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Nurses' perceptions and experiences of caring for patients who die in the emergency department setting

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ABSTRACT

Introduction: The number of people dying in emergency departments (EDs) is increasing. However, EDs are not well designed or resourced for safe and effective End-Of-Life (EOL) care encounters, and there is little evidence regarding clinicians' perceptions and experiences of providing such care when the death is sudden and unexpected.
Aim: This study explored nurses' perceptions and experiences of caring for patients who die suddenly and unexpectedly in the ED.
Methods: Open-end responses were collected as part of a larger descriptive survey design. The qualitative data were analysed thematically.
Results: 211 ED nurse completed the online survey. Within the qualitative data, five themes were identified during analysis: 1) key elements of EOL care, 2) systemic and environmental barriers, 3) educational deficits, 4) role ambiguity, and 5) emotional impact. Participants identified communication, a standardised approach, and better educational preparedness as the most important elements of EOL care when the death was sudden and unexpected.
Conclusions: ED nurses want to provide high quality care to dying patients and their families. However, their efforts are hampered by systemic and environmental barriers outside their control. There is a need for a culture shift to overcome the barriers that currently obstruct ED nurses from providing meaningful and effective EOL care in the ED.

1. Introduction

Caring for patients who die suddenly and unexpectedly in emergency department (ED) settings can be challenging and complex. EDs are designed and staffed for rapid diagnosis, treatment, referral and discharge, and may not be adequately equipped to care for dying patients and their families [1]. Furthermore, ED clinicians tend to prioritise lifesaving activities over family-centred end-of-life (EOL) care [2,3]. Importantly, sudden and unexpected deaths can occur as a result of an acute event such as a car accident, or as a result of an unexpected event in the trajectory of a life limiting illness. As the number of people presenting to and dying in EDs increases as our population ages [4], the provision of safe, effective EOL care in this setting is imperative. In order to improve care for people dying suddenly and unexpectedly in the ED, nurses' voices need to be heard. Therefore, the purpose of this paper is to bring these voices to the foreground so that quality EOL care can be delivered in this very complex and challenging environment.

2. Background

Between 2017 and 2018, there were approximately 8 million presentations to Australian public hospital emergency departments, an increase of 3.4% from the previous year [5]. A small number of these people either died in the ED or were pronounced dead on arrival [6]. Historically, the provision of EOL care in the ED has not been prioritised as highly as 'saving lives' [3]. However, EOL care is becoming increasingly recognised as 'urgent care' and therefore a core role for ED nurses [4,7–9].

The quality of EOL care in the ED has important implications for individual patients and for their family, for healthcare providers, and

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for society. Even in the context of a chronic or life-limiting illness, death in the ED can be sudden or unexpected, and therefore a significant traumatic stressor for family members, particularly when they are separated from their dying loved ones, such as during unsuccessful resuscitation attempts [10]. In Australia, as it is in other parts of the world, previous research exploring the experiences and needs of family members bereaved by the sudden and unexpected death of a loved one found the quality of EOL care can either positively or negatively impact the grieving process [11,12]. Effective EOL care that includes family presence and provides appropriate support for family members can minimise grief and suffering [4], facilitate closure [13,14] and reduce the incidence of post-traumatic stress [15]. Conversely, unresolved grief from a sudden 'bad' death and ineffective EOL care can cause many problems for family members in the following weeks, months or years [4]. These problems include post-traumatic stress [16], chronic insomnia, depressive symptoms, increased susceptibility to illness [16,17], anxiety [18], hypertension, cardiac events and increased risk of sudden cardiac death [19]. On a societal level, unresolved grief can place additional demands on an already stretched healthcare system, with the bereaved suffering long term coping problems and subsequent ill health [19].

There is little evidence regarding the quality of current EOL care or nurses' perceptions of providing EOL care in Australian EDs [20]. From the scant evidence available, EOL care in the ED setting has been identified as poor [2,20,21]. Previous research has explored the experience of ED clinicians providing EOL care to patients with dementia [22], with terminal illness such as cancer [2,23] and to residents presenting to the ED from residential aged care facilities [24]. Findings indicate many nurses do not believe they have the knowledge, skills or resources to provide effective EOL care in the ED. A national survey of Australian ED clinicians was undertaken to assess barriers and enablers to providing EOL care for cancer patients. The results indicated that most clinicians (83.8%) agreed that caring for the dying was part of their role. However, the same proportion (83.8%) also believed the ED was not the right place to die [2]. The results of this survey echo findings from other studies conducted internationally, in which clinicians reported that it was not always achievable to provide effective EOL within the constraints of the emergency setting [25,26]. There was little research found examining the experiences, perceptions and needs of nurses providing EOL care in the ED setting in relation to sudden and unexpected deaths.

3. Aim

This study aimed to explore nurses' perceptions and experiences of caring for patients who die suddenly and unexpectedly in an ED setting.

4. Methods

4.1. Study design

A qualitative descriptive approach was used for this study. The aim of this approach is to bring together the views of clinicians (in this case, nurses) and researchers in order to explore issues of clinical importance, such as sudden and unexpected deaths in emergency departments [27]. Qualitative description provides 'a comprehensive summary of an event in the everyday terms of those events' [28, p. 336]. This study was part of a larger investigation of clinicians' perceptions of providing end of life care in the ED. Respondents completed several numeric questions regarding provision of EOL care, which were adapted with permission from an existing survey [29]. Participants were then asked through five open-needed questions to provide further reflections on the areas covered in the survey regarding the five topics; 1) elements of end-of-life care, 2) communication, 3) staff roles, 4) family presence, and 5) the environment and systems, as well as their overall values, beliefs and wishes regarding EOL care in the ED. The findings reported here pertain to the nurses' responses to these open-ended questions. The survey can be viewed in Appendix 1.

4.2. Sample and recruitment

Nurses currently working in an Australian ED who had cared for patients who died in the ED setting were advised of the study via an email to members from the College of Emergency Nursing Australasia (CENA) and the Australian Nursing and Midwifery Federation (ANMF). Recruitment flyers were posted on relevant professional social media websites.

4.3. Ethical approval

Ethical approval was gained from Flinders University Human Research Ethics Committee (Project number 7627). Potential participants were provided with a URL directing them to an online information sheet that gave them access to the online survey (SurveyMonkey). Participants were advised that submitting the survey would indicate their consent to participate. To ensure participant anonymity, no IP addresses were collected during the data collection process and hence the responses were anonymous.

4.4. Data analysis

Data analysis was informed by the methods of grounded theory coding, which allowed the researchers to define what was happening in the data and begin to understand its meaning [30]. Thematic analysis was accomplished using a constant comparative approach [30,31] that allowed the researchers to begin building ideas inductively while at the same time minimising the imposition of existing theories or personal beliefs on the data. Focused coding was then undertaken to synthesise and explain larger segments of the data [30,31]. The most significant and/or frequent initial codes were raised to the level of focused codes, which were used to sift through large amounts of data. The research team then compared and refined coding [30] and re-named some codes to improve their fit. Data analysis was deemed complete when no new codes or concepts could be identified within the categories, that is, theoretical saturation has been reached [31]. Please see Appendix 2 for an example of the coding process.

5. Results

A total of 211 ED nurses completed the online survey; 85% female, 14% male and approximately 1% of undisclosed gender. Most participants (87%) were aged 26–55 years and over three quarters (77%) worked at either major regional, metropolitan or tertiary referral hospitals. The number of responses to the open-ended questions ranged from 57 to 81. Five themes were identified during analysis; 1) key elements of EOL care, 2) systemic and environmental barriers, 3) educational deficits, 4) role ambiguity, and 5) emotional impact.

5.1. Key elements of end-of-life care

Effective communication emerged as the most important element of EOL care. Open and honest communication was valued highly and included accurate prognostic information, explanations about the futility of particular tests and interventions, managing patient and family expectations, and dealing with unrealistic expectations in a timely manner. Participants recommended that explanations be communicated in a clear, easily understood language, minimising jargon and tailoring information to individual levels of understanding. Participants warned against avoiding or delaying difficult conversations and not allowing enough time for unhurried conversations. They also recommended interdisciplinary conversations to ensure consistent information was given to patients and families and nominating one family spokesperson wherever possible to streamline conversations.

> *It is exhausting when five family members phone you and ask the same questions and you have other patients to care for. I try to ask if they can nominate one person, it is usually ok. (Nurse, Metropolitan ED).*

Several other issues were highlighted as key elements of EOL care. They included prioritising EOL care in the same category as life-saving interventions, determining patient's and family wishes, supporting patients/families during the dying process, ensuring staff continuity to build rapport, and offering after-death support to families, such as follow-up phone calls and referral to bereavement counselling.

Family presence was seen as a vital element of effective EOL care. Participants stressed the importance of allowing and respecting individual patient and family choices regarding family presence, allowing/encouraging family to take a break, allocating a dedicated staff member to support family, and acknowledging cultural differences. Support for family presence during resuscitation was divided between being highly beneficial and too traumatic. Many advocated for offering supported family presence during resuscitation and allowing family to decide if they wanted to be present.

> *Many staff hesitate to have family present, making excuses as to why family should or shouldn't be present in resus situations. I believe it should be offered without hesitation to the family, providing they have a support person (staff) with them and stand out of the way but be present. If they are not comfortable to be present, they still need someone with them to offer support, answer any questions. I also believe in some cultures it is imperative to have family present, especially if the person being resuscitated dies. They believe it is of spiritual importance to be with their loved one when they pass away. (Nurse, Regional ED).*

5.2. *Systemic and environmental barriers*

Overcrowding, time pressures, competing priorities, staffing constraints, national emergency access targets, bed block, and inappropriate admissions from aged-care were raised as significant barriers to providing effective EOL care in the ED.

> *Our Emergency Departments are currently way too busy to support a dignified end of life strategy. There is way too much pressure on staff and beds to complete EOL care with the dignity it deserves. (Nurse, Metropolitan ED)*

Critically-ill patients were often prioritised over dying patients due to inadequate staffing ratios. Participants described being torn between providing life-saving interventions to critically-ill patients and providing holistic EOL care to dying patients and their families. They described trying their best but were frustrated by unpredictable workloads and significant time constraints, *'workloads cannot be predicted and there will be times when priorities compete' (Nurse, Metropolitan ED*).

The absence of a standardised approach to EOL care in the ED was identified as another significant barrier, leading to ad hoc and subjective care that was dependent on the skills and attitude of individual nurses. Staff were allocated to support dying patients and their families on an impromptu basis rather than based on their skills and expertise. Advance care planning issues were also highlighted, including frustrations around absent/inadequate advance care directives, confusing documentation processes, and conflicts between patient and family wishes. Participants also highlighted incidences where EOL wishes were not respected by clinicians; for example, when 'Not for Resuscitation' orders were ignored.

Participants emphasised that ED environments are designed to maximise visibility rather than privacy, and stressed that a busy, noisy ED is not an ideal place for dying patients. While some EDs had dedicated spaces/rooms for dying patients and their families, most did not. EDs that did have dedicated rooms often used them for mental health patients or as consulting rooms rather than for their intended purpose. Some dying patients were transferred to the resuscitation room, risking confusion about the patient's prognosis.

> *Most of the time the patient is moved to resus due to no single rooms available. This means the family anticipate we are going to be able to do something to save their loved one unless it is explained to them that we are moving their loved one to resus to provide privacy only. (Nurse, Metropolitan ED).*

Participants called for patients to be transferred to a ward if death was not imminent, believing 'prolonged dying' should not occur in EDs. However, they warned that moving dying patients could reduce patient's feelings of worth and there was the possibility of patients dying in transit. While in the minority, some participants did describe excellent EOL care in their ED and believed EDs were well placed to provide such care.

> *EDs are well placed to care for the dying patient. Our departments may be busy and noisy, and our systems sometimes not geared towards respecting the dying patient. But, when collaborative teams work together, and circumvent rigid systems, we can, and do, provide respectful and dignified care for our dying patients and their loved ones. (Nurse, Metropolitan ED).*

5.3. *Educational deficits*

Participants felt educationally unprepared to provide safe effective EOL care in the ED, with some avoiding dying patients for fear of doing the 'wrong thing'; '*I feel that in my role as a nurse, we do not have any kind of counselling training and so I always worry that I am not saying the right thing' (Nurse, Metropolitan ED)*. The nurses stressed the need for education, which included recognising end-of-life, determining appropriate levels of treatment, transitioning between lifesaving and comfort care, and improving symptom control (e.g. pain, breathlessness). Improving communication skills was seen as a key issue, with many staff not knowing what to say to dying patients and their families, thus avoiding them altogether. As one participant stated; 'I *only have 18 months experience in the workforce so still feel uncomfortable with sensitive discussions'* (Nurse, Metropolitan ED). Therefore, calls were made for targeted education around difficult conversations, delivering bad news, and counselling skills, and for senior staff to mentor junior staff in these skills.

Participants believed quality of EOL care was dependant on the knowledge and skills of the staff on duty and the skill mix at any given time, rather than being tailored for individual patient/family needs. Proactive staff who went 'over and above' were seen as delivering a higher standard of care.

> *EOL in the ED is incredibly variable. In my experience, the particular doctors on make a very big difference, as well as the staff mix of nurses and the work load of the department. Sometimes I feel we do well, other times I feel like I'm fighting a losing battle in achieving what I believe to be best care for the dying patient and their family. (Nurse, Rural ED).*

Participants also highlighted the need to educate staff working in aged care in order to prevent unnecessary transfers to the ED when a patient is nearing or at the EOL; *'sometimes the family have said that they wanted their loved one to stay at the nursing home, but staff felt they couldn't deal adequately with the patient' (Nurse, Metropolitan ED).* However, they acknowledged that while some unnecessary transfers were the result of limited knowledge and skills, others were prompted by family members who overrode patients' EOL wishes to request life-saving interventions. Absent or unclear Advance Care Directives and not knowing the patients' EOL wishes were also believed to lead to unnecessary ED admissions and as a result, patients died in the ED, rather than in their home as the next quote attests;

> *I am sometimes concerned when a patient who has come from a nursing*

> *home has a very clear and concise end of life care plan and NFR order, yet they are still sent to hospital by nursing home staff or at the insistence of the family. I am sure that he patient would much rather die in familiar surroundings than in a hospital. Sometimes the family have said that they wanted their loved one to stay at the nursing home, but staff felt that they couldn't adequately deal with the patient (Nurse, Metropolitan ED).*

5.4. Role ambiguity

There was limited agreement amongst participants regarding whose role it is to care for patients dying in the ED and/or their grieving families. A multi-disciplinary approach was seen as ideal practice, with nurses, doctors, social workers and chaplains working together to ensure the best possible care at the EOL.

> *I think that the care of grieving relatives should be done as a muti-d team. Relatives have varying needs, questions and requirements. People look to doctors, nurses, social workers and chaplains for various needs. I have cared for families who want to talk to the doctor about one issue, … and the nurse, another, and the social worker for something else (Nurse, Regional ED).*

However, systemic and staffing barriers often resulted in a less synergistic approach. Some participants believed social workers and chaplains were best placed to provide EOL care due to their targeted education and training around grief counselling and their ability to devote one-on-one care that nurses and doctors were unable to provide in a busy ED setting. However, many EDs did not have access to social workers and chaplains outside business hours – or at all in some regional, rural and remote EDs. Due to their continual presence in the ED, some participants believed nurses were best placed to provide care to dying patients/families. Others disagreed, citing competing priorities and a lack of training as significant barriers to nurses providing effective EOL care; *'I have had no formal training or ever been provided with information on caring for the dying patient'* (Nurse, Metropolitan ED).

Participants also highlighted differing roles in EOL care within the multi-disciplinary team. For example, doctors were seen to be responsible for explaining the cause of death, answering questions, and making the difficult decision such as when to cease medically futile treatment; *'nurses don't have to make the hard decisions and live with the consequences like doctors do. … it was nice when the doctor made the decision not to push on with cruel futile treatment'* (Nurse, Metropolitan ED). Social workers and chaplains were seen as ideal support personnel for dying patients and their families; '*they are a great resource … they do have training for these situations that nurses don't'* (Nurse, Metropolitan ED). In the absence of social workers and chaplains, nurses stepped into the EOL support role once a decision had been made to cease life-saving interventions. Some participants believed the role title was unimportant to patients and families as long as someone was able to provide this care.

> *Families don't particularly care about what your title is when you are consoling them after their loved one has died. They simply want comfort and guidance as to what happens next (Nurse, Outer Metropolitan ED).*

5.5. Emotional impact

Participants were frequently distressed that many patients and families were not receiving effective EOL care due to multiple barriers previously outlined. Participants wanted to do more for patients and families during the dying process and after death and lamented their inability to spend more time with dying patients and their families; *'when the ED is busy, you don't get that time to give to the patient and families and you can feel like not the right care was given … it stays with you'* (Nurse, Metropolitan ED). Participants were also impacted by EOL conversations, which they described as difficult and stressful, and often 'taboo.' *It is a difficult topic. ED nurses are not specialised in EOL care … it's a topic that is almost taboo in society. That makes our job more difficult' (Nurse, Metropolitan ED).*

Dealing with death and dying on a regular basis impacted the emotional wellbeing of staff, and they requested better and more consistent debriefing. There was commonly no time to formally debrief after a failed resuscitation attempt or a particularly traumatic death and many staff had to organise their own informal debrief with colleagues. Some participants called for mandatory formal debriefing after every death; others recommended it after certain circumstances such as a traumatic death, death of a child, post-accident, or after cardiac arrest. Poorly-timed formal debriefing (many days or weeks after the death) and debriefing led by non-expert facilitators were considered unhelpful by some and a breach of policy by others.

> *Debriefings I have attended give me the s**ts. Run by non-experts, with poor resolution, no follow up, time limited, days later. Cannot stop in the middle of a day to debrief a death. Feel like we are educating the debriefer. (Nurse, Metropolitan ED).*

6. Discussion

ED nurses want to provide high quality care to dying patients and their families and recognise the deleterious effects on everyone involved when this does not occur. Examples of excellent EOL care were reported; but they were related to the efforts of individual clinicians, rather than systematised approaches. Open, sensitive and timely communication within the clinical team and with the patient and family was considered the most important element of EOL care. Participants also stressed the importance of prioritising the care of dying patients, ensuring family feel welcome to be present during resuscitation attempts if they wish, and caring for family during the dying process and in their bereavement.

This research also highlighted multiple barriers which currently may jeopardise the quality of EOL care provided in the ED. Our findings suggest that the frustration and guilt experienced by many ED nurses when they were unable to provide high quality EOL care was largely due to influences outside their control. Many EDs are working over capacity as an ageing population places increased demands on the existing infrastructure [32,33]. Failure to manage these systemic issues may result in poor patient outcomes, dissatisfaction among ED clinicians and contribute to high staff turnover [34,35].

Many EDs are stark, chaotic environments with few comfortable, private spaces within which to provide care to dying patients and their families [25,36]. Lack of private spaces for EOL care is most commonly due to overcrowding or because rooms set aside for this use have been reappropriated, for example to accommodate mental health patients. This reappropriation occurs because the provision of life-saving care is often prioritised over care of the dying, something that has been reported previously among ED clinicians [2,3,9–11]. Our study also found the aspects of chaos, overcrowding and lack of private spaces to be present in many Australian ED's.

Nurses in the current study reported that the competing needs of acutely unwell patients in conjunction with staffing deficits meant they were often unable to dedicate enough time or provide continuity of care to dying patients and their families. This need for more time has also been reported in other research that examines the provision of end-of-life care in the ED [25,36] in relation to emergency nurses in the USA. A culture shift within EDs is needed to address this uneven prioritisation and to promote EOL care as urgent care [4]. While some systemic barriers such as staffing, overcrowding, bed blocks and inappropriate transfers from aged-care are usually outside the control of individual ED clinicians, small changes could be made to improve EOL care such as altering existing physical spaces to ensure a quiet area for dying patients and reallocating staff teams to promote continuity of care.

Lack of a standardised approach to the provision of EOL care was highlighted as another important barrier in the current research. This lack is also reflected in the findings of a study by Wolf and colleagues who found that there was often uncertainty around team members' roles, and conflict sometimes occurred between professional groups regarding the best way to manage EOL care and who is appropriately skilled to provide that care [25]. This uncertainty extended to knowledge and skills, with many participants feeling educationally unprepared to provide quality EOL care, something that has also been highlighted in previous research [37]). ED nurses in the current study stressed the need for targeted education around the provision of safe and effective EOL care such as; having difficult conversations, determining patient and family wishes, recognising EOL, determining appropriate treatment levels, and improved pain and symptom management. However, education alone may be ineffective if systemic barriers remain unaddressed. This suggests that a whole of system approach is therefore required to develop a standardised and sustainable approach to the provision of safe, effective EOL care in the ED, supported by appropriate policies and guidelines.

6.1. *Limitations*

The moderate sample size may limit transferability to similar contexts. Additionally, the structure of the survey tool with pre-defined sections may have influenced participant comments to some degree, however, this aspect was desired in the research as the participants were able to elaborate on specific areas of care within the ED. Irrespective of these limitations, this study does provide a unique insight into the perceptions and experiences of Australian nurses when caring for patients who die suddenly and unexpectedly in the ED.

7. Conclusions

ED nurses want to provide high quality care to dying patients and their families and recognise the harmful effects on everyone involved when this does not occur. However, multiple barriers exist which jeopardise this care. A conscious shift in attitude is required; care of the dying and their families deserves the same processes and considerations that are applied to life-saving care. Specific training in how to provide this care, including communication skills, recognising end-of-life, processes for determining a patient's wishes for care, is considered essential by ED nurses. They also highlighted the importance of a dedicated physical space in the ED for EOL care, role clarity, the availability of a multi-disciplinary team and debriefing opportunities as vital components in the provision of safe and effective EOL care in the ED. A systematised, yet flexible approach is required, as occurs with other conditions treated in the ED, so that the care of dying patients is not reliant on the presence of passionate individuals but becomes the business of the whole hospital.

Ethical statement

No individual identifiers were collected to ensure anonymity of participants. The Flinders University Social and Behavioural Research Ethics Committee approved the study (Number 7627).

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Declaration of Competing Interest

None

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ienj.2019.100789.

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