Place of death for the 'oldest old': ≥85-year-olds in the CC75C population-based cohort

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ABSTRACT

Background

Deaths are rising fastest among the oldest old but data on their transitions in place of care at the end of life are scarce.

Aim

To examine the place of residence or care of ≥85 year-olds less than a year before death, and their place of death, and to map individual changes between the two.

Design of study

Population-based cohort study.

Setting

Cambridge City over-75s Cohort (CC75C) study, UK.

Method

Retrospective analysis of prospective data from males and females aged ≥85 years at death who died within a year of taking part in any CC75C survey (n = 320); death certificate linkage.

Results

Only 7% changed their address in their last year of life, yet 52% died somewhere other than their usual address at the time of death. Over two-thirds were living in the community when interviewed <1 year before death, but less than one-third who had lived at home died there (less than one-fifth in sheltered housing). Care homes were the usual address of most people dying there (77% in residential homes, 87% in nursing homes) but 15% of deaths in acute hospital came from care homes.

Conclusion

More than half the study sample of individuals of advanced old age had a change in their place of residence or care in their last year of life. These findings add weight to calls for improved end-of-life care in all settings, regardless of age, to avoid unnecessary transfers. The study data provide a baseline that can help plan and monitor initiatives to promote choice in location of care at the end of life for the very old.

Keywords

aged; aged 80 or over; aging in place; frail elderly; terminal care.

INTRODUCTION

End-of-life care for older people is now an acknowledged priority.[1] Recent UK policy initiatives and reports recognise the increasing number of people who will be dying in very old age.[2–5] Emphasis on a care pathway approach highlights the importance of the place of care, place of death, and transitions between them.[6–8] The NHS End of Life Care Programme's aims include reducing emergency admissions and transfers from care homes to hospital in the last week of life, alongside providing the support needed to enable people to die where they choose.[9] The policy drive to facilitate 'good deaths' at home envisages savings on costly acute care, enhancing value for money at the same time as choice, quality, and equality.[2,10,11]

In many developed countries, deaths, including in-hospital deaths, are rising fastest among ≥85-year olds.[1,12,13] Data are scarce on older people's place of care trajectories before death,[14] particularly for the very old, but are important for planning and monitoring improvements. This study's objective was

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to provide new understanding by examining survey records and death certificates from individuals aged ≥85 years, interviewed less than a year before death in a longitudinal population-based study.

METHOD

The Cambridge City over-75s Cohort (CC75C) study is a population-based sample representative of Cambridge's older people that began in 1985–1987. The study methodology has been described in detail elsewhere.[15,16] Briefly, the baseline survey enrolled 95% of individuals aged ≥75 years, approached from six general practices. Participants were followed up with surveys repeated every few years (92% of survivors were included in the last survey). Data thus gathered over more than two decades offer a rare opportunity to examine residence transitions in extreme old age shortly before death.[17] Figure 1 depicts the sampling frame, and Figure 2 depicts the construction of a subsample of 'oldest old' people in their last year of life for this analysis: *n* = 320 males and females who died aged ≥85 years within a year of participating in any of CC75C's seven surveys (1985–2007).

A combination of data sources was used to identify changes in place of residence between final interview and death; the information available may not have included all transitions in this period. Interview data on 'type of accommodation' were cross-checked with administrative databases. 'Usual address' and 'place of death' details were retrieved from death certificates. All three loci were coded into categories reflecting changes since the 1980s (Box 1). In the UK, although a doctor must record causes of death, other death certificate details, such as the usual address, are usually provided by the relative registering the death.

All analyses were performed in Stata 9.2 (data version 2.2).

RESULTS

Study sample

A total of 321 people participated in surveys less than a year before they died aged at least 85 years, comprising 80% of participants still alive at survey (median time of last interview before death = 28 weeks, interquartile range = 16–41 weeks). Death certificate residence data were available for all but one participant (analysis sample *n* = 320). Table 1 outlines their sociodemographic characteristics. Half these 'oldest old' participants were aged 85–89 years, and half were aged at least 90 years at death. Overall, two-thirds were female (male:female ratio 2:3 in the 85–89 years age-band, 1:4 in the older group). There were no demographic differences between those who were or were not interviewed in their last year of life.

How this fits in

Numbers of deaths are rising fastest in many developed countries among ≥85 year olds. Current policy is to enable people to be cared for until death where they would prefer. However, not only are preferences difficult to assess, but even data on the transitions in place of care of the oldest old at the end of life are scarce. This study found that only 7% of individuals aged ≥85 years in a population-based sample changed their address in their last year of life, yet more than half died somewhere other than their usual address at the time of death. Over two-thirds were living in the community when last interviewed less than 12 months before death, but fewer than one-third who had lived at home died there. Of the individuals who died in acute hospitals, 15% came from care homes, predominantly residential homes. The findings will help planning to implement the End of Life Care Strategy.

Address less than a year before death

Just over two-thirds of participants were community dwelling when last surveyed (Table 1), including 17% in sheltered housing. Excluding these partially supported settings, more males still lived at home than females (70% versus 44%). Twice as many ≥90 year olds were living in care (38%: 27% in residential homes, 9% in nursing homes) as

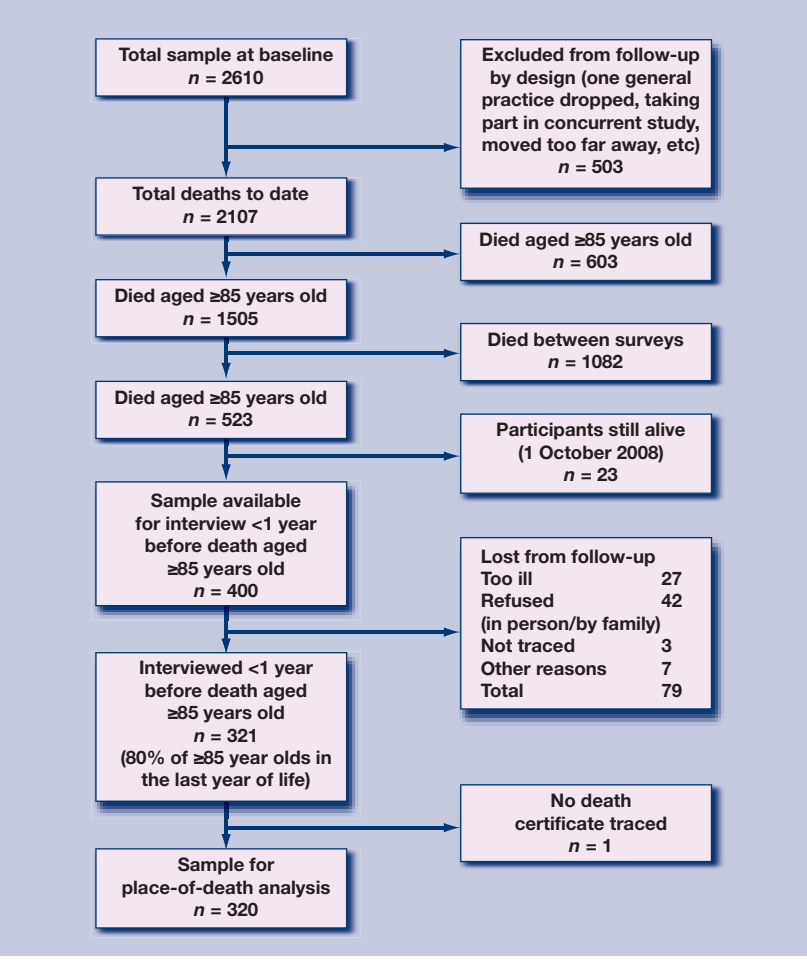
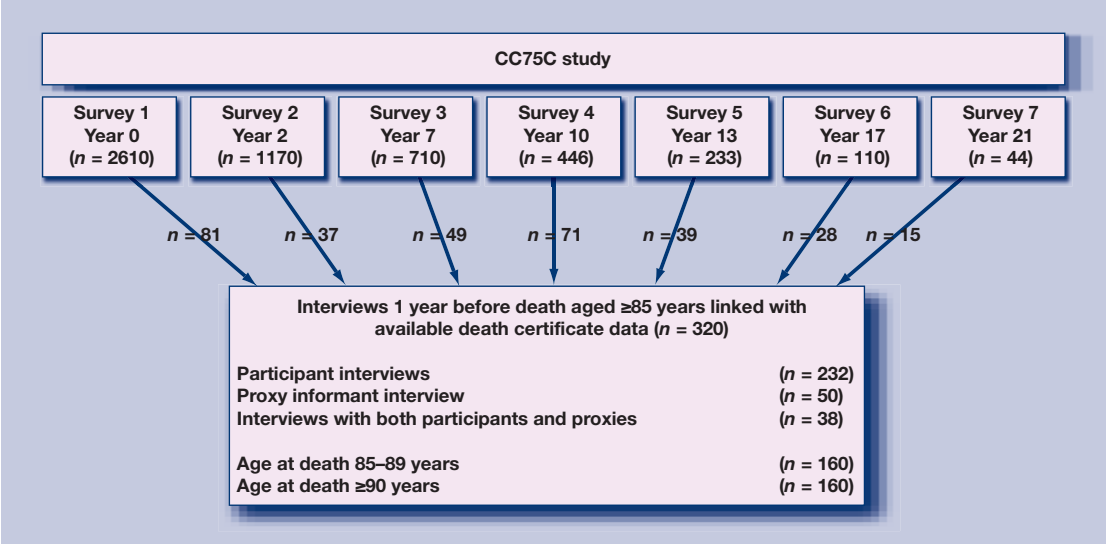


Figure 1. CC75C study: sampling frame for participants who died aged ≥85 years within a year of interview.



Online ***Figure 2. The 'oldest old' in their last year of life: how this analysis sample was constructed.***

85–89 year olds (19%: 16% in residential homes and 3% in nursing homes).

Usual address at death

Table 2 details what proportions were subsequently in different accommodation according to death certification — usual address at death and place of death — but these changes are best understood in conjunction with the individual-level data illustrated in Figure 3. By the time of death the percentage living in care homes was virtually unchanged among those in their late 80s, but had risen to 44% of those dying in their 90s or older (from 38% when interviewed), with a further 5% whose 'usual address' was a long-stay hospital (Table 2). Living in residential care was twice as common at death for older males than for 85–89 year-old males (18% versus 9%), and higher for females, but the age-band difference was less marked (32% versus 21%). There was a three- to four-fold increase in the need for long-term nursing care by the time of death for both sexes, from just a few per cent aged <90 years whose usual address was a nursing home, compared with 14% of ≥90 year olds (25% including long-stay wards: males 17%, females 24%).

Place of death

Just over half the sample died in hospital (10% on long-stay wards, 41% in acute settings). Table 2 shows age and sex differences. Almost half those dying in their late 80s were in acute settings, compared with one-third of the older group; overall 50% of males and 37% of females died in acute hospitals; 7% more died in long-stay hospitals than had these units recorded as their usual address. Only 2% died in hospices.

Box 1. Classification of place of residence in the CC75C study.

1. The community-dwelling category denoted anyone living in a 'house, flat, or granny flat'. The wording 'own home' used in the tables and figures is a summary term for this group, with no financial meaning: it includes people who owned their homes, rented (privately or from the local council), and those living with relatives.
2. The other non-institutional setting — 'warden-controlled' accommodation — includes any sheltered housing, whether or not a warden lived on site. The level of support provided in sheltered accommodation has declined, although there is considerable variation.
3. The distinction originally made between 'council residential home' and 'private residential home' has become less accurate and less useful as local authority services have moved to the private sector. These were replaced by a single 'residential home' category.
4. Following the Office for National Statistics practice of treating long-term nursing care beds as one category, whether in nursing homes or long-stay NHS wards, the baseline CC75C survey did not include a separate response option equivalent to the new 'nursing home' category, only 'long-stay hospital'. Regulatory changes for the care home sector over the last two decades — such as dual registration (residential and nursing care) — complicated the interpretation of old addresses. All addresses were checked against current and past lists of sheltered accommodation schemes and care homes. The coding 'nursing home' was applied to all homes providing any nursing care.
5. Those coded as either hospital or 'other' were also double-checked.

Table 1. Sociodemographic profile of the sample.

	Age at death, years		Sex		Total
	85–89 (*n* = 160), *n* (%)	≥90 (*n* = 160), *n* (%)	Males (*n* = 102), *n* (%)	Females (*n* = 218), *n* (%)	All (*n* = 320), *n* (%)
Age at death, years					
Mean (SD),	**86.9 (1.4)**	**94.3 (3.3)**	**89.0 (3.5)**	**91.4 (4.7)**	90.6 (4.5)
85–89	–	–	**68 (67)**	**92 (42)**	160 (50)
≥90	–	–	**34 (33)**	**126 (58)**	160 (50)
Sex					
Males	**68 (42)**	**34 (21)**	–	–	102 (32)
Females	**92 (58)**	**126 (79)**	–	–	218 (68)
Marital status[a]					
Married	**47 (30)**	**12 (8)**	**47 (47)**	**12 (6)**	59 (19)
Widowed	**87 (55)**	**123 (77)**	**44 (44)**	**166 (77)**	210 (66)
Separated/divorced	2 (1)	4 (2)	2 (2)	4 (2)	6 (2)
Single	20 (13)	21 (13)	**7 (7)**	**34 (16)**	41 (13)
Other	1 (1)	0 (0)	0 (0)	1 (1)	1 (<1)
School leaving age, years[b]					
≤14	112 (70)	109 (70)	72 (72)	149 (70)	221 (70)
≥15	47 (30)	46 (30)	29 (29)	64 (30)	93 (30)
Accommodation when interviewed					
Own home[c]	**97 (61)**	**69 (43)**	**71 (70)**	**95 (44)**	166 (52)
Sheltered housing	30 (19)	23 (14)	13 (13)	40 (18)	53 (17)
Residential home	**25 (16)**	**43 (27)**	**13 (13)**	**55 (25)**	68 (21)
Nursing home	**5 (3)**	**15 (9)**	3 (3)	17 (8)	20 (6)
Hospital	3 (2)	10 (6)	2 (2)	11 (5)	13 (4)

SD = standard deviation. [a]Marital status was unknown for three people. [b]School-leaving age was unknown for six people. [c]'Own home' includes living in a house, flat, or granny flat. Significant differences between age-bands and sex groups are highlighted in bold print (P<0.05 Pearson χ^2/Fisher's exact test as appropriate).

Transitions before death

Figure 3 represents the movements between different places of residence or care during the last year of life from where participants lived when last interviewed, to where their usual address when they died and where they actually died. The direction of movement is predominantly up the 'ladder of care', with only a handful of exceptions: a few transfers

Table 2. Usual address at time of death and place of death by age and sex.

	85–89 years, *n* (%)			≥90 years, *n* (%)			Males, *n* (%)	Females, *n* (%)	Total, *n* (%)
	Males	Females	Males + Females	Males	Females	Males + Females			
Usual address at time of death									
Own home[a]	**49 (72)**	**47 (51)**	**96 (60)**	**20 (59)**	**45 (36)**	**65 (41)**	**69 (68)**	**92 (42)**	161 (50)
Sheltered housing	10 (15)	**20 (22)**	**30 (19)**	3 (9)	**14 (11)**	**17 (11)**	13 (13)	34 (16)	47 (15)
Residential home	**6 (9)**	**19 (21)**	**25 (16)**	6 (18)	40 (32)	**46 (29)**	**12 (12)**	**59 (27)**	71 (22)
Nursing home	2 (3)	**4 (4)**	**6 (4)**	4 (12)	**20 (16)**	**24 (15)**	6 (6)	24 (11)	30 (9)
Hospital, long-stay	1 (1)	2 (2)	3 (2)	1 (3)	7 (6)	8 (5)	2 (2)	9 (4)	11 (3)
Total	68 (100)	92 (100)	160 (100)	34 (100)	126 (100)	160 (100)	102 (100)	218 (100)	320 (100)
Place of death									
Own home[a]	13 (19)	17 (19)	30 (19)	7 (21)	15 (12)	22 (14)	20 (20)	32 (15)	52 (16)
Sheltered housing	1 (2)	**6 (7)**	7 (4)	1 (3)	**1 (1)**	2 (1)	2 (2)	7 (3)	9 (3)
Hospice	3 (4)	2 (2)	5 (3)	1 (3)	0 (0)	1 (1)	4 (4)	2 (1)	6 (2)
Residential home	5 (7)	**15 (16)**	**20 (13)**	**3 (9)**	**39 (31)**	**42 (26)**	**8 (8)**	**54 (25)**	62 (19)
Nursing home	2 (3)	**5 (5)**	7 (4)	4 (12)	**18 (14)**	22 (14)	6 (6)	23 (11)	29 (9)
Hospital, long-stay	7 (10)	7 (8)	14 (9)	5 (15)	13 (10)	18 (11)	12 (12)	20 (9)	32 (10)
Hospital, acute	37 (54)	40 (43)	**77 (48)**	13 (38)	40 (32)	**53 (33)**	**50 (49)**	**80 (37)**	130 (41)
Total	68 (100)	92 (100)	160 (100)	34 (100)	126 (100)	160 (100)	102 (100)	218 (100)	320 (100)
Transitions									
Place of death not usual address	44 (68)	**51 (55)**	**97 (61)**	18 (53)	**52 (41)**	**70 (44)**	**64 (63)**	**103 (47)**	167 (52)

[a]'Own home' includes living in a house, flat, or granny flat. Significant differences between age-bands and sex groups are highlighted in bold print (P<0.05 Pearson χ^2/Fisher's exact test as appropriate).

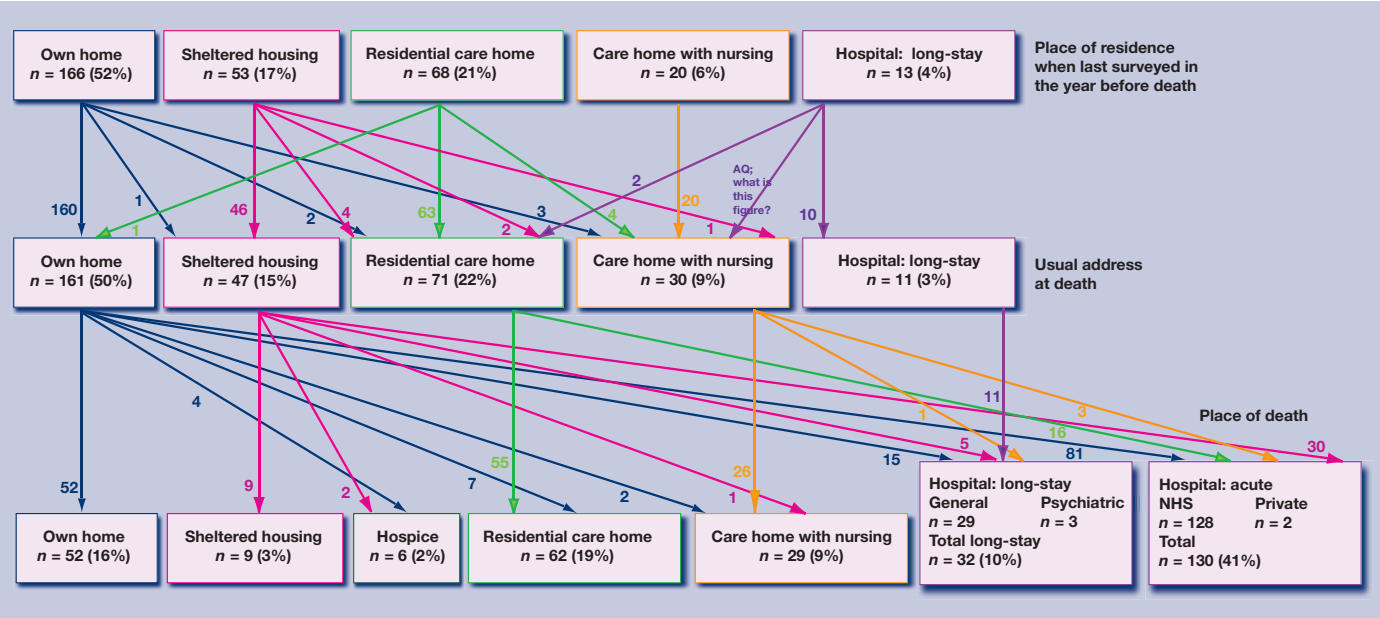


Figure 3. Movements between residential or care settings during the last year of life (n = 320 people who died aged ≥85) from their place of residence when interviewed less than a year before death, to their 'usual address' registered at death and where they died.

from long-stay hospital to care homes and one person who moved from residential care to her son's home. Compared with death certificate-recorded 'usual address', community addresses appear considerably less frequently as the registered 'place of death'. Only 16% of all deaths were at home: fewer than one-third of the 50% of participants who still lived in their own or a relative's home died there. People whose usual address at death was in sheltered housing (15%) were even less likely to die there: less than one-fifth. The 19% dying in residential care was only slightly less than the 22% with a residential home as their 'usual address'. However, as Figure 3 shows, these were not all the same people: 16/71 (23%) people living in residential homes died in acute hospitals and 7/62 (11%) people who died in residential care usually lived at home. Settings that provided nursing care transferred fewer people to other institutions. Similar numbers died in nursing homes as were living there.

Long-stay hospital deaths included all those usually resident, but also included less permanent patients, presumably more recently admitted. Care homes were the usual address of most people dying there (77% in residential homes, 87% in nursing homes) but 15% of deaths in acute hospital came from (predominantly residential) care homes. Overall, whereas only 7% had a 'usual address' recorded on their death certificate that differed from where they lived when interviewed less than a year before, for 52% the registered place of death was not their usual address (see Table 2 and, for details by age-band and sex, Table 3). Individuals in their 90s or 100s were more likely to have died at their usual address than 85–89 year olds, as were females, regardless of age.

Age and time

As the study findings draw on interview data spanning over two decades, a check was carried out

Table 3. Deaths at usual address by age and sex.

	85–89 years, *n* (%)			≥90 years, *n* (%)			Males, *n* (%)	Females, *n* (%)	Total, *n*	Total as % of all living at each address	Total as % of all deaths at the usual address
	Males	Females	Males + Females	Males	Females	Males + Females					
Own home[a]	13	17	30	7	15	22	20	32	52	32	34
Sheltered housing	1	6	7	1	1	2	2	7	9	19	6
Residential home	5	13	18	3	34	37	8	47	55	77	36
Nursing home	2	3	5	4	17	21	6	20	26	87	17
Hospital, long-stay	1	2	3	1	7	8	2	9	11	100	7
All deaths where place of death was usual address	22 (32)	**41 (45)**	**63 (39)**	16 (47)	**74 (59)**	**90 (56)**	**38 (37)**	**115 (53)**	153	48	100

[a]*'Own home' includes living in a house, flat, or granny flat. Significant differences between age-bands and sex groups are highlighted in bold print (P<0.05 Pearson χ^2/Fisher's exact test as appropriate).*

for temporal trends, stratifying by age to avoid confounding. Figure 4 plots proportions for earlier and later study periods of (a) study participants living in different settings at death, and (b) their place of death, showing separately 85–89 year olds and ≥90 year olds. Percentages of community dwellers and home deaths have declined in both age-bands. While it has become slightly more common to live, and die, in sheltered housing before the age of 90 years, this is increasingly uncommon for anyone older. Nursing home residence has risen steeply in both age-bands, as have nursing home deaths but in residential care homes, the number of residents aged ≥90 years has risen only slightly, and deaths of individuals aged ≥90 years have shown no increase. Acute hospitals have remained the location with the highest proportion of deaths across the years for very old people dying before or after 90 years of age.

DISCUSSION

Summary of main findings

This is the first study linking death certificate records with population-based data gathered prospectively from very old people in the last year of life. With CC75C study data for participants who died aged ≥85 years, place of residence less than a year before death was compared with usual address at death and place of death. About two-thirds were living in the community, but of the half who still lived at home, fewer than one-third died at home, and in sheltered housing only one-fifth. Just over half died in hospital: 41% in acute and 10% in long-stay wards. The majority of transfers to both were from the community, with a sizeable minority from residential care. The numbers living and dying in nursing homes appeared more constant than in residential homes, but included different individuals, typifying the tendency for people to move up the 'ladder of care'. The proportions dying in any long-term-care setting were almost twice as high for ≥90 year olds (51%) as for 85–89 year olds (26%). Conversely, only one-third of the oldest old died in acute hospitals, compared with almost half the younger age-band. Overall, more than half these very old people died somewhere other than their usual address.

Strengths and limitations of the study

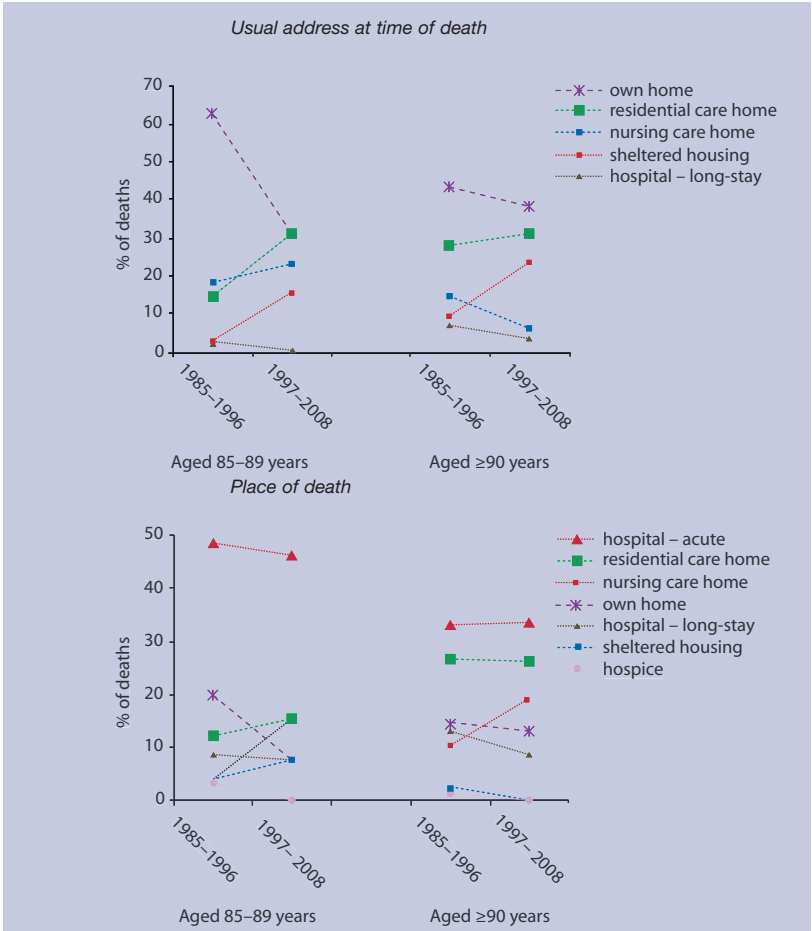
A particular strength of the study is the opportunity to examine changes at an individual level, revealing movements between residential categories that are not apparent from group statistics that large national datasets provide. For example, from death certification there was a difference of just 3% between the proportions with a residential home recorded as their usual address and as their place of death, but individual trajectory tracing showed that nearly one-quarter of these residents died elsewhere. The authors' prospective cohort study provided data from the year before death for a section of the population — predominantly frail individuals in advanced old age — which is now difficult to access due to current research ethics and governance regulatory procedures that are intended to protect vulnerable people.[18] Individually linking anonymised study and death certificate data offered a unique additional perspective to public records, meriting examination as there is scant information on which to base urgently needed planning for the rising numbers of deaths in very old age.[19]

CC75C is one of the longest running studies of the very old, with inevitable contemporary contextual changes and study design issues. Approaches to these challenges include consistency in accommodation classification (Box 1), age-band stratification to clarify cohort effects (Figure 4), and comparison with national trends. Although the present study attempted to identify all address changes through administrative databases, the study design did not include tracking all transitions between surveys and death, so some may have been missed. Likewise, no data are available on significant changes after interview that could affect transitions; for example, health or marital status. Moreover, given that the interval from last interview to death ranged from less than a week to almost a year, the study findings do not describe the full final year of life and so most likely underestimate transitions.

Death certificates, despite acknowledged limitations, are a valuable tool for examining place of death,[20,21] but 'usual address' data are less frequently used and, to the authors' knowledge, less validated. In the study sample, study personnel were familiar with circumstances of the recently deceased, so noticed inconsistencies, for example a former private address was given by the next-of-kin as the usual residence despite the participant's permanent move into care. These moves are complex, so such perceptions are perhaps not uncommon. Similar misclassifications are unquantifiable but the effect would again mean the study findings may underestimate transitions.

Comparison with existing literature

Comparisons with national mortality statistics suggest that CC75C's low proportions of home deaths and negligible hospice deaths are in line with nationwide trends.[22] Care home residence in CC75C has risen more sharply than national trends in long-term-care availability,[23] and the proportions of residential care and nursing home deaths are both higher and increasing more than national rates. There is growing evidence that, just as home deaths are



Although both nursing and residential care homes have become more common places of residence for the oldest old at the end of life over the last 2 decades and more since the CC75C study began, only nursing homes have become a more common place of death. The majority of ≥90 year olds and the vast majority of 85–89 year olds in the study continued to die in hospital.

Figure 4. Study participants' usual address at death and place of death by age-band.

facilitated by the availability of community palliative services,[24,25] levels of deaths in institutions are strongly influenced by access,[26–29] a finding from younger old-age groups that the present study suggests is similar for the oldest old. Conversely, the present study findings show proportions dying in hospital that are 5–10% lower than nationally for both age-bands. However, Cartwright's seminal study of dying in England in 1987, contemporary with the current study's start, found 44% of ≥85 year olds had died in hospital[30] — similar to CC75C findings for 85–89 year olds. Other previous study findings are not directly comparable, as they include wider age ranges or focus on cancer deaths.[31,32]

A recent study roughly contemporary with the present one, reporting ≥85 year olds' all-cause mortality trends in England and Wales, could not detail different institutional settings separately but found very similar levels and declines in home deaths.[21] In Wales, trends over two decades (1981–2001) showed the numbers of hospital deaths in individuals aged ≥85 years had doubled, care home deaths tripled, and deaths in the community were down by one-third.[13]

Research from Europe — notably the Belgian Sentinel Network and the Dutch Longitudinal Aging Study Amsterdam (LASA) — has contributed detailed information on transitions before death, both using retrospective methods and including younger old-age ranges. LASA interviewed relatives of deceased participants concerning care and transitions in the last 3 months of life.[27] Despite different methods, time frame, and age range — the mean age (85 years) of even their oldest group (≥80 years) was less than the present study's youngest — they also found that half changed their place of care before death (LASA 50% in the last 3 months, CC75C 52% in the last 12 months). Of those who had moved, 39% had done so less than a week before death.

Sentinel GPs' reporting of deceased patients' transfers in the last 3 months revealed 80% had been transferred <1 month and 33% <1 week before death (all non-sudden deaths aged >1 year, 32% aged ≥85 years).[14] The present data do not include the timing of transitions, but the wide discrepancy between the proportions whose usual address at death had changed since interview (7%) and whose place of death was not their usual address (52%) suggests many were transferred close to death.

Implications for future research and clinical practice

More than half the study participants died somewhere other than their usual address. Recent UK reports and policy initiatives are raising awareness that supportive services developed for cancer patients need extending to people approaching death from other conditions, and aim to reduce the reported mismatch between 'preferred place of care' and place of death.[2–5,10,33–35] Older people in particular are least likely to seek, be offered, or receive specialist end-of-life care.[24,36]

There have been calls for improved joint working between specialists in elderly, primary, and palliative care, and expanding specialist training for generalists is a priority.[11,37–42] Lack of such support for older people at home and in care, especially in residential homes, contributes towards many potentially traumatic moves near the end of life.[43]

Contract changes mean UK GPs are no longer responsible for out-of-hours care, resulting in adverse loss of continuity of care for people at the end of life.[44] Disruptive transitions are often crisis responses, but avoiding transfer to nursing or acute care does not necessarily mean a good death in the 'preferred place of care'.[45] Preferences can change, and ascertainment is difficult and perhaps not always desirable.[46]

Some older people prefer to die in supported settings rather than at home, where they may fear either being alone or becoming a 'burden'.[47,48] Sadly, many care homes lack the staffing levels, awareness, or expertise to provide the support that dying older people deserve: over 60% of residents in a US residential homes study were alone when they died.[49] Initiatives to improve end-of-life care in care homes need to be extended,[6,50–52] but likewise general hospital acute care must address the needs of the rising numbers of very old people dying in hospital.[37] The current study's findings provide important data to help inform the planning necessary to implement the UK's new End of Life Care Strategy.[2]

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Ethics committee

Each CC75C study phase was approved by Cambridge Research Ethics Committee (current reference numbers: 05_Q0108_308 and 08_H0308_3).

Competing interests

The authors have stated that there are none.

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