



# Exploring Ageing and Dying.

Developing a research programme to explore the end of life care needs of older people with conditions other than cancer.

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# Outline

- Why focus on older people?
- Aims of research programme
- Research to date and key findings
  - Technology and natural death, heart failure, COPD, palliative care in acute hospitals
- Older people and the 'good death'
- Challenges
- Discussion



## The Times, June 1<sup>st</sup> 2009

- The NHS has held a series of 30 “reverse e-auctions”, where bids are driven down instead of up, for £195 million worth of contracts for palliative and dementia care for patients leaving hospital.
- In Walsall, the Working Together Specialist Care Agency won a contract to provide palliative care to elderly people in the last few months of their life. Within weeks, the local authority stopped the company taking on any new cases, and then terminated the contract after it emerged that **dying people were not receiving the pain relief and help with feeding and washing that they required.** The Care Quality Commission (CQC), the health regulator, confirmed that the agency had been deregistered after an investigation.



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- Frail older people and their families, with or without dementia, at the end of their life are regarded as **a drain on hospital resources** and are not treated in the same way as younger patients with cancer.  
(Generalist palliative care provider, cited Shipman et al, 2008: 337).
- A proportion of dying older people receive **'very poor'** care in NHS acute hospitals  
(Richards, 2006)

Jack died in the end of a lung infection. But what in fact killed him was a combination of Parkinson's disease, severe arthritis, enlarged prostate and damaged heart...**The problem was that while there were lots of people in charge of different parts of Jack's body, none was in charge of Jack.** He was shunted backwards and forwards between 3 different hospitals. All of us in the family suspected that Jack was dying, but the fiction that, apart from his Parkinson's, his problems were temporary...It was fiction that deprived Jack of the care he really needed (Hoyland, 1997: 8).



For those of us that work with older people, it is self-evident that deficiencies in end of life care provision are inextricably linked to deficiencies in the wider health and social care services available to older people. Older people are dying with unmet physical, psychological and social needs and in situations that do not respect their individuality because these are the situations in which they live. ...**Experiences of ageing and dying are inter-related** and we therefore cannot consider end of life care, something predominantly provided to older people, without acknowledging the pervasive ageism that influences later life experiences, (Gott, 2008).



# Aims of the Research Programme



- To explore the current end of life experiences of older people and their families and identify areas of unmet need
- To examine the role of age (and cohort) in determining end of life expectations and experiences
- To consider the applicability of specialist palliative care philosophy to the needs of older people and their families
- To develop appropriate models of care that address unmet needs



- To develop appropriate methodologies to investigate these issues
- To develop a theoretical framework drawing upon multidisciplinary perspectives to support empirical research
- To develop research capacity in this area through training and support
- To effect practice and policy change



# Technology and natural death: a study of older people

Jane Seymour, Merryn Gott, David Clark, Sam Ahmedzai, Gary Bellamy

Funded by the ESRC/MRC



## Funded by ESRC/MRC from 02/2001 – 03-2003

- Qualitative study using vignette technique to explore older people's preferences for care at the end of life
- **Home:** Dying 'at home' cornerstone of UK policy & indicator of 'good' end of life care
- But older people themselves have mixed views about dying at home with key barriers including: care of the carer, loneliness, living in poor material circumstances, not wanting to die alone & perceived lack of specialist equipment.



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**Alice:** *Is home a better place to die than in hospital? Not necessarily I would think. I mean the equipment that they have in hospitals nowadays you wouldn't get at home, erm, breathing apparatus and so on. So I don't know, so long as you're your family there and the people you love... I think that would be the main thing.*

**Joan:** *We reached a stage where this hospice at home took over and they just literally moved all the equipment they needed to care to look after my husband. It was just like him being in hospital.*



# A longitudinal study to explore palliative care needs in heart failure

Merryn Gott, Sheila Payne, Neil Small, David Seamark, Salah Gariballa, Chris Parker, Sarah Barnes

Funded by the Department of Health



## Funded by DoH: 08/2003-09/2006

- 542 people with HF (NYHA III/IV) and 213 carers completed QoL and service use questionnaires every 3 months for 2 years or until death
- In-depth interviews with 40 participants on 2 occasions
- Post bereavement interviews with carers
- 8 focus groups with primary care professionals



- **Symptom burden and prevalence** were high with over half of patients experiencing breathlessness and/or fatigue daily
  - *It's the tiredness that affects me most. I sit on the edge of the bed and I put my slippers on. Then I put one arm in my dressing gown and I've to rest before I can get the other arm in...and then I've to sit on the need a bit while I trot off to the bathroom...I brush my teeth, wash my hands and then I've to sit on the toilet seat to get my breath back...I just dread morning really, (Women aged 85, NYHA III).*



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- Patients reported little **support in maintaining function**. Only one quarter received any Social Services during the past 24 months.
- **Autonomy and decision-making** were compromised by a low level of understanding of HF, including in relation to prognosis.
  - *The treatment were good and I thought it would give me a new lease of life, but there were no explanations about how you'd be after. I mean I keep thinking "well how the hell long does it go on like this? I mean it's a year and nothing's happened. (Women, aged 77, NYHA III).*



- Very little evidence of **advance care planning** was identified. Bereaved carers, patients and GPs confirmed that a lack of discussion of prognosis meant there was no ‘way in’ to discuss ACP
  - *Well I think on the whole it is fair to say that the vast majority of us do not tell patients that it’s a terminal illness....it is very difficult to actually turn around and say to somebody “you have a diagnosis of heart failure and actually your prognosis is worse than that for cancer, (GP).*



- Overall **patient and family satisfaction** with care was relatively high, although areas of improvement were identified in relation to primary care, including longer consultation times, continuity of care, communication, bereavement support, access and perceived ageism
- Carer satisfaction with end of life care management was generally good, but some examples of poor care were reported, particularly in hospital settings



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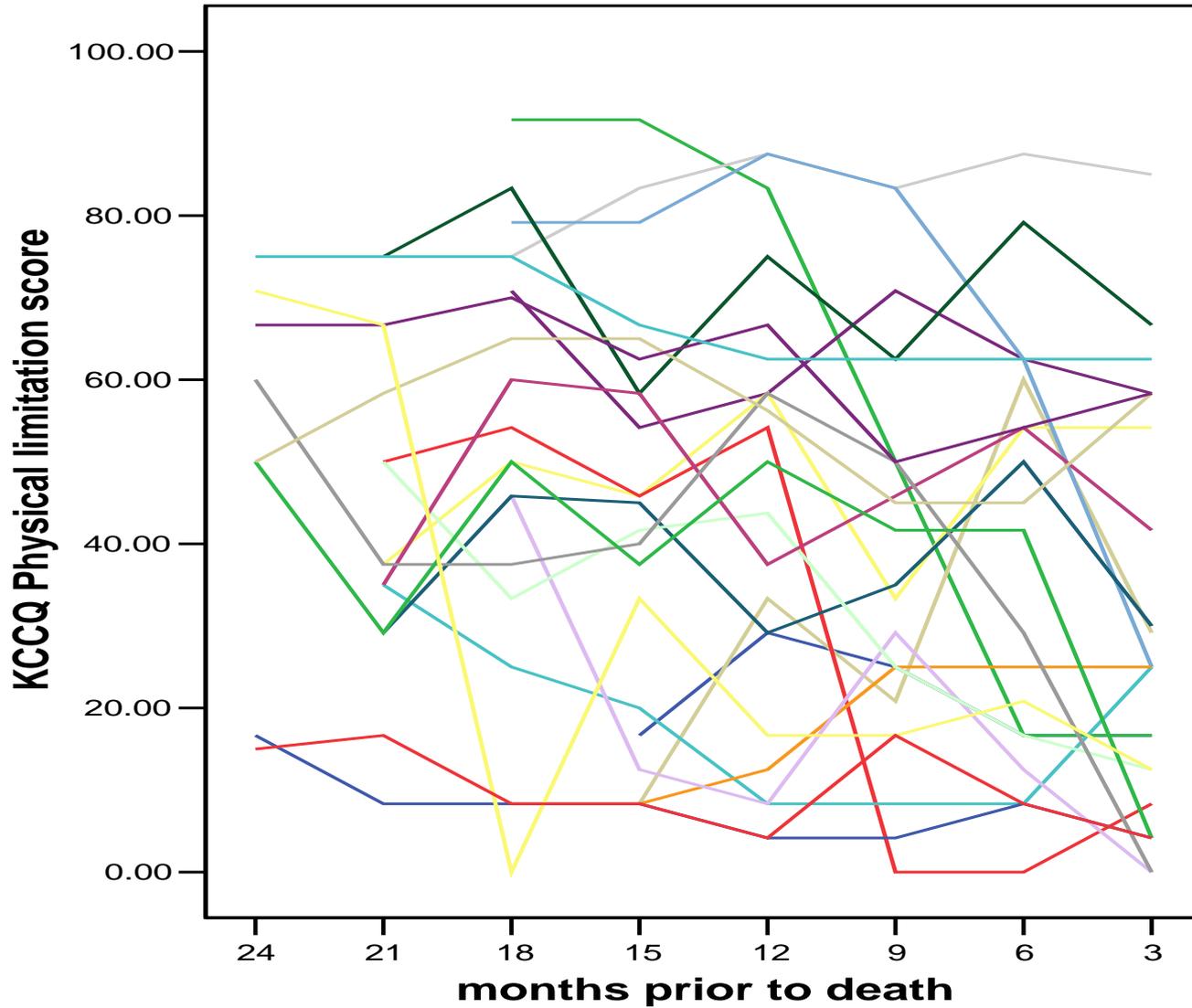
*She (Registrar) decided he needed a stomach x-ray because his stomach was very bloated....So less than an hour before he died poor man there were three of us trying to lift him onto an x-ray plate...He was talking to me and I knew that he knew he was dying, there was no 2 ways about it (Wife, aged 47).*



- Few bereaved carers reported receiving any **bereavement support**, although all would have welcomed this. At the very least, a condolence letter from the GP practice was expected.
  - *I never head another word from the practice at all...I got nothing from his GP. Not even a phone call or anything, (Daughter, aged 54).*



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# A pilot study to explore palliative care needs in COPD

Merryn Gott, Sarah Barnes, Sheila Payne, Neil Small, David Seamark, David Halpin, Charlotte Ruse, Clare Gardiner.

Funded by the Dunhill Medical Trust



## Funded by Dunhill Medical Trust 01/2008 – 01/2009

- 64 patients aged 53-89 years with moderate and advanced COPD & 16 nominated carers were recruited from primary care practices in Barnsley and Honiton
- Completed questionnaires exploring quality of life and service use
- In-depth interviews with 21 patients
- Five focus groups with 39 primary and secondary care clinicians



## Findings

- Patients reported a **high symptom burden**
  - *Right from the morning when I wake up, my first thought isn't about what are we going to do today, it's about am I going to breathe...*
- Evidence of **reduced quality of life**
- Evidence of **depression** in one fifth of patients
  - *I think I'm going to struggle....it's a financial struggle if I can't work....a physical struggle if I can't breathe...which would lead to a mental struggle.*



## Findings

- **Access to specialist services was very limited** – none reported SPC input, only 1 reported having been visited by a social worker, although 24 reported receiving help with personal care from a family carer
  - *I worry what I would do if something happened to my husband. I'd have to be in a home.*
- Carer scores on the FACQ-PC were comparable to a cancer sample



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## Findings

- **Patient understanding of COPD** was poor
  - 34/64 patients knew their condition was called ‘COPD’
- Many HCPs over-estimated the extent to which patients understood their condition
  - *R: So from your experience patients with COPD are aware of their diagnosis?*
  - *GP3: Absolutely, yes*
  - *GP2: Yes*



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## Findings

- No patients reported having discussed prognosis or ACP with a clinician
- However, **many had concerns about death**
  - *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.*
- A minority of participants confirmed that **not thinking about dying** was an important coping strategy for them
  - *I'm just living day to day, week to week...I'm not maudlin thinking about how much worse it could get.*



## Findings

- Clinicians confirmed that **they rarely discussed prognosis with COPD patients:**
  - *GP: I think we discuss it particularly badly, what their prognosis realistically is. I think because it's not classed as a terminal illness even though it's a life ending illness, that it's very difficult to turn around to somebody and say 'you're going to die'.*
  - *Registrar: Unfortunately we normally end up doing it when things are in extremis, it's very hard to actually find out from patients themselves at that point, you talk to relatives and, which does make things a bit difficult.*



## Key barriers

- Too little time, no training, 'where', patients too old, patients too young, patients too well, patients too ill.....
- Conflict between palliative care and chronic disease management
  - *Oxygen nurse: because it's not curable then the aims are to keep people as well as they can for as long as they can. So your aim is to try and motivate somebody into doing more, keep up with the exercise and this that and the 'other...If you then turn round and say we want to get you going but you're going to die, it's just crossed messages isn't it, so.. you know a lot of people say why should I if I'm going to die at the end of it anyway?*



# Transitions to palliative care for older people in acute hospitals

Merryn Gott, Christine Ingleton, Jane Seymour, Mike Bennett, Bill Noble, Mark Cobb, Clare Gardiner.

Funded by the Department of Health, SDO.



## Aims

- To examine how and when transitions to a palliative care approach are made within two UK acute hospitals.
- To explore how communication about a transition to a palliative care approach is communicated to patients and families.
- To identify the proportion of 'avoidable' hospital admissions amongst inpatients with palliative care needs and cost these economically. This will enable the case for moving a proportion of palliative care management from acute to community settings to be explored.



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## Methods

- Phase 1: focus groups
- Phase 2: census of palliative care needs
- Phase 3: individual interviews 6 months apart
- Phase 4: focus groups



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# Older people and the 'good death'



## 'A good death'

- 'Palliative care identifies itself as something beyond a technical discipline, it incorporates a philosophy of care. The philosophy should be viewed as a moral tale or cultural script (Seale, 1998). ...The palliative care movement has advocated a concern with quality of life as its defining focus....Integral to the understanding of quality has been a particular version of the 'good death' (Walter, 1994).'

Gott et al, 2008: 114

- 'The understandings of the 'good death' have become little more than a shallow caricature of the original rich vision of the hospice founders ...'

Seymour, 2007: 10



## **'A good death'**

- Pain free death
- Open acknowledgement of the imminence of death
- Death at home, surrounded by friends and family
- An 'aware' death in which personal conflicts and unfinished business are resolved
- Death as personal growth
- Death according to personal preference and in a manner that resonates with a person's individuality



## Pain free death

- High prevalence of unmet symptom needs in both HF and COPD. Concerns expressed about pain.
  - *Is dying going to be painful? I'm frightened of pain. I'm no hero. So that's the only concern I have, not am I going to die, but how am I going to die?*
- However, in both HF and COPD, there was more concern expressed about *'suffocating to death'*



## Open acknowledgement of the imminence of death

- Few reports of discussions of prognosis in either HF or COPD.
- However, many participants acknowledged there was *'more behind than in front'* because of their age.
- Yet 'dying old' wasn't necessarily seen as easier: *'I don't want to die yet, even though I'm old'*.
- Not thinking about dying was seen as an important coping strategy in managing the day-to-day reality of living with a chronic condition: *'you tell yourself you're going to get better'*.



## Death at home

- Ideal, but not realistic
  - *My main concern is dying alone. I've been told bluntly that there's a 90% chance I'll die in my sleep, but I'd hate to think I'll go like that. I'd like a few hours warning. And also loneliness is my main concern, but what can you do about that?*
- Borne out by statistics showing a rise in deaths in hospital, particularly in 'non-cancer'
- Some early evidence from SDO study that ('generalist') clinicians don't see hospital as an appropriate setting to receive palliative care
- Potential conflict between practice/policy priorities and older people's preferences



## Death according to personal preference

- *‘Now a person facing death is preferably a knowledgeable consumer, and end of life care a menu of choices or ‘wishes’ to be selected’ (Seymour, 2007)*
- Lack of opportunities for patients to express preferences (or have information on which to base them) identified
- However, also few preferences for personal control over the nature of dying identified
- Decision making underpinned by an equal, if not greater, concern for the family rather than for the individual
- Decision making also heavily influenced by perceived role/experience of ‘deep old age’ in contemporary society
  - *I don’t want to end up housebound....No I wouldn’t want to live if I have to have a life like that.*



All people approaching the end of life need to have their needs assessed, their wishes and preferences discussed and an agreed set of actions reflecting the choices they make about their care recorded in a care plan (DoH, 2008).

### Presupposes:

- We can identify those approaching 'the end of life'
- People know they have a life limiting illness and want to discuss this
- People have the information on which to form wishes and preferences
- People want to, and are able to, form wishes and preferences
- Wishes and preferences can be acted upon
- People act out of individual interest
- Preferences and choices are context free and 'rational'



## Challenges

- How to develop models to improve generalist palliative care provision (within the context of shrinking health and social care budgets worldwide)?
- How to capture and ensure older people's views are heard by practice and policy makers?
- How to learn from international examples of best practice?
- How to build research capacity in this area?



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## References

- Aldred H, Gott M, Gariballa S. Advanced heart failure: impact on older patients and informal carers. *Journal of Advanced Nursing* 2005; 49(2):116-24.
- Barnes S, Gott M, Payne S, Parker C, Seamark D, Gariballa S, Small N. Recruiting older people into a large, community-based study of heart failure. *Chronic Illness* 2005; 1: 321-329.
- Barnes S, Gott M, Payne S, Parker C, Seamark D, Gariballa S, Small N. Communication in heart failure: perspectives from patients and primary care professionals. *Journal of Health and Social Care in the Community* 2006; 14(6): 482-490.
- Barnes S, Gott M, Payne S, Parker C, Seamark D, Gariballa S, Small N. Characteristics and views of family carers of older people with heart failure. *International Journal of Palliative Nursing* 2006;12(8): 380-389.
- Barnes S, Gott M, Payne S, Parker C, Seamark D, Gariballa S, Small N. Prevalence of symptoms in a community-based sample of heart failure patients. *Journal of Pain and Symptom Management* 2006; 32(3): 208-216.
- Barnes S, Gott M, Payne S, Parker C, Seamark D, Gariballa S, Small N. Predicting mortality among a community-based sample of older people with heart failure. *Chronic Illness* 2008; 4(1): 5 - 12.
- Clark A, Seymour J, Sanders C, Gott M, Welton M. Evaluating a peer education programme for advance end-of-life care planning for older adults: The peer educators' perspective. *Int J Disabil Hum Dev* 2009;8(1):in press.
- Clark D. Between hope and acceptance: the medicalisation of dying. *BMJ* 2002; 324: 905-907.
- Clarke A, Seymour JE, Welton M, Sanders C, Gott M, Sharpe I, Thompson D, Richards M, Franklin C, Cock M. *Opening the door for older people to explore end of life issues* 2006; London: Help the Aged.
- Gardiner C, Gott M, Payne S, Seamark D, Small N, Halpin D, Ruse C, Barnes S. Living with advanced COPD: patients concerns regarding death and dying. *Palliative Medicine*. In press.
- Gott M, Ahmedzai SH, Wood C. How many in-patients at an acute hospital have palliative care needs? Comparing the perspectives of medical and nursing staff. *Palliative Medicine* 2001; 15(6): 451-60.
- Gott M, Seymour J, Bellamy G, Ahmedzhai S, Clark D. Older people's views about home as a place of care at the end of life. *Palliative Medicine* 2004; 18(15): 460-67.

Gott M, Barnes S, Payne S, Parker C, Seamark D, Gariballa S, Small N. Predictors of quality of life in older people with heart failure recruited from primary care. *Age and Ageing* 2006; 35(2): 172-177.

Gott, M, Barnes S, Payne S, Parker C, Seamark D, Gariballa, S, Small N. Patient views of Social Services provision for older people with advanced heart failure. *Health and Social Care in the Community* 2007; 15(4): 333-342.

Gott M, Barnes S, Payne S, Parker C, Seamark D, Gariballa S, Small N. Dying trajectories in heart failure. *Palliative Medicine* 2007; 21: 95-99.

Gott M, Small N, Barnes S, Payne S, Parker C, Seamark D, Gariballa S. Older people's views of a good death in heart failure: implications for palliative care provision. *Social Science and Medicine* 2008; 67(7): 1113-1121.

Gott M. At odds with the end of life care strategy. *Nursing Older People* 2008; 20(7):24-7.

Gott M, Gardiner C, Payne S, Small N, Seamark D, Halpin D, Ruse C, Barnes S. Barriers to advance care planning in COPD. *Palliative Medicine*. In press.

Gott M, Ingleton C, Gardiner C, Ryan T, Seymour J, Noble B, Bennett M, Cobb M. How can we improve end of life care for older people in acute hospitals? *Nursing Older People*. In press.

Gott M, Gardiner C, Payne S, Small N, Seamark D, Halpin D, Barnes S. Discussing prognosis in COPD: patient views. *Respiratory Medicine* (under review).

Gott M, Gardiner C, Payne S, Small N, Seamark D, Halpin D, Barnes S. The impact of Shipman on prescribing for dyspnoea in end stage COPD. *Progress in Palliative Care* (under review).

Gott M, Ingleton C. (eds). *Living with Ageing and Dying: International Perspectives on End of Life Care for Older People*. (In preparation). Oxford: Oxford University Press.

Ingleton C, Gott M, Kirk S. The beginning of the end (of life care strategy). *Journal of Clinical Nursing* 2009; 18: 935-937.

Ryan T, Ingleton C, Gott M, Gardiner C, Nolan M. End of life care in dementia. *Nursing Older People*. In press.

Sanders C, Seymour J, Clarke A, Gott M, Welton M. Development of a peer education programme for advance end of life care planning. *International Journal of Palliative Nursing* 2006; 12(5): 214-223.

Sargeant A, Payne S, Gott M, Small N, Oliviere D. User involvement in palliative care: Motivational factors for service users and professionals. *Progress in Palliative Care*, 2007, 15(3), 126-132.

Seymour J, Bellamy G, Gott M, Ahmedzai S, Clark, D. Using focus groups to explore older people's attitudes to end of life care. *Ageing and Society* 2002; 22(4): 415-426.

Seymour J, Bellamy G, Gott M, Clark D, Ahmedzai S.H. Good deaths, bad deaths: older people's assessments of risks and benefits in the use of morphine and terminal sedation in end of life care. *Health, Risk and Society* 2003; 4(3): 287-303.

Seymour J, Witherspoon R, Gott M, Ross H, Payne S. (2005) *End of Life Care: Promoting Comfort, Choice and Well-being for Older People*. Bristol: Policy Press.

Seymour JE, Sanders C, Clarke, A, Gott M, Welton M, Sharpe I, Thompson D, Richards M, Franklin C, Cock M. *Planning for Choice in End of Life Care. An Educational Guide* 2006; London: Help the Aged.

Seymour J. Windows on suffering: sociological perspectives on end of life care. *British Sociological Association Medical Sociology Conference*, September, 2007.

Shipman C. et al (2008) Making a difference. Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups. *BMJ* 337:a1720.

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*. In press.

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