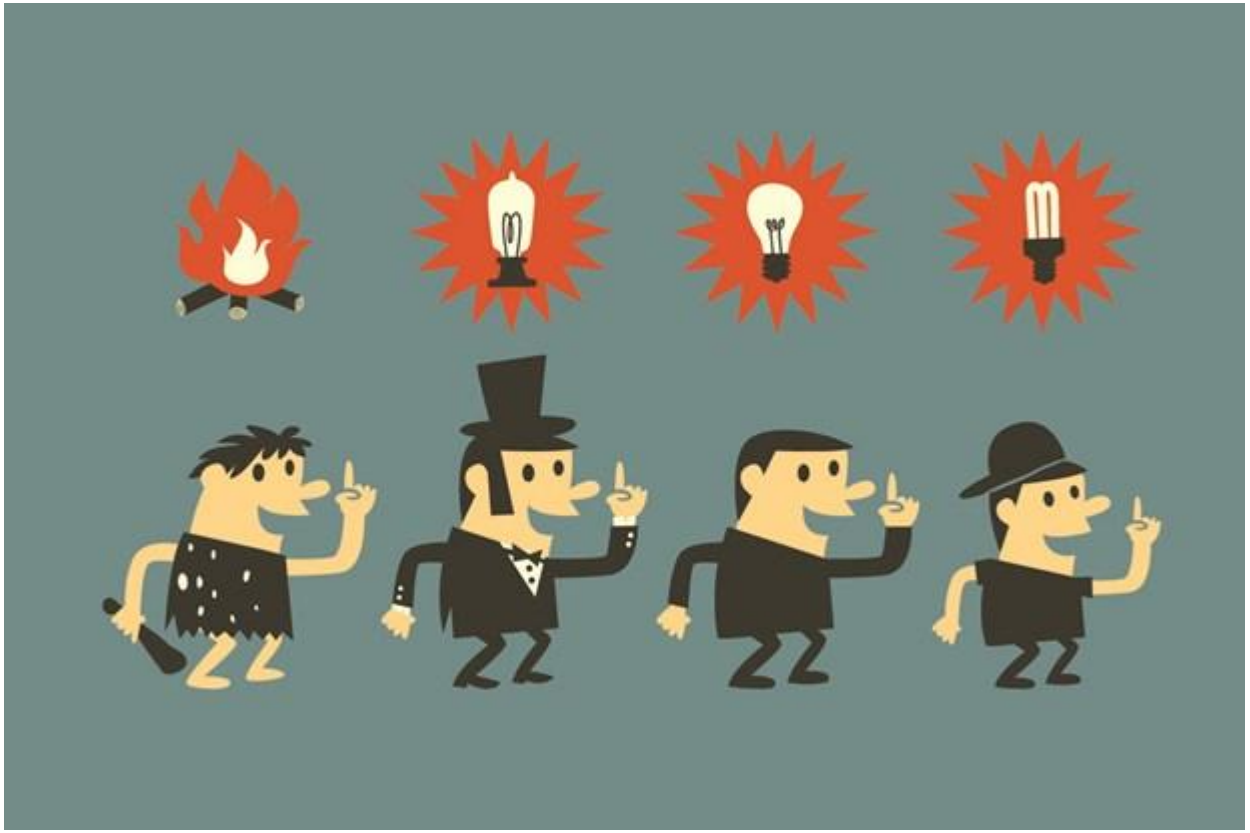
- No communication about prognosis/eol
- Some participants didn't want to talk about dying or make 'choices'
- Are there really choices to be made?
- Fundamentally their understandings of a 'good death' were not congruent with the model that underpins SPC
- Tension between 'living' & 'dying'/hospital culture
- Language of pall care; generalist/specialist tension
- Multi-morbidity
- (Dis)continuity of health (& social) care
- Changing models of primary care
- Ageism
- Poverty


BOAT!
LAND!
SleepyMoose.com
perspective...

*The doctor decided he needed a stomach x-ray because his stomach was very bloated....**so less than an hour before he died poor man there were three of us trying to lift him onto an x-ray plate**. ..He was talking to me and I knew that he knew he was dying, there was no two ways about it (Heather, carer of HF patient).*

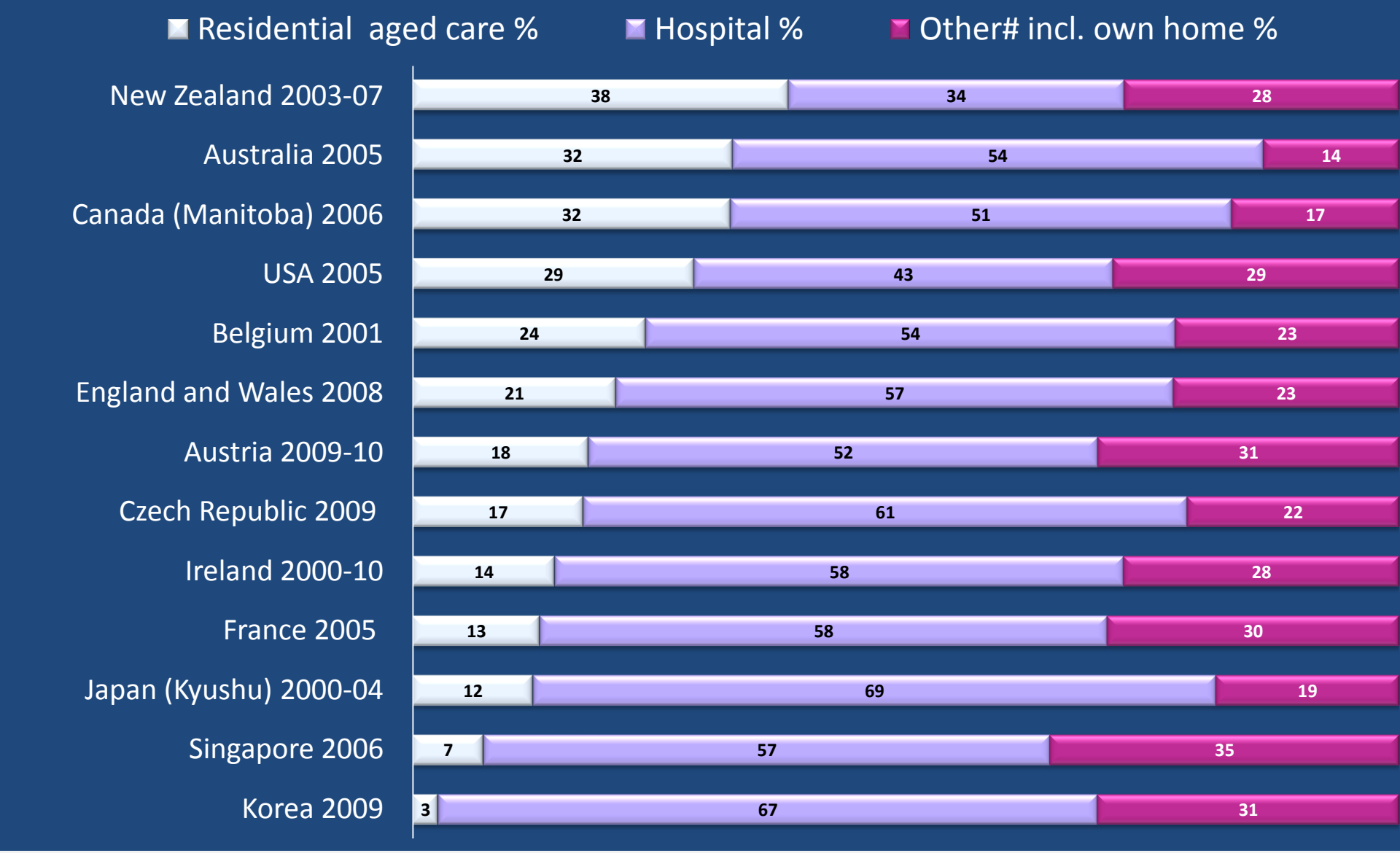


Small N, Barnes S, Gott M, Payne S, Parker C, Seamark D, Gariballa S. Dying, death and bereavement: a qualitative study of the views of carers of people with heart failure in the UK. *BMC Palliative Care* 2009, 8:6.



2. Identify strategies to reduce avoidable hospitalisations amongst patients with palliative care needs

International Comparison of Place of Death for those >65



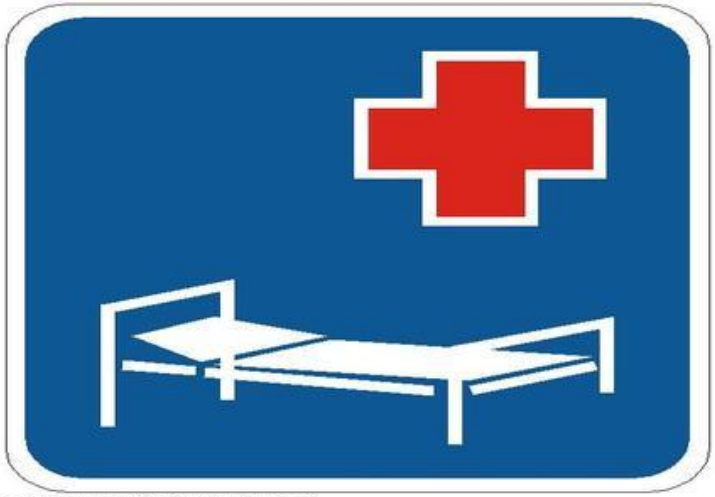
Broad JB, Gott M, Kim H, Byd M, Chen H, Connolly MJ. Where do people die? An international comparison of deaths occurring in hospital and residential aged care settings in 45 populations, using published and unpublished available statistics. *International Journal of Public Health*. doi: 10.1007/s00038-012-0394-5.

At any one time 1/5 – 1/4 of inpatients meet criteria for palliative care need

2/3 of inpatients who meet criteria for palliative care need will have died within 12 months

5-30% of patients meeting criteria for palliative care need will have a SPC referral

Only 1/3 inpatients identified by a standardised tool as having palliative care needs will be identified as having those needs by medical/nursing staff

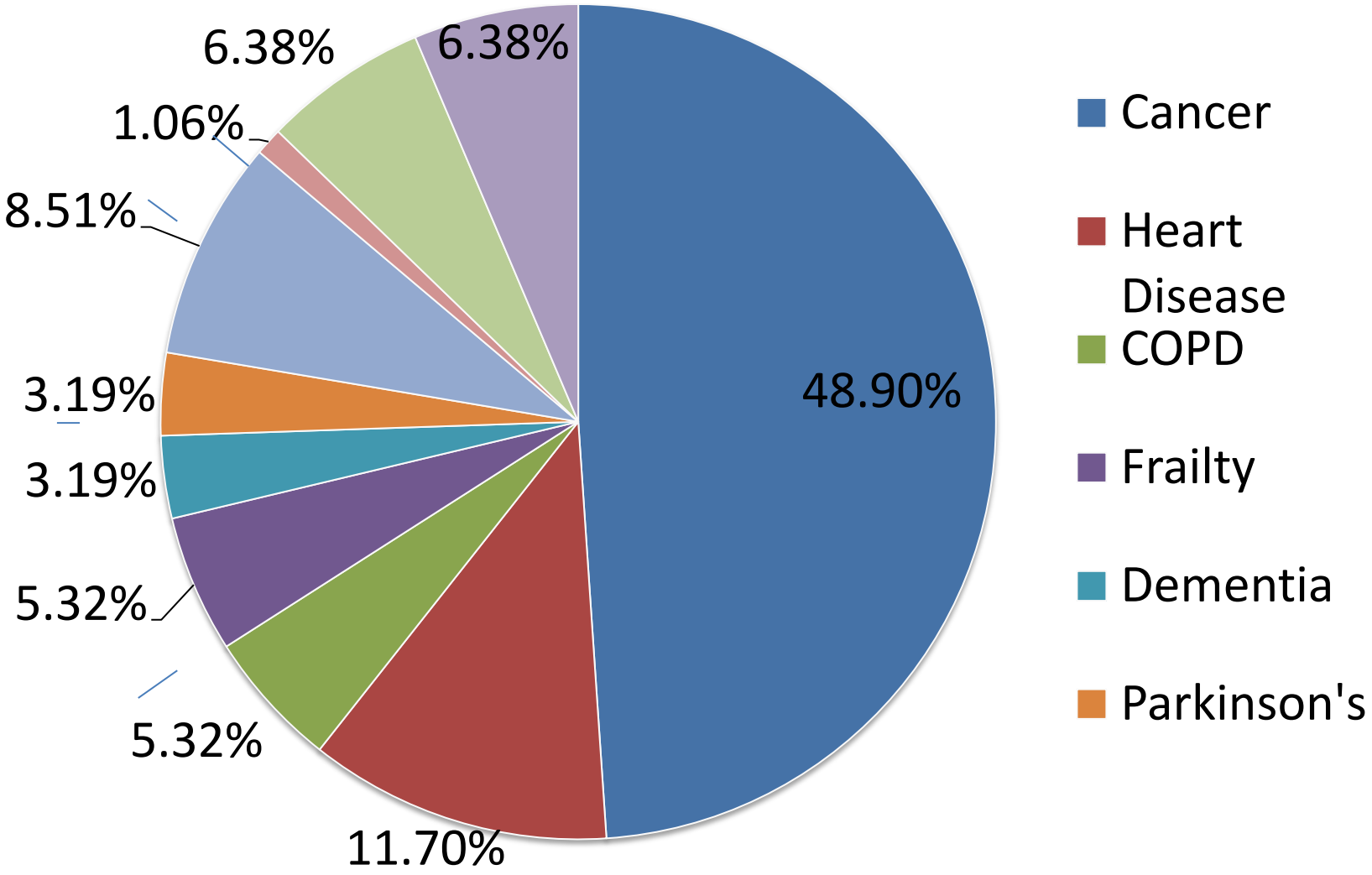


Researcher: And is prognosis routinely discussed with patients in hospitals?
Participant: We never do that . . . I think for a variety of reasons. We don't routinely do that.

2/3 show no evidence of a palliative approach to care

Gott, C. M. et al (2001); *Palliative medicine*, *15*(6), 451-460. Gardiner, C., Gott, M et al (2013). *Palliative medicine*, *27*(1), 76-83. Gott, M. et al. (2013). *BMC palliative care*, *12*(1), 15. Gott, M., et al (2011). Transitions to palliative care in acute hospitals in England: qualitative study. *Bmj*, *342*. Gott, M et al (2012). *Journal of palliative care*, *29*(3), 147-153.

Primary diagnosis



Maximizing scare health care resources must be a priority given the current economic climate. In end-of-life care, such economic rationalization is linked to improving quality because most people would prefer to die in their own homes. High quality community-based services cost no more, and can cost less, than hospital-based care.

(UK Department of Health, 2010)



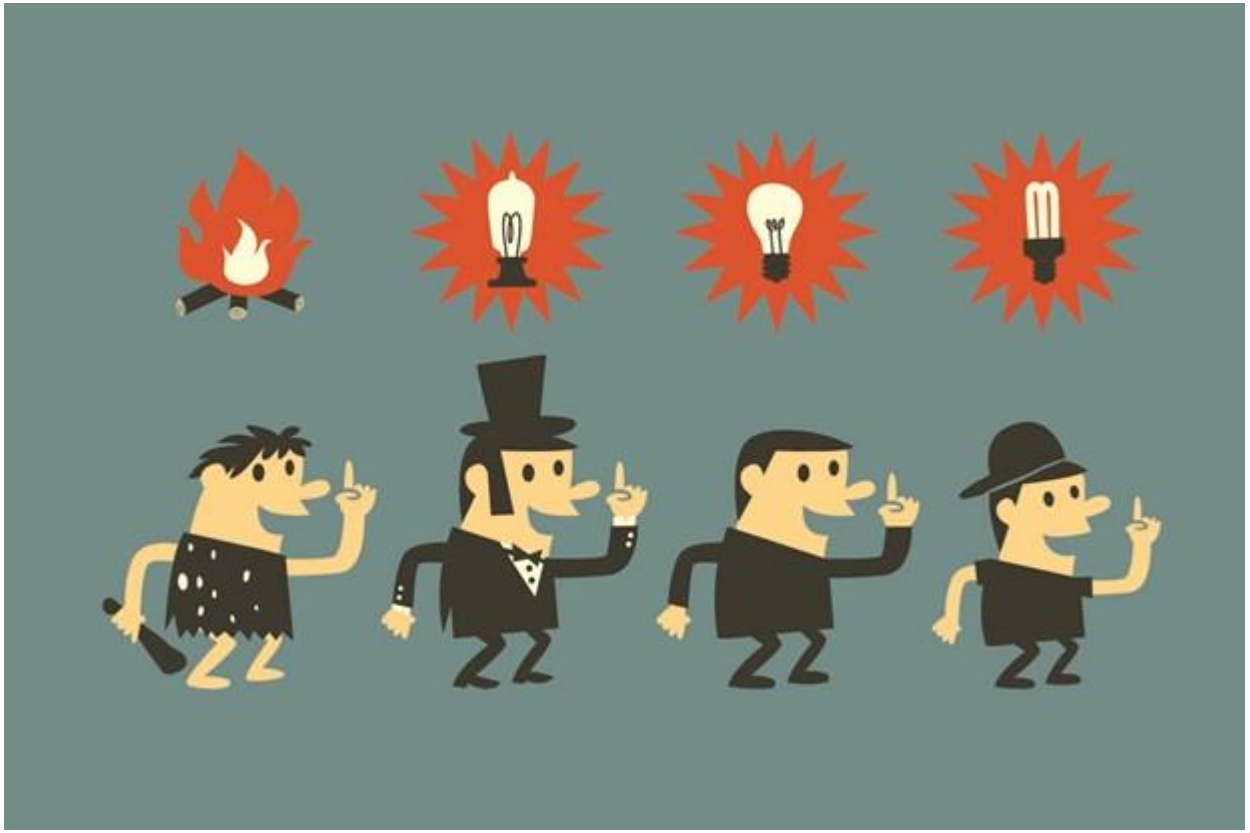
Exploring the extent, and predictors of, 'avoidable' hospitalisations, in England and NZ

- What are potentially avoidable admissions? Who decides?
- From SPC perspective rooted in local context numbers are much lower than previous estimates (4-20%)
- Only predictor of avoidability we've found was in NZ context - being resident in Aged Res Care
- Identified nothing is known about patient view and experience of hospital admission

What are the benefits of hospital admission from a patient perspective?

- I feel **safe** here because I can press the buzzer three times and know that somebody is going to come running whereas I can't do that at home.
- The hospital have been **marvellous** like in respect of helping me to stay at home. They have given me a hospital bed and they have helped me with things around the home to make my life easier like raise my chairs and rails.
- If I don't go to hospital something might happen. **I might die.**

Robinson, J., Gott, M., Gardiner, C., & Ingleton, C. (2015). A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs. *Palliative Medicine*, In press.



3. Upskilling the ‘generalist’ palliative care workforce

598 HCPs working at ACH

Estimated a fifth of their patients in last year of life

A fifth had received palliative care education



Spent one fifth of their time caring for dying patients

Three quarters felt that they would benefit from increased pall care knowledge

Participants who had received training reported greater confidence in pall care delivery and higher frequency of eol discussions

Frey, R. A., Gott, M., Raphael, D., O'Callaghan A, Robinson, J., Boyd, M., ... Snow, B. (2014). Clinical staff perceptions of palliative care-related quality of care, service access, education and training needs and delivery confidence in an acute hospital setting. *BMJ Supportive & Palliative Care, 4* (4), 381-389

National Cancer Action Team
Part of the National Cancer Programme

Driving improvement and quality in cancer services

NHS

Connected *online booking system*



Upskilling nursing workforce

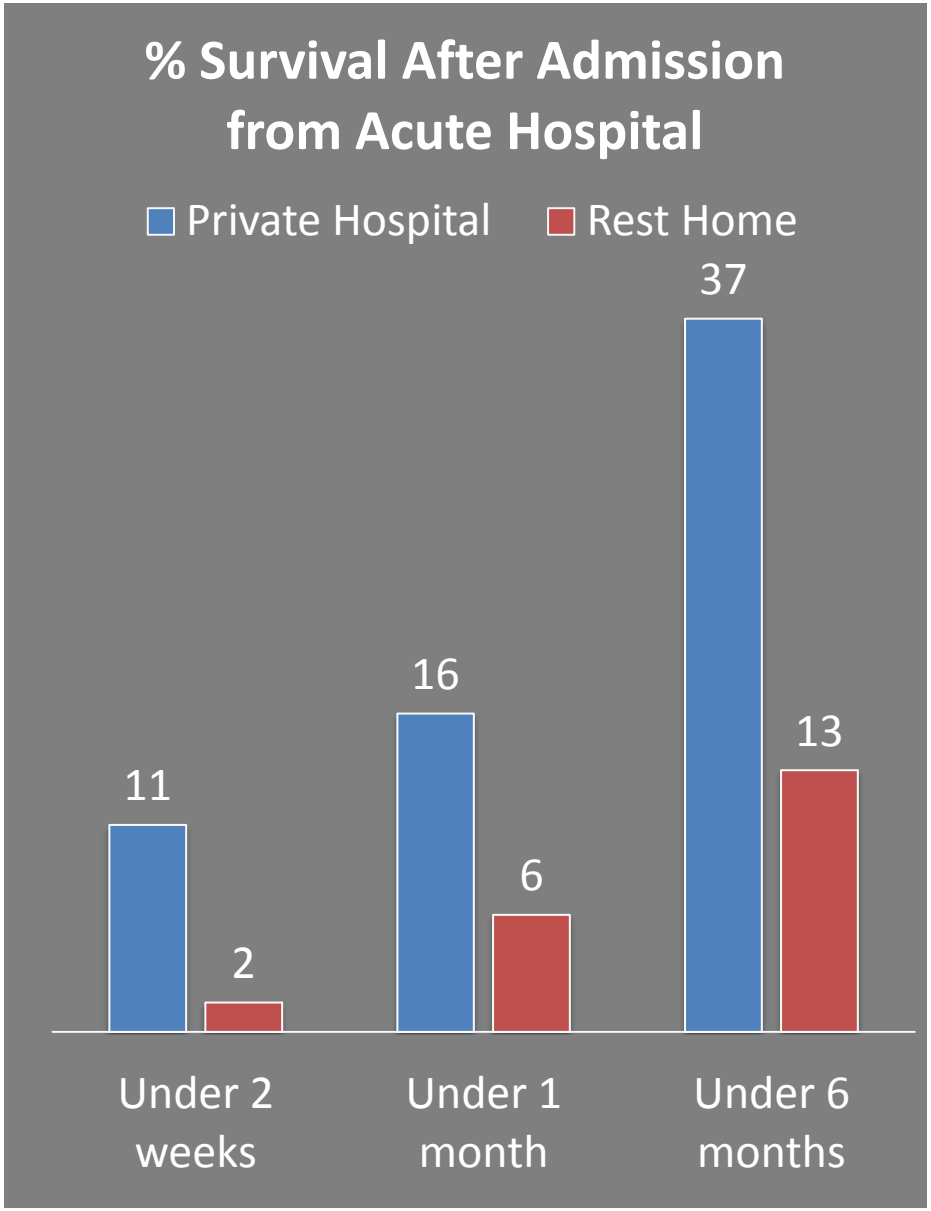
- Palliative care thread running through undergraduate
- New specialty palliative care pathway
- Development of new nurse practitioner pathways
- Masters and PhD students in palliative care
- Educational activities e.g. one day conference

THE UNIVERSITY OF AUCKLAND
FACULTY OF MEDICAL AND HEALTH SCIENCES

- **The Hospice Friendly Hospitals programme** is an all systems initiative to change hospital cultures relating to dying, death, and bereavement. It has built up a network of champions for change; produced materials for advocacy, public education, and professional training; and published a set of quality standards for end of life care in Irish hospitals. Its innovative measures include improving the mortuary environment, enhancing dignity when returning a dead relative's belongings, using symbols to denote a death on the ward, and raising staff confidence in recognising the dying process. Such work deserves recognition beyond Irish shores.

  Clark *BMJ* 2010;341:c5843

Residential Aged Care: De Facto NZ Hospice



Connolly M, Broad J, Kerse, Boyd M, Gott M. (2014) Residential Aged Care - The De Facto Hospice for New Zealand's Older People. *Australasian Journal on Aging* 33 (2), 114-120.

They spent 50-75% of their time caring for residents at the end of life

431 healthcare staff recruited from 46 ARC facilities across Auckland: HCA (61%) Nurse (25%) Clinical Manager/Care Coordinator (5.1%) Other Health (5.8%)

47.2% had formal palliative care training



80.5% would like palliative care training

The less accessible palliative care supports were perceived to be, the greater the likelihood of wanting palliative care education.

Higher scores for burnout predicted a decreased likelihood of engaging in formal palliative care training

Average 'burnout score' of 2.8 (SD = .96). A score of 2.5 - 3.4 indicates danger of burnout.

Frey, R., Boyd, M., Foster, S., Robinson, J., & Gott, M. (2014). Burnout matters: The impact on residential aged care staffs' willingness to undertake formal palliative care training. *Progress in Palliative Care,*

Barriers and facilitators to palliative care management amongst Health Care Assistants

- HCA's provide the bulk of care for residents at the end of life and reported extensive experience and expertise
- They identified their best learning about palliative care came through peer mentoring which they preferred to didactic teaching
- A lack of opportunity for debriefing following bereavement was identified
- Ultimately they felt their key role in palliative care management was not acknowledged by the wider team

Fryer S, Bellamy G, Gott M. "Sometimes I feel like they just don't hear me" The experience if Health Care Assistants in caring for imminently dying residents in Aged Residential Care. *Palliative Medicine.* Under review.

HCA 2: We spend a lot of time with residents; sometimes the RN's just don't listen. And you think, they are dying and you can just tell... just deteriorating.

HCA 4 :[Resident], she had pneumonia in the end I think. She was just getting weaker and weaker and not talking. I said to [RN], you better call the family, but she didn't. She [resident] died, and the family came in and got very upset with her because they expected to know. She should have called the family.

HCA 5: It was a bad mistake

HCA 1: You could tell with her breathing

HCA 5: We work with the residents all the time you know, and sort of know, we pick up things what's wrong with them then go and tell the RN's then it's up to them, it's not up to us.

HCA 2: They think, oh you're just a caregiver; you don't know what's happening, but we're with them every day.

Supportive Holistic Aged Residential Education

Rosemary Frey, Michal Boyd, Jackie Robinson, Merryn Gott, Sue Foster, Tess Moeke-Maxwell, Lynda Smith, Jenny Thurston

Six month pilot study in 2 ARC facilities in Auckland

The key components of SHARE are:

- ***Clinical coaching*** by a specialist palliative care nurse (SPN) from Mercy Hospice Auckland and a Gerontology Nurse Specialist (GNS) from ADHB
- ***Support*** with the development of 'goal of care' plans for residents who meet GSF criteria for palliative care need
- ***Role modelling*** of conversations related to palliative care (including documentation with residents, families and GP's)
- ***Debriefing*** amongst all ARC staff following a resident's death

Evaluation:

- Pre-test/Post-test Staff Questionnaires
- Post-Intervention Staff Interviews
- Records Review Data (results of the GSF-PIG, number of hospitalisations, and number of residents with ACP's).


Palliative care beyond cancer:
where to from here?



© James O'Mara / Getty Images

‘Usual care’ includes good quality palliative care for everyone who needs it

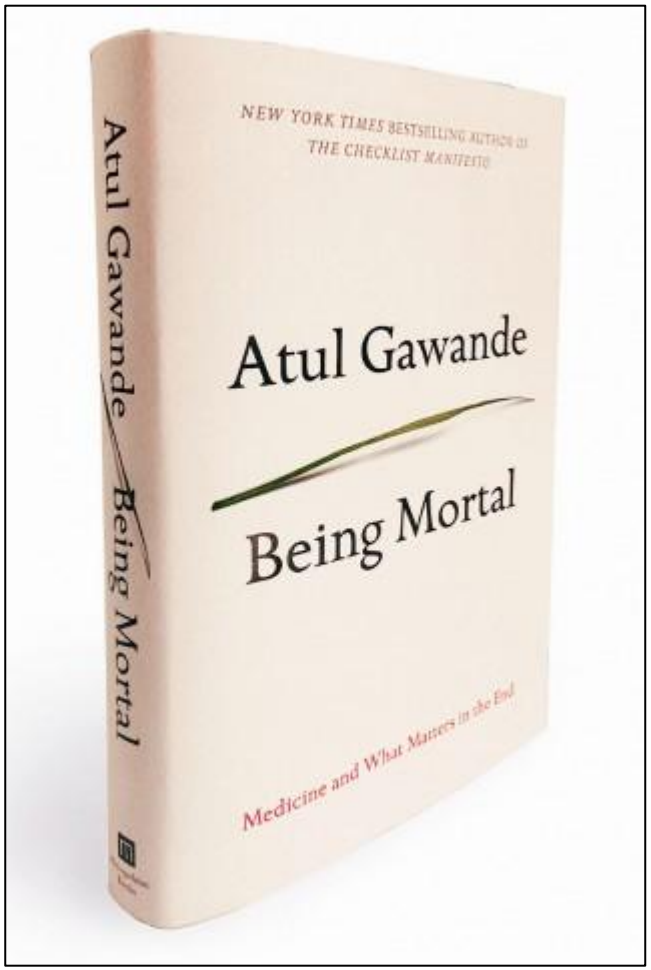


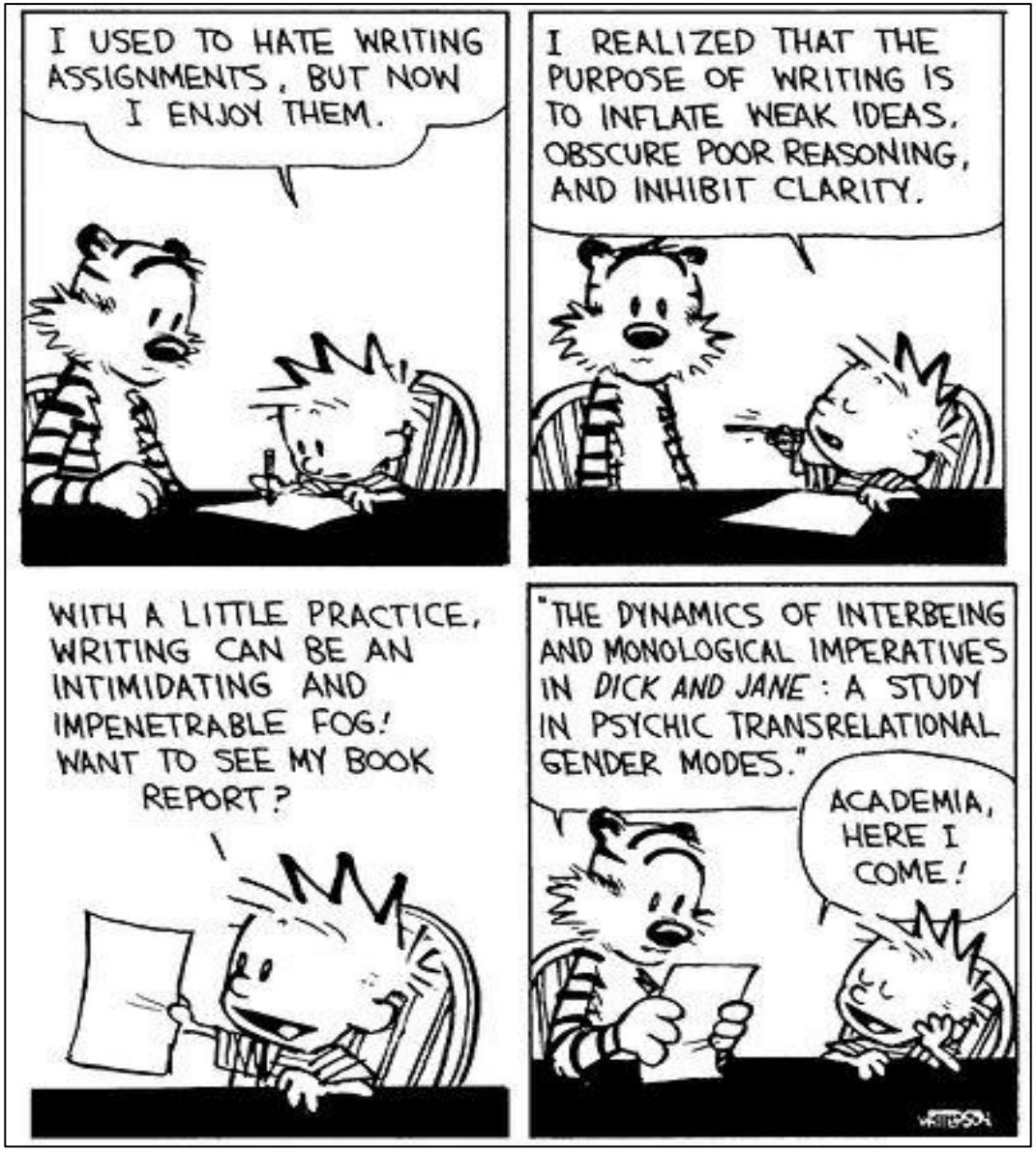


‘Terminal care should not be a facet of oncology, but of geriatric medicine, neurology, general practice and throughout medicine’

Globalisation




NEW YORK TIMES BESTSELLING AUTHOR OF
THE CHECKLIST MANIFESTO
Atul Gawande
Being Mortal
Medicine and What Matters in the End
Atul Gawande
Being Mortal


I USED TO HATE WRITING ASSIGNMENTS, BUT NOW I ENJOY THEM.
I REALIZED THAT THE PURPOSE OF WRITING IS TO INFLATE WEAK IDEAS, OBSCURE POOR REASONING, AND INHIBIT CLARITY.
WITH A LITTLE PRACTICE, WRITING CAN BE AN INTIMIDATING AND IMPENETRABLE FOG! WANT TO SEE MY BOOK REPORT?
"THE DYNAMICS OF INTERBEING AND MONOLOGICAL IMPERATIVES IN *DICK AND JANE*: A STUDY IN PSYCHIC TRANSRELATIONAL GENDER MODES."
ACADEMIA, HERE I COME!



m.gott@auckland.ac.nz