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Place of death in dementia - Dutch patients rarely die in hospital

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ABSTRACT

Objective

The objective of this study was to identify personal- level characteristics associated with location of death for persons who died of dementia in the Netherlands.

Study Design and Setting

This was a follow-back study based on all persons (n=17,814) aged 65 and older who died in 2006 in the Netherlands where at least one of the underlying causes of death was dementia as determined by the Dutch cause of death registry from Statistics Netherlands. Site of death was classified into hospital, at home or long-term care facility. Using multinomial logistic regression, associations between personal characteristics and location of death were examined.

Results

Approximately 4% died in hospital, 4% died at home and 92% died in a long-term care facility. Only 12% were hospitalized in the year before death. We showed that increased age, being single, living in an institution the year before death, and having a household income below the median of 14,410 euros, were all associated with an increased likelihood of dying in a long-term care facility or hospital compared to dying at home.

Conclusion

Most people with dementia as one of the causes of death died in a long care facility suggesting that most acute care in severely demented persons is handled within long-term care facilities in the Netherlands. Less people are admitted into long-term care facilities therefore, more people are expected to stay longer at home. Considering our results, future studies should investigate whether this leads to an increase in people with dementia dying in hospital.

1. INTRODUCTION

In the Netherlands, approximately 260,000 people are living with dementia (1). Of these, approximately two-thirds live in at home, while the remaining third resides in a nursing home or an accommodation linked to a nursing or residential care home (2,3). However, the majority of people with dementia die in a long-term care facility (LTCF) (4). Research shows that place of death is highly associated with quality of life at the end of life (5). A survey conducted in the United States of family members of people who lived with chronic illnesses, such as dementia, reported a less favorable dying experience in institutionalized settings than at home with hospice services (5). Both people with dementia (6,7) and care professionals (8) prefer that people with dementia die at home. However, people with dementia have high care needs (9), making care at home challenging and in reality, it may be unrealistic to expect that this type of care can be provided at home (2,3).

In a study examining variables associated with place of death across Europe, it was found that increasing age, male gender and nursing bed availability increased the likelihood of a nursing home death relative to death at hospital or at home (4). More hospital beds in the healthcare region decreased the chances of home and nursing home death (4).

Previous authors (4,5) have mainly looked at the association between location of death and state or country-level characteristics in persons with dementia, but there are few papers that have evaluated the association between personal characteristics and location of death(10). In this study, our main aim was to examine the personal characteristics associated with location of death for people with dementia who died in the Netherlands in 2006. Potentially some of these factors are modifiable and enable us to increase the chance of dying at home which is desired by patients, family members, professionals and governments.

2. METHODS

2.1 Subjects

We used data from the Statistics Netherlands [*Centraal Bureau voor de Statistiek*] 2006 cause of death registry (11). This registry contains individual level data extracted from all death certificates issued in the Netherlands in 2006 (see Figure 1). Each death certificate listed up to three causes of death. We included individuals 1) who were aged 65 years or older at death 2) who died at home, in a hospital, in a psychiatric unit, nursing home or elderly home, and 3) for whom one or more of the causes of death was: Alzheimer's disease (International Classification of Diseases, Tenth Revision (ICD-10): G30); vascular dementia (ICD10: F01); or unspecified dementia (ICD10: F03)). We excluded individuals who died in an 'unknown' or 'other' setting.

We obtained gender, date of death, primary and secondary causes for death and location of death from the death certificate dataset. We used the personal identifier number to merge these data with records from the Dutch hospitalization data (DHD) for the calendar year before the person died. We extracted data on the number of times the person was admitted and readmitted to hospital, whether the admissions were acute or planned and

the type of hospital, the person's location previous to each admission and where he or she was discharged to. In addition, we used the personal identifier to extract information from Dutch municipal records on date of birth and country of birth, nationality, household income, whether the person lived in an independent or long-term care facility and marital situation in 2005. We used the year previous to death as this data would be complete for everyone in the dataset. The date and month of birth were unknown for 400 people, all of whom were born outside the Netherlands. We assumed that these people were born on the first of January in their year of birth.

2.2 Statistical analysis

We analysed the data using a multinomial logistic regression model with location of death categorized into three categories as the dependent variable. The three categories for location of death were: 1) in a hospital or psychiatric unit; 2) in a nursing or elderly home; or 3) at home [reference category]. Independent variables included: gender; age; marital status; independent living or long-term care accommodation; household income and the number of times the individual was hospitalized in the year prior to death. We categorized age into three categories: 65 to 74 years; 75 to 84 years; and over 85 years. The median income was 14,410 euros therefore we converted this into a dummy variable for median income. Cultural background was a variable available only for people who were hospitalized in the year prior to death and was a dichotomous variable indicating whether a person was born in the Netherlands or elsewhere. We summed the number of times a person was hospitalized in the year before death and then created a categorical variable with three categories: never hospitalized; hospitalized once; and hospitalized two or more times. We classified income as above or below the median income in the study population, household as 'independent' or 'institutionalized', and marital status as 'married or cohabitating' and 'not married or cohabitating or widowed'. Because marital situation and type of household are closely related, we evaluated collinearity to determine if the chi-square tests showed an association at the 0.05 level of significance. An interaction term between marital status and type of household was also included as the p-value was less than 0.1

In our primary analysis, we performed multinomial logistic regression in two steps. In the first step, we carried out univariate multinomial logistic regression to examine associations between location of death and each of our independent variables. Variables that had a relative risk ratio (RRR) with a p-value less than 0.10 were entered into the multivariate model at the start of the second step. We then performed a manual backward elimination procedure. We removed independent variables from the model one at a time, starting with the variable with the highest p-value, until all variables had a p-value less than 0.05.

The dataset from people who were hospitalized contained more variables (cultural background, living location before and after hospitalization). Therefore, we performed a secondary analysis to assess whether these additional variables were associated with location of death in this previously hospitalized population. First, we evaluated whether there was a difference in personal level characteristics between hospitalized and non-hospitalized people using univariate logistic regression to look if the results we found in the hospital population could then be applied to the non-hospitalized population. We

reran the two step multinomial logistic regression described above on the hospitalized people only. We carried out all statistical analyses in STATA version 12 (12).

3. RESULTS

Figure 1 shows a flow chart of the patient selection process. In 2006, 135,372 death certificates were recorded. From this dataset, 23 persons were excluded because they did not have a personal identification number. In 2006, 18,028 (13%) persons aged 65 years or older had dementia listed as at least one of the causes of death. A total of 214 (1.2%) people were excluded because they died in an unknown location ($n=91$, 0.5%) or other location ($n=123$, 0.7%). We present the personal characteristics of the people included in our analyses according to place of death in Table 1. The majority ($n=10,818$, 61%) of persons who had dementia listed as one of the causes of death were over 85 years old, and 9,570 (55%) were not institutionalized the year before death. Approximately 4% ($n=756$) died in hospital or in a psychiatric hospital, 707 (4%) died at home, and 92% died in a long-term care facility ($n=16,351$). Of the people that died in the long-term care facility (LTCF); 1,659 (10%) died in an elderly home and 14,692 (90%) died in a nursing home.

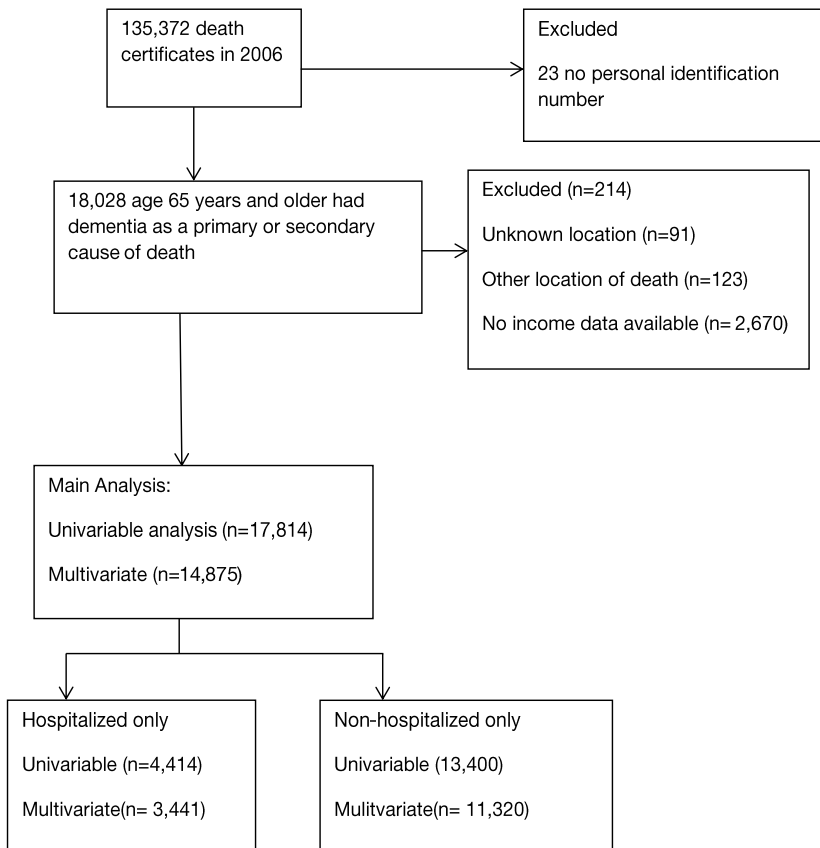


Figure 1 | Flow Chart

Table 1 | Baseline Table of Personal characteristics of people with dementia who died in 2006 in the Netherlands, according to location of death.

	Hospital N=756		LTCFs n=16,351		Home N=707		Total N=17,814		p-value
	N	%	n	%	n	%	n	%	
Gender									
Female	435	57.5%	11,384	69.6%	394	55.7%	12,213	68.6%	***
Male	321	42.5%	4,967	30.4%	313	44.3%	5,601	31.4%	
Age									
65 to 74	62	8.2%	746	4.6%	78	11.0%	886	5.0%	***
75 to 84	370	48.9%	5,450	33.3%	290	41.0%	6,110	34.3%	
over 85	324	42.9%	10,155	62.1%	339	47.9%	10,818	60.7%	
Marital status									
Not married, divorced, widowed	329	43.5%	8,323	50.9%	236	33.4%	8,888	49.9%	***
Married/cohabitating	427	56.5%	8,028	49.1%	471	66.6%	8,926	50.1%	
Type of household 2005									
Not institutionalized	554	78.0%	8,390	52.1%	626	94.6%	9,570	54.8%	***
Institutionalized	156	21.9%	7,715	47.9%	36	5.4%	7,907	45.2%	
Number of hospitalizations one year before death									
Zero times	0	0.0%	12,949	79.2%	451	63.8%	13,400	75.2%	***
Once	529	70.0%	2,326	14.2%	150	21.2%	3,005	16.9%	
>1	227	30.0%	1,076	6.6%	106	15.0%	1,409	7.9%	
2005 Household income									
<14,410	235	38.2%	7,227	51.6%	110	15.6%	7,572	50.0%	***
Equal or above 14,410	380	61.8%	6,783	48.4%	409	57.9%	7,572	50.0%	

*means 0.05, ** p<0.001 ***p<0.0001

3.1 Univariate models:

We present the results of the univariate multinomial logistic regression models in Table 2. All variables, including the interaction term between marital status and type of household, were statistically significantly associated with location of death. We found no evidence of collinearity between univariate variables.

3.2 Main multinomial logistic model

Based on the backwards selection procedure, we included gender, age, household income, type of household, marital status and the interaction term between marital status and type of household in the final multivariate model (Table 3).

After correcting for marital status, type of household and income, people 75 to 84 years were more likely than people aged 65 to 74 to die in a hospital or LTCF than at home. People, who were married or cohabitating, were less likely to die in a hospital or a LTCF than at home compared to those who were neither married nor cohabitating or widowed. The relative risk ratio of dying in the hospital or LTCF compared to at home was higher for subjects who lived in an institution than for those living at home. People with an income equal to or over 14,410 euros, were less likely to die in a hospital or LTCF than at home compared to people with an income of less than 14,410 euros. In supplementary analyses using death in hospital as the reference group we found being over 85 years age, being married or cohabitating and having an income below the median increased the likelihood of dying in a LTCF compared to a hospital. For details see Appendix 1.

3.3 Secondary analysis: Hospitalized versus not hospitalized one year before death

Table 4 identifies the differences between people hospitalized one year before death and those that were not. Of the people included in this study, 4,414 (12.5%) were admitted to the hospital in the year before death. Variables associated with being hospitalized versus not hospitalized in the logistic regression one year before death were being (regression model not shown): male (OR 1.58 95% CI 1.47 to 1.69), under age 85 years (OR= 0.63 95% CI 0.55 to 0.74), married or cohabitating (OR=1.14 95% CI 1.07 to 1.22). People who lived in LTC were less likely to be hospitalized than those living at home (OR =0.37 95% CI 0.34 to 0.40) (see Table 4). However, among people who lived in long term care, nursing home residents were less often hospitalized than elderly home residents (OR= 0.66 95%CI 0.59 to 0.74). People with an income above or equal to the median were more likely (OR =1.51 95% CI 1.40 to 1.62) to be hospitalized than those who had a lower income.

Table 2 | univariate analysis for main analysis

Reference home	n	Hospital		LTCF	
		Relative Risk Ratio (95% CI)	p-value	Relative Risk Ratio (95% CI)	p-value
Gender	17,814				
Female		1.00			
Male		0.93 (0.76-1.14)		0.55 (0.47-0.64)	***
Age	17,814				
64-74					
75-84		1.61 (1.11-2.32)	*	1.96 (1.51-2.55)	***
85+		1.20 (0.83-1.73)		3.13 (2.42-4.05)	***
Marital status	17,814				
Not married, divorced, widowed					
Married/common-law		0.65 (0.53-0.80)	***	0.48 (0.41-0.57)	***
Type of Household in 2005	17,477				
Not institutionalized					
Institutionalized		4.90 (3.35-7.16)	***	15.99 (11.41-22.41)	***
2005 income dummy based on median <14,410	15,144				
<14,410					
Equal or above 14,410		0.43 (0.33-0.57)	***	0.25 (0.20-0.31)	***
Marital status and type of household with interaction term					
Marital status	17,814				
Not married, divorced, widowed					
Married/common-law		0.73 (0.58-0.93)	*	0.64 (0.53-0.76)	***
Type of Household in 2005	17,477				
Not institutionalized					
Institution		3.90 (2.38-6.40)	***	11.36 (7.36-17.53)	***
Interaction term	17,477				
Not institutionalized, not married, divorced or widowed					
Institutionalized, married		1.46 (0.66-3.23)		1.83 (0.90-3.69)	

*means 0.05,**p<0.001 ***p<0.0001

Table 3 | multinomial logistic regression complete model: factors associated with place of death for people 65 and older with dementia (n=14,875)

Reference home	Hospital		LTCF	
	Relative Risk Ratio (95% CI)	p-value	Relative Risk Ratio (95% CI)	p-value
Age				
64-74				
75-84	1.62 (1.04-2.54)	*	1.88 (1.36 -2.58)	***
85+	1.14 (0.73-1.78)		2.03 (1.47-2.79)	***
Marital status				
Not married, divorced, widowed				
Married/common-law	0.67 (0.52-0.87)	**	0.84 (0.69-1.03)	*
Type of household				
Not institutionalized				
Institutionalized	4.38 (2.85-6.73)	***	13.69 (9.33-20.09)	***
Income				
<14,410				
Equal or above 14,410	0.60 (0.45-0.80)	***	0.49 (0.39-0.62)	***

means 0.05, **p<0.001 ***p<0.0001

3.4 Secondary analysis: Multinomial logistic regression on people hospitalized one year before death

Variables that were associated with place of death in the univariate multinomial logistic regression model among people hospitalized one year before death and were included in the backwards selection procedure comprised gender, age, marital status, type of household, number of hospitalizations one year prior to death, personal income, location prior to last hospitalization and emergency admission. An interaction term between marital status and type of household was also included as the p-value in the univariate model for this interaction term was less than 0.1. In the backwards selection procedure we found five variables that were related to location of death for people that were hospitalized in the year before death; increased age, being institutionalized, income lower than the median, and whether it was an emergency admission all influenced the likelihood of dying in a LTCF or a hospital compared to death at home (see Table 5).

Table 4 | Baseline differences in people hospitalized versus not hospitalized one year prior to death

Variable	Never hospitalized	%	Hospitalized at least once	%	Total	p-value
location of death						***
Hospitalized	0	0%	756	100%	756	
LTCF	12,949	79%	3,402	21%	16,351	
Home	451	64%	256	36%	707	
Total	13,400	75%	4,414	25%	17,814	
Gender						***
Females	9,524	78%	2,689	22%	12,213	
Males	3,876	69%	1,725	31%	5,601	
Total	13,400	75%	4,414	25%	17,814	
Age						***
65-74	617	70%	269	30%	886	
75-84	4,306	70%	1,804	30%	6,110	
85	8,477	78%	2,341	22%	10,818	
Total	13,400	75%	4,414	25%	17,814	
Marital status						***
Not married	6,795	76%	2,093	24%	8,888	
Married	6,605	74%	2,321	26%	8,926	
Total	13,400	75%	4,414	25%	17,814	
Type of household 2005						***
Single persons	2,576	64%	1,468	36%	4,044	
Living with partner	3,146	71%	1,301	29%	4,447	
Living with children	860	80%	219	20%	1,079	
Institution	6,764	86%	1,143	14%	7,907	
Total	13,346	76%	4,131	24%	17,477	
Type of household in 2005 (recoded)						***
non-institutionalized	6,582	69%	2,988	31%	9,570	
institutionalized	6,764	86%	1,143	14%	7,907	
Total	13,346	76%	4,131	24%	17,477	
Marital status						***
<14,410	5,969	79%	1,603	21%	7,572	
Equal or above 14,410	5,389	71%	2,183	29%	7,572	
Total	11,358	75%	3,786	25%	15,144	
Marital status*type of household in 2005						***
Non-institutionalized, single	10,642	74%	3,706	26%	14,348	
Institutionalized, married	2,704	86%	425	14%	3,129	
Total	13,346	76%	4,131	24%	17,477	

means 0.05, **p<0.001 ***p<0.0001

Table 5 | Backwards regression hospitalized people only (n=3,441)

	Hospital		LTCF	
	Relative Risk Ratio (95% CI)	p-value	Relative Risk Ratio (95% CI)	p-value
Age				
64-74				
75-84	2.61 (1.37-4.96)	**	2.39 (1.41-4.04)	**
85+	2.05 (1.08-3.90)	**	2.59 (1.54-4.37)	***
Type of Household in 2005				
Non-institutionalized				
Institutionalized	2.99 (1.53-5.82)	**	4.46 (2.37-8.38)	***
Household Income				
<14,410				
equal or above 14,410	0.48 (0.30-0.74)	***	0.38 (0.25-0.57)	***
Location prior to last hospitalization				
Institution				
Own home	0.31 (0.13-0.74)	*	0.27 (0.12-0.62)	**
Emergency admission				
Planned				
Emergency	3.62 (2.4-5.41)	***	1.66 (1.20-2.30)	**

*means 0.05,**p<0.001***p<0.0001

4. DISCUSSION

Main findings

In this study among of 17,814 people with dementia listed as a cause of death who deceased in 2006, we showed that increased age, being single, living in an institution the year before death, and having an income below the median of 14,410 euros were all associated with an increased likelihood of dying in a long-term care facility compared to dying at home. People were at higher risk of dying in a hospital rather than at home if they were between the ages of 75 to 84, single, lived in an institution the year before death and had an income below 14,410 euros. It is important to mention that the majority of the people in this study died in a long-term care facility and very few died at home or in hospital unlike what has been found in other countries (10,13). This is surprising because a year before death, over half of the population with dementia-related deaths were still living at home. Only 12% of the entire population was ever hospitalized the year before death. We found hospitalization occurred more often in people who were: males, younger

than 85 years old, married or cohabitating, living at home, and had income over the median compared to women, people older than 85, being single, living in LTC and having an income lower than the median. These factors did not change the results of the main analysis very much although an emergency admission in the year before death was found as an explanatory factor which increased the likelihood of people who were hospitalized to die in a LTCF or hospital compared to death at home.

Explanation of main findings

Our findings may indicate that people spend a relatively short palliative or terminal stage in a long-term care facility. In the Netherlands, elderly people often go to long-term care facilities to receive end of life care as they require more medical care than those who live at home and from what can be provided at home. It is commonly believed that persons with dementia in the Netherlands live six years in the community and two years on average in a LTCF (14). In our evaluation, people lived for a shorter period of time in a long-term care setting and were rarely hospitalized in the last year of life.

People who died at home were more frequently admitted to hospital in the year before death than those that were living in a long-term care facility which is not entirely surprising as most care can be provided in the LTCF. However, people who were institutionalized in the year before death were more likely to die in a hospital or LTCF than people living at home. It could be that these people were sicker than the people who were living at home and the LTCF sent them to hospital for a treatment they could not provide. Statistics Netherlands data did not provide information on the medical interventions performed, so we cannot validate this possible explanation and further research is recommended.

It is important to distinguish between nursing homes and elderly care homes. The first have in home physicians and skilled nurses and focus on care, while the latter have nurse helpers and external GPs with a focus on assisted living. This care configuration resembles the nursing home setup in most other countries. However, you need a lower level indication than a nursing indication to enter an elderly care home, thereby serving 'lighter' persons than nursing homes. Internationally, Dutch nursing home are atypical because of the in home physicians and they seem to be better equipped to offer care until death without hospital admissions compared to other countries as well as the elderly care homes. In this analysis, we merged these two types of LTCF together because there was not a difference in identified characteristics in our main analysis (data not shown). The persons who died in an elderly home were hospitalized more frequently in the year before death than those that died in the nursing home. This may be explained by the presence of in home nursing home physicians who can provide appropriate care in medical emergencies whereas in elderly homes people need to go to hospital to receive this care.

Comparison with existing literature

A recent English study (10) (n=388,899) that looked at death certificates where dementia was mentioned, also evaluated the relationship between location of death and explanatory variables over 10 years. They found that 55.3% percent died in a care home, 39.6% died

in hospital, and 5.1% died either at home or a hospice. The authors (10) attributed the decrease in hospitals deaths over time to an increase in availability of care home beds. An American study (13) (n=286,282) that compared site of death in persons with dementia found in 2009 that 48.8% died in a nursing home, 17.5% in an acute care hospital and 22.8% at home. These results greatly differ from the Dutch results where the percentage of deaths at home and hospital were both 4% and the majority (92%) died in a nursing home which may reflect the level of care provided in Dutch nursing homes and care within the community. What was surprising in the American study (13) was that 65.2% of people with dementia had a hospitalization in the last 90 days before death whereas in this study only 12% were hospitalized the year before death (13). A possible explanation why more people in the Netherlands die in nursing homes is because of the presence of nursing home physicians whereas in the united states there are only nurses caring for people in the nursing homes.

The English study (10) found an increased chance of dying in a care home when people were older, in an area of increased care bed provision and with greater affluence. We not only found increased age to increase the likelihood of dying in a LTCF but also being single and an income below the median.

People who died at home in the English study (10) were more likely female, in a relationship, living in an affluent area, having an underlying cause of death as cancer which was fairly consistent with our results except people who were more likely to die at home in this study were also younger and we did not find a gender effect. Personal income was also found to be related to location of death in an American literature review (15). Previous literature (13,15) also found cultural background to be influential in location of death which is in contrast to our findings.

A review by Bardrakalimuthu (16) found that studies relying on death certificate data show that patients with dementia die more frequently in care homes than any other locations. In contrast, in prospective studies death was more common in their own residence and hospital. Our results are consistent with the studies that relied on death certificate data. Our results are also in line with the findings from Houtiekker et al. (2010) who also found that the majority of Dutch persons with dementia die in a long-term care facility (4).

Strengths and limitations

Strength of this study include its large sample size, the ability to also look at hospitalization data as well as to identify transitions in living situation.

Because of its size this study risks being over-powered. Therefore, we reported confidence intervals instead of p values since these also provide information on the range of uncertainty. As we have taken the cause of death as dementia from the death certificate, it is possible that this is an underestimate of people with dementia in the Netherlands, especially if the person had mild cognitive impairments. Registration bias is also possible as there may be better registration of death in the nursing home compared to registration of death in a hospital.

Recommendations for further research

Most people with dementia die in a LTCF in the Netherlands. From our data, it appeared that the relative risk of dying in a LTCF or hospital compared to home decreased if the person was married or cohabitating but the care needs of persons with dementia are complex especially in the end of life stage and are not always possible for caregivers to fulfill (17). Currently, there is a government mandate to decrease the number of long-term care beds and to provide care within the community as a budgetary cutback measure (18). Further research examining the type of care provided in nursing homes would give a better indication of the type of care people with dementia in the community need and possibly, to indicate whether it is realistic to expect that people with dementia spend the last phase in their life at home.

CONCLUSION

As the central and local government enable older people to stay longer at home potentially enabling them to die in their most preferred location (i.e. at home), it is unclear if these plans will create a cycle of vulnerable people going in and out of hospital every time there is a crisis at home. Policy-makers should focus on the current and future types of support required for death at home in persons with dementia. In fact, many initiatives are already being set up currently such as nursing home physicians doing consultations at home and being on 24/7 call.

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Supplementary section 1 | Recoding of the reference group to compare deaths in LTCF vs. Hospital

Reference Hospital	Home		LTCF	
	Relative Risk Ratio (95% CI)	p-value	Relative Risk Ratio (95% CI)	p-value
Age				
64-74				
75-84	0.62 (0.39-0.96)	*	1.15 (0.81-1.62)	
85+	0.88 (0.56-1.38)		1.76 (1.25-2.49)	***
Marital status				
Not married, divorced, widowed				
Married/common-law	1.20 (1.16-1.95)	**	1.25 (1.05-1.49)	**
Type of household				
Not institutionalized				
Institutionalized	0.21 (0.13-0.33)	***	3.26 (2.66-3.99)	***
Income				
<14,410				
Equal or above 14,410	1.65 (1.15-2.19)	***	0.83 (0.69-1.00)	*

means 0.05, **p<0.001 ***p<0.0001