Exploring the quality of the dying and death experience in the Emergency Department: an integrative literature review.

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Abstract

Aim: The aim of this integrative literature review was to explore the quality of the dying and death experience in the Emergency Department from the perspective of staff and carers.
Background: Death in the Emergency Department is common. Understanding the quality of the death and dying experience of patients and their family members is crucial to building knowledge and improving care.
Design: Systematic integrative literature review reported following the PRISMA guidelines. *Data Sources :* Pubmed, Cumulative Index to Nursing and Allied Health Literature , Magonline (internurse), and the Cochrane library. Articles used were published in English during 1990-2017.
Review Method: Appraisal and thematic analysis.
Results: Sixteen articles are included. Eight themes emerged from the literature : *care in the Emergency Department is about living not dying, staff perceive that death is a failure ,staff feel underprepared to care for the dying patient and family in this environment, there is limited time for safe standards of care, staff stress and distress, staff use of distancing behaviours, the care of the dying role is devolved from medics to nurses at the end of life, and patients and staff perceive that the Emergency Department is not the preferred place of death*
Conclusion: There are areas of concern about end of life care in the Emergency Department. To improve practice and to ensure that a good death occurs, further research is needed. There is a need to understand more about the experience of caregivers when a relative or friend dies in the Emergency Department.

Contribution of the paper

- **Why is this review needed?**
  - Initiatives to improve care of the dying are currently in the forefront of healthcare.
  - Research into the care of the dying is widespread particularly in the hospice and older person care sectors. However, there is little research into the care of the dying in emergency settings and virtually no studies exploring the experience of informal carers in these settings.
  - Identifying strategies which may enhance the experience of dying for both patients and carers in the emergency setting has the potential to change and improve practice and outcomes.

- **What are the key findings?**
  - The culture of the Emergency Department ensures a strong focus on life saving, therefore is not conducive to staff providing end of life care according to established palliative care principles.
  - Medical and nursing staff feel overwhelmed and underprepared to care for those at the end of life and their carers. More formal and informal education is needed.
  - Staff feel a sense of failure when a patient dies which impacts on their ability to care holistically for the bereaved carers.

- **How should the findings be used to influence practice, research and education?**
  - Findings highlight the potential for carers to have a poor experience in the ED following a death in the department. Nurses in practice may use this review to inform policies that ensure interventions to prevent this are delivered in a compassionate and timely manner.
  - The lack of research into the unique experiences of bereaved carers in this environment is emphasised. This demonstrates the need for further research.
  - Findings from this review may be used to inform curriculum development around palliative care in general and end of life care in the Emergency Department in particular.

Key words: Integrative literature review, Emergency department, death and dying, nursing, carers.

Introduction

Individuals may present to the Emergency Department in the end stages of life, from acute injury or from more chronic underlying causes. Ensuring these people are placed on the most appropriate pathway is essential, as they may not be in the most suitable environment for their needs. Emergency medicine is about triaging, diagnosing and treating life-threatening trauma and diverse medical / surgical conditions and managing prehospital and in-hospital emergency care(http://www.rcem.ac.uk, 2015). There is a societal expectation that the goal of emergency care is immediate resuscitative, life- preserving treatment (Chan, 2006, Clarke, 2008), rather than holistic care of the dying person, focusing on comfort and the achievement of a good death (Clarke, 2008).

Background

In health care generally, there is a growing amount of discussion of death and what makes a good death. Pivotal work in the United States by Glaser and Strauss, published in the mid- 1960s (Glaser and Strauss, 1965, Glaser and Strauss, 1968) brought the idea of improving the death and dying experience for hospital patients in both acute and non-acute areas into mainstream discussion (Clark, 2007). Glaser and Strauss , both sociologists working in the US healthcare system ,were instrumental in promoting the concept of awareness of dying , where both the patient and carer are aware of the approach of death, as opposed to closed dying where the patient was not aware, which had previously been the norm (Seale et al., 1997). This patient-focused stance was revolutionary, allowing the needs of the dying person to be fully explored and his or her problems to be those defined by the patient rather than by medical / nursing staff or relatives. There is evidence that as far back as 1975, clinicians in the Emergency Department were beginning to discuss the management of the dying; and that this discussion has continued (Cauthorne, 1975, Jones, 1978, Soreff, 1979, Ordog, 1986, Adamowski et al., 1993, Edlich and Kubler-Ross, 1992, Tye, 1996). Topics of discussion include Jones (1978) work on communication between relatives and staff in the Emergency Department, including the need for a comprehensive and compassionate approach, which was echoed by Sorreff (1979) and Ordog (1986). Recommendations included clear instructions on breaking bad news, supporting the family through their initial reactions and looking after the multidisciplinary team(Parrish et al., 1987) . There is evidence from the writing of Tricia Scott, that Emergency Department personnel attempt to find meaning in even very difficult situations following a death (Scott, 2013). The writer discusses the ‘dualistic culture’ (Scott, 2013) which exists in the Emergency Department from the perspective of staff in which speed, rigor and perhaps separation of feelings are side by

side with the spiritual matters which come to the forefront when dealing with sudden death.

This emphasis on a holistic approach mirrors the principles of the emerging speciality of palliative care, being developed in the UK by Cicely Saunders (Clark, 2007), who was instrumental in opening the worlds' first modern hospice in 1967 (Clark, 2007). The term 'palliative care' could be said to have originated in Canada from the work of Derek Doyle in the 1970s and '80s (Doyle, 2003, Fadul et al., 2009). His work was hugely influential in deciding upon a definition of the concept, ultimately accepted by the World Health Organisation (WHO) : Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification of symptoms , assessment of the entire patient and the holistic treatment of problems (Gomez-Batiste et al., 2013). The ultimate aim of palliative care is the achievement of a good death (Emanuel and Emanuel, 1998).

Despite the importance of palliative care, concern has been expressed that the concept is not widely taught in medical education generally (Sullivan et al., 2003, Meo et al., 2011, Frey et al., 2014, Horowitz et al., 2014, Cheng and Teh, 2014), although the Royal College of Emergency Medicine does have a guidance document about end of life care (http://www.rcem.ac.uk, 2015). Linked to this, there is relatively little mention of end of life care in Emergency Department textbooks (Rabow et al., 2000, Markovchick et al., 2011). This is despite the early work by pioneers in the 1970s as mentioned above, emphasising the need for staff education to enable better care experiences for dying patients and their carers. Interestingly, these papers (Cauthorne, 1975; Jones, 1978; Soreff, 1979; Ordog, 1986; Adamowski et al., 1993; Edlich and Kubler-Ross, 1992; Tye, 1996) advocated core palliative care principles (NICE, 2017), although the term 'palliative care' was not mentioned and there does not appear to have been any explicit attempt to link-up the two specialties of emergency medicine and palliative care.

Currently, there is no one accepted model of palliative death and dying care integration within the Emergency Department in the United Kingdom or elsewhere in the world (Weil et al., 2015, Chan, 2004, Chan, 2006, Chan et al., 2016, DeVader et al., 2012). Internationally, there is increasing recognition that this is an area of concern. Initiatives such as encouraging closer multi-disciplinary team working, are taking place in order to close the gap between these two specialities; in the United States (Lamba and Quest, 2011, Lamba et al., 2014, Quest et al., 2012, Young et al., 2016), Australia (Weil et al., 2015, LeBrocq et al., 2003), and the UK (Bailey et al., 2011b, Bailey et al., 2011a). There is a conscious drive to include formal palliative care education in the medical and nursing curricula in many areas (DeVader et al., 2012; Quest et al., 2012) and

initiatives to improve research in this vital area are being developed (Chan, 2006; Lamba et al., 2014). Emphasis is beginning to be given to looking at patient care in a more holistic manner than perhaps has been done in the past with a focus on viewing individual patient conditions as fluid and constantly changing, and assisting staff to be prepared for these changes (Bailey et al., 2011c).

This paper will review what is currently known about the quality of the death and dying in the Emergency Department, and what the experience is like for the carers and the staff looking after these individuals. Allowing people who have been through the reality of watching a loved one die or caring for a patient who is dying, to tell their story through whatever medium, is a very powerful concept and a way to humanise clinical events (Greenhalgh, 2017).

A note on definitions: End of life care is a term that has been used interchangeably with palliative care, hospice and terminal care. Various writers have debated this term and proposed new definitions (Izumi et al., 2012, Neuberger, 2016, Greater Manchester and Networks., 2015). For the purposes of this paper, the definition proposed by NHS (National Health Service) England (NHS 2016) , where end of life care is defined as support for people who are in the last months or years of their lives, is the preferred definition. Dying and death is the culmination of end of life care.

The term 'carer' is used as a generic term for friends, families, loved ones (Ewing and Grande, 2013, Fuller, 2012, Dosser and Kennedy, 2014). Throughout this paper the term 'carer' is used to signify caregivers, relatives, family members, friends and loved ones.

The review

Aim: The aim of the review was to explore the quality of the death and dying experience in the Emergency Department from the perspective of staff and carers.

Design and methods.

A systematic integrative literature review was conducted (Aveyard et al., 2016). The review was designed with the aim of discovering the quality of death and dying in the ED, from the perspective of staff and carers.

Search methods

Firstly a systematic search of Pubmed, the Cumulative Index to Nursing and Allied Health Literature, Magonline (internurse), and the Cochrane library was undertaken. The search was limited to research papers written in English and published within the period 1990 – 2017. The

search started In 1990, as this was the date in which the World Health Organisation (WHO) set out the scope and definition of palliative care and began to suggest how these should be pursued as public health issues (WHO, 1990) . This was a global landmark for palliative care. The WHO paper published recommendations for the implementation of palliative care at the national level and therefore it could be assumed that papers published after this point are influenced by the ideas contained in this paper. Secondly the 'snowball method' (Perez-Bret et al., 2016) was used. This involves selecting studies cited by the articles found. It is recognised that electronic searching may not identify all published material and hand searching was also undertaken looking at (for example) journal contents pages and reference lists.

Inclusion and exclusion criteria for electronic database reviews

Inclusion criteria:

Target population (the dying person) over age 18

Care setting (Emergency Department)

Papers written in English

Papers published between 1990 – 2017.

Primary research

Research looking at the experiences of clinical staff and carers.

Exclusion criteria

Care setting both Emergency Department and another area for example death and dying in the ED and in acute general medical care.

Papers which focus on the concept of resuscitation.

Inclusion and exclusion criteria for snowball method

Inclusion criteria

Target population (the dying person) over age 18

Care setting (Emergency Department) – adult patients over 18 only

Papers written in English

Papers published between 1990 – 2017.

Qualitative and quantitative studies looking at death and dying in the Emergency Department

Exclusion criteria

Care setting both Emergency Department and another area for example death and dying in the Emergency Department and in acute general medical care.

Papers which focus on the concept of resuscitation

Screening

A search strategy was devised using a combination of Medical Search Headings (MeSH) terms and key words.

Table 1: MESH

Thirty two articles were then examined. Of these, three were literature reviews of published work (Norton et al., 2011, Roe, 2012, Olsen et al., 1998) and were therefore excluded, not describing original research. They were, however, extremely useful and helped to inform the literature search. Figure 1 below presents a diagrammatic representation of the search strategy.

Figure 1 : Prisma flow diagram to show search strategy (Moher et al., 2009)

Search outcome

Fourteen articles were excluded after full text screen and two during data extraction. Sixteen articles were included in the final analysis.

Table 2 shows the characteristics of each paper. The papers were assessed for relevance and quality of research using the assessment tool available from NICE (National Institute of Clinical Excellence) (Zeng et al., 2015, NICE, 2012), chosen because of the clarity of the material and the scoring system. Many assessment tools are available and the NICE tool has much in common with other available tools (Ryan et al., 2007, Saini and Shlonsky, 2012, Flemming, 2007, Greenhalgh, 2014). The score for each paper can be seen in Table 2 below. It is worth noting that whilst there are many studies looking at the experiences of nursing and medical staff, no study specifically asked carers for their point of view.

Table 2.

Quality appraisal.

The papers studied are mainly qualitative papers, with three quantitative and two mixed methods study also included. In order to analyse papers written using different methods, it was appropriate to undertake a thematic analysis. This approach allows a qualitative synthesis of original qualitative, quantitative and / or mixed methods studies through the extraction of first data codes and then emerging themes (Thomas and Harden, 2008, Dahan-Oliel et al., 2012). Themes are built from the text of selected studies allowing full appreciation of the richness and depth of the data (Dahan-Oliel et al., 2012).

Data abstraction and synthesis

Text from the selected studies was coded by highlighting relevant parts of the text and assigning code words to these areas. Following this an iterative process was used to develop categories by combining codes. Descriptive themes were attached to each category and are discussed below.

Results.

After analysis, eight themes emerged from the literature: *care in the ED is about living not dying, staff perceive that death is a failure , staff feel underprepared to care for the dying patient and family in this environment, there is limited time for safe standards of care, staff stress and distress, staff use of distancing behaviours, the care of the dying role is devolved from medics to nurses at the end of life,* and *patients and staff perceive that ED is not the preferred place of death*

Figure 2 is a graphical representation of the relationship between these themes. It is intended to show visually that the themes are all inter-related, and that each theme flows from the previous one and is indivisible from it.

Figure 2: Issues which may contribute to the quality of the death and dying experience in the Emergency Department from the perspective of staff and carers

The themes.

Staff perceive that the focus of care in the Emergency Department is about living, not dying.

This was the most common theme to emerge (Bailey et al., 2011b, Bailey et al., 2011c, Grudzen et al., 2011, Wolf et al., 2015, Kongsuwan et al., 2016, Smith et al., 2009, Decker et al., 2015, Chan, 2011, Weil et al., 2015, Marck et al., 2014). Patients are seen as 'living' and the focus is on preserving life, until life ends, therefore there is no period of time where a patient is said to be 'dying'(Bailey et al., 2011c) . Bailey et al also found an emphasis on 'spectacular life-saving'. Bailey at al's' (2011b) ethnographic study explored patient pathways towards death in the Emergency Department (Bailey et al., 2011b). This builds on work by Timmermans (2005) who explored the various pathways towards death and the cultural influences on these pathways. The authors found that there were two ways of dying (trajectories) which they define as spectacular (acute, sudden, resulting in traumatic loss of life, will always include a resuscitation event) and subtacular (quiet, expected deaths, often of those who have been ill for a long period of time, not a priority to staff). Patients who had 'spectacular' deaths were not considered to be 'dying', and there was much necessary action around these deaths.

Similarly, a Singaporean retrospective study (Yash Pal et al., 2017) looking at deaths among people over 65 in the Emergency Department, found, that there were two main trajectories of dying: patients with a known chronic illness and those who experience sudden death. Of those who had a known illness, very few had had previous end of life care discussions which led to unnecessary and aggressive life preserving treatment being given (Yash Pal et al., 2017).

Staff perceive that death is a failure.

In a further paper (Bailey et al., 2011c) found that staff felt that the Emergency Department was not appropriate for end of life care and that death was seen as out of place, with the dead body almost seen as taboo, to be hidden away, staff perceiving the body itself to be a physical sign of failure. Failure in the context of Emergency Department death is mentioned by Marck et al (2014) and Kongsuwan et al (2016). One nurse participant is quoted as saying that 'palliative care in the Emergency Department is focusing on saving life'(Kongsuwan et al., 2016), thus denying the possibility of death being seen as a natural part of life. One study of the views of clinical staff, found that stigma was associated with dying in the Emergency Department, especially if the dying patient was young – 'it looks like [the Emergency Department] didn't do their job' (Wolf et al., 2015).

Staff feel underprepared to care for dying patients and their carers in the Emergency Department.

Staff feeling unprepared to care for dying patients was a common theme. Nursing staff felt particularly underprepared, (Bailey et al., 2011b, Beckstrand et al., 2012b, Decker et al., 2015, Hogan et al., 2016) although both Weil et al (2015) and Smith et al (2009) show that this is a concern for the whole multidisciplinary team. Feeling underprepared took the form of a desire for formal education (Bailey et al (2011)in order to replace /enhance relying on learning from others, and their own experience (Bailey et al., 2011b)..

Physicians not feeling prepared to assist patients who are dying in the Emergency Department was identified by Smith et al (2009) in a focus group study. Smith et al (2009) concluded that palliative care is neither a goal of emergency medicine trainees nor a focus of their training, and this was mentioned as a statement of fact rather than a desire to change things (Smith et al., 2009). Further education in pain and symptom management was however a goal for all staff groups in the same study, and emergency medicine residents in particular were troubled by the lack of this (Smith et al., 2009) . In addition, diversity education was identified as needed as there was a perception that ethnic minority patients have a worse outcome as regards pain and symptom management; a perception borne out by the literature (Pletcher et al., 2008, Dickason et al., 2015, Mills et al., 2011).

Inconsistency in the use of the term palliative was an education-focused problem found in the work of Weil et al (2015), who discovered that participants in general thought palliative care was synonymous with terminal care (Weil et al., 2015). This is an unhelpful confusion which is common throughout the literature (Smith, 2011), and could be assuaged by further education (Head et al., 2014, Kamel et al., 2015).

There is limited time for safe standards of care.

Six of the published articles mentioned the lack of time and / or resources to allow staff to properly care for the dying patient and their carers in the Emergency Department. Perhaps unsurprisingly, when Beckstrand et al (2012) asked emergency nurses what things they felt would improve end of life care in the Emergency Department, the first and most important finding was increased time (Beckstrand et al., 2012b, Beckstrand et al., 2012a). Interestingly this shows that the perception of the nurses was that dying patients require more time and consistent nurse presence, and that dying patients and families were currently not receiving optimal care because the time was not available. One nurse mentioned that she knew what to

do (to care for dying patients) but unfortunately, she never had the time to carry out essential care of the dying (Beckstrand et al., 2012b).

These researchers also mentioned the need for a better environment for the dying This would optimally include a comfortable room in which to nurse these patients and allow more privacy at the end of life. These findings echoed the earlier work of Beckstrand et al (2008), who found that emergency nurses workload was too great to enable the time needed for good end of life care (Beckstrand et al., 2008). This was perceived as an important obstacle in the practice of end of life care and one that caused distress to the nurses surveyed, also known as a constant issue and problem for the (USA) Emergency Nurses Association (Wolf et al., 2017).

Lack of space, time and staff are again cited as the most important challenges for emergency nurses in attempting to care for end of life patients in the Emergency Department, in Wolf et al's 2015 study (Wolf et al., 2015). Nurses were distressed by resource limitations, perceiving that patients may feel 'neglected' because 'we're always short staffed'. It is an issue perceived as something which it may not be possible to 'fix' – one respondent stated that education is not the answer, 'it's not going to … bring those resources' (Wolf et al., 2015). Nurses felt impoverished by this inability to give patients the time they need, and this had a real impact on practice (Ceci, 2006). Lack of resources impacts everything – nurses are traumatised because they have to prioritise some patients over others, and importantly make decisions, for example about moving a bereaved family out of an area so that another patient may move into it (Wolf et al., 2015). This trauma has a huge effect on staff and is a large part of the general stressors affecting those who work in the Emergency Department (Johnston et al., 2016).

A lack of time is echoed in the work of Kongsuwan et al (2016) , Decker et al (2015) and Marck et al (2014). Findings indicated that the stress of being unable to provide what the participants describe as a 'peaceful' death (due to lack of time) was particularly great for the nurses in Kongsuwan et al's study, partly perhaps because, as the writers remark, the study took place in a prominently Buddhist country where the concept of a peaceful death is particularly important to practitioners of the Buddhist faith for spiritual reasons (Kongsuwan et al., 2016). The participants in Deckers (2015) study describe a less than optimal death trajectory as one in which there is no time and no space to care for patients and relatives during and after death in the Emergency Department (Decker et al., 2015). Marck et al (2014) found that the busy nature of the Emergency Department with its lack of time, privacy and senior staff led to poor communication between patients carers and staff, potentially leading to a suboptimal care experience. Following on from this, Hogan et al (2016) emphasised the need for nurses to feel

they have done their best for their patients and this involved trying to manage the constraints of lack of time and space as well as possible (Hogan et al., 2016).

Staff stress and distress.

Stress and distress from the viewpoint of the staff caring for these individuals was specifically mentioned in five of the papers. Staff in Bailey et al's 2011 study discussed feeling completely out of control when caring for a dying patient in the Emergency Department and because of this, feeling powerless. The stress felt can be overwhelming (Bailey et al., 2011c). The writers focus on this further in a congruent paper (Bailey et al., 2011a) discussing a devised model to explore the development of emotional intelligence in nursing staff around death and dying in emergency work. The aim of the model is to build awareness in managing the emotive aspects involved in care delivery and develop fundamental skills of nursing patients near the end of life. Other writers have commented on the particular need for Emergency Department nurses to maintain emotional intelligence (Codier, 2014, Codier and Codier, 2015, Powell et al., 2015), stating that development of emotional intelligence in the clinical setting holds the potential for both improved patient care and reduced burnout amongst nursing staff(Codier, 2014).

Hogan et al (2016) discusses the effect on nursing staff of witnessing the grief of others. The researchers found participants mentioning that they felt they were looking into peoples' lives in the most sad and tragic moments (Hogan et al., 2016). Nurses discussed how they dealt with this kind of emotional stress, and concluded that the need to feel they had done their best was extremely motivating in these circumstances (Hogan et al., 2016).

Poor communication as a source of stress and distress is specifically mentioned only in the paper by Smith et al (2009) who wrote that poor communication between staff, families and between other departments in the hospital and community, leads to poorer outcomes (Smith et al., 2009). An example mentioned in the text is problems occurring when the patient has a do not attempt resuscitation form in their community notes but this is not known when the patient presents to the Emergency Department. This therefore may potentially lead to the need for further discussions about resuscitation, possibly causing distress to all parties.

Staff use of distancing behaviours.

The use of distancing behaviours was mentioned in seven of the studies. Caring for carers both during the dying process and following death was seen as particular challenging (Bailey et al., 2011c, Kongsuwan et al., 2016, Decker et al., 2015). A lack of time, and perhaps emotional energy are cited as reasons for this with some staff reporting to use distancing behaviours

towards carers because they do not have the time or ability to get more 'involved' (Bailey et al., 2011b, Decker et al., 2015), and some staff report a feeling of almost resentment towards the carers because of a perception that very sick patients at end of life present to the Emergency Department because carers cannot cope (Smith et al., 2009).

From the carers point of view, distancing behaviours are recognised for what they are, and contribute to an overall negative experience (Bailey et al., 2011b), with carers citing general lack of communication, and issues such as feeling in the way or being ignored (Decker et al., 2015). It is important to note that these views are second order constructs, told informally (by carers) to nursing staff who have then repeated them to the researchers. No study specifically asked carers for their point of view, as previously stated.

The care of the dying role is devolved from medics to nurses at the end of life.

Despite the stress, and the feeling that dying patients do not belong in the Emergency Department, some nurses felt privileged when looking after dying patients (Hogan et al., 2016). Participants in Bailey et al's (2011) study felt that as soon as the patient was declared 'palliative' – i.e. no more active treatment, the care passed over to the nursing staff – the care was 'relinquished' to the nurses (Bailey et al., 2011c). This is explored further in another paper by the same authors (Bailey et al., 2011a) who describe how care of the dying is seen by nurses themselves as a predominantly nursing role, implying that nurses who are 'good' at their job, and manage to develop emotional intelligence as above, find reward in their practice, leading to a more positive experience for all concerned. The idea that care of the dying is the province of nurses predominantly is borne out by other literature and could be explored further (Lopera Betancur, 2015, Browall et al., 2014, Gagnon and Duggleby, 2014, Smith, 2012).

Patients and staff perceive that the Emergency Department is not the preferred place of death

Patients views, studied in 2011 (Grudzen et al., 2011) were that attending the Emergency Department would be just a 'safety net' if symptoms were out of control or they were concerned about being a burden to their families. It would be inappropriate to die in the Emergency Department (Grudzen et al., 2011). As mentioned above, the idea that staff had failed in some way if a patient died was paramount.

The idea of palliative care having a negative connotation in the Emergency Department is explored further by Smith et al (2009); the authors quote an Emergency Department physician as saying that people who go into emergency medicine as a career want to 'sort of act, and do, cure' (Smith et al., 2009). Without meaning to be uncaring, indeed this very idea – that care in

the Emergency Department is about living not dying – is in itself a source of distress for staff (Decker et al., 2015, Weil et al., 2015); end of life patients who are requiring palliative care 'get left' and 'come last' in the list of priorities in the Emergency Department (Decker et al., 2015). Another study found that patients presenting to Emergency Department with a palliative 'label' or being referred to palliative care whilst in the Emergency Department (but perhaps not expected to die whilst in the department), were immediately linked to limited care in the Emergency Department and an assumption of a 'terminal prognosis'(Weil et al., 2015).

Alternatively, Marck et al (2014) found that there is a perception that patients presenting at the end of life may undergo futile and pointless treatment in the Emergency Department. 65 % of the respondents to their online survey felt that patients near the end of life are subjected to medical treatment which is unlikely to benefit them (Marck et al., 2014). The authors write that it is important to challenge constantly the need for investigations and treatment and instead question where the best place is for this patient to be (Marck et al., 2014).

Discussion

Despite a comprehensive search, only sixteen articles met the inclusion criteria. The review findings suggest that patients whose lives cannot be saved may have a relatively poor experience of care, along with their carers, when they die in the Emergency Department. The reasons for this are multifactorial and as has been shown, they include the very culture of the Emergency Department, lack of palliative care training for staff and lack of a suitable environment in which to care. Other findings from this review have explored staff stress and distress, the use of distancing behaviours as ways of coping and the eventual take -over of care by nursing staff when patients are considered beyond saving. Ultimately, both patients and staff perceive that Emergency Department is not the best place to die, for all these reasons. The themes are closely linked (see figure 2) and are not distinct, stand alone themes. To address any of the issues means addressing all of the issues.

The idea that the Emergency Department is a place where the focus is on living rather than dying is the main theme to emerge from the literature. The attitude is borne out by the 2015 Best Practice Statement from the (United Kingdom) Royal College of Emergency Medicine(http://www.rcem.ac.uk, 2018); the document begins by stating that members should 'start from a presumption of prolonging life and not hastening death' (http://www.rcem.ac.uk, 2015). As an illustration, Chan (2011) writing about deaths in the Emergency Department mentioned that a female patient attended the Emergency Department with a gunshot wound to her chest and in PEA (pulseless electrical activity, a cardiac condition with a generally grave

prognosis (Littmann et al., 2014)) – but was saved due to an unusual intervention. The staff member reported 'at least five nurses jumped to [this patient]' (Chan, 2011). The patient was very severely unwell, but there was a chance of saving her – this was the patient that the staff attempted to save.

As mentioned earlier, these concerns are not new. Similar issues were being raised in the Emergency Department literature in the mid-1970s (Cauthorne, 1975, Jones, 1978, Soreff, 1979), and the themes from these papers resonate with current findings. Several writers have mentioned the need for further research into ways of improving end of life care in the Emergency Department (Quest et al., 2013, Quest et al., 2011, Chan, 2006); it seems clear that energy needs to be put into ensuring this research happens and that , as Beemath and Zalenski (2009) state, society recognises that birth as well as death are key milestones of life (rather than a 'failure' on the part of the staff attempting to save the patient) and that medical and nursing training needs to be focused on both of these milestones, allowing good deaths to take their rightful place alongside good resuscitations, where both are recognised as different kinds of excellent care (Beemath and Zalenski, 2009).

Having shown that professionals feel underprepared, currently, it appears that the culture of the Emergency Department therefore is not conducive to providing good, holistic palliative care to patients whose lives are drawing to an end. There are colliding ideologies when medical and nursing staff are expected to provide good palliative care in an environment which is not set up for this, either in terms of time for safe care or the physical environment. It is clear that this in itself is a source of stress. Perhaps palliative care is not a realistic approach in an area which is, of necessity, devoted to saving life. Adopting the principles of palliative care certainly demands a culture shift and it may be unrealistic to expect staff to alternate comfortably between saving lives and providing excellent palliative care. One solution put forward by LeFebvre and Platts-Mills, writing in the context of elderly care in the Emergency Department, is to find a way of taking pride in the important responsibility of caring for dying patients and their families (LeFebvre and Platts-Mills, 2016). The writers suggest that a way to do this would be to mirror the approach used for other acutely ill patients such as to have a defined protocol for treatment, as there exists for the management of sepsis. They do go on to acknowledge that deciding when to initiate such a protocol would be very difficult and the pathway would and could not follow a simple algorithm. However there are initiatives in the UK, such as the preferred priorities for care document (Preston et al., 2012, Patel et al., 2012), similar to an advanced directive for people at the end of life, and also in other parts of the world (Ng et al., 2013, Stanford et al.,

2013, Yonashiro-Cho et al., 2016). There is evidence that more research is needed to fully integrate these initiatives into practice(Houben et al., 2014).

Several studies reported the use of distancing behaviours from the professional staff, for a variety of reasons. However, consistent with previous literature, this review found that nurses have a pivotal role to play in the management of the death and dying experience once this has become inevitable (Norton et al., 2011, Olsen et al., 1998, Roe, 2012). Historically, as in many areas of professional nursing (Laurant et al., 2005, Martinez-Gonzalez et al., 2014), this has been led by medical staff (Cauthorne, 1975, Jones, 1978) but as noted above, when care is relinquished by physicians, nurses take over and manage the end of life phase (Bailey et al., 2011a, Bailey et al., 2011c). Although this may imply a lack of collaborative working, the literature does show that it is beginning to be recognised that caring for the palliative and actively dying in the Emergency Department must use a multi-disciplinary model (Quest et al., 2009, Quest et al., 2013, Lamba et al., 2014).

The Emergency Department is not generally the preferred place for death, as the only study looking at patients views showed. An individual facing a terminal illness is likely to worry about how the people close to them will cope. This was the most important concern mentioned in the paper by Grudzen et al (2011) which detailed reflections of patients at the end of life visiting the Emergency Department (Grudzen et al., 2011). Family was seen as very important and the participants mentioned a real need to maintain self-sufficiency for as long as possible for the sake of their carers. Not being a burden is seen as highly important. In the light of the discussion above regarding poor experiences of carers, it is clear that care for the patient cannot be separated from care for the carer, poor care towards one will impact on the other and on the staff caring for them. Carers are the lasting legatees of these experiences and their opinions matter. Rather like at a birth, people do not forget the experience of a loved one's death and how this happened (Cronin et al., 2015, Dosser and Kennedy, 2014, Fuller, 2012) .

Despite this, none of the articles examined directly asked the carers about their experiences. When their views are mentioned it is as a secondary source, voiced in the opinion of the nursing and medical staff. This is a major gap in the literature and one that needs to be filled. Voices of carers need to be heard; as Fraser (2012) states, involving carers makes a difference to outcomes for patients (Fraser, 2012). To improve the outcomes for patients of the future, carers views must be sought.

Strengths and limitations

Strengths of this review have been noted including the original area of exploration and the exacting integrative review process undertaken. Limitations of the study relate to the search strategies undertaken, the heterogeneity of the studies identified (including several from the same data set) and limitations of the quality framework used. There is also the potential for language bias (all the studies were in English) and publishing bias (publications post 1990 only).

Implications for practice, research and education

This review has shown that while there is a body of evidence to suggest that care of the dying patient in the Emergency Department needs to be improved, there is a general lack of research evidence available regarding the experience of carers when a patient dies in the Emergency Department. There is therefore (since it is impossible to study the experience of patients who have died) little evidence to inform practice related to how best to care for dying patients and their carers in the Emergency Department. Findings from this review highlight the need for further study in this area, especially concerning how best carers can be supported and what their needs might be in this situation.

Conclusion

There is ongoing multinational societal and healthcare debate on the need for high quality care at the end of life. This integrative review has made a contribution to these discussions through bringing together literature about care of the dying individual in the Emergency Department and the support needs of their families and friends (carers). This area has not been well explored to date and as highlighted, the views of the carers have not been researched. This review has therefore raised awareness about this important issue, articulating the need for further work to inform practice and contribute to the evidence base for end of life care.

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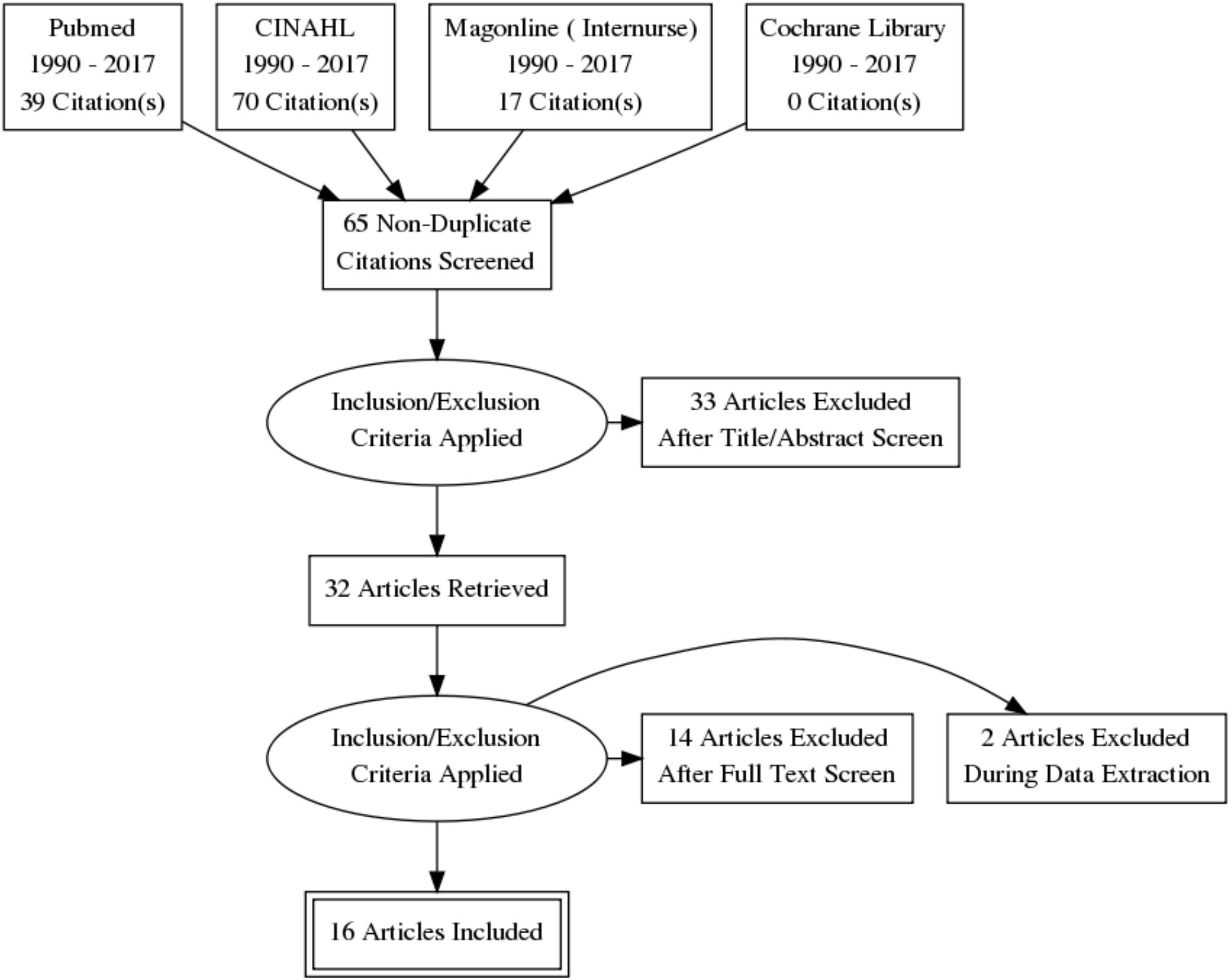
Figure(s)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Criteria Applied
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After Title/Abstract Screen
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Criteria Applied
14 Articles Excluded
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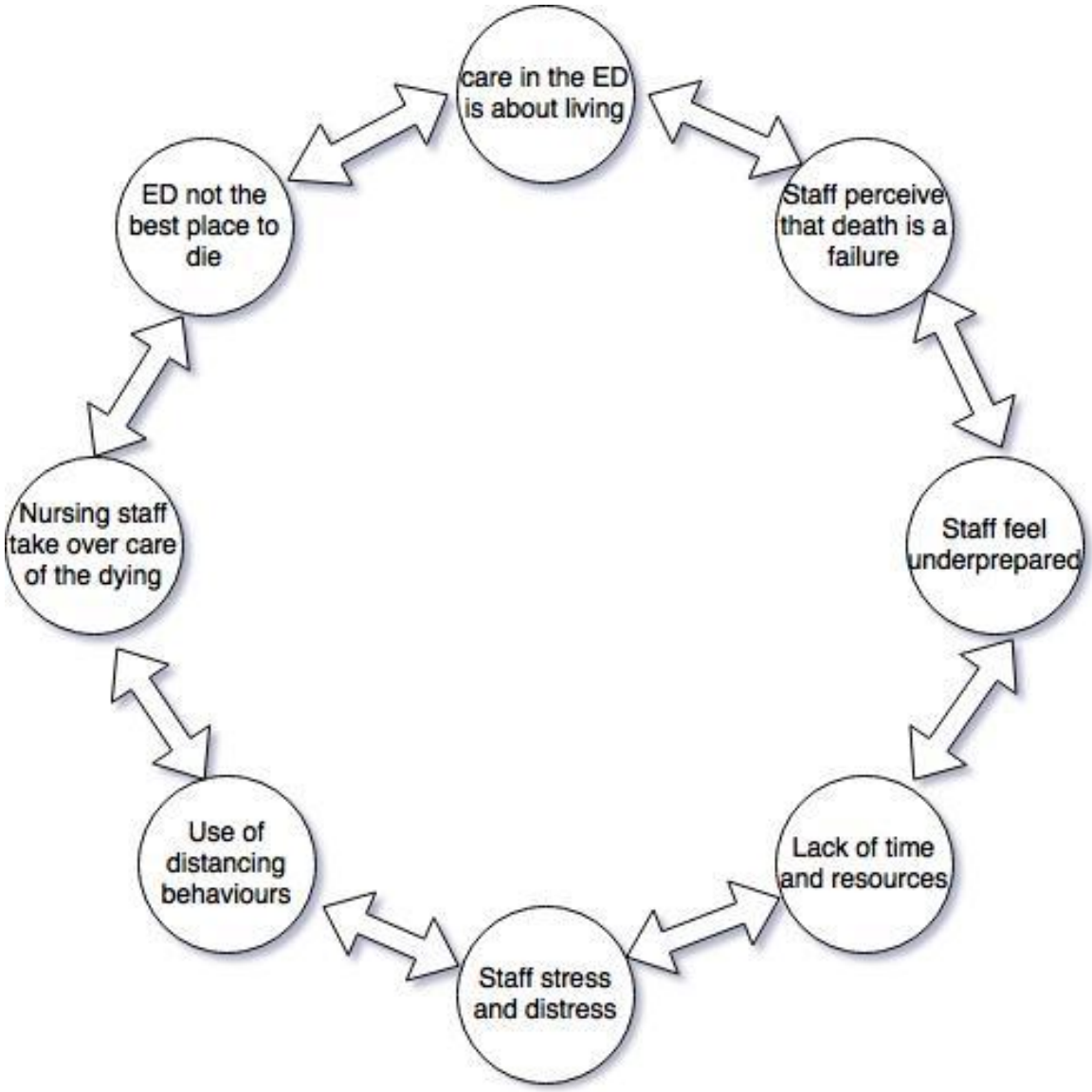
16 Articles Included

Figure(s)

Figure 2: Issues which may contribute to the quality of the death and dying experience in the ED from the perspective of staff and carers.



Table(s)

Table 1: search terms MESH headings

Concept	Dying	Emergency Department	Caregivers	ED staff	End of life
MeSH	Death Death, Sudden	Emergency Service, Hospital	Caregivers , Family , Spouses , Friends .	Nurses ,Medical Staff ,Allied Health Personnel .	Terminal care , Palliative care , Death, Sudden
Keywords	Dying , Death	'Emergency Department' , Accident and Emergency , Emergency Nursing	Carers , Spouse	Doctors , Chaplains , Nurses , Allied Health Professionals	'End of life care ' Palliative care OR sudden death

Table(s)

Table 2.

Article number	Author / Year / Country	Study Objectives	Setting / Sample Size	Methods	Results and main themes	Study Limitations	NICE score
1.	Bailey et al 2011. UK	To explore end of life care in the ED and to provide an understanding of how care is delivered to the dying, deceased and bereaved in the emergency setting.	Large urban ED. Observations – n = 100 + Interview: Staff n= 15 Patients and relatives n=13.	Qualitative: Ethnographic approach using observation and interviews.	Patients who die in the ED are cared for in 2 ways – subtacular (worse experience) and spectacular (better experience).	Data collected from 1 ED only, not necessarily generalizable to other ED within and without the NHS. Majority of data collected from nurses, physician data limited and from SPRs only, may not be reflective of entire medical team.	++
2.	Bailey et al 2011. UK	To examine how space is used to 'care' for patients at the end of life and to explore further meaning behind attitudes to the dying in the emergency setting.	Large urban ED. Observations – n = 100 + Interview: Staff n= 15 Patients and relatives n=13.	Qualitative: Ethnographic approach using observation and interviews	Patients near the end of life who require palliation are often segregated in the ED and have little status. Some deaths are seen as 'out of place' and are concealed.	Data collected from 1 ED only, not necessarily generalizable to other ED within and without the NHS. Majority of data collected from nurses, physician data limited and from SPRs only, may not be reflective of entire medical team.	++
3.	Bailey et al 2011. UK	To explore how emergency nurses manage the emotional impact of death	Large urban ED. Observations – n = 100 + Interview:	Qualitative: Ethnographic approach using observation and interviews	ED nurses develop expertise in EoL care by progressing through 3 stages of development: 1. Investment of the self. 2	Data collected from 1 ED only, not necessarily generalizable to other ED within and without the NHS. Majority of data collected from	++

		and dying in emergency work.	Staff n= 15 Patients and relatives n=13.		Management of emotional labour 3. Development of emotional intelligence.	nurses, physician data limited and from SPRs only, may not be reflective of entire medical team.	
4.	Beckstrand et al 2012 b. USA	To determine what suggestions emergency nurses have for improving EOL care.	Postal survey sent to national geographically dispersed random sample of 1000 emergency nurses.	Qualitative: Questionnaire survey using open-ended question: 'What aspects of EoL care would emergency nurses change to improve how patients die in an ED?	5 major themes: increasing the amount of time ED nurses have to care for dying patients, allowing family presence during resuscitation, providing comfortable patient rooms, providing privacy, providing family grief rooms.	Responses were only obtained from nurses who were members of ENA and therefore can be generalised only to emergency nurses who ae members of ENA.	++
5.	Beckstrand et al 2012 a. USA	To determine how ED design affects EoL care nursing	Postal survey sent to 500 randomly selected members of the emergency nurses association (ENA).	Quantitative: 25 item questionnaire survey	2 main themes: lack of privacy for dying patients and their families, and general lack of space in the ED.	Nurses were not asked about the date of construction of their ED, not about how many shifts they worked per month.	++
6.	Beckstrand et al 2008. USA	To determine what obstacles impede the delivery of end of life care in emergency departments	Postal survey sent to geographically dispersed random sample of 700 ED nurses	Quantitative: 70 item questionnaire survey.	Response rate of 46.3%. Nurses reported that the greatest obstacles to EoL care were lack of time, poor design of ED depts. and family members not understanding what 'life-saving measures' means.	Small sample size, although randomly selected. Not generalizable to emergency nurses who are not members of ENA.	++
7.	Grudzen et al 2011. USA	To understand perceptions regarding their illness of patients who present to the ED at the end	Urban Public Hospital. Convenience sample of 13 seriously ill ED patients with advanced	Qualitative: Semi structured one on one interviews. Grounded theory used to analyse.	Patients with advanced illness present to ED when symptoms are out of control. They often have financial concerns, want to spend time with family and do not want to be a burden.	Small sample size. Generalizability to other EDs is limited. All subjects were seen by palliative care in the ED which may have influenced answers. Triangulation of findings through	+

		of life	illness.		Religious faith is important as is control over their own fate.	interviews with carers and staff may have provided richer data. Ethical approval for the study was not mentioned.	
8.	Wolf et al (2015). USA.	To explore emergency nurses' perceptions of challenges and facilitators in the care of patients at the EOL.	Questionnaire survey sent to 1,879 ED nurses geographically dispersed nationally. 2 Focus (n= 17 nurses) groups took place at an emergency nursing annual conference.	Mixed Methods: quantitative questionnaire survey and focus groups.	Emergency nurses are comfortable providing EoL care in the ED. Challenges to providing good care include lack of space, time and staff, also mismatch between the goals of emergency care and those of EoL care as well as the emotional burden of caring for the dying.	Limited generalizability of findings due to self-selecting samples both for the survey and the focus groups.	+
9.	Kongsuwan et al 2016. Thailand	To describe the meaning of nurses' lived experience of caring for critical and dying patients in the emergency rooms.	3 emergency rooms of tertiary hospitals in Southern Thailand.	Qualitative: in-depth individual interviews with 12 ED nurses. Data analysed using van Manen's hermeneutic phenomenological approach.	Experiences of caring for critical and dying patients revealed 4 thematic categories: defying death, no time for palliative care, lacking support for family and privacy for peaceful deaths.	As the study was conducted in Thailand, the possibility that Buddhist beliefs influenced the results (Buddhists require a calm and serene atmosphere before death in order to achieve enlightenment) may be considered to be a limitation and make the findings less generalizable. The authors do not recognise any limitations, which is in itself a limitation.	+
10.	Smith et al 2009. USA	To explore the attitudes, experiences and beliefs of emergency providers (doctors,	2 academic EDs in Boston, USA.	Qualitative: 3 focus groups with 26 providers. Data analysed using grounded theory approach,	Six themes: participants equated palliative care with EoL care, participants disagreed about the feasibility and desirability of providing palliative care in the ED, patients for who a	Limited generalisability to other settings. The extent to which participants interacted with the palliative care teams is unknown. Small sample size and risk of selection bias. Physicians were inexperienced and therefore	++

		nurses, social workers and technicians) about palliative care in the ED.			palliative approach has been established often visit the ED because of symptoms, lack of communication between different departments leads to undesirable outcomes, conflict around withholding life-prolonging treatment is common, and training in pain management is inadequate.	again findings not generalizable to all physicians.	
11.	Decker et al 2015. Australia	To describe the experiences of emergency nurses in providing end of life care in the emergency department.	3 EDs within an Australian tertiary hospital network.	Qualitative: 3 focus group interviews. Data analysed using grounded theory.	10 categories emerged from the data that described a social process for managing death in the ED, with the categories linked via the core category labelled 'dying in the ED is not ideal'.	Findings not generalizable to other settings in a different part of Australia, or other settings. Study very small.	++
12.	Weil et al 2015. Australia	To explore the understanding of palliative care by healthcare professionals caring for patients with advanced cancer attending emergency departments for EoL care.	2 Australian University Hospitals (first, focus group, stage), telephone interviews with purposive sample of staff across Australia.	Qualitative: 2 stage study, 8 focus groups followed by 11 semi structured phone interviews.	Main theme – health professionals held contradictory (and unhelpful) understandings of palliative care and its application in the ED. Palliative label may lead to unduly limited care in the ED.	Self-selected sample possibly representing people who were already interested in the topic, therefore may not be representative of other health care professionals. Focus groups can be influenced by particularly vocal participants.	++
13.	Chan 2011.	To identify	Level II trauma	Qualitative:	Data gave rise to 7	Limited generalisability outside	++

	USA	different trajectories of approaching death in an effort to describe the EOL experience in the ED.	centre ED Northern California	ethnographic approach, interpretive phenomenological study. Participant observation, brief interviews and in-depth interviews.	trajectories of approaching death in the ED. The author states that recognising and using these trajectories will allow appropriate care, ease transition to EoL care and benefit patient, family and clinician by allowing all possibilities to be explored including appropriate anticipatory planning.	single community hospital in California. Small sample size and risk of selection bias. Only experienced individuals were included.	
14.	Hogan et al 2016. Canada	To explore the experiences of emergency nurses who care for patients who die in the emergency department in the Canadian context.	Large Canadian academic health sciences system. 11 ED nurses.	Qualitative design, interpretive descriptive approach.	Three major themes: 'It's not a nice place to die' 'I see the grief' and 'Needing to know you've done your best'. Environment of care was a big factor in complicating the care of dying patients and their families (unpredictability, busyness, noise, lack of privacy, need to manage several patients simultaneously).	Limited generalisability due to small sample size and self-selecting sample.	++
15.	Marck et al 2014 Australia	To assess the barriers and enablers regarding end-of-life care for cancer patients as perceived by Australian ED clinicians.	Online survey sent to members of the College of Emer- gency Nursing Australasia (CENA), the Australian College of Emergency	Mixed methods survey	Three major themes: Care of the dying patient – respondents felt it was rewarding caring for the dying but overwhelmingly felt that ED was not the right place to die. Patient and family understanding – respondents felt that prior understanding was lacking. Futile medical treatment –	Very low response rate (13%). Professionals who responded may have a particular interest in EoL care, which limits generalisability.	++

			Nursing (ACEN) and the Austral- asian College for Emergency Medicine (ACEM), who were. currently working in an Australian ED . 681 respondents.		respondents felt that many dying patients undergo treatment in the Emergency Department which is unlikely to benefit them.		
16.	Yash Pal et al 2017 Singapore	To determine the incidence and nature of death among patients aged ≥ 65 years in an ED, and characterise their trajectories of dying.	Retrospective study of one tertiary ED in Singapore. Deaths in patients over 65 were retrospectively examined. 401 deaths.	Quantitative retrospective review study.	The study identified two main trajectories of dying: chronic illness and sudden death. In the chronic illness section, patients had generally not had EoL discussions or plans, leading to a poor care experience.	Single centre study, results may not be generalizable. Model may represent an oversimplification of the dying process. Retrospective nature of the study makes it liable to inherent bias from lack of information.	+

Key: EoL – End of Life
ED - Emergency department
ENA –Emergency Nurses Association (USA)
SPR - Specialist Registrar (UK).