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What is known about the information barriers faced by paramedics when attending community palliative care patients? A narrative literature review.

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Abstract (up to 150 words)

Background: Electronic Palliative Care Coordination System (EPaCCS) can provide a solution to support paramedic staff. It is important to understand what needs to be in place to maximise benefits and avoid harms when providing end of life care (EoLC).

Aims: To review the evidence of what is currently known about the challenges of paramedics delivering high quality EoLC, and the current use of EPaCCS.

Methods: Narrative review of the literature, focusing on the views and opinions of ambulance emergency staff referring to palliative and EoLC and/or current use and views of EPaCCS.

Findings: We included five qualitative studies, addressing three themes: lack of access to patient information; proposed electronic solution; content of electronic system.

Conclusion: EPaCCS can support ambulance-based emergency staff with EoLC. Research is required to identify the format information should take on the EPaCCS and the essential content needed to inform their decision making.

Background

End of life care (EoLC) is recognised as an essential element of paramedic practice (Kirk, 2017). The UK has an ageing population with a subsequent rise in adult mortality, in addition healthcare costs increase sharply in the last year of life, largely due to repeated hospital admissions (Luta et al, 2020). When considering unscheduled care, many patients in the last year of life will access care via 999 ambulances, resulting in paramedics being increasingly involved in palliative care situations (Pentaris and Mehmet, 2019). Acknowledging this, the need for healthcare services to provide coordinated, high quality, patient focussed EoLC is ever increasing (AGE UK, 2019). Further research to understand what needs to be in place to maximise benefits and avoid harms for patients at end of life (EoL) is essential (Leniz et al, 2019).

Whilst paramedics recognise the importance of their role in EoLC, there is evidence that they perceive the need for further education, increased confidence and support when attending EoLC situations (Kirk, 2017). A systematic review of the literature around paramedics' views regarding EoLC found that they perceive challenges and had concerns around making EoLC decisions (Pentaris and Mehmet, 2019). Key within this is, the lack of information available to paramedics 'at scene'. Recognising the need for accurate, contemporaneous, patient specific information in the acute setting, many developed countries, including the UK, US and Australia are focussed on implementing an electronic record, as a way of sharing information with healthcare professionals who may need it when providing unscheduled care (Peran et al, 2021). A 2008 Department of Health End of Life Care Strategy found 70% of people, given the right support at the end of life, would prefer to die at home; a concept which is reflected in many other studies (Murphy and Van der Velde, 2022). Furthermore, the Department of Health End of life Care Strategy reported that an Electronic Palliative Care Coordination System (EPaCCS) (then referred to as locality registers) would be introduced as a mechanism of improving coordination of care for patients with palliative conditions (Department of Health, 2008). Furthermore, there is the potential for significant cost saving by implementing EPaCCS

with the Department of Health in England estimating saving of £133,200 in hospital admissions for every 200,000 patients (NHS Improving Quality, 2013). There are, however, mixed views as to whether an NHS wide system or individual and local web-based services would be the optimal solution (Allsop et al, 2021).

There is increasing UK policy supporting patients' ability to access their own healthcare records (Birtwistle et al, 2022); this could influence existing EPaCCS, that currently may not facilitate this (Allsop et al, 2021). There is also a view that all palliative care patients, along with their informal caregivers, should be able to initiate, view and propose changes to their electronic palliative healthcare record (Allsop et al, 2021). However, patient decision making for place of EoLC is complex; a 2015 systematic review identified that patients' decision-making, with respect to preferred place of death, often changes during their disease trajectory (Hoare et al, 2015). This supports the need for dynamic, easily accessible, contemporaneous, patient specific palliative care records (Hoare et al, 2015).

A recent national report (O'Brian, 2022) identified that on average 9% (n = 44,283) of Welsh Ambulance Service Trust (WAST) unscheduled calls were in relation to patients with a palliative condition. The same study found that of the 33,000 deaths in Wales per year, 81% (n = 27,070) were identified as 'likely due to a palliative condition', however, only 22% (5,414 of 27,070) of these patients had a palliative condition documented within their GP healthcare records prior to death (O'Brian et al, 2022). There is evidence that many areas across the UK are implementing local palliative care patient information systems, with one study suggesting that a standalone web-based system may have advantages over an NHS wide system, including facilitating cross-region access to information across various healthcare settings (Allsop et al, 2021). Whichever patient information sharing system is adopted, an issue remains as to the format and content of the platform.

We aimed to review the evidence of what is currently known about the challenges of paramedics in delivering high quality, patient focused EoLC, and the current use and views of EPaCCS.

Method

We undertook a narrative literature review and elicited key themes that emerged from the evidence. A search of the electronic databases MEDLINE (OVID), Embase (OVID), AMED (OVID) and CINAHL (Ebsco) was undertaken, along with a general search of Google Scholar. The search was designed in MEDLINE (OVID) using a combination of controlled vocabulary (MeSH) and text-words describing and combining the concepts of paramedics, ambulance-based emergency staff and palliative or 'terminal' patients (see Table 1). This was then translated into the correct syntax and vocabulary for the other databases and restricted to articles published in English and accepted any type of study design.

We included any peer-reviewed research focusing on the views and opinions of paramedics referring to palliative and EoLC and/or the use of EPaCCS. We excluded papers which did not report any primary data, and/or did not include paramedics and palliative or EoLC. We also excluded any studies which did not include unscheduled health systems comparable to those operated in the UK. Duplicates were removed from the search and two reviewers (EH, NP) independently screened the titles, abstracts and full papers were screened against the inclusion and exclusion criteria. Any conflicts were discussed, and decisions made on whether papers were to be included.

Results

The initial database search, on 2nd November 2023, identified 126 articles. Limiting these to English language excluded 20 articles. The abstracts of the remaining 106 articles were screened independently for relevance and 86 articles were excluded. 20 articles were obtained and screened in full text, from which a further 14 articles were excluded, leaving six studies included in the review (Goodwin et al, 2021; Lord et al, 2012; Murphy and Van der Velde, 2022; Patterson et al, 2019; Simpson et al, 2023; Standing et al, 2020); see Figure 1 for the PRISMA2020 flow chart (Page, 2021).

Four of the included studies were undertaken in England (Goodwin et al, 2021; Simpson et al, 2023; Standing et al, 2020; Patterson et al, 2019) one study undertaken in Ireland (Murphy and Van der Velde, 2022) and another in Australia (Lord et al 2012). All studies were qualitative in their design, either through focus groups interviews/workshops or semi-structured interviews. All studies included paramedics in the interviews (Goodwin et al, 2021; Lord et al 2012; Murphy and Van der Velde, 2022; Patterson et al, 2019; Simpson et al, 2023; Standing et al, 2020; ~~Patterson et al, 2019~~). Three studies also included wider health and social care professionals (Goodwin et al, 2021; Standing et al, 2020; Simpson et al, 2023) and one study also included the views of patients and family members (Standing et al, 2020). The studies looked to understand views on the role of paramedics in EoLC (Murphy and Van der Velde, 2022; Lord et al 2012) and Advance Care Planning (ACP) in last year of life (Goodwin et al, 2021); paramedics' informational needs in EoLC, access to EPaCCS (Patterson et al, 2019) and information sharing (Standing et al, 2020); and views on how to improve responses for patients dying at home (Simpson et al, 2023). While not all studies aimed directly to explore EPaCCS, all studies provided information relating to EPaCCS. Table 2 provides an overview of the included studies including the location, study design, participants, key themes and summary of the key findings reported by the authors.

The evidence covered three main themes of interest to our review: lack of access to patient information; proposed electronic solution and; content of such electronic system.

Lack of access to patient information

Practitioners are reliant on the information that is available in the immediate patient environment, however, collaboration and increased communication is needed to be able to meet patients' needs in EoLC (Murphy and Van der Velde, 2022). All of the included studies identified a lack of access to patient information as a challenge to paramedics when assessing palliative care patients at home (Goodwin et al, 2021; Murphy and Van der Velde, 2022; Simpson et al, 2023; Standing et al, 2020; Patterson et al, 2019). Relevant patient information that is currently available can often be varied in detail, consistency and accuracy (Patterson et al, 2019) frequently leading to unwanted and potentially avoidable hospital admissions (Goodwin et al, 2021; Simpson et al, 2023). Standing et al (2020) and Lord et al (2012) both report that without access to up-to-date information, some paramedics felt they had no choice but to transfer the patient to hospital.

Proposed electronic solution

Paramedics perceive that access to EPaCCS have the potential to improve the care provided to patients at end of life and reduce unwanted hospital admissions (Goodwin et al, 2021; Patterson et al, 2019). There is also the potential that EPaCCS could significantly improve the ability of out-of-hours health care professionals to provide care in line with patients' wishes (Goodwin et al, 2021; Patterson et al, 2019). The studies also identified potential practical and technical challenges to implementing EPaCCS solutions including digital infrastructure and professional uptake (Standing et al, 2020; Patterson et al, 2019). There are also some concerns as to who would update and input the information onto the system leading to potential time burden and duplication of information if undertaken by non-paramedics (Standing et al, 2020).

Content of electronic system

The studies reported a lack of key information for EPaCCS. Standing et al (2020) identified a need for concise information as irrelevant information can make the process burdensome and ineffective.

The majority of content is described as ACP, including preferred place of care and preferred place of death or do not attempt cardiopulmonary resuscitation (DNACPR) documentation (Goodwin et al, 2021; Standing et al, 2020; Patterson et al, 2019). One study reported other potentially beneficial content such as pertinent medical history, clinical observations or parameters and contact details for health care professionals providing community-based care (Patterson et al, 2019).

Discussion

This literature review has captured the information needs and content of electronic solutions to support EoLC for patients by paramedics. We included five qualitative studies which highlighted EPaCCS would provide a positive approach and solution to more holistic and patient centred EoLC by paramedics. However, our included studies did not identify specific EPaCCS currently in use by paramedics, nor did they provide insights into the format EPaCCS should take to understand the essential information needed for use in practice.

Our review identified a perceived need for a solution to facilitate paramedics providing EoLC, supporting the ambition of the UK's Health EoLC strategy for EPaCCS as a mechanism to improve the coordination of care for patients with palliative conditions (Department of Health, 2008).

Paramedics report being reliant on, and limited to, the information that is available, which can be out of date and inaccurate resulting in potentially avoidable hospital admissions (Kirk, 2017; Pentaris and Mehmet, 2019). There has been no national standardised approach to the implementation of EPaCCS (Allsop et al, 2021), however implementation of an NHS wide solution is viewed as being challenging, both financially and logistically (Patterson et al, 2019). The wider evidence indicates that the implementation of EPaCCS, or other digital healthcare records, has the potential to significantly improve patient care, yet there continues to be a paucity of evidence relating to the format and information content of the electronic palliative care record. The studies from our review have provided some evidence to address the current lack of understanding of the views and needs of paramedics (Allsop et al, 2021). However, the included studies did not identify the format EPaCCS should or could take.

Birtwistle et al (2022) undertook a national survey of EoLC commissioners to map EPaCCS in England. Their survey identified patients currently with an EPaCCS record, fewer than a 1/3 had key information relating to their preferences of care documented (Birtwistle et al, 2022). A scoping review of the role of paramedics when providing palliative care identified an EPaCCS program in use in London allowing patients to access and suggest changes to their own record (Peran et al, 2021). Peran *et al* (2021) also identified a system allowing patients to register themselves for an electronic palliative care record. Our review identified key content which would be of use to paramedics included Advance Care Plans and/or DNACPR documentation (Goodwin et al, 2021; Standing et al, 2020; Patterson et al, 2019) as well as other key patient information (e.g., medical history, clinical observations etc; Patterson et al, 2019). Allsop *et al* (2021) and Petrova *et al* (2018) suggest, as a priority, that all palliative care patients, along with their informal ~~care-givers~~caregivers, should be able to initiate, view and propose changes to their own electronic palliative healthcare record. However, the studies included in our current review did identify potential barriers to the implementation of EPaCCS, including technical infrastructure, ‘buy-in’ from healthcare professionals and establishing who would be responsible for updating the patient information.

Strengths and limitations

Whilst not a systematic review *per se*, we have followed a systematic approach to identify the existing evidence of the challenges and experiences paramedics face in providing EoLC and their perceptions lack of use of EPaCCS, reflecting wider reviews of EPaCCS in existing health systems (e.g., Allsop et al, 2021; Leniz et al, 2020). This review has identified, albeit limited, direct understanding of the views of paramedics on the use of EPaCCS, expressing positive views of the content needed and their use, in practice, addressing some of the gaps in the wider evidence to understand the needs directly involved in the use of electronic solutions for those directly impacted by them (Allsop et al, 2021). Furthermore, the studies that have been reported are largely qualitative in nature; to the best of our knowledge, we have not identified any higher quality studies,

such as randomised controlled trials of the implementation and evaluation of the use of EPaCCS by paramedics.

Conclusion

EPaCCS are recognised and welcomed by paramedics as an approach and solution to provide holistic patient centred EoLC. Although it is important to acknowledge the different information needs of the various healthcare roles, the EPaCCS should be undertaken with paramedics and other healthcare professionals in the community in mind, to ensure that it is completed to a standard where it is clinically useful and can inform decision making (Simpson et al, 2023; Standing et al, 2020). However, given there is currently a lack of evidence as to what format this should take, it is crucial to identify the content or information that would be considered useful by paramedics and other relevant health care professionals, to aid their ability to care for palliative patients in the community and inform their decision making.

Keywords

Palliative care, end of life care, paramedic, unscheduled care, electronic records

Key Points

- Many patients in the last year of life will access unscheduled care via 999 ambulances, resulting in paramedics increasingly providing palliative and end of life care (EoLC).
- Electronic Palliative Care Coordination System (EPaCCS) may provide a solution to the current lack of easily accessible, accurate patient information needed to support paramedics' clinical decision making when attending EoLC patients.
- There is limited evidence of understanding the views and needs of paramedics, many of whom would be directly affected by the implementation of an EPaCCS.
- We undertook a narrative literature review to understand what is currently known about the challenges of paramedics delivering high quality, patient focused EoLC, and the current use of EPaCCS.
- We identified five qualitative studies evaluating the views of paramedics as well as other health and social care professionals, patients and caregivers; the evidence identified a lack of access to patient information were supportive of electronic solutions to support access to patient information and consideration to the type of content the systems would need.
- Further research is needed to identify the content and format needed for EPaCCS to be used by ambulance staff.

Reflective questions (3)

- Think about the last palliative care patient that you provided emergency care to, do you feel you had sufficient information readily available? If not why not?
- Do you think having access to an electronic palliative care system would be helpful for you?
- What are the challenges that might be faced with the integration of such a system?

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Fig 1: Search criteria

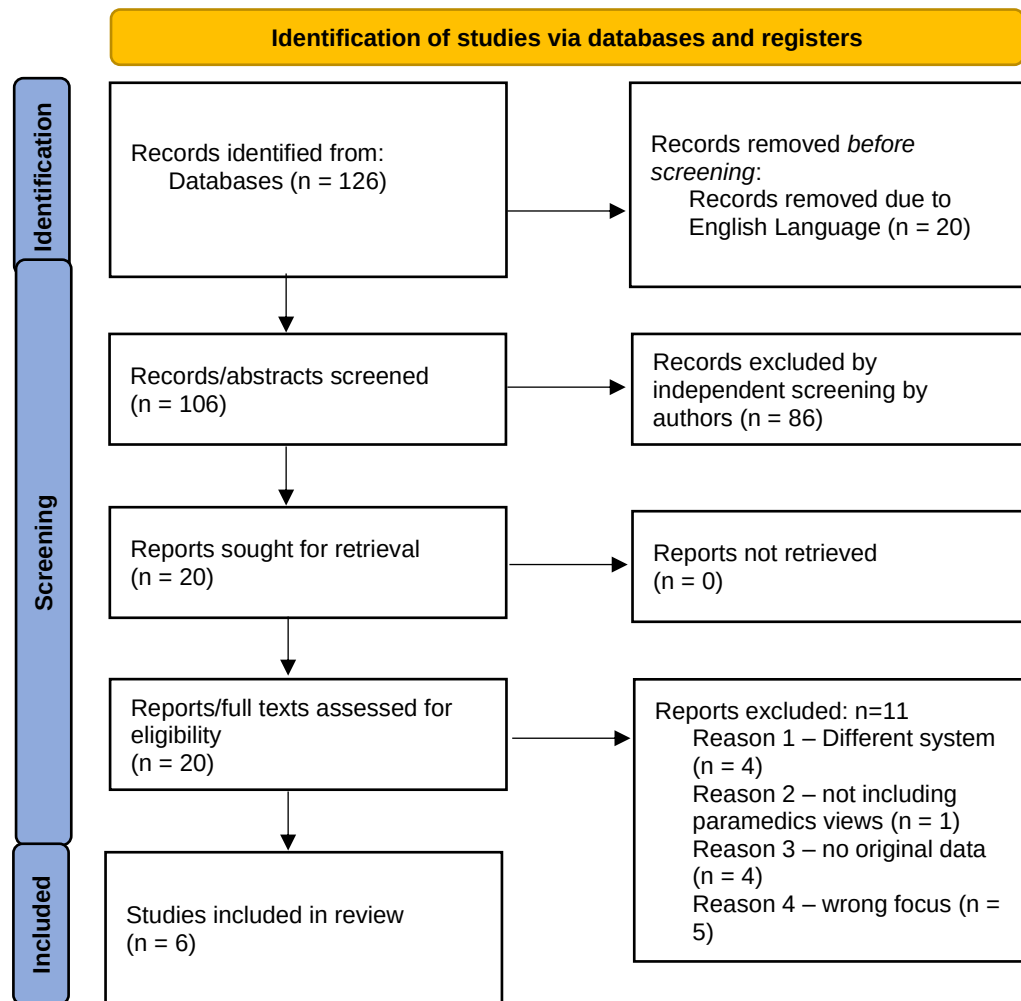


Figure 2: PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers (Page, 2021)

Table 1. Ovid MEDLINE(R) ALL <1946 to October 31, 2023>

1	exp Paramedics/	96
2	exp Emergency Medical Technicians/	6048
3	(ambulance adj2 (crew* or personnel)).tw,kf.	762
4	paramedic*.tw,kf.	10183
5	1 or 2 or 3 or 4	15124
6	Exp Palliative Care/	63588
7	Terminal care/	32007
8	Terminally ill/	6819
9	((palliative or terminal or end of life) adj2 patient*).tw,kf.	12030
10	6 or 7 or 8 or 9	95733
11	5 and 10	104
12	Limit 11 to English language	84