Ambulance staff and end-of-life hospital admissions: A qualitative interview study

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Abstract

Background: Hospital admissions for end-of-life patients, particularly those who die shortly after being admitted, are recognised to be an international policy problem. How patients come to be transferred to hospital for care, and the central role of decisions made by ambulance staff in facilitating transfer, are under-explored.

Aim: To understand the role of ambulance staff in the admission to hospital of patients close to the end of life.

Design: Qualitative interviews, using particular patient cases as a basis for discussion, analysed thematically.

Participants/setting: Ambulance staff (n = 6) and other healthcare staff (total staff n = 30), involved in the transfer of patients (the case-patients) aged more than 65 years to a large English hospital who died within 3 days of admission with either cancer, chronic obstructive pulmonary disease or dementia.

Results: Ambulance interviewees were broadly positive about enabling people to die at home, provided they could be sure that they would not benefit from treatment available in hospital. Barriers for non-conveyance included difficulties arranging care particularly out-of-hours, limited available patient information and service emphasis on emergency care.

Conclusion: Ambulance interviewees fulfilled an important role in the admission of end-of-life patients to hospital, frequently having to decide whether to leave a patient at home or to instigate transfer to hospital. Their difficulty in facilitating non-hospital care at the end of life challenges the negative view of near end-of-life hospital admissions as failures. Hospital provision was sought for dying patients in need of care which was inaccessible in the community.

Keywords

Hospitals, patient admissions, ambulances, palliative care, allied health personnel, interviews

What is already known about the topic?

- Hospital admissions immediately prior to the end of life are considered negatively in many policy documents, with home assumed to be a better place to die.
- Ambulance staff struggle with limited patient information and the need to make time-critical decisions when caring for end-of-life patients.
- Little is known about why end-of-life ambulance transfers to hospital occur.

What this paper adds?

- Ambulance staff positively viewed home deaths, but were limited in facilitating them.
- Barriers for non-conveyance to hospital included difficulties arranging out-of-hours care, limited available patient information and service emphasis on emergency care.

Implications for practice, theory or policy

- Accessible hospital care is important and highly relevant in end-of-life provision for some patients.
- Sociological focus on personnel actions and the social structure in which they conducted these provides useful lens to consider end-of-life admissions.

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Introduction

End-of-life hospital admissions, particularly for those who die shortly after admission, are viewed as failures in many international healthcare systems. They are typically referred to as ‘preventable’, ‘avoidable’ and ‘undesirable’ because they contravene the prevalent approach of managed and planned end-of-life care and seem to negate ideas about patient choice over place of death. While in practice hospital admissions for such patients have been demonstrated to be sometimes desirable and necessary, and the presumption that most patients want to die at home has been challenged, apparently inappropriate hospital admissions remain a persistent policy concern. In the United Kingdom, for instance, the proportion of deaths in hospital is used as a measure of end-of-life care quality, with fewer admissions being a mark of success.

In the United Kingdom, ambulance services can have a critical role in these admissions, especially in decisions about whether to transfer dying patients to hospital. End-of-life admissions are known to be in part a consequence of barriers faced by ambulance staff in providing care to patients they attend. It is recognised in policy that ambulance staff work with patients close to the end of life is made difficult by limited availability of information on patient history and care preferences and the need to make time-critical decisions. Research with ambulance staff has shown that these decisions require sensitive balancing of patient preferences with the views of family and carers and relevant policies. Weighing up the risks and benefits of hospital for these patients is challenging, particularly within a typical context of urgent patient care needs and limited staff education on end-of-life care practices.

We investigated how these challenges affect staff and in practice how they lead to admissions. We explore how and why patients at the end-of-life are transferred to hospital through the use of semi-structured interviews with ambulance staff who were involved in the admission of patients close to the end of life to a large English hospital.

Methods

The study and case-patients

The research presented was part of a retrospective study about end-of-life hospital admissions, which used what Yin has called an embedded, multiple unit of analysis, single-case study approach. Interviews were conducted with healthcare staff, including ambulance staff (n = 30) and next-of-kin (n = 3) involved in hospital admissions for patients close to the end of life. Interviews were clustered together to form cases which described a patient’s admission to hospital, with nine admissions in total across the dataset. These were the basis for discussion in the interview.

Ambulance interviewees included paramedics (senior ambulance staff, n = 2), student paramedics (n = 3) and an emergency care assistant (junior ambulance staff, n = 1). This article also draws on interviews with other healthcare staff from hospital and community settings included in the dataset.

The deceased patients who were the focus of the interview clusters (‘case-patients’) were purposively selected for inclusion if they had died within 3 days of admission to hospital, were aged more than 65 years and had either cancer, chronic obstructive pulmonary disease (COPD) or dementia recorded on their medical certificate of cause of death. All case-patients died in a large English hospital that serves a geographically diverse area with varying levels of economic deprivation. Four of the nine cases included in the total dataset involved interviews with ambulance staff. Of these cases, three case-patients were female and all were aged more than 70 years, with two aged between 80 and 89 years and one aged more than 90 years. Half of the case-patients lived at home cared for by family members, and half lived in residential homes. Many of the case-patients had been previously admitted to hospital in the last year for a range of symptoms including infections, fractures and symptoms directly related to their dementia, COPD or cancer diagnosis. Table 1 outlines further characteristics of these case-patients.

Interviews

Ambulance staff were identified from ambulance vehicle records in the patients’ hospital notes, which were matched to staff details with the help of a research paramedic in the local ambulance service. The majority of ambulance staff interviews were conducted in person (n = 5) at either the interviewees’ place of work or at the hospital, with one conducted over the telephone; all lasted approximately 30 min and were audio-recorded. The interviews were semi-structured and explored the interviewees’ involvement in the admission of a case-patient in particular and, prompted by this discussion, their views on providing care to patients close to the end of life in general.

All study interviews were conducted in 2012–2013 by Hoare and occurred within a month of the case-patient’s death. Participants who agreed to take part were sent study information in advance, with consent taken at the interview. Identifying details have been changed to protect the anonymity of the deceased case-patients and the interviewees. The study was approved by the Hertfordshire Research Ethics Committee (England; #11/EE/0491), and approval to view the patients’ medical records to identify potential interviewees was granted by the then National Information Governance Board (ECC 1-5 (G)/2012).

Analysis and synthesis

Interviews produced highly detailed accounts of the ambulance staff decisions to facilitate admission to hospital for both case-patients and similar patients they had cared for.
previously. They provided a rich description of the problems ambulance staff encountered and an understanding of how they made sense of the case-patients’ situation and how it could best be resolved. The analysis and synthesis of these accounts were informed by Giddens’ structuration theory. Structuration theory acknowledges both the individual and the society they live in and emphasizes their interaction.20 In this approach, interviewees were understood to be knowledgeable about their actions—in this case, their involvement in the admission.20 The epistemological rationale was that an individual’s knowledge about what they did may be investigated empirically via the accounts they provide of their actions.21–23 It is not assumed that these accounts are objective descriptions necessarily, but it is assumed that such accounts guide individuals’ actions and furnish them with motives and explanations that they then provide for themselves and for others.21–23 Such accounts are of critical importance in understanding the dynamics of human interactions within organizations.

Interviews were professionally transcribed verbatim and analysed by Hoare18 thematically. Transcripts were primarily coded “in vivo”,24 with sections of text tagged using words and themes given by interview participants as well as with descriptive phrases. This coding process was completed for each transcript on paper and then downloaded into the analytic software NVivo. After completing this process for several ‘cases’ (groups of interviews conducted about a patient and their admission), codes were mapped and grouped together to create a coding framework, which was revised and refined as more interviews were coded. Data were synthesised by identifying and summarising the key topics. This process was informed by relevant end-of-life care literature to foster an understanding of trends in end-of-life care practice as well as sociological literatures to better appreciate the social position of the ambulance staff. Both literatures provided perspectives on the participants’ accounts of their actions20–23 and supported the synthesis by helping to provide a narrative to draw the discrete themes identified in the analysis together. Additional analysis was conducted as appropriate to clarify points and check the veracity of conclusions. Further details on the analysis and synthesis are available elsewhere,18 including early findings.25 Quotations in the text are followed by the interviewees’ code and transcript page number.

Findings

Ambulance interviewees had an important role in the hospital admission of all of the case-patients: regardless of time of admission or condition, all were brought to hospital via ambulance. The ability of interviewees to keep patients close to the end of life at home was hindered by three key factors: (1) the limited availability and accessibility of additional care support in the community, (2) the limited information ambulance staff had about the patient and their condition and (3) a perceived ambulance service emphasis on hospital care. Factors were interlinked, and each is considered in turn below to understand why ambulance interviewees conveyed patients close to the end of life to hospital.

Availability and accessibility of care

Keeping a patient close to the end of life at home and not transferring them to hospital was difficult for ambulance interviewees, even when they thought it was in the patient’s best interests, due to practical problems in arranging alternative care in the community. Non-hospital care required negotiation between ambulance interviewees and other healthcare providers, including the patients’ general practitioner (GP). However, accessing their help often took too long or where alternative care was thought necessary, was inaccessible or unavailable.

Untimely care. Ambulance interviewees described a struggle to access help from other healthcare providers. This was particularly acute when help was needed ‘out of hours’ – at night and at weekends – when alternative services were unavailable or had limited capacity. For ambulance interviewees seeking advice or care for a patient close to the end of life, this could mean a significant wait which often exceeded the time staff felt either that they could stay with the patient or that the patient could wait for care:

Sometimes I’ve been waiting an hour/an hour and a half [to speak to a GP], […] which is far too long. However, if I could

<table>
<thead>
<tr>
<th>Case-patient</th>
<th>Previous place of care</th>
<th>Time of admission</th>
<th>Interviewee code</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Home</td>
<td>Weekday, daytime</td>
<td>AP1</td>
</tr>
<tr>
<td>B</td>
<td>Home</td>
<td>Weekend</td>
<td>AP2</td>
</tr>
<tr>
<td>C</td>
<td>Residential home</td>
<td>Weekday, early morning</td>
<td>AP4</td>
</tr>
<tr>
<td>D</td>
<td>Residential home</td>
<td>Weekday, daytime</td>
<td>AP6</td>
</tr>
</tbody>
</table>

These patients were admitted out-of-hours (between 6 p.m. and 8 a.m. on a weekday and anytime on a weekend).


Ambulance interviewees were also challenged by an apparent absence of services available for those thought to be within hours of death. Interviewees recognised that patients needed healthcare support at this time and described examples where colleagues had stayed with patients at home until they had died. Where this was not thought to be feasible, ambulance interviewees described frustration at the need to seek this support from hospital through admissions:

So I’ve been out to people that have had emphysema and they’re right at the end of their last legs, but because it’s not been cancer they won’t all come out. The GP will come out but you can’t get anybody else out. [...] Who do you get to come out and support the family in those last few hours of life? (AS2, 6)

Limited information

It was difficult for ambulance interviewees to consider keeping patients close to the end of life at home and not facilitate transfer to hospital without relevant patient information. These patients were often too unwell to communicate effectively with ambulance interviewees, who were therefore dependent on information provided by those present and available documented decisions made by other healthcare staff. Incomplete or absent information meant interviewees struggled to prevent hospital admissions.

Uncertain prognosis. Ambulance interviewees without access to background patient information were obliged to assess the prognosis of patients close to the end of life from their presenting states. This made evaluating the clinical suitability of hospital care difficult, and where it was unclear, ambulance interviewees tended to instigate transfer to hospital to mitigate the risk of a patient missing out on life-saving care:

[...] it’s obviously, it’s not a good feeling if it is clear that you’re taking someone to hospital who’s, you know, who doesn’t stand a very good chance of leaving there, you know of coming out again. You know, it well, it’s a bit hard really I guess isn’t it because you never know someone’s outcome. It’s very tough to say really because on one hand you kind of feel you have to give someone every chance but then you come to a point where it may not be appropriate. (AS6, 4)

Uncertain status. Knowing if a patient close to the end of life had been formally identified as ‘end of life’ by another healthcare service was important for ambulance interviewees to consider instigating community-based care rather than transfer to hospital. The presence of advance care planning documentation meant a patient close to the end of life was potentially eligible for home-based care packages that ambulance interviewees could help initiate:

I know technically a DNR [Do Not Resuscitate order] is only when [they’ve] actually arrested we don’t start, but however if that’s in place, for me anyway, personally, I would start looking at, well, that is in place, doctors are aware that [they are] gonna pass, can I speak to an out of hours doctor just to work out a way. However, if that’s not in place then obviously it hasn’t been discussed, and then we’ve got no other choice but to go to hospital. (AS4, 5–6)

Ambulance end-of-life care

Ambulance interviewees were generally supportive of enabling death at home for the end-of-life patients to whom they had been called. However, their ability to do so was countered by a presumed ambulance service orientation towards hospital care, exacerbated by the practical difficulties outlined above in accessing alternative care and confirming whether a patient was close to the end of life.

Hospital care. Ambulance interviewees recognised the facilitation or provision of emergency care as an important aspect of fulfilling their responsibility towards patients close to the end of life. Not conveying these patients to hospital was considered with hesitation by all ambulance interviewees, and some described potential professional repercussions of doing so. Thus, while ambulance interviewees were advocates of death occurring at home for end-of-life care patients, their practice was orientated towards hospital transfer:

I think it’s a harder decision to leave someone who’s dying at home than it is to take them in because you’re never going to get it wrong taking them in [...] It probably is wrong but it’s not wrong as in black and white if that makes sense. (AS5, 8)

Care needs. Leaving clearly unwell end-of-life patients at home was equated by ambulance interviewees with abandoning them and reneging on their professional duty. The difficulty ambulance interviewees had in meeting these patients’ care needs in the community, and the convention staff had towards hospital care, meant admission was often considered ‘unavoidable’:
there are times when it’s just unavoidable to take people into a hospital and I think in this case there was no option, we couldn’t leave [them] at home really, [they were] in a rather, well a very unsuitable environment, [their] family obviously weren’t coping and [they were] soiled, the bed was absolutely soaked, [they were] in a tiny room, totally inappropriate for [their] needs. (AS1, 1–2)

Prerequisite evidence. The scope of ambulance interviewees to provide alternative care to very unwell patients, other than facilitating hospital care, depended in part on whether staff could establish that a patient close to the end of life was different to a typical patient. However, the limited amount of evidence available to ambulance interviewees, which could confirm that a patient was for end-of-life care, meant staff were reliant on their own assessment of the patient’s condition. Since distinguishing between a sick patient needing urgent transfer to hospital from a sick dying patient who could be cared for in the community was often difficult, as identified above, hospital care was often considered inevitable:

I think, yeah, in the absence of all that [evidence of advance care planning] and in the absence of any direction from the family you’re back to doing what clinically you know will give that person the best outcome. (AS3, 5)

Recognised by others

The problems faced by ambulance interviewees, in particular of limited resources and information to keep patients close to the end of life at home, were recognised by other healthcare provider participants. They similarly concluded that hospital was often the only option for ambulance staff when caring for end-of-life patients. For instance, a hospital emergency department doctor stated that

but actually, you know, I think they [A’s family] called for help because help was needed, and the paramedics came to the only place that they had access to, and actually the only place that has access to the only treatment that’s going to help. (Dr1, 7)

Discussion

Main findings

Ambulance interviewees performed an important role in end-of-life admissions, deciding on, and then carrying out, transfers from community to hospital. Their ability to keep patients close to the end of life at home was hindered by practical problems in addressing patient needs, and an ambulance service focuses on facilitating hospital care. The hospital therefore occupied an important role in the end-of-life care provision of patients close to the end of life, challenging the contention that such hospital admissions are preventable or avoidable.

Difficulty of ambulance provision. The problems faced by the ambulance interviewees in providing care to end-of-life patients are partly typical of the challenges for ambulance care generally. Collaboration between ambulance staff and other care services is recognised to be hindered by limited integration and a complicated healthcare system in the United Kingdom. Ambulance staff also commonly work in uncontrolled environments – homes and public spaces – where decisions must be made quickly and where the provision of additional care and ability to diagnose symptoms is limited. ‘Arriving as strangers’ is thus typical and means staff are dependent on what can be assessed from the immediate patient environment and what the people who are there know and can articulate.

These difficulties were heightened when providing care to those at the end of life. Ambulance interviewees were significantly hindered in organising the care that they recognised was necessary for patients close to the end of life outside of the hospital setting. They were often called to such patients by family members when community-based care seemed exhausted and additional care was urgently required, matching existing evidence. However, without the necessary patient information, assessing what pre-existing care packages had been arranged for patients close to the end of life was difficult. This was compounded by the time of day ambulance interviewees were called to patients close to the end of life, which was typically, but not exclusively, ‘out-of-hours’ when support from other healthcare services is not available at full capacity. Moreover, the pervasive absence of background clinical information and recorded patient status meant the assessment of the potential benefit of hospital care was difficult. Ambulance interviewees were instead reliant on their prognosis assessment, a process recognised to be challenging, particularly for staff with limited resources. This helps explain the priority ambulance interviewees gave to documented decisions such as resuscitation status, a practice reported elsewhere. Together these factors help to clarify why ambulance interviewees facilitated admission to hospital, which offered a certainty absent at home: of care, of information and of confirmation of irreversibility of condition.

Ambulance care and end-of-life provision. The perception ambulance interviewees had of the role of ambulance services in end-of-life care was significant in their decision to transfer to hospital. The reservations they described about keeping patients close to the end of life at home accords with findings in other ambulance research and suggests a service-wide hesitancy about enabling home deaths for end-of-life patients, despite unfavourable policy rhetoric about end-of-life deaths in hospital. This may be explained by the role of the ambulance service in both general healthcare provision and in end-of-life care.

In general healthcare provision, ambulance staff have very limited scope to provide alternative care to facilitating
admission, in part because of the restricted role of the ambulance service beyond immediate clinical care and the subsequent transfer of patients to hospital. In the United Kingdom, for example, while the 1966 Millar Report led to the development of ambulance services beyond transfer to hospital, the 2005 Bradley report was described as prompting a ‘quantum culture leap’ by seeking to change the aim of the service from primarily conveying patients to hospital to also providing care in the community where appropriate. National Health Service (NHS) expectations of the service remain, however, orientated towards hospital care: ‘Patients will always be taken to hospital when there is a medical need for this’. The decision for ambulance staff who have been called to a sick patient is primarily between transfer to hospital or to an alternative destination where staff can obtain care for the patient from another service. This limited choice is also relevant elsewhere, including in North America, Australia and New Zealand, where even specially trained prehospital practitioners typically resolve patient needs either through on-scene provision of care or conveyance to hospital. Within a context of limited information about the patient to determine whether they are at end of life, and inaccessible alternative care provision, it is unsurprising therefore that ambulance interviewees chose to take patients to hospital.

In end-of-life care policy, ambulance staff have often been given a relatively minor role, particularly in regard to the care of unwell end-of-life patients and admissions to hospital. There is limited end-of-life care reference to ambulance staff in policy documents from Ireland, Singapore, Australia and Switzerland, countries with national palliative care policies. In the United Kingdom, while the landmark 2008 End of Life Care Strategy made reference to the importance of ambulance provision, this was primarily in relation to the prompt transfer of patients from hospital to home. A 2012 NHS Improving Quality paper widened the scope of ambulance service involvement in end-of-life care, but still retained a focus on transfers between settings. Furthermore, there has also only been limited inclusion of end-of-life care issues in ambulance training until recently; end-of-life care education is recognised to be variable, particularly for non-specialists, circumstances that have also been reported in Germany and the United States. These circumstances help explain the ambivalent orientation of ambulance interviewees towards hospital care for patients close to the end of life, despite a general consensus that end-of-life deaths at home were positive. More broadly, these structural limitations emphasise the difficulty for ambulance staff in preventing the end-of-life admissions to hospital.

**Implications for research, policy, clinical practice and research**

The experience of ambulance interviewees in facilitating hospital admissions of patients close to the end of life contributes to our understanding of end-of-life care. While such admissions are often negatively described in end-of-life care policy, it is apparent that the accessibility of hospital care played an important role in the end-of-life provision for both patients close to the end of life and ambulance interviewees. Hospital care was seen to meet the care needs of patients without complex negotiation with other healthcare providers, which was recognised to be difficult and often not feasible. In this context, discussions about the relative appropriateness of hospital admission for patients seem irrelevant, because hospital was often recognised to be the only place ambulance interviewees could have sought care.

**Future considerations**

The analysis of this article was informed by a sociological analysis of end-of-life admissions. Focusing on personnel actions and the social structure in which admissions occurred meant that key tensions and difficulties confronted by ambulance interviewees involved in end-of-life admissions were explored. This sociological lens productively orientates analysis beyond a limiting focus on culpability and organisational performance and is advocated for future research that considers the multiple organisations involved in end-of-life admissions.

**Limitations**

The study findings are specific to the accounts of a small number of ambulance staff in one location in England involved in the admission of a case-patient to hospital. The significance of the conclusions which can be drawn from this sample must therefore be modest, and the reasons for the case-patients admissions may not be representative of individuals in other situations admitted to hospital shortly before death. The focus on patients admitted to hospital within 3 days of death, however, accords with current trends in England. Death in hospital typically occurs following an emergency rather than planned admission, with nearly a third (32%) of deaths occurring within 3 days of admission and most deaths within a month of admission. The detailed accounts provided by ambulance and other healthcare professionals of these admissions are valuable because of the depth of insight they provide into the challenges faced by those facilitating end-of-life admissions. Furthermore, while the small sample size means that it is not possible to generalise to the ambulance service nationally, the similarity of the problems ambulance interviewees experienced to those found by others suggests that the findings may have relevance beyond this sample. The research identifies the critical but difficult role ambulance staff have in end-of-life admissions, with further research necessary to assess the scope of the difficulties and how they may be addressed.
Interviews with staff were conducted in 2012–2013, and it is possible although unlikely that in the intervening period, the issues described above have improved. For instance, the establishment of the 2013 Urgent and Emergency Care Review actively sought to increase the amount of urgent and emergency care available in the community. In 2015–2016, ambulance staff nationally spent on average longer time with patients compared to the period 2011–2012. This was attributed in part to staff treating more patients at the scene, suggesting fewer end-of-life patients may have been transferred to hospital. However, changes in end-of-life care have not been so rapid. Recent publications indicate that the problems of access to services by ambulance staff remain pertinent. While locally the ambulance services have implemented various end-of-life strategies to alleviate the decision-making difficulties faced by ambulance interviewees, the underlying issues which extended beyond the ambulance service and which directed the decisions of staff have endured. Consequently, the issues faced by ambulance interviewees remain relevant for understanding why end-of-life patients are admitted to hospital.

Conclusion
Ambulance staff fulfil an important role in the admission of end-of-life patients to hospital, providing care to patients recognised as often being very unwell and in significant need of urgent care. However, ambulance interviewees were limited in the care they could provide because of absence of patient information, restricted access to alternative healthcare services than hospital and a perceived service remit orientated towards hospital care for ill patients. As such, for end-of-life patients in need of care, facilitating hospital admission was often the only option.

Acknowledgements
The authors would like to thank the participants and those involved in the set-up and running of the study. In particular, they are grateful to the research paramedic who identified ambulance staff involved in the care of case-patients and has continued to provide support after the end of data collection.

Declaration of conflicting interests
The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding
The author(s) disclosed receipt of the following financial support for the research, authorship and/or publication of this article: This paper presents independent research part funded by the National Institute for Health Research Collaborations for Leadership in Applied Health Research and Care (NIHR CLAHRC), Cambridge and Peterborough, and NIHR CLAHRC East of England. The writing of the paper was funded by the NIHR School for Primary Care Research (NIHR SPCR). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care. The Marie Curie Design to Care programme is a service improvement programme. This research forms part of the design phase of this programme, which is funded by Marie Curie, the UK’s leading charity caring for people living with any terminal illness and their families.

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References


49. National End of Life Care Intelligence Network. What do we know now that we didn’t know a year ago? New

