Timing of GP end-of-life recognition in people aged ≥75 years:
retrospective cohort study using data from primary healthcare records in England

Abstract

Background
High-quality, personalised palliative care should be available to all, but timely recognition of end of life may be a barrier to end-of-life care for older people.

Aim
To investigate the timing of end-of-life recognition, palliative registration, and the recording of end-of-life preferences in primary care for people aged ≥75 years.

Design and setting
Retrospective cohort study using national primary care record data, covering 34% of GP practices in England.

Method
ResearchOne data from electronic healthcare records (EHRs) of people aged ≥75 years who died in England between 1 January 2015 and 1 January 2016 were examined. Clinical codes relating to end-of-life recognition, palliative registration, and end-of-life preferences were extracted, and the number of months that elapsed between the code being entered and death taking place were calculated. The timing for each outcome and proportion of relevant EHRs were reported.

Results
Death was recorded for a total of 13,149 people in ResearchOne data during the 1-year study window. Of those, 6,303 (47.9%) records contained codes suggesting end of life had been recognised at a point in time prior to the month of death. Recognition occurred ≥12 months before death in 2,248 (17.1%) records. In total, 1,659 (12.6%) people were on the palliative care register and 457 (3.5%) were on the palliative care register for only a minority of people dying with cancer,11 many people aged ≥75 years living with frailty,12 and there is growing evidence that people dying with frailty have needs that may benefit from palliative intervention;13 however, prediction of mortality is challenging and trajectories of frailty towards death are highly variable.14,15

The primary aim of this study was to investigate when GPs first enter a code in electronic health records (EHRs) to show that they are anticipating the end of life for people aged ≥75 years. The secondary aim was to investigate the timing of coding for palliative registration and for patient preferences for care and place of death.

METHOD

Setting
EHR data from primary care services in England were analysed. Data were supplied by ResearchOne, a UK-based, not-for-profit organisation that extracts de-identified health record information from SystmOne. SystmOne is an EHR management system used by approximately 34% of GP practices in England.16,17

Participants
Data were requested for all people aged ≥75 years who died between 1 January 2015 and 1 January 2016. If the cause of death was classified as an external cause of mortality (based on the International Statistical Classification of Diseases and Related Health Problems, 10th Revision18), data for that person were excluded.

Study design
The authors extracted Read codes recorded in EHRs prior to death; records including codes that were entered any time after the month of death or >10 years before the month of death were excluded. The primary aim of this study was to investigate when GPs first enter a code in electronic health records (EHRs) to show that they are anticipating the end of life for people aged ≥75 years. The secondary aim was to investigate the timing of coding for palliative registration and for patient preferences for care and place of death.

INTRODUCTION

More than two-thirds of deaths in England occur in people aged ≥75 years, a number that is predicted to rise with population ageing.1 End-of-life care is a national priority,2,3 with a recommendation that patient contact should be enhanced throughout the year before death, rather than there being a focus on the final few days of life.4 In England, GPs coordinate and deliver the majority of palliative care. Financial incentives are attached to recording end-of-life care and maintaining a register of patients in need of palliative care, irrespective of age,5,6 despite this, older people are believed to be less likely to receive high-quality end-of-life care.7,8

Understanding palliative registration and the recording of preferences in older populations is limited by a paucity of data. It is possible that older people’s access to palliative care is influenced by the mix of malignant and non-malignant conditions in later life;9 for example, in England, people with cancer are around 11 times more likely to be on the palliative care register than people with non-malignant diseases,10 and a study in six Scottish general practices found that around a fifth of people with non-malignant conditions were on the palliative care register, compared with two-thirds of patients with cancer.11 Many people aged ≥75 years have needs that may benefit from palliative intervention;12 however, prediction of mortality is challenging and trajectories of frailty towards death are highly variable.14,15

The primary aim of this study was to investigate when GPs first enter a code in electronic health records (EHRs) to show that they are anticipating the end of life for people aged ≥75 years. The secondary aim was to investigate the timing of coding for palliative registration and for patient preferences for care and place of death.

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How this fits in

Identification of end of life can be challenging for clinicians, particularly in older people living with frailty. In this study, fewer than half of people aged ≥75 years who died had a code in their electronic health record (EHR) to suggest that their death was anticipated by their GP. End-of-life codes in EHRs were entered near to death (median 4 months prior). In the minority of older decedents (aged ≥75 years) for whom end of life was recognised, only a small proportion were on the palliative care register or had their preferences for place of care or death recorded.

month of death were excluded. Read codes were aligned onto a common timeline by calculating the number of months before death at which the code was entered.

Outcome measurement

Read codes relating to end-of-life recognition were identified using the NHS Technology Reference data Update Distribution (TRUD) Read code browser (https://sd.digital.nhs.uk/trud3/user/guest/group/0/home). Targeted searches were carried out using information from the Quality and Outcomes Framework (QOF) guidance for coding end-of-life care (version 32). Read codes from the Gold Standards Framework, and palliative care codes highlighted in the Care.data GP data specification 1.0 (see Supplementary Table S1). Further searches were conducted in the TRUD browser using keywords related to ‘terminal’, ‘palliative’, ‘hospice’, and ‘end of life’, a complete list of codes used during the data extraction are given in Supplementary Table S2.

Analysis

As information regarding the date of death was provided in year/month format, the authors calculated the time prior to death of the code being entered. The primary outcome of interest was any code relating to end-of-life recognition. As multiple codes are often entered during a single consultation with a GP, the authors examined the number of months prior to death for the first code or codes that contained information relating to end-of-life recognition. Secondary outcomes were the number and percentage of codes relating to entry onto the palliative care register, and for preferences for place of death and place of care. For all outcomes, the authors calculated the time before death of the first instance of a code relevant to that particular outcome.

RESULTS

Participants

EHRs were available for 13 149 people aged ≥75 years who died between 1 January 2015 and 1 January 2016. The majority of decedents were female (55.6%) and the mean age at death was higher for females (88.1 years, standard deviation [SD] 6.1) than for males (85.7 years, SD 5.6) (Table 1).

Identification coding

In total, 6303 (47.9%) of the 13 149 decedents had Read codes in their EHR that indicated that their GP recognised they were nearing the end of life. End of life was first recognised at least 12 months prior to death in only 2248 (17.1%) of decedents (Figure 1a); the median time of entry for all codes was 7.5 months before death (interquartile range [IQR] 3.5–13.5 months). Table 2 contains a breakdown of the 20 most common Read codes in the group that first indicated end-of-life recognition. The most common code was ‘not for resuscitation’, which was included for 17% of all cases; this was more than twice as common as the next most-frequently recorded code, ‘preferred place of care — home’, which was recorded in 8.4% of all decedents.

Coding for the palliative care register

The EHRs of 1619 (12.3%) of the 13 149 decedents contained codes relating to the palliative care register. Palliative registration occurred 12 months prior to death in only 457 (3.5%) of decedents (Figure 1b); the median time of the first palliative care register code being entered was 4.3 months before death (IQR 1.1–13.6 months).

Coding for preferences for place of care

The EHRs of 2987 (22.7%) decedents recorded a preference for the place of care (Figure 1c). The first recorded preference for place of care occurred at least 12 months prior to death in only 670 (5.1%) decedents (Figure 1c). The median time of first coded preference for place of care was 7.3 months before death (IQR 4.3–11.5 months).

Of the 2987 people with a recorded preference for place of care, the most preferred place of care was their own home (50.9%), followed by a care home (41.5%, including care home, nursing home, and residential care) (Table 3). Discussions about preferences for place of care were judged to be inappropriate in 1.3% of cases, and 0.9%...
of decedents were undecided about their preferred place of care.

A small number of people (n = 588, 4.5%) were asked about their preference regarding place of care more than once before they died. In this group, 115 (19.6%) people changed their preference, with the majority of those (n = 38, 33.0%) changing their preference from their own home to a care home. Of the 473 people with a static preference, the most preferred options were to receive care in a care home (n = 231, 48.8%) and their own home (n = 228, 48.2%) (data not shown).

Table 2. Twenty most common Read codes in first coded instance of end-of-life recognition in primary care, N = 13,149

<table>
<thead>
<tr>
<th>Read Code description</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not for resuscitation</td>
<td>2232</td>
<td>17.0</td>
</tr>
<tr>
<td>Preferred place of care: home</td>
<td>1104</td>
<td>8.4</td>
</tr>
<tr>
<td>Preferred place of care: discussed with patient</td>
<td>671</td>
<td>5.1</td>
</tr>
<tr>
<td>Resuscitation: discussed with patient</td>
<td>657</td>
<td>5.0</td>
</tr>
<tr>
<td>Palliative care</td>
<td>579</td>
<td>4.4</td>
</tr>
<tr>
<td>On gold standards palliative care framework</td>
<td>523</td>
<td>4.0</td>
</tr>
<tr>
<td>Preferred place of care: care home</td>
<td>418</td>
<td>3.2</td>
</tr>
<tr>
<td>Preferred place of death: home</td>
<td>417</td>
<td>3.2</td>
</tr>
<tr>
<td>Preferred place of care: discussed with family</td>
<td>401</td>
<td>3.0</td>
</tr>
<tr>
<td>Preferred place of death: discussed with patient</td>
<td>361</td>
<td>2.7</td>
</tr>
<tr>
<td>Preferred place of care: nursing home</td>
<td>296</td>
<td>2.3</td>
</tr>
<tr>
<td>Preferred place of death: discussed with family</td>
<td>237</td>
<td>1.8</td>
</tr>
<tr>
<td>On end-of-life care register</td>
<td>231</td>
<td>1.8</td>
</tr>
<tr>
<td>Preferred place of death: care home</td>
<td>212</td>
<td>1.6</td>
</tr>
<tr>
<td>Patient aware of diagnosis</td>
<td>159</td>
<td>1.2</td>
</tr>
<tr>
<td>Preferred place of death: discussed with family</td>
<td>138</td>
<td>1.0</td>
</tr>
<tr>
<td>Preferred place of death: care home</td>
<td>123</td>
<td>0.9</td>
</tr>
<tr>
<td>Referral to palliative care service</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

IQR = interquartile range.

Coding for preferences regarding place of death

The EHRs of 1713 (13.0%) decedents contained a recorded preference for place of death. The first recorded preference for place of death occurred at least 12 months prior to death in 425 (3.2%) decedents (Figure 1d). The median time of first coded preference for place of death was 6.6 months before death (IQR 3.1–12 months).

Of the 1713 people with a recorded preference for place of death, the most preferred place to die was in a care home, nursing home, or in residential care (47.5%), followed by their own home (43.9%)...
A small proportion of people were undecided about their preferred place of death (3.4%), and only two people declined to discuss their preferences in this regard.

A small number of the cohort (n = 358, 2.7%) had their preference for place of death recorded more than once before they died. In this group, 68 (19.0%) people changed their preference, with the majority (n = 25, 36.8%) changing it from their own home to a care home. In the 290 (81% of 358) people with a static preference, a care home (n = 172, 59.3%) and their own home (n = 110, 37.9%) were the most preferred places for death (data not shown).

**DISCUSSION**

Summary

Improving access to end-of-life care is a national priority and the findings presented here suggest there is still much to be done to improve recognition of end of life in older populations in primary care. In this study, end of life was acknowledged in the EHRs of fewer than half of all those aged ≥75 years who died in one calendar year, were included in the SystmOne database, and whose death was not classified as having an external cause of mortality. A small proportion of people whose deaths were anticipated were coded as being on the palliative care register. The majority of codes indicating end-of-life recognition or palliative care registration were entered in the last few months of life.

The recording of preferences for care and place of death are key targets for improving the quality of end-of-life care, but only a small proportion of people had their preferences for care recorded. When preferences were recorded, the majority of people preferred to die at home or in a care home. Only two people had declined the opportunity to discuss preferences for place of death, suggesting that when initiated, these conversations were acceptable to people aged ≥75 years.

**Strengths and limitations**

The authors accessed routine information on a large population of deaths that occurred over the course of 1 year, avoiding many of the challenges of gathering data from this vulnerable patient group. The data were provided by ResearchOne, which extracts information from the SystmOne clinical records management system. SystmOne is used by around one in three practices in England; however, these are more likely to be located in the east of England. Regional clustering was a potential bias for all of the major primary care databases at the time of data extraction; this limitation is common to all research conducted using major primary care databases and, in 2016, SystmOne was found to be more geographically representative than two other major research databases, namely the Clinical Practice Research Datalink and The Health Improvement Network.17

In the study presented here, coding suggested that many older people aged ≥75 years who consult with a GP may not be recognised as being in the last year of life. It is important to acknowledge that coding in EHRs may not accurately reflect the care delivered, and that financial incentives may distort the recording of information; however, low levels of recording in an area of practice that is incentivised are more likely to be a true reflection of current care. The study raised the question of whether older people’s end-of-life needs were being considered and opportunities to adopt a palliative care approach were being taken, but the study design did not allow the authors to exclude the possibility that records were not being coded when end of life was actually anticipated. Information on end-of-life discussions may have been present in ‘free-text’ areas of the EHR, which (for reasons of confidentiality) are not routinely available to researchers. Place of death is used across the world as a measure of the quality of end-of-life care, so information that is suitable for future international comparisons has been provided. It is important to acknowledge that choice of place of death is a controversial subject: it may not be a priority for people near end of life, whose experiences relating to effective symptom control are likely to be more important.21 However, palliative outcome measures, such as the Integrated Palliative care Outcome Scale (IPOS),22 are not currently recorded routinely in primary care settings.

It was not possible to examine specific diagnoses in the data, and how these may have impacted on coding patterns in primary care. Study participants were aged ≥75 years and, based on a study by Gale et al,12 it is likely that a high proportion would have been living with frailty. Changes to the General Medical Services contract in 2016 require primary care teams to identify and intervene with people who are frail, including discussing summary care records that often contain information on care preferences;23 as the data were collected before the contractual changes, any recent changes to the recording of care would not be apparent in the findings presented here.

**Table 3. Preferred place of care in 2987 (22.7%) decedents for whom it was recorded**

<table>
<thead>
<tr>
<th>Preferred place of care</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>1521</td>
<td>50.9</td>
</tr>
<tr>
<td>Care home</td>
<td>702</td>
<td>23.5</td>
</tr>
<tr>
<td>Nursing home</td>
<td>517</td>
<td>17.3</td>
</tr>
<tr>
<td>Hospital</td>
<td>134</td>
<td>4.5</td>
</tr>
<tr>
<td>Discussion not appropriate</td>
<td>40</td>
<td>1.3</td>
</tr>
<tr>
<td>Patient undecided</td>
<td>28</td>
<td>0.9</td>
</tr>
<tr>
<td>Hospice</td>
<td>22</td>
<td>0.7</td>
</tr>
<tr>
<td>Residential care</td>
<td>20</td>
<td>0.7</td>
</tr>
<tr>
<td>Community hospital</td>
<td>9</td>
<td>0.3</td>
</tr>
<tr>
<td>Relative’s home</td>
<td>4</td>
<td>0.1</td>
</tr>
<tr>
<td>Patient declined to participate</td>
<td>2</td>
<td>0.1</td>
</tr>
</tbody>
</table>

*Total = 2999 as some participants were asked more than once.*

**Table 4. Preferred place of death in 1713 (13.0%) decedents for whom it was recorded**

<table>
<thead>
<tr>
<th>Preferred place of death</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>752</td>
<td>43.9</td>
</tr>
<tr>
<td>Care home</td>
<td>443</td>
<td>25.9</td>
</tr>
<tr>
<td>Nursing home</td>
<td>300</td>
<td>17.5</td>
</tr>
<tr>
<td>Residential home</td>
<td>70</td>
<td>4.1</td>
</tr>
<tr>
<td>Patient undecided</td>
<td>58</td>
<td>3.4</td>
</tr>
<tr>
<td>Hospice</td>
<td>47</td>
<td>2.7</td>
</tr>
<tr>
<td>Hospital</td>
<td>22</td>
<td>1.3</td>
</tr>
<tr>
<td>Unusual place of residence</td>
<td>17</td>
<td>1.0</td>
</tr>
<tr>
<td>Community hospital</td>
<td>2</td>
<td>0.1</td>
</tr>
<tr>
<td>Patient declined discussion</td>
<td>2</td>
<td>0.1</td>
</tr>
</tbody>
</table>
Comparison with existing literature

Providing individualised care that is in line with patient preferences is a cornerstone of both the end-of-life policy from the Department of Health and guidelines on care for dying adults published by the National Institute for Health and Care Excellence. The importance of discussions about preferences for place of death is debated, but still emphasised, in current national guidelines and the recording of preferences has been shown to significantly increase the likelihood that a person will die at home.

Two previous articles reported that a majority of people who were asked stated that they would prefer to die at home, assuming adequate support. This preference is not always fulfilled and, in 2016, the majority of deaths among people aged 75–84 years in England were in hospital. In the study presented here, care homes (including nursing and residential homes) constituted the most commonly recorded preference for place of death, accounting for almost half of the recorded preferences.

The discussion and recording of preferences may occur more commonly in care homes, where staff need to know how to proceed if a resident becomes unwell, and where a higher proportion of dying trajectories are anticipated. A higher proportion of decedents in this study had preferences for care recorded, compared with preferences for place of death; there is evidence to suggest that asking about preferences for place of care may be a more appropriate target to improve experiences at the end of life.

A recent meta-analysis of international data by Gomes et al suggested that up to 20% of people change their preferences for place of death as they near the end of life. In the analysis presented here, only a small proportion (2.7%) of people had their preference for place of death recorded more than once but, in that subset, 19.0% of people changed their preference for place of death — this is in line with the findings of Gomes et al’s meta-analysis. A higher proportion of people (4.5%) had their preferences for place of care recorded more than once, and a similar proportion (19.6%) made a change to their preferred place of care.

Being on a palliative care register has been associated with a reduced likelihood of hospital death, but whether it improves access to services that will meet the needs of people dying with frailty or multimorbidity is unclear. Ongoing work in Europe and the UK has highlighted shortcomings in current models of end-of-life care for older people: services are often fragmented and focus on specific patient characteristics (such as age and diagnosis), rather than needs and symptoms. Qualitative work with GPs has highlighted the need for access to expertise and training to improve knowledge and skills in end-of-life care.

Patients and carers view proactive planning and information sharing as important, but initiating conversations about end-of-life care is seen as a challenge by many GPs. This is particularly the case when patients are older and frail, because prognostication is difficult. GPs also report concerns about the resource implications of identifying older or frail patients for the palliative care register.

Implications for practice and research

Identifying end-of-life status is seen as essential to ensuring that older people’s needs for palliative care are met. This study found low levels of recording regarding end-of-life identification, but further work is needed to ascertain whether recognition of end of life occurs in a less-formal context or is recorded in free-text areas of GP records, particularly when it is perceived that preferences may have changed.

Future research should also aim to determine whether recording end-of-life identification and patient preferences in EHRs leads to any changes in care or patient outcomes. Increasing the number of people placed on the palliative care register could help planners and policy makers to understand the scale of this work and, in future, direct resources to primary and community care services to provide high-quality palliative care for everyone who needs it.
REFERENCES


