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Potential Barriers in the Provision of End of Life Care by Paramedics in the Community.

No conflict of interest

Keywords: End of life, palliative, community, paramedics, barriers, challenges

Abstract:

Background: Patients and families are increasingly relying on ambulance services in caring for palliative and end of life patients due to the ageing population, limited advanced care planning and insufficient palliative care services in the community.

Main findings: Research is limited regarding paramedic involvement in end of life care. Many paramedics require end of life care training to manage this cohort of patients. Discharges from the acute sector to the community setting requires urgent attention, including the implementation of advanced care plans to guide practice.

Conclusion: Paramedics require EOL training to effectively treat patients. Palliative care services require additional resources, skilled healthcare professionals and adequate funding to manage the increasing number of patients dying at home. Improved referral pathways, including hospital discharge are needed between paramedics and community nursing/ palliative care teams to ensure best outcomes for patients. Advanced care planning must be addressed by all HCPs.

Introduction

Considering the ever-ageing population, paramedics are increasingly attending palliative and end of life patients in the community. Patients and family often call 999 in times of distress when they are unable to contact the patient's palliative care team or general practice (Murphy-Jones, Lavery, and Stonehouse, 2021). There is considerable variation in palliative care services across the United Kingdom [UK]. Cox et al (2016), found in their review of London palliative care services, that only nine of the thirty hospital palliative care teams and seventeen of the twenty-six community palliative care teams were available seven days a week. Not only are many services not available seven days a week, but the majority do not operate 24 hours a day. Williams et al (2018) identified 695 safety incidents involving adverse outcomes for palliative patients cared for by out-of-hours services within a four year and ten-month period, with 199 of these incidents related to delayed access to medication. These authors recognised that this figure likely underrepresents adverse outcomes of palliative patients due to the subjective nature of identifying harm.

The Joint Royal Colleges Ambulance Liaison Committee [JRCALC] (2019) end of life care protocol recommends ambulance clinicians share decision making with other healthcare professionals [HCPs], such as general practitioners or care teams. The current funding model for palliative care services in the UK is heavily reliant on charitable funding with only 30% of income sourced from the government and National Health Service [NHS] (Jackson, 2022). Hospice UK (2023) reported that hospices in England have had a 47 million pound pay cut in the last two years due to inflation without an increase in funding. As a result, palliative care services are unable to service the community 24 hours a day and it appears patients are

therefore suffering adverse health outcomes. An analysis by Marie Curie (2023), predicts that by 2048 patients requiring palliative care support in the UK will increase by 147000 as a direct result of the ageing population, and will greatly overwhelm palliative care services. This review will explore the role of paramedics in end-of-life care in the community by acknowledging current practice in the NHS and identifying requirements to improve practice.

The importance of symptom management in end-of-life care

Ineffective symptom control is one of the most influential factors for a palliative patient, their family or caregivers to call 999 (Blackmore, 2022). Star and Boland (2018) highlight the most common symptoms at EOL, notably pain, nausea and vomiting, breathlessness, delirium, opioid induced constipation and upper respiratory tract secretions. They stress the importance of careful assessment and the trial and consideration of non-pharmacological treatments, both before and in combination with pharmacological therapies. However, in a community setting this can be time consuming and not always practical. An evaluation of 284 inpatients unknown to palliative care within 88 UK hospitals by Tavabie et al. (2023), found that 93% of this cohort had unmet needs, with 75% of these needs involving distressing physical symptoms. While this study highlighted the lack of symptom control for patients dying in hospital, it did not identify why these patient's symptoms remained uncontrolled, or why these patients were unknown to hospital palliative care teams. If the rate of symptom control is insufficient in hospitals where patients have direct access to health care professionals, it is therefore reasonable to infer that this rate is

significantly higher for patients in the community, contributing to an increasing reliance on emergency paramedics.

Gerber et al., (2021) suggests a lack of knowledge and experience as contributing factors to inadequate symptom management, based on interviews of Australian nurses, however, these research findings may not be transferable to paramedic experience of practice in the UK. Similarly, the findings in the UK study by Kirk et al (2017) looking at the perceptions and confidence levels of paramedics in end of life care, highlighted the necessity of specific education to ensure competence and skilled care. Additionally, a literature review undertaken by Pentaris et al (2019) in the UK examining paramedics attitudes and perceptions of EOL care, similarly suggest the requirements of appropriate education and training to address skills and confidence levels in complex EOL care situations. However, a limitation noted in this study is the lack of UK studies included in the review. These researchers also stress the necessity of further research in the UK in this area of practice.

Paramedics within the UK adhere to the JRCALC (2019) guidelines to guide clinical practice. The guidelines are created by an independent committee of multi-disciplinary HCPs, and each specific protocol is developed by specialist sub-groups (Class Professional Publishing, 2023). JRCALC does not disclose members of the sub-group that consulted on the End of Life Care guideline and therefore the knowledge base can only be analysed by the listed references. The committee itself contains no specialist palliative care professionals and the End of Life Care guideline is based on dated research between 1979 and 2017 (JRCALC and AACE [Association of Ambulance Chief Executives], 2019). Clinical practice guidelines can be an invaluable resource for HCPs, especially those with limited clinical experience to guide safe decision making (Harris, et al., 2021; Ebben, et al., 2013). However, in

the authors opinion, the JRCALC End of Life Care guideline, reflects the apparent lack of existing literature and evidence to support end of life practice in the community.

On examining the JRCALC End of Life Care guideline (2019), it was identified that paramedics are unable to provide adequate symptom management due to an inability to prescribe anticipatory medication. One such example is in the management of delirium and agitation in dying patients, a common symptom at EOL requiring urgent assessment and care, wherein both (JRCALC and AACE, 2019) and the National Institute for Health and Care excellence (2023) [NICE], have similar recommendations. JRCALC suggests managing agitation with both pharmacological and non-pharmacological strategies and NICE guidance recommends clinicians consider administering low doses of haloperidol if de-escalation techniques are unsuccessful (JRCALC and AACE, 2019; NICE, 2023). NICE (2015) conducted a literature review to identify which benzodiazepines and anti-psychotics are most effective in treating agitation in end of life. The review concluded that no such evidence existed, and as a result, clinicians are hesitant to administer sedative medication due to fears of over-sedating dying patients (NICE, 2015). JRCALC suggests utilising patient's own anticipatory medication to reduce agitation (JRCALC and AACE, 2019).

It is not within the JRCALC paramedic scope of practice to prescribe antipsychotic or sedative medication for management of delirium. However, Advanced Paramedic Practitioners in Urgent Care are authorised to administer midazolam for agitation to end of life patients who have not already been prescribed anticipatory medication (JRCALC and AACE, 2019). The London Ambulance Service has a maximum of fourteen Advanced Paramedic Practitioners in Urgent Care

available to respond to patients in the community, pan London, per day (Hitchisson, 2024) These advanced practitioners cover a large geographic area and may be delayed in responding to patients at end of life in comparison to their paramedic colleagues. Therefore, if a patient has not been pre-emptively prescribed anticipatory medication, it may pose a significant barrier in controlling distressing symptoms in dying patients. In response to the COVID-19 pandemic, the Welsh Ambulance Service began carrying anticipatory medication on emergency ambulances, the initiative continues and a recommendation by the authors is that this should be extended to the rest of the UK (O'Brian, et al., 2023). A further recommendation is the requirement for all HCP's to have specific training in all aspects of EOL care, particularly symptom management.

Communication and discharge planning

The Ambitions for Palliative and End of Life Care (2021-2026) framework highlights good communication as an essential component to coordinated care (NHS England, 2021). Discharge planning plays an essential role in handing over care from inpatient to community teams (Merlane and Booth, 2020). NICE (2019), conducted a literature review of studies related to discharging end of life patients and transitioning from hospital to community settings. The study concluded that no relevant research could be identified (NICE, 2019). This is extremely concerning and demonstrates the urgent requirement for research in this area of practice.

Merlane and Booth (2020), utilised the Leadership Alliance for the Care of Dying People (2014) five priorities in the One Chance to Get it Right document, to create a framework that allows for safe discharge of patients at end of life. While the

authors acknowledge that the One Chance to Get it Right document is somewhat dated, the advice of 21 organisations all with a vested interest and expertise in end of life care, is a valuable resource with such limited available literature (Leadership Alliance for the Care of Dying People, 2014). The most important point Merlane and Booth (2020) described, in the author's perspective, is a discussion with the general practitioner. Sending a discharge summary to the patient's general practice is not sufficient to ensure that primacy of care is effectively handed over to community services. These authors acknowledged best practice as providing the patient with an emergency healthcare plan and discharge letter.

There is no standardised emergency healthcare plan across the UK, which poses as a significant organisational barrier in the delivery of end of life care. The Ambitions for Palliative and End of Life Care framework, Ambition three; maximising comfort and wellbeing, suggests the use of care plans to document the patient's preferences and priorities (NHS England, 2021). Ambition four, suggests that records should be shared with all HCPs involved in the patients care (NHS England, 2021). In London, patients have the option to create a universal care plan that enables their wishes to be shared between relevant HCPs including local ambulance services, out of hours general practitioners, community nurses, palliative care teams, and the patient's general practice (Universal Care Plan for London, n.d.). This online system is an efficient way to communicate essential information between HCPs and ensure that decisions are made in line with the patient's wishes. Therefore, a recommendation is that the Universal Care Plan system requires urgent installation across the whole of the UK to ensure effective sharing of information.

Advanced Care Planning

Advanced care planning allows clinicians to provide individualised care when a patient no longer has capacity to advocate for themselves (NHS England, 2021). Advanced care plans are not legally binding, however can be used to guide HCPs to make decisions in the best interest of the patient, whether that be to commence or withhold treatment (NHS England, 2022). Care plans can also consider social wishes such as preferred place of care, patients priorities, or family involvement in their death (British Geriatrics Society, 2020). When a patient lacks capacity, decisions must be made in their best interest, as per the (Mental Capacity Act, 2005 principle 5). The Act states that the patients wishes, especially those documented when the patient had capacity, must be considered when making best interest decisions.

Ambulance clinicians have no knowledge of the patient or established relationship before entering their residence. Therefore, advanced care plans are an essential resource to ensure patients receive individualised care (Patterson, et al., 2019). Patients over the age of 70 believe that advanced care planning led by HCPs is of benefit to their current and future health by allowing for patient centred planning (Bielinska, et al., 2021). The presence of emergency care plans is an effective solution to information sharing if they are regularly updated to reflect the patient's current condition and accessible to the patient's multidisciplinary health care teams (Patterson, et al. 2019). Despite a small sample size of ten interviewees, the Patterson et al (2019) study highlighted the importance of electronic record sharing of advanced care plans to improve paramedic confidence in decision making for palliative patients. This study is a first step in recognising accessible care plans as an essential component in community end of life care

The evidence is clear that advanced care plans are still not being discussed or introduced by HCPs. Seydel, et al (2022) identified discomfort of nurses as a barrier to communicating with patients and their caregivers about end of life care. Sutherland (2019) had a similar perspective in reference to doctors and medical students who also feel uncomfortable having end of life discussions. In the authors clinical experience, it is often unclear which HCPs are responsible for having end of life discussions. Having no established responsible party, leads to the assumption that advanced care planning and end of life discussions have been conducted by another HCP. Advanced care planning also allows ambulance clinicians to exclude reversible conditions that may not be caused by the patient's palliating disease and may benefit from hospital admission (Blackmore, 2022).

The Ambitions for Palliative and End of Life Care framework (NHS England, 2021) recognises that carers often experience distress due to multiple HCPs working independently of each other. It is the responsibility of all HCPs to be involved in end of life care conversations and planning to ensure both the patient and carers are supported (Mackenzie and Lasota, 2023). The current JRCALC end of life guideline heavily relies on the presence of advanced care planning and does not offer guidance for out-of-hours support when the patient's care teams are not available (JRCALC & AACE, 2019). A further recommendation by the authors suggests this guideline needs to be updated in line with new research to help guide ambulance clinicians to confidently make evidence-based end of life care decisions. See table 1 for further recommendations.

Table 1- Recommendations to improve end of life care in the community

Topic	Proposed improvements
Advanced care planning	<p>All patients with a palliative condition should commence advanced care planning from the point of diagnosis.</p> <p>An updated care plan after every consultation or end of life discussion is crucial.</p> <p>Universal health care system expanded across the UK.</p>
Primary care provider	<p>Patients to be assigned an accountable General Practitioner or trained HCP to have primacy of care in the community.</p> <p>Patients to be reviewed on regular intervals based on their prognosis, e.g.</p> <ul style="list-style-type: none"> - Reviewed every 6 months for prognosis >1 year - Monthly for prognosis <1 year - Weekly for prognosis <3months - All practices should have regular Gold Standard Framework meetings and implement the Marie Curie Daffodil Standards
Discharge from hospital	<p>Verbal consultation with General Practitioner and District Nursing team prior to discharge to make them aware of the patient's prognosis.</p>
Funding	<p>Prioritise an increase in NHS funding for end of life care, allowing teams to operate 24 hour a day and prevent costly hospital admissions.</p> <p>Funding for general practices to employ additional HCPs to be assigned to palliative patients.</p>

	Additional funding for palliative care research to generate practical solutions to treat palliative patients in the community.
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Education

Within the UK, paramedics must register with the Health and Care Professions Council to practice and identify as a paramedic (HCPC, 2023). End of life care practice significantly differs from the life sustaining approach paramedics are trained to adopt when providing patient care (JRCALC & AACE, 2019). The varied nature of calls to ambulance services requires ambulance clinicians to have a high level of clinical knowledge and excellent skill set for holistic assessment (Blackmore, 2022). However, Givati, Markham, Street, (2018) advise that paramedics are not always highly trained in end of life care unless they seek further education beyond a Bachelor's degree. While paramedics may be able to identify a patient as palliative, they are not experts in treating palliative conditions, nor are they able to provide follow up care to a patient once leaving the scene (Eaton-Williams, et al., 2020). Performing a holistic assessment allows paramedics to provide a thorough referral to other HCPs and facilitate individualised care (Murphy-Jones, Lavery, and Stonehouse, 2021). From the authors experience more paramedics are now attending end of life care courses in university post qualifying, this should be encouraged in yearly appraisals to enhance knowledge. Additionally, the use of other forms of training must be considered. Shushtari, et al (2022), were successful in improving competency and knowledge in end of life care after a nine module E-Learning course. See table 2 for further recommendations to enhance competence.

Table 2 – Proposed strategies to improve end of life care education for paramedics

Improving education	Proposed strategy
E-learning	<p>E-learning courses could be implemented via the Electronic Staff Record system currently utilised by the NHS to provide training with topics such as;</p> <ul style="list-style-type: none"> - identifying palliative patients - common symptoms and treatments - communication in end of life care
Observational shifts	<p>Emergency HCPs may benefit from observing district nurses/ community palliative care nurses to improve knowledge in caring for patients at EOL in the community. Ambulance clinicians observing palliative care teams may increase knowledge and aid referrals. Placements in hospice settings, this could be undertaken pre and post registration.</p>
Further education	<p>An increase in the number of paramedics up skilled to scope of practice of advanced paramedic practitioner in prescribing.</p> <p>Updated JRCALC (2019) end of life care guidance to offer advice regarding out of hours support when the patient's care teams are unavailable or for those unknown to palliative care teams.</p>

Conclusion

Considering the ageing population, patients are living longer with multiple comorbidities. The population of the UK is becoming increasingly reliant on already overwhelmed community and palliative care services resulting in calls to 999 and inappropriate admissions to hospital. The current system is not sustainable and does not have the capacity to support future patients. It is evident that the emergency and community sectors both have improvements to make, but to improve the current healthcare system, as advocated by the charities and experts in palliative and end of life care, urgent funding and staff training is required in palliative and end of life care for all HCPs, including paramedic staff.

Without improvement in end of life patient discharge, effective interdisciplinary communication and advanced care planning, end of life care will remain suboptimal. Calls to 999 for end of life care are becoming an increasing occurrence. Ambulance clinicians are prepared to help but need more education in end of life care as well as the support of palliative care and general practitioner colleagues. End of life care needs to be viewed as a priority, to allow parents, grandparents, children, friends, neighbours, and other loved ones to die with dignity, in their preferred place of care.

Key points:

- A lack of availability of palliative care services and palliative care funding is causing an increased reliance on paramedics to attend palliative and end of life patients in the community.
- Patients approaching end of life in the community may have unmanaged distressing symptoms that are unable to be pharmacologically controlled by paramedics.
- Advanced care planning can greatly assist decision making for paramedics when arranged prior to ambulance attendance.
- Palliative and End of life care education within paramedic science degrees in England must be prioritised.

Reflective Questions:

- In clinical practice, what are the most common reasons for a palliative or end of life patient or their family member to call 999?
- What referral options are available in your workplace for a patient who is palliative or approaching end of life?
- What information or decisions should be included in advanced care planning?
If a patient does not have an advanced care plan, how else can you determine the patient's preferences for treatment?

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