Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis

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Abstract

Aim: place of death is an important component of the quality of a person's death. The aim of this study was to undertake a systematic review and narrative synthesis of the literature concerning place of death of people with dementia and the preferences for location of death of people with dementia as well as family carers and healthcare providers preferred location of death for patients with dementia.

Methods and results: studies relying on death certificate data show that patients with dementia die more commonly in care homes than other locations contrasting with prospective studies which show that death is more common in own residence and hospital. Age (older), gender (male), availability of hospital and nursing home beds and enrolment in hospice, influence place of death. There is very limited evidence of patients, family carers and healthcare providers’ views on preferred location of death for patients with dementia and the only study included reported that, family carers views are more agreed to rather than patients own views regarding place of death.

Conclusion: this study on place of death raises exploratory questions on end-of-life care for patients with dementia which has implications on health and social care policies related to dementia.

Keywords: dementia, place of death, end-of-life care, older people

Introduction

Dementia is a major contributory factor to death in Western society. For 15% of all deaths in England between 2001 and 2009, some 631,078 people, Alzheimer’s disease, dementia or senility was mentioned on their death certificates [1]. The prevalence of dementia is increasing as the population ages, with Alzheimer’s disease affecting 20% of people over the age of 80: this creates challenges of meeting the support and care needs of people living and dying with dementia and meeting the costs of such care. While there is conflicting evidence whether people living with dementia at home have longer survival than those in care home [2, 3], it is clear that deaths in hospital are considerably more expensive to the health care system than those at home [4].

Dementia differs from other terminal illnesses in several respects. Progression is slow, over a period of several years and prognosis is very unpredictable. Patients and family often do not perceive dementia as a terminal illness: indeed, death is rarely due to dementia per se, more often due to intercurrent infections of the chest or urinary tract: people die ‘with dementia’ rather than ‘of dementia’. As dementia advances, cognition and communication channels become increasingly limited and decisional incapacity becomes almost universal: decisions must be made by surrogates guided by health and social care professionals rather than the patients themselves. Advanced Care Planning is thus of particular importance in dementia, fostering autonomous decision-making for when the person has lost their capacity to make such decisions: this has been strongly stimulated in
the USA since the introduction of the 1990 Patient Self-Determination Act.

Patient involvement in decisions concerning their care is a central component of high-quality End of Life Care (EOLC) (EOLC strategy). Patient participation in EOLC decisions in dementia depends upon their cognitive capability and care professionals’ abilities to communicate with them [5]. People with mild dementia have positive views towards being involved in decisions concerning their EOLC [6], although it is at times challenging to determine their views. However, in practice people with dementia are much less likely to participate in discussions concerning their future care than those with heart failure [7]: decisions about EOLC in Advance Directive documents are less often addressed in dementia than in other terminal conditions [8].

An important component of high-quality EOLC is receiving care and dying in the person’s preferred place (EOLC strategy); in practice, EOLC often does not meet patients’ previous wishes [9] including meeting their stated preference for place of death. Place of death is influenced by the nature of the final illness, the presence of co-morbidities, socioeconomic and personal care circumstances and age. Exploring with patients their preferences for place of care and death is thus an important part of conversations concerning their future care and EOLC. General practitioner (GP) awareness of where patients would prefer to die has been reasoned to be an important indicator of high-quality EOLC: one study found four-fifths of elderly patients who had discussed with their GP their preferred place of death died in that location [10].

Family carers frequently feel they lack knowledge concerning the end of life in dementia and worry about discussing EOLC prematurely, fearing that will affect their loved one’s future care adversely [11]. Although wanting to be involved in their relative’s EOLC decisions, they feel uncomfortable making decisions on their behalf in situations of uncertainty and express feelings of stress, guilt, fear, doubt and anxiety [11]. Although physicians, nurses and relatives agree on many aspects of EOLC decision-making for nursing home residents with dementia, relatives attach more importance than physicians to residents’ advance directives and have more permissive attitudes towards hastening death [12, 13].

It is thus important to investigate the views of people with dementia concerning place of death, and whether their views are consistent with those of their family carers and healthcare providers.

**Aims**

To undertake a systematic review and narrative synthesis of the literature concerning people with dementia with regard to:

- their place of death;
- their preferences for place of death;
- their family caregivers’ and health-care providers preferences for their place of death.

**Method**

Studies published in English language between 1985 and 2010 were identified through searches of electronic databases; AMED, BNI, CareData, CINAHL, EBMR, EMBASE, HMIC, Health Business Elite, Medline, PsychInfo and Social Science Citation Index. The Cochrane database, ASSIA and older people and dementia specialist resources (such as the Alzheimer’s Society library) were screened as were unpublished ‘grey’ evidence sources (research registers, conference proceedings, etc.). Hand searches were undertaken of two frequently cited journals, *Journal of Pain and Symptom Management* and *Journal of American Geriatrics Society*.

The search was developed with the support of a Medical School Library Information Technologist. Figure 1 summarises the final search terms subsequent to several iterations of development of the search strategy.

This broad search generated 4,148 titles that were screened to exclude articles that were clearly not pertinent to the reviews questions. The two authors read 49 abstracts independently to identify potentially relevant papers, with any disagreements resolved by discussion: the two authors then read 19 papers in full, of which 6 were agreed to meet study criteria (Figure 2).

Studies were excluded if

- not published in English language;
- primary focus on dementia in people under age 65;
- concerned with EOLC issues such as nutrition and pain relief but not having complete data on place of death;
- reporting only on factors influencing hospitalisation of people with dementia;
- contained only aggregate data on place of death (e.g. including nursing home deaths as deaths at home);
- guidelines or opinion pieces with no new empirical data.

![Figure 1. Summary of search strategies. (1) Search strategy for place of death; (2) search for patients, carers and healthcare professionals views on place of death.](image-url)
Data from each paper that were pertinent to the review questions were recorded in a study-specific data-extraction form. Both authors coded the extracted data from each paper independently, resolving disagreements by discussion. Data synthesis employed a narrative approach, a descriptive qualitative approach is now widely used in synthesis of heterogeneous studies [14]. The narrative approach is commonly used in understanding heterogenous data with contradictory layers of meaning and to understand the data in the context of social change [15]. The narrative approach also facilitates an investigation into how studies are structured, and the results, contested or accepted, which can help us describe, understand and even explain important aspects of a clinical issue in real-world [15]. This is very important in a study looking at place of death in dementia as care in dementia has evolved over very many decades. EOLC which plays an important aspect of holistic care in dementia is still an emerging concept with debates over how and when EOLC should be discussed with patients and carers [16]. Place of death has huge implications on EOLC and place of death in many ways is influenced by the availability of medical and social care in a country alongside cultural and traditional practices in providing care to the elderly with or without dementia. These complexities will be better served by using a narrative approach in understanding the studies included for the systematic review. The other reasons for using a narrative approach are due to (i) lack of methodologically rigorous in particular prospective studies which focus on place of death as primary measure; (ii) evidence to suggest that there is a lack of diagnostic accuracy in at least 25% of death certificate data, which is a wide margin leading to bias; (iii) engage in a discussion model to facilitate inclusion of place of death as an important issue to be considered while talking about EOLC issues in dementia. These issues are further explored in the discussion section. Each paper was weighted for its overall contribution towards answering the review questions using Gough’s ‘Weight of Evidence’ criteria [17] (Table 1).

Table 2 summarises the included papers; their aims, methods, key findings and weightings on Gough’s criteria.

Table 1. Gough’s ‘Weight of Evidence’ framework [17]

<table>
<thead>
<tr>
<th>Each paper is weighted (high, medium and low) on three initial criteria, followed by a fourth criterion combining these three:</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Coherence and integrity of the evidence in its own terms: a generic and non-review-specific judgement about the quality of execution of the study, either qualitative or quantitative, based on the generally accepted criteria for evaluating the quality of the types of evidence.</td>
</tr>
<tr>
<td>(2) Appropriateness of the form of evidence for answering the review question: a review-specific judgement about the research method and design employed for answering the review questions: the fitness for purpose of that form of evidence.</td>
</tr>
<tr>
<td>(3) Relevance of the evidence for answering the review question: a review-specific judgement about the relevance of the focus of the evidence for the review question: for example, the sample, type of evidence gathering or analysis that is central to the review question.</td>
</tr>
<tr>
<td>(4) Overall assessment of study contribution to answering the review question: a combination of these three sets of judgements combined to form an overall assessment of the extent that a study contributes evidence to answering the review question.</td>
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Results

Where do patients with dementia die?

Table 3 summarises the five papers providing data on place of death for people with dementia [1, 4, 18–20].

The three studies of death certificate data [1, 18, 19] all report death in dementia to be more common in care homes than other locations, with variation in place of death across European countries [18]. The oldest study [4] found hospital deaths to be more common (51%) than death in care homes (40%). One study [19] reports a higher percentage of deaths at patient’s own residence (54%) than any other locations: the study population was a selected group of patients enrolled in a home hospice programme for dementia: such enrolment increased patients dying at their preferred location of death.

Factors influencing location of death in dementia were investigated in four studies [1, 18–20]. Older age, male gender, availability of hospital were associated with hospital deaths, availability of nursing home beds was associated with
deaths in nursing home and enrolment in hospice was associated with deaths in own residence.

**Where would patients with dementia prefer to die?**

Only two small studies [19, 21] were identified that investigated dementia patients’ preferences for place of death: both studies were limited in the data provided. One did not report preferences for place of death per se, only that those enrolled with the home hospice for dementia were more likely to die at their location of choice (90 versus 45%; OR: 9.67, 95% CI: 2.6–27.0) and less likely to die in hospital (OR: 0.04; 95% CI: 0.01–0.2) [19]. The second, a small study of group homes for people with dementia in Japan reported that 14 residents preferred to die in group home (42%), 15 preferred home (46%) and none preferred hospital [21]. The authors state

<table>
<thead>
<tr>
<th>First author/publication</th>
<th>Study aims</th>
<th>Study method, population and time period</th>
<th>Key findings</th>
<th>Weight of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>National End of Life Care Intelligence Network Report [1]</td>
<td>To examine place of death for people for whom Alzheimer’s disease, dementia and senility were recorded</td>
<td>Retrospective death certificate data for place of death for those usually resident in England between 2001 and 2009 Included those who died with Alzheimer’s disease, dementia or senility</td>
<td>Most deaths occur in care homes fewer in hospitals ‘Senility’ associated with highest number of home deaths</td>
<td>HHH-H</td>
</tr>
<tr>
<td>Houttekier et al. [18]</td>
<td>To study the place of death of older people with dementia in Europe</td>
<td>Retrospective death certificate data on all deaths in 2003 of people aged 65 and older in five European countries (Belgium, Netherlands, England, Wales, Scotland)</td>
<td>Place of death depended on country of residence, age, sex, and availability of hospital and nursing home beds</td>
<td>HHH-H</td>
</tr>
<tr>
<td>Mitchell et al. [20]</td>
<td>To describe where older Americans in relation to state health system factors</td>
<td>Retrospective death certificate data in 2001 Included Alzheimer’s disease, vascular and unspecified dementias</td>
<td>Increasing nursing home and decreasing home and hospital death with increasing age Large variation in % of hospital deaths between states (5–37%) Highest proportion of hospital deaths in states with greatest provision of hospital beds, fewer nursing home beds and fewer decedents aged 85 and older</td>
<td>HMH-H</td>
</tr>
<tr>
<td>Lane et al. [4]</td>
<td>To compare location of death and previous residence among Medicaid eligible persons with Alzheimer’s dementia</td>
<td>Retrospective dementia register study of Medicaid eligible individuals in South Carolina 1988 to 1994 Included Alzheimer’s disease, vascular dementia, alcohol-related dementia and other conditions leading to dementia</td>
<td>Persons with dementia tended to live at home, but died in hospital</td>
<td>HHH-H</td>
</tr>
<tr>
<td>Shega et al. [19]</td>
<td>To evaluate the impact of hospice enrollment on terminal care of patients with dementia</td>
<td>Retrospective dementia register study of people with dementia enrolled with PEACE hospice programme who died 2000 to 2001</td>
<td>Patients enrolled with hospice more likely to die at home and in location of their choice compared to those not enrolled with hospice</td>
<td>MMM-M</td>
</tr>
<tr>
<td>Nakanishi and Hondo [21]</td>
<td>To clarify the processes of decision-making and end-of-life care for patients with dementia in group homes in Japan</td>
<td>Retrospective cross-sectional survey of group homes</td>
<td>Place of death influenced by staffing levels, staff training and family wishes concerning end of life care</td>
<td>MMM-M</td>
</tr>
</tbody>
</table>
that only six patients had died at their preferred place of death, although the authors do not report where these deaths occurred.

**What are the preferences of family carers and healthcare providers for location of death for patients with dementia?**

Only one small study was identified that addressed this question, again with very limited data [21]: the paper reports that in 32 out of 33 cases the wishes of family members for place of death was achieved but provides no information concerning what locations the family members had preferred. The present authors have been unable to obtain this information from the authors. No study was identified of healthcare providers preferred location of death for patients with dementia.

**Discussion**

**Summary of findings**

This review reveals that while there is some knowledge concerning place of death for people with dementia, very little is known about patient, family carer and health professional preferences or the extent to which patients discuss their preferences with their families and healthcare providers. Studies of death certificate data show that patients with dementia die more commonly in care homes than other locations: in contrast, prospective studies show that death is more common in own residence [19] or hospital [21]. In the only study that looked at preferences it appears that preferences of proxy decision-makers are met more often than those of the patients themselves.

**Strengths and limitations**

To our knowledge, this is the first systematic review of place of death and preferred place of death of people with dementia. Of the five studies of place of death, three [1, 18, 20] rely on dementia being included as a primary or contributory cause for death in death certificate data. Death certificates are an unreliable data source for the prevalence of dementia: <25% of people diagnosed with dementia during their life had this recorded as the underlying cause of death on death certificates [22].

Only two studies investigated patient preferences for location of death: one relied on carers’ opinions of patients’ preferences [19] and the second [21] had a small sample size. Only one study investigated family carers’ views. While factors influencing place of death such as age, availability of hospital and nursing home beds and patient’s preference were addressed in these studies, there are other important factors such as do not hospitalise orders [23], carer preference [21], physician attitude [13] and physician awareness of patient’s opinion [10] which influence place of death in dementia and have not been investigated in the literature to date.

**Comparison with existing literature**

A recent systematic review of EOLC in dementia [16] concluded that the literature is yet to address the particular challenges that dying with dementia poses and that there is a need for further investigation of interventions and outcome measures for EOLC in the settings where the majority of people with dementia live and die. This is consistent with the present review which has found very limited evidence concerning place of death and patient preferences for place of death in dementia.

It is of concern that one study of patient preferences [21] found the family’s wishes to be met more often that those of patients. Studies of EOLC in the elderly have similarly found care provided to have been provided at locations different from that desired by patients [9, 10]. In dementia, advanced directives concerning EOLC are frequently used to restrict rather than request care [8].

**Implications for policy and practice**

This study raises interesting issues in relation to EOLC for people with dementia which have implications for care provision and health and social care policy.

1. Despite evidence that moving into a care home setting is associated with reduced longevity and the difficulties of a hospital admission for a patient with dementia, it appears to be the case with the relatively limited data that the most common place of final days of life and place of death for a person with dementia is either care home or hospital.

2. There is very limited documentary evidence to say that discussions concerning place of death are included in advance directives or care planning involving healthcare providers, carers and patients with dementia.

3. Policy currently focuses mainly on place of death and in-patient admissions close to the end of life. Greater benefit might come from a greater focus on place of care, seeking to optimise the experience of patients as they approach their last weeks and days of life.

4. The EOLC wishes of people with dementia will have to be studied further alongside wishes of their carers and families. However, as a first step awareness and education about end-of-life issues in dementia will have to be disseminated to the wider public and among health and social care professionals.

Maintaining care at home until the end of life may often not be possible due to the long duration of the behavioural and dependency care needs associated with advanced dementia. While transfer to a care home setting may have adverse impact on longevity, adequate provision of appropriate long-term care facilities with staff skilled in the care of people with dementia could help optimise quality of EOLC and reduce undesired deaths in hospital. Such decisions might need to take into account not only health economic considerations but also patient and carer satisfaction with care and place of...
death. As people with dementia move towards the end of their lives, arguably, the focus may have to shift from hospitalisation, invasive medical treatments and harmful psychotropic drugs to the provision of a place of care, comfort and dignity.

Whenever possible, it is important to have these discussions with patients at appropriate times and settings, often several discussions over a period of time. Patient preferences can then be documented and shared with care providers in the future as part of an advance directive. Zweig and Meher suggest a four-step process in such EOLC planning [24]:

1. identify patient preferences;
2. communicate medical prognosis;
3. define goals of care and
4. implement a management plan consistent with those goals.

Implications for future research
This review has identified a paucity of literature concerning the review questions. Further research is urgently needed, both quantitative and qualitative studies, with patients, family carers and health and social care providers, investigating their preferences, attitudes and opinions concerning place of death in dementia and their perceptions of the facilitators and barriers to meeting patient preferences, in order to inform policy.

Conclusions
Place of care and place of death are important components of EOLC discussions with people with dementia. There is limited evidence on location of death and very little concerning preference over locations. Studies are urgently needed to investigate the factors that patients, family carers and clinicians consider when considering locations of care and death: in turn these will inform service provision and policy on long-term care and hospitalisation towards the EOL of people with dementia.

Key points
- People with dementia die in hospitals and in places of care.
- There is very limited evidence of patients, family carers and healthcare providers’ views.
- Where available, family carers views are more agreed to rather than patients own views.

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None declared.

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