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Staff stakeholder views on the role of UK paramedics in advance care planning for patients in their last year of life

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Background: Early advance care planningh as clear benefits for patients approaching the end of their life, yet many of those attended by UK paramedics do not have this planning in place.
Aims: To explore staff stakeholder views on the role of UK paramedics in advance care planning, including the use of the Gold Standards Framework Proactive Identification Guidance for screening and referral of patients.
Methods: In-depth semi-structured telephone interviews with paramedics, general practitioners, Emergency Department and community doctors and nurses in the South West of England.
Results: Seventeen staff stakeholders participated. Four main themes were identified: a lack of advance care planning; variation across health conditions; a lack of joined-up care; poor-quality end of life conversations. Paramedic use of the Gold Standards Framework Proactive Identification Guidance to screen and refer patients for advance care planning was seen as feasible and acceptable, with perceived benefitssuch as identifying patients not accessing primary care, and the potential to reduce avoidable hospital admissions.
Conclusions: UK paramedics are well-placed toscreen and refer patients for advance care planning. Further research is needed to explore how this type of intervention might be developed to fit into a community-centred approach aimed at improving advance care planning.

Keywords: Palliative care, End of life, Paramedics, Emergency medical technicians, Advance care planning, Terminal care

Background

In the UK, the General Medical Council (GMC) defines patients as 'approaching the end of life' (EOL) when they are likely to die within the next 12 months.[1] The quality of end of life care (EOLC) in the UK is variable,[2, 3] and identifying patients in the EOL phase is challenging, particularly in those people with diagnoses other than cancer.[2, 4]

It is important that patients approaching the EOL are identified early. This increases the effectiveness of care delivery[5]: giving time for comprehensive community support to be organized, ensuring that patient preferences are implemented,[6] providing psychosocial support and guiding patients' expectations.[7, 8] Once patients nearing the EOL are identified, advance care planning (ACP) is a process of formal decision-making that aims to help them establish decisions about future care.[9] This can be especially useful in instances where patients may lose capacity to make these decisions later on.[9] Advance planning assists in identifying and respecting patient's wishes regarding their EOLC, improving care and diminishing stress, anxiety and depression in surviving relatives.[10, 11]

Early recognition of decline can indicate likely needs, better planning, and fewer avoidable hospital admissions.[12, 13] This is important, as UK research indicates that around 52% of hospital admissions involving EOLC could be safely avoided.[14]

Despite the clear benefits of early ACP, a growing body of literature from the United States suggests that many patients attending the emergency

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department have unmet palliative care needs.[15–18] Similar findings are seen in the UK, where the current use of ACP is variable.[12] In a recent national survey of UK paramedics, most participants (80%) reported attending at least one patient a month they believed to be in their last year of their life, but who were not formally recognized as such by the health care system.[19]

Although many patients accessing UK ambulance services are in the last year of their lives,[19] the role of ambulance services in recognizing patients approaching the EOL is overlooked. As emergency care staff who meet patients in moments of crisis, paramedics may be uniquely positioned to objectively identify individuals' unmet needs.[20] The National Institute for Health and Care Excellence (NICE) provide two examples of available tools for assisting clinicians with timely identification of people approaching the EOL.[21] These include the Supportive and Palliative Care Indicators Tool (SPICT) from NHS Scotland[22] and the Gold Standards Framework Proactive Identification Guidance (GSF PIG).[23] The GSF PIG is an established and evidence-based screening tool to identify patients nearing the EOL, with online training packages accessible to varying healthcare settings.[23] The GSF PIG was chosen for this research as it is identified as an available assessment tool in the local ambulance service guidelines.[24] However, it is not currently integrated into the patient care record, and so there remains no formal process for identifying and referring patients thought to be approaching the EOL. The tool is made up of 3 steps for the paramedic: asking themselves if they would be surprised if the patient they are seeing dies in the next year, months, weeks, or days; checking the patient against a list of general indicators of decline; checking the patient against specific clinical indicators.[23] Formal use of this tool for screening in the acute setting could be the first step towards implementing a more efficient way of addressing patient needs, thereby improving outcomes for this population.[25]

The aims of this study were to explore NHS staff stakeholder views on:

- Current management of end of life care within the NHS.
- The concept of paramedics using the GSF PIG to identify patients in their last year of life and refer to primary care for advance care planning where appropriate.

Methods

Approval for this study was obtained from the Health Research Authority (19/HRA/5061) and the University of the West of England Faculty of Health and Applied Sciences Research Ethics Committee (HAS.19.08.015).

An exploratory qualitative approach[26] was used, comprising semi-structured telephone interviews with paramedics, GPs, Emergency Department staff, and community nurses. Participants were eligible to take part if they were working in one of these roles for either the South Western Ambulance Service NHS Foundation Trust (SWASFT), Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group (BNSSG CCG) or the University Hospitals Bristol NHS Foundation Trust (UH Bristol). Eligibility criteria also included having had experience, involvement or interest in EOLC.

A purposive sampling technique was adopted to gain rich and robust information about the specific topic of interest, and increase the transferability of the findings.[27] The study was promoted through adverts circulated via the Research and Development teams at SWASFT, BNSSG CCG and UH Bristol. Participants were invited to contact the study team to take part. Potential participants received a study information sheet, privacy notice and consent form from the researcher via email and were asked to return the signed consent form if they were willing to participate. Verbal confirmation of consent was audio-recorded at the start of the interview.

Data were collected between December 2019 and February 2020. An interview schedule (Appendix 1) was developed by the study team, including two paramedics, two senior academics in Emergency Care, the research manager and Macmillan project lead from SWASFT, an academic GP, a Patient and Public Involvement advisor, and a member of the National Institute for Health Research (NIHR) Research Design Service. Questions aimed to explore participants' views on a paramedic screening and referral intervention (using the GSF PIG), aimed at improving ACP in patients in the last year of life. Telephone interviews lasted between 20–45 min, and were conducted by one of two members of the study team (AP, LG) at a time convenient to the participant. Audio-recordings of the interviews were made using Skype for Business. Recordings were professionally transcribed verbatim and anonymised.

Data were analysed thematically using a well-established iterative process of data reduction, constant comparison, organization and understanding.[28] Transcripts were imported into the data management software NVivo 10, where two authors (AP, LG) read the transcripts several times, and then independently coded selections of text to represent instances of a concept.[29] Codes were reviewed in terms of their relationship to other codes and combined to create more developed themes.[29] From this analysis,

distinctions could be made between the different levels of themes (e.g. main overarching themes and subthemes within them).

Results

Participants ($n = 17$) included eight paramedics, four GPs, two Emergency Department doctors, two Emergency Department nurses, and one community nurse. 67% of participants were female.

The findings are presented in two sections: current UK management of EOLC, and views on a paramedic screening and referral process for ACP using the GSF PIG.

Current management of EOLC in the UK

When discussing the current management of EOLC in the UK, four main themes emerged: lack of advance care planning; variation in EOLC across health conditions; lack of joined-up care; poor quality EOL conversations.

Lack of advance care planning

Stakeholders from all clinician groups spoke about a lack of advance care planning, and many recounted experiences of meeting patients in emergency situations, who were obviously approaching EOL, but who had no written plan in place.

> Within our own surgery … we've recently done an audit. A lot of patients have died and they didn't have documentation of advance care planning or Do Not Resuscitate forms in place, and yet, probably we knew that they were going to [die]. GP002

When asked why advance care plans were not completed for patients, stakeholders suggested a variety of contributing factors. Patients and family members were perceived to act as potential barriers to ACP, and stakeholders suggested that family members often did not want to accept an EOL status, or were worried that ACP would mean a cessation in treatment.

> This gentleman was 103 and so from the offset it was very, very apparent to me as the doctor that this gentleman was approaching end of life … [but] when I had that conversation with the family … introducing the idea that he was really incredibly unwell and was probably not going to survive … they were really shocked and - it sounds dramatic but they were horrified that I was suggesting that he shouldn't go on a ventilator. I quite often find that the difficulties are when the family … are not onboard with the fact that that patient is in their end of life phase. EDD002

Stakeholders also suggested that health care professionals could act as barriers to completing advance care plans, where no single clinician wanted to take responsibility for initiating this process. Participants discussed ambiguity around the responsibility to prepare plans.

> Whose job is it? Interesting I think, and for me there's a little bit we can learn about ownership. If that conversation has been had with you, we should be helping people understand that responsibility.CN001

Workload issues were especially apparent when stakeholders spoke about the role of the GP in completing advance care plans. GPs were seen to have an increasing workload, and while many participants suggested that it should be the responsibility of the GP to complete the ACP, there was an acknowledgement of the limited time available for GPs to do this.

> I think the pressure of time within general practice is, you know, advance care planning takes time. It involves you setting aside enough time to have an adequate patient centred, or relative centred, relative involved conversation. GP004

Stakeholders discussed the implications of attending to patients approaching EOL without an ACP: a lack of clear planning was seen to result in an escalation of care, often resulting in avoidable hospital admissions for patients.

> I've quite recently taken someone into resus who was at their end of life but we had to take them because there was no care plan there at all for them. P007

Participants also emphasized the difficulty of providing appropriate and personalized care to these patients, who were often in crisis and sometimes during out-of-hours.

> Out of hours and in hours is probably the biggest fundamental difference in our job, like, whether you can speak to the patient's GP surgery or not means you either know everything about them, or you know nothing. P001

Variation in quality of EOLC depending on setting/condition

Stakeholders noted variation in EOLC and ACP, depending on the care setting and patient's health condition. For example, participants gave accountsof good practice from nursing and care homes.

> I've got homes now who are saying to me … that they will not take [residents] without Treatment Escalation [Plans]. And I love that, because I can go back to the GPs, I can go back to the

> community nurses, and say actually you need to have that conversation. CN001

Patients with cancer were perceived to receive better EOLC than patients with other conditions, such as COPD and heart failure. Participants suggested that it was rare for cancer patients to present without a written plan, whilst for others this was much more common.

> We go to COPD patients quite a lot, and I think they're probably one of the strongest groups that … when things do progress that they're not recognised as 'end of life.' Whereas if you've got your patient that's been diagnosed with terminal cancer they're recognised earlier on. P001

Lack of joined up care

Participants spoke about issues with the EOLC structure, and suggested there was often a lack of collaboration between healthcare professionals and primary/secondary care.

> That's still the sticky wicket for me, that actually we're not all on the same page all the time, because of the pressures that we're under. CN001

Paramedic participants expressed frustration at their inability to view care plans on their electronic systems, instead having to rely on the patient or family members to offer these documents, where they existed.

> I don't think paramedics out on the road perhaps get as much information and help as they should really … turning up to a patient and perhaps not knowing what their views are and if an advance care plan is in place. P011

There was also a perception amongst stakeholders that paramedics were not supported in making decisions regarding patients approaching EOL, and that community support for EOLC was limited.

Poor quality EOL conversations

Stakeholders spoke about a societal 'issue' relating to EOL conversations and suggested a widespread reluctance amongst the general public to discuss the concept of death, which could complicate discussions regarding ACP.

> I think that as a society we just don't want to talk about dying and death. EDD002

However, other participants suggested that some healthcare professionals also avoided such conversations, and many felt that NHS staff should take more responsibility and be more proactive in initiating conversations about death and EOL.

> People don't like talking about death do they, even in our job … it's a really taboo subject which is crazy, because it's the only thing in life you can be sure of. P007

Views on a paramedic screening and referral tool

The majority of participants had not heard of the GSF PIG, and only one had ever used it in practice. When discussing the possibility of paramedics using this tool to identify and refer patients for ACP, three over-arching themes emerged: acceptability and feasibility; potential positive outcomes; potential challenges.

Acceptability and feasibility

All stakeholders were positive about the general idea of paramedics using the GSF PIG to identify and refer patients for ACP. Participants felt that paramedics would be able to use the tool appropriately when attending patients and were well-placed to do so.

> Paramedics would be suited to carry out this kind of screening. They already make a lot of referrals … they're the ones that are going out there into people's homes. EDN001

However, participants suggested a number of challenges to the feasibility and acceptability of paramedics screening and referring patients for ACP. For example, a number of participants questioned the likely number of new ACP referrals this intervention would generate, and suggested that this would need to be closely monitored. Others felt that incentives may need to be introduced in order for GPs to manage the resulting demand.

> I suppose you'd have to do some kind of work in terms of feasibility of what kind of numbers of referrals we're looking at. EDD002

> If you increase the work stream for the GPs, the GPs are quite likely to ask for compensation for that. GP003

Others suggested the possibility of creating a specialist EOL team, who could then act on referrals generated by this process.

> You could have a team that responded to any end of life calls as they come in … the referral can then go onto the end of life team, who could then go out that day and do that advance care plan at the patient's home. P007

There was also concern regarding the need for additional training for paramedics to appropriately use the tool and obtain consent to electronically refer to a GP for ACP. Some stakeholders felt that the sensitive nature of these conversations might

require the training of specialist paramedics for this role.

Potential positive outcomes

All participants suggested that any intervention aiming to increase the number of advance care plans would be positive, both for patient care, and for staff caring for them. Better EOLC for patients was discussed in terms of managing patient expectations, providing appropriate medication/escalation of care, and supporting patients to die in their place of choice.

> I think it'll be a good thing because in the long run it will allow people to have a more dignified death in their place of choice, as opposed to being admitted to hospital unnecessarily. P007

Specific benefits were anticipated for those patients who do not regularly access healthcare services, such as visiting their GP, and who might otherwise slip 'under the radar'

> We might be better at picking up the ones that maybe don't attend GP, who probably are in their last year of life but aren't so acutely unwell that they're needing home visits, but then aren't well enough to get to the GP's surgery. P002

Although paramedics acknowledged that this screening and referral process would result in a longer 'on-scene' time, they suggested that this would be a good investment of time for the ambulance service, and that increasing the number of patients with an advance care plan in place would consequently reduce ambulance calls, offer clear pathways for referral and make subsequent care easier. Similar benefits were also proposed for GP services, where a paramedic screening and referral system was proposed to reduce workload in the long run by helping GPs identify appropriate patients.

> In the early days, I believe, perhaps on scene times will be slightly longer. However, it will be of benefit to the whole health care system in general, because we're not taking people in [to hospital] as regularly. P005

Stakeholders also felt that an increase in the number of patients with an advance care plan should reduce the number of avoidable attendances to the emergency department, and also reduce the number of EOL conversations being are initiated in this environment.

There was also the perception amongst participants that increases in ACP could enable family members and patients to prepare for crisis situations, providing them with a clear pathway of care, and managing expectations.

Potential negative outcomes

A number of challenges were suggested to the proposed paramedic screening and referral process, mainly centred around GP capacity to complete ACP for those referred. Stakeholders expressed concerns that current workload is already problematic for GPs, and suggested that paramedic referrals might not be acted upon.

> I would be concerned about the increased workload for the GP, because we're under a lot of pressure already, and unless I can see a good benefit from identifying more patients who could die within a year, I would be reluctant to take on additional work. GP003

Concerns were also expressed by participants regarding the increased workload for paramedics responsible for completing screening and making referrals. Some stakeholders felt that an emergency situation might be an inappropriate time to initiate a discussion regarding EOLC, depending on the time-critical or sensitive nature of the situation.

> In that acute situation where that person has phoned an ambulance, [it] usually means that they're either pretty unwell or they think they are, and is that necessarily the right time to be introducing that [conversation]? EDD002

There were also concerns regarding how patients or family members might react to a referral for EOLC being initiated by a paramedic, and that the patient may not have capacity to engage in such conversations during an emergency.

Some participants also questioned the quality and validity of the tool itself, with some paramedics expressing concern that they might identify someone as being EOL incorrectly. Training in how to use the tool was therefore deemed essential.

> It seems quite a straightforward tool, but I would want to be rest assured that everybody knows how to use it. P010

Discussion

This study investigated stakeholders' views on the role of paramedics in ACP for patients in the last year of life. By engaging a variety of stakeholders, insights were gained regarding the potential impact of this tool on the EOLC pathway.

In keeping with previous studies, our findings show that current EOLC in the UK is variable.[2,3] While patients with conditions such as cancer tend to have good access to information about their illness, and clearly structured models of care,[30,31] patients with other life-limiting conditions such as chronic obstructive pulmonary disease (COPD)and heart failure are

less likely to be given the opportunity to discuss their EOLC, including their preferred place of death.[32–35]

While some examples of good EOLC practice were given, many participants suggested a general lack of collaboration for EOLC in the UK. Previous studies also report poor channels of communication across the primary/secondary care interface, including incompatible electronic record systems,[3] and uncertainty regarding what services are available to physicians.[2] Out of hours care episodes were seen as particularly problematic by our participants. This is mirrored in the literature, where hospital admission at the very end of life is perceived to be linked to the organization of out of hours services. These may be more aligned to the management of acute situations, increasing the likelihood of a patient dying in hospital irrespective of their stated preference.[33, 36]

Poor quality EOL conversations were a main theme in this study. Early and realistic discussions regarding treatment outcomes and possible cessation are vital for successful ACP, and to ensure patient preferences are met.[3,37] Delayed discussions are attributed to varying factors including prognostic uncertainty and a lack of clear indicators of disease progression,[3] professionals' lack of confidence to initiate EOL conversations,[2,3] reluctance from family members, and societal attitudes towards death.[2]

The use of the GSF PIG as a potential EOL screening and referral tool was perceived positively by stakeholders in our study. Interestingly the GSF PIG already features in local ambulance service guidelines,[24] but only two of the participants were aware of the tool. Aligning with previous literature regarding heart failure patients and haematology cancer patients, stakeholders emphasized current difficulties in identifying appropriate patients,[2,38] and suggested that a more formal use of such a tool by paramedics could facilitate ACP for patients in their last year of life.[3] Previous literature suggests that identification of EOLC needs by emergency clinicians may be especially important for vulnerable populations without access to high-quality outpatient care.[20,39] Participants in our own study felt that paramedics would be especially well-placed to identify patients using this tool following appropriate training. This finding is echoed in a recent UK national survey of paramedics exploring the identification of patients with EOLC needs,[19] where the majority of participants reported that they could (94%) and should (97%) perform this role. However these findings, along with our own, may be subject to response bias, as it is possible that these studies are more likely to recruit paramedics who are interested in improving EOLC.

The study findings indicate that UK paramedics could screen, identify and refer patients to primary care where ACP is indicated. If primary care services were able to act on these referrals, then ACP would increase in these patients who are more challenging to identify as approaching EOL. A more formalized approach to paramedic screening and referral of patients in their last year of life could increase ACP for those who are seemingly more challenging to identify and more likely to 'fall through the net'. Stakeholders felt that increased ACP would benefit all services and departments involved in the EOLC pathway. Although the additional time required to identify patients (by paramedics) and complete advance care plans (by GPs) was acknowledged, participants were confident that this would be offset by a reduction in ambulance calls and avoidable hospital admissions.[2] An increase in care planning was also expected to support patients' preferences and enhance patient and carer experience, as supported in previous literature.[10,11]

Study limitations

This study focused on the views of NHS staff stakeholders, and as such the views of patients and family members are not represented. Funding is being sought for future work to include the perspective of these additional stakeholders. All participants were from a single geographical region of England (the South West), and our findings should not be generalized to other regions of the UK, or to other countries. Participants were volunteers and our sample may not be representative of all professional groups or individuals who contribute to EOLC. The experience and opinions of those taking part is subject to recall and other biases, and will not reflect thefull range of experience and views of other healthcare professionals.

Conclusion

Optimal end of life care requires responsive multidisciplinary teams to collaborate closely across primary, community, hospital and hospice settings to initiate and deliver ACP.[40] This study builds on previous literature and adds new knowledge by bringing together the views of stakeholders from all stages of the EOLC pathway. Our findings will help to inform future interventions to increase the identification and referral of patients for ACP, and suggests that one way of initiating this process may be for paramedics to use a more formalized approach to screening and referring patients in their last year of life, and refer them to primary care services for ACP. Our findings indicate that a paramedic screening and referral tool would be a welcome intervention to paramedic practice. The NHS England Five Year Forward View[41] recommends that out-of-hospital care become a much larger part of what the NHS does, and advocates

the design of innovative models or care with enablement of the NHS workforce to deliver them.[41] The results of this study could inform the design of further research to explore how a paramedic-based intervention to identify patients approaching the end of life might be developed to fit into a more community-centred approach that improves and enhanced ACP in end of life care.

Disclosure Statement

In accordance with Taylor & Francis policy and our ethical obligations as researchers, the authors report no potential competing interests.

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Appendix

Interview Guide

Title of study: What are stakeholders' views on a paramedic screening and referral intervention aimed at improving advanced care planning in patients in the last year of life?

RE-CHECK CONSENT

Interview questions:

1. Please can you describe your job role and how you interact with End of Life patients in your role? (not just in the last days of life)
2. What are your views on the current management of patients who are in the last year of their lives? From your experience, are there any particular challenges around managing these patients and putting Advanced Care Planning in place?

We will be using the Gold Standards Framework Proactive Identification Guidance as the intervention for the study. Have you had any experience of using the Gold Standards Proactive Identification Guidance before? As you know … ../If not I will give you a brief description of what it is:

It is a validated intervention to assist in recognizing patients in the last year of life. It is made up of 3 steps. The first step involves 1 question: would you be surprised if the patient you are seeing dies in the next year, months, weeks, days? If the answer is no then you have recognised someone who could be in the last year of life. If you are unsure then you move to step 2. This step gives a list of general indicators of decline, and if your patient has any of these indicators, you have again recognised someone who could potentially be in the last year of life. If you are unsure of the answer at step 2, you move to step 3. This includes specific clinical indicators broken down into diseases/conditions, for example 3 admissions for exacerbation of COPD would be an indicator that the patient is in the last year of life. Does that make sense?

(3) Ultimately the aim is for paramedics to use this tool and recognize more patients in the last year of life, refer them to the GP, so that an Advanced Care Plan can be put in place. What are your thoughts on this?
(4) What impact do you think this would have on patients?
(5) How do you think it might impact on families and carers?
(6) How might it impact on GP surgeries?
(7) How might it impact on ambulance services?
(8) How might it impact on Emergency Departments?
(9) Do you think a paramedic screening and referral process would be feasible to implement? And how would it work in practice?
(10) If an intervention like this was to be implemented, what do you think appropriate outcome measures would be? E.g die where the patient wishes, increase ACPs, reduce anxiety
(11) Do you have any suggestions on how we might collect data for these outcome measures?
(12) Are there particular groups or types of patients that you think an intervention like this might be best suited to? E.g. COPD
(13) Are there particular situations where you think this intervention might be most applicable? E.g. not been to the GP for a long time

Thank you for your time. The interview is now complete.