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Unplanned, urgent and emergency care: what are the roles EMS provide for older people with dementia? An integrative review of policy, professional recommendations and evidence

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ABSTRACT

Objective: To synthesise the existing literature on the roles emergency medical services (EMS) play in unplanned, urgent and emergency care for older people with dementia (OPWD), to define these roles, understand the strength of current research and to identify where the focus of future research should lie.

Design: An integrative review synthesised reports, briefings, professional recommendations and evidence. English language articles were included if they made any reference to the role of EMS in the urgent or emergency care of OPWD. Preparatory scoping and qualitative work with frontline ambulance and primary care staff and carers of OPWD informed our review question and subsequent synthesis

Results: Seventeen literature sources were included. Over half were from the grey literature. There was no research that directly addressed the review question. There was evidence in reports, briefings and professional recommendations of EMS addressing some of the issues they face in caring for OPWD. Three roles of EMS could be drawn out of the literature, emergency transport, assess and manage and a 'last resort' or safety net role.

Conclusions: The use of EMS by older people with dementia is not well understood, although the literature reviewed demonstrated a concern for this group and awareness that services are not optimum. Research in dementia care should consider the role EMS play, particularly if considering crises, urgent care responses, and transitions between care settings. EMS research into new ways of working, training or extended paramedic roles should consider specific needs and challenges of responding to people with dementia.

INTRODUCTION

It is reported that emergency ambulance crews frequently encounter older people with dementia (OPWD) and it can be difficult to take history, assess pain and access suitable alternatives to the emergency department, especially out of hours. In 2009-10 the cost of urgent and emergency ambulance services in England was £1.5 billion.[1] Although 999 emergency call-outs are associated with only 2% of unscheduled care activity, they are thought to be responsible for about 22% of commissioning costs.[2] With the present landscape of financial austerity, the recent NHS England Urgent and Emergency Care Review[3] and the national focus on dementia care[4] it is pertinent to ask what role ambulance services or emergency medical services (EMS) have in the urgent and emergency care of OPWD.

Currently around 670 000 people in England are estimated to be living with dementia.[5] Research in the last five years has begun to consider the impact of having a dementia on the emergency use of hospital services: A US study found that patients arriving in the Emergency Department (ED) by EMS have higher prevalence of cognitive impairment (CI) than those arriving by other means (13% versus 8% $p < 0.01$). [6] The presence of a dementia diagnosis also means that an older person is more likely to be admitted to hospital as an emergency than those who do not have a dementia diagnosis.[7] Other studies have shown OPWD admitted to hospital have longer length of stay and higher mortality than comparable patients without dementia. [8, 9] Analysis of one UK hospital's emergency

admissions data found people with a dementia diagnosis were more likely to arrive at the ED via ambulance than those without a dementia diagnosis: 82% vs 54% odds ratio 3.73 (95% CI 3.49 – 3.99)(Unpublished data, Okereke U., CLAHRC-CP Fellowship Report, 2011).

There is a body of research that explores extended roles for paramedics/EMS personnel that go beyond the traditional ‘emergency’ care roles to urgent and even primary care roles.[10, 11] There is another body of EMS research around falls, for example the SAFER 2 study[12]. Older people with dementia are at high risk of falling[13, 14] and have a similar number of chronic medical conditions as older people without dementia.[15] However, to date none of this research has specifically looked at the needs of OPWD.

This review seeks to synthesise the existing literature on the roles EMS play in unplanned, urgent and emergency care for OPWD, to define these roles, understand the strength of current research and to identify where the focus of future research should lie.

METHODS

We predicted that the literature would be sparse and diverse and used integrative review methodology which critiques and synthesizes the literature on a topic, allowing for a combination of diverse methodologies and literature types.[16, 17] Our aims were to bring an evidence informed commentary on how EMS respond to OPWD and derive a research agenda that logically flows from our synthesis.

Preparatory Phase

To inform our review question and subsequent synthesis MB and JF held a workshop with frontline ambulance and primary care staff and carers of OPWD. MB held discussions with an Alzheimer’s Society carers’ group on use of 999 ambulance services. In both cases a summary was written up and sent to group participants and any disagreements or comments invited. Participants responded that the summaries represented their views and a few additional comments were received.

Workshop participants were asked to put forward, from their experience, reasons for a 999 ambulance call-out to older people with dementia. Group discussion agreed that there were three overlapping categories: clinical reasons, lack of information and carers not coping.

The visit to the carers’ support group gave a very different perspective. Most of the participants had not yet had experience of calling 999 and the focus of discussion was largely on information needs: carers’ sense that they were ill-prepared but wanted to prepare for this eventuality, surprise or frustration at the barriers to healthcare professionals having access to the right information, and the resultant worry about the additional onus of responsibility this placed on carers; the need to brief professionals about the OPWD’s medical history.

This engagement with members of the public early in the research process shaped the review question. Findings from the review were then fed back to patient and public representatives to further ensure our review findings had resonance with the experience of frontline staff and carers.[18]

Literature Search

We used systematic and iterative search techniques. All databases available via NHS Evidence were searched (MEDLINE, EMBASE, CINAL, Psych INFO, AMED and HMIC) using terms to encompass the context – pre-hospital urgent or emergency care – and the condition – dementia. End of life (EoL) was used as a search term alongside dementia. We knew from recent publications and discussions with paramedic colleagues that, there might be relevant observations about EoL care for OPWD in pre-hospital EoL literature (Table 1). Iterative search techniques included recommendations from colleagues, forward citation searching, searching references of selected papers and relevant internet sites or email newsletters.

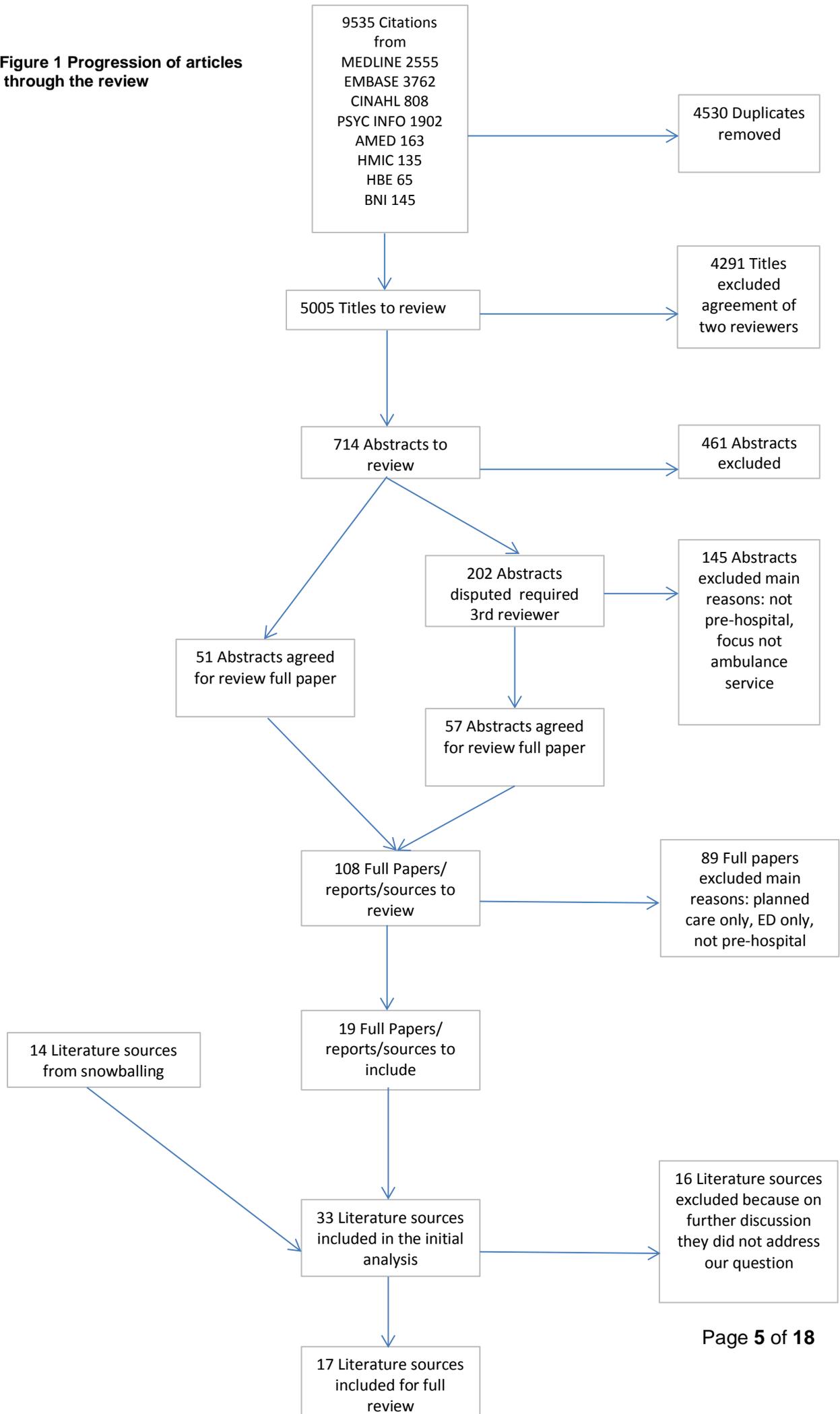
Articles were included if their scope covered the pre-hospital urgent or emergency care of OPWD where EMS could have a role. We excluded any roles in patient hospital discharge. No time limit was imposed but the earliest source was from 1992. Only studies that had, at least, an abstract in English were reviewed. We did not restrict the type of literature included, thus included national reports, briefings, guidance and internal reports alongside articles and studies from peer reviewed journals. We wanted to understand the evidence and narrative around EMS roles.

Table 1: Search terms used in the systematic search

CONTEXT: pre-hospital, emergency or urgent care i.e. where we would expect the ambulance service to have a role	CONDITION: OPWD/cognitive impairment/End-of-life
urgent adj3 care OR 'urgent-care' OR urgent care .ti,ab emergenc*.ti,ab prehospital* OR pre-hospital.ti,ab ambulance*.ti,ab ambulance OR "emergency medical" adj3 service* ((patient* adj3 transport*).ti,ab paramedic*.ti,ab (((emergency OR "emergency care" OR "emergency medical" OR ambulanc*) adj3 (crew* OR staff OR practitioner OR team* OR technician))))).ti,ab care adj3 pathway*.ti,ab	dement*.ti,ab alzheimer*.ti,ab ((Cognit* AND (disord* OR impair* OR declin* OR function*))).ti,ab ((memory adj2 (complaint* OR impair* OR problem* OR loss*))).ti,ab (("End of Life" OR end-of-life).ti,ab

We identified 5005 documents from the systematic search, screened 714 abstracts and included 108 for fuller review. Of these 108, 19 sources were included for analysis. Each document source (title or abstract or full paper) was independently reviewed by two reviewers, at each stage in the systematic search. At abstract review a third experienced systematic reviewer reviewed disagreements and made a decision. A further 14 documents were identified from iterative techniques and at least two authors reviewed for inclusion. These 33 sources were included for an initial analysis and 17 documents were included in our final synthesis (Figure 1).

Figure 1 Progression of articles through the review



Information extraction and initial analysis

We extracted information from the initial 33 sources into a data extraction form (DEF), in addition to recording standard descriptive details we included information under four headings that formed the start of our analysis: Lens, ambulance role descriptor, ambulance role components and 'nuggets'[19]. Lens reflected the professional background or assumptions of the authors, for example EMS, or palliative care research. Ambulance role descriptor captured the role of EMS described and ambulance role component was more specific about what EMS were actually doing. 'Nuggets' captured particular ideas or quotes from the sources that seemed most relevant.

After this initial analysis 16 sources were excluded because second review by the team clarified that, despite being of related interest, they did not strictly meet our review inclusion criteria. It became clear we had included some sources inappropriately, for instance, only because they resonated with paramedic experience of dealing with people with dementia in their work, or gave weight to the argument that ambulance services are 'forgotten' in research, even though the source itself did not specifically deal with dementia or could not be expected to include EMS. Reasons for initial interest and subsequent exclusion were noted in the DEF.

Emerging roles from the descriptor and component fields were distilled into a smaller set of roles, and the 'Lens' field was further honed into four broad perspectives (Box 1).

Box 1: Perspective of the Literature Source

1. Ambulance Service/Emergency Medical Service(EMS)
2. End-of-Life(EoL)/Palliative Care
3. Dementia Care
4. Urgent and Emergency Care of Older People

Subsequent thematic analysis of the key points from each source defined and refined the key issues to emerge from the literature. After cross-checking these with themes that emerged from our preparatory consultation and examination by the full review team, the validity of our findings was discussed and confirmed at a post review stakeholder meeting of carers and relevant professionals.

Quality appraisal

We applied an informal critical appraisal, influenced by the CASP[20] approach. Many of the sources were reports, briefings and guidance which were not expected to meet any of the agreed quality appraisal criteria. Given the paucity of any information on our review topic, we aimed for inclusivity and agreed not to exclude any documents on quality appraisal grounds. A field in the DEF captured this. (The DEF is available, on request, from the authors).

RESULTS AND SYNTHESIS

Description of evidence

The 17 literature sources included are summarised in Table 2 and Table 3. Over half (n=10) were from policy and professional literature (Table 2) of which only three were found via the systematic search. The evidence base in this grey literature included case studies, internal service evaluations, workshop reports, best practice guidance and briefing statements. Work, based on one small scale staff survey and frontline experience, undertaken by Great Western Ambulance Service (GWAS) aimed at improving pre-hospital care of OPWD and their carers', is the basis of the evidence in three sources: the original report[21], a workshop[22] and a briefing[23] by the UK Ambulance Service Network (ASN¹). There was one non-UK grey literature source, a dementia training resource for Australian EMS personnel[24].

The remaining seven documents were from journals (five of which were from the systematic search) and included a literature review, an information/training article, three US evaluative studies around training, knowledge, triage of patients (psychiatric, distressed senior, Alzheimer's) and two English qualitative studies of EoL care for people with dementia (Table 3).

Following analysis, the literature could be divided into four role categories: emergency transport, assess and manage, last resort/safety net and EMS role not considered. In the synthesis 'emergency transport' and 'assess and manage' roles are discussed together as 'emergency transport' was not found as a stand-alone role in any of the literature (Box 2).

Box 2: Role categories

1. **Emergency Transport & Assess and Manage**

When the EMS role is described within their expected roles, either as a means of getting a person to medical help as quickly as possible, usually hospital, or as making an assessment of a patient, deciding on what immediate management is appropriate and providing treatment, onward referral or conveyance to hospital.

2. **Last Resort/Safety Net**

When the role is described as an EMS crew responding outside of their expected or appropriate remit to a situation that is not a medical emergency, though it may be a crisis or urgent care need.

3. **EMS role not considered**

When the EMS role is not described and in that context the omission is notable.

¹ The ASN no longer exists it has been subsumed into the Urgent & Emergency care workstream of the NHS Confederation

Table 2: Summary of the grey literature included in the review

Title	Search Source	Research Method	Perspective	Study/Report Focus	Pertinent Key Messages/ Findings	Role	Literature Type	Year	Country
GREY LITERATURE									
Urgent Care Pathways for Older People with Complex Needs - Best Practice Guidance Department of Health [28]	Google Browsing	Expert opinion and published research	Urgent and Emergency Care of Older People	To develop a practical ambulance service and A&E urgent care pathway for older people with complex needs that will drive up the quality of assessments for older people	The report specifically addresses falls, confusional states and hip fracture. Dementia can be a complicating factor in all of these. Recommends that ambulance clinicians should routinely assess for confusion using a cognitive assessment instrument. Highlights the 'unique position' ambulance clinicians have in attending patients in their own home (and therefore able to contribute to wider patient assessment e.g. about living conditions such as hygiene and food).	Assess and Manage	Best Practice Guidance	2007	UK
Dementia Training for Ambulance Workers. Learners Guide: Paramedics. Community Services and Health Industry Skills Council [21]	Google Browsing	Information Article/ Training Material	Ambulance/ EMS & Dementia Care	To up-skill ambulance workers in managing crisis situations in the community that involves people with dementia and their carers	The development of a training resource specifically aimed at ambulance workers implicitly acknowledges the key role of EMS in assessment and management of OPWD.	Assess and Manage	Training Resource	2009	Australia
Great Western Ambulance Service (GWAS) NHS Trust and the Department Of Health Joint Pre-hospital Dementia Report. O'Leary et al [18]	Google browsing & Systematic Search	Survey/ Questionnaire	Ambulance/ EMS & Dementia Care	To share results from scoping a project for the improvement of pre-hospital and urgent care for individuals with dementia and their carers at GWAS	Five key areas identified to improve service for OPWD; training, care/referral pathways, communication, assessment and treatment tools, support for patients and carers. Though these seem sensible areas to address from the brief report of the survey it is not clear how robust the findings are. Additionally an information leaflet was produced for GWAS clinicians.	Assess and Manage	Report	2011	UK
CLAHRC Fellowship Project Report - Ambulance services and dementia (Unpublished data, Okereke U., 2011)	From Colleague	Mixed Methods	Ambulance/ EMS & Dementia Care	To inform the development of integrated care pathways for people with dementia	OPWD, 60+ significantly more likely to attend A&E via ambulance than other transport means.	Assess and Manage	Internal Report	2011	UK
The Silver Book: Quality Care for Older People with Urgent & Emergency Care Needs. Banerjee & Conroy et al [27]	From Colleague	Expert opinion and published research (modified nominal group technique)	Urgent and Emergency Care of Older People	To provide best practice guidance on care for older people over the first 24 hours of an urgent care episode	Recommends a whole systems, integrated, person centred approach as the only means to achieve the best outcomes for frail older people with health and social crises. Identifies that the ambulance service (EMS) has a key role to play and can be an important contributor in doing things differently – for example, referring non-conveyed patients directly to urgent care, community and primary care services, including falls services.	Assess and Manage	Best Practice Guidance	2011	UK

Title	Search Source	Research Method	Perspective	Study/Report Focus	Pertinent Key Messages/ Findings	Role	Literature Type	Year	Country
East of England Ambulance Service Regional Innovation Fund Dementia Project (Unpublished report, Parker, E, EEAS Internal Report, 2011)	From Colleague	Service Evaluation	Ambulance/ EMS & Dementia Care	To evaluate new pilot dementia referral pathways for ambulance staff and the dementia training rolled out for EEAS staff	Dementia care raised as a priority in the ambulance trust, pathways in place in some areas, problems with no forward funding for the trust regional dementia lead role. Some training in place.	Assess and Manage	Internal Report	2012	UK
The Route to Success in End of Life Care - Achieving Quality in Ambulance Services. National End of Life Care Programme [26]	Systematic Search	Case Studies	Ambulance/ EMS & EoL/Palliative Care	To provide practical support for health and social care professionals, service planners, managers and commissioners to address the challenges with and improve the quality of end of life care provided by ambulance services by working together at individual, system and strategic levels	Highlights the ongoing role EMS may have at end-of-life, particularly for those with COPD or dementia. Describes a need for ambulance services and other organisations to work more closely together to overcome barriers and enable ambulance services to play their full part in providing high quality end of life care.	Assess and Manage & Last Resort/ Safety Net	Report	2012	UK
Seeing Ambulance Services in a Different Light: More than a Patient Transport Service. Ambulance Services Network [20]	Browsing ASN Website	Case Studies	Ambulance/ EMS	To describe and highlight wider role of ambulance services	There is an implied message that the ambulance service provides a "last resort/safety net" role in the statement "Dementia patients are sometimes taken to hospital when local care homes do not have the capacity to make a proper assessment. This can happen even at times when the patient does not have urgent or emergency needs that are unrelated to their dementia." However it is unclear what particular evidence this assertion is based upon.	Assess and Manage, Emergency Transport & Last Resort/ Safety Net	Briefing	2010	UK
Dementia Care Workshop: Partnership Working to Improve Care for People with Dementia. 10 February 2011, London. Ambulance Services Network [19]	Browsing ASN website	Workshop Presentation	Ambulance/ EMS & Dementia Care	To highlight role of ambulance services in dementia care	ASN acknowledging the role of EMS in delivering National Dementia Strategy in England. Half day workshop which included a talk on the GWAS work as the example of EMS working to improve pre-hospital and urgent care for people with dementia and their carers.	Assess and Manage, Emergency Transport & Last Resort/ Safety Net	Meeting Presentation	2011	UK
Understanding out of Hospital Dementia Care. Healthcare at Home [32]	Systematic Search	Workshop Report	Dementia Care	To consider how a home-based model of care be created that will keep dementia patients out of hospital	Need for a dementia care co-ordination service and suggested gold standard pathway. Though any role for EMS in this is not considered.	Not considered	Report	2011	UK

Table 3: Summary of the academic literature included in the review

Title	Search Source	Research Method	Perspective	Study/Report Focus	Pertinent Key Messages/ Findings	Role	Literature Type	Year	Country
ACADEMIC LITERATURE									
A model strategy for teaching prehospital personnel management of patients with Alzheimer's disease. Cason et al [22]	Systematic Search	Survey/ Questionnaire	Ambulance/ EMS & Dementia Care	To describe and evaluate training of pre-hospital personnel to deal with Alzheimer's Disease	An early piece of work demonstrating awareness of the role pre-hospital personnel have in caring for OPWD, specifically those with Alzheimer's Disease and the need for training in appropriate patient management techniques to deliver positive care.	Assess and Manage	Peer Reviewed Journal Article	1992	USA
Hospital follow-up of patients categorized as not needing an ambulance using a set of emergency medical technician protocols. Schmidt et al [24]	Systematic Search	Data Analysis of Hospital and EMS Data	Ambulance/ EMS	To evaluate Emergency Medical Technician (EMT) ability to safely apply transport option protocols	EMT transport option protocols led to a 9% under-triage rate. Patients with psychiatric complaints and dementia were at high risk for under-triage. In the discussion the authors propose that this could be due to the difficulty in taking history for this group of patients and that EMTs may therefore need further education about appropriate assessment of people with psychiatric complaints and dementia.	Assess and Manage	Peer Reviewed Journal Article	2001	USA
Paramedic assessment of pain in the cognitively impaired adult patient. Lord B [23]	Systematic Search	Literature Review	Ambulance/ EMS	To systematically locate evidence relating to the use of pain assessment tools that have been validated for use with cognitively impaired adults and to identify those that have been recommended for use by paramedics	The author found a lack of consensus and research evidence on the most appropriate pain-assessment tool for use with cognitively impaired adults in a pre-hospital setting. He recommends research to test the utility, validity and reliability of the Abbey Pain Scale in identifying pain in this at-risk population in the pre-hospital setting, and research to evaluate the effectiveness of paramedic pain management practice in older adults.	Assess and Manage	Peer Reviewed Journal Article	2009	N/A
Lost and Found: How to treat Alzheimer's patients Spaulding S and Zygowicz WM [29]	Search of Target Journals	Information Article/ Training Material	Ambulance/ EMS & Dementia Care	An information article for EMS personnel including a section on the appropriate EMS interaction (approach, assessment and management) with the Alzheimer's patient	EMS (via 911) is the first call and last resort of families in crisis. It is important to provide the right response when interacting with dementia patients. Awareness of dementia and Alzheimer's disease helps providers understand what patients and families are going through and enables them to provide the best medical care and customer service.	Assess and Manage & Last Resort/ Safety Net	Professional Journal Article	2010	USA

Title	Search Source	Research Method	Perspective	Study/Report Focus	Pertinent Key Messages/ Findings	Role	Literature Type	Year	Country
Psychiatric emergencies in the suburbs: An EMS response to the distressed senior. Bernick et al [25]	Systematic Search	Record Review	Ambulance/ EMS	To review and convey an awareness of the initial assessment of seniors with diverse psychiatric emergencies	Quantified the psychiatric emergencies for a cohort of patients (dementia being a factor in some of these emergencies). Identifies that care givers (of senior patients) often rely on EMS as initial responder to meet their crisis. Highlights role of appropriate assessment by EMS and that they are often the first call in a crisis (a safety net).	Assess and Manage & Last Resort/ Safety Net	Conference Abstract	2012	USA
Improving end of life care for the person with dementia: A practical approach from general practice. Evans G [31]	Systematic Search	Case Studies	EoL/Palliative Care & Dementia Care	To share experience and learning of caring for people with dementia who live in care homes	The paper highlights a case where the author felt an ambulance might have been called to a care home for an OPWD had the GP not been on site. An example of the presumption of the 'last resort/safety net' role it is perceived that EMS play in the care of OPWD.	Last Resort/ Safety Net	Peer Reviewed Journal Article	2009	UK
Barriers to providing end-of-life care for people with dementia: a whole-system qualitative study Denning KH et al [30]	From Colleague	Whole-system qualitative study	EoL/Palliative Care & Dementia Care	To identify barriers to people dying with dementia and their carers receiving good end-of-life care, and to identify good practice that might inform improvements in care.	Five areas were identified as barriers to providing good end-of-life care. Care pathways was one of these areas and the role of ambulance services in providing out-of-hours care when other support services were unavailable, often leading to hospital admission was specifically highlighted.	Last Resort/ Safety Net	Peer Reviewed Journal Article	2012	UK

Synthesis

'Emergency transport' and 'assess and manage' roles

Emergency transport is considered in two of the documents and the 'assess and manage' role considered in fourteen. The majority of the literature for this review is from 2009-2012 and linked to the developing policy focus on considering and planning for the impact of dementia on modern society.[4] However, there was one much earlier source from 1992 which was a small US based evaluation of a training programme to teach pre-hospital personnel management of Alzheimer's patients[25]. Three issues were identified from research around aspects of care carried out by EMS practitioners that relate to their role in the care of OPWD:

- Ambulance crews don't have access to validated pain assessment tools for OPWD.[26] The review author noted, "*Reference to cognitive impairment and the consequent impact this condition has on the paramedic's ability to assess pain is rarely mentioned in the paramedic literature.*"
- There is limited evidence of under triage for patients with dementia by emergency medical technicians using a triage protocol. This study highlighted the difficulty of assessing patients with dementia and that the, then current (2001), protocols do not specifically address dementia. [27]
- Anxiety is the most common diagnosis in the 'distressed senior' and most transported to hospital. [28]

Work undertaken by English ambulance services and a dementia training resource for Australian ambulance workers indicate that there is recognition within EMS for the need to provide improved care to OPWD. However the majority of the literature is setting out probable problems and there is a lack of any evidence and tested interventions to address them.

Two sources with an EMS perspective address wider roles that ambulance services can have, beyond emergency transport, consider OPWD as a particular patient group for whom the EMS may have a significant role: 'Seeing ambulance services in a different light: More than a patient transport service'[23] and 'The route to success in end of life care: achieving quality in ambulance services' [29]. The latter report highlights the ongoing role EMS may have at the end of life, particularly for those with COPD or dementia; "*Ambulance services and staff have a more significant role and contribution during this period [end-of-life] than might be first thought. People at the end of life may have contact with ambulance services on several occasions, for example when a complication occurs which creates a sudden health crisis, or for an unrelated event such as a fall.*"[29]

Two English 'Best Practice Guidance' documents which focus on the urgent and emergency care of older people draw out ambulance service roles around appropriate assessment and management of OPWD. Neither source directly explores the role of EMS in the care of OPWD because dementia, delirium and ambulance roles are discussed in isolation. However, both do highlight the 'on-scene' role EMS have in attending the patient at home or in the community. The 2007 UK Department of Health guidance[30] recommends that ambulance clinicians should routinely assess for confusion using a cognitive assessment

instrument. They also note the 'unique position' ambulance clinicians have in attending patients in their own home and state, "*Often no other healthcare professional is made aware that the ambulance service has attended this group of patients [here referring to patients who have fallen, a significant proportion of whom may have dementia] and there is therefore a missed opportunity to utilise the valuable information collected about the person and the fall.*"[30] The 2011 'Silver Book'[31] suggests that there "*is scope for delivering a more specialist programme in geriatric medicine for ambulance clinicians.*"

A 'last resort' or 'safety net' role

The EMS role as a 'last resort' or 'safety net' is considered in seven of the documents, however is mentioned in passing rather than with substantial exploration of the role and the evidence base for the statements made is not clear. For example:

- The briefing paper from the ASN states that "*Patients find the current system for accessing NHS services confusing and frustrating...Many people therefore dial 999 for non-emergencies because they know that they will receive advice or a response.*"[23] In the specific dementia-related case study the authors describe dementia patients being taken to hospital when a care home does not have the capacity to make a proper assessment – even if the person does not have an urgent or emergency care need.
- In presentations from the ASN dementia care workshop [22] a reason for calling 999 is cited as "*Primary carer is exhausted, frustrated and simply did not know what else to do*".
- Two US papers make mention of the safety net or last resort role; "*EMS frequently provide the initial evaluation of the 'distressed senior'*"[28] and "*Calling 911 is the first option or last resort for families [of OPWD] in crisis*". [32]
- The report considering the role of EMS in EoL care[29] refers to anxious carers and family members calling 999 for emergency support if there are worsening symptoms or a sudden crisis. It does not frame this in an 'inappropriate call' or 'last resort' context as some of the other sources do but rather considers how best to improve the response.

An English qualitative study investigating barriers to providing end-of-life care for OPWD provides a stronger evidence base for this last resort/safety net role: Denning et al highlighted the issue of ambulance services responding 'out-of-hours' when other, perhaps more appropriate services, are unavailable, leading to hospital admission due to lack of alternatives.[33] Another English study dealing with EoL care for OPWD highlighted an incident at a care home where 999 would have been used as a safety net had the GP not been on site in that particular case.[34] However, this is one case study and an interpretation by the author of what may have happened.

Role of EMS in urgent and emergency care of OPWD not considered

The role of EMS was not considered in one particular document and we found the absence notable. The report from a discussion workshop 'Understanding out of Hospital Dementia Care' describes a system "not fit for purpose" where "*Patients and carers are left to navigate*

their way through a complex and often baffling health and social care system. This can lead to the all-too familiar outcome of patients ending up in inappropriate care settings...^[35] This resonates with the last resort/safety net role of other documents but it was striking that a document about out of hospital care did not once consider the role of EMS.

LIMITATIONS

This international review identified literature sources only from the UK, US and Australian EMS. All the grey literature retrieved, with the exception of the dementia training resource for ambulance workers,[24] is UK based and the unpublished reports are all from the East of England reflecting the authors' local access. As there was a small number of different research settings identified in the literature we are uncertain how generalisations can be made to other contexts. However, there are sufficient similarities between the UK, US and Australian EMS to provide a useful contribution to understanding the role of EMS in dementia care in these countries. As we did not include any non-English language literature we cannot be sure how useful it may be to EMS systems in other countries, though the roles identified may serve as a useful starting point for research.

Systematic searching may have excluded articles where the role of EMS is only mentioned in the full text. We tried to guard against this by including papers at abstract that looked like there may be an ambulance service role, however some papers may not have been identified by the pre-hospital search terms. It is highly unlikely that this excluded any significantly different or new roles from those already found.

There was a large degree of heterogeneity between the included studies and a general lack of research investigating the role of EMS in dementia care, so some residual publication bias may be present in the review.

The paucity of research made it difficult to make judgements on what the basis of the evidence was for many of the statements made. Formal quality assessment was not carried out as this review does not attempt to synthesise the empirical findings but rather provides an overview of the current narratives and research.

DISCUSSION

The use of 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. There were notable omissions in the literature reviewed initially, for example, 'Understanding out of hospital dementia care' the role of EMS was overlooked. This omission was also clear in some of the literature we removed in the last round of exclusions. The 2011 'Joint statement on the emergency care of older people'[36], asserts "*It is essential to provide the best care for frail older people at the first opportunity* [our emphasis] *to ensure optimal efficiency of the health and social care system.*" Although speaking about older people in general, not just those with dementia, the statement does not mention ambulance services; instead the 'first opportunity' appears to be at the hospital door. A review of the definition of crisis in dementia care [37] did not select papers that reported crisis and use of EMS, though conversely EMS work describes crisis in dementia care as a trigger for calling EMS. This is very likely due to the inclusion criteria for the review which required the paper to define crisis. There was a common narrative (in both

UK and US based literature) describing EMS taking on a last resort or safety net type role but this is not well defined and we found no empirical evidence to support this view.

The 'emergency transport' role was not as evident in the literature as we were initially led to believe: the strong narrative for this came from the briefing 'Seeing ambulance services in a different light: more than a patient transport service'[23] and from paramedic reviewers. However, we excluded research that only included EMS calls as outcome measures [38] or co-variables [39]. For example, a paper exploring the prevalence of depression and cognitive impairment in older adult ED patients that examined differences between patients arriving by EMS and by other means.

This scoping work has highlighted a populist narrative around 'inappropriate' calls (the last resort/safety net role) and identified recurrent themes about crews needing better training in assessing OPWD, the absence of an alternative to hospital, the lack of integration in health care and that 999 (or 911 or equivalent) is the default option due to lack of knowledge or access to more appropriate services. Few of these assumptions have been tested empirically. The review revealed literature of varying quality, focus, and depth. There is an emerging consensus about the lack of information, information sharing, service integration and missed opportunities of ambulance crews in attending to people at home. Yet these issues have not been studied with respect to OPWD who have additional care needs, not least co-morbidities that may exacerbate the current challenges.[40] There are high levels of patient satisfaction and trust in NHS ambulance staff,[41] they have a duty to respond and they offer one-to-one patient care. In the absence of evidence, emergency services and EMS personnel will respond to the perceived needs with training, pathways development, use of non-validated but 'best fit' tools (such as the Abbey Pain Scale for pain management). There is an increasing interest internationally in extended paramedic roles and skills [3, 10, 11]. A recent review looking at which extended paramedic skills are making an impact [10] found the strongest evidence base for paramedic skill development was in assessing and managing acute minor conditions in older patients and found the most promising means of reducing demand on EDs to be interaction of paramedics with other community services. Although Evans, McGovern *et al* concluded that the evidence was not strong enough to guide policy, their findings point towards redesign or reconfiguration of paramedic practice and the role of EMS to encompass both 'assess and manage' and 'last resort/safety net' roles. Our review would add that when doing this, specifically considering the additional needs of OPWD is essential.

CONCLUSIONS AND RECOMMENDATIONS

There is no common framework to understand or interpret how emergency care for OPWD should be provided or how effectiveness can be judged. There is an urgent need to address these issues which will become more acute, given forecast demographics. In clinical practice there are ever increasing numbers of service development initiatives that tend to focus on the 'assess and manage roles' attempting to go beyond, or avoid, the 'emergency transport' role and robust evaluation of their effectiveness should be a priority. Our review found insufficient evidence to quantify the extent to which EMS acts in the different roles identified and was unable to establish how ambulance responses meet the needs of OPWD – potential questions for future research. If the last resort/safety net role of EMS is reframed as

rapid response to urgent care needs for OPWD perhaps this is an appropriate EMS role and interventions to address these needs could be tested.

Research in dementia care should consider the role EMS play, particularly if considering crises, urgent care responses, and transitions between care settings. EMS research into new ways of working, training or extended paramedic roles should consider specifically the challenges and needs of responding to people with dementia. A mixed methods project combining qualitative interviews and surveys could be conducted to further develop our understanding the role of EMS in dementia care. Findings of this research could contribute to the development of a framework to improve emergency care and adjudicate on EMS effectiveness.

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