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The ageing and de-institutionalisation of death—Evidence from England and Wales

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ABSTRACT

Increasingly, age of death is postponed until very old age, and care of those who are dying is challenged by medical co-morbidities and the presence of dementia. Although most people would prefer to die at home, currently in England and Wales only about 20 per cent of those aged 65 years and over die at home, and this proportion falls to about 10 per cent among those aged over 85 years. To explore recent and likely future trends in age and place of death, mortality statistics from 2006 to 2013 were analysed and projected to 2050 using age- and gender-specific rates. Results confirmed recent increasing age at death and indicated a trend for increasing proportions of older people to die at home. Projections indicated large increases in home-based deaths, particularly for men aged 65 and over. Consistent with people's wishes, there may be a partial return to the view that dying at home is a normal experience. Resource allocations are likely to need to shift to support people dying at home and their formal and informal carers.

1. Introduction, purpose, aims and background

Through the 20th century the world was ageing both at an individual and population level, and this is expected to continue across the 21st century [1,2]. In England and Wales, this ageing of the population saw life expectancies at birth increase from around 70 years (both sexes combined) years in the mid-20th century to around 80 years today, and they are expected to rise to 85–90 years by the mid-21st century [2]. Furthermore, the 21st century will be a century of centenarians. The number of centenarians in England and Wales is expected to increase from approximately 17,000 in 2015 to almost 300,000 by 2050 [3], but could reach 1.8 million [4]. This development will bring with it a new demography of death [2]. In the 1950s, the annual number of deaths in England and Wales was around 500,000. By 2050, the annual number of deaths in England and Wales will be approaching 700,000 and 94 per cent will be among those aged 60 years and over, with 73 per cent among those aged 80 years and over and almost 10 per cent among those aged 100 years and over.

The purpose of this study was to analyse recent trends in place of death in England and Wales and to project these trends into the future. The study was undertaken to examine how the provision of care and support for dying people may need to be re-assessed in coming decades. If death and dying should be de-institutionalised, then the onus of care and support around death and dying may well move to the family with support from community care workers. This could then raise concerns over the ability of community care workers to provide the magnitude of such support and of families to cope with the realities of providing support around death and dying.

The new demography of death, which is predicted for the 21st century, will pose challenges for the provision of end-of-life care of increasing numbers of extreme aged persons. This challenge is confounded by the prospect – for the time being at least – of an increasing number of these extreme aged persons living and dying with dementia, which is a major public health problem [5,6]. Across the more developed world certainly, end-of-life care has become a high profile issue, and a key element of this is where people die as this indicates where a person was receiving care at the end of life. If more people die at home, then the availability, quality and ability of home care has to be addressed [7].

A systematic review of the literature that analysed 210 studies reporting the preferences of just over 100,000 people from 33 countries, including 34,021 patients, 19,514 caregivers and 29,926 general public members, found that home is the preferred place of care and death for the majority of people and most do not change this preference. Estimates of a preference for dying at home ranged

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from 31 to 87 per cent for patients, from 25 to 64 per cent for caregivers, and from 49 to 70 per cent for the public [8]. Even when a caveat covering "no longer able to care for oneself" is added, the overwhelming preference is "home" [9].

Various national studies have researched place of death in recent years with a view to both elucidating the situation and to informing public health policy (for example, Refs. [7,10–12,13,5,14,15,16]). Much of the research has focused either on the whole population or on people with terminal illnesses such as cancer. Broad et al. [16] analysed place of death data from 45 countries and the proportion of deaths in hospitals ranged from 78 per cent in Japan to 20 per cent in China, and in the 21 countries with data on place of death of older people, a median of 18 per cent died in care homes. Utilizing death certificate data for 2003, Houttekier et al. [5] found in a five country European study that place of death was related to available hospital and nursing home beds.

Preferred place of death is a sensitive and difficult issue to investigate, and it should be remembered in considering any data around this that many individuals who do not die at home, although this may well be their stated preference, do so for very good reasons such as the need for medical care or extended nursing care in the time before death. Studies reveal that 50–70 per cent of cancer patients would prefer to be cared for and die at home (for example, Ref. [17–19]). In the period 1985–1994, patients with cancer in England were more likely to die in hospices than in hospitals or nursing homes [11], and the preference for hospice as place of death was highlighted in a later study by Thomas et al. [13].

2. Methods

2.1. Data sources

In this paper, we utilized place of death data for England and Wales for the 8 year period 2006–2013 and we considered specifically deaths of people aged 65 years and over. The data have been provided by the Office for National Statistics from the 'Mortality Statistics: Deaths Registered' publications from 2006 to 2013. In addition, future deaths data for England and Wales have been extracted from the 2012-based population forecasts of the Office for National Statistics.

2.2. Classification of place of death

In the data provided by the Office for National Statistics, place of death at different times is classified in one of seven main categories, namely *at home*, *care homes*, *hospices*, *hospitals* (acute or community not psychiatric), *psychiatric hospitals, other communal establishments*, and *elsewhere*. Furthermore, care homes are listed as local authority (LA) or non-local authority (non-LA); hospices as National Health Service (NHS) or non-NHS; and hospitals and psychiatric hospitals as NHS or non-NHS.

The classifications are:

Home is the usual residence of the deceased (according to the informant), where this is not a communal establishment;

Care homes include homes for the chronic sick, nursing homes, homes for people with mental health problems and non-NHS multifunction sites;

Hospices include Sue Ryder Homes, Marie Curie Centres, oncology centres, voluntary hospice units, and palliative care centres;

Hospitals (acute or community, not psychiatric, and NHS and non-NHS);

Psychiatric hospitals include psychiatric hospitals and units, nursing homes for people with mental health problems, care and rehabilitation homes for elderly people with mental health problems, and special security psychiatric hospitals;

Other communal establishments include schools for people with learning disabilities, holiday homes and hotels, common lodging houses, aged persons' accommodation, assessment centres, schools, convents and monasteries, nurses' homes, university and college halls of residence, detention centres, prisons, remand homes, young offender institutions, secure training centres;

Elsewhere includes all places not covered above. This category also includes people who are pronounced dead on arrival at hospital.

Care homes do not appear as a named category until 2010 and psychiatric hospital is no longer listed after 2009. While this means the categories for place of death are not comparable over the complete period 2006–2013, it is still possible to analyse over the whole period of observation for home, hospice, and hospital and over a shorter period of observation (2006–9 and 2010–13 respectively) for psychiatric hospital and care home respectively.

2.3. Analytic strategy

The analyses carried out are both retrospective and prospective in the form of projections. Retrospectively, death statistics for England and Wales have been analysed for the period 2006–2013 for the total number of deaths and more specifically for deaths among those aged 65 years and over (65+) and those aged 85 years and over (85+) respectively for males and for females separately. The prospective analyses have considered how projected mortality in England and Wales will impact on the distribution of deaths according to place of death to 2050 under two different place of death scenarios. Both scenarios are applied to the official ONS predicted number of deaths moving forward [2].

In the first scenario, simple linear models for the proportions of deaths by place of death based on 2006–2013 trends are utilized to estimate future place of death among both males and females aged 65+ and 85+ respectively. Age and gender specific proportions of deaths at home are then projected to 2050 using the predicted number of deaths moving forward [2]. This scenario assumes that the trends observed in 2006–2013 proportions with regard to place of death continue to 2050. The use of age classification 65+ and 85+ respectively is based on the data available from the Office for National Statistics.

In the second scenario, it is assumed that among those aged 65+, the 2013 proportion of home deaths remains constant. This is an attempt to reflect a situation where changing family structures and living arrangements may restrict the potential for home deaths and where hospice deaths may become a preferred option as a result.

These two scenarios are used to illustrate differences that could occur with regard to the future place of death, reflecting thereby different needs for care and support, both institutional and otherwise. The scenarios are not attempt to suggest the most likely outcomes, and other scenarios could be included but the number is limited to just two for ease of presentation and illustration.

3. Results

3.1. All deaths and deaths in old age

Mortality data for England and Wales reveal that over the period 2006–2013, the total number of deaths varied around 500,000 annually, with a peak of almost 507,000 in 2008 and a trough of just over 482,000 in 2011. Females accounted consistently for 52 per cent of the total number of deaths annually. In the same period, the number of deaths among those aged 65+ varied between just over 402,000 in 2011 to more than 427,000 in 2013, and there is an increasing proportion of the total number of deaths among those aged 65+. The death rates for males and females aged 65 +,

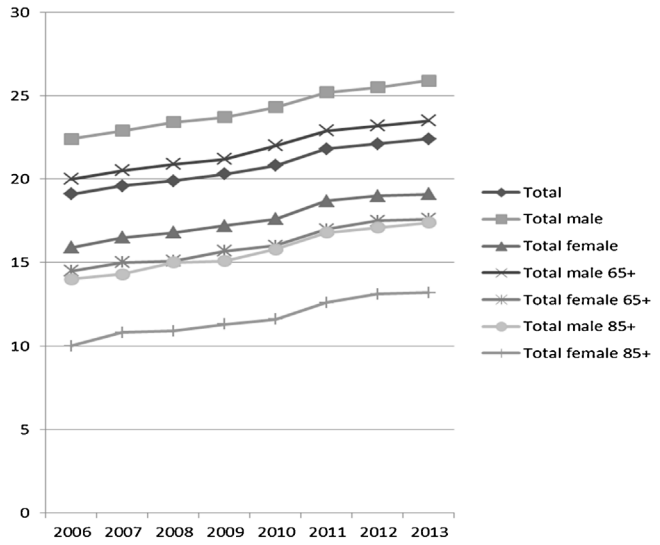

Fig. 1. The proportion of home deaths among all deaths for the groupings by age and gender, 2006–2013, England and Wales.

however, have declined steadily in the period observed, so that the increasing number of deaths does indeed reflect the strong ageing of the population.

The number of deaths among those aged 85+ has increased from 168,000 in 2006 to more than 197,000 in 2013, and the proportion of the total number of deaths among those aged 85+ has increased. Once again, however, the death rates for males and females aged 85+ have declined in the period observed.

Death is overwhelmingly institutionalised with only between 19 and 22 per cent of all deaths occurring at home in the period 2006–2013. Furthermore, this institutionalisation of death focuses primarily on care homes and hospitals, with only a modest proportion of deaths occurring in hospices. In the period 2010–2013, the proportion of care home deaths among both men and women dying aged 85+ increased. As far as deaths in hospitals are concerned, proportions have declined for both males and females aged 65+ and aged 85+, and in this instance in both age groups males are more likely than females to die in hospital.

Hospices account for much smaller proportions of place of death for those aged 65+ and those aged 85+, for both males and females, and again with females less likely than males in these two age groups to die in a hospice.

It would appear for those aged 85+ that deaths in care homes and at home have replaced hospitals as place of death to some extent. From 2010 to 2013, the proportion of deaths at home and in care homes for those aged 85+ has increased by around 6 per cent points for males and for females, while the proportion of deaths in hospitals for this group decreased by 6 per cent points respectively for males and females.

While the numbers of both males and females aged 65+ and those aged 85+ dying in care homes increased steadily over the period 2010–2013, the numbers in these age groups dying in hospitals over the same period have declined. The number of home deaths and hospice deaths has also increased over this period for the group aged 85+, and for both males and females.

As mentioned, the proportion of home deaths is relatively low over the whole period of observation, although the proportions are increasing year-on-year both in the whole population and among the older age groups (Fig. 1 and Table 1). This trend is in the opposite direction to that observed for the period 1974–2003 by Gomes & Higginson [14], who reported an average annual change of -0.5 per cent and annual fluctuations of no more than 1 per cent.

Table 1
Numbers (1000s) and proportions of deaths by year and home deaths in England and Wales, 2006–2013.

	2006	2007	2008	2009	2010	2011	2012	2013
All deaths	500	502	507	489	491	482	497	505
All male deaths	239	240	242	237	237	233	239	245
	48%	48%	48%	48%	48%	48%	48%	48%
All female deaths	261	262	265	252	254	249	258	260
	52%	52%	52%	52%	52%	52%	52%	52%
All home deaths	95	98	101	100	102	105	110	113
	19%	20%	20%	20%	21%	22%	22%	22%
Males								
Total home deaths[a]	54	55	56	56	57	59	61	63
	23%	23%	23%	24%	24%	25%	26%	26%
65 years and over[b]	37	38	40	39	41	42	45	47
	20%	21%	21%	21%	22%	23%	23%	24%
85 years and over[c]	8	8	9	9	10	11	12	13
	14%	14%	15%	15%	16%	17%	17%	17%
Females								
Total home deaths	41	43	45	44	45	46	49	50
	16%	16%	17%	17%	18%	18%	19%	19%
65 years and over	33	34	35	34	36	37	40	41
	14%	15%	15%	16%	16%	17%	18%	18%
85 years and over	11	13	13	13	14	15	16	16
	10%	11%	11%	11%	12%	13%	13%	13%
All								
Total home deaths	95	98	101	100	102	105	110	113
	19%	20%	20%	20%	21%	22%	22%	22%
65 years and over	70	72	75	73	77	79	85	88
	17%	17%	18%	18%	19%	20%	20%	20%
85 years and over	19	21	22	22	24	26	28	29
	12%	12%	12%	13%	13%	14%	15%	15%

[a] The percentage expresses the total number of male home deaths as a percentage of all male deaths – similarly for females and for all.
[b] The percentage expresses the number of male 65+ home deaths as a percentage of all male 65+ deaths – similarly for females and for all.
[c] The percentage expresses the number of male 85+ home deaths as a percentage of all male 85+ deaths – similarly for females and for all.

From 2006 to 2013, home deaths in the total population of England and Wales increased as a proportion from 19.1 per cent to 22.4 per cent. For males, the proportions are higher (rising from 22.4 per cent to 25.9 per cent) than for females (rising from 15.9 to 19.1 per cent) although the female proportion of home deaths has been rising faster than the male proportion in this period. On average, females still outlive males (for example, Ref. [20]) and are therefore more likely than males to be caring for their spouses until death. This alone probably contributes to the fact that males are more likely to die at home in old age than females, something repeated in the findings of Gomes & Higginson [14]. For the same reason (no surviving spouse), females are more likely to die outside their home than males with females aged 85+ the most likely to experience institutionalised death (Table 1).

3.2. *Future distribution of deaths according to place of death*

In this section, we consider how projected mortality in England and Wales will impact on the distribution of deaths over place of death if recently observed trends continue under the two scenarios outlined above with regard to the development in home deaths.

In the first scenario, it is assumed that the trends observed in 2006–2013 proportions with regard to place of death continue to 2050.

If the 2006–2013 trends in the proportion of home deaths among those dying aged 65+ and 85+ respectively and for males and females separately are projected to 2050 (Fig. 2), the proportion of home deaths among all deaths of those aged 65+ will increase from 20 per cent in 2013 to 45 per cent in 2050, an absolute increase from 87,000 home deaths in this age group to 279,000. For those aged

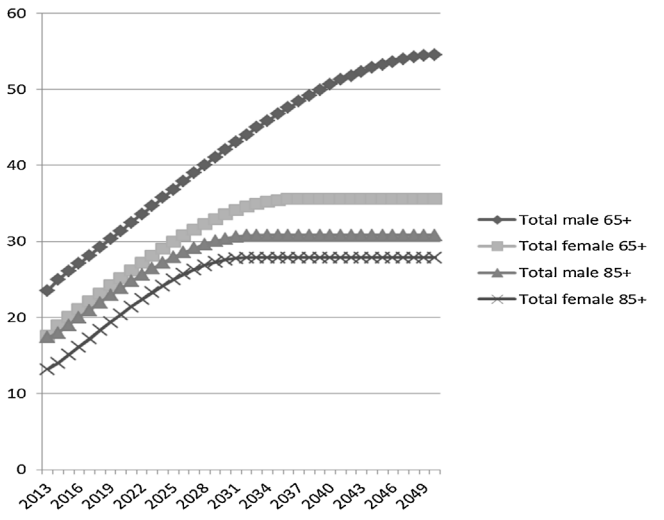

Fig. 2. The proportion of home deaths among all deaths for the groupings by age and gender, 2013–2050, England and Wales.

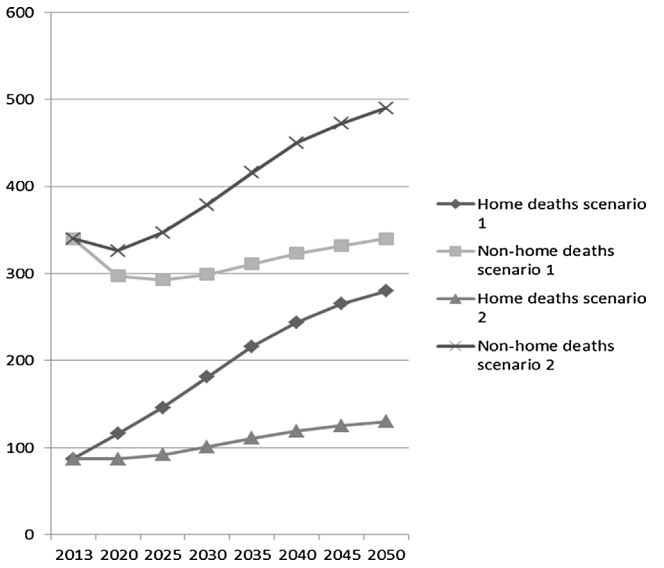

Fig. 3. The absolute number of home and non-home deaths under two scenarios, 2013-2050. Thousands.

85+, the proportion of home deaths would increase from around 15 per cent in 2013 to around 29 per cent in 2050, an absolute increase from 29,000 home deaths in this age group to 118,000. These trends would of course be matched by a decline in the proportion of non-home deaths among older people in England and Wales, a trend already observed in the 2006–2013 period – however, because of the ageing of the population and of death [2], the number of non-home deaths among those aged 65+ after declining to around 290,000 by 2025 would return to the 2013-level of around 340,000 by 2050.

In the second scenario, it is assumed that among those aged 65+ the 2013 proportion of home deaths remains constant. This scenario would see the number of home deaths still increase from 87,000 aged 65+ in 2013 to 130,000 in 2050 This in turn would mean that non-home deaths would increase from 340,000 aged 65+ in 2013 to 490,000 in 2050.

Fig. 3 illustrates the development from 2013 to 2050 in the number of home and non-home deaths among those aged 65+ for each of the scenarios outlined.

These two scenarios present different policy and practice challenges depending on the institutional or home-based nature of death.

4. Discussion and policy implications

This study has as its point of departure the new demography of death that the 21st century is predicted to bring to England and Wales. The evidence is that ages at death will continue to increase, with more and more people reaching extreme old age. At the same time, it is likely that life expectancies at birth will also continue to rise, taking life expectancy at birth in England and Wales to 100 years or more by the end of the 21st century, although recent developments have suggested that perhaps the increase in life expectancy is stagnating – or even showing signs of a decline [21]. While this may have an impact on our length of life, it will not have an impact on our death, except perhaps by death occurring slightly earlier than predicted. This is unlikely to have a significant impact on the findings of this paper.

The analyses presented here show how place of death and therefore implicitly the need for different structures of care provision will develop under two different scenarios with regard to home deaths, given the expected demography of death predicted for the coming decades in England and Wales [2]. The demography of death will in itself see the need for end-of-life care increase noticeably to the middle of the century with the number of those aged 65+ dying increasing from around 427,000 to around 620,000.

If we factor place of death into this purely demographic forecast, then our analyses suggest there will be striking challenges to the structure of care provision, dependent on the death-setting.

In the first home-death scenario, if trends observed in 2006–2013 in the proportion of deaths occurring at home continue, we will see an increase in the number of deaths in homes from around 87,000 in 2013 to around 280,000 in 2050. The number of non-home deaths is projected to decline to less than 300,000 by 2030, but is then projected to increase to its 2013 level of around 340,000 by 2050. Such a development begs the question of whether home-based end-of-life care provision will be able to deliver and whether families and communities are prepared for this development. In addition, while these trends may in some ways reflect a de-institutionalisation of death so that coping needs around death will move to the home, presumably with a need for specialised nursing support to family members in the home, there is no longer-term removal of pressure in absolute terms on institutions with regard to providing end-of-life care as the number of institutional deaths remains constant.

However, if as in the second scenarion the proportion of home deaths among those aged 65+ remains at its 2013 levels, then the onus will fall more squarely on non-home end-of-life care provision and other (institutional) settings will become increasingly important for end-of-life care.

The challenge is of course not just simply one related to increasing numbers. An increasing number of people approach death with extremely complex care needs associated with multi-morbidity and frailty [22], and the resilience, capacity and training of the health and social care workforce will demand attention. Under both scenarios, it is important that individual care providers are able to good end-of-life care.

Our analyses show that there could be marked increases in both home and non-home deaths in the coming decades simply as a result of the future demography of death, and this will have a significant impact on care provision in the community. Both policy makers and practitioners need to work together to develop and implement a response to this demography of death and its implications for end-of-life care in both home and non-home settings,

and this response will also need to involve family and community members in light of changing family formation and structure.

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