

Understanding place of death for patients with non malignant conditions: a systematic literature review

Executive Summary

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Executive Summary

Background

Healthcare towards the end of life places major resource burdens on the NHS, with between 10-20% of all healthcare expenditure spent on care in the last year of life. As well as cost, the quality of end of life care is a growing priority for the public and for patients and their families, and this includes being cared for and dying in the place of their choice.

Most cancer patients (50-70%) prefer a home death, but this is not the reality they experience; in the UK, 59% of all deaths occur in hospitals, a further 17% in care homes, and only 18% at home, with marked regional variations.

For those with conditions other than cancer, the proportions dying at home differ markedly according to condition, with only 12% of deaths from respiratory or neurological causes occurring at home, and almost all dementia deaths occurring in care homes (55%) or hospital (39%).

High quality end of life care needs to occur in the preferred setting, and be supported by appropriate resources for that setting. The factors and preferences which influence place of death in cancer have been described, but much less is understood about these factors and preferences in non malignant conditions. This systematic literature review synthesizes the available evidence for the first time.

Aim

For those with advanced non malignant conditions, to identify, critically appraise, and synthesize the published evidence on:

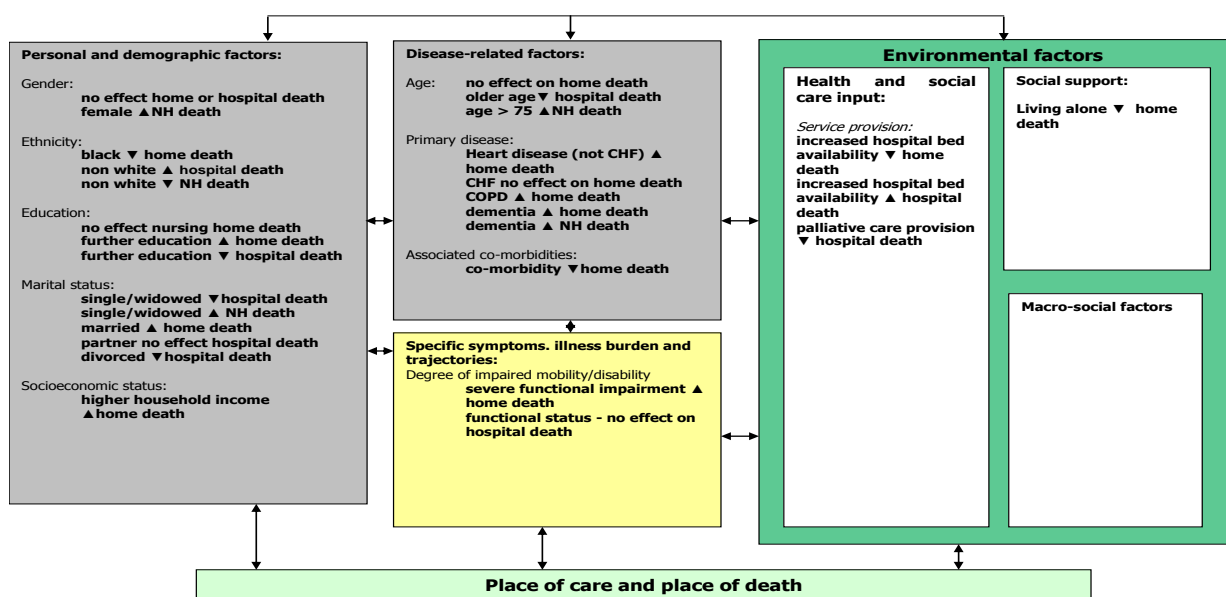
- Preferences regarding place of care and place of death
- Factors influencing place of death
- Key transitions towards end of life

Methods

Using standard systematic review methods, we identified, reviewed, and synthesized the national and international evidence on these areas. Both qualitative and quantitative evidence was identified, extracted, quality assessed, and synthesized. The strength of quantitative evidence was graded high, medium and low quality, and a narrative synthesis of qualitative evidence was produced to complement the quantitative findings.

Results

A conceptual model of the factors influencing place of care and death in advanced non malignant conditions has been developed, and in the context of this model, factors where there is moderate/strong quality and strength of evidence can be described:



Personal and demographic factors:

- Hospital deaths are more likely among minority ethnic groups
- Those more likely to live alone (single or widowed) are less likely to die at home, and more likely to die in care homes, while those who are married are more likely to experience home death.
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Disease-related factors:

- Higher levels of co-morbidity reduce the chance of home death, and increase the chance of hospital death.
- Illnesses where there is a longer trajectory of functional impairment (even if severe) are associated with increased home death (possibly because of the time available for planning and preparation)
- Older patients, especially those with dementia, are most likely to die in care homes

Environmental factors:

- Increased availability of hospital beds is consistently associated with reduced likelihood of home death and greater likelihood of hospital death, although the effect is small
- Greater palliative care provision (across conditions) reduces the chance of hospital death

Although environmental factors, including health and social care input, are perhaps most amenable to influence, there is relative little evidence as yet in this area.

The combined quantitative and qualitative evidence also reveals that:

- Just under half of patients with advanced non malignant conditions report a preference for home death (this is notably lower than among cancer patients).
- Among older people, across conditions, preferences for place of care and death are complex, highly dependent on circumstances, and may change over time.
- Across all conditions, considerations of carer/family burden (as well as personal considerations) are a major influence on the preferences of those with advanced disease, and this resonates with evidence on the factors which precipitate transition into hospital or nursing home care, and likelihood of death in those places.
- For those with chronic heart failure and chronic obstructive pulmonary disease:
 - the lack of a clearly predictable pattern of illness has a marked impact on awareness of deterioration and subsequent perspectives about place of care and death
 - preferences may not always be consistent with a desire for 'open' awareness of death

- Those who prefer hospital care may relate hospital to a sense of safety and/or the perception of better chance of survival.
- Those with long term neurological conditions may prefer to plan ahead, with often profound concern about burden on their family carers.
- Dementia is associated with greater odds of nursing home death, while co-morbidity is associated with reduced odds of home death.
- Other factors associated with increased likelihood of home death in non malignant conditions include being married, having further education, and having higher household income.
- Living alone, the absence of an informal carer, and cognitive impairment or dementia all reduce the likelihood of home death, increase the likelihood of transition into nursing home care, and increase likelihood of nursing home death.

Conclusions

The evidence on the factors influencing place of death in non malignant conditions is complex and inter-related. However, clear implications for practice, policy and research emerge from this synthesis of the evidence.

Practice and policy implications:

1. A preference for home death (while still common among non cancer patients) is less prevalent than for cancer patients, so attention should be given to achieving *preferred* place of care and death in non malignant conditions, wherever that place is.
2. For those with non-cancer conditions, the presence or absence of a family or informal carer is a key component in achieving home death. Effective and sustained carer support, especially in context of longer illnesses trajectories, is likely to increase home death rates.
3. Minority ethnic groups, and those with lower socio-economic status achieve lower rates of home death; best practice initiatives need to target this imbalance, while still taking *preferred* place into account.

4. For older people, advance care planning is especially important, as their preferences are complex, highly dependent on circumstances, and may well evolve over time. The advance care planning they require therefore needs skilled professionals who can re-visit preferences and planning sensitively and frequently in response to change.
5. In addition, older people are more likely to die in care homes, especially if there is cognitive impairment or dementia. Resources need to be targeted both at improving care home deaths and ensuring the opportunity for home death among older people (especially those who live alone) is adequately supported, when desired and feasible.
6. For those with end-stage heart or respiratory disease, the conception of an 'open' awareness of approaching death and forward planning of health care to accommodate decline (derived largely from models of care in cancer), is not always appropriate. Again, skilled advance care planning is important, to work across the range of awareness, and to respond to rapidly changing circumstances.
7. In those conditions with longer trajectories, for instance some long term neurological conditions, advance planning may be welcomed and home death can be supported even when there is marked functional impairment.
8. The increase in the ageing population, with correspondingly higher levels of co-morbidity, will likely mitigate against home deaths and in favour of hospital deaths, unless innovative approaches can be developed to support those with complex co-morbidities in the community.
9. Increased resources for the delivery of palliative care early in the illness trajectory across non malignant conditions will likely reduce hospital deaths.

Research implications:

There are major gaps in the current evidence to inform practice and policy, and research is particularly needed:

10. To provide insights into how preferences for place of care and death among those with advanced non malignant conditions evolve over time and with advancing illness, and what factors shape these preferences.
11. To understand how duration and trajectory of illness affect transitions in place of care, and place of death.
12. To determine how health and social care provision in non cancer conditions can influence place of care and death.