Research

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

For many people, home is more than a physical space; it represents familiarity, the presence of loved ones, and the possibility of enjoying "normal" life[1-3]—reasons why well over half of people with a progressive illness want to die at home.[4] Several countries are making substantial reforms to enhance home care.[5] In October 2004, both the United States and Australia announced further increases in funding for home care. The United Kingdom has invested £12m in the NHS end of life care programme (2003-6). Other initiatives are developing globally (for example, tele-homecare projects, paid leave for informal carers of dying patients in Canada).

Despite these efforts, 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.[6] In the UK, the proportion of home deaths for patients with cancer is falling, from 27% in 1994 to 22% in 2003.[7 8] The widening gap between preferences and reality is poorly understood because of fragmented research and conflicting findings.[9-11] 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

Taking previous models into account,[12-15] 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.[16-20] Place of death may result from interactions between three main groups of factors: those related to the illness, the individual, and the environment.

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 (see table A on bmj.com). In a previous systematic review we contacted more than 300 authors and researchers to identify grey literature on place of care and death in those with cancer.[4] Their references were accessed and searched. We assured the comprehensiveness of the search by scanning the references of three other reviews.[21-23] In addition, we hand searched the most recent issues of six relevant journals (*Palliative Medicine* (2003-4), *Journal of Palliative Care* (2003-4), *Journal of Pain and Symptom Management* (2003-4), *Journal of Palliative Medicine* (1998-2000 and 2003-4), *Supportive Care in Cancer* (2003-4), and *BMC Palliative Care* (2002-4, available online) and checked reference lists of retrieved articles.

Selection criteria

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 included any studies conducted in specific populations (for example, one sex only, patients with a specific type of cancer, patients cared for at home) but noted this in the quality assessment and synthesis.

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

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P+ *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.*
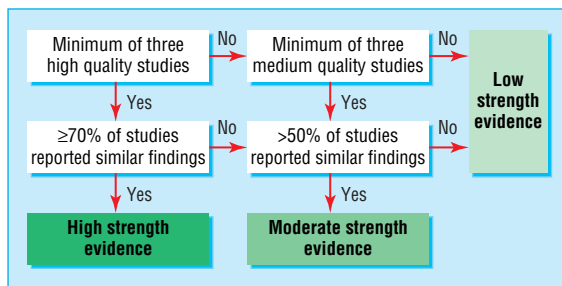
Fig 1 Algorithm for grading the strength of evidence. High quality studies had performed multivariate analysis and had a quality score of ≥70%; medium quality studies had multivariate analysis but a quality score of <70% or did not have multivariate analysis but had a quality score of ≥60%; and low quality studies had no multivariate analysis and a quality score of <60%. This method of grading evidence was based on a previous system used on risk factors,[27] similar to the SORT taxonomy, a patient centred approach to grading evidence.[28] To increase the methodological quality and robustness of the findings we raised the level for considering high quality scores for individual studies and high consistency of findings from 50% to 70%; said that high quality studies had to have used multivariate analysis; took high strength evidence exclusively from high quality studies; and required a minimum of three high quality or three medium quality studies about a topic

death with subsequent events (such as bereavement problems) rather than predisposing factors. We also excluded reviews, papers reporting duplicate data, comments, case histories, qualitative studies, historical, ethical or educational analysis, unpublished material, and papers not written in English, Spanish, Italian, or Portuguese.

Data extraction

Data were extracted to a standard form and datasheets under the headings of general information, eligibility criteria, study design, sample, assessment of place of death, factors, response rate, analysis, results, and quality assessment score. BG extracted the data from the papers. IJH 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).[24] Our quality appraisal focused on aspects relevant for observational studies—the most appropriate and frequent design for testing associations in the real world. We developed detailed guidelines to ensure uniform criteria between reviewers and resolved disagreements by consensus. The final quality score was expressed as a proportion, with higher scores meaning higher quality.

In addition to assessing the quality of individual studies, we graded the body of evidence (from multiple studies). This is a less common approach but is increasingly recognised as pertinent because it provides a conclusion that incorporates both outcomes and quality of studies.[25] Using the key elements for grading systems suggested by the US Agency for Healthcare Research and Quality[26]—quality, quantity, and consistency of the evidence—we determined three overall grades of the strength of evidence: high, moderate, low. These were assessed for each potential factor with the algorithm described in figure 1.

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 also conducted a sensitivity analysis to

determine whether a different grading threshold altered the findings. When relevant we have referred to variables for which there was low strength evidence in the results. We then extracted the odds ratios reported in the papers and plotted them for factors associated with place of death for which there was high strength evidence, and revised the model as necessary.

Results

Characteristics of eligible studies and agreement between reviewers

We identified 224 articles from the electronic searches, excluding duplicates, and included 45 (20%) papers (fig 2). Hand searching, references provided by key experts, and follow-up of reference lists added 16 papers. The 61 papers accounted for 58 original studies; one paper provided two different sets of data (which we considered as two different studies); four papers reported on secondary analyses (these were merged with the first report) (see bmj.com for full list of references). Apart from nine studies that included patients without cancer (between 3% and 18%), all other studies were conducted exclusively in those 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 B-D on bmj.com for a full description of included studies). We disagreed on the data extraction of two papers and the quality assessment of six papers. These were minor disagreements, however, and didn't alter the grading of the 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 1). Although home was the most common reference point in high quality studies (20 studies), it was compared with many places: metropolitan hospital, hospital, medical setting, hospital and hospice, institutional setting, acute hospital and chronic care facility, or elsewhere. Reflecting all these variations, the quality of the studies was highly varied (quality scores ranged from 33% to 88%).

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 (table 2). There were contradictory 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 (table 2). Except in one dataset,[30][31] 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: two studies reported no effect,[32][33] and two suggested that people who die at home may experience more pain.[15][34] There were few data on the influence of other symptoms and comorbidities, though two studies showed that people with more than one illness were more likely to die in hospital.[35][36]

Individual factors

Demographic variables—Six high quality studies supported the influence of social conditions (such as education, social class,

Table 1 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

income), reporting data on over 1.3 million people in the UK, the US, Australia, and Italy.[12 13 37–40] Two other high quality studies, however, showed no effect.[32 41] Sixteen high quality studies analysed age,[11 13–15 30 32 33 38–46] but the findings were extremely inconsistent, more often within than between countries.

Personal variables—Home death was associated not only with a preference for the home but also by the expression of a preference,[44] confirmation from nurses,[42] and an agreement between the preferences of patients and carers for home death.[47] Two weak studies suggested that increasing awareness of dying may be associated with a home death.[48 49]

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.[44] Findings were, however, consistent for the influence of the intensity of home care. Patients who died at home not only had more homecare input but also more frequent home visits. This effect was found to be more significant in the last weeks of life.[36 42] In the US, Italy, and Spain high quality evidence showed that people in rural environments are more likely to die at home,[12 34 45] but there were conflicting findings for Canada, Australia, and the UK.[37 41 50–52]

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. Seven high quality studies, including nearly 80 000 patients, showed that being married increased the chances of dying at home, though moderate quality evidence, the sensitivity analysis, and two other high quality studies did not support this finding.[30–32]

Macrosocial factors—Although there was high quality evidence supporting a trend towards home death in some areas of the US,[45] Italy,[38] and Canada,[41] the same number of medium quality studies suggested a trend towards admission to hospital in some other regions of the US and in Italy.[12 53 54] One study directly explored differences in place of death between countries and found that dying at home was less common in the UK than in Ireland and Italy.[55]

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 (fig 3).

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 (fig 4). Environmental factors were the most influential.
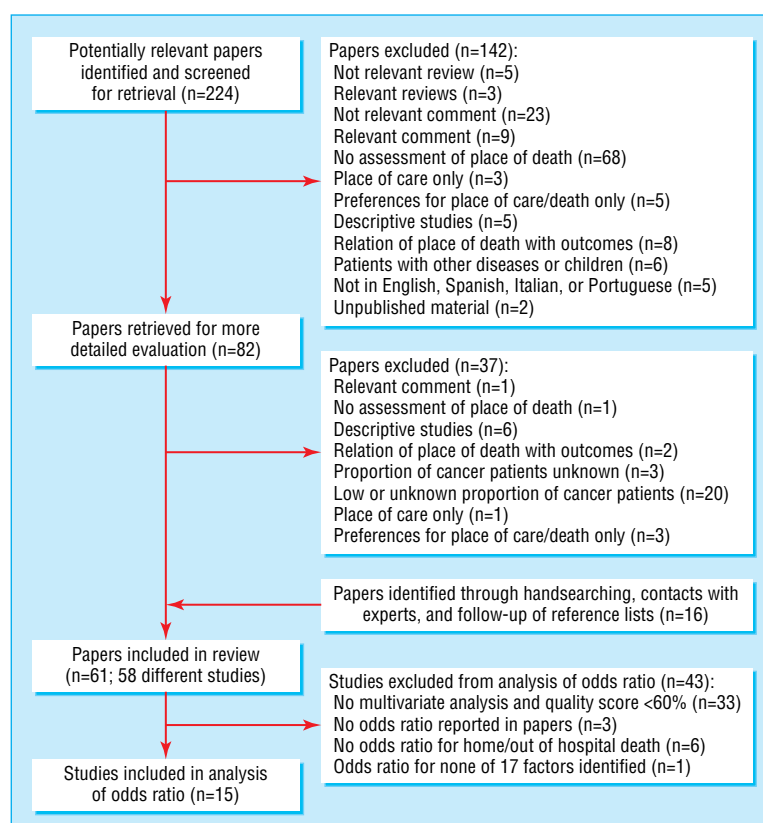

Fig 2 Flow of studies through review

Table 2 Factors associated with place of death, their grades and consistency

Variables	High strength evidence			Moderate strength evidence (death more likely in)	Sensitivity analysis (high and medium quality studies) Death more likely in
	Death more likely in	Consistency*	No of patients		
Factors related to illness					
Type of cancer:					
Non-solid tumours (leukaemia, lymphoma)	Hospital[11 12 38-40 43 50]	100% (7/7)	50 850		Hospital
Lung cancer				No effect	No effect
Prostate ; gastrointestinal tract; breast				No effect	No effect
Dying trajectory:					
Long length of disease†	Home[13 39-41 45 50]	100% (6/6)	53 113		Home
Low functional status‡	Home[14 15 33 42]	80% (4/5)	4 477		Home
Symptoms:					
Fatigue/weight loss/weakness; dyspnoea/breathlessness; nausea/vomiting; psychological symptoms				No effect	No effect
Pain				No effect	No effect/home
Individual factors					
Demographic variables:					
Good social conditions§	Home[12 13 37-40]	75% (6/8)	1 340 410	No effect	No effect
Ethnic minorities¶	Hospital[11-14 30 37 39 43]	100% (8/8)	1 341 480		Hospital
Sex				No effect	No effect
Personal variables:					
Patient's preferences	Home[33 44 46 47]	80% (4/5)	975		Home
Environmental factors					
Healthcare input:					
Use of home care	Home[38 45 50]	75% (3/4)	41 050		Home
Intensity of home care**	Home[15 30 33 43 46]	100% (5/5)	1 517	Home	Home
Availability of home care					Home
Availability of inpatient beds	Hospital[13 14 46]	75% (3/4)	8 174		Hospital
Previous admission to hospital	Hospital[15 33 42]	100% (3/3)	1 220		Hospital
Long length of admission††				Hospital	Hospital
Continuity and family physician support				Home	Home
Rural environment	Home[12 45 50]	75% (3/4)	46 304		Home
Areas with greater hospital provision	Hospital[11 13 41]	75% (3/4)	30 396		Yes
Social support:					
Living with relatives‡‡	Home[14 29 46]	100% (3/3)	3 803	Home	Home
Extended family support§§	Home[32 33 47]	100% (3/3)	943		Home
Being married	Home[11-14 38 45 50]	78% (7/9)	78 364	No effect	No effect
Caregiver's preferences	Home[33 42 47]	100% (3/3)	1 023		Home
Caregiver's age				No effect	No effect
Caregiver's sex				No effect	No effect
Caregiver's relationship to patient				No effect	No effect
Macrosocial variables:					
Historical trends	Home[38 41 45]	100% (3/3)	52 779	Hospital	Home/hospital

*Shown as percentage (No of high quality studies pointing in same direction/total No of high quality studies on topic).
†Assessed by No of days/months/years from diagnosis till death (with different cut points: 1, 2, 6, and 12 months).
‡Measured by activities of daily living and Karnofsky index, among other systems.
§Included living in areas of low deprivation, medium or high social class, higher level of education or increased years of study, and medium or high income.
¶Included non-whites, black minorities, Hispanics, immigrants, and those whose first language was not English.
**Assessed by No of homecare visits/week or total No of homecare visits.
††Related to No of days as inpatient (either at hospital or at hospice).
‡‡ Includes both living with spouse (as opposed to living alone) and living with caregiver.
§§Assessed by No of available caregivers and quality of family support.

Discussion

In this systematic review 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 could 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.[50] Two factors that enable planning and discussions about preferences were associated with home death: a long trajectory of disease and low functional status. Functional status is often used to predict the length of survival in terminally ill patients,[56] which is often the basis of referral to palliative care. The US Mortality Followback Survey, in patients with and without cancer, found that function acts as a "gatekeeper" to palliative care (which is mainly provided at home in the US), facilitating admission to these services for the most functionally impaired.[57 58]

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)

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.[21] Koffman et al found that despite wanting to be at home, many people from ethnic minorities feel they aren't provided with enough choice.[59] Possible explanations—whether environment, resources, housing, availability of private/statutory/voluntary care, or culture—need further investigation.
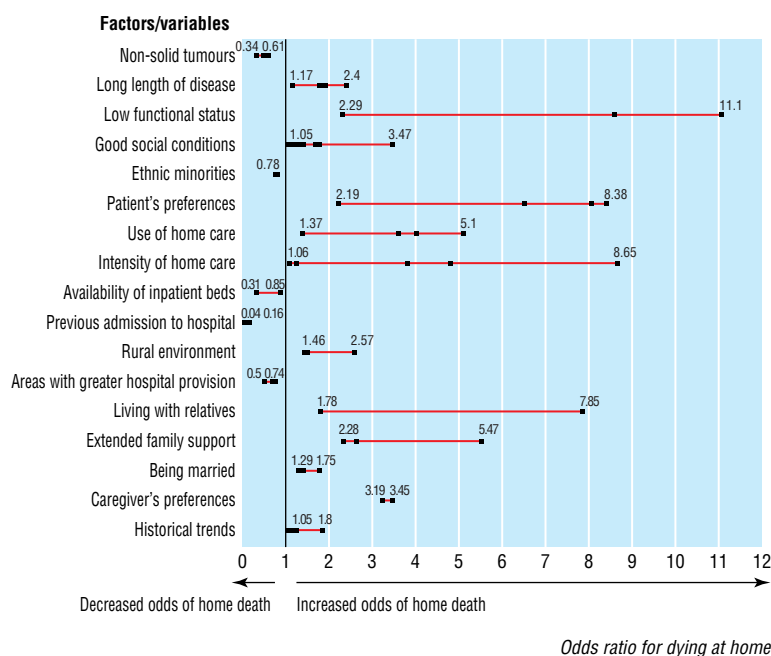

Fig 3 Factors with high strength evidence from 15 studies. Each point represents results on one study, except when study provided ranges, when both odds ratios are shown. Numbers indicate minimum and maximum odds ratios for each variable
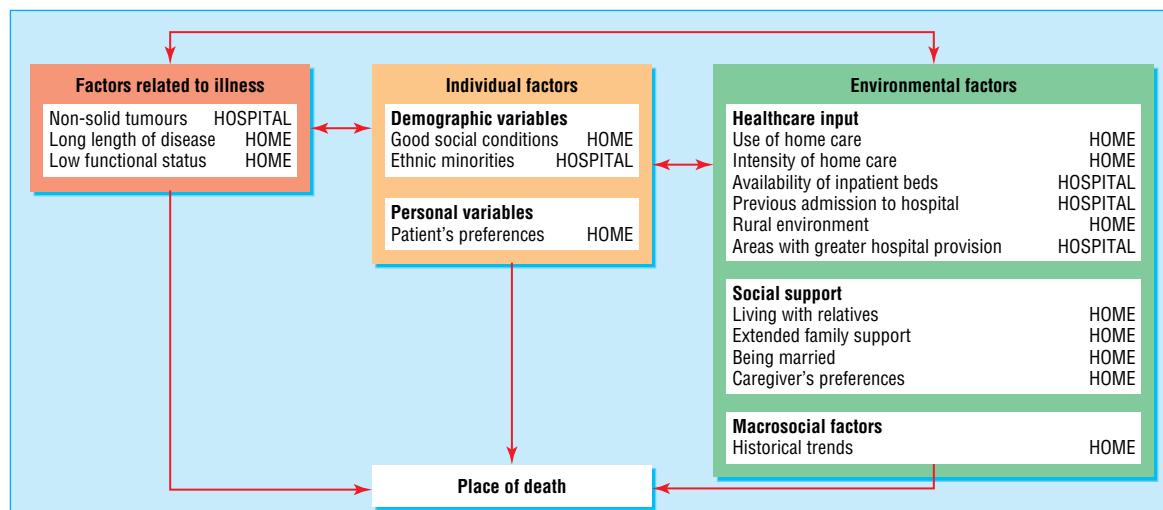

Fig 4 Model of variations of place of death

Healthcare input

The place where patients with cancer die depends heavily on the formal healthcare services available in their local area. Not surprisingly, contact with hospitals was related to hospital death, and provision of home care—particularly of intensive home care—with dying at home. There was, however, an apparent paradox for patients living in rural areas: these patients have increased difficulties in accessing health care[60] and palliative care,[50] yet they are more likely to die at home. Even in countries where this difference didn't seem to apply, such as in the UK, other geographical variations exist.[37] 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 at home. 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. More difficult though, is the scenario for those who live alone and have no family to take care of them. Our findings also revealed the importance of families' wishes for place of care and death, suggesting that a final decision on this matter is reached through negotiation between the patient and family.

Macrosocial factors

Although the effect of historical trends towards home death should be considered with caution, our findings suggest that 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: the three assessment tools developed in the UK documenting care progress and planning end of life care[61–64]; home based models of palliative care such as in North America where more than 90% of these services are provided at home; tele-homecare, used in the US, Canada, Japan, and Europe[65–68]; the inclusion of training in end of life care as mandatory for physicians; and the compassionate care benefits, in the form of a paid leave for carers of dying patients implemented by the Canadian government since January 2004.

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. By appraising the end of life tools, we found that they all showed gaps in some risk factors: the preferred place of care document is vague on assessing factors related to illness, probably because it is a record held by the patient[61 62]; the Liverpool care pathway misses the preferences of patients and families[63]; the gold standards framework offers detailed care planning yet overlooks patients' functional status, ethnicity, and caregivers' preferences.[64] 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

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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

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contract in the UK, where general practitioners will be able to opt out of out of hours care. We should be aware that 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, we identified two important gaps in current initiatives. All 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. Initiatives such as the Canadian compassionate benefits system should be taken up as examples of creative and fair measures to respond to families' needs. 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. The model represents an evidence based answer to the rights of terminally ill patients to die at home with dignity.[69] We strongly encourage its use in the development and evaluation of future strategies by policy makers to enable more home deaths and by practitioners to enable their patients to die at home if they wish so.

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