Nurses’ early and ongoing encounters with the dying and the dead: a scoping review of the international literature

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Nurses’ early and ongoing encounters with the dying and the dead: a scoping review of the international literature

Kerry Jones, Jan Draper and Alison Davies

Abstract

Background: End-of-life care is high on policy and political agendas in the UK and internationally. Nurses are at the forefront of this, caring for dying patients, ‘managing’ the dead body, and dealing with the corporeal, emotional and relational dimensions of death. Little is known about nurses’ prior or early professional experiences of and reactions to death, dying and the corpse and how these might influence practice. Aims: To appraise the international literature on nurses’ early experiences of death, dying and the dead body, to better understand how these might influence subsequent practice, and how this might inform our teaching of death, dying and last offices. Methods: A scoping review was undertaken of peer-reviewed publications between, 2000 and 2019, which included nurses working in hospital, care homes and the community. Medline, PubMed, PsychINFO and CINAHL databases were searched and 23 papers meeting the inclusion criteria were read. Arksey and O’Malley’s (2005) five-stage approach was adopted to scope the relevant international literature, using where relevant the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement. Selected papers were independently reviewed and subjected to thematic analysis, leading to the generation of five overarching themes. Results: The five themes were: different philosophies of care; relationships; knowledge; impact of death; and giving care. The studies came from diverse geographical locations across different settings and were primarily qualitative in design. Conclusions: Students and registered nurses are impacted both positively and negatively by their early encounters with death and dying. Good communication with patients, families and between professionals, understanding of what constitutes a ‘good’ death, and high-quality mentorship and support were of particular importance.

Key words: Death ● Dying ● Nursing ● Patient and families ● Support

End-of-life care is high on policy and political agendas both in the UK (Department of Health and Social Care (DHSC), 2016) and internationally (World Health Organisation and Worldwide Palliative Care Alliance, 2014), and in interdisciplinary academic and practice debates globally (Higginson, 2016).

The UK Department of Health and Social Care (2008) end-of-life care strategy set out several priorities, including patient choice about where they can die, and health care practices that involve the patient and their family in decisions about their end-of-life treatment.

End-of-life care is for people understood to be in the last year of life; however, this can be difficult to predict, and some people might receive end-of-life care in their last weeks or days (Marie Curie, 2020). Nurses are at the forefront of this, caring for dying patients, dealing with the corporeal, emotional and relational dimensions of death and ‘managing’ the dead body.

Little is known about early professional experience of and reactions to death, dying and the corpse. Our overarching aim in this paper is to explore and understand how these experiences influence subsequent practice in end-of-life care.

Background

Caring for people at the end of life is a fundamental part of being a student nurse and registered nurse. It is complex and requires physical, intellectual, emotional and spiritual skills to meet the needs of both the patient and their family (Parry, 2011). Yet, there is significant evidence of variable standards in the quality of end-of-life care as identified by the Independent Review of the Liverpool Care Pathway in England (DHSC, 2013) and internationally.
Nurses’ commitment to deliver such care depends on their own attitudes towards death, dying and the dead body (Henoch et al, 2017), which can be established early in their career (Parry, 2011). Early experience, therefore, either before nursing or early in training and undergraduate education, is likely to influence the development of these attitudes to death, dying and the dead, and these early encounters can have a lasting effect (Terry and Carroll, 2008; Anderson et al, 2015). There is some indication that students with prior experience have more positive attitudes towards care of the dying, particularly if the death was expected, painless and took place in a quiet environment (Gillan et al, 2013; Henoch et al, 2017). Conversely, negative reactions to previous experience (i.e. deaths that were sudden and preceded by aggressive treatment) can adversely affect care (Charalambous and Kaite, 2013). Prior experience in care of the dying can also increase emotional burden (Arslan et al, 2014), stress (Andersson et al, 2016), increase staff turnover and decrease job satisfaction (Anderson et al, 2015).

Death and dying and post-mortem care (i.e. in which the body is washed and prepared for a funeral) are major sources of stress for students (Österlind et al, 2016), what Cooper and Barnett (2005) call ‘death anxiety’. Despite the complexity of end-of-life care, student nurses (particularly in hospital settings) are often the ones delivering such care (Cooper and Barnett, 2005), further increasing this anxiety. Some nursing students have not encountered death and dying prior to commencing training. Therefore, confronting a dead body for the first time can be a key stressor (Edo-Gual et al, 2014). Although research on post-mortem care is limited (de Swardt and Fouche, 2017), there is some evidence of the negative psychological impact of performing last offices (Nyatanga and Vocht, 2009). Concerns about the emotional impact of these first encounters on the development of nurses’ future practice have prompted increased education on the use of different methods to teach end-of-life care (in both theory and practice). These methods range from ‘real-life’ simulation techniques (Gillan et al, 2013, 2014b; McGarvey et al, 2015; Ferguson and Cosby, 2017), ‘cinemeducation’ (the use of film in medical education (Gillan et al, 2013) and to the use of cadavers in anatomy classes (McGarvey et al, 2015).

The purpose of this ‘death education’ (Anderson et al, 2015) is to create opportunities for students to experience death in a ‘stress-free environment rather than encounter death for the first time in a hospital setting in the presence of relatives’ (McGarvey et al, 2015:249), with the intention that this will enhance preparation and reduce fear (Österlind et al, 2016). Mentorship in practice (Terry and Carroll, 2008; Österlind et al, 2016) and positive role modelling (Anderson et al, 2015) are also crucial to supporting students’ learning in practice.

Given the potential for early encounters to influence the subsequent delivery of end-of-life care, we were interested to explore nurses’ early experiences of death, dying and the dead body, to better understand these accounts and how they shape and influence subsequent practice. We were also interested to explore how all this might inform our teaching of death, dying and last offices in the UK and internationally.

Methods

The review set out to map the existing literature and to identify gaps in research. Arksey and O’Malley’s (2005) five-stage approach, as further developed by Levac et al (2010), to conducting a scoping review was adopted. This involved: identifying the research question; identifying relevant studies; selecting studies; charting the data; collating, summarising, and reporting the results. A scoping review is used when the research question is less defined, and the quality of the studies included is not as rigorously evaluated as in a systematic review. It provides an overview that enables clarification of the research question and the depth of knowledge of the subject matter.
Identifying the research question
The overarching research question was: ‘what are registered nurses’ and student nurses’ first encounters and ongoing experiences of care of the imminently dying (that is, in the last few hours and days of life) and the dead body?’ We were also interested in the factors that might influence the provision of nursing care and organisational factors such as mentoring and support, team working and professional relationships.

Identifying relevant studies
To identify relevant studies in the nursing, psychological and medical literature, the following databases were searched using Boolean terms: Medline, PubMed, PsycInfo and CINAHL (from September, 2018–November, 2018). The primary search terms were: ‘nurses and dying patients’, ‘nurses’ attitudes towards care and dying’, ‘nursing care and deceased body’, ‘education, nursing and dying’, ‘nursing, training and dying’, coupled with secondary descriptors of ‘nurses and students and deceased body or corpse’.

All relevant articles were identified on:
1. Nurses’ experiences of encountering and caring for a dying person
2. Nurses’ and student nurses’ attitudes and provision of care toward dying people and those who have died
3. The influence of mentoring and support within organisations (hospitals and hospices) and in the community (nursing and residential homes) for nurses and student nurses.

Selecting studies
Figure 1 illustrates the screening process for identifying suitable studies for inclusion in the review. The final 23 papers were independently assessed by two investigators (KJ and JD) and a third reviewer was called upon for any disagreements (AD).

First, the titles and abstracts of all articles retrieved through the initial database search were screened. Second, the full texts of all studies that could potentially meet the inclusion criteria were obtained. Full text articles were then examined in detail by two reviewers (KJ and JD) working independently to determine whether the study met criteria for inclusion in the review.

Any disagreements were referred to a third reviewer (AD). Reference lists of all included studies were also checked for potentially relevant papers from 2000 to 2019 to reflect the policy agenda. The grey literature was not considered as part of the review due to the rapid nature of the review and timescales.

This review recognises the potential for bias due to the limitations in rigour and that the conclusions are based on the studies available for review, as opposed to the quality used to generate conclusions, as with a systematic review (Grant and Booth, 2009). Yet, this scoping review has identified implications for practice (Grant and Booth, 2009; Levac et al, 2010; Peterson et al, 2017).

The inclusion criteria and exclusion criteria for this review are outlined in Box 1.

Charting the data and collating the results
The data were analysed in two phases. First, data from articles were charted and then collated by (i) author and the year of publication; (ii) location of the study; (iii) aims and main concept of the study; (iv) participants; (v) healthcare context (e.g. hospital, community, residential or nursing care); (vi) method of data collection; (vii) data analysis and key findings (Levac et al, 2010).

<table>
<thead>
<tr>
<th>Box 1. Inclusion and exclusion criteria</th>
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<tbody>
<tr>
<td><strong>Inclusion criteria</strong></td>
</tr>
<tr>
<td>• Primary studies and literature reviews</td>
</tr>
<tr>
<td>• Covering adult care</td>
</tr>
<tr>
<td>• Peer-reviewed</td>
</tr>
<tr>
<td>• Published 2000–2019</td>
</tr>
<tr>
<td>• Written in English</td>
</tr>
<tr>
<td>• By nurses and student nurses</td>
</tr>
<tr>
<td>• From all geographical areas</td>
</tr>
<tr>
<td><strong>Exclusion criteria</strong></td>
</tr>
<tr>
<td>• Opinions, editorials, dissertations, conference presentations, discussion papers or blogs</td>
</tr>
<tr>
<td>• Covering paediatric care</td>
</tr>
<tr>
<td>• Not peer-reviewed</td>
</tr>
<tr>
<td>• Published before 2000</td>
</tr>
<tr>
<td>• Written in languages other than English</td>
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<tr>
<td>• By allied health professionals, clinicians</td>
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Figure 1. Flowchart of the study selection process
The second phase involved thematic analysis of key themes across the 23 papers. The papers were independently reviewed and data referring to nurses’ first and ongoing encounters with the dying and the dead were independently selected and coded. These were then brought together and compared for similarities and differences.

The review generated 15 subthemes. These were then organised into the final five themes: different philosophies of care; relationships; knowledge; impact of death; and giving care. The findings are summarised in Table 1.

### Table 1. Summary of papers included in the review (n=23)

<table>
<thead>
<tr>
<th>Study and country</th>
<th>Aims of study</th>
<th>Method of data collection, method of analysis, sample size and type</th>
<th>Key findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anderson et al (2015), New Zealand</td>
<td>To explore the earliest memorable patient death experience of New Zealand registered nurses</td>
<td>Semi-structured face-to-face interviews, with interpretative analysis and thematic analysis of 20 NZ registered nurses</td>
<td>Seven themes: event significance; emotional challenges; sharing the experience; learning; feeling unprepared; responses to death; finding benefits</td>
</tr>
<tr>
<td>Andersson et al (2016), Sweden</td>
<td>To describe nurses’ experiences of caring for dying patients in surgical wards</td>
<td>Interviews, with qualitative, descriptive study/content analysis of six registered nurses</td>
<td>Nurses felt unprepared to face dying patients due to a lack of knowledge about palliative care</td>
</tr>
<tr>
<td>Arslan et al (2014), Turkey</td>
<td>To explore attitudes of nursing students to caring for dying patients</td>
<td>Frommelt Attitudes Toward Care of the Dying Scale and statistical analysis of 222 3rd year students from university nursing schools</td>
<td>Previous experience of caring for terminal patients resulted in higher scores; religious believers scored higher</td>
</tr>
<tr>
<td>Charalambous and Kaite (2013), Cyprus</td>
<td>To interpret students’ experiences of coming face-to-face with cancer care during their clinical placements</td>
<td>Reflective/narrative diaries from student nurses and hermeneutic phenomenology of 12 diaries from fourth grade undergraduate, pre-registration student nurses</td>
<td>Seven themes identified. Students emphasised the need for theoretical and practical preparation for death and dying</td>
</tr>
<tr>
<td>Cooper and Barnett (2005), England</td>
<td>To examine what aspects of caring for dying patients cause anxiety in student nurses during their first year of training</td>
<td>Nurses’ reflective diaries, two focus groups and qualitative descriptive study of 38 student nurses who had just completed their first year of training at a university in the UK</td>
<td>Eight themes identified relating to students’ anxiety about caring for dying patients. Aspects of the caring role rather than personal fear of death formed the source of much of their anxiety</td>
</tr>
<tr>
<td>Costello (2006), England</td>
<td>To investigate hospital nurses’ experiences of ‘good and bad’ deaths in hospital</td>
<td>In-depth interviews and semiotic analysis of 29 registered nurses</td>
<td>Experiences influenced by how much nurses were able to exert control over the dying process. Management of death in hospital is a source of conflict for nurses</td>
</tr>
<tr>
<td>Edo-Gual et al (2014), Spain</td>
<td>To explore nursing students’ experiences of death and dying in clinical practice</td>
<td>Semi-structured interviews of 12 nursing students and hermeneutic analysis using the Colaizzi seven-step procedure</td>
<td>Five themes: impact; training in end-of-life care; ethical issues; coping; and learning. Central theme was the impact of the encounter with death</td>
</tr>
<tr>
<td>Espinosa et al (2010), USA</td>
<td>To explore the experiences of intensive care nurses who provide terminal care in the ICU</td>
<td>Individual interviews and focus groups and phenomenological Colaizzi’s steps for data analysis of 18 registered nurses delivering terminal care in an ICU</td>
<td>Three major themes: barriers to optimal care; internal conflict; coping. Providing terminal care creates significant personal and professional struggles among ICU nurses</td>
</tr>
<tr>
<td>Grubb and Arthur (2016), England</td>
<td>To investigate the relationship between student nurses’ attitudes towards care of the dying and 1) demographics, 2) course factors and 3) experience of caring for people who are dying</td>
<td>Cross-sectional survey using Frommelt’s Attitude Toward Care of the Dying Scale and statistical analysis of 567 student nurses</td>
<td>91.9% had positive experience towards care of the dying. More positive scores were associated with time on course and experience of caring for the dying</td>
</tr>
<tr>
<td>Heise and Gilpin (2016), USA</td>
<td>To explore nursing students’ perceptions of their first experience with the death of a patient</td>
<td>Descriptive mixed methods. Online survey with qualitative and quantitative components. Pilot study of 33 student nurses</td>
<td>Students reported emotional distress and feelings of inadequacy with regard to communicating with and supporting the family of the dying patient</td>
</tr>
<tr>
<td>Hjorleifsdottir and Carter (2000), Scotland</td>
<td>To investigate whether fourth year undergraduate nursing students raise concerns about communication with terminally ill and dying cancer patients and their families</td>
<td>Interviews and content analysis of 12 student nurses in their fourth year of undergraduate study</td>
<td>Communicating with terminally ill and dying cancer patients in the acute setting is difficult for students and issues about death and dying tended to be ignored. Lack of support and guidance was a major concern</td>
</tr>
<tr>
<td>Holms et al (2014), Scotland</td>
<td>To explore the experiences of ICU nurses who had provided EoLC to patients and their families</td>
<td>Semi-structured, in-depth interviews and method/analysis not specified of five ICU nurses</td>
<td>ICU nurses do not feel adequately prepared to give proficient EoLC. Those who felt more confident in EoLC had learned what to do over time</td>
</tr>
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Notes: EoLC=end-of-life care; ICU=intensive care unit.
Nurses lacked proper support for providing high-quality care, focusing on symptoms management and optimal pharmacologic therapies, with a perceived deficit in psychosocial issues.

Participants understood broad scope of palliative care; however, their understanding was superficial and focused on the imminently dying phase.

The care of patients with ESHF is dominated by a focus on symptoms management and optimal pharmacologic therapies, with a perceived deficit in other aspects of palliative management.

**Results**

**Characteristics of reviewed studies**

The studies came from diverse geographical locations, including Australia (4), Cyprus (1), New Zealand (1), Norway (1), Spain (1), Sweden (3), Turkey (1), US (3) and UK (8), encompassing a variety of different settings including hospitals, hospices, nursing homes and residential care. The methods of the studies were primarily qualitative in design, comprising interviews, focus groups, and reflective diaries or case studies. Three were quantitative studies, two of which used the Frommelt Attitudes Toward Care of the Dying (FATCOD) scale (Frommelt, 1991) to assess attitudes to care of the dying; and one was a survey. There was one mixed-method study.

The impact of registered and student nurses’ first encounters with the death of a patient was the focus of eight studies, which described the way in which such an event can negatively influence subsequent end-of-life practice. The impact of seeing and handling a dead body was associated with intensive care and focused on the imminently dying phase. The care of patients with ESHF is dominated by a focus on symptoms management and optimal pharmacologic therapies, with a perceived deficit in psychosocial issues.

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the focus of six studies and concerned student and nursing staff responses to observing and coping with the physical changes involved during post-death practice. Some 12 studies explored registered and student nurses’ commitment to providing high-quality care, which could be realised if nurses and students were able to facilitate person-centred practices and a ‘good death’.

Some 13 studies focused on the need for improved education and training to better prepare students and registered nurses to care for dying people and the dead body. The focus on team working and professional relationships, including the impact of poor communication, was described by 11 studies. A further six studies identified the importance of good role models and mentors in supporting students and registered nurses in their end-of-life practice. Of the reviewed studies, nine focused on student nurses and 14 described registered nurses’ experiences.

The review generated five themes: different philosophies of care; relationships with patients and families; knowledge; impact of death; and giving care.

**Themes generated**

**Different philosophies of care**

Barriers to the provision of optimal end-of-life care can exist due to internal conflict and disagreement among professionals (McCallum and McConigley, 2013). Indeed, McCallum and McConigley (2013), in their Australian study of 5 nurses, found that nurses experienced a ‘conflict of care’, which posed dilemmas associated with decisions made by doctors to provide aggressive medical treatment. Nurses experienced conflict with decisions they perceived could cause suffering among patients who were subjected to such treatment. One nurse participant in McCallum and McConigley’s study demonstrated their sense of unease, saying that:

‘the doctors keep pushing, they are trying to be God and they push just another day, another day of aggressive management’ (McCallum and McConigley, 2013:28).

Nurses’ distress was due to the doctors’ focus on the persistent provision of treatment that nurses considered prolonged the dying phase.

Similarly, Hov et al (2009), in their Norwegian study, found that nurses working in nursing homes experienced dilemmas in carrying out doctors’ instructions to deliver care they considered would prolong the suffering of those who were dying. Nurses expressed a sense of isolation when their aim was ...

‘to do what they thought was best for the patient’ (Hov et al, 2009:655)

... of whom they had greater in-depth knowledge, because they had cared for them for some considerable time. Nurses questioned doctors’ decisions, and, in some instances, there were disagreements among colleagues about what ‘best’ care meant, which then led nurses to doubt their own skills and professional knowledge.

Moreover, nurses felt powerless when their knowledge of the patient was not considered. One nurse said:

‘I felt the work was meaningless, because the only purpose was to make him survive for a little while against his wishes’ (Hov et al, 2009:655).

Research conducted in nursing homes in the UK (Irvin, 2000) reported similar conflict both within nursing teams and between nurses and doctors concerning decisions about the best care to provide for the dying.

Similarly, nurses’ dissatisfaction with carrying out doctors’ instructions was also reported in a study of Swedish nurses coordinating care in different localities (Törnquist et al, 2013). These nurses expressed frustration that doctors did not listen to their concerns for patients, of whom they had long-term knowledge, and that some older patients were suffering unnecessarily due to doctors’ decisions to prolong life.

One nurse respondent argued:

‘they seem to think they can cure to the end. The physicians have no knowledge about palliative medicine’ (Törnquist et al, 2013:654).

Nurses also reported that doctor’s attitudes were that:

‘they knew best, even if they haven’t seen the patient for the last 6 months’ (Törnquist et al, 2013:654).

Research among nurses in the USA conducted by Espinosa et al (2010) found that one of the main barriers to the provision of optimal care to dying patients was the significant difference between the medical (cure) and nursing (care) models of care. When doctors were pushing treatment, nurses were frustrated about delivering care to patients they considered was
fundamental, unnecessary or had no apparent benefit. These nurses were driven by a philosophy of care in which they had a strong desire for the patient to be ‘comfortable and to create good memories for the family’ (Espinosa et al, 2010:277). Several studies also highlighted the consequences of these different philosophies of care (McDonnell et al, 2002; Hov et al, 2009; McCallum and McConigley, 2013; Holms et al, 2014).

Fundamentally, the medical model of care with its emphasis on cure and life-sustaining treatments (Wotton et al, 2005), body systems (Espinosa et al, 2010) and the fragmented medicalised body (Liaschenko et al, 2011) is at odds with a nursing model of care that privileges holistic and person-centred care (Arslan et al, 2014). These different approaches come to a head when doctors press for aggressive treatment options, particularly in acute environments, such as intensive care units (ICUs) or cardiac care units, settings normally associated with recovery and hope.

For example, in their Australian study of patients with end stage heart failure, Wotton et al (2005) found there were tensions between cardiac and palliative care teams, with cardiac physicians promoting life-sustaining treatments and regarding the transition to palliative care as ‘having failed the patient’ (2005:22). Nurses were often at the forefront of initiating communication across these different teams and ‘the need for communication, negotiation and advocacy was the most frustrating and time-consuming aspect of their role’ (Wotton et al, 2005:21).

The delivery of psychosocial care is also influenced by these different care philosophies. The review highlighted that psychosocial care of patients is considered a critical aspect of care delivery for dying patients. However, in their study of palliative care in hospitals in Northern Ireland, McDonnell et al (2002) found that psychosocial aspects of care were often neglected, due to the focus of treatment being on the physical symptoms of the dying patient. Other factors contributing to a lack of psychosocial care included work pressures and the demands of the ward, with over half the 263 nurses reporting being prevented from delivering high-quality care due to the demands of a busy ward (McDonnell et al, 2002). Additionally, over 75% of nurses in the study reported a lack of education on death and dying when they were undergraduates, which continued throughout their career due to poor provision of post-registration education in end-of-life care. Yet, it is at these undergraduate and early career stages that attitudes towards care of the dying are shaped and this can impact on the extent to which nurses feel able to develop supportive relationships with dying patients and their families (Parry, 2011).

Relationships
Several papers recognised the importance of establishing strong relationships with patients and families as integral to providing high-quality end-of-life care. In Johansson and Lindahl’s (2012) Swedish study of registered nurses’ experiences of looking after palliative care patients, nurses described their relationship with patients as unique, which deepened their involvement in the care at the end of life.

Parry’s (2011) qualitative study of Welsh nursing students’ early encounters with patients suggested that the relationship with families was just as important as that with patients. However, these strong relationships could evoke strong emotion among student nurses, which made the subsequent death of the patient more difficult to handle (Parry, 2011).

Similarly, Edo-Gual et al (2014) stated that the impact of a patient’s death was found to be greater when a good relationship with a patient had been established and there was a fear of ‘emotional contagion’ (2014:3504) when witnessing family distress. Other studies identified tensions in balancing the nearness and distance of emotional involvement with patients and families (Hov et al, 2009; Johansson and Lindahl, 2012; Liaschenko et al, 2011) and how nurses develop coping mechanisms to reduce the impact of such emotional engagement (Johansson and Lindahl, 2012; Anderson et al, 2015; Andersson et al, 2016). While self-protecting strategies might reduce the nurses’ emotional stress, this could lead to a lack of concern towards the patients (Hov et al, 2009:657).

Linked to the development of relationships with patients and families is the issue of effective communication at end of life and several studies identified communication as a key priority (Hjörleifsdóttir and Carter, 2000; Espinosa et al, 2010; Charalambous and Kaite, 2013; Edo-Gual et al, 2014; Watts, 2014).

Inadequate communication between patients and medical staff, as well as a lack of physician awareness of a patient’s end-of-life choices, appear to contribute to less optimal provision of care (Irvin, 2000; Holms et al, 2014; Heise and Gilpin, 2016). In a Scottish study of registered nurses working in ICU, Holms et al (2014) found that good communication within the multidisciplinary team was vital. All reported breakdowns in communication caused mixed messages and inconsistencies in end-of-life care.
practice, ‘especially the decisions to withhold/withdraw treatment’ or ‘families being given false hope’ (Holms et al, 2014:552).

The impact of poor communication was not confined to registered nurses’ experiences, but also to student nurses. Hjorlfreisdottr and Carter’s (2000) study of 4th year undergraduate Scottish students suggested that students were often in the unenviable position of not being fully informed about a patient’s prognosis, since they were at the lowest level of the staffing hierarchy. However, patients and families frequently asked students lots of questions (which students felt unable to answer) and expected them to be able to ‘translate’ what doctors had said about possible outcomes.

Knowledge

Although nurses consider palliative care to be a privilege and are committed to delivering high-quality end-of-life care (McDonnell et al, 2002; Johansson and Lindahl, 2012), there is significant evidence that nurses’ knowledge of end-of-life care and palliative care is poor (Andersson et al, 2016) and superficial (Watts, 2014). A recurrent theme across the studies was nurses feeling unprepared to deliver care at the end of life (McDonnell et al, 2002; Anderson et al, 2015; Andersson et al, 2016; Heise and Gilpin, 2016).

In Anderson et al’s (2015) New Zealand study on the earliest memorable death, the registered nurses they interviewed felt ill-prepared for their first encounter with death and reported a lack of skills and knowledge about death and dying. They were frustrated by this lack of knowledge and felt it influenced their ability to deliver high-quality end-of-life care.

Students are often the ones providing end-of-life care, particularly in hospital settings, because they are at the front line of care (Cooper and Barnett, 2005). They are therefore particularly vulnerable ‘caught between doing the “best” for the patient within the limitations of his/her role and knowledge’ (Cooper and Barnett, 2005:428). It is therefore important that students are prepared and supported effectively, because their prior experience of the death (of either a significant other or patient) can influence their future attitudes towards the care of the dying (Arslan et al, 2014).

In a Turkish quantitative study of students’ attitudes (n=222) towards dying patients using the 1991 Frommelt Attitudes Toward Care of the Dying (FATCOD) Scale, Arslan et al (2014) found that students with previous clinical experience of caring for the dying and those who reported having a religious belief had more positive attitudes toward caring for the dying patient. A similar finding was reported by Grubb and Arthur (2016) in their UK FATCOD study of students (n=567) attitudes towards care of the dying. They reported that ‘being at a later point in their course of study and having experience of death and dying were independently associated with more positive attitudes’ (2016:86).

The studies report several knowledge gaps. These include a lack of knowledge about definitions of palliative care and end-of-life care (Watts, 2014) and assumptions that these are only associated with patients who have cancer (Anderson et al, 2013; Watts, 2014). There also appears to be a lack of knowledge about when palliative care should start (Watts, 2014).

Watts’s (2014) qualitative study of Welsh undergraduates (n=11) found that students’ understanding of palliative care was superficial and ‘focused on the imminently dying phase’ (2014:291). Although students initially associated palliative care with cancer, they subsequently came to appreciate that it also embraced other life-limiting conditions. Watts (2014) concluded that ‘participants’ tendency to associate palliative care with care of the imminently dying could set limits on their future practice and restrict opportunities for optimal care of all those for whom a palliative care approach might confer benefit’ (2014:291).

Students in Cooper and Barnett’s (2005) UK study of first-year undergraduate nurses reported feeling inadequate and powerless in dealing with the physical suffering of patients. They also reported feeling ill-prepared about knowing what to do or say and dealing with unexpected death. Other gaps in knowledge relate to clinical skills such as symptom control (Irvin, 2000; Watts, 2014) and last offices (Edo-Gual et al, 2014).

As well as deficits in clinical skills, a key issue identified was lack of knowledge of psychosocial skills and communication skills (McDonnell et al, 2002). Perhaps unsurprisingly, a number of studies also identified a difference in knowledge between nurses working in end-of-life specialist areas and those working in general acute care (Johansson and Lindahl, 2011) and the need for the philosophy of palliative ‘to be implemented and integrated into acute-care settings’ (Johansson and Lindahl, 2011:2040).

This lack of knowledge and skills is a key barrier to the delivery of high-quality end-of-life care (McDonnell et al, 2002). Consequently, many of the papers highlighted the inadequacies of both pre- and post-registration education (Charalambous and Kaite, 2013) and the need

Particular areas highlighted included preparing for nurses’ first encounters with death and dying (Anderson et al, 2015), including how to recognise the signs of imminent death, equipping nurses with more emotional preparation (Costello, 2004; Cooper and Barnett, 2005), and how to break bad news (Edo-Gual et al, 2014). Other studies also highlighted the importance of ethical reasoning and conflict management (Hov et al, 2009), emotional counselling (Holms et al, 2014), last offices (Edo-Gual et al, 2014), and how to talk more openly about death (McDonnell et al, 2002), and enhancing communication skills and psychosocial skills (McDonnell et al, 2002; Costello, 2004; Espinosa et al, 2010; Edo-Gual et al, 2014).

Anderson et al (2015) suggested that better education can help decrease anxiety and increase positive coping, although Watts (2014) warned that there was a ‘dearth of empirical evidence of education initiatives on professional practice and patient outcomes’ (2014:292).

The review did not focus specifically on the death and dying education literature, which has developed significantly over the past decade. However, several of the included studies suggested ways in which death and dying education could be enhanced and that educationalists ‘have a duty to explore other means of support to enable students to cope more effectively’ (Cooper and Barnett, 2005:430). The papers identified the need for a range of approaches to enhancing this ‘death education’ (Anderson et al, 2015), including the use of simulation (Heise and Gilpin, 2016), drama (Parry, 2011), more effective integration of theory with clinical practice (Cooper and Barnett, 2005; Andersson et al, 2016; Grubb and Arthur, 2016), better use of reflection (Andersson et al, 2016) and opportunities for students to talk about emotional aspects of death and dying (Costello, 2004; Arslan et al, 2014). Others highlighted the importance of positive role models and mentorship (Charalambous and Kaite, 2013; Andersson et al, 2016) and clinical supervision (Irvin, 2000).

Impact of death
The studies indicated that death can have significant impact on nurses’ early and subsequent encounters with death and dying (Cooper and Barnett, 2005; Edo-Gual et al, 2014). The memory of this first death can be so vivid that ‘participants appeared to be re-living the encounter, complete with emotions they experienced at the time’ (Anderson et al, 2015:698). The impact can be worse when the patient is younger (Espinosa et al, 2010), the death is sudden (Heise and Gilpin, 2016) or the patient has been known for a long time (Espinosa et al, 2010).

The negative impact of death on nurses can exert a lasting effect (Edo-Gual et al, 2014; Anderson et al, 2015), influencing future attitudes (Arslan et al, 2018) and care delivery (Charalambous and Kaite, 2013). This can include the fear of being present at future deaths (Charalambous and Kaite, 2013) and of it happening on their shift (Hov et al, 2009), leading ultimately to what Cooper and Barnett (2005) call ‘death anxiety’. There is evidence of nurses developing avoidance tactics (Anderson et al, 2015), expressing an unwillingness to care for the dying patient (Arslan et al, 2014), finding other nursing tasks to do (Irvin, 2000) or focusing on the physical tasks of end-of-life care and not the emotional aspects (Anderson et al, 2015). Many of the papers drew attention to the emotional impact of death on nurses, including distress (Holms et al, 2014; Heise and Gilpin, 2016), sickness and absence (Hov et al, 2009), which could ultimately result in ‘crusty nurses’ who are emotionally disengaged (Espinosa et al, 2010).

Many of the studies framed death in either ‘good’ or ‘bad’ terms. For example, Costello (2004) suggested that a ‘good’ death was one that is expected, often medicalised, with a high level of awareness by relatives, and an absence of distressing symptoms. Such good deaths created limited disruption to the ward routine. Nurses want to provide a good death (Irvin, 2000; Johansson and Lindahl, 2012) and prevent patients dying alone (McCallum and McConigley, 2013). These good deaths appear to benefit nurses as much as patients and relatives (Costello, 2004).

In contrast, a ‘bad’ death was one where there was limited control over the events leading up to the death, or one that was out of context (for example, when a patient is in transit), or when there was limited time to deliver high-quality end-of-life care, or where pain control was poor (Watts, 2014). A bad death was also when patients were left alone (Edo-Gual et al, 2014), or when there was poor execution of Do Not Resuscitate orders or transferring patients very close to death (Liaschenko et al, 2011), or when there was conflict between nurses and doctors (Costello, 2004).
In addition to the impact on nurses of the dying process itself, some of the studies also highlighted the effects—both positive and negative—of nurses’ interactions with the dead body. As well as being integral to providing high-quality end-of-life care, nurses also have an influential role in last offices (Cooper and Barnett, 2005)—what Quested and Rudge (2003) describe as transforming the patient into a corpse. The studies discussed how caring does not stop when the patient is dead (Quested and Rudge, 2003) and that it is a privilege to care for the dead body (McCallum and McConigley, 2013).

Many of the papers discussed the impact of first seeing a dead body (Cooper and Barnett, 2005), how nurses could remember the first time they saw the face of a dead person (Edo-Gual et al, 2014), the way they were shocked by how the person looked when dead (Parry, 2011), and the rapid changes in the body following death (Johansson and Lindahl, 2012), including its colour (Edo-Gual et al, 2014), in particular the colour of the lips and tongue (Anderson et al, 2015).

Several papers also highlighted how nurses felt ill-prepared for last offices, in particular, packing orifices (Cooper and Barnett, 2005), wrapping the body and covering the head and face (Parry, 2011), and ‘closing the bag’ (Edo-Gual et al, 2014). In their seminal examination of last office manuals, Quested and Rudge (2003) argue that nurses ‘enact the transition between life and death, and from person to corpse’ (2003:553) and discuss the devices used by nurses to manage this most ambiguous and troubling boundary and how, in doing so, nurses segregate the living and the dying.

**Giving care**

Several studies revealed that both registered and student nurses held a deep desire to deliver high-quality end-of-life care, irrespective of setting (Irvin, 2000; Johansson and Lindahl, 2012). However, delivery of this care was influenced by several factors, including the support that staff received, the places of dying and death, and the emotional sequelae of providing end-of-life care, which at times could be perceived as a ‘heavy burden’ (Hov et al, 2009). Several studies highlighted the tension between trying to balance the two different aspects of emotional work and physical care, and wrestling with the need to be close to patients while also maintaining a professional distance (Hov et al, 2009; Anderson et al, 2015).

Hov et al’s (2009) study of nurses working in residential and municipal settings for older people identified that nurses were impacted by their work with the dying. Several nurses reported going off sick or feeling compelled to change their occupation as a result. Some nurses also described a physiological response when caring for the dying, such as:

‘my stomach tightens. Therefore, I get pains. I lose my appetite, [and] I get this lump in my chest’ (Hov et al, 2009:656).

Another way of dealing with death was described by John Costello (2004) in his interviews with 29 registered nurses in the UK. They described how the management of death was concerned with maintaining cultural practices and ward routines. These routines were disrupted by unexpected deaths, for example, those that occurred during mealtimes or when patients were in transit (2004:598). Deaths that disrupted ward routines were regarded as ‘bad’ deaths. In contrast, when there was a high degree of predictability that a patient would die imminently, nurses were able to prepare families for death and to arrange last rites for those patients requiring them. Such ‘good deaths’ did not ‘disrupt the sentimental order’ (2004:598) and nurses felt in control and gained satisfaction from their role in handling ‘peaceful and natural’ deaths, especially if they occurred at night. In these instances, nurses felt able to provide high-quality palliative care.

Johansson and Lindahl (2012) similarly described how the nurses in their study were ‘striving for ideal care’ (2012:2036) and had a strong desire to do their best for patients and families. When this had been achieved, nurses derived a sense of gratefulness for having been involved in a patient’s care at the end of life.

Nurses were also more likely to deliver good care if they had reflected on their own mortality (Johansson and Lindhal, 2012) and were therefore more comfortable with their own thoughts about death and dying (Wotton et al, 2005).

While nurses had high expectations of delivering good-quality care (Irvin, 2000) they expressed disappointment or feelings of failure when this was not possible (Irvin, 2000; Johansson and Lindahl, 2012). Dissatisfaction and inadequacy with the care provided were perceived by nurses to be related to staff shortages (Irvin, 2000) and a lack of time for being with a patient to complete the care they felt needed to happen (Johansson and Lindahl, 2012).

Many of the studies referred to the significance of place. Place is important for making a good
death (Liaschenko et al., 2011) and delivery of end-of-life care occurs in many different places, including ICU, acute wards, the community, as well as ‘designated’ spaces such as hospices. The studies revealed that these contrasting settings impacted upon nurses’ perceived ability to deliver care (McDonnell et al., 2002; Liaschenko et al., 2011; Johansson and Lindahl, 2011; McCallum and McConigley, 2013; Charalambous and Kaite, 2016). Some of the papers highlighted that acute settings that focus on ‘cure’ and the prevention of death (Liaschenko et al., 2011) are not designed for dying (McCallum and McConigley, 2013) and are in fact not good places to die (Hjörleifsdóttir and Carter, 2000; Johansson and Lindahl, 2012; McCallum and McConigley, 2013; Holms et al., 2014). In these acute settings, nurses are providing patients with both acute and end-of-life care and delivering cure and care in the same place, which is difficult (Johansson and Lindahl, 2012; McCallum and McConigley, 2013). Some of the papers described how this created a feeling of being in ‘constant change’, as nurses tried to coordinate care and balance their work in caring for patients with very different needs (Liaschenko et al., 2011; Johansson and Lindahl, 2012; Törnquist et al., 2013).

Johansson and Lindahl (2012), in their small Swedish study in general wards, highlighted that dedicated rooms for palliative care created ‘a more conducive atmosphere’ (2012:2028). Such rooms were regarded as inducing a sense of peace, calmness and harmony, enabling patients and families to spend time together, which made the nurses ‘feel more comfortable, satisfied and secure in their work’ (2012:2038).

In contrast, Liaschenko et al. (2011) studied end-of-life care in ICU settings in three hospitals in the USA. Primarily focused on saving life and preventing death, imminent death in the ICUs signalled a change in the purpose of the space, which nurses achieved by ‘converting the hectic, noisy, and visually stimulating ICU space into one far more ambient’ (Liaschenko et al., 2011:817). Creating such a space, even in an ICU setting, enabled attention to be given to the psychological needs of the patient, as well as the physical. They described how nurses turned the focus away ‘from the survival functions of ICU machines’ (2011:817) towards creating a calm atmosphere, by drawing curtains around the patient, preparing families for death, and facilitating time for families and patients to spend time together. Yet, as McCallum and McConigley (2013) argued, curtains have limited value in shielding or containing death.

Despite the obvious need to support nurses in delivering end-of-life care, many of the studies in the review highlighted that a lack of support was a key issue (Irvin, 2000; McDonnell et al., 2002; Holms et al., 2014). Some nurses felt isolated and unsupported while involved in care at the end of life and felt that more resources should be dedicated to support nurses, for example, through psychological support, mentoring and coaching (Irvin, 2000; McDonnell et al., 2002; Törnquist et al., 2013; Holms et al., 2009; Parry, 2011; Törnquist et al., 2013). This was particularly the case when nurses were working in isolation in community/municipal settings (Törnquist et al., 2013). Consequently, nurses often felt unable to support co-workers when faced with emotionally challenging work with dying patients (Irvin, 2000; McDonnell et al., 2002; Törnquist et al., 2013; Holms et al., 2014). While nurses regarded regular and systematic supervision to be a critical aspect of their work, this could be denied by managers for economic reasons (Törnquist et al., 2013). Nurses’ attributed managers’ decisions as a lack of understanding of the complexity of nurses’ work with dying patients and the deceased (Törnquist et al., 2013).

Student nurses and newly qualified nurses were particularly vulnerable when the emotional impact of a death of a patient was not acknowledged by more senior colleagues (Anderson et al., 2015). However, in other studies, being part of a team and having the opportunity to talk about a patient’s death meant that nurses felt the emotional impact of this work was acknowledged, and they subsequently felt better able to cope (Costello, 2004; Espinosa et al., 2010; Anderson et al., 2015; Andersson et al., 2016). The role of mentors (Parry, 2011; Espinosa et al., 2010; Andersson et al., 2016) and good role models (Charalambous and Kaite, 2013; Anderson et al., 2015) were also cited as critical factors in student nurses’ and newly qualified nurses’ ability to cope with experiences of death and dying. In turn, it is important that mentors also receive support (Cooper and Barnett, 2005; Charalambous and Kaite, 2013).

Discussion

The aim of this scoping review was to identify student nurses’ and registered nurses’ early encounters with death, dying and the corpse. The literature identified for inclusion is heterogeneous and focuses on five main themes: different philosophies of care; relationships; knowledge; impact of death; and giving care. In these studies, care of the dying and their families was the point at which contrasting philosophies of care
came into full view, with a focus either on cure or care of the dying. The differentiation between the medical (cure) and nursing (care) models of care and the fragmentation of a medicalised body (Espinosa et al, 2010; Liaschenko et al, 2011) was considered by nurses to be consequential for the care provided to dying patients (McDonnell et al, 2002; Hov et al, 2009; McCallum and McConigley, 2013; Holms et al, 2014).

Indeed, the findings demonstrate that ‘the division of medical work makes specific physicians in specific spaces responsible for specific body parts, while no one is responsible for the embodied whole patient’ (Liaschenko et al, 2011:815). Doctors’ persistence with cure and treatment over holistic care was often seen as futile by nurses, who are the ones tasked with carrying out doctors’ instructions (Wotton et al, 2005; Törnquist et al, 2013).

The studies also highlighted that while psychosocial care is considered an essential aspect of care of the dying patient, this was often neglected when the focus of treatment was on the physical symptoms of patients (McDonnell et al, 2002). This neglect was found to impact upon the extent to which undergraduate nurses in the early stages of their career could develop supportive relationships with dying patients and their families (Parry, 2011).

The second primary theme emerging from the review was the significance of relationships with patients and families and which was considered integral to the provision of person-centred care. Studies indicated that developing relationships with patients at the end of life enabled nurses to deliver high-quality care. However, this could also impact negatively upon nurses when a patient died, particularly if they were exposed to ‘emotional contagion’ when witnessing a family’s distress (Edo-Gual et al, 2014). The ability to support families at such a critical time was also dependent upon effective communication within teams, which were often considered hierarchal. Poor communication led to inconsistencies about decisions about treatment options and in some instances gave families misguided hope. Student nurses were not fully informed of a patient’s condition or their wishes, some of which were recorded (for example, ‘do not resuscitate’ orders, living wills, advance directives).

While several studies found that some nurses felt privileged to be providing care for dying patients, their knowledge of end-of-life and palliative care was lacking, which was the third theme highlighted by the review. Studies suggested there was a dearth of education and training on the subject, and, consequently, nurses felt unprepared to deliver optimal care to dying patients (Irvin, 2000; Hov et al, 2009).

The review purposely did not focus on the educational literature about death and dying. However, many of the included studies made some recommendations regarding education and training. Several suggested that to best prepare students and registered nurses for work with the dying, education should focus on recognising the signs of imminent death, emotional preparation and how to break bad news (McDonnell et al, 2002; Costello, 2004; Espinosa et al, 2010). Papers also suggested that reflection practices, positive role models and mentors could aid nurses’ preparation for end-of-life care (Charalambous and Kaite, 2013; Andersson et al, 2016) and thereby mitigate the impact of death on nurses. However, although these studies suggest such training can reduce ‘death anxiety’, there is a lack of empirical research demonstrating the effectiveness of such education and training (Watts, 2014).

The fourth theme identified by the review was the impact of nurses’ early encounters with death. The studies indicated that this can have a profound effect, including vivid recollection, physical ailments and anxiety, such that some students and nurses feared being present around dying patients or being able to tend to a corpse and perform last offices (Arslan et al, 2014; Anderson et al, 2015). Of note was that some students and registered nurses were not prepared for changes in the body after death, such as rapid discolouration, or for undertaking tasks such as packing orifices (Cooper and Barnett, 2005).

These factors could impact on sickness and absence rates, but also on nurses’ willingness to care for the dying, to the extent that some reported finding other nursing-related work to undertake or focusing primarily on the physical needs of patients and not the emotional (Irvin, 2000; Anderson et al, 2015; Arslan et al, 2014).

As a consequence of these early encounters with death and dying, nurses framed deaths as being either ‘good’ or ‘bad’. Patients dying in pain, alone, suddenly, at a young age or where there was limited control over the events leading to death were reported as being particularly negative (Espinosa et al, 2010). In contrast, ‘good’ deaths were those that did not disrupt ward routine, were expected, medicalised, lacked signs of distress, and where relatives understood that death was imminent (Costello, 2004). Several studies demonstrated that some nurses strived to facilitate a good death for patients by ensuring they were not alone.
The desire to provide good care, the final theme of the review, was seen across all settings, including hospitals, municipalities and care homes (Irvin, 2000; Johansson and Lindahl, 2012). However, the extent to which high-quality care could be delivered depended upon the level of support that staff received, as well as perceptions that this work could in fact be a burden (Hov et al, 2009). Where there was a dearth of support, some nurses coped by adopting a professional distance or placing the responsibility of tasks onto other staff. Others coped by trying to strike a balance between carrying out the ‘work of emotion’ and tending to the physical needs of the patient (Hov et al, 2009; Anderson, 2015). Nurses who had considered their own mortality felt able to deliver optimal care, yet were disappointed if this was not possible because, for example, a death was unexpected or there were staff shortages (Irvin, 2000).

The ability to provide high-quality care was also influenced by the location in which patients died. For example, acute settings where the culture was focused on recovery and cure were considered inappropriate places to die (Hjörleifsdóttir and Carter, 2000; McCallum and McConigley, 2013; Holms et al, 2014). There was also evidence that nurses found it challenging to deliver both cure and care to different patients in the same setting (Liaschenko et al, 2011; Johansson and Lindahl, 2012; Törnquist et al, 2013). However, when they were able to provide spaces for patients and families which were quiet and calm and induced a serene atmosphere, this led nurses to feel more satisfied and comfortable in their role (Johansson and Lindahl, 2011; Liaschenko et al, 2011). However, some studies reported that it was difficult for nurses to create such atmospheres in busy wards and acute settings.

Additionally, the extent to which student nurses and more experienced nurses felt able to provide an appropriate atmosphere and to support patients and families was influenced by the support they received from colleagues, mentors, good role models, or through clinical supervision. Several studies demonstrated that these support mechanisms were lacking and therefore students and registered nurses felt isolated and unable to support other staff (Irvin, 2000; McDonnell et al, 2002; Holms et al, 2014).

Nurses reported feeling particularly vulnerable if their senior colleagues did not understand the emotional impact of the death of a patient (Anderson et al, 2015). In contrast, other studies indicated that, when nurses were part of a team and were able to discuss a patient’s death, this was valued and enhanced their ability to cope (Costello, 2004; Espinosa et al, 2010; Anderson et al, 2015; Andersson et al, 2016).

While the authors recognise that a systematic review begins with a primary research question as its focus, a scoping review allows for a more general question and exploration of the relevant literature, as opposed to providing answers to a more limited question. Unlike a systematic review that uses an established Cochrane protocol, for example, this scoping review did adopt the PRISMA checklist, which includes items deemed essential for transparent reporting.

Conclusions

This review suggests that both students and registered nurses are impacted positively and negatively by their early encounters with the dying and the dead. Positive experiences are influenced by: good communication with patients and their families, as well as with and between professionals; perceptions of what constitutes a good death; and good mentorship and support. Conversely, where these factors were absent or where there was conflict concerning different philosophies of care, nurses had more negative experiences. This could lead to anxiety and distress concerning the management of death and the dead body and to a range of practices—both emotional and physical—designed to avoid such situations in the future. There is therefore more we could be doing as clinicians, nurse educators, managers and researchers to ensure that nurses are well educated and supported in caring for the dying patient and managing the dead body.

The findings reveal a deeper understanding of the influences of nurses’ early encounters
with death and dying—and these are relevant for individual nurses, workplace mentors and managers. They could help inform the delivery of high-quality end-of-life care across a range of settings, including acute, community, hospices and care homes.

This could include developing high-quality mentorship and supervision and promoting open communication regarding the emotional challenges of delivering end-of-life care. The findings could also be used to inform pre- and post-registration nurse education, and how we prepare students to care for those who are dying and the management of the dead body. Research needs to be conducted about how we could better shape positive IJPN

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