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A Census-based longitudinal study of variations in survival amongst residents of nursing and residential homes in Northern Ireland

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Abstract

Background: despite the intensive services provided to residents of care homes, information on death rates is not routinely available for this population in the UK.
Objective: to quantify mortality rates across the care home population of Northern Ireland, and assess variation by type of care home and resident characteristics.
Design: a prospective, Census-based cohort study, with 5-year follow-up.
Participants: all 9,072 residents of care homes for people aged 65 and over at the time of the 2001 census with a special emphasis on the 2,112 residents admitted during the year preceding census day.
Measurements: age, sex, self-reported health, marital status, residence (not in care home, residential home, dual registered home, nursing home), elderly mentally infirm care provision.
Results: the median survival among nursing home residents was 2.33 years (95% CI 2.25–2.59), for dual registered homes 2.75 (95% CI 2.42–3.17) and for residential homes 4.51 (95% CI 3.92–4.92) years. Age, sex and self-reported health showed weaker associations in the sicker populations in nursing homes compared to those in residential care or among the non-institutionalised.
Conclusions: the high mortality in care homes indicates that places in care homes are reserved for the most severely ill and dependent. Death rates may not be an appropriate care quality measure for this population, but may serve as a useful adjunct for clinical staff and the planning of care home provision.

Keywords: *residential facilities, mortality, aged, longitudinal studies, elderly*

Introduction

The projected increase in both the number and proportion of older people raises questions about the future financing and provision of care. If this is associated with an increasing requirement for care, the roles of both informal carers and the caring services will be of greater importance to the well-being of tomorrow's society. Although the numbers and proportions utilizing institutional care has fallen in recent years [1] care homes provide an important and sizeable component of care for older people with the greatest need for care, and will continue to do so. Community Care reform in the UK during the 1990s placed greater emphasis on supporting older people in the community wherever possible, so that places in care homes are now reserved for the most frail and vulnerable. Care assessment and admission criteria for residents are now well developed and standardised, although appropriateness of placements remains an issue [2].

There is relatively little routinely available information about the health of older people in care homes. Population surveys, such as the General Household Survey [3] and health surveys which provide rich sources of information about the health of people living in private households usually exclude residents of communal establishments. Indeed, studies of variations in mortality rates are often at pains to exclude care homes as these may 'bias' the findings [4]. Even one of the most basic public health metrics—an examination of mortality rates within care homes-–has rarely been performed in the UK due to data limitations, though it does occur more frequently in US research [5].

The aim of the current study is to produce an estimate of the mortality rates within nursing and residential homes in Northern Ireland; and to assess variation in these rates by characteristics of residents. Care arrangements in Northern Ireland are similar to those in the rest of the UK with the exception that health and social services were (at the time of the study) jointly commissioned by four Boards and jointly

delivered by eleven Community Health and Social Services (HSS) Trusts, an arrangement that is thought to promote greater integration of services [6]. Northern Ireland has the highest proportion in the UK of older people in care homes [1].

Methods

Northern Ireland Mortality Study

The Northern Ireland Mortality Study (NIMS) is a prospective longitudinal study, with the entire population of Northern Ireland enumerated at the 2001 Census forming the cohort. This includes all residents enumerated in nursing and residential homes. The dataset is maintained in a secure setting by the Northern Ireland Statistics and Research Agency (NISRA). Calculation of mortality rates was possible due to an exercise undertaken by NISRA to link the death records of all Northern Ireland residents who had died in the 5 years following the 2001 Census to the decedents' Census returns. Overall 94% of these deaths were matched to a census record, the greatest proportion of unmatched records being to younger individuals, details of which have been described elsewhere [7]. The combined dataset containing the relevant subset of Census variables, characteristics of the care homes and the death records were anonymised, held within a secure setting provided by NISRA and made available to the research team for this study.

Identification of homes

Although the Census is acknowledged to provide the most comprehensive description of the UK population, issues have been raised about the accuracy of information relating to communal establishments and to the separation of patients and staff (see below). Banks *et al.*, for example, have indicated that smaller homes may not have been enumerated as communal establishments [1]. Information on nursing and residential homes held by the Regulation and Quality Improvement Authority (RQIA) was therefore used in preference to Census data. This regulatory list is both comprehensive and accurate, and the RQIA data provided a classification of care homes that was more relevant to a health and social services context than the Census, such as the type of care the homes are registered to provide. These data automatically exclude other community care facilities such as sheltered accommodation or Fold housing schemes.

There were 339 registered care home providers for older people in the RQIA data, open as of Census day 2001. NISRA staff linked the individual census records of residents to these homes using dedicated software that uniquely identifies all properties in Northern Ireland. Information was available for residents in 302 of these homes. The homes unmatched to census records had similar characteristics to those that were linked.

The RQIA register provided data that allowed homes to be classified according to registration type. Homes were classified as residential or nursing and a third category, 'dual registration', was included for the 24% of homes registered to provide beds for both residential and nursing residents, though the appropriate designation of cohort members within these homes could not be ascertained. All homes were further classified as Elderly Mentally Infirm (EMI) if they were registered as providing care for residents assessed as having a cognitive impairment.

Identification of residents and 2001 census characteristics

A further problem with census data related to care homes is that a number of residents were misclassified as staff. The resolution offered by the Office for National Statistics is to consider all those aged 75 and over, and those aged 16–74 and economically inactive as client residents [8]. This algorithm was used to remove 34 economically active care home residents giving a total of 9,072 residents in 302 homes. However, this includes a significant proportion that may have been resident for some time and whose health status and mortality risk is likely to be different to that of more recently arrived residents. Therefore, in order to get a better picture of the characteristics of more recent entrants, an additional census question, asking about 'usual address one year ago' was used to separate more recent entrants from longer term residents. This reduced the number of residents in the cohort to 2,112 and the number of homes to 257. Residents admitted for respite care were not included in the cohort as only permanent residents were enumerated in the census.

The characteristics of cohort members were as defined on the 2001 census form, though only a limited range of variables were available: age, sex, marital status and two measures of self reported morbidity; one on the presence of limiting long term illness (LLTI) and another on general health (GH) in the preceding year. The LLTI question had a yes/no response while the GH question offered three responses—good, fairly good or not good.

Statistical analysis

Analysis was limited to residents aged 65 or over at the time of the 2001 census. Differences in the distributions of resident-level and home characteristics by home type were assessed using chi-square, ANOVA and *t*-tests. The relationship between resident and home characteristics and risk of death during the 5 years of follow-up was investigated using Cox proportional hazards models. Standard errors were adjusted for clustering of observations at the care home level, using the cluster command in STATA version 10 (Stata, College Station, TX). Significance levels of categorical variables were assessed using Wald Tests, as the robust standard errors generated using the cluster command may invalidate the use of likelihood ratio tests. Age in years was fitted as categorical variables. The proportional hazard assumption was graphically checked from survival curves for each explanatory variable. Sensitivity analyses were conducted using multi-level logistic models with dead or alive at 5 years as the outcome and residents nested within a care home level using the

Table 1. A comparison of characteristics of 2,112 residents admitted to care homes in the year preceding the census, and the population not in care homes aged 65 years and over as of Census day 2001

	Residential No. (%)	Dual No. (%)	Nursing No. (%)	Total No. (%)	Not in care home No. (%)
Homes	100	63	94	257	
Residents	577	640	895	2112	205566
Sex					
Male	146 (25)	203 (32)	233 (26)	582 (27)	85085 (41)
Female	431 (75)	437 (68)	662 (74)	1530 (72)	120481 (59)
Age					
65–74	65 (11)	70 (11)	112 (13)	247 (12)	116712 (57)
75–84	259 (45)	306 (48)	367 (41)	932 (44)	70762 (34)
85–94	236 (41)	240 (38)	373 (42)	849 (40)	17189 (8)
95+	17 (3)	24 (4)	43 (5)	84 (4)	903 (<1)
Marital status					
Single/divorced/widowed	506 (88)	523 (82)	708 (79)	1737 (82)	5327 (32)
Married	71 (12)	117 (18)	187 (21)	375 (18)	11081 (68)
General health (%)					
Good	81 (14)	42 (7)	54 (6)	177 (8)	67881 (33)
Fair	319 (55)	269 (42)	265 (30)	853 (40)	83642 (41)
Poor	177 (31)	329 (51)	576 (64)	1082 (51)	54043 (26)
Limiting long term illness[a]					
No	60 (11)	23 (4)	<10 (≈1)	<100 (≈5)	85971 (44)
Yes	507 (89)	613 (96)	>885 (≈99)	>2005 (≈95)	108725 (56)
Elderly mentally infirm care					
Yes	458 (79)	552 (86)	603 (67)	1613 (76)	–
No	119 (21)	88 (14)	292 (33)	499 (24)	–

[a]Data in some cells suppressed due to low numbers.

xtmelogit command in STATA10. Interpretation of the models did not change compared to that for cluster-adjusted Cox regression models and are not presented here.

Results

Care homes had a minimum of 3 and a maximum of 127 beds, and a minimum of one and a maximum of 79 residents (mean 30.7) living in them on Census day 2001. There were 60 homes with less than 20 beds, and 12 homes with more than 75 beds. Residential homes formed the greater proportion of homes (48%), though because they tended to be smaller than dual registered or nursing homes, contained only 27% of residents (Table 1). Nursing homes comprised 37% of care homes and contained 42% of residents; dual registered homes accounted for 24% of homes and 30% of residents. Overall, residents had a mean (s.d.) age of 83 (7.3) years and 74% were female. Even after adjustment for differences in age, care home residents were more likely than their peers in the community in 2001 to be female (OR 1.42; 95% CI 1.29–1.56) and to be in poorer health (OR comparing 'not good' to 'good' general health 2.87; 95% CI 2.77–2.98); and of reporting LLTI (OR 11.78; 95% CI 9.49–14.62). There was little difference in the age or gender proportions of residents across home type, though they demonstrated the expected residential to nursing home gradients in morbidity. While almost all resident in nursing and dual-registered homes report a LLTI and say that their GH was fair/not good, it was interesting to note that 11% of residents in residential homes did not report a LLTI and 14% said their GH was good.

At 5 year follow-up, 1373 (65%) of the 2112 residents admitted in the year prior to follow-up had died, compared to 22% of those in the community on Census day 2001. The median survival among residents admitted to homes in the previous year was 2.33 years (95% CI 2.25–2.59) for nursing home residents, dual registered 2.75 (95% CI 2.42–3.17) and residential home residents 4.51 (95% CI 3.92–4.92) years. Most of the higher mortality of residents is due to their older ages and poorer health status (see Table 2), though even after adjustment for age and sex residents in nursing homes were more than twice as likely to die during the follow-up period than their community dwelling peers. The mortality rate in dual registered homes fell much closer to the rate in nursing homes than that for residential homes, which was expected as these homes contain between 50% and 90% nursing beds. A comparison of recent entrants to homes with all residents present at Census day confirmed that the former had a lower risk of death over the 5 years following the census (HR 0.89; 95% CI 0.83–0.95—see supplementary Table available at *age and ageing* online).

Table 3 shows that the demographic and health factors predicting mortality risk in the community also operate for residents in homes, though their effects are attenuated with reduced gradients for age, sex and self-reported health among this relatively sicker population. Within homes the hazard ratios for these factors were generally smallest for residents in the nursing homes and most pronounced in

Table 2. Relative mortality rates over 5 years by place of residence for 2,112 recent entrants to care homes and 205,566 non-institutionalised individuals aged 65 and over. Data represents hazard ratios and 95% confidence intervals

	Count (%) dead	Unadjusted	Adjusted for age and sex	Adjusted for age, sex and general health	Adjusted for age, sex, general health and marital status
Not in care home	205566 (22)	Reference	Reference	Reference	Reference
Residential home	577 (54)	3.22 (2.87,3.62)	1.74 (1.53,1.97)	1.69 (1.49,1.92)	1.63 (1.44,1.85)
Dual registered home	640 (66)	4.75 (4.25,5.32)	2.57 (2.26,2.93)	2.13 (1.85,2.46)	2.09 (1.81,2.40)
Nursing home	895 (70)	5.38 (4.87,5.95)	2.90 (2.63,3.20)	2.19 (1.98,2.43)	2.17 (1.96,2.41)

residential homes, though stratification by homes produced much wider confidence intervals than in models based on the whole care home population.

The relationship between mortality risk and residence in a home with EMI provision was inconclusive amongst recent entrants, though suggestive of an increased risk, especially for nursing home residents (HR 1.17; 95% CI 0.95–1.44); the analysis that included all 9,072 residents (supplementary Table available at *age and ageing* online) demonstrated higher mortality risk for homes with EMI provision (HR 1.10; 95% CI 1.01- 1.20). The protective effect of marriage was evident for older people not in care homes (HR 0.81 95% CI 0.79, 0.82), but not for care home residents as a whole (HR 0.99 95% CI 0.84, 1.18).

Discussion

To the authors' knowledge, this is the largest population-based study in the UK quantifying the variations in mortality rates across care homes for older people. It was possible because of a mortality linkage study covering the whole population and comprehensive information relating to care home provision. The study demonstrated the significant mortality of residents in care homes; after adjustment for age and sex, mortality risk was 1.7 times greater in residential homes, 2.6 times higher in dual registered home and 2.9 times higher for nursing home residents than equivalently aged people living in the community. The relatively small attenuation of these differentials with the addition of census-based health measures may be a sign of their lack of specificity for this population and because an unknown (but probably large) proportion of residents' census forms were completed by proxy. There was no measure of mental health in the UK census but the higher hazard ratios for homes with EMI provision, which being averaged over all residents in these homes, supports the increased mortality risk for residents with mental health problems found in other studies [9–12]. The well-recognised protective effect of marriage at older ages [13, 14] was not seen for the care home population, and this was not unexpected given that the bonds of social, material and task support [15, 16] have already been largely severed on admission. Furthermore, as being married reduces a person's risk of admission to a care home [17–19], people who are admitted despite having this protective factor are probably in poorer health at the time of admission.

The primary methodological shortcomings of this study arise because it was not based on data collected specifically for the study of mortality rates in care homes but relied on data collected for other purposes, albeit from the census and death registrations. While the census is the most comprehensive assessment of the population, it has recognised shortcomings in terms of identifying both homes and residents [1]. The first of these was circumvented by using a list of homes from the organisation with statutory responsibility for registering and inspecting homes. This precluded the misclassification of homes and the inclusion of other types of non-institutional care facilities. However, it was not possible with this process to match 37 (10.9%) of the 339 homes identified as being open at the time of the census, though we are not aware of any systematic bias in the unlinked homes. It is impossible to ascertain how successful our ability to produce a cohort consisting only of residents was but given that recommended algorithm [8] resulted in the removal of only 34 residents this is not likely to have seriously affected the results.

On Census day, the occupants of care homes will have been resident for differing lengths of time giving significant potential for survivor bias. The census did not record the date of entry to the home but we were able to identify those admitted within the previous year and analysis showed that these more recent residents had significantly lower mortality risk than the residents of longer duration. This is at variance with others who found that newly admitted residents were more likely to die in the first few months of admission because of their more acute clinical condition [9]. It is possible that our cohort of residents entering within a year of the census had already experienced this period of early attrition leaving a relatively healthy residual group of residents, in which case the mortality risks of those entering care homes are larger than recorded here. Further research is being undertaken to quantify mortality according to time of admission using changes of address registered with General Practitioners to identify time of admission; this research will use the Northern Ireland Longitudinal Study [20]

The findings here are generally in keeping with those produced in other studies though direct comparison to mortality rates in other settings is difficult, not least because of differing entry criteria, and variations in levels of supply and of alternative community support that could substitute for institutional care. Cohen-Mansfield *et al.* found a median survival of 2.75 years in nursing home residents but the recent emphasis in the USA has been on variations in 1 year survival rates

Table 3. Distribution and hazard ratios of personal characteristics for 2,112 recent entrants to care homes aged 65 and older, stratified by residence

	Residential		Dual		Nursing		All homes		Not in homes	
	Number (% Dead)	Hazard ratio (95% CL)	Number (% Dead)	Hazard ratio (95% CL)	Number (% Dead)	Hazard ratio (95% CL)	Number (% Dead)	Hazard Ratio (95% CL)	Number (% Dead)	Hazard ratio (95% CL)
Sex										
Female	146 (64)	Reference	203 (68)	Reference	233 (73)	Reference	582 (69)	Reference	120481 (20)	Reference
Male	431 (51)	1.60 (1.23,2.10)	437 (65)	1.16 (0.90,1.48)	662 (69)	1.37 (1.13,1.65)	1530 (63)	1.34 (1.18,1.53)	85085 (24)	1.66 (1.63,1.70)
			Interaction $P = 0.54$				Interaction $P < 0.001$			
Age										
65–74	65 (31)	Reference	70 (54)	Reference	112 (56)	Reference	247 (49)	Reference	116712 (13)	Reference
75–84	259 (53)	2.36 (1.51,3.68)	306 (62)	1.30 (0.92,1.83)	367 (65)	1.29 (0.96,1.74)	932 (61)	1.50 (1.23,1.83)	70762 (28)	2.33 (2.28,2.38)
85–94	253 (37)	3.20 (2.03,5.06)	264 (79)	1.78 (1.24,2.55)	416 (80)	1.85 (1.40,2.45)	849 (72)	2.09 (1.72,2.54)	17189 (53)	5.09 (4.96,5.24)
95+	+	5.84 (3.30,10.34)	+	3.13 (1.65,5.95)	+	2.43 (1.64,3.63)	84 (85)	3.25 (2.39,4.41)	903 (66)	8.07 (7.43,8.76)
			Interaction $P = 0.05$				Interaction $P < 0.001$			
Self Reported health										
Good	81 (56)	Reference	329 (69)	Reference	54 (78)	Reference	177 (63)	Reference	67881 (12)	Reference
Fairly good	319 (49)	0.81 (0.56,1.16)	269 (64)	1.24 (0.77,2.01)	265 (70)	0.94 (0.72,1.23)	853 (60)	0.96 (0.78,1.19)	83642 (21)	1.65 (1.60,1.69)
Not good	112 (63)	1.26 (0.86,1.84)	329 (69)	1.52 (0.95,2.43)	576 (69)	1.00 (0.76,1.31)	1082 (68)	1.29 (1.05,1.58)	54043 (35)	3.01 (2.93,3.09)
			Interaction $P < 0.001$				Interaction $P < 0.001$			
Marital status										
Single/divorced/ widowed	506 (53)	Reference	523 (65)	Reference	708 (72)	Reference	1737 (65)	Reference	101400 (26)	Reference
Married	71 (61)	1.36 (0.98,1.88)	117 (71)	1.12 (0.82,1.54)	187 (62)	0.78 (0.61,0.99)	375 (65)	0.99 (0.84,1.18)	104166 (17)	0.81 (0.79,0.82)
			Interaction $P = 0.01$				Interaction $P < 0.001$			

+ − counts for 95 + age group aggregated into 85–94 group for presentation due to low numbers.
Hazard ratios refer to the 85–94 and 95 + age groups.

[9, 11, 21]. Within the UK, Dale *et al.* estimated the median survival of residents in 32 Manchester area nursing homes as being 5.9 years [22]. Only Rothera *et al.* [23] has previously compared different type of care homes and showed an 85% higher mortality risk in nursing than in residential homes, though the different levels of adjustment makes comparison difficult. They found a median survival in nursing homes of 1.5 years, though the follow up period of 20 months did not allow median survival to occur for the other care home populations.

The availability of mortality rates for care homes raises the possibility of using it as a metric for standards of care or to explore differences between types of provider (for example larger/smaller, or private /public sector) or to produce league tables. However, the relationship between mortality and quality of care is oblique and would require, as a minimum, the capture of appropriate types and levels of morbidity data on admission to adjust for variations in case-mix. In addition, the inherent precision of the mortality estimates is likely to produce large amount of year-on-year variation in rankings, even amongst care homes where mortality rates are high. Such problems have been well illustrated in the literature surrounding hospital league tables [24], and given that all care in care-homes could be considered end-of-life care [25] the relevance of mortality as a measure of care provision quality is unclear [26]. Measures of quality of care and of variations in admissions thresholds should be assessed through more direct measures of assessment. However, it is probable that the availability of the magnitude of the mortality rates and variation between types of care homes may be useful for clinicians and staff who have to define care plans for patients and family members, and also for those planning for future health care needs.

Key points

- Routine mortality data are not available for the UK Care home resident population.
- The Northern Ireland Mortality Study (NIMS) enables the analysis of death rates for the whole Northern Ireland population, including care home residents.
- Median survival in Northern Ireland care homes ranges from 2.3 years in nursing homes to 4.5 years in residential homes.

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Supplementary data

Supplementary data are available at *Age and Ageing* online.

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