

People like us will become old and very frail

Jane Seymour

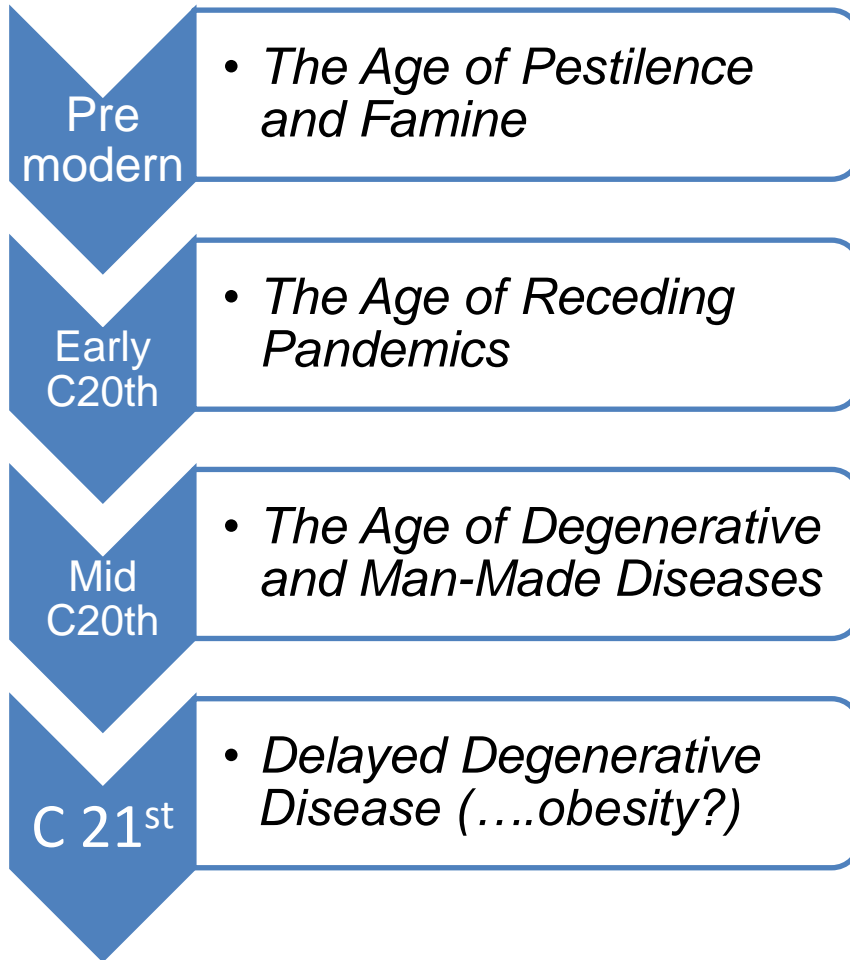
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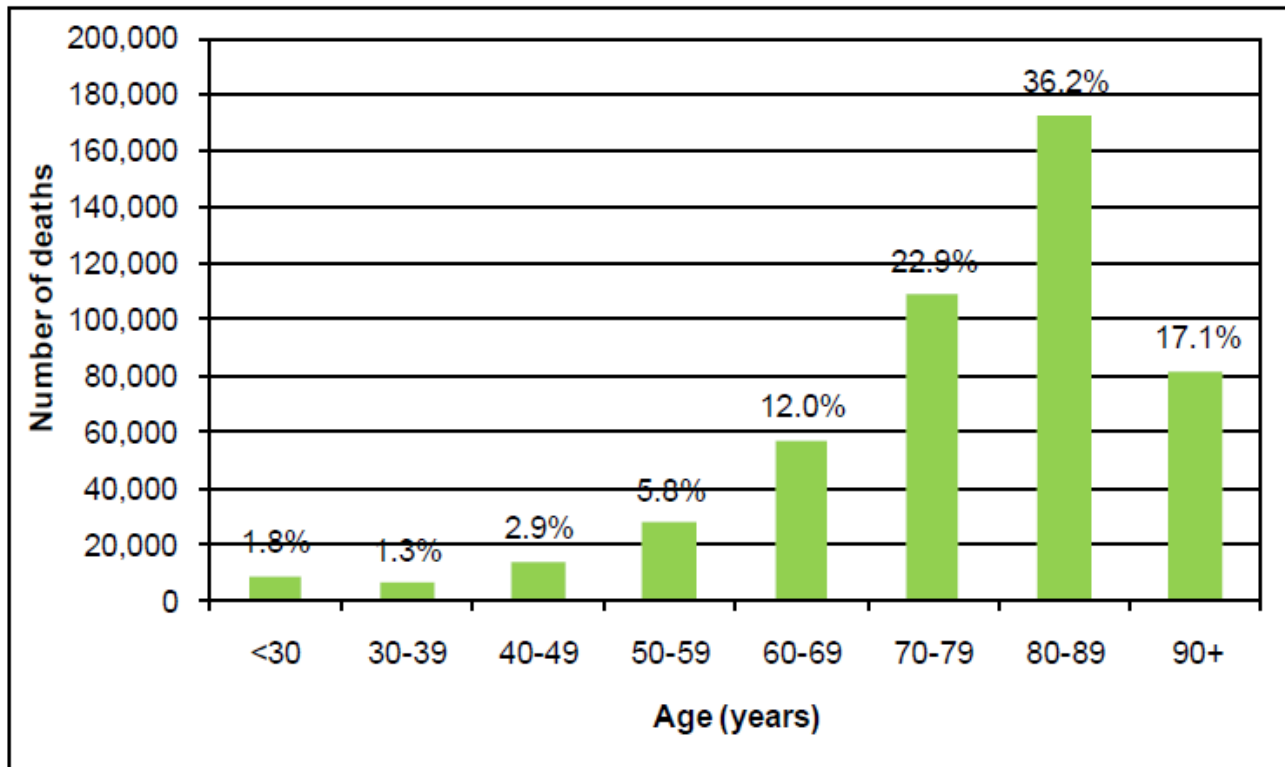
The historical contingency of death



Omran, A.R (2005. First published 1971) ["The epidemiological transition: A theory of the epidemiology of population change"](http://www.milbank.org/quarterly/830418omran.pdf), *The Milbank Quarterly* **83** (4): 731–57, <http://www.milbank.org/quarterly/830418omran.pdf>

The concentration of death in old age

Figure 1.1: Number of deaths by age in England, 2008 (labels give percentage of deaths)



Source: South West Public Health Observatory from Office for National Statistics data

Deaths of older adults in England. National End of Life Care Intelligence Network, 2010 <http://www.endoflifecare-intelligence.org.uk/>

Unmet needs for palliative care in England

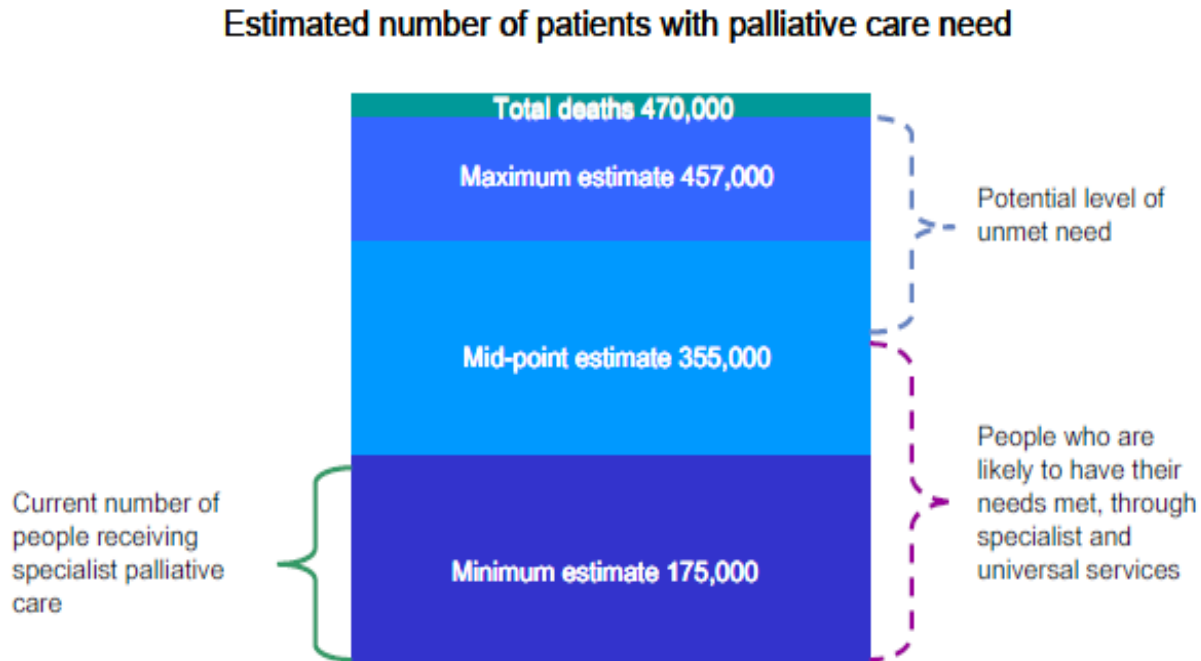


Figure 1 – estimated levels of palliative care needs

Palliative Care Funding Review, 2011; see: <http://palliativecarefunding.org.uk>

This talk

- Perspectives on frailty: cultural, clinical, social
- Frailty, mortality and palliative care needs: the evidence/ clinical significance
- Insights from the CECo programme of work: places of care; processes of decision-making; priorities for older people
- A new model of palliative care for frailty: preventive and proactive palliative care

CECo Older Adult Theme: Strands of work



1. Self perceived priorities for end of life care:

Socio-demographic diversity; challenges of living alone; carers' needs.

2. Processes of care decision making at the end of life:

Critiques of 'choice' and 'control'; identifying information needs; advance care planning

3. Places of care at the end of life:

Interventions to enable better quality of care in 'place'; understanding 'transitions'.

Frailty: the 'subtacular'¹ death?

- An elderly patient with advanced dementia and Parkinson's disease was sent to the emergency department from a nursing home on a Friday evening. The patient was unconscious and an ECG showed acute myocardial ischaemia.
- The patient's wife had requested that the patient should not have active treatment but the home care staff called the GP in a panic when his condition deteriorated.
- The GP had never met the patient and sent him to hospital. Little information was provided. A middle ranking doctor in accident and emergency called a consultant. They struggled to work out what best to do.
- Eventually, an end of life pathway was started. The patient died in emergency admissions shortly afterwards ².

1. Bailey, C et al (2011) Trajectories of End-of-Life Care in the Emergency Department. *Annals of Emergency Medicine*, 57(4):362-9 ;

2. Based on a case in: National Confidential Enquiry into Patient Outcome and Death (2009) *Caring to the End? A review of the care of patients who died in hospital within four days of admission*. NCEPOD.

Living / dying on the edge?

“They are somehow outside the dominant frames both socially and clinically. They are not obviously dying, nor do all of them look fragile. However, in order to matter, to be listened to by services, they need to be inside this frame”

Nicholson C (2009) *Holding it together: a psycho-social exploration of living with frailty in old age*. City University; PhD thesis



Frailty: clinical and social science perspectives

- The 'trajectory' model ¹
- The 'phenotype' or syndrome: weakness, poor endurance, weight loss²
- A complex product of the relationship between person and a disabling environment?³
- The 'fourth age'? ⁴

1. Lunney et al. 2003 *Jama*, 289(18):2387-2392; 2. Fried et al. (2004) *J Gerontol A Biol Sci Med Sci*, 59(3):255-263; 3. Shakespeare (2008) *J Med Ethics*, 34(1):11-14; 4. Gilleard, Higgs (2010) *Aging & Mental Health*, 14, 2, 121-128.

How does frailty relate to palliative care needs among older people?

Palliative care

- Individualised care and symptom control in life threatening disease
- Not age, diagnosis, place or time specific
- Based on needs and wishes
- Includes community services, respite and day care
- Health, social and voluntary sectors working together
- Interacts with other services, including geriatric care

Frailty

- Can be **primary**- and independently associated with mortality
- Often **secondary** to disease
- Related to **multi morbidity**¹ (estimated 80% of over 80 year olds)
- Declining **social participation and complex activity** predict death

Based on description in the Palliative Care Funding Review, 2011, see:

<http://palliativecarefunding.org.uk>

Ster MP, Svab I (2009) How to Research Multimorbidity in General Practice? *Zdrav Varst*, 48(2):51-61

Frailty, disability and comorbidity

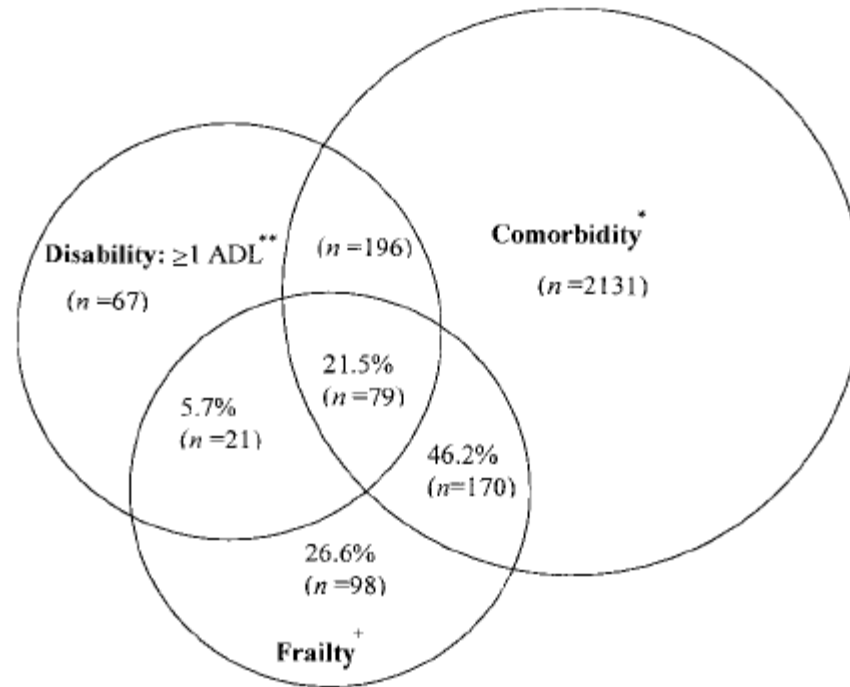
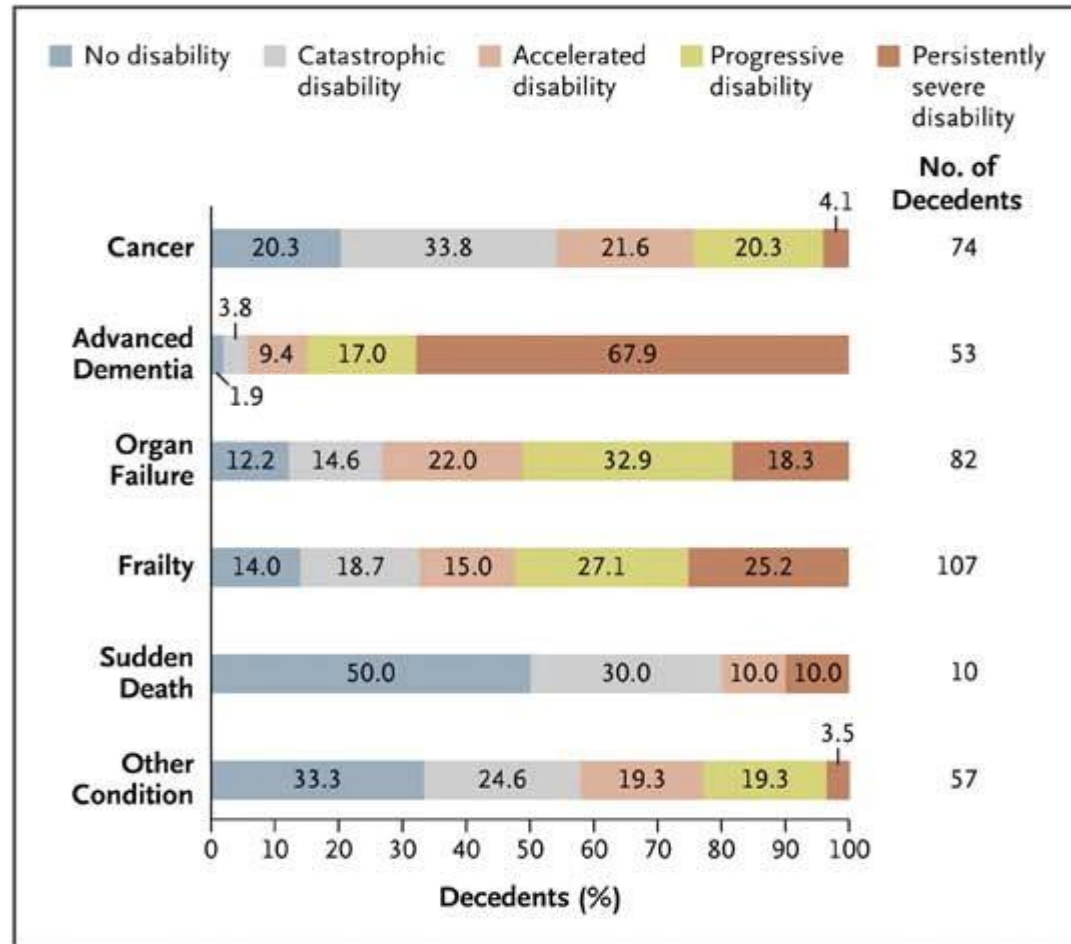


Figure 1. Prevalences—and overlaps—of comorbidity, disability, and frailty among community-dwelling men and women 65 years and older participating in the Cardiovascular Health Study (Ref. 23, reprinted with permission). Percents listed indicate the proportion among those who were frail ($n = 368$), who had comorbidity and/or disability, or neither. Total represented: 2762 participants

Fried *et al.* 2001) Frailty in older adults: evidence for a phenotype. *J Gerontol A Biol Sci Med Sci*, 56(3):M146-156.

Trajectories of disability in the last year of life



383 community dwelling older decedents (Gill et al. 2010, *NEJM*, 363(13):1173-1180)

Clinical consequences of frailty ¹

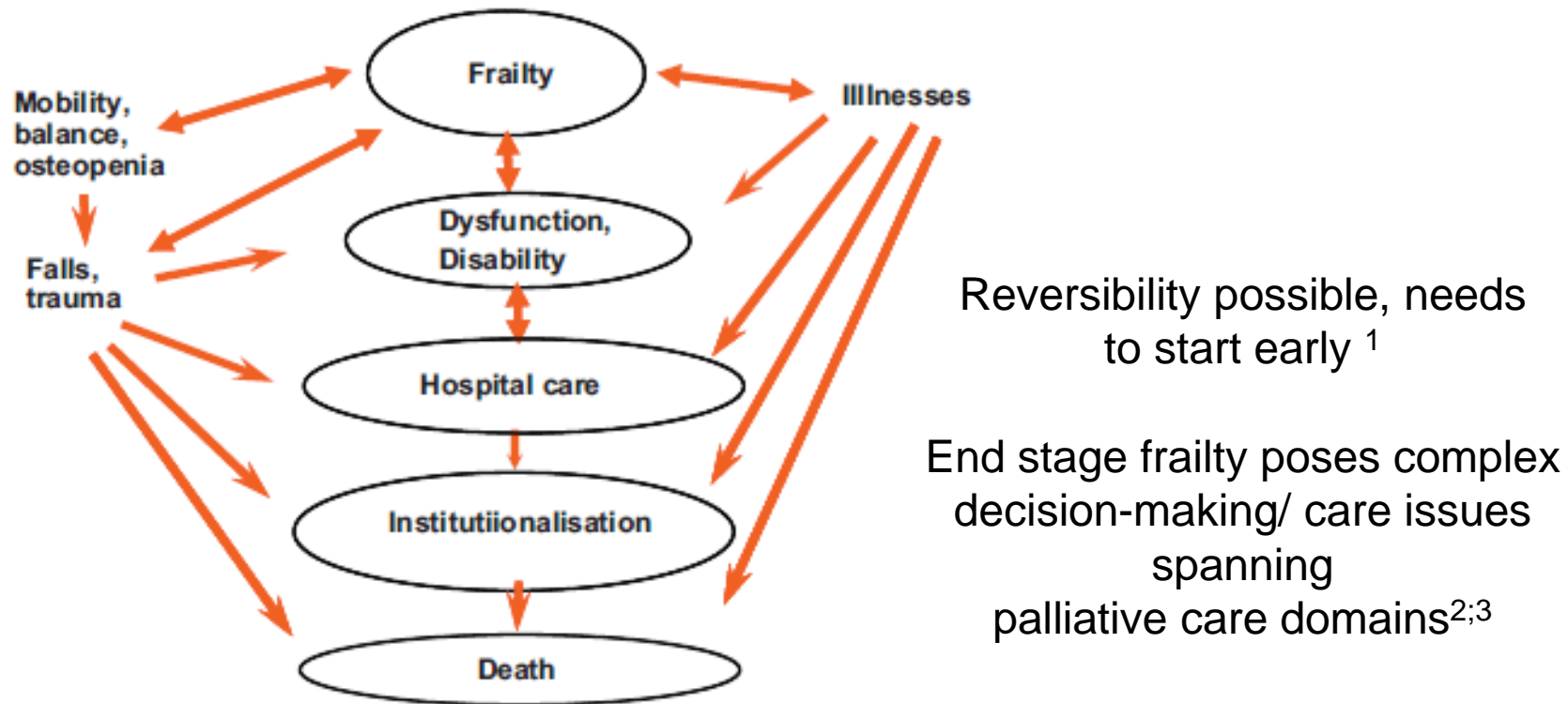


Fig. 4. Clinical consequences of frailty. Low reserves in frailty may lead to consequences *per se* or via illness and trauma with which frailty has a bidirectional relationship.

1. Strandberg et al (2011) *European Geriatric Medicine*, 344-355; 2. Boockvar et al (2006) *JAMA*, 296(18):2245-2253; 3. Raudonis et al. (2010) *Geriatric Nursing*, 31 (5):379-384

Places: care homes

- Life expectancy circa 9-12 months on entry to nursing home; 40% residents have dementia
- “....Commission the service and then walk away” ¹
- Greater needs than other citizens, but much less access to fundamental NHS services, which are the rights of all^{1;2}
- Whole systems approach is necessary; instead of unbalanced focus on inadequacies of care homes and staff

1. Seymour, et al. (2011) Do care homes have the resources they need to provide end of life care? *Palliative Medicine*, 25 (2):125-138
2. British Geriatrics Society (2012) *Failing the Frail: A Chaotic Approach to Commissioning Healthcare Services for Care Homes*. BSG, London

Places: hospitals

- A 2010 census of hospital patients in Lancaster and Sheffield shows that a third of patients have palliative care needs (according to GSF criteria)
- Higher than previous research has suggested: other surveys have suggested 9.4%, 13% and 23% of inpatients as having palliative care needs
- Patients with palliative care needs are overwhelmingly frail, older people, with multiple co-morbidities and multiple previous admissions to hospital

Gardiner et al (2012) Extent of palliative care need in the acute hospital setting: a prospective survey of two acute hospitals.
Palliative Medicine, available online



Transitional places: the revolving doors of the care system



- 30 older adults with lung cancer, stroke or heart failure: *67 moves in the 3 months before interview*¹
- Important care decisions transferred at the same time as patients
- Crisis care, rather than anticipatory care the norm

1. Hanratty et al (2012) Older adults experiences of transitions between care settings at the end of life in England – A qualitative interview study. *Journal of Pain and Symptom Management*, 44(1):74-83.

Understanding carers' needs

- Older patients often have older carers, who struggle¹
- Relatives/ friends: 'guardians'¹ or 'conductors' of care but 'second fiddles' in institutions:²
- The Carer Support Needs Assessment Tool (CSNAT)³ is evidence based across 2 domains:
 - *Support to enable them to provide care*
 - *Direct personal support for themselves*

The doctors at the two hospitals never knew what the other was doing – it felt like I had to keep an eye on what was going on, telling them what had been happening – they didn't seem to keep each other informed – it was a huge worry for me¹.

1. Kennedy et al (2011) *Exploring the key concerns and support needs of older carers of people with advanced cancer*. Final Report submitted to Macmillan Cancer Support; 2. Lawson et al.(2012) From 'Conductor' to 'Second Fiddle' - Older adult care recipients' perspectives on transitions in family caring at hospital admission. *International Journal of Nursing Studies*, avail. online. 3. Ewing and Grande (2012) Development of a carer support needs assessment tool (CSNAT) for end of life care practice at home. *Palliative Medicine*, avail. online.

Processes: decision making for future illness and incapacity

BMJ

RESEARCH

The impact of advance care planning on end of life care in elderly patients: randomised controlled trial

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ABSTRACT

Objective To investigate the impact of advance care planning on end of life care in elderly patients.

Design Prospective randomised controlled trial.

Setting Single centre study in a university hospital in Melbourne, Australia.

Participants 309 legally competent medical inpatients aged 80 or more and followed for six months or until death.

Interventions Participants were randomised to receive usual care or usual care plus facilitated advance care planning. Advance care planning aimed to assist patients to reflect on their goals, values, and beliefs; to consider future medical treatment preferences; to appoint a surrogate; and to document their wishes.

Main outcome measures The primary outcome was whether a patient's end of life wishes were known and respected. Other outcomes included patient and family satisfaction with hospital stay and levels of stress, anxiety, and depression in relatives of patients who died.

Results 154 of the 309 patients were randomised to advance care planning; 125 (81%) received advance care planning, and 108 (84%) expressed wishes or appointed a surrogate, or both. Of the 56 patients who died by six months, end of life wishes were much more likely to be known and followed in the intervention group (25/29, 86%) compared with the control group (8/27, 30%; $P<0.001$). In the intervention group, family members of patients who died had significantly less stress

(intervention 5, control 15; $P<0.001$), anxiety (intervention 0, control 3; $P<0.02$), and depression (intervention 0, control 5; $P<0.002$) than those of the control patients. Patient and family satisfaction was higher in the intervention group.

Conclusions Advance care planning improves end of life care and patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives.

Trial registration Australian New Zealand clinical trials registry ACTRN12608000539336.

INTRODUCTION

Since the 1990s there has been an increasing awareness of the inadequacy of end of life care and of the poor knowledge of patients' wishes about their medical treatment at a time when they lose the capacity to make

decisions,^{1,2} resulting in patients being cared for in a way they would not have chosen.³ This has continued to the present day.⁴ Apart from progress in palliative care, the main focus to deal with these needs has been the development of advance care planning. Advance care planning is a process "whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care, should he or she become incapable of participating in medical treatment decisions."⁵ The process of advance care planning informs and empowers patients to have a say about their current and future treatment. Advance care planning and the importance of improving end of life care are both supported by legislation in Australia,⁶ the United Kingdom,⁷ and the United States,^{8,9} and are endorsed by professional bodies, including the Australian,¹⁰ British,⁷ and American¹¹ medical associations.

Elements of advance care planning include clarifying a patient's understanding of their illness and treatment options; understanding their values, beliefs, and goals of care; and identifying their wishes. If required a substitute decision maker (surrogate) is nominated.^{12,13} The potential barriers to advance care planning include the availability of trained staff with the time, competence, and confidence to discuss advance care planning with patients; organisational commitment and policy to support advance care planning; and ensuring that doctors understand and support advance care planning.^{14,15} Carrying out effective advance care planning in elderly patients is challenging, especially when they are acutely unwell and have a short length of stay in hospital before discharge.

Much of the focus on advance care planning has been on improving the completion rate of advance directives.^{16,17} Such improvement does not necessarily improve medical care^{18,19} or end of life care.¹⁹ Models of advance care planning such as the Respecting Choices programme have shown that a coordinated, systematic, patient centred approach to advance care planning by trained non-medical facilitators can improve outcomes for patients.^{20,21} Evidence also shows that advance care planning and end of life discussions reduce stress, anxiety, and depression in surviving relatives.²²⁻²⁵

- Advance care planning—anchor of a new model for palliative care ?
- Evidence that older people can engage and help others¹
- ACP practice needs to be mindful of lived worlds of frailty

1. Seymour et al. (2011) Peer education for advance care planning: volunteers' perspectives on training and community engagement activities. *Health Expectations*, DOI: 10.1111/j.1369-7625.2011.00688.x

The 'lived world' of frailty ¹

- **A step change in identity:**
 - 'Funnily enough, I didn't think about [ageing] a lot until the stroke happened'* (Graham, 78)
 - 'It's a complete reversal of my life'* (Andrew, 80)
 - 'I feel like a fish out of water'* (Lena, 80)
 - 'I was fine until I was about 75 and then everything fell apart, you know'* (Howard, 83)
- **An existential challenge:** *I've still got my life about me but the flame is getting less'* (Jonathan, 85)
- **A struggle to balance continuity with loss:** see, also, Nicholson, 2009

1. Lloyd L, Calnan M, Cameron A, Seymour J, Smith R. (2012) Identity in the fourth age: perseverance, adaptation and maintaining dignity. *Ageing and Society*, Available online

Experiences of health and social care

- Good experiences:
 - *bolster dignity and self-respect*
 - *enable the emotional work to 'persevere' while adapting to change*
- Poor care common, often because of risk aversion and lack of nursing skill¹
- 'World class nursing'² rather than 'World class commissioning'?

1. Calnan et al. (2012) "I often worry about the older person being in that system": exploring the key influences on the provision of dignified care for older people in acute hospitals. *Ageing and Society*, online. 2. Cox K: Opinion. *Nursing Times* 2007, 103(51):12; 2.

Care in crisis?

- *‘The lack of investment in care workers, ...in sharp contrast to the level of responsibility and skills required to provide quality home care. (Equality and Human Rights Commission, 2012:96)*
- *There are huge issues around the funding of care being in crisis, but there is a deeper and hidden crisis around the quality of care. (Age UK, evidence to Select Committee on Social Care, Para 68 , vol 1)*

4 problems with palliative care

- Palliative care has remained separate from the mainstream and delivered close to the end of life
- Too much emphasis on 'diagnosing dying' as a key to palliative care transition- this means a disease focus
- Concerns about palliative care as a scarce resource leads to risk of over specialisation (nursing and medicine) instead of partnership working
- Emphasis on choice should be replaced by emphasis on negotiation and healing ¹

1. Jerant et al. The TLC model of palliative care in the elderly: preliminary application in the assisted living setting. *Annals of Family Medicine* 2004, 2(1):54-60.

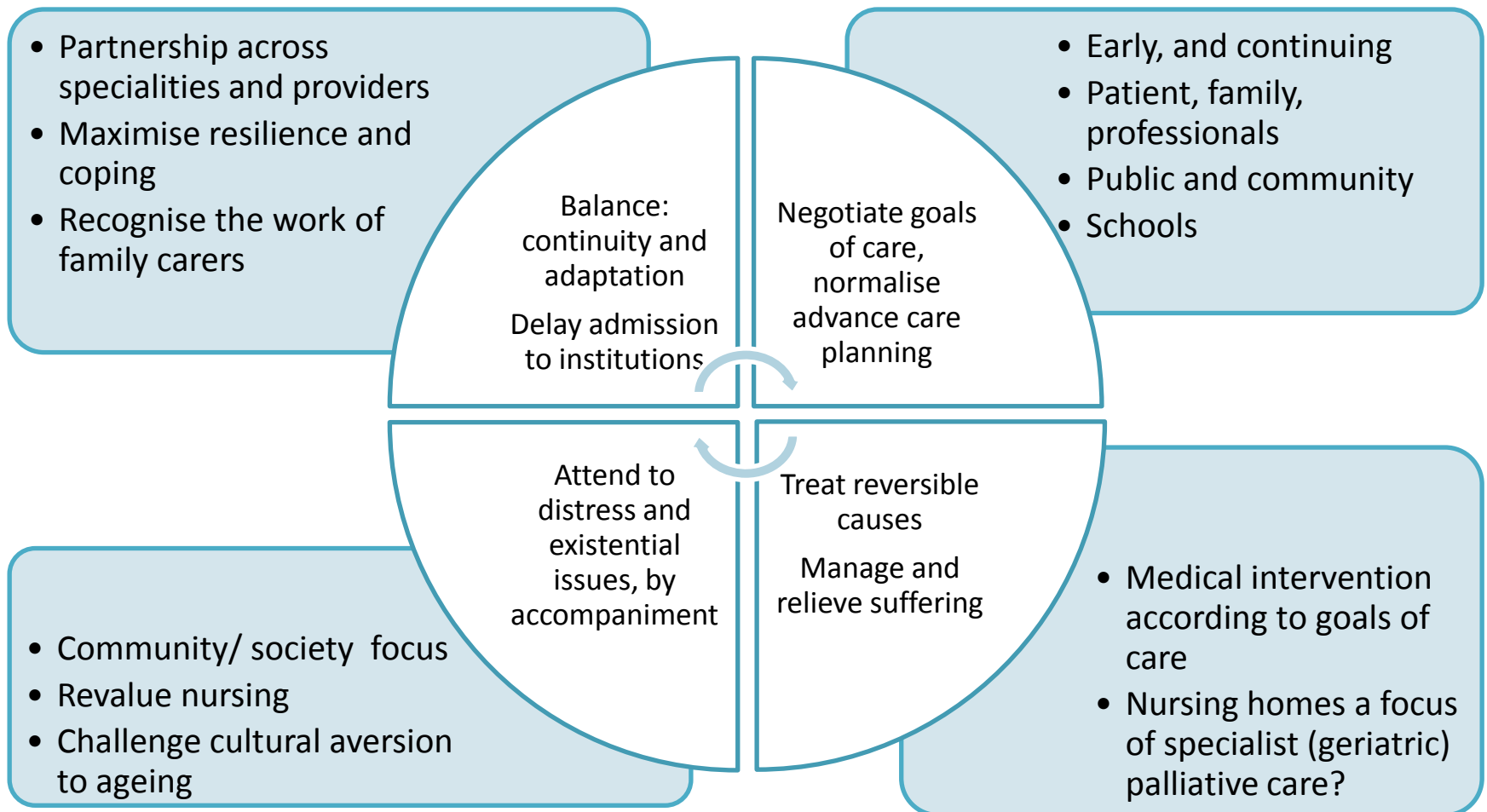
Elements of a new model?

Table 1. TLC Model of Palliative Care for Elderly Patients

Letter	Model Element	Elaboration
T	Timely	Proactive rather than reactive approach to avoid prolonged unnecessary suffering
	Team oriented	Nurses, social workers, trained laypersons, and others involved
L	Longitudinal	Balance of palliative and curative measures evolves with time
C	Collaborative	Patients, family members, and providers share decisions
	Comprehensive	All empirically supported domains of palliative care are addressed

Jerant et al, 2004

Preventive and proactive palliative care: a partnership model



Summary

- Frailty will be the major public health challenge of the 21st century
- Currently, frail older people, particularly those with dementia, have palliative care needs that are largely unmet
- A new model of palliative care 'preventive, proactive palliative care' may provide a framework for development
- Getting care right for frail older people will benefit others with 'non traditional' causes of palliative care need