

University of Southampton

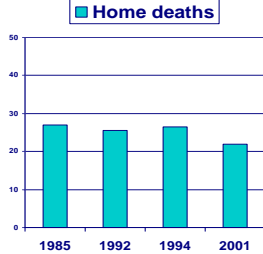
Where do people want to die?

Professor Julia Addington-Hall
Chair in End of Life Care

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Home deaths in UK are declining

- Most cancer patients would prefer to remain at home
- but most of them die in institutions
- Home death paradox (Thorpe, 1993)



Year	Home deaths
1985	~28
1992	~26
1994	~27
2001	~22

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Increasing home deaths

- Government policy to increase the proportion dying in place of choice
- with expectation that for vast majority this means home
- good fit with emphasis of Department of Health on promoting patient choice
- Also driven by expectation of cost-savings??

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Initiatives to increase home deaths

- Using existing community services differently
- Innovative service developments
- Palliative care education for health professionals
- Support and education for informal caregivers
- End of life care pathways
- Primary care palliative care registers

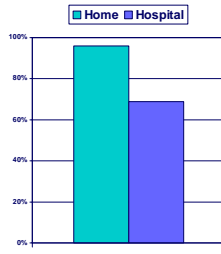
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Obviously a good thing?



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Place of death was right place

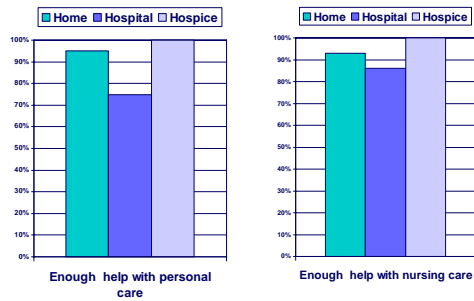


Place of death	Percentage
Home	~95%
Hospital	~70%

Yes, it was the right place

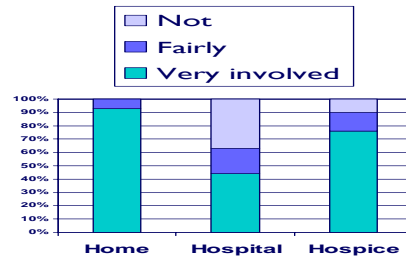
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Care in last 3 days of life, by place



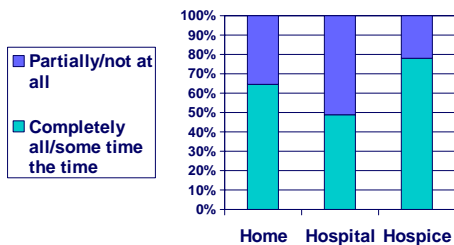
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Involvement in care decisions, by place



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Pain control in last 3 days, by place



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A good thing all round?

- Patients get better care
- As well as the care they want
- Consistent with the politicians' agenda of promoting patient choice
- And it may reduce healthcare costs

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But ...

- The evidence-base for the focus on home deaths is not as robust as has been claimed
- If we fail to understand it properly, we will not take a balanced look at this important issue
- This will ultimately lead to some patients and families receiving sub-optimal care, and, in some cases, being set up to fail
- And to ignoring important problems

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So,

- Look critically at:
 - the literature on preferences for home death, and at the notion of 'preferences' in this context
 - at whether dying in place of choice matters to patients
 - at whether some patient groups are at particular risk of being disadvantaged by the focus on home deaths
 - At the impact on carers
 - And at the importance of improving care for those dying in hospital



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Preferences for home deaths

Higginson and Sen-Gupta (2000)



- **18 studies;**
 - 9 with major deficits
 - Only 2 were longitudinal
- **5 of general public:**
 - 51% - 91% preferred home death
- **13 patient studies:**
 - all > 50% preferred home death
- **Concluded that most cancer patients want to die at home**

13  

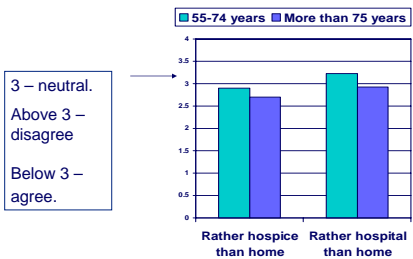
Not by all ...

Thomas et al, 2004

- longitudinal qualitative study of terminally ill cancer patients in UK
- 24% preferred home, 20% hospice, 22% home or hospice

14  

Older peoples' place of death preferences





3 – neutral.
Above 3 – disagree
Below 3 – agree.

General Practice patients in London. Catt, Blanchard, Addington-Hall, Zis, Blizard, King (2005).



Preferences change over time?

- **Hinton (1994).**
90% of home palliative care patients preferred home at first – 50% did so later in illness
- **Townsend et al (1990).**
67% preferred home under ideal, but 49% under existing, circumstances

16  



Do many people have preferences?

- **Karlsen and Addington-Hall (1998)**
According to bereaved relatives, 38% expressed a preference – 75% of whom wanted to die at home
- **Brazil et al (2005)**
Again, according to bereaved relatives, 68% expressed a preference, 63% of whom wanted to die at home
- **Thomas et al (2004)**
Qualitative prospective study; 76% expressed a preference

17  



Do clear, certain preferences 'exist'?

- Or are they artefacts of the quantitative research methods used?
- **Thomas et al (2004)** observed when using qualitative methods that:
 - preferences were not simple (or necessarily positive) choices waiting to be discovered,
 - but stronger or weaker leanings in a direction, qualified by speculation by how things might change with events

18  



Does dying in place of choice matter?

- Enabling patients to die in place of choice seen as part of enabling them to die with dignity by enabling them choice over their EOL decisions (Chochinov et al 2002)
- But a recent Canadian survey of hospitalised severely ill inpatients found that 'to die in the location of your choice' was rated as extremely important by only 17% of the sample (Heyland et al 2006)

19  



What was extremely important to patients?

1. To have confidence in your doctors	56%
2. Not to be kept alive on life support when there is little hope for recovery	56%
3. That information is communicated by the doctor honestly	44%
4. To complete things and prepare for life's end	44%
5. Not to be a physical and emotional burden on your family	42%
6. To have adequate care at home on discharge	42%
7. To have relief of symptoms	39%
24. To die in location of your choice	17%

20  



So, do cancer patients prefer home deaths?

- More patients than currently die at home would prefer to do so given ideal circumstances:
 - with sufficient support to avoid burdening their families,
 - and if able to retain their dignity, with controlled symptoms
- But many do not have well-formed preferences, despite what the literature suggests

21  


So, do cancer patients prefer home deaths?

- Others – perhaps particularly older people – prefer to die elsewhere, particularly in hospices
 - Do we know about the values and preferences of other potentially disadvantaged groups – for example, members of ethnic minority groups?
- And it may matter less than other aspects of EOL care to most people
 - Why does policy then focus on this aspect? Is it because it is easier to get other aspects of EOL care right at home – or for other reasons?



22  

Many people die in hospitals

- And will continue to do so
- **Dying in hospital can be associated with:**
 - High-technological interventions
 - Active treatments
 - Inadequate symptom control
 - Poor psychological and spiritual support
 - Little attention to needs of families
 - Inadequate nursing care

23  

- Research studies have demonstrated the challenges of providing high quality end of life care in hospital for 40 years
- Does the current focus on home deaths enable us to avoid this challenge by arguing that people shouldn't die in hospital?

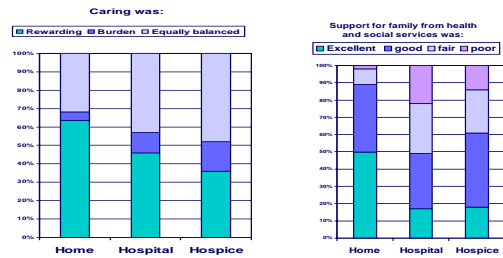
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Have to improve dying in hospital

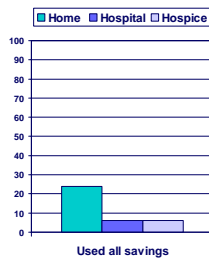
- Not avoid it by arguing that everyone (or nearly everyone) wants and should die at home
- People will continue to die in hospital during admissions for investigations for symptom control, during active treatment, unexpectedly, from choice ...
- Dying in hospital has to be a legitimate choice if families are not to be put under excessive pressure to take on or continue caregiving roles

Experiences of informal caregivers



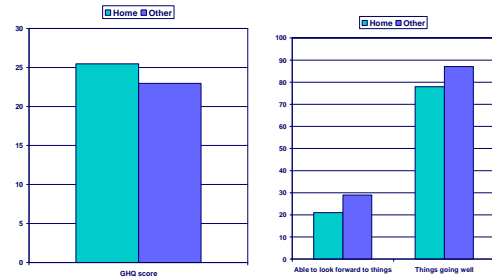
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Experiences of informal caregivers



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Do home deaths increase bereavement distress?



Data from RSCD. Spouses only. Addington-Hall and Karlsen (2000).



In conclusion

- Home death rates are low and there is much room for improvement
- But, evidence that 'most' cancer patients would prefer to die at home should be interpreted with care
- Need to recognise that most people will die in institutions – many in acute hospitals
- And (continue to) face the challenge of improving care in this setting



In conclusion

- this issue is a good example of the importance of reviewing critically the evidence underpinning health policy - even (or particularly) when it appears to be self-evidently good
- Policy and practice must be based on evidence – not ideology