The provision of care for residents dying in UK nursing care homes

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Abstract

Objectives: to identify the care currently provided to residents dying in UK nursing care homes.
Method: study participants were residents who had died within 38 nursing care homes in southeast England over a 3-year period. The nursing care homes had been recruited to take part in a cluster randomised controlled trial looking at different models of facilitation while implementing the Gold Standards Framework in Care Homes (GSFCH) programme. Two researchers examined the notes and daily records of all residents who died in each of these homes between the 1 June 2008 and the 31 May 2011.

Results: a total of 2,444 residents died during the 3-year period. Fifty-six percent of these residents died within a year of admission. The support from specialist healthcare services to residents during their last 6 months of life was variable.

Conclusions: nursing care homes have established links with some external healthcare providers. These links included the GP, palliative care nurses and physiotherapy. As dependency of resident increase with 56% residents dying within a year of admission these links need to be expanded. The provision of health care that meets the needs of future nursing care home residents needs to be ‘proactively’ obtained rather than left to chance.

Keywords: dying, nursing homes, older people, health care provision, older people

Introduction

Internationally, the population has increased both in number and age leading to changes in the place of care for older people in Europe [1]. In 2001, over half of all beds allocated for health care in the UK were in independent nursing homes [2]. Since then, the number of beds in nursing care homes in England has increased still further from 180,708 in 2003 to 215,524 in 2012 [3]. Care homes clearly provide a place of care where older people live. They are now also recognised as a place for end-of-life care for older people. A recent publication revealed that 19% of all deaths in England now occur in care homes [4].

Although there has been an expansion in the number of care homes in the UK, there is little information published about the current health care needs for this population. A recent study looking at mortality in older care home residents in England and Wales highlighted this lack of information [5]. While information has been published on the resident’s demographics, their medical diagnosis and length of stay, there is little about care provision [5, 6]. The data presented in this article adds to this. Care provision, for 2,444 residents in their last 6 months of life, is presented alongside their demographic data. These residents had died in 38 nursing care homes that were participating in the Gold Standards Framework in Care Homes (GSFCH) programme.

Method

Thirty-eight nursing care homes in southeast England were participating in a trial looking at different models of facilitating the implementation of the GSFCH programme. Two researchers examined the notes of all residents who died in each nursing care home between the 1 June 2008 and the 31 May 2011 and extracted information that included: demographics; diagnoses; attendance at out-patients; use of A&E; hospital admissions; professional visits to the home; place and type of death. The notes were examined for the last 6 months of life or for their length of stay (whichever was
shorter). Information was obtained from all available records within the care home.

Prior to data collection a steering group (all authors) was convened and pro formas agreed for data collection. Collection of data from residents’ records included the categorisation of the residents diagnosis, type of death [7] and the appropriateness of hospital admissions (see Table 1). The use of end-of-life care tools including advance care planning and resuscitation decisions was recorded but is reported elsewhere. Residents were recorded as having one medical diagnosis (except for category ‘other’ in Table 2) regardless of how many types were recorded, e.g. residents with osteoporosis and arthritis were recorded as having a ‘musculoskeletal disorder’. Only current diagnoses were documented. Data collection was undertaken by two researchers. Ethical approval was granted (09/H0715/74).

Results

Over the 3-year period 2,444 residents died within the 38 nursing care homes. Most provided care for residents with dementia and old age. One nursing care home closed in March 2010. The data collected for the time that this nursing care home was open is included. There was no attrition among the remaining homes.

The length of the study allowed time for researchers to both build relationships with the participating nursing care home staff and gave opportunity to locate ‘missing’ notes. As a consequence very little data remained missing; where data are missing, numbers are reported alongside percentages.

Demographic details

The mean age was 85 years (range 33–107 years) with 61% being female. The mean length of stay was 20 months with a median of 8 months (range 1–6,393 days). Nineteen percent of residents died within their first month of admission and 34% residents within the first 3 months of admission. Fifty-six percent died within a year.

### Table 1. Criteria for judging the decision to admit a resident to hospital to be inappropriate

<table>
<thead>
<tr>
<th>Inappropriate hospital admissions included</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 A dying resident admitted to hospital and they had wanted to die in the nursing care home</td>
</tr>
<tr>
<td>2 A physically and mentally frail resident admitted to hospital without a GP assessment visit and their condition was potentially manageable within the nursing care home</td>
</tr>
<tr>
<td>3 Resident wanted to remain in the nursing care home and not go into hospital but the family/GP insisted. This admission was not for an acute event</td>
</tr>
<tr>
<td>4 A physically and mentally frail resident admitted for a condition that was not reversible—yet the reason given for the decision to admit was for treatment</td>
</tr>
<tr>
<td>5 A physically and mentally frail resident dying with advanced dementia</td>
</tr>
</tbody>
</table>

### Table 2. The residents recorded medical diagnoses

<table>
<thead>
<tr>
<th>Medical diagnosis</th>
<th>Valid % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other</td>
<td>53.8 (1,235/2,294)</td>
</tr>
<tr>
<td>Organic mental health (dementia only)</td>
<td>47.5 (1,123/2,360)</td>
</tr>
<tr>
<td>Heart disease</td>
<td>43.8 (1,098/2,304)</td>
</tr>
<tr>
<td>Muscular skeletal</td>
<td>34.5 (790/2,292)</td>
</tr>
<tr>
<td>Stroke</td>
<td>32.7 (755/2,309)</td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td>31.1 (736/2,369)</td>
</tr>
<tr>
<td>Cancer</td>
<td>23.7 (546/2,305)</td>
</tr>
<tr>
<td>Functional mental disorder</td>
<td>22.8 (522/2,288)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>20 (457/2,287)</td>
</tr>
<tr>
<td>Urinary and gynaecological disease</td>
<td>18.7 (428/2,289)</td>
</tr>
<tr>
<td>Respiratory disease</td>
<td>16 (367/2,291)</td>
</tr>
<tr>
<td>Lower GI problem</td>
<td>10.5 (240/2,287)</td>
</tr>
<tr>
<td>Neurological disorders</td>
<td>9.7 (222/2,291)</td>
</tr>
<tr>
<td>Upper GI problem</td>
<td>5.3 (121/2,287)</td>
</tr>
<tr>
<td>Skin</td>
<td>4.1 (94/2,286)</td>
</tr>
<tr>
<td>Elderly/frail</td>
<td>3.8 (86/2,291)</td>
</tr>
</tbody>
</table>

### Resident diagnosis

All written diagnoses were categorised (see Table 2)—this allowed residents to have multi-morbidities accounted for. While the median number of medical diagnoses was four the incidence of multi-morbidities is likely to be higher (e.g. a resident was prescribed thyroxin but there was no written diagnosis of hypothyroidism).

We were able to observe a change in the recording of residents’ diagnoses year on year. For example, whilst a total of 79% residents were documented as having dementia or cognitive impairment, the recorded diagnosis of dementia increased year-on-year from 44 to 51% in the third year.

### External visits by residents for professional advice

During their last 6 months of life residents were supported by healthcare professionals from both hospital and community settings.

A small proportion of residents (n = 252/2,314 or 1%) left the nursing care home to visit a professional rather than have a professional come into the nursing care home to see them. This included such visits as attending their local GP service for ear syringing and visiting the community dermatology clinic.

Residents were documented as attending hospital for three main reasons: out patient appointments (OPAs); A&E (no admission to a ward); and, for admissions to a hospital ward (which may or may not have been planned). Twenty-three percent residents (543/2,318) attended OPAs between 1 and 64 occasions. The residents attending the greatest number of OPAs were those undergoing dialysis treatments. Eleven percent (n = 274/2,317) residents attended the A&E department between one and four occasions. Thirty-four percent residents (n = 789/2,320) were admitted to hospital in their last month of life of which 58% were deemed to be inappropriate (see Table 1). Twenty-five residents had two inappropriate hospital admissions during their last month of life; nearly half (11 residents) remained as inpatients for their entire last month of life.
Professional visits to residents

A variety of professionals visited residents in the nursing care homes (see Table 3). GPs visited most often with 96% of residents being seen in their last 6 months of life. Podiatrists, opticians and the palliative care nurse saw 20% or more of the residents. Interestingly, 44% residents were recorded as having heart disease and, while not all of these would have heart failure, only six residents (0.3%) had a visit from a heart failure nurse. Similarly, while 48% residents had dementia and 23% had a functional mental disorder, only 11% residents being seen in their last 6 months of life. Podiatrists, opticians and the palliative care nurse saw 20% or more of the residents. Interestingly, 44% residents were recorded as having heart disease and, while not all of these would have heart failure, only six residents (0.3%) had a visit from a heart failure nurse. Similarly, while 48% residents had dementia and 23% had a functional mental disorder, only 11% residents were recorded as being supported by the mental health services visiting them in the nursing care home.

The staff within the nursing care homes requested additional medical support. There were a number of out of hour’s requests to the GP service. In the resident’s last month of life, 50% (1,107/2,317) had an ‘out of hours’ visit on one to six occasions. In the penultimate month only 37% (564/2,338) of residents had an out of hours visit. During their last 6 months of life there were also a number of 999 ambulance visits requested (n = 147) for residents who were not transferred to hospital. Following medical advice by the ambulance staff plus or minus the resident’s GP management of the resident’s condition occurred within the home.

Place of death

The majority of the residents (72.5%) died in the nursing care home. Twenty-seven percent died in hospital with the remaining residents (0.5%) dying elsewhere: six residents died in the hospice; five in an ambulance and two in their relatives’ house while visiting them. Every home had residents who died elsewhere (percentage of elsewhere to nursing care home deaths varied from 4 to 59%). Details on place of death were only missing for 16 residents.

Type of death

Type of death was categorised as sudden, acute, terminal or dwindling [7]. Data were missing for 75 residents. A sudden death was one where the resident had collapsed and died or was found to have died, but for that resident death at that time had been totally unexpected. Four percent (102/2,369) of residents were recorded as having such a death. An acute death was one that occurred with deterioration over a few days such as following an event such as a fractured neck of femur, a stroke or an infection (a one off occurrence not multiple infections). Nineteen percent of residents (454/2,369) were recorded to have died from an acute event. A terminal death was recorded for residents with a diagnosis of cancer, Parkinson’s, motor neurone disease or who was admitted specifically for terminal care. Using this classification 26% (621/2,369) died from a terminal disease. By far the greatest numbers of residents died a dwindling death (50%). These numbers only add up to 99% – this is because sudden deaths 4.3, dwindling 50.3, acute 19.2 and terminal 26.2. This was recognised as being a slow deterioration over a matter of weeks/months.

Discussion

This study provides demographic data on 2,444 residents. Unlike previous studies this information relates to the care they received during their last 6 months of life. It is one of the largest studies specific to end-of-life care in nursing homes that has been conducted in the UK. It is unique in that there is little missing data.

When compared with earlier UK studies it becomes apparent that the residents living in nursing care homes are changing. In 1997, it was reported that of 884 residents 28% died within the first year of their admission [7]. A little later, out of 252 residents who died 47% had lived in the nursing care home for less than a year [8]. In our study, the percentage of residents who died within their first year was as much as 56%. This supports the work carried out by the British Geriatric Society that highlights that residents admitted into nursing care homes are becoming increasingly frail with considerable complex healthcare needs [9]. There is now an urgent need to ensure that the staff in the nursing care homes not only recognise the need for end-of-life care in their setting but also accept responsibility for providing it. Regulating bodies could provide a significant role by insisting that end-of-life care now becomes part of the statutory training for staff in care homes.

Previous work in nursing care homes shows that staff struggle with recognising end-of-life care [10, 11]. It is reported to be easier to recognise end-of-life care for residents dying of cancer [12]. However, less than a quarter of residents in this study died with cancer while the majority died with a dwindling trajectory. The data from this study showed that 269 residents...
(11%) with a dwindling death died in the hospital. An admission to hospital of a frail older person that ends in death costs between £2,352 and £3,779 [14]. In their last month of life 203 of these 269 residents had one to two inappropriate hospital admissions. Such admissions/deaths may be reduced by increasing the medical care provision to nursing care home residents and medical support to staff.

In the UK, avoiding inappropriate hospital admissions has become a target that many services are now measured against in an attempt to improve care provision and to decrease hospital costs.

Providing nursing care homes with regular external professional support (such as heart failure nurse specialists, dementia nurse specialists) may result in a more pro-active rather than a reactive response to meeting older people's healthcare needs. In this study, 264 residents had an acute event that resulted in them dying in hospital. This is not a new finding. An earlier study reported that 61/228 residents that were admitted to hospital for an acute event subsequently died [13]. Those residents experiencing an acute event were the most likely to die in hospital. Increasing medical or specialist nurse provision to nursing care homes may reduce the need for hospital transfer and the number of non-emergency 999 ambulance calls.

The use of the out of hours service reduced in the month prior to a resident's death. This may have occurred as a result of implementing the GSFCH programme which encourages planning ahead.

Within this study 20% of the residents were visited by palliative care nurses. The palliative care services did not solely provide a service for residents with a cancer diagnosis. However, 24% residents had an active cancer diagnosis. This is considerably higher than the 9% reported in 1997 by Sidell et al. [7] and that of 6% in 2008 [13]. This may be explained by the fact that two-thirds of the nursing care homes in this study were in SE London and had established links with their local hospice home care team which resulted in patients being actively transferred to these nursing care homes for their end-of-life care if they were reasonably stable. This change highlights a growing need for specialist palliative care to become more engaged with nursing care homes and vice versa. Interestingly by the end of the study, continuing care funding for end-of-life care had been reduced on average from £900 to under £700/week (personal communication). This perhaps requires attention if nursing care homes are to be encouraged to provide end-of-life care.

Few residents received input from other types of Clinical Nurse Specialists (CNS). Of 2,444 residents the respiratory CNS saw 16 residents, the Heart Failure CNS 6 residents and the dementia CNS 45 residents. There is a need to develop increased supportive links between nursing care homes and CNS [9]. The palliative care nurses have clearly achieved this (see Table 2) and could play an instrumental role encouraging nursing care homes to refer residents to other specialist CNSs as appropriate. Given the predicted increase in dementia, links with mental health teams need more pro-active attention. In this study, only 11% residents had support from the mental healthcare team. This may be a consequence of care home staff’s knowledge or the availability of such a resource in a locality. However, a failure to identify the mental health care needs of frail older people has clearly given permission for healthcare services to ignore their needs.

There are a number of limitations. Firstly, all 38 nursing care homes were participating in the GSFCH programme. The programme encourages collaboration with other healthcare professionals and advance care planning with residents and their families. It is likely that the health provision within these homes is in fact generous compared with nursing care homes not taking part in such a programme.

Another limitation is that the study only reports on the care provision to residents within UK nursing care homes. Internationally, this may be very different. However, the population internationally is also increasing in both number and age. While the approach in other countries may vary there will still be a need for them to match care provision with need.

Conclusion

This article has considered the care provision to 2,444 residents during their last 6 months of life. They were identified to be elderly, have multi-morbidities with 56% dying within their first year of admission.

It would seem care homes acting as 'isolated' providers of care is not an option if residents' health and social care needs are to be met. There is an urgent need to identify what care our current nursing care home residents need. As well as ensuring that care homes meet their staff’s mandatory educational/training needs, commissioning bodies clearly have a responsibility to fully fund the increasing demand for end-of-life care for frail older people dying in care homes. As this group increases in number and complexity the provision of care should not be left to chance.

Key points

- Fifty-six percent of residents died within a year of admission.
- The provision of health care that meets the needs of future nursing care home residents needs to be 'proactively' obtained.
- There is an urgent need to identify what care our current nursing care home residents need.

Conflicts of interest

None declared.

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References


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Perceived age discrimination in older adults

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Abstract

Objectives: to examine perceived age discrimination in a large representative sample of older adults in England.

Methods: this cross-sectional study of over 7,500 individuals used data from the fifth wave of the English Longitudinal Study of Ageing (ELSA), a longitudinal cohort study of men and women aged 52 years and older in England. Wave 5 asked respondents about the frequency of five everyday discriminatory situations. Participants who attributed any experiences of discrimination to their age were treated as cases of perceived age discrimination. Multivariable logistic regression analysis was used to estimate the odds ratios of experiencing perceived age discrimination in relation to selected sociodemographic factors.

Results: approximately a third (33.3%) of all respondents experienced age discrimination, rising to 36.8% in those aged 65 and over. Perceived age discrimination was associated with older age, higher education, lower levels of household wealth and being retired or not in employment. The correlates of age discrimination across the five discriminatory situations were similar.

Conclusion: understanding age discrimination is vital if we are to develop appropriate policies and to target future