

# Factors influencing death at home in terminally ill patients with cancer: systematic review

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## Abstract

**Objectives** To determine the relative influence of different factors on place of death in patients with cancer.

**Data sources** Four electronic databases—Medline (1966-2004), PsycINFO (1972-2004), CINAHL (1982-2004), and ASSIA (1987-2004); previous contacts with key experts; hand search of six relevant journals.

**Review methods** We generated a conceptual model, against which studies were analysed. Included studies had original data on risk factors for place of death among patients, >80% of whom had cancer. Strength of evidence was assigned according to the quantity and quality of studies and consistency of findings. Odds ratios for home death were plotted for factors with high strength evidence.

**Results** 58 studies were included, with over 1.5 million patients from 13 countries. There was high strength evidence for the effect of 17 factors on place of death, of which six were strongly associated with home death: patients' low functional status (odds ratios range 2.29-11.1), their preferences (2.19-8.38), home care (1.37-5.1) and its intensity (1.06-8.65), living with relatives (1.78-7.85), and extended family support (2.28-5.47). The risk factors covered all groups of the model: related to illness, the individual and the environment (healthcare input and social support), the latter found to be the most important.

**Conclusions** The network of factors that influence where patients with cancer die is complicated. Future policies and clinical practice should focus on ways of empowering families and public education, as well as intensifying home care, risk assessment, and training practitioners in end of life care.

## Introduction

More than half of people with a progressive illness want to die at home.<sup>1</sup> Despite efforts to enhance home care worldwide,<sup>2</sup> preliminary data reported in the 2004 WHO analysis of palliative care showed that most people in the UK, the US, Germany, Switzerland, and France die in hospitals.<sup>3</sup> We determined the relative influence of different factors on place of death for patients with cancer and developed a model to explain the variations.

## Methods

### Theoretical model for study and analysis

We developed a conceptual model of place of death and its determinants on the basis of five relevant theories and models applied in health research.<sup>4-8</sup> Place of death may result from interactions between three main groups of factors: those related to the illness, the individual, and the environment.

### Search strategy

In September 2004, we searched four electronic databases (Medline, PsycINFO, CINAHL, and ASSIA) using MeSH headings (palliative care, terminal care, hospice care, terminally ill patients, hospice/s, death and dying, hospital and palliative nursing) and keywords. We also searched references from previous researches,<sup>1-9-11</sup> hand searched the most recent issues of six relevant journals (see [bmj.com](http://bmj.com) for details), and checked reference lists of retrieved articles.

### Selection criteria and data extraction

Studies were included if they reported original data testing the effect of predisposing variables on place of death. More than 80% of the patients had cancer. Predisposing variables were defined as those associated with patients dying in a certain place. We excluded studies with no assessment of place of death, with unknown diagnosis, exclusively on non-malignant diseases or children, on preferences or attitudes about place of death rather than actual place of death, and on association of place of death with subsequent events (such as bereavement problems) rather than predisposing factors (for further exclusion criteria, see [bmj.com](http://bmj.com)).

Data extraction was standardised (see [bmj.com](http://bmj.com)). We assessed a 20% random sample of papers to check the accuracy of the data extraction process.

### Quality assessment and grading evidence

We appraised the individual studies and evaluated their quality using a standardised scale (see [bmj.com](http://bmj.com)).<sup>12</sup> We developed detailed guidelines to ensure uniform criteria between reviewers and resolved disagreements by consensus. In addition to assessing the quality of individual studies, we graded the body of evidence (from multiple studies).<sup>13</sup> We determined three overall grades of the strength of evidence: high, moderate, low. These were assessed for each potential factor with an algorithm (see [bmj.com](http://bmj.com)).

### Data synthesis

We first described the included studies, but could not do meta-analysis because of heterogeneity, and grouped factors affecting place of death following the model by strength of evidence. They were analysed for the direction of the effect (home or hospital) and consistency of findings (number of studies reporting the same effect out of the total number of studies on the topic). We extracted and plotted odds ratios for high strength evidence.

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Details of the full search strategy, including key words (table A), the quality assessment scale, three extra tables (of high (table B), medium (table C), and low (table D) quality studies), and full references for all identified studies are on [bmj.com](http://bmj.com)



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Study settings and proportion of patients who died at home

Setting	No (%) of studies	Range of patients (%) who die at home
Home care	22 (38)	27-94
General (countries, regions)	22 (38)	5-75
Palliative care, hospice care	8 (14)	3-61
Hospital, cancer centre, oncology unit, tertiary facility, and patients with specific types of cancer	6 (10)	12-46
Total	58 (100)	3-94

Results

Characteristics of eligible studies and agreement between reviewers

We identified 224 articles from the electronic searches, excluding duplicates, and included 45 (20%) papers. Hand searching, references provided by key experts, and follow-up of reference lists added 16 papers (see [bmj.com](http://bmj.com) for full list of references). Most studies were in patients with cancer.

The results were gathered from over 1.5 million patients from 13 different countries, mostly from the UK, the US, Australia, and Canada (see tables on [bmj.com](http://bmj.com) for a full description of included studies).

Heterogeneity between studies

Studies were heterogeneous in five main areas: design, population, methods of data collection, categories of place of death, and quality. Only six studies were longitudinal. The proportion of home deaths varied according to setting (table). The quality of the studies was highly varied (quality scores ranged from 33% to 88%) (see [bmj.com](http://bmj.com) for details).

Factors affecting place of death and their relative effects

We found high strength evidence for 17 factors associated with place of death for patients with cancer and moderate strength evidence for 20. There were contra-

dictory findings for the influence of social conditions, marital status, and the direction of historical trends. The sensitivity analysis identified a further variable—the availability of home care.

Factors related to illness

Evidence was highly consistent for three factors: non-solid tumours, length of disease, and functional status (figure). Except in one dataset,<sup>14 15</sup> low functional status was associated with dying at home. Functional status was usually assessed when the patient was admitted to the service, not at the time shortly before death. There were conflicting results for pain.<sup>16 17</sup>

Individual factors

*Demographic variables*—Six high quality studies supported the influence of social conditions (such as education, social class, income), reporting data on over 1.3 million people in the UK, the US, Australia, and Italy.<sup>18-23</sup> Two other high quality studies, however, showed no effect.<sup>24 25</sup>

*Personal variables*—Home death was associated not only with a preference for the home but also by the expression of a preference,<sup>26</sup> confirmation from nurses,<sup>27</sup> and an agreement between the preferences of patients and carers for home death.<sup>28</sup>

Environmental factors

*Healthcare input*—Use and intensity of home care were associated with a home death, though this was not supported by one UK multivariate analysis.<sup>26</sup> Patients who died at home not only had more homecare input but also more frequent home visits. In the US, Italy, and Spain high quality evidence showed that people in rural environments are more likely to die at home,<sup>18 17 29</sup> but there were conflicting findings for Canada, Australia, and the UK.<sup>20 25 30-32</sup>

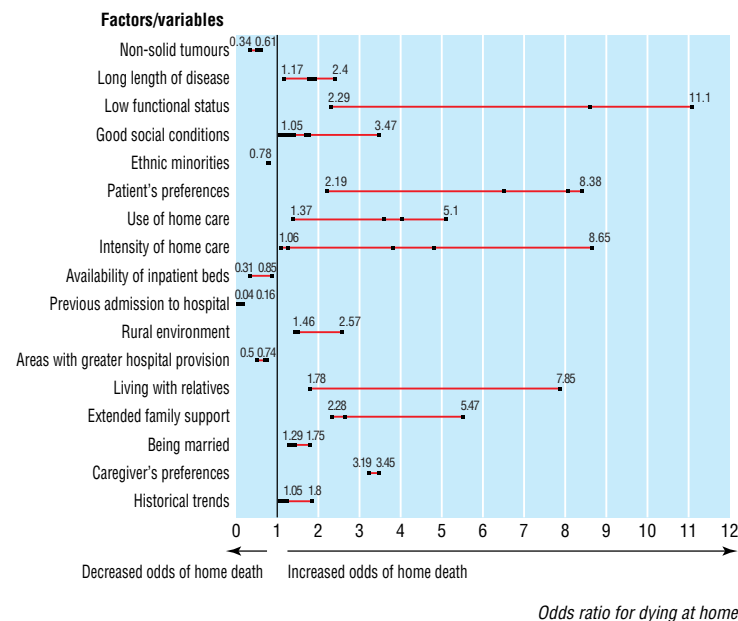
*Social support*—Social support influenced place of death through four factors: living arrangements (whether the patient was living with the spouse or the caregiver), the extent of family support (mainly the number of informal carers), marital status, and caregiver's preferences.

*Macrosocial factors*—Although there was high quality evidence supporting a trend towards home death in some areas of the US,<sup>29</sup> Italy,<sup>21</sup> and Canada,<sup>25</sup> the same number of medium quality studies suggested a trend towards admission to hospital in some other regions of the US and in Italy.<sup>18 33 34</sup> (Dying at home was less common in the UK than in Ireland and Italy.<sup>35</sup>

The final model

From the 17 factors with high evidence to support their effect on place of death, six were the most strongly associated with home death: low functional status, an expressed preference for home death, home care and its intensity (that is, frequent visits), living with relatives, and being able to count on extended family support. These factors showed the largest increase in the odds of dying at home, with maximum odds ratios ranging from 5.1 to 11.1 (figure).

Our final version of the model weighted the importance of the different groups of factors (related to illness, the individual, and the environment) and listed the variables with high evidence in each group (see [bmj.com](http://bmj.com) for model). Environmental factors were the most influential.



Factors with high strength evidence from 15 studies. Each point represents results on one study, except when study provided ranges, when both odds ratios are shown. Numbers indicate minimum and maximum odds ratios for each variable

## Discussion

We found strong evidence for the complicated network of factors that affect the place where patients with cancer die. Our review has several limitations: the completeness of search, heterogeneity between studies, criteria for grading the strength of evidence, classification of place of death, the state of knowledge on the topic, and the reliance on retrospective and cross sectional data in many studies. Thus, we show associations which do not necessarily indicate directionality or cause.

### Factors related to illness

The influence of such factors highlights the issue of the timing of palliative care. Patients with non-solid tumours may be less likely to die at home because they have multiple options for treatment, even in the advanced stages of disease. Their transition and referral to palliative care is often blurry or missed.<sup>30</sup> Two factors that enable planning and discussions about preferences were associated with home death: a long trajectory of disease and low functional status.

### Individual factors

Generally patients' preferences seem to have a powerful influence on achieving a home death. This might be due to patients' personal investment in attaining this end of life goal, but it also seemed to be mediated by a clearer recognition of the patients' preferences by the others involved in care—both professional and informal carers—presumably allowing the mobilisation of resources to fulfil that wish. The influence of social factors and ethnicity on place of death, however, raises the problem of equity as it may reflect a differential access to home care by socially disadvantaged people.<sup>9</sup>

### Healthcare input

The place where patients with cancer die depends heavily on the formal healthcare services available in their local area. There was, however, an apparent paradox for patients living in rural areas: these patients have increased difficulties in accessing health care<sup>36</sup> and palliative care,<sup>30</sup> yet they are more likely to die at

#### The different factors in the model

*Factors related to illness*—clinical changes that occur because of illness. These relate to what caused the disruption in patients' lives (the illness) and symbolise a threat to patients' continuity

*Individual factors*—account for the maintenance of patients' individuality, comprising demographic variables (relatively stable and unchangeable characteristics defining the patients' identity) and personal variables (which reflect the patients' beliefs, wishes, and inner resources to cope with the illness)

*Environmental factors*—contextual determinants that comprise variables related to the healthcare input available and received by the patients and carers, the patients' social support networks, and macrosocial factors (defined as determinants at a group or system level related to a certain sociohistorical moment, political approach, and culture defining a wide group of people)

#### What is already known on this topic

Numerous studies worldwide on factors affecting the place where terminally ill cancer patients die have resulted in three decades of fragmented evidence

#### What this study adds

There is high quality and consistent evidence for the effect of 17 factors on place of death

The most important factors linked to dying at home are patients' low functional status, patients' preferences, use and intensity of home care, living arrangements, and extended family support

Actions to enable people to die at home should focus on the empowerment of families, public education, home based models of care, assessment of risk, and training of practitioners in palliative care

home. Even in countries where this difference didn't seem to apply, such as in the UK, other geographical variations exist.<sup>20</sup> These differences question whether home deaths in some areas result from limited resources and lack of alternatives rather than preferences.

### Social support

The effect of patients' social support network mirrors the active involvement of families in end of life care. Our findings show that the sustainability of keeping terminally ill patients at home depends on how close the families are and how able they are to care for their loved ones. The sharing of responsibilities between family members, besides taking the burden of care from one person's shoulders, also offers a source of mutual support for carers.

### Macrosocial factors

Macrosocial forces might play a part on where patients die. Further comparisons between countries might determine the influence of different health policies and stages of development of palliative care, but also of different cultural beliefs and attitudes on place of death and dying at home.

### Support for current initiatives to improve home death

Our findings compel any initiative aiming to enable people to remain at home to respond adequately to all the identified risk factors.

Worldwide, many initiatives target some of these factors.<sup>37-44</sup> There are three main criticisms of these initiatives. Firstly, most are not horizontal programmes—that is, they do not address all key areas and risk missing important aspects. This is particularly conspicuous for risk assessment (see [bmj.com](http://bmj.com)). What is also worrying is when key areas can potentially be compromised—for example, as a result of changes in the organisation of the health system. That might happen with the new general practitioner contract in the UK, where general practitioners will be able to opt out of out of hours care. This may compromise the general

practitioners' ability to provide continued care to terminally ill patients at home (especially out of hours), which will not help to reduce crisis admissions to hospital.

Secondly, all current initiatives are focused on assessment and intervention. Preventive strategies such as raising public awareness of palliative care have not yet been regarded as a priority, although this could deal with risk factors before problems arise. Ways of helping families and enhancing their power are also still limited. Thirdly, there are still few data related to the evaluation of these initiatives, especially on their impact in place of death, which limits the extent to which we know if their goals are being achieved.

Actions to enable people to die at home should prioritise ways of empowering families and public education, balanced with a continuing effort to improve home based models of care (assuring intensive, sustained, and coordinated home care), early and continuous risk assessment, and training on palliative care not just for specialists but also for primary care professionals.

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## Endpiece

### Education

Education is not the filling of a pail, but the lighting of a fire.

William Butler Yeats (1865-1939).  
The Quotations and Sayings Database  
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