

Manuscript Title: Views and Experiences of Nurses in Providing End-of-Life Care to Patients in an ED Context: A Qualitative Systematic Review

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ABSTRACT

INTRODUCTION:

With an increase in the population living with terminal illness, many patients are accessing emergency departments during the last days of their life. Yet emergency departments are often not well prepared to provide end-of-life care. The aim of this review was to identify and synthesize studies that describe the views and experiences of emergency nurses in providing end-of-life care so as to understand the barriers and challenges that they face while caring for these patients and to identify factors that can support appropriate care delivery.

METHOD:

A qualitative meta-synthesis was undertaken using a thematic approach. Study quality was assessed using the JBI-QARI tool. Five databases were searched in June 2016.

RESULTS:

Eleven qualitative studies met the inclusion criteria and were assessed as having high quality. Sixty nine findings were identified, combined into eleven descriptive themes and then synthesized into three analytical themes: (1) incongruent emergency department environment and end-of-life care, (2) lack of resources, systems and capacity, and, (3) end-of-life care as a rewarding act or an emotional burden.

CONCLUSION:

The review identified a need for: (i) additional training for nurses, (ii) the development of clear guidelines in the form of pathways and protocols, (iii) having a separate space for the dying, and, (iv) providing a supportive environment for staff dealing with a high emotional burden and challenging workloads. In order to improve end-of-life care, organizations must work on the barriers that hinder care provision.

KEYWORDS: end of life care, emergency department, nursing

WHAT THIS PAPER ADDS

What is already known on this subject

Several studies have been conducted to explore the views and experiences of emergency nurses in providing end-of-life care to patients in an ED context. The current state of scientific knowledge in relation to end-of-life care indicates the need to synthesize these studies to build deeper insights in this area and to inform practice and policy.

What this study adds

Key implications for emergency nursing practice from this research includes the need for a clear record of the patient's wishes in an emergency, quiet space for dying, policies and pathways for these patients, addressing staffing issues and education.

INTRODUCTION

It is every person's right to receive quality care throughout their lives, including at its end[1]. Evidence from patients and families on a 'good death' reveals a desire for a compassionate and dignified death[2]. According to the International Council for Nurses' position statement, it is one of the obligations of nurses in an end-of-life (EOL) situation to respect the patients' wishes and provide comfort measures[3].

Due to difficulties in symptom management at the EOL, terminally ill patients often present to the emergency department (ED)[2,4]. However, EDs and their staff, whose primary focus is rapid identification and resuscitation of acutely ill and injured patients, are not necessarily prepared to provide EOL care. Understanding the barriers and challenges that emergency nurses face while caring for EOL patients, and identifying factors that can support emergency nurses in delivering care, is essential to improving the experience of patients at the EOL in the ED. We therefore conducted this systematic review to explore the question: "what are the experiences of nurses in providing EOL care in the ED?"

METHODS

A qualitative systematic review was undertaken to explore and describe the phenomenon of interest. The review adheres to the ENTREQ guidelines ("Enhancing Transparency in Reporting the Synthesis of Qualitative Research")[5] to report the synthesis of the studies including literature searching and study selection, methodology and methods, critical appraisal and synthesis of findings. The review adopted an aggregative thematic approach[6, 7].

Search Strategy

In collaboration with a university librarian, the first author (AM), undertook database searches from their start date to June 2016. The databases included MEDLINE (OVID),

CINAHL, EMBASE, ASSIA and PsychINFO. First, an initial search of CINAHL and MEDLINE was undertaken to identify relevant synonyms and keywords. The search strategy can be found in the on-line supplementary file 1. Second, comprehensive searching was done using a search grid modified to each database. Third, manual searching of the reference lists of all the included papers was undertaken. The abstracts and full text of all the studies found via the search strategy were reviewed. Where necessary, we attempted to contact authors of selected studies for further information. Studies were included in the review as follows: (i) if they utilized a qualitative methodology or a qualitative part of mixed method studies; (ii) emergency nurses were the main or the majority of the participants; (iii) from any country; (iv) utilized English language; and, (v) any date.

Studies were excluded if: (i) they used purely quantitative methodology; (ii) the participants were not registered nurses or the majority were not nursing staff and nurse's views were not described separately; (iii) the setting was other than ED; (iv) the focus was on palliative care (where that care was not delivered as part of EOL care). The whole search and the selected studies were reviewed by the second author.

Quality Assessment

The papers were read and independently critically appraised by two reviewers (AM and CE) using the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI)[8, 9]. This tool consists of 10 questions which can be answered 'Yes', 'Unclear' or 'No' (see supplementary file 2 for a list of the questions). The response to each question is assigned a score of 1.0, 0.5 or 0 respectively. Each paper is assessed against all 10 questions and given an overall quality score of between 10-0. Any discrepancies in opinion amongst the reviewers were resolved through discussion. The quality assessment was used

(i) to judge the relative contribution of each study to the overall synthesis, and, (ii) to assess the methodological rigor of each study.

Data Extraction

Data was extracted from the included papers using a JBI-QARI standardized extraction tool[10]. Extraction was initially done by the primary reviewer (AM) and was then discussed with the second reviewer (CE), through regular meetings.

Data Synthesis

Data synthesis followed the thematic synthesis approach described by Thomas and Harden[11]. Both reviewers were involved in the data synthesis. Initially the primary reviewer categorized the findings and wrote a description of those findings. Afterwards, the findings were discussed with the second reviewer and confirmed. Each paper was read several times and then line by line coding was undertaken and each finding was assigned a level of credibility (unequivocal, credible and unsupported), as per JBI guidelines[12].

- Unequivocal (U): Findings were accompanied by satisfactory illustrations
- Credible (C): Lack of clear association between findings and illustrations
- Unsupported (US): Findings not supported by data

Following an inductive approach, the findings were then organized into descriptive themes based on similarities in meaning. The relationships between the themes were explored, compared and contrasted to develop a set of higher order analytical themes which constitute the findings of the review. This was initially done by the primary reviewer and then reviewed by the second reviewer.

Assessing confidence in the review findings

Confidence in the review findings was evaluated by each of the reviewers using the GRADE CerQual approach [13]. Each review finding was assessed in terms of its constitutive

studies, along four dimensions: (i) methodological limitations; (ii) relevance; (iii) coherence; (iv) adequacy of data. Each analytical theme was then assigned a level of confidence ranging from high, moderate, low to very low.

RESULTS

The search process and the results obtained are illustrated in a search flow diagram (Fig. 1). The studies included in the review and a summary of the quality assessment are shown in table 1

Figure 1- Search-flow diagram

Table 1- Studies included and quality assessment

Author	Dates	Location	Methodology	Method	Participants	Main theme	JBIR QARI Quality Appraisal Score (can range from very low to very high quality, with scores ranging from 0-10)
Bailey, Murphy and Porock	2011 ¹⁴	United Kingdom	Qualitative ethnographic approach	Observations and individual interviews with staff, patients and relatives	<ul style="list-style-type: none"> Emergency nurses, patients with terminal illness and relatives 	<ul style="list-style-type: none"> Death 'out of place' Concealing the dirty work of dying 	10
Bailey, Murphy and Porock	2011 ¹⁵	United Kingdom	Ethnographic research	Observations and individual interviews with staff, patients and relatives	<ul style="list-style-type: none"> Emergency nurses, patients with terminal illness and relatives 	<ul style="list-style-type: none"> Investment of the therapeutic self in the nurse-patient relationship Managing emotional labour in emergency work Developing emotional intelligence Barriers to transition 	8.5
Bailey, Murphy and Porock	2011 ¹⁶	United Kingdom	Ethnographic research	Observations and individual interviews with staff, patients and	<ul style="list-style-type: none"> Emergency nurses, patients with terminal illness and relatives 	<ul style="list-style-type: none"> Two distinct trajectories of end-of-life care: the spectacular and the subterranean 	10

				relatives			
Decker, Lee and Morphet	2015 ¹⁷	Australia	Grounded theory approach	Focus group interviews	• Emergency nurses	• Death not in the ED	9.5
Granero-Molina, Diaz-Cortes, Hernandez-Padilla, et al.	2016 ¹⁸	Almeria, Spain	Phenomenological qualitative study-	Focus group interviews and individual interviews	• Emergency nurses and physicians	• Being exposed in a cold world • Being self-critical with Professional attitudes • Family obstinacy and "hospital rescue"	10
Hogan, Fothergill-Bourbonnais, Brajman et al.	2016 ¹⁹	Ottawa, Ontario, Canada	Qualitative interpretive descriptive approach	Individual interviews	• Emergency nurses	• "It's not a nice place to die" • "I see the grief" • "Needing to know you've done your best"	9
Jelinek, Marck, Weiland, et al.	2013 ²⁰	Australia	Exploratory Qualitative approach	Focus group interviews and individual interviews	• Emergency nurses, physicians, palliative care clinicians and oncologists	• Limitations of the environment • Limitations of available resources • The role and expectations of staff providing care	9
Kongsuwan, Matchim, Nilmanat, et al.	2016 ²¹	Southern Thailand	Hermeneutic phenomenological approach	Individual interviews	• Emergency nurses	• Being critical and dying in ER • Caring for critical and dying patients in ERs	9
Tse, Hung and Pang	2016 ²²	Hong Kong	Qualitative approach	Individual interviews	• Emergency nurses	• Doing good for the dying • Patients • Facilitating family engagement and involvement • Enhancing personal growth and professionalism • Expressing ambiguity toward resource deployment.	9
Weatherhead	2014 ²³	United Kingdom	Qualitative approach	Focus group interviews	• Emergency nurses and health care assistants	• Death in the ED • Barriers to providing effective EOLC • Views on Established Interventions • Suggested Interventions to Improve EOLC in the ED	10
Wolf, Delao, Perhats et al.	2015 ²⁴	United States	Mixed method approach	Surveys and focus group interviews	• Emergency nurses	• Knowledge and skills • Education • Attitudes and	9

						beliefs about death and dying <ul style="list-style-type: none"> • Appropriateness of setting • Resource limitations • Emotional intelligence • Management of patient and family issues • Desire to honor patient and family wishes • Coordinated care models 	
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Characteristics of the selected studies

This review included 11 studies, including 10 published papers and 1 PhD dissertation. All the papers were published in the last five years with several studies published in the year 2016[18,19,21,22]. Although study participants included doctors, emergency nurses (charge nurse, clinical nurse educator, staff nurse, senior nurse) and palliative care nurses, the current analysis only included findings that were directly attributable to ED nurses. Altogether, within the included studies, there were a total of 165 nurse participants having two to twenty-five years' experience working in EDs. The studies were conducted in the UK (n=4), Australia (n=2), the USA (n=1), Canada (n=1) Spain (n=1), Thailand (n=1) and Hong Kong (n=1). All the studies focused on understanding, describing and exploring the perceptions of nurses in the provision of EOL care. Additionally, one of the studies focused on how nurses manage the emotional impact of EOL care and presented an educational model for developing competency in EOL care delivery[15]. All the studies had utilized a qualitative approach except one study, which was a mixed methods study[24].

Methodological quality

All studies were appraised and scored using the JBI QARI tool[9] (see Table 1 for the summary score, and supplementary file 3 for the full evaluation of quality). All studies

were of relatively high quality with scores ranging between 8.5 to 10. Four studies[14,16,18,23] were particularly high scoring, with consistent congruency between methodology and research objectives, methods and analysis of the results. All the studies sought ethical approval and had conducted the research in an ethical way. Only one study was unclear in describing the influence of the researcher on the research and vice versa[15]. Two authors were contacted for methodological clarifications.

Data extraction and synthesis

Seventy-four findings were extracted and appraised for credibility. One of the findings was found to be based on the views of emergency medical consultants and palliative care nurses and was, therefore, not included. Amongst the remaining 73 findings, 65 were rated as unequivocal, 4 were credible and 4 were unsupported. After excluding unsupported findings, the remaining 69 findings were categorized into 11 descriptive themes and further synthesized into 3 analytical themes, shown in Fig. 2. The full thematic synthesis can be found in the on-line supplementary file 4.

Figure 2- Forming analytical themes from descriptive themes

Assessing confidence in the review findings

Each review finding (analytical theme) was given a 'moderate' CERQUAL grade.

Analytical theme one: incongruent ED environment in relation to EOL care

The first analytical theme described an incongruence between the environment of ED and EOL care. The associated sub-themes (see figure 2) highlight nurses' concerns about the segregation of terminally ill from critically ill patients[14,15,16]. As described in some studies, the care given to the critically ill is intense, in contrast to the care for those who are in their last hours in the ED and who may be segregated, for example - left in the corner bay. One participant expressed that *"I've seen it so many times and if the patient's going to die,*

and hopefully we can get them upstairs to the side room to die, if not we'll stick them in bay 10 [corner bay] out of the way pull the curtains pop your head round every few minutes or if we get busy every half hour..." (p.1373)[14]. Additionally, studies described an ED culture where resuscitation takes priority [17,22,23]. For example, one of the participants shared *"We do the quick-fix, doesn't matter about the long-term implications, just fix or break them that's it because we stabilise and ship them out..."* (p.31)[23]. It was identified that it can be difficult to build a therapeutic relationship due to the short periods of time that patients are in ED[15]. The workload in the ED was also identified as a concern: *"sometimes you are unable to do that (meet emotional and physical demands) because of your workload..."* (p.209)[19]. Also, in many studies, nurses reported a feeling that the ED was an undesirable environment for dying patients as it was a noisy place and there is no time for spiritual or psychological support[16,19,17,18,23].

Analytical theme two: lack of resources, systems and capacity

This theme described the impact of inadequate resources and capacity on EOL care. Nurses in many studies discussed staff shortages as one of the main reasons why dying patients were neglected[26]. Generally, they considered palliative care champions (rather than ED nurses) to be the right individuals to deal with EOL care: *"We have nurses for most things in the ED...so it wouldn't be a bad idea if we had someone to communicate with for advice because it's very hard to take on board everything that's actually happening in the department."* (p.37)[24] Participants expressed their desire for a proper room where patients and families could spend quality time together[21,20,23]. In situations where there was already a room allocated for the dying, it was greatly appreciated in helping to promote a peaceful death: *"It [the Osiris room] is a good place for dying patients, compared to the*

medical ward. ...he [the EOL patient] has suffered for a long time, let him be more comfortable in the EOL room with his family accompanying him.” (p.226)[22]

Studies also highlighted a lack of staff confidence and knowledge to communicate with the dying and their families[18,24]. The need for clear systems (e.g. guidelines, tools or pathways) which could be used as a quick reference to decide the best intervention was also suggested[23]. This was linked to a perceived need for protocols to ensure that EOL care was consistent and coordinated[22]. *“In terms of knowing... how to treat the patient and...what the plan is, I think ...that makes it [death] good.” (p.72)[22]* In addition to this, participants noted that communication with families could be challenging, for example, where they felt that the family’s decisions did not coincide with the patients’ wishes. They desired further support with educating families[23,32] *“So far, they [the families] would agree to give the patients [opioid-type] medication...initially, they might not accept the interventions;...spend time and communicate with them to consider the best interests of the patients...to let [the] patient pass away more peacefully....” (p.227)[22]*

Participants reported a lack of proper documentation about patients’ last wishes: *“It wasn’t appropriate when she had specifically requested when she was awake and completely able that she did not want to die in hospital.” (p.33)[23]* Therefore, proper systems for documentation were also suggested[23].

Analytical theme three: a rewarding act or an emotional burden

The third theme described the diverse responses of the participants regarding the care of the dying. The theme derived from two of the descriptive themes which include providing the best care and avoiding the death. Some participants expressed a sense of great satisfaction in providing care: *“There is nothing more satisfying than to be able to give someone good palliative or EOLC...” (p.31)[23]* It was evident that many nurses tried to

provide the best care possible[19,17,23,24]. Some participants related this to their inspiration to work as a nurse[20,22]. In addition to the care given to the patients, care for the families was also considered to be an important aspect: *“Allowing them to stay with the dying patient is important...this could help [them] to get through the grieving process well.”* (p.227)[22]

Conversely, some participants expressed a sense of emotional burden and recognized that sometimes they would avoid speaking to the patients and their families to avoid negotiating complex emotional issues[15,19,24]. Moreover, some participants shared a feeling of helplessness that they could not do anything for the family’s loss which created a sense of frustration amongst staff[19,17] Some participants shared that they have become so desensitized with such deaths that they do not even pay attention to the dying[21,17,18]. As reflected in one of the statements *“You know, during codes, ...everybody is doing a job. But, as far as end-of-life care, it’s almost like a non-verbal, “Well, they’re done—we’re done with that—there’s nothing more we can do; let’s go do something for somebody we can do something for.”* (p.28)[24]

DISCUSSION

The review aimed to explore the views and experiences of nurses in providing EOL care in the ED. Eleven qualitative studies were included and the results of the thematic synthesis generated three analytical themes derived from eleven descriptive themes. The themes are discussed below in relation to the review objectives.

Perceptions of ED nurses on providing EOL care in an ED context

This review found that the culture and the environment of EDs have a great impact on the care of dying patients. Nurses often described these as incongruent with the provision of good care. Previous evidence suggests that the advancement in technology has contributed to a perception that death is mostly preventable[25] and perceived as a failure if it occurs in

the ED[23], regardless of whether it is a sudden death from acute or terminal illnesses[26,27,28]. Similar findings were reflected in this review as well, with the participants perceiving that the ED was an undesirable place for dying as it was more resuscitation focused

The review also highlighted two distinct emotional attitudes and responses of nurses in providing EOL care: doing their best out of a sense of duty, or avoiding the situation due to a sense of overwhelming emotional burden. Also, the review found that staff often felt unable to invest time or emotional energy into providing EOL care, even if they wanted to, which caused them distress. This issue of not being able to invest time and emotional energy is not limited to the care of dying only; similar concerns have been raised by emergency nurses regarding overall care in the ED [29,30,31].

The review also highlighted a perceived lack of competency amongst some staff to provide psychological and spiritual care. Interestingly, in the studies included in this review, physicians did not seem share concerns about the lack of competency. However, in other studies, similar concerns about the lack of competency and the need for training has also been raised by physicians [32,33]. A particular challenge reported across all professional groups is dealing with uncertainty regarding patients' lack of knowledge regarding their disease prognosis [20].

The barriers and challenges that ED nurses face while caring for patients at the end days of their lives

The synthesis highlighted a lack of systems and lack of capacity which had a negative impact on care. The fast-paced nature of the work and the demands of acutely ill patients meant that it was difficult to find time for dying patients. The lack of time contributed to lack of rapport with the patient and family[28]. Other studies also affirm that most EDs are under

pressure to transfer patients to maintain through-put[34,35]. Hence, the frequent shifting of patients to different areas contributes to lack of rapport.

Apart from the lack of time, the lack of sufficient staffing was another challenge described by these studies. EOL care requires substantial time and the staff reported they could not spend adequate time in direct care. High workload and stress in the ED are well-described even in studies that do not address EOL care[35,36,37].

The review highlighted that the lack of quiet space also acts as an obstacle in the provision of EOL care.

The lack of knowledge about a patient's last wishes causes frustration amongst staff, as their interventions may not coincide with the patient's desires. Devader et al.[4] have highlighted that the lack of documentation of patient wishes may be due to a lack of timely referral or access to palliative care services or lack of funding to afford a lawyer to document their preferences.

Factors that can support in delivering EOL care in the emergency department

The review suggests that there may be a need for more guidance (pathway/protocols) and the palliative care champions in the ED[22,23]. There are several generic EOL care protocols and tools in existence (for example, National Institute for Health and Care Excellence (NICE) Guideline[38]). However, these may not always be helpful in an ED context. For example, evidence affirms that the protocols developed for EOL care fail to address the abrupt changes and uncertainties in a patient's condition in the ED[25,39].

Additionally, the review highlights a need for proper documentation and for the availability of a private space for the dying patient and the bereaved family.

Limitations

There are several limitations of the review. The majority of the studies are from western high income contexts and the extent to which they can be transferred to lower income or other cultural settings is unclear. Apart from this, in one of the studies participants were comprised of a mixed group of professionals interviewed in focus group discussion[20] which might have influenced the views of emergency nurses. Also, the search ended in 2016 therefore the studies been published after that are not included in the review.

Implication for the Practice/Policy Development and Future Research

The implications of this review for practice development are summarized in Box 1 and emphasize the need for a clear record of the patient's wishes in an emergency, quiet space for dying, policies and pathways for these patients, addressing staffing issues and education.

Further, our review has highlighted a number of gaps in the literature which need additional research enquiries to improve the EOL care in the ED. The impact of EOL care champions in care provision in the ED needs exploration. Also, the research regarding the impact of experience, knowledge and environment on ED nurses and its wider impact on EOL care in the ED needs investigation. Moreover, the impact of a uniform record for patient preference in improving patient and family's satisfaction also needs to be explored. Additional research needs to be conducted in the developing countries as well, in order to have insight into this phenomenon of EOL care provision in ED, as there was only one study done in the developing country.

- A system for recording and maintaining a record of patient's preferences, which can be used across all the healthcare settings [40]
- Initiation of policies and pathways for EOL care[41]
- Multidisciplinary approach to education and clarification of pathways. [35,40]
- Address staff shortage and workload
- Provide a quiet and private space for the dying patient [40]
- Form Palliative Care teams, local ED palliative champions and work toward 24/7 referrals

- Debriefing sessions for staff and training on stress management[36,37,42,43]

Box 1- Key recommendations for practice and policy

CONCLUSION

This review examined the perceptions of emergency nurses on providing EOL care and identified the factors that can support them in delivering EOL care. The fast-paced nature of the emergency department, lack of proper space, lack of training to communicate well with patients and lack of information about patients' last wishes were some of the obstacles in providing EOL care in the emergency department. EOL care appears to be a particularly neglected and problematic issue in the ED. Nurses need adequate training on EOL care provision including communication, spiritual and psychological care. In addition, effective care pathways and guidelines need to be established. Ideally, there should be a separate place for the dying patient to help improve their experiences and those of their families.

CONFLICT OF INTEREST

No conflict of interest

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