

Title: When do GPs recognise end-of-life in people age 75+? Evidence from electronic healthcare records in primary care

Main text [2450 words] + 4 tables + 1 figure

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How this fits in

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

Abstract [250 of 250 words]

Background

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

Aim

To investigate the timing of EoL recognition, palliative registration, and recording of EoL preferences in primary care for people age ≥ 75

Design and Setting

Electronic healthcare records of people who died in England between 01/01/2015 and 01/01/2016 from the ResearchOne database.

Method

We extracted clinical codes relating to EoL recognition, palliative registration and EoL preferences, and calculated months before death of code entry. We report the proportion and timing for each outcome.

Results

13,149 people in ResearchOne had a record of death during the one-year study window. 6,303 (47.9%) records contained codes suggesting EoL had been recognised any time prior to month of death. Recognition occurred ≥ 12 months before death in 2,248 (17.1%) records. 1,659 (12.6%) people were on a palliative register, 457 (3.4%) for ≥ 12 months before death. 2,987 (22.7%) people had a code for preferred place of care, and 1,713 (13.0%) people had a code for preferred place of death. Where preferences for place of death were recorded, care home (47.5%) and home (43.9%) were the most common.

Conclusion

EoL recognition in primary care appears to occur near to death, and for only a minority of people age ≥ 75 . Our findings suggest that older people's deaths may not be anticipated by health professionals, compromising equitable access to palliative care.

Keywords.

End of life, palliative, primary care, coding, prognostication.

Introduction

More than two thirds of deaths in England occur in people aged over 75, a number 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 focusing on the final few days of life.⁴ In England, general practitioners (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}

Our understanding of palliative registration and 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 In England, people with cancer are around 11 times more likely to be on a palliative register than people with non-malignant diseases.¹⁰ A study in six Scottish general practices found around one fifth of people with non-malignant conditions were on a palliative register, compared with two-thirds of patients with cancer.¹¹ Many people aged over 75 are 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 to show that they are anticipating end of life for people age 75 and over. The secondary aim of this study was to investigate the timing of coding for palliative registration, and patient preferences for care and place of death

Methods

Setting

We analysed electronic health record (EHR) data from primary care services in England. Data were supplied by ResearchOne, a UK based not-for-profit organisation that extracts de-identified health record information from SystemOne (an electronic health record management system used by **approximately 38% of GP practices** in England).¹⁶

Participants

We requested data from all people age ≥ 75 who died between 01/01/2015 and 01/01/2016. We excluded people where their cause of death was classified as an external cause of mortality (International Classification of Diseases codes version 10).

Study design

We extracted Read codes recorded in EHRs prior to death. We excluded Read codes entered any time after the month of death, or more than ten years before the month of death. 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.¹⁷ Targeted searches were carried out using information from the Quality Outcomes Framework (QOF) guidance for coding end-of-life care (version 32), Read codes from the Gold Standards Framework (GSF),¹⁸ and palliative care codes highlighted in the 'Care.data' GP data specification 1.0.¹⁹ We conducted further searches within the TRUD browser using keywords related to 'terminal', 'palliative', 'hospice', and 'end of life'. A complete list of codes requested during the data extract can be found in **supplementary table 1**.

Analysis

Because date of death information was provided in year/month format, we calculated time prior to death of code entry in months. The primary outcome of interest was any code relating to end-of-life recognition. Because multiple codes are often entered during a single

visit, we examined the number of months prior to death of entry for the first batch of codes that contained information relating to end-of-life recognition. Our secondary outcomes were codes relating to entry onto the palliative register, and codes for preferences for place of death and place of care. For all outcomes we calculated the time before death of the first instance of a code relevant to the outcome.

Results

Participants

EHRs were available for 13,149 people who died between 01/01/2015 and 01/01/2016 (Table 1). A majority of decedents were female (55.6%). Mean age at death was higher for females (88.1 years, **sd: 6.1**) than for males (85.7 years, **sd: 5.6**)

TABLE 1 HERE

Any code relating to identification

In total 6,303 (47.9%) of the 13,149 decedents had Read codes in their EHR that indicated their GP recognised they were nearing end of life. End-of-life was first recognised at least 12 months prior to death in only 2,248 (17.1%) of decedents (Figure 1), **median time of entry for all codes was 7.5 months before death (interquartile range, 9.9 months).**

FIGURE 1 HERE

Table 2 contains a breakdown of the 20 most common codes first indicating end-of-life recognition. The most common code was 'not for resuscitation', included for 17% of all cases, and was more than twice as common as the next most frequent code 'preferred place of care - home', in 8.4% of all decedents.

TABLE 2 HERE

Coding for the palliative care register

EHRs of 1,619 (12.3%) of the 13,149 decedents contained codes relating to the palliative register. Palliative registration occurred 12 months prior to death in only 457 (3.4%) of

decedents (Figure 1), **median time of first palliative register code was 4.3 months before death (interquartile range, 12.5 months).**

Codes relating to preferences for place of care

EHRs of 2,987 (22.7% of 13,149) decedents had recorded preference for place of care. First recorded preference for place of care occurred at least 12 months prior to death in 670 (5.1%) decedents (Figure 1). **Median time of first coded preference for place of care was 7.3 months (interquartile range, 7.2 months).**

Of the 2987 people with a recorded preference for place of care, the most preferred place of care was home (50.9%), followed by care home (41.5%, including care home, nursing home and residential care). Discussions about preferences for place of care were judged to be inappropriate in 1.3% of cases, and 0.9% of decedents were undecided – see table 3 for details. A small number of people (588, 4.5% of 13,149) people were asked about their preference for place of care more than once before they died. In this group, 115 (19.6% of 588) people changed their preference, with the majority (n=38, 33.0% of 115) changing their preference from home to care home. In the 473 (80.4% of 588) people with a static preference, care home (n=231, 48.8% of 473) and home (n=228, 48.2% of 473) care were the most preferred.

TABLE 3 HERE

Codes relating to preferences for place of death

EHRs of 1,713 (13.0% of 13,149) decedents contained a recorded preference for place of death. First recorded preference for place of death occurred at least 12 months prior to death in 425 (3.2%) decedents (Figure 1). **Median time of first coded preference for place of death was 6.6 months (interquartile range, 8.9 months).**

Of the 1,713 people with a recorded preference for place of death, the most preferred place to die was in a care home (47.5%, including nursing and residential homes), followed by home (43.9%). A small proportion of people were undecided about their preferred place of death (3.3%), and only two people declined to discuss their preferences for place of death –

see Table 4 for further details. A small number of people (n=358, 2.7% of 13,149) people had their preference for place of death recorded more than once before they died. In this group, 68 (19.0% of 358) people changed their preference, with the majority (n=25, 36.8% of 68) changing their preference from home to care home. In the 290 (81% of 358) people with a static preference, care home (n=172, 59.3% of 290) and home (n=110, 37.9 % of 290) death were the most preferred.

TABLE 4 HERE

Discussion

Summary

Improving access to end-of-life care is a national priority and our findings 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 electronic health records of fewer than half of all over 75s who died in one calendar year. A small proportion of people whose deaths were anticipated were coded as being on the palliative register. The majority of codes indicating end-of-life recognition or palliative registration were entered within the last few months of life.

Recording of preferences for care and place of death are key targets for improving the quality of end-of-life care, but we found that only a small proportion of people had their preferences for care recorded. Where preferences were recorded, the majority of people preferred to die at home or in a care home. Only two people declined the opportunity to discuss preferences for place of death, suggesting that (when initiated) these conversations were acceptable to people age over 75.

Strengths and limitations

We accessed routine information on a large and complete population of deaths that occurred over the course of one year, avoiding many of challenges of gathering data from this vulnerable patient group. **Our data were provided by ResearchOne, who extract information from the SystmOne clinical records management system. SystmOne is used by almost one in four practices in England, but these are more likely to be located in the**

east of England.²⁰ This limitation is common to all research using the major primary care databases, and in 2016 ResearchOne was found to be more geographically representative than CPRD and THIN (two other major research databases)²⁰

We acknowledge that coding in EHRs may not accurately reflect the care delivered, and financial incentives may distort recording of information. In our study, coding suggested that many older people may not be recognised as being in the last year of life. Low levels of recording in an area of practice that is incentivised are more likely to be a true reflection of current care. **Our study raises the question of whether older people's end-of-life needs were being considered, and opportunities to adopt a palliative care approach taken.**

However, our study design did not allow us to exclude the possibility that records were not being coded when end of life was anticipated. **Information on end of life discussions may have been present in 'free text' areas of the electronic record, which (for reasons of confidentiality) are not routinely available to researchers.** Place of death is used across the world as a measure of end-of-life care, so we have provided information **suitable for future international comparisons.** It is important to acknowledge that choice of place of death is a controversial subject, and may not be a priority for people near end of life, where experiences relating to effective symptom control are likely to be more important.²¹

However, palliative outcome measures are not currently recorded routinely in primary care settings.

We were not able to examine specific diagnoses in our data, and how these may have impacted coding patterns in primary care. Study participants were aged 75 or over, and a high proportion would have been living with frailty.¹² Changes to the GMS contract in 2016 require primary care teams to identify and intervene with people who are frail, including discussion of summary care records which often contain information on care preferences.²² Our data were collected before the contractual changes, so any recent changes to the recording of care would not be apparent in our findings.

Comparison with existing literature

Providing individualised care that is in line with patient preferences is a cornerstone of end-of-life policy from the Department of Health and Social Care³ and in the National Institute

for Clinical Excellence (NICE) guidelines on care for dying adults.²³ The importance of discussions about preferences for place of death is debated,²⁴ but their importance is still emphasised in current national guidelines, and recording of preferences has been shown to significantly increase the likelihood that a person will die at home.²⁵ A majority of people who are asked, state they would prefer to die at home, assuming adequate support.^{26, 27} This preference is not always fulfilled, and in 2016 a majority of deaths amongst people age 75-84 in England were in hospital.²⁸ A higher proportion of decedents in this study had preferences for care recorded compared to preferences for place of death. There is evidence to suggest that questions about preferences for place of care may be a more appropriate target to improve experiences at the end of life.²⁹

In our study, care home (including nursing and residential homes) was the most commonly recorded preference for place of death, accounting for almost half of the 1,713 recorded preferences. 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. DNACPR coding was the most common indicator of end-of-life recognition, and again this is more likely to be considered for patients in care homes compared to the community. A recent meta-analysis of international data suggests that up to 20% of people change their preferences for place of death as they near end of life.³⁰ In our analysis, only a small proportion (2.7%) of people had their preference for place of death recorded more than once. In this subset, 19.0% of people changed their preference for place of death. 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 register is associated with a reduced likelihood of hospital death,¹¹ 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,³¹ and in the UK³² has highlighted shortcomings in current models of end-of-life care for older people. Services are often fragmented, and focused on specific patient characteristics (such as age and diagnosis) rather than needs and symptoms. Qualitative work with general practitioners has highlighted the need for access to expertise and training to improve knowledge and skills in end-of-life care.³³ Patients and carers view pro-active planning and information sharing as important, but initiating conversations about end-of-life care is seen as a challenge by many

GPs.³⁴ This is particularly the case when patients are older and frail, because prognostication is difficult.³⁵ GPs also report concerns about the resource implications of identifying older or frail patients for the palliative register.³⁶

Implications for research and or practice

Identification of end-of-life status is seen as essential to ensuring that older people's needs for palliative care are met. We found low levels of recording end-of-life identification, but further work is needed to see whether recognition of end-of-life occurs less formally or is recorded in free text areas of GP records, particularly when it is perceived that preferences may have changed. Future work should also aim to see whether recording end-of-life identification and patient preferences in electronic health records leads to any changes in care or patient outcomes. **Increasing the number of people placed on the palliative register could help planners and policy makers to understand the scale of this work and direct resource to primary and community care services in order to provide high quality palliative care to everyone who needs it in the future.**

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Ethical approval

Approval for this study was granted by the ResearchOne ethical review panel with oversight from the UK NHS Health Research Authority and the UK Government Health and Social Care Information Centre Confidentiality Advisory Group. ResearchOne was approved by the UK National Health Service (NHS) National Research Ethics Service (11/NE/0184)

Competing interests

The authors declare that they have no competing interests

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TABLES AND FIGURES

Table 1: Demographic information from 13,149 people who died in England between 2015 and 2016

Gender		
Female (n, %)	7310	(55.6)
Male	5839	(44.4)
Age at month of death (years)		
All (mean, SD)	86.6	(6.0)
Female	88.1	(6.1)
Male	85.7	(5.6)

Figure 1: end-of-life recognition and recording of preferences in 13,149 decedents in England

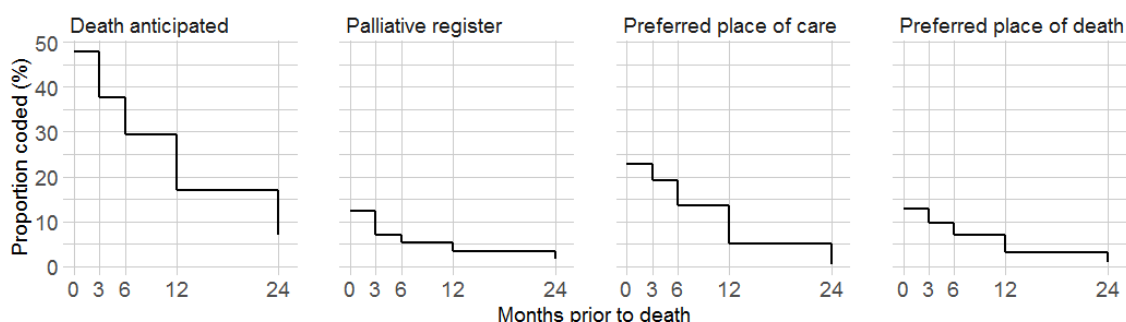


Table 2: Twenty most common Read codes in first coded instance of end-of-life recognition in primary care

Read Code Description	n	%	Time of code entry (months before death)	
			Median	IQR*
Not for resuscitation	2232	17.0	9.0	13.9
Preferred place of care - home	1104	8.4	7.4	7.0
Preferred place of care - discussed with patient	671	5.1	7.7	6.5
Resuscitation discussed with carer	657	5.0	7.2	8.5
Palliative care	579	4.4	5.4	14.9
On gold standards palliative care framework	523	4.0	6.2	14.5
Preferred place of care - care home	418	3.2	7.3	6.5
Preferred place of death: home	417	3.2	6.7	8.7
Preferred place of care - discussed with family	401	3.0	7.7	6.4
Preferred place of death discussed with patient	361	2.7	7.3	6.9
Preferred place of care - nursing home	296	2.3	8.1	7.7
Preferred place of death: discussed with family	237	1.8	7.0	6.6
On end-of-life care register	231	1.8	6.5	11.4
Preferred place of death: care home	212	1.6	7.0	7.3
[V]Palliative care	198	1.5	5.4	19.7
Palliative care plan review	184	1.4	7.7	15.2
Has end-of-life advance care plan	180	1.4	13.1	17.6
Patient aware of diagnosis	159	1.2	12.9	36.8
Preferred place of death: nursing home	138	1.0	9.2	12.4
Referral to palliative care service	123	0.9	4.4	8.9

*Interquartile range

Table 3: Preferred place of care in 2,987 (22.7%) decedents who had a recorded preferred place of care

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

Table 4: Preferred place of death in 1,713 (13.0%) decedents who had a recorded preferred place of death

Preferred place of death	n	%
Home	752	43.9
Care home	443	25.9
Nursing home	300	17.5
Residential home	70	4.1
Patient undecided	58	3.3
Hospice	47	2.7
Hospital	22	1.3
Usual place of residence	17	1.0
Community hospital	2	0.1
Patient declined discussion	2	0.1