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### Using ambulance service patient care records to understand 999 call-outs to older people with dementia: Initial report from a review of 358 records

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#### ABSTRACT

**Objectives:** To use local ambulance service patient care records at an aggregate level to study the use of emergency medical services (EMS) by older people with dementia in two English counties. To understand how and where in the patient care record (PCR) dementia is recorded. To measure the proportion of patients aged 75 and over who had an emergency (999) ambulance response who have dementia recorded in the PCR. To carry out a descriptive analysis of any associations with age, gender, reason for the call, time of call, residential status or call outcome.

**Methods:** Four days of PCRs from two counties (UK) for patients aged 75 and over were reviewed and non-patient-identifiable data extracted. Data for the total number of call-outs for those days were obtained from the computer aided dispatch (CAD) system.

**Results:** In 4 days' records for Cambridgeshire and Hertfordshire (2304 records) over one third of call-outs (830) were to patients aged 75 and over. Data were obtained from 358 paper records. Dementia was recorded on 14.5% of records and another 7.0% recorded details suggesting dementia or cognitive impairment. Around 15% of call-outs to  $\geq$ 75-year-olds were to care homes. Ambulance crews attended higher proportions of 'older old' people than the local population percentages of 85 to 89-year-olds and  $\geq$ 90-year-olds. The most common reason (27.5%) for a call-out was a fall.

**Conclusions:** This is the first paper to look in detail at the numbers of older people with dementia seen by emergency ambulance crews as documented in PCRs. It gives a benchmark for others looking at ambulance service data and highlights possibilities and pitfalls of using ambulance service PCR data.

#### **KEY POINTS**

Caring for older people with dementia is a key issue for frontline staff in all areas of healthcare, however it is not well researched or understood for ambulance services.

This small scale record review of paper based patient care records found that dementia was recorded in 14.5% of call-outs to people 75 or over, this is in line with current prevalence estimates for this age group. Dementia was recorded as 'free-text'.

Not surprisingly, the most common reason for a call-out was a fall. The data also showed that ambulance crews attended higher proportions of 'older old' people than the local population percentages of 85 to 89-year-olds and ≥90-year-olds.

This is the first paper to look in detail at the numbers of older people with dementia seen by emergency ambulance crews as documented in patient care records. It provides a benchmark for others looking at ambulance service data to understand use of services by people with dementia.

#### INTRODUCTION

#### Background/rationale

There is a common narrative that urgent and emergency care of older people with dementia is not optimal. There are also anecdotal stories that older people with dementia are more likely to be taken to hospital because ambulance crews cannot assess them properly or access alternative services. People may be calling 999 for 'inappropriate' reasons, such as non-medical crises, and out-of-hours (OOH) services and care homes may be unnecessarily calling ambulances. A recent review found the use of ambulance services or EMS by older people with dementia is not well understood. The literature reviewed demonstrated a concern for this group, need for training for EMS staff and awareness that current services are not optimal (Buswell et al., 2014b). We set out to use aggregate data from ambulance service patient care records (PCRs) to understand 999 call-outs to older people (>75 years) with dementia, aware from the outset that dementia may not be consistently recorded.

#### **Aims and Objectives**

We aimed to understand the use of emergency ambulance services by older people with dementia in two English counties.

Our study objectives were:

- A. To understand how and where in the PCR dementia is recorded.
- B. To measure the proportion of patients aged 75 and over who had an emergency (999) ambulance response who have dementia recorded in their PCR (dependent on A).
- C. To carry out a descriptive analysis of any associations with age, gender, reason for the call, time of call, residential status or call outcome (dependent on A).

We selected to look at records for persons aged 75 and over, even though health services often define older persons from aged 65 and over. This was for pragmatic reasons of keeping the sample size manageable for this paper-based sample. (reviewer 1 point 1)

#### **METHODS**

This initial study was carried out on a small sample of paper records as it was not known in advance where in the patients' records dementia would be recorded. With the electronic PCRs (ePCR) for this region there are multiple possible places that dementia could be recorded and, as we were not confident we would find them all, an initial review of paper PCRs was needed to establish a baseline. We anticipated that dementia may not be well recorded because there is not a specific 'tick box' in the PCR to direct recording. However, in 2012 some dementia awareness training had taken place across East of England Ambulance Service (EEAS) and this may have affected how crews recognise and record dementia.

Non-patient-identifiable data were obtained from a review of four days' PCRs of EEAS 999 call-outs to patients aged ≥75 in two counties (Cambridgeshire and Hertfordshire). The days were two midweek days and two weekend days in February, May, August and November in the financial year 2012-13. Fields from which we extracted were:

- Age (categorised into age-bands: 75-79, 80-84, 85-89, 90+)
- Gender
- Outcome (transported or not transported to hospital)
- Time of call (categorised into time-bands: 00:00–07:59, 08:00–18:29, 18:30–11:59)
- Primary complaint. The content of this free text field was categorised into twelve categories (Paramedic Impression) by an emergency care practitioner.
- Social/family history. The content of this free text field was categorised as Care Home, Community or Not Indicated. In the community category we also recorded if the record stated that the person was living alone.

The whole record was searched for mention of dementia and for text suggesting possible dementia. How dementia was documented by crews and where in the PCR it was noted was recorded.

The EEAS Computer Aided Dispatch (CAD) system provided the total number of call-outs across the East of England and for just Cambridgeshire and Hertfordshire for a) all ages and b) those aged  $\geq$ 75.

The age-sex distribution of our sample was compared to the general population in Cambridgeshire and Hertfordshire and dementia prevalence as recorded in the PCR was compared to prevalence estimates from the Cognitive Function and Ageing Study (CFAS II), a large UK-based longitudinal multicentre study looking at health and cognitive function in older people. (Matthews et al., 2013)

To determine whether it is possible to collect information from the PCR data on possible contextual factors that may influence outcomes for older people with dementia after 999 ambulance call-outs, information was collected on outcome, time of call, paramedic impression and social family history. All proportions are reported with confidence intervals.

#### RESULTS

There were 7922 CAD records for call-outs<sup>a</sup> for all ages across the region on the four days and 2304 for Cambridgeshire and Hertfordshire. Of the CAD records 4243 (54%) were scanned copies of paper records. The scanning software could not read the age field in 650 (15%) of these. The remaining 3593 paper-based records for the region were searched to select those for people aged ≥75: 1229 records. From these we extracted data for call-outs to people aged 75 or older in Cambridgeshire and Hertfordshire only: 358 records.

#### Over 1/3 of call-outs were to ≥75-year-olds

Call-outs to people aged  $\geq$ 75 accounted for 35.4% (95% CI 34.4-36.5) of all records, 34.2% (95% CI 32.7-35.8) of the available paper-based records and 36.0% (95% CI34.1-38.0) of records for Cambridgeshire and Hertfordshire only. In Cambridgeshire and Hertfordshire 7.8% of the general population are  $\geq$ 75.

a This is all calls where a response was sent, ie a call where a PCR would have been produced. It is a reliable number as it relates to the number of incidents that actually occur. For example, an accident on a main road may receive multiple calls from the public, but only one response is sent.

#### Age-sex distribution

In our sample 216 patients attended were female, 60.3% (95%CI 55.3-65.4), and 142 were male, 39.7% (95%CI 34.6-44.7). This is in line with the sex distribution for the Cambridgeshire and Hertfordshire ≥75-year-old population: 58.8% (95%CI 58.6-59.1) female and 41.2% (95%CI 40.9-41.4) male (Source: ONS Mid-2012 Population Estimate).

The age distribution of our sample suggests the ambulance service sees higher proportions of older old people (≥85-year-olds) than the general population distribution for Cambridgeshire and Hertfordshire (Source: ONS Mid-2012 Population Estimates): higher by a factor of 1.57 for 85-89 year-olds and 2.20 times higher for ≥90-year-olds (Figure 1). Conversely, proportions of EMS call-outs to not quite so old people are lower: 75 to 79-year-olds account for only 19% of call-outs, less than half (48%) the proportion of the local population this age (39.7%). EMS call-outs to 80 to 84-year-olds (27.9%) more closely reflect the population distribution (30.8%).



Figure 1: Age distribution of patients aged ≥75 from review of 358 PCRs compared to the general population aged ≥75 in Cambridgeshire and Hertfordshire (confidence intervals displayed as black lines).

#### Living situation

The type of residence was indicated in the 'Social / Family History' field in 344 records, 96% of all 358 records. Of these 54/344 (15.7%, 95% CI 11.9-19.5) were people in nursing or residential care homes and 290/344 (84.3%, 95% CI 80.5-88.1) were community living.

Just over a third of calls-outs to those living in the community were to people recorded as living alone (38.6%, 95% CI 33.0-44.2), close to half of the women and a quarter of the men, (respectively 44.7%, 95% CI 37.6-51.8, and 22.4%, 95% CI 15.1-29.7). This is lower than the 50% of  $\geq$ 75-year-olds living alone nationally (women: 61%, men: 35%). (Source: 2011 General Lifestyle Survey, Office for National Statistics). Although crews recorded details about home situation and level and type of care, this was not sufficiently consistent to be used.

#### **Dementia recording**

Dementia was recorded on 14.5% (95%Cl 10.9-18.2) of records and another 7.0% (95%Cl 4.3-9.6) had details noted that suggested possible dementia or cognitive impairment such as "memory loss", dementia drugs or often simply "?dementia".

Of the definite dementia recording 51/52 were recorded in the 'Previous Medical' field, the other was in the 'History/MOI'<sub>b</sub> field. Of the 24 cases with notes indicating possible dementia 18 were recorded in the 'Previous Medical' field, 5 in the 'Treatment, Advice and Notes' field and one in the 'History/MOI' field.

Levels of dementia recording are in line with estimates from CFAS II (Matthews et al., 2013) by age, sex and residential status – living in care-homes or community-dwelling (Table 1)

Ageband	EEAS PCRs % (95% CI)	CFAS II % (95% CI)
Women	(not indicated = 6)	
Care home	n = 38	n = 130
75-84	62.5 (29.0-96.0)	76.0 (59.3-87.2)
85+	33.3 (16.5-50.2)	71.1 (60.0-80.1)
Community	n = 172	n = 2123
75-84	8.8 (2.6-14.9)	5.9 (4.9-7.8)
85+	13.0 (6.2-19.9)	17.0 (14.2-21.9)
Men	(not indicated = 8)	
Care home	n = 16	n = 42
75-84	14.3 (-11.6-40.2)	72.0 (44.6-87.0)
85+	33.3 (2.5-64.1)	55.6 (31.5-77.4)
Community	n = 118	n = 1612
75-84	10.9 (3.3-18.6)	6.4 (5.2-8.1)
85+	11.1 (2.7-19.5)	11.9 (8.6-16.3)

 Table 1: Dementia prevalence by age and sex and place of residence as recorded on Ambulance Service

 PCRs compared to prevalence in the CFAS II study

#### Call-out reasons, time of call and outcomes

The reason for a call (see Figure 2) was recorded in 97% of PCRs, most commonly a fall: 27.5% (95% CI 21.0-34.0) of this ≥75-year-old sample or 9.4% overall. This is in line with estimates that about 8% of emergency ambulance responses each year are for a fall (Snooks et al., 2012). For those PCRs where dementia was recorded almost half were for a 'fall': 24/50 (48.0%, 95% CI 34.2-61.8). This single problem far outweighed others, the next largest categories being less well-defined composite categories: 20.9% (95% CI 15.5-26.3) classed 'Other Medical Problem', where a specific medical complaint was recorded, and 14.6% (95% CI 10.3-19.0) 'Non-specific', a category which included various descriptions such as 'off legs', 'unwell', confusion or pain. These twelve categories that we derived for 'Paramedic impression' required a level of clinical judgement and interpretation of the free text and are not validated. However, we are confident with the 'fall' category as it was always clear where a fall was documented. It was not possible from this routine data to be clear how

b MOI: Mechanism of Injury



many of the falls were from a standing height or how many represented someone being found on the floor. (reviewer 1 point 2)

Figure 2: Call-out reasons - paramedic impression of the presenting complaint

There were no significant differences in the times of call-outs to people whose PCR recorded they had dementia and those with or without any suggestion in their record of possible dementia.

Just under two-thirds of ≥75-year-olds attended to by an ambulance crew were transported to hospital, regardless of age, gender or whether dementia was recorded: 217/351 (61.8%, 95% CI 56.7-66.9). It should be noted that we are aware of differences in rates of conveyance to hospital between outcomes recorded in paper versus electronic PCRs – higher transport rates reported in ePCRs, as we have reported elsewhere. (Buswell et al., 2014)

#### LIMITATIONS

It is possible that there is bias in this sample examined through paper PCRs as there may be differences in the populations for whom paper PCRs and ePCRs are used. Anecdotally, paramedics have reported that they are more likely to complete a paper PCR if they are leaving the patient at home and an ePCR if they are transporting a patient to hospital (Buswell et al., 2014). Therefore there may be some bias in the transported rates reported and indeed the population characteristics.

The coding system used to categorise the free text description in the 'Presenting Complaint' field has not been validated. For some categories, such as a fall, the description is unambiguous and we report these reasons with confidence. Nonetheless, we can only report

the paramedic impression, rather than the true reason for a fall. Whether a fall constitutes the presenting complaint or whether in fact it is the outcome of other underlying conditions or issues is open to debate. The high frequency of 'falls' in older people makes this is an important indication to report.

#### **DISCUSSION AND CONCLUSIONS**

This record review quantifies (in a small and population specific sample) what many ambulance crews may perceive in their day to day practice: That they are called to a significant number of older people, one-third of call-outs to ≥75 when only 7.8% of the Cambridgeshire and Hertfordshire population are ≥75. We had anticipated poor recording of dementia, so were encouraged by the level of recording of dementia (14.5%), a proportion in line with population-based age-specific prevalence estimates, perhaps reflecting increasing awareness of this group of patients. This suggests either, if the population ambulance crews are called to reflect the general population of this age, that recording is fairly accurate, or, if recording is poor, they are seeing higher levels of dementia and those recorded are just the 'tip of the iceberg'. One might presume that crews record dementia only where it is recorded in notes on scene or a family member or carer alerts them to the diagnosis. Ambulance crews are quite careful not to diagnose and are taught to put '?' after any clinical impressions they have. We decided to quantify the records where dementia or cognitive impairment was a possibility (a further 7% besides definitely recorded dementia) because wording such as "confusion – unclear whether more than usual" clearly cannot be used to distinguish, say, delirium from delirium superimposed on dementia. Suggesting recording is 'poor' is not a reflection on the practice of crews as the records we reviewed had no clear field to record dementia if it was not the presenting complaint and therefore it is up to individual practitioners whether it is relevant and how to record it.

The high level of completion by crews of the social/family history field in forms was also noteworthy. Although recording in this free text field was not consistent, notes frequently detailed how the person was living: alone or with carers, and their care arrangements. This suggests that ambulance crews believe that this information is important to record for the ongoing care of the person they are attending.

The most common reason for a call-out was a fall and where dementia was recorded the proportion of call-outs for a fall went from just over a quarter to almost half. This review of routine records did not allow further unpicking, however this warrants follow up, potentially falls research would do well to look at the impact of dementia.

The changing role of the ambulance service from a patient transport service to a service that brings care to the patient, responds to non-emergencies and has a role in promoting health has been discussed in documents and reports (Ambulance Service Network, 2010, Department of Health, 2007, Department of Health, 2005, National Audit Office, 2011) and in the recent NHS England Urgent and Emergency Care Review (NHS England 2013a,b). With the national focus on dementia care (Department of Health, 2009) these findings provide a basis for future much-needed research on the use of ambulance services by people with dementia for urgent and emergency care. In particular, their role as a link in how care is co-ordinated for older people with dementia who use emergency ambulance services but may not need secondary care needs closer examination. From our experience using these paper-based PCRs, and from discussions about the possibilities of using the ePCRs in EEAS,

these would not seem an ideal data source for studying use of ambulance services by older people with dementia. It may be different in other areas of the UK or internationally if more consistent record keeping is used.

#### **Research Governance**

Letter of Access granting permission to carry out the study from EEAS and included in the RODES study protocol, Research into Older people with Dementia and their carers' use of Emergency Ambulance Services (RODES), Protocol number: HSK/SF/UH/00049, Dr R Southern, University of Hertfordshire, Health and Human Sciences ECDA Chairman

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Contributors MB and JF were involved in the design of the study.

MB carried out data extraction with input from PL and DA and analysis with input from JF.

MB drafted the article with all authors contributing to the writing of the article.

#### Collaborators None.

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Disclaimer None.

Competing interests None.

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