

Emergency department staff priorities for improving palliative care provision for older people: A qualitative study

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ABSTRACT

Background: Emergency department-based palliative care services are increasing, but research to develop these services rarely includes input from emergency clinicians, jeopardizing the effectiveness of subsequent palliative care interventions.

Aim: To collaboratively identify with emergency clinicians improvement priorities for emergency department-based palliative care for older people.

Design: This was one component of an Experience-based Co-design project, conducted using semi-structured interviews and feedback sessions.

Setting/participants: In-depth interviews with 15 emergency clinicians (nurses and doctors) at a large teaching hospital ED in the United Kingdom exploring experiences of palliative care delivery for older people. A thematic analysis identified core challenges that were presented to 64 clinicians over five feedback sessions, validating interview findings, and identifying shared priorities for improving palliative care delivery.

Results: Eight challenges emerged: Patient Age; Access to Information; Communication with Patients, Family Members and Clinicians; Understanding of Palliative Care; Role Uncertainty; Complex Systems and Processes; Time Constraints; and Limited Training and Education. Through feedback sessions clinicians selected four challenges as improvement priorities: Time Constraints; Communication and Information; Systems and Processes; and Understanding of Palliative Care. As resulting improvement plans evolved 'Training and Education' replaced 'Time Constraints' as a priority.

Conclusions: Clinician priorities for improving emergency department-based palliative care were identified through collaborative, iterative processes. Though generally aware of older palliative patients' needs, clinicians struggled to provide high quality care due to a range of complex factors. Further research should identify if priorities are shared across other EDs, and develop, implement and evaluate strategies developed by clinicians.

Key statements

What is already known about the topic?

- Previous research shows emergency clinicians have mixed views and limited understanding towards provision of palliative care for older patients with palliative care needs in the emergency department.
- There is little evidence of inclusion of emergency clinicians within research processes to address these disparities beyond exploration of experiences.
- Few emergency department-based palliative care studies have used a collaborative approach or included more than one professional group.

What this paper adds

- This study demonstrated that despite mixed views and limited understanding of palliative care in the emergency department, multidisciplinary clinicians are willing to engage in collaborative research to address and improve its delivery.
- Emergency clinicians collaborated with academic researchers and identified eight challenges facing emergency based palliative care, and four key improvement priorities: Communication and Information; Systems and Processes; Understanding of Palliative Care, and Training and Education

Implications for practice, theory or policy

- This study identifies both clinician needs in emergency department-based palliative care delivery, and a methodological approach to further this research that supports international recommendations focusing on shared-decision making and collaborative approaches.
- Locally developed emergency department palliative care programs could benefit from integrated working with palliative care teams to help reduce isolation and add specialist knowledge.

Keywords: Palliative Care, Frail older adults, Emergency department

INTRODUCTION

Palliative care, the holistic care of a person with a life-limiting illness and their family(1), is often needed in the Emergency Department (ED) due to increasing visits from older people (65+) with co-morbidities and end-of-life care needs. (2-5) This is due to a demographic shift in developed countries, whereby advances in medical treatments and living conditions have enabled people to live for longer with complex co-morbidities, with estimates that the over 65 population will have increased by two-thirds by 2030.(6-8) The complexities of managing these conditions, coupled with challenges accessing community-based care, often results in ED visits.(6, 8, 9)

The presence of older, palliative patients in the ED may appear incompatible with traditional emergency medicine. However, persuasive arguments for the ED to adapt and develop its care delivery include improved patient-centered care and patient-family satisfaction, and reduced costs, length of stay and intensive care treatments.(5, 10, 11) Nevertheless, there remains limited exploration into the palliative care knowledge, needs and experiences of emergency clinicians.(12-16) Subsequently, on-going debates over the exact role of emergency clinicians in palliative care delivery, coupled with resource limitations such as time and space, leave clinicians vulnerable and often without direction in the management of these patients. (10, 12, 17, 18)

To ensure palliative care is delivered effectively it is vital to understand the perspectives and experiences of the ED nursing and medical clinicians. Absence of their insight and involvement leaves quality improvement efforts open to errors and misunderstandings about clinicians' capacity, ability and concerns.(19, 20) This can lead to hostility and breakdown of relationships between those leading change processes and the clinicians implementing them.(21-23) Involvement of clinicians in identifying improvement priorities ensures that intervention measures are mindfully created and implemented.(22-24)

This paper focuses on an exploration of ED nurses' and doctors' experiences, expectations and main concerns about palliative care delivery for older people as part of a co-design project to improve the quality of care.(20, 25) Through participation in interviews and feedback sessions, clinicians collaboratively identified priorities for improving this aspect of care provision. Our goal is to contribute to a growing body of knowledge about the challenges of incorporating palliative care into the ED, providing insight that can help focus and shape interventions to improve ED-based palliative care.

A study was conducted which aimed to improve palliative care delivery in an ED through exploration of shared experiences and collaborative working between older palliative care patients, their families and ED staff. This paper focuses on staff experiences.

METHODS

Study Design

This doctoral study conducted by (RW) was grounded in Experience-based Co-design (EBCD), a form of Participatory Action Research (PAR) that makes use of qualitative research methods. (20, 25) EBCD is an approach that enables clinicians, patients and family caregivers to explore their experiences of particular clinical situations, identify shared challenges, and design improvement strategies in partnership by following a six stage process (Table 1). (20, 26)

To gather clinician's experiences of palliative care in the ED audio-recorded, semi-structured interviews were conducted with ED nurses and doctors (Table 2). Interview data were analyzed for major themes and their implications for clinical practice.(27) Across feedback sessions with emergency clinicians, themes were fed back to validate the analysis, and determine if the reported experiences were shared. From the themes clinicians selected four priorities for improving palliative care delivery for older people and their families.

The study, conducted from 2011 to 2014, was approved by the National Research Ethics Service and a London Research Ethics Committee. Patient and family caregiver perspectives and collaborative co-design work are reported elsewhere.(28, 29)

Setting

The study was based at an urban UK teaching hospital caring for approximately 170,000 patients annually from a diverse demographic. Approximately 16,000 are aged 65 or older. Previous research at the study site identified 102 deaths in the ED of people aged >65 over a 1 year period. Over half (58/102) presented with a diagnoses indicating underlying palliative care needs, 29 had recorded symptoms a week prior to death, 28 had complex social issues recorded 3 months preceding death; however, only eight were known to palliative care services.(4) The ED itself was divided between resuscitation, minor and major injury units, a pediatric ED, a conference room, and several small consultation rooms. All interviews and feedback sessions were conducted in consultation or conference rooms.

Participants

The recruitment strategy used purposive and convenience sampling to enroll ED nurses and doctors from all levels of care provision (Table 2), to gather a range of ED-based palliative care experiences. [Author] informed clinicians about the study at morning handover meetings, provided information sheets and enrolled consenting clinicians. Clinicians provided written consent prior to their individual interview. Feedback sessions, conducted during clinical training days, were audio recorded and clinicians signed consent forms regarding their participation. Although participation in feedback sessions was not mandatory no one chose to opt out.

Primary Data Collection and Processing

Semi-structured, audio-recorded interviews lasted approximately 40-60 minutes. They were conducted by [author], a palliative care research nurse with qualitative training. A topic guide served as a prompt to explore definitions, understanding and experiences of palliative care provision, education and training, and clinicians perspectives on how ED-based palliative care could be improved. Four data sources provided an audit trail for each interview: the audio recording; an anonymized verbatim transcript; interview field notes with initial observations; and reflective field notes which supported critical thinking about the conduct of interviews.

Primary Analysis of Interview Data

Once transcribed, interview data were analyzed and coded by (author) using thematic framework analysis. (30) Coding first identified key quotes, terms and case examples which were then categorized using a coding tree into themes. Themes focused on ED clinician knowledge, attitudes, and experiences about older palliative patients and palliative care. Analytical saturation was achieved at the point where no new codes or themes emerged. Further analysis was conducted by [Authors] who reviewed and validated the data, coding scheme, saturation, and the framework for clinical significance. Differences in opinion were resolved through discussion of the data to reach a consensus.

Validation of Data Analysis

To validate the analytical findings with the clinicians, a feedback session was designed and facilitated by [author] on five occasions lasting between 30-60 minutes depending on the level of clinician engagement in discussions. The purpose was twofold; to gain clinician validation and consensus of the analysis, and to identify clinician priorities for improving ED-based palliative care delivery for older people. This type of activity is key for engaging clinicians within EBCD research,(26) reducing

researcher bias, and ensuring transparency and rigor in the analysis. (31, 32) A framework was developed to present each theme's apparent clinical significance (Table 3).

Feedback sessions opened with reiteration of the study purpose and presentation of the thematic findings, as per Table 3, supported by anonymized interview quotes. Clinicians discussed their initial responses. A facilitated discussion validated the findings by identifying 1) if clinicians shared the experiences, 2) if they agreed with the themes identified by the analysis, and 3) if any important issues had been missed. Lastly, using individual forms, clinicians ranked the themes in order of the extent to which they impeded daily delivery of high quality palliative care to older people.

RESULTS

Characteristics of Study Participants

Fifteen clinicians participated in interviews; nine nurses (four junior, two senior and three with management or supervisory roles), and six doctors (one junior, two senior and three with management roles) (Table 2). We did not seek to obtain similar information during the feedback sessions, but a total of 64 emergency clinicians (nurses n=56; doctors n=8) including junior and senior members of the medical and nursing teams participated.

Findings: Clinicians' Priorities for Improving ED-Based Palliative Care

Eight themes emerged from the primary analysis of interview data (Table 3). These were presented alphabetically to avoid any appearance of prioritizing or bias: 1) [patient] age, 2) barriers, 3) communication with patients, family members and other clinicians, 4) understanding of palliative care, 5) role uncertainty, 6) complex systems and processes, 7) time constraints, and 8) limited training and education. Across all feedback sessions clinicians validated these findings, only recommending that 'barriers' be renamed as 'information' and combined with 'communication' to reduce confusion and increase clarity (Table 3). In descending order, clinicians prioritized the three most important areas for improving ED-based palliative care as: 'communication and information', 'complex systems and processes' and 'time constraints'.

Clinician discussions often referred to policy-driven 'time constraints' that impeded their ability to provide high quality care. The main issue was the '4-hour target', a quality improvement measure implemented in 2004 by the National Health Service (NHS) in England, which stated that the time from arrival to admission, transfer or discharge should not exceed four hours. It aimed to improve the flow of

patients through the ED, removing seriously ill patients on trolleys in corridors waiting to be treated or admitted.(33) While this measure undoubtedly increased the pressure on ED staff to process patients through the ED, it was beyond the scope of this study to influence national policy making. Therefore, in consultation with leadership from the ED and [authors] the fourth ranked theme ‘limited training and education’ replaced ‘time constraints’ as an improvement priority. During this consultation the decision was also made to include ‘understanding palliative care’ as a fourth improvement priority, based on the observations and insights of [author] from interviews and feedback sessions. She identified a prominent lack of consensus in defining palliative care and its delivery in the ED that could jeopardize the effectiveness of clinicians-selected improvement priorities and any subsequent activities.

Improvement Priority 1: Communication and Information

As clinicians discussed the challenges underpinning the selected themes they often returned to communication and information. While some had positive experiences of palliative patient interactions the majority found the ED environment hindered difficult conversations. Noise, lack of time, ever-increasing demands, struggles to know who to refer and when to refer, and most importantly, how to talk to patients and their families at such a poignant moment of life inhibited initiation and exploration of deeper issues:

‘...how do you expect someone to spill out their innermost demons and fears in a short period of time to a complete stranger in an environment where someone’s, kicking off beside them’? (Registrar, Interview 13)

As the intermediary between the community and tertiary care emergency clinicians rely on other services to provide vital information and additional support to ensure patients are given appropriate care. Clinicians reported mixed experiences of communicating with other disciplines, particularly when trying to determine goals of care:

‘...I had a patient referred to the ED by the community nurse. I called her and she refused to talk to me because it was out of hours, she said I had to call the consultant, and I said “but you just sent the patient here” ...’ (Registrar, Feedback Session 5)

'...I think there is a lot of bad documentation from the community, a person needing palliative care should have that information...so they don't lie around for hours while you don't know what to do...' (Senior Staff Nurse, Feedback Session 3)

Improvement Priority 2: Complex Systems and Processes

Clinicians discussed the 'systems and processes', often expressing dissatisfaction with factors preventing delivery of timely care. Inefficient mechanisms for accessing vital information about older palliative care patients at the community-ED interface were frustrating, particularly when patients were referred to the ED with little or no information about their condition and goals of care:

'...unless the GP [general practitioner/primary care physician] writes the letter and is sure to give it to them, you could end up with a patient coming in with the ambulance letter and nothing else...Which is much less helpful than if you've got their background, history and what their GP's assessment was.'
(Registrar; Interview 2)

Efficient working within an environment with rapid clinician turnover was complicated by complex systems. Subsequently many clinicians were unaware of or unable to access hospital-wide systems and processes, for example in-hospital support services, or information on care goals:

'I haven't seen a pathway through the ED...a process that guides you except for your own judgement and the idea that somebody should be comfortable...I think it would be useful. I don't know whether that exists within the hospital sort of beyond the ED...' (Senior Staff Nurse, Interview 4)

Improvement Priority 4: Limited Training and Education

Discussions about training and education revealed clinicians' feelings towards ED-based palliative care often related to their expressed degree of confidence. Professional background did not appear to be a factor, with both nurses and doctors reporting a limited amount of formalized pre- and post-qualification palliative care education. While more confident clinicians were highly motivated to provide ED-based palliative care, often seeking out individual training, they still struggled to provide it, especially when working with less informed or confident colleagues. Many clinicians expressed concern, feeling

unprepared or ill-equipped to provide palliative care for older terminally ill patients, particularly addressing emotional responsibilities and complex needs of older patients. ED-provided training was particularly challenging as emergency clinicians are expected to be familiar with a vast number of conditions. Routine updates therefore cover a range of topics:

'...there are so many different specialties that come in...you'll highlight this, input on this and then...time will pass and we'll need to go back to this again because people have forgotten or need a bit of a reminder' (Practice Development Nurse, Interview 8)

Improvement Priority 7: Understanding of Palliative Care

The theme 'understanding of palliative care' caused most contention across all interviews and feedback sessions. Clinicians grappled with the concept both generally and specifically to its provision in the ED and a range of perspectives and understanding emerged:

'...how I see palliative care...I'm not doing anything. I'm backing away...I don't tend to focus on the end of life bit. I tend to focus on what we can do...because my ED brain says I need to be doing something...' (Staff Nurse, Interview 7)

A small number demonstrated significant understanding and expertise. They outlined the complexities of identifying and providing palliative care within the ED, firmly stating that it was both possible and part of their role:

'...I think an ED needs to recognize that a lot of what it's doing is going to involve palliative care...unfortunately it's often used as a short hand for avoiding doing anything else to somebody, although that's a very limited view set... but the reality is in hospitals I think...that it's an alternative to active treatment' (Staff Nurse, Interview 14)

Although clinicians expressed mixed opinions on the appropriateness of integrating palliative care into the ED, they agreed that the selected improvement priorities represented the most important and substantial challenges to their provision of care for older people, and as such needed addressing:

'... I suppose its [palliative care] lacking because they... just need a bit more... We don't have enough information about their care in the past and...you need to make instant decisions. You can't leave people hanging around for hours...the emotional side of it is stressful... families who are upset, patients deteriorating at that point... in your heart you want to make it a good death...or you want to make it a good experience and get them to the right place...it's an important time for them, but you don't have any training on that. You have your life support training, but you don't have any death support training...' (Staff Nurse, Interview 9)

DISCUSSION

This paper presents findings from a co-design project in which clinicians reported their experience and understanding of ED-based palliative care delivery for older people.(28) Although clinicians consistently demonstrated a desire to provide high quality care, a range of challenges impeded them. Our findings parallel challenges cited by emergency clinicians in similar research,(2, 12, 14-17, 34-37) although to our knowledge, none has moved beyond exploring experiences and onto service redesign with emergency clinicians by exploring shared concerns and selecting department-wide improvement priorities.

The selection of improvement priorities can be understood in the context of the wider culture in which clinicians worked. Common misunderstandings and misconceptions about palliative care were exacerbated by the unique ED environment. (15, 38, 39) Increasing visits by older people with complex needs challenged traditional mechanisms.(40, 41) Subsequently, clinicians selected improvement priorities addressing factors routinely obstructing high quality care to vulnerable populations, avoiding those requiring philosophical debate or wider consensus. For example, challenges to communication and information sharing can be rapidly understood and addressed. Understanding and addressing how a patient's age can influence care delivery and decision-making processes is more complex, but may provide another lens to understand the clinician's selection of priorities.

In Table 3 'patient age' demonstrates some of the complexities in caring for older patients. During interviews clinicians referred to having to address a myriad of issues in a short time frame as 'a can of worms'. They also expressed different reactions to the death of an older person compared to a younger person. This included a disinclination to include older people with full mental capacity in end-of-life

decision-making processes.(42) These findings suggest a degree of ageism,(43) and possible explanation for the improvement priorities selected.

The inclusion of ‘understanding of palliative care’ was added at the suggestion of [author], who identified that any improvement priority would be problematic without departmental consensus defining palliative care. The lack of consistency and understanding regarding palliative care and its clinical application is well documented.(38, 44) As with the wider literature, we observed the provision palliative care in the ED was contested by some clinicians,(12) while others saw it as a key part of their role.(16, 37) Variation in opinion appeared to correlate to individual knowledge of palliative care. Greater knowledge, training, and education meant greater comfort incorporating palliative care into routine practice.(12, 14, 45) However, even for trained, motivated clinicians, complex conversations could be impeded by complicated systems and environmental challenges.(36)

The challenge for some clinicians was the apparent paradox between the life-saving and sustaining focus of the ED, and the palliative needs they were confronted with. Subsequent conflicts in the decision-making processes for clinicians could lead to confusion in care delivery roles.(12, 14, 15, 37) This was often found at the community-ED interface with patients referred to the ED for seemingly non-‘emergency’ issues, or with inadequate information regarding urgent goals of care.(15)

Although the ‘appropriateness’ of ED use by older, palliative care patients is still debated,(46) they continue to attend and emergency clinicians must respond to their needs. Our findings demonstrate the willingness of clinicians to engage in research, offer insight into their practice and daily challenges and identify core areas in care delivery requiring improvement. Indeed, drawing clinicians, as well as patients into the decision-making processes, such as in this research, (28, 29) is an approach increasingly recommended to get to the heart of challenges in ED-based palliative care.(46, 47)

Our findings also have implications for the broader palliative care community. Within the clinician experiences, willingness to bridge gaps in care delivery was hindered by a sense of isolation, both from the community and inpatient setting. However, the selected improvement priorities sign-post where palliative care providers can integrate and support emergency clinicians. Basic involvement of palliative care team consultations for patients in the ED has been trialed (48) but is not without its challenges, notably the availability of palliative care teams out-of-hours.(5) Our findings though, speak to a more integrated approach, whereby palliative care inpatient and community teams seek opportunities to

support the ED. For example, developing or implementing palliative care models tailored to local populations and availability of resources. Indeed, later stages of this research project saw the inpatient palliative care team assume an active role in the ED in response to the selected improvement priorities.(28, 29) We found the palliative care team well-positioned to guide emergency clinicians as they developed new care processes. We recommend that EDs partner with local palliative care teams when seeking to develop their palliative care delivery. Palliative care teams have valuable insights that can support emergency clinicians, for example, guideline development, training programs and redesigning the clinical environment.(5) They may also increase communication between community/inpatient settings and the ED, reducing logistical and miscommunicated information that occur within existing systems and processes.

The parallels between this research and research conducted beyond the UK strengthen the generalizability of findings from this single site study. (2, 13, 15) A potential limitation of the findings was the ratio of nurse to doctor participants in feedback sessions. This could have distorted the importance given to some themes over others. However, the experiences of the participants showed marked similarities across the interviews. Furthermore, the number of nurses to doctors was proportionate to staffing levels within the ED. Finally, the presence of more than one discipline and the collaborative selection of improvement priorities is a strength of this study. Few other studies have included more than one provider group or extended the research beyond exploring experiences.

CONCLUSION

Clinician interviews and feedback sessions were an effective, iterative method of identifying and understanding concerns, experiences, and priorities regarding ED-based palliative care. Feedback sessions encouraged clinicians to actively engage with the research process and identify key findings to elicit change. The correlation between our findings and other, similar research suggests that wider collaboration and shared learning may be beneficial.

In response to time pressures and limited resources for quality improvement efforts, we recommend that EDs developing palliative care services consider partnering with local palliative care teams, and gain department-wide consensus defining palliative care. Improvement efforts should focus on timely access to patient information, particularly in relation to decision-making. Routine training and education should include ‘soft skills’ like communication, to increase confidence in initiating difficult conversations

appropriately and effectively, within safe and flexible systems and processes.(49) This study adds to a growing body of knowledge highlighting the challenges of ED-based palliative care and providing the foundations for participatory strategies to address them.

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Table One

Table 1: The Six Stages of an EBCD Study
Stage 1: Setting up the project
Stage 2: Gathering clinicians experiences
Stage 3: Gathering patient and family caregiver experiences
Stage 4: Bringing clinicians, patients and family caregivers together in the first co-design event
Stage 5: Ongoing co-design work in small groups
Stage 6: A celebration and review event

Table Two

Table 2: Participant Characteristics				
Interview Number	*Gender	Age	**Role	***ED Experience
1	F	34	House Officer/FY2 (Intern)	4.m
2	F	33	Registrar (Resident)	6.m
3	F	30	Staff Nurse	6.yr
4	M	34	Senior Staff Nurse	4.5.yr
5	F	27	Staff Nurse	14.m
6	F	31	Sister and Emergency Nurse Practitioner	7.yr
7	M	38	Staff Nurse	15.y
8	F	42	Practice Development Nurse	18.yr
9	F	29	Staff Nurse/Agency Nurse	1.yr
10	M	49	Emergency Consultant (Attending)	20.yr
11	F	44	Emergency Consultant (Attending)	18.yr
12	F	35	Deputy Sister	6.yr
13	M	31	Registrar (Resident)	2.yr
14	F	37	Staff Nurse	6.yr
15	F	45	Emergency Consultant (Attending)	18.y

*F=Female, M=Male. **Roles are given for UK with US equivalent. ***M=Months, Y=Years
 Mean age 35 (range 27-49); Median ED clinical experience 6 years (range 4 months to 20 years);
 73% female.