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## REVIEW

## The nurse's role in palliative care: A qualitative meta-synthesis

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<sup>1</sup>VID Specialized University, Faculty of Health Studies, Bergen, Norway <sup>2</sup>Department of Obstetrics and Gynaecology, Haukeland University Hospital, Bergen, Norway <sup>3</sup>Department of Clinical Science, University of Bergen, Bergen, Norway

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Ragnhild Johanne Tveit Sekse, Department of Obstetrics and Gynecology, Haukeland University Hospital, Bergen, Norway. Emails: ragnhild.johanne.sekse@helse-bergen. no, rsekse@gmail.com Aims and objectives: To explore how nurses, across various health systems, describe their role in providing palliative care for patients with life-threatening illnesses. Background: Despite the fact that nurses make up the largest group of healthcare professionals, little is known about their role in palliative care, across health services. Design: A qualitative systematic review of studies.

**Methods:** A search was made for relevant articles, published between January 2000–June 2016. Twenty-eight articles were selected and analysed using thematic synthesis.

**Results:** The themes that emerged from the analysis were as follows: *Being available*, which gave nurses a pivotal role in palliative care and paved the way for *Being a coordinator of care* for patients and relatives, as well as for other health personnel. *Doing what's needed* was to handle an enormous breadth of activities, always in a holistic framework of understanding. *Being attentively present and dedicated* as well as using flexible and nontraditional methods was essential in the role. *Standing in demanding situations* dealt with lack of time and resources, limited legitimacy, handling ethical dilemmas and being in need of support and knowledge.

**Conclusion:** Being available as well as a coordinator characterises the nurse's role across healthcare systems. The nurse acts as a link between different levels of health care, between different professions and between patient and family, which contribute to ensuring the quality of care to the individual patient. The review illuminates that the basic tenets of care in nursing are also fundamental to the nurse's role in palliative care. To be able to give individually tailored palliative care to patients with life-threatening illnesses and their relatives, the nurses need all their knowledge of basic nursing. Situations challenge nurses in practical, relational and moral dimensions of care and make demands on their role in a comprehensive way. **Relevance to clinical practice:** Nurses need knowledge and training, guidance and support to fulfil their role.

#### KEYWORDS

advanced illness, end of life, nurse, palliative care, role, terminal

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## <sup>2</sup> WILEY Clinical Nursing 1 | INTRODUCTION

Nurses meet patients who suffer from life-threatening illnesses in all healthcare settings. This requires knowledge and expertise in palliative care wherever nurses work in the health system. Cicely Saunders (1978, 196), the founder of the modern Hospice movement, emphasised just the need for skilled and experienced nursing as an essential element in the management of terminal malignant disease.

Palliative care, which is based on the modern Hospice philosophy movement, provides guidelines for the care of seriously ill and dying patients to improve quality of life for patients and their families. The approach is multidisciplinary to address the complexity of needs for patients and relatives. World Health Organization (2011) underscores that the lack of training and awareness of palliative care among health professionals constitutes a major barrier to the improvement of care. The European Association for Palliative Care (EACP) specifies 10 core competencies for health personnel (Gamondi, Larkin, & Payne, 2013) and states that all personnel need knowledge and competence in these areas but at different levels based on their exposure to various dimensions of practice (De Vlieger, Gorchs, Larkin, & Porchet, 2004; Gamondi et al., 2013).

However, efforts to ensure quality of life for patients in need of palliative care are demanding on many levels, due to differences in resource allocation, cultures and healthcare systems. A UN report (UN News Centre, 2014) identifies unmet needs for palliative care worldwide. A current trend is to see palliative care as an approach that should be integrated in a standard of care (Coyle, 2015; World Health Organization, 2011).

Such a change can challenge what is seen as specific for palliative care as opposed to basic care. Nevertheless, this change may lead to a focus on the patient's quality of life at an earlier stage of the course of the disease and not just at the end of life, thus creating a more fluid transition through the various phases in the illness trajectory (from curative treatment to life-prolonging treatment and end-of-life care). As such, a palliative approach is required regardless of where the patient is in the course of a severe disease, although it is, naturally, particularly important at the end of life. However, this review relates to WHO's definition of palliative care as an approach that improves the quality of life of patients facing the problems associated with life-threatening illness. Our focus concerning palliative care encompasses seriously ill and dying patients.

Patients receiving palliative care can be encountered anywhere in the health systems. Although nurses make up the largest group of healthcare professionals, there is a scarcity of knowledge of their role in carrying out palliative care across institutions and their place of work in the healthcare system.

However, some studies have looked at the nurse's role in a specific field or from a specific nursing perspective. Walshe and Luker (2010) did a review of 46 papers to construct a detailed account of the district nurse's role in providing palliative care. Offen (2015) did a meta-ethnography on the district nurse's role in palliative care. The study found, among other things, uncertainty surrounding the nurse's role. In another literature review of the role of

## What does this paper contribute to the wider global clinical community?

- Nurses' availability and competence give them a natural position as coordinator.
- Professional knowledge and person-oriented competence are highly intertwined in the nurse's role.
- The nurse's role is challenged in all dimensions of care: the practical, the relational and the moral.

the specialist palliative care nurses in the community (Mulvihill, Harrington, & Robertson, 2010), one of the findings was a need for clarification of the nurse's role. These reviews, which are all from the same level of health care, namely home care, demonstrate a need for clarification of the nurse's role. Knowing that the profession of nursing may be difficult to describe, there is a need for clarifying its role and function, not least in the cooperation with other professions in a multidisciplinary team, so crucial in palliative care.

Summing up, palliative care is integrated in all levels of the healthcare services: in the community, nursing homes, hospitals and palliative care units and hospices. However, reviews of the nurse's role in palliative care have mainly been done in one particular context, namely home care. There is a need for descriptions of the nurse's role in performing palliative care across institutions and wherever nurses work in the healthcare system. On this background we want to illuminate how nurses describe their own role in giving palliative care to patients with severe incurable disease and uncertain life span, across various health levels and institutions. The aim of this review was therefore to explore how nurses, across various healthcare systems, describe their role in providing palliative care.

### 2 | METHODS

#### 2.1 | Problem identification and design

Initially, the authors had a long process of narrow down the subject under study, and, in particular, to identify the purpose of the review. After some initial searches and reviews of articles, we decided to do a qualitative review.

The meta-synthesis was inspired by thematic synthesis described by Ring, Ritchie, Mandava, and Jepson (2011). A thematic synthesis identifies recurring themes, analyses these themes and draws conclusions (Ring et al., 2011). The purpose of the method is to develop analytical themes through a descriptive synthesis and find explanations relevant to our particular review questions on how nurses experience their role in palliative care.

#### 2.2 Search methods and outcome

An initial search was performed using MEDLINE, EMBASE, CINAHL, OVID Nursing, British Nursing Index, PsycINFO, AMED and ISI Web of Science in February 2015. The search terms "palliative care," "terminal care" and "end-of-life care" were combined with "nursing/ nurse's role," "impact," "competence," "function" and "responsibility," both as keywords and text words.

The initial search included all kinds of studies, across countries and institutions, regardless of further specialisation in palliative care, and with no design or language limits, but restricted to the period from the year 2000 until 2015 due to the number of studies. Despite the year limits, 3,096 articles were found when duplicates were removed. All citations (titles and abstracts) were screened independently by the two researchers using the established eligibility criteria (Table 1). The initial search was followed by reflections and refocusing on the review question. A new search was performed, still based on the initial search, but with some minor modifications and limited to gualitative studies (Table 1). This search produced a total of 415 articles, and with the articles found in reference lists, 426 articles were screened using the inclusion and exclusion criteria listed in Table 2. Eighty-nine articles were read in full and 28 of these met the inclusion criteria. An updated search based on the search for qualitative research was performed in June 2016. The same databases were searched, except the OVID Nursing database. None of the 58 articles found were of interest for the review and no further articles were added (Figure 1).

As the study was a literature review with no direct contact with patients, we did not apply for ethical approval nor did we address any data protection agency.

#### 2.3 | Quality appraisal

Consolidated criteria for reporting qualitative research (COREQ) were used to evaluate the quality of the studies. The COREQ checklist is grouped into three domains: (i) research team and reflexivity, (ii) study design and (iii) data analysis and reporting (Tong, Sainsbury, & Craig, 2007).

All articles were peer-reviewed. The first domain, research team and reflexivity, was the most weakly described. Few studies

**TABLE 1** Inclusion and exclusion criteria applied to the literature search

Inclusion criteria	Exclusion criteria
Qualitative studies focusing on	
Nurses with basic education in nursing, expert nurses, specialist nurses	Other health personnel's as well as caregivers' and relatives' experiences of the nurse's role
Nurses with both long and short work experience	Review articles; official reports, book reviews; theoretical articles, dissertations; conference abstracts and editorials
Nurses providing palliative care across institutions, wherever they work in the healthcare system	
Peer-reviewed articles published in English or a Scandinavian language	

#### **TABLE 2** Search history

A: Se	earch history from CINAHL May 2016		
S1	(MH "Palliative Care") OR "palliative care" OR (MH "Hospice and Palliative Nursing") OR (MH "Terminal Care+")		
S2	(MH "Nursing Role") OR "nursing role" OR "Nurse's Role"		
S3	(MH "Qualitative Studies+") OR "qualitative research" OR qualitative		
S4	S1 AND S2 AND S3 Limiters - Published Date: 20000101- 20160630		
B: Search history from MEDLINE May 2016			
1	exp Palliative Care OR palliative care.mp		
2	exp Terminal Care OR terminal care.mp		
3	1 OR 2		
4	exp Nurse's Role OR nurses's role.mp. OR nursing role.mp		
5	exp qualitative research/ or qualitative.mp.		
6	3 AND 4 AND 5 AND		
7	limit 6 to yr="2000 -Current"		

recognised and clarified to readers the researchers' background and experience, and few had a description of and/or reflections concerning their interactions with the participants in the study.

Various study designs, representing different philosophical schools and disciplines, were applied. One third of the articles explicitly described a phenomenological methodology, using different forms of individual interviews as well as focus group interviews. All studies reported sample size and the majority how participants were recruited. Many of the studies also described the context in which data were collected. Roughly three in four articles included the study's limitations.

While two of the 28 studies used focus group interviews (n = 36) and one study conducted individual telephone interviews (n = 21), three studies had a mixed methodical approach. One study used observation and audio-recorded four nurses in 38 interactions with 34 patients, another article used 20 nonparticipant observations, followed by focus groups and individual semistructured interviews with 25 nurses. One study conducted reflective diaries with nurses in addition to interviews.

Most studies included a detailed description of the selected method of analysis as well as the process of analysis. However, there were some weaknesses concerning the absence of a description of the process of analysis among the authors, as well as reflections on the validation of the findings.

#### 2.4 | Thematic synthesis

The process of thematic synthesis in the current review involved three steps (Ring et al., 2011). In the first step the authors read the studies separately a number of times to become fully immersed in the data. At this step we noted the findings that described the research questions. In the second step, free codes were organised into descriptive themes by the first and last author. In the third step

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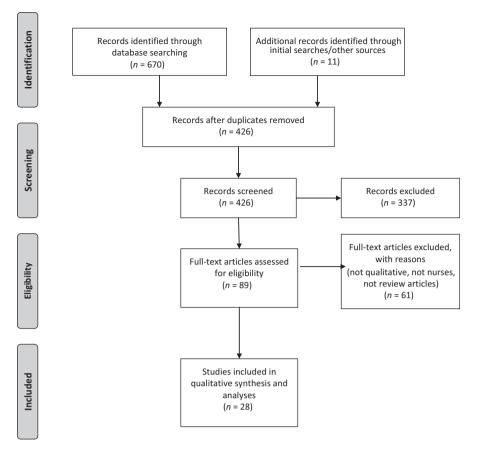


FIGURE 1 PRISMA 2009 flow diagram II

the descriptive themes were generated in analytical themes (Ring et al., 2011). The whole process was performed by the first and last authors, both individually and together, to arrive at a new interpretation that went beyond the original studies. The process of analysis was a continuous discussion and reflection between first and last author.

#### 3 | FINDINGS

Altogether, 834 participants working in various settings and institutions, giving palliative care, were included in the review. The majority of participants worked in different departments in hospitals or in home care. The 28 studies selected for inclusion were spread throughout four continents and 10 different countries. Thirteen articles were from Europe of which eight were from the United Kingdom. A summary of the studies is shown in Table 3.

#### 3.1 | Being available

The nurses' availability, being on duty around the clock created their role (Andersen, Ytrehus, & Grov, 2011; Espinosa, Young, Symes, Haile, & Walsh, 2010; Howell et al., 2014; Raphael, Waterworth, & Gott, 2014). Among the health professions, nurses generally spent the most time with the patients. Even though the patients received care from many other health professions, they always need basic

care, such as help with personal hygiene and nutrition. As King, Melvin, Ashby, and Firth (2010) reported: "The nurse is the one who is there and continues to be there when other health personnel may not considered it necessary." The nurses, working around the clock and taking care of the patients' fundamental needs, were responsible and available.

Spending the most time with the patients, and having frequent and regular contact allowed nurses and patients to develop a special connection. Being in the patients' home and /or at their bedside and responding to the patients' needs, enabled the development of a relationship of trust as well. Findings show that the quantity of time was essential in building relationship in palliative care. This connection was a facilitator for giving individual care and nursing, found on various wards in hospitals and in home care, across continents (Andersen et al., 2011; Austin, Luker, Caress, & Hallett, 2000; Ward-Griffin, McWilliam, & Oudshoorn, 2012). Without the opportunity to achieve this position, nurses stated that they would hardly be able to provide optimal care to dying patients.

Across several continents and contexts, the nurses described their role as being the patient's advocate (Arbour & Wiegand, 2015; Howell et al., 2014; McCallin, 2011; McCallum & McConigley, 2013; Raphael et al., 2014; Törnquist, Andersson, & Edberg, 2013; Verschuur, Els, Groot, & van der Sande, 2014). In this role nurses watched over the quality and continuity of care. Being the patient's advocate also meant ensuring that the patient understood the doctor's or other healthcare personnel's information and feedback, that

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	Core findings	<ul> <li>Great responsibility to help the patient</li> <li>The impact of availability and time</li> <li>Solidarity</li> <li>Solidarity</li> <li>The nurse described as an "instrument" that can relieve anxiety and shortness of breath. Nursing approaches characterised as individual, relational and professional</li> </ul>	<ul> <li>Educating the family</li> <li>Advocating for the patient</li> <li>Encouraging and supporting family presence</li> <li>Managing symptoms</li> <li>Protecting families and creating positive memories</li> <li>Family support</li> <li>Mentoring and teaching</li> <li>A higher comfort level with role expression was associated with long clinical experience</li> </ul>	<ul> <li>Early referral of patients to the district nursing service</li> <li>Family circumstances</li> <li>Availability of services and equipment</li> <li>Availability of services and use in the services of the processes that contributed to high quality care:</li> <li>Relationship with patient and family</li> <li>Relationship with other healthcare professionals</li> <li>A positive outcome achieved when patients retained control over their circumstances and died a peaceful death, supported by their family (Continues)</li> </ul>
	Sample and method	N = 7 RN Phenomenological-hermeneutic approach Interviews Analysed by Malterud's four-step method	N = 19 critical care nurses Phenomenological approach Interviews Analysed by Coliazzi's method	N = 62 RN A critical incident approach to elicit factors associated with the provision of high quality or poor care Semi structured Interviews Thematic content analysis
	Aim	To investigate what nurses perceive as their focus when caring for COPD patients who suffer from anxiety and dyspnoea when hospitalised	To understand the experience of critical care nurses and to understand their perceptions of activities and roles that they performed while caring for patients and families during the transition from aggressive life-saving care to palliative and end-of-life care	To identify community nurses' perception of quality care provision for patients requiring palliative care
	Location of study	Med. Pulm. Dep. Hospital, Norway	Med. Surg. Crit. Units, USA	Comm. health care, UK
ABLE 3 Table of included studies	Title	Palliative Nursing for Patients with Chronic Obstructive Pulmonary Disease (COPD)	Self-described nursing roles experienced during care of dying patients and their families. A phenomenological study	Palliative care: community nurses' perceptions of quality
TABLE 3 Table	Author/Year	(1) Andersen et al. (2011)	(2) Arbour & Wiegand (2015)	(3) Austin et al. (2000)

**TABLE 3** Table of included studies

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	Core findings	<ul> <li>Recognition of dying</li> <li>Nursing care challenged</li> <li>Impact of single rooms</li> <li>Clinician preparedness and coping The study clarifies the context's significance for the opportunity to provide good palliative care</li> <li>Nurses' attitude to death had an impact on care</li> <li>To provide curative care to fellow</li> <li>patients while providing palliative care to dying patients is challenging</li> </ul>	<ul> <li>Emotional impact on patients and families</li> <li>The struggle to balance the needs of patients and families</li> <li>Nurses' contributions to care</li> <li>Importance of relieving suffering</li> <li>Transdisciplinary care connections</li> <li>Treatments to control symptoms</li> <li>Imminence of death</li> <li>Communication, a key currency in care</li> </ul>	<ul> <li>Being open for the presence of the other</li> <li>being satisfied</li> <li>Being frustrated</li> <li>Being ambivalent</li> </ul>	<ul> <li>Barriers to optimal care</li> <li>Internal conflict</li> <li>Coping</li> <li>Coping</li> <li>The role cannot be seen independently of context and culture</li> <li>(Continues)</li> </ul>
	Sample and method	N = 25 RN Nonparticipant observation, Focus group interviews Individual semistructured interviews Content analysis	N = 15 RN Individual interviews and focus group interviews Analysis by a qualitative descriptive approach	N = 10 RN Phenomenological-hermeneutic approach Narrative interviews Structural analysis	N = 18 Intensive care nurses Phenomenological approach Interviews and Focus group interviews Colaizzi's step for analysis
	Aim	To explore nurses' recognition of and responsiveness to dying patients and to understand the nurses' influence on end-of-life care	To use a qualitative descriptive study to explore the experience of nurses caring for patients with Malignant bowel obstruction (MBO) and their families, to add to the understanding of this phenomenon	The aim of this study was to illuminate and interpret the meaning of nurses' lived experience when meeting severely ill patients' expressions in the home care setting	To increase awareness and understanding of the experiences of ICU nurses who provide terminal care
	Location of study	Two acute med. wards in hospital, Australia	Palliative care unit, inpatient acute care oncology units, ambulatory cancer setting, Canada	Home care, Norway	Intensive care, USA
(Continued)	Title	The "dis-ease" of dying: Challenges in nursing care of the dying in the acute hospital setting. A qualitative observational study	Nurses experiences caring for patients and families dealing with malignant bowel obstruction (MBD)	When expressions make impressions—Nurses' narratives about meeting severely ill patients in home nursing care: A phenomenological-hermeneutic approach to understanding	ICU Nurses' Experiences in Providing Terminal Care
TABLE 3 (Cont	Author/Year	(4) Bloomer et al. (2013)	(5) Daines et al. (2013)	(6) Devik et al. (2013)	(7) Espinosa et al. (2010)

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Core findings	<ul> <li>Comfort and relief</li> <li>Peace and ease</li> <li>Spirituality and meaning</li> </ul>	Important to be involved during the early palliative phase. The patient's physical condition provided district nurses with a "reason" to visit. Uncertainty about whether it was appropriate to explore the patient's psychological concern in the early palliative phase • Education alone is unlikely to improve practice without an under- standing of the tensions faced by the district nurses in their work	<ul> <li>Integrated care system</li> <li>Communication</li> <li>The intensive care environment</li> <li>Education and training</li> <li>Staff distress</li> </ul>	<ul> <li>The personal ideal</li> <li>The actual</li> <li>The unknown</li> <li>The alone</li> <li>Tension</li> <li>Antitension</li> <li>Based on the six essences a model was developed illustrating the emotional fluctuations and tensions that experience with caring for dying people involves</li> <li>(Continues)</li> </ul>
Sample and method	N = 15 hospice nurses Hermeneutic phenomenological approach Semistructured interviews and reflective diary Analysis inspired by Colaizzi and Van Manen	N = 34 district nurses Semistructured interviews Interviews were coded, and thematic content analysis was conducted	N = 5 RN Phenomenological approach Semistructured in-depth interviews Burnard's 14-step framework guided the analysis	N = 28 RN, newly qualified Phenomenological approach In-depth interviews Analysis through an interactive process of questioning and analysis
Aim	<ol> <li>To explore the meaning of com- fort care for hospice nurses</li> <li>To provide an understanding of how this work is pursued in the hospice setting</li> <li>To examine the means by which hospice nurses provide comfort to hospice patients</li> </ol>	The aim of this study was to examine UK district nurses' role in supporting palliative care cancer patients	Aim not clearly formulated To explore the experiences of ICU nurses who had provided EOLC to patients and their families	To develop an understanding of care for dying people in hospital from the perspective of newly qualified staff nurses
Location of study	Hospice, UK	Home care, UK	Intensive care, UK	Med. wards in two acute hospitals, UK
Title	Living with dying: a hermeneutic phenomenological study of the work of hospice nurses	Supporting cancer patients with palliative care needs	A study of the lived experiences of the registered nurses who have provided end-of-life care (EOLC) within an intensive care unit (ICU)	Caring for dying people in hospital
Author/Year	(8) Evans and Hallett (2007)	(9) Griffiths et al. (2007)	(10) Holms et al. (2014)	(11) Hopkinson et al. (2003)

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	Core findings	<ul> <li>Summary of interactions:</li> <li>Assessment</li> <li>Issues addressed during the assessment phase</li> <li>Planning</li> <li>Interventions</li> <li>Evaluation</li> <li>Crosscutting themes</li> <li>CPC-CNS provides multifaceted care, requiring wide-ranging knowledge to enable them to act as liaison points in a complex health service, respond independently to the fluctuating meeds of patients</li> </ul>	Nurses: • Connecting • Providing comfort • Working together • Know what they are doing	<ul> <li>Nature of rural nursing</li> <li>Nursing role in providing palliative care in rural communities</li> <li>Impact of physical residential setting on nurses' provision of palliative care</li> </ul>	Coordinated the input of other agencies, provided information and emotional support for patients and careers and carried out physical care task. Willingness to carry on working with patients and families, where relationships were difficult, and other agencies sought to withdraw (and actually did) (Continues)
	Sample and method	N = 4. Community palliative care clinical nurse specialist (CPC-CNS) Observation and audio-recorded during interactions with 34 patients Thematic analysis	N = 22 RN and 22 dying patients Phenomenological approach In-depth interviews Thematic content analysis	N = 21 community nurses Explorative descriptive design Individual telephone interviews Thematic content analysis	N = 24 RN Focus on lived experience Semistructured interview Thematic analysis
	Aim	To describe CPC-CNS activities during interactions with patients	To explore the perception of patients and nurses of palliative care and, in particular, the concept of the expert palliative nurse	To explore nurses' experiences of providing palliative care in rural communities, with a particular focus on the impact of the physical residential setting	To examine the relationship between community nursing roles and the delivery of palliative care, from the perspective of best practice described in the Gold Standards Framework (GSF)
	Location of study	Comm. care, UK	Two acute hospitals and two hospices, Scotland	Rural areas, Australia	District nurse, UK
tinued)	Title	Community palliative care clinical nurse specialists: a descriptive study of nurse- patient interactions	Nurses' and patients' perceptions of expert palliative care	Nurses' experiences providing palliative care to individuals living in rural communities; aspects of the physical residential setting	Community palliative care: role perception
TABLE 3 (Continued)	Author/Year	(12) Howell et al. (2014)	(13) Johnston and Smith (2006)	(14) Kaasalainen et al. (2014)	(15) King et al. (2010)

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	Core findings	<ul> <li>Professional roles and relationships</li> <li>Talking to patients and families</li> <li>Managing task-oriented nursing</li> <li>Emotional work</li> <li>Their position close to the patient privileged nurses in terms of noticing physiological or psychosocial issues</li> <li>Their presence at the bedside enabled the development of positive relationships with patients, and was a crucial element of the care trajectory</li> </ul>	Nurses used the process of moderated guiding to manage different expectations in end-of-life care that included: • Checking out • Involving • Supporting	<ul> <li>The nurse as protector</li> <li>Conflict of care</li> <li>Peace and quiet</li> <li>Within these areas, the characteristics of an ideal death and barriers to provide an ideal death were identified. Palliative care neglected in high-dependency unit</li> </ul>	<ul> <li>Lack of preparedness for patients' deaths</li> <li>Reflecting on own nursing roles for dying patients</li> <li>Reflecting on the meaning of death and personal experiences of the death of their own family members</li> <li>Coping with caring for dying patients</li> </ul>	<ul> <li>Beliefs about end-of-life care</li> <li>End-of-life care in the intensive care context</li> <li>Facilitating end-of-life care (Continues)</li> </ul>
	Sample and method	N = 20 RN Interview Systematic thematic content analysis	<ul> <li>N = 30 RN</li> <li>Grounded theory</li> <li>Semistructured interviews</li> <li>Constant comparative techniques.</li> <li>Theoretical sampling and memo writing furthered theoretical</li> <li>development</li> </ul>	N = 5 RN A descriptive exploratory approach Semistructured interviews Thematic analysis	N = 15 RN Individual interview Boyatzis' thematic analysis	N = 5 RN intensive care nurses Semistructured interview Inductive coding approach
	Aim	To systematically explore hospital- based nurses' accounts of the transition to palliative care, and the potential role of nurses in facilitating more effective palliative care transitions	To generate a grounded theory of nursing practice in end-of-life care	To describe the provision of end- of-life care in an open high- dependency unit	To explore the experiences and perceptions of nurses care for dying patients and their families in the acute medical admission setting	The purpose of this study was to explore the end-of-life care beliefs and practices of intensive care nurses
	Location of study	Hospital, Australia	End-of-life care, New Zealand	Hospital, Australia	Acute med. wards, Hong Kong	Hospital Intensive care, Australia
	Title	The role and significance of nurses in managing transitions to palliative care: a qualitative study	Moderated guiding: a grounded theory of nursing practice in end-of-life care	Nurses' perceptions of caring for dying patients in an open critical care unit: a descriptive exploratory study	Experiences and perceptions of nurses caring for dying patients and families in the acute medical admission setting	End-of-life care in the intensive care setting: A descriptive exploratory qualitative study of nurses' beliefs and practices
	Author/Year	(16) Kirby et al. (2014)	(17) McCallin (2011)	(18) McCallum and McConigley (2013)	(19) Mak et al. (2013)	(20) Ranse et al. (2012)

TABLE 3 (Continued)

Author/Year Title	Title	Location of study	Aim	Sample and method	Core findings	
(21) Raphael et al. (2014)	The role of practice nurses in providing palliative and end-of- life (EoL) care to older patients with long-term conditions	Rural and urban areas, New Zealand	To explore the role of practice nurses in the provision of palliative and end-of-life care to older patients with long-term conditions	N = 21 RN A descriptive exploratory approach Interview Inductive coding approach	<ul> <li>Variability of PN involvement in EoL care</li> <li>Education and training in EoL care</li> <li>What PN can (and do) contribute to EoL care</li> </ul>	
(22) Schaepe et al. (2011)	A Spider in the Web: Role of the Palliative Care Nurse Specialist in Uganda—An Ethnographic Field Study	Hospital and home care, Uganda	To explore the role of the palliative care nurse specialist (PCNS) in Uganda within the context of the experiences and challenges that PCNSs face in delivering palliative care	N 20 RN Ethnographic field study Observation and interviews Analysis method from Burnard	<ul> <li>Physical care</li> <li>Psychosocial care</li> <li>Spiritual care</li> <li>Spiritual care</li> <li>Networking and Advocacy</li> <li>The nurse interacts as a "spider in the web." Through regular contact with patients, the nurse is in a strong position to assess their problems. The nurse needs a high level of knowledge about all the aspects of holistic care, but every nurse does not have these qualifications</li> </ul>	
(23) Törnquist et al. (2013)	In search of legitimacy— registered nurses' experience of providing palliative care in a municipal context	Four different municipalities, Sweden	To describe RNs' experience of providing palliative care for older people in a municipal context	N = 20 RN Focus group Conventional content analysis	<ul> <li>Being the one who cushioned the effects of unclear responsibilities</li> <li>Having limited legitimacy in the municipal context</li> <li>Being in need of support</li> </ul>	
(24)Verschuur et al. (2014)	Nurses' perceptions of proactive palliative care: a Dutch focus group study	Four institutions, ten different teams, the Netherlands	To explore nurses' perceptions and experiences of proactive identification of problems and requirements among patients with palliative care needs	N = 16 RN Focus groups Analysed by initial coding	<ul> <li>The start of proactive palliative care</li> <li>Communication, support, and guidance</li> <li>Cooperation with GPs and medical specialists</li> <li>Nurses as patient advocates</li> </ul>	
(25) Wallerstedt and Andershed (2007)	Caring for dying patients outside special palliative care settings: experiences from a nursing perspective	Home care and hospital, Sweden	Nurses' experiences in caring for ill and dying patients outside palliative care settings	N = 9 RN Phenomenological approach Interviews Analysis according to Giorgi	<ul> <li>Ambition and dedication</li> <li>Everyday encounters</li> <li>Satisfaction/dissatisfaction</li> </ul>	
					(Continues)	

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	Core findings	<ul> <li>Home-based palliative care nursing was depicted as a dialectical experience, revealing three relational practice patterns:</li> <li>Making time-forfeiting time</li> <li>Connecting-withdrawing</li> <li>Enabling-disabling</li> <li>Nurses attempted to negotiate the tensions between these opposing approaches to palliative care</li> </ul>	<ul> <li>Question 1</li> <li>Hard to rank competence necessary</li> <li>Clinical knowledge and guidelines</li> <li>Family training</li> <li>Physician skills and relationship management</li> <li>Teamwork</li> <li>Question 2</li> <li>Education</li> <li>Physician issues</li> <li>Education</li> <li>Physician issues</li> <li>Freedback on current practices</li> <li>Financial issues</li> <li>Barriers</li> <li>Work meaning and job attitudes</li> </ul>	<ul> <li>End-of-life care for dying cancer patients</li> <li>End-of-life care for family members</li> <li>End-of-life care for family members</li> <li>Cultural sensitivity and communication</li> <li>Moral distress and self-limitations</li> <li>Self-reflection and benefit-finding</li> <li>Death is taboo in traditional Chinese culture. This increases the difficulty of effective communication between nurses, patients and families</li> </ul>
	Sample and method	N = 3 palliative care nurses 19 in-depth interviews and participant observations Analysis after guidelines by Lofland and colleagues	N = 353 RN Members of the Hospice and Palliative Nurses Ass. Part of a large survey with two open-ended questions Inductive thematic approach	N = 28 RN Semistructured interviews Qualitative thematic analysis
	Aim	To examine client/caregiver/care provider relationships within the sociocultural context of home- based palliative care, from the perspective of nurses	To gain a better understanding of palliative nursing practice to learn more about the particular issues, concerns and needs of palliative and hospice nurses.	To elucidate Chinese oncology nurses' experience of caring for dying cancer patients
	Location of study	Home care, USA	USA	Cancer hospital, China
nued)	Title	Negotiating relational practice patterns in palliative home care	Voices from the bedside	Chinese oncology nurses' experience with caring for dying patients during their final days: a qualitative study
TABLE 3 (Continued)	Author/Year	(26) Ward- Griffin et al. (2012)	(27) White et al. (2013)	(2015) (2015)

patient and family were properly informed, and helping patients express things that they found it difficult to talk about (Arbour & Wiegand, 2015; Howell et al., 2014; Verschuur et al., 2014).

Establishing early contact with patients and relatives to facilitate individual comprehensive care was described as important for providing optimal care. Some studies concerning home care in the UK and in several institutions in the Netherlands (Austin et al., 2000; Griffiths et al., 2007; Verschuur et al., 2014) illuminated the importance of establishing contact as early as possible, before the patients entered the palliative stage, to build trust and relationships with them. The study by Griffiths et al. (2007) found that establishing early contact was linked to quality of care. However, studies show that early contact was often not established. For example, Griffiths et al. (2007) found, in the UK, that a patient's physical condition often provided district nurses with a "reason" to visit. As a result, nurses did not get involved as early as they would like as there were no "nursing tasks" to undertake until a later stage in the patient's illness. The study by Verschuur et al. (2014) found that nurses who worked at different institutions experienced patients as unable or unwilling to talk about prognoses and impending death at an early stage of the illness.

#### 3.2 | Being a coordinator of care

The nurses' availability made them natural points of contact for the patient and the family, as well as for other health professionals. Hence, the nurses described themselves as coordinators of services, aiming at providing care for the patients and their families (Austin et al., 2000; Daines et al., 2013; Hopkinson, Hallett, & Luker, 2003; Howell et al., 2014; King et al., 2010; Raphael et al., 2014; Törnquist et al., 2013; Wallerstedt & Andershed, 2007). Schaepe, Campbell, and Bolmsjo (2011) showed that nurses, whether working in home care or hospital in Uganda, described their role as "spiders in a web." Their work was characterised by networking with other professionals and between the patient and the family. Being available and doing what was needed gave the nurses a natural role as a hub of other services. Kaasalainen et al. (2014) found that nurses in rural Australia described themselves as "jacks of all trades." Being a liaison and a coordinator was seen as important for continuity of care, and was achieved by building relationships with other services. Without the opportunity to be in this position, the nurses could rarely provide optimal care to the dying patients. In the study by Austin et al. (2000) the nurses working in UK home care, appeared as "gatekeepers" to services provided by other professionals. The nurses described their provision of palliative care in four Swedish municipalities as at times even buffering the effect of the many different care providers and unclear responsibilities (Törnquist et al., 2013). The study by King et al. (2010) draws a picture of the district nurse in the top of the tree, "without her (the nurse) the whole world would collapse... [...]...and there is not anyone else who would pull it all together." In many ways, the nurse acted as coordinator and liaison point in a complex health service.

In the coordination of care the nurses had key roles in communication with all persons involved. Good communication with the family and the patients, the team and particularly the doctors, was crucial. Kirby, Broom, and Good (2014) found that the core values of the nurses' role in an Australian hospital were alleviating suffering, maintaining dignity and performing comfort care. These values shaped the nurse–patient conversations, which were the key elements of being there for the patient. Johnston and Smith (2006) found in the context of two acute hospitals and two Hospices in Scotland that in the nurses' perception of their role, communication was seen as listening, facilitating communication and providing information. Some studies revealed the importance of clarifying needs and preferences, while others stressed the importance concurrently with uncovering the demands of the situation (Verschuur et al., 2014).

#### 3.3 Doing what's needed

Nurses performed a variety of activities in the field of palliative care (Hopkinson et al., 2003; King et al., 2010; Kirby et al., 2014). Such activities would be tasks identified and performed by nurses in the course of their work, illustrated both on acute wards and in home care across continents (Hopkinson et al., 2003; Howell et al., 2014). The observational study of Howell et al. (2014) found that nurses in home care handled an enormous breadth of activities within a framework of assessment, planning, intervention and evaluation, ranging from the relatively routine to the complex. All the activities often formed the nurses' day-to-day interactions with patients and relatives (Hopkinson et al., 2003; Howell et al., 2014). According to Schaepe et al. (2011), the nurses' role in home care in Uganda involved providing holistic care that was physical, psychosocial and spiritual. Howell et al. (2014) found that the nurses described all the activities as hard to measure and some constituted "hidden work," such as work not registered or documented, but nevertheless a prerequisite for care.

At the end of life, the "doing what's needed" was also described as giving comfort care. Comfort care encompassed task-oriented nursing such as bathing, hair care, mouth care, and emotional, psychological and existential comfort care. The study by McCallum and McConigley (2013) found that nurses working in a critical care unit in Australia perceived their role as being to protect the patients' dignity by making sure that they were well cared for, performing basic nursing. This basic nursing was echoed in most studies across various contexts and continents. The nurses viewed their role in palliative care as keeping patients comfortable and pain-free (Evans & Hallett, 2007; Howell et al., 2014; Kaasalainen et al., 2014; McCallum & McConigley, 2013). Adequate pain relief and symptom management were seen as essential. The nurses described pain control as bringing comfort in itself for the patients. Even in an acute unit, end-of-life care was considered to be a complex area of practice and the nurses performed the same basic activities (Ranse, Yates, & Coyer, 2012).

However, the experience of dying was not just a problem of physiology. The nurse's role in symptom management improved the

patient's functional status and well-being and built bridges to other areas in life, such as conversations about emotional issues. Hence, providing psychosocial and spiritual care to the patients went hand in hand with direct hands-on physical care (Kaasalainen et al., 2014; Schaepe et al., 2011). The study by Daines et al. (2013) found that the best part of working with palliative care patients across institutions, in acute care and outpatient care as well as in a palliative care unit, was when nurses were able to find the right combination of medical and nonmedical intervention to achieve comfort. The nurse's role across continents and institutions included helping patients with the "soul pain," referring to the more psycho-existential dimension of suffering (Evans & Hallett, 2007; Howell et al., 2014; Kaasalainen et al., 2014; Zheng, Guo, Dong, & Owens, 2015).

#### 3.4 Being attentively present and dedicated

The nurses described their vision of how palliative care should be for them to feel they fulfilled their role. This vision expressed the nurses' personal competencies. In the study by Hopkinson et al. (2003), nurses working on acute medical wards in the UK found a strong *personal ideal*—the nurse's personal view of how to care for dying patients. The findings revealed that nurses felt comfortable and satisfied in their work with dying patients if their experiences matched this personal ideal.

The great solidarity and responsibility reported by the nurses shed light on their dedication in palliative care, focusing on personalised and individualised care (Andersen et al., 2011; Daines et al., 2013; King et al., 2010). Wallerstedt and Andershed (2007) described in their findings the nurses' strong ambition and dedication to give the dying patients and relatives care of high quality. The nurses' dedication to patients also showed in their willingness to carry on working with patients and relatives when relationships were difficult and other agencies sought to withdraw (King et al., 2010). Interpersonal skills and qualities such as kindness, warmth, compassion and genuineness were essential personal characteristics for the nurses.

Other words for the nurses' role as being dedicated and present were to *open oneself to the other*. The study by Devik, Enmarker, and Hellzen (2013) found that being dedicated meant being open to the presence of the other. To be open meant to experience the patients' lives, sensing their milieu and their history and context, and presupposes openness to the nurse's own existence and emotions. When caring for patients who emotionally touched them, the nurses revealed that they were exposed to an emotive situation in which they opened themselves to the patients' and relatives' vulnerability. Being involved and dedicated meant that nurses exposed themselves to joys and sorrows. Moreover, studies from several contexts across continents revealed that to give comfort care, the nurses used nontraditional work methods and themselves as instruments, with creativity and personal engagement (Andersen et al., 2011; Espinosa et al., 2010; Evans & Hallett, 2007; Ward-Griffin et al., 2012).

Nurses talked openly about the fact that some nurses were better at providing terminal care than others (Espinosa et al., 2010;

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Evans & Hallett, 2007; Mak, Chiang, & Chui, 2013). The nurses who were less able to provide satisfactory terminal care were described as a showing a lack of personal involvement or as not being present or dedicated. Findings also mentioned nurses who "turned off" or became "crusty" as a coping mechanism (Espinosa et al., 2010). This was not viewed as a positive response from nurses who worked in palliative care.

Some studies from acute wards described, in further detail from Australia and Hong Kong, that nurses were not prepared for the role of palliative care (Bloomer, Endacott, O'Connor, & Cross, 2013; Mak et al., 2013). The nurses took a passive approach to the dying patients, and continued to provide active care and treatment until someone else said that the patient was dying. At times, nurses reported to be task-oriented to get the work done. The findings revealed that nurses' attitudes to death and their personal competence had an impact on the care they provided.

#### 3.4.1 | Being a supporter

One way of being present and dedicated was to support and educate the patients and their families (Andersen et al., 2011; Arbour & Wiegand, 2015; Devik et al., 2013; Howell et al., 2014; King et al., 2010; McCallin, 2011; Ranse et al., 2012). Exploring the patient's and relatives' informational understanding, and their situation, manner of coping and perspective on the future were core values. The nurses reported that some patients were well informed, others poorly and some families coped well while others did not cope at all. The study by McCallin (2011) found that guidance helped the nurses move the patient and the family through the end-of-life phase. Back et al. (2014) found that nurses may had an important role in engaging patients in emotional work to facilitate coping and acceptance. Zheng et al. (2015) showed in their study that effective communication could reduce the patient's psychological distress. Patients with knowledge about coping strategies and disease, was a relief, also to the nurses' workload (Andersen et al., 2011). Being a guide and supporter was about building therapeutic relationships with the dying patients and the family (Johnston & Smith, 2006; McCallin, 2011).

Caring for the patient's family was reported to be a particularly important part of the nurse's role in palliative care. The role encompassed making the families feel comfortable, well supported, and not alone (Daines et al., 2013; McCallin, 2011; Zheng et al., 2015). Several studies (Espinosa et al., 2010; Johnston & Smith, 2006; Zheng et al., 2015) found that building trust with the patient's family was essential.

#### 3.5 Standing in demanding situations

Several studies point to the increasing volume and complexity of the nurses' workloads, in addition to limited time for reflection and debriefing (King et al., 2010; Zheng et al., 2015). The strong curative culture reflected a tension that existed with regard to the value placed on end-of-life care. The study by Ranse et al. (2012) identified a need for emotional support to intensive care nurses providing

end-of-life care. The country, context, culture and actual place of care had significance for the nurse's opportunities to provide palliative care and handle different demanding situations. Poverty and lack of access to medicine are great challenges in some parts of the world and the findings by Schaepe et al. (2011) demonstrated that it is difficult to deliver good palliative care when morphine is out of stock. Kaasalainen et al. (2014) found that it was challenging for nurses to be available and to do what is needed when patients lived in rural areas in Australia. A study from China showed that death was taboo in some cultures, and may often complicated communication between nurse, patient and families (Zheng et al., 2015).

At the same time as working with end-of-life care was seen as a gift that was enriching, nurses felt somewhat lonely and overburdened (King et al., 2010; Wallerstedt & Andershed, 2007).

#### 3.5.1 | Lack of time and resources

"Being there" and spending time with the patient and the family gave nurses a great opportunity to create trust and give comfort care. However, several studies problematised time and the lack thereof in palliative care (Hopkinson et al., 2003; Kaasalainen et al., 2014; King et al., 2010; Kirby et al., 2014; Wallerstedt & Andershed, 2007; Ward-Griffin et al., 2012). This became apparent both in acute wards in hospitals as well as in home care and Hospice. Ward-Griffin et al. (2012) described how the nurse's care role in US home care was often demanding when time was limited. Nurses reported that sometimes there was only time to listen to minor problems. Furthermore, lack of time had a detrimental impact on patients and impacted the nurses' ability to create intimacy (Kaasalainen et al., 2014). Some studies pointed to that the nurses' steady increase in workload, both in the acute ward and in home care, across continents (Hopkinson et al., 2003; Kaasalainen et al., 2014; King et al., 2010), resulted in less time and destructive and stressful factors in their encounters with both patient and family. Some studies from acute wards reported limitations on time in many ways stating that these wards were not ideal places for dying patients and their families (Holms, Milligan, & Kydd, 2014). The shortage of time influenced palliative care in a dissatisfactory way (Wallerstedt & Andershed, 2007).

Time constraints were frequently discussed, with the majority of nurses noting the difficulties of providing emotional support for patients, in addition to their other clinical and bureaucratic daily tasks (Devik et al., 2013; Kirby et al., 2014). Wallerstedt and Andershed (2007) demonstrated that nurses, working in home care as well as in hospital in Sweden, were dissatisfied with having a constant lack of time when providing palliative care. On the other hand, nurses were very satisfied when they were able to fulfil special wishes and provide holistic care.

#### 3.5.2 | Handling ethical dilemmas

The findings show that, across institutions and cultures, the nurse's role encompassed moral and ethical dilemmas. One ethical dilemma

was what was considered aggressive medical management, particularly when the nurses knew it would not change a patient's outcome (Espinosa et al., 2010; Kaasalainen et al., 2014; McCallum & McConigley, 2013). Nurses working in critical care units at times experienced a conflict when the current treatment options no longer enhanced life, and a palliative approach was needed to replace it (McCallum & McConigley, 2013). This was at times a greater challenge in an active medical unit used to curative care. The nurses talked about palliative care as neglected as the main focus in these units was to save lives, but also because the nurses were not adequately prepared or comfortable with such care (Bloomer et al., 2013). The latter study found that the priorities were at times set according to the nurses' preferences rather than to a patient's need.

### 3.5.3 | Limited legitimacy

Although nurses have a unique position and a pivotal role in end-oflife care, several studies found that the profession is not granted sufficient recognition and legitimacy (Espinosa et al., 2010; Raphael et al., 2014; Törnquist et al., 2013; Verschuur et al., 2014; Wallerstedt & Andershed, 2007). This limited legitimacy was found across several continents and contexts and there were several reasons for this precarious position.

Some studies, for example, from intensive care units in the USA and rural and urban home care in Australia, found that while doctors planned the care, the nurses, who spent the most time with, and knew the patients the best, were not involved in the planning (Espinosa et al., 2010; Raphael et al., 2014). The physician's focus on, for example, organ dysfunction could be frustrating to nurses caring for the holistic aspects of the patients. This was a barrier to optimal terminal care. In a study by Raphael et al. (2014), one half of the nurses said the doctors handled care for end-of-life patients, even though the doctor saw the patients the least. In a Swedish study (Törnquist et al., 2013), the findings show that the physicians did not listen to the nurses and did not want to prescribe in accordance with their advice, even though the nurses were more familiar with the patients. In this culture and context the doctor was likely to be the lead care provider. The study identified that nurses from four different municipalities in Sweden had limited legitimacy. Moreover, the findings concerning nurses' role linked to both home care and hospital in Sweden (Wallerstedt & Andershed, 2007), and from Hospice in the USA (White, McClelland, VanderWielen, & Coyne, 2013), demonstrated poor collaboration with the doctors. The nurses' expertise in palliative care, as well as nursing care skills, was not acknowledged. Being alone with crucial decisions, particularly when working night shifts, with no access to colleagues or physicians was at times overwhelming. The nurses had to make medical assessments and resolve acute situations on their own. They frequently performed tasks that were the physicians' responsibility. Nurses seem to be accorded limited legitimacy both within their own organisation and in relation to other health professionals (Törnquist et al., 2013).

#### 3.5.4 | In need of support and knowledge

Nurses working with terminal care felt an unmet need for regular and systematic supervision, as well as for emotional support from colleagues (Espinosa et al., 2010; Hopkinson et al., 2003; Kirby et al., 2014; Ranse et al., 2012; Törnquist et al., 2013; Wallerstedt & Andershed, 2007). Moreover, they experienced insufficient support from their leaders and little understanding and commitment regarding their own physical and mental health (Wallerstedt & Andershed, 2007). Nurses working in intensive care also reported a lack of debriefing (Ranse et al., 2012). However, a study from acute wards in the USA (Espinosa et al., 2010) found that talking to other nurses about the experience with terminal care, could provide support and reassurance.

Moreover, several studies across continents (Espinosa et al., 2010; Griffiths et al., 2007; Holms et al., 2014; Zheng et al., 2015) demonstrate that nurses lack knowledge needed in palliative care. Advanced knowledge was required to fulfil the nurses' ambitions of giving satisfactory terminal care. The studies by Holms et al. (2014) and Espinosa et al. (2010) found that nurses in acute wards did not feel adequately prepared to give end-of-life care. They felt insufficiently trained, lacked support and had problems with communicating with the physicians. Some studies revealed a need for modifying the environment so that it would be better suited for terminal care as well as a need for organisational support (Ranse et al., 2012).

Across the studies, both in intensive care and in home care, the nurses expressed a need for more education and training concerning terminal care and how to communicate with families (Espinosa et al., 2010; Griffiths et al., 2007; Holms et al., 2014; King et al., 2010; Raphael et al., 2014; Törnquist et al., 2013).

#### 4 | DISCUSSION

This review shows that nurses, across healthcare institutions, have a unique position in palliative care. The nurses hold all things together," like "a spider in the web" or "jack of all trades" as identified in the current review (Kaasalainen et al., 2014; King et al., 2010; Schaepe et al., 2011). Nurses in home care in particular have to master a range of activities, often alone, there and then in the patient's home. This is also echoed in a review by Mulvihill et al. (2010) that demonstrates that nurses in home care act as a linchpin in their role in palliative care. The nurse's core role encompasses availability and coordination of healthcare services.

However, the current review demonstrates that the nurses' many activities make the role difficult to describe. Becker (2009, 14) states that the activity of palliative nursing is a complex mix of many hands-on skills and personal qualities bound together in an eclectic discipline that is inherently difficult to define. Florence Nightingale (1860/1969) pointed to some of these complexities in general nursing when she expressed: "the very elements of nursing are all but unknown." Allen (2015) claims that nurses' work has always included a wide range of background activities, including some that do not

entail direct care delivery. She states that "nursing is relational and not just of people." Nurses connect different parts of the health system that have, or need to have, some relationship with each other. In her research project, Allen (2015, xi) reveals that nurses to a considerably extent do organisational work, acting as coordinators for the whole patient trajectory. This coordinating work is to a large degree invisible, she argues. Examples are routine chores, a variety of diverse little tasks that are carried out in between other necessary tasks, or bodywork and engagement with intimate aspects of people's life and death that may be difficult to talk about (Allen, 2015, 4). In spite of this great impact on the quality of care with regard to fluency, coherence and continuity of treatment and care, nurses' coordination work is invisible and undervalued (Allen, 2015, 3). Allen (2015) elaborates that the elements of nursing are in need of revision, but as the nurse's work cannot be easily explained, such a revision poses a challenge. How do we revise something we cannot properly put into words? Nevertheless, there is an urgent need to make the role clearer and make the nurses' invisible work more visible, in palliative care as well as in general care.

Moreover, the findings in our review clarify the significance of culture and context for the opportunity to provide palliative care. Several studies demonstrate that in busy hospital wards, with focus on fast and effective curative treatment, it was difficult for nurses to make the shift to palliative care. Findings in the current study also illuminated that busy hospital wards lack the tranquillity, privacy and space needed to provide holistic end-of-life care. Feo and Kitson (2016) echo this finding and argue that patient-centred fundamental care is often poorly executed in acute care settings, due to the invisibility and subsequent devaluing of such care. The impact of the biomedical model, the managerial approaches to care and the devaluing of fundamental care by nurses themselves are reasons for the lack of focus on fundamental care in the acute health systems (Feo & Kitson, 2016). Further on they argue that nurses often delegate fundamental care to less skilled nurses or less educated personnel. Nurses even believe that delivering fundamental care is no longer part of their job (Feo & Kitson, 2016).

One may ask if fundamental care is easier to overlook or hide in a fast track acute care setting. However, our review reveals that basic nursing is fundamental to quality of life on many levels in palliative care, and is a corner stone in the nurse's role, and thereby in individual fundamental care. The findings even reveal that basic nursing in itself constitutes a relief. Nevertheless, there is a need to unravel the nurse's role, to make the invisible work of nursing in palliative care more visible. Even though the biomedical model to some extent is dimmed in palliative care, and more influenced by a holistic model, we may wonder why basic nursing is not more valued and clarified. Regardless of the different contexts of care, there is a need for revitalising and making fundamental care more visible in the definition of the nurse's role. Making nurses' invisible work more visible will lead to a greater clarification of the role. We suggest that as fundamental care is so crucial in palliative care, the nurses have a unique opportunity to reveal and put into words what their role encompasses.

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Further on, the findings reveal that the nurse's role includes a relational, a practical and an ethical dimension. The nursing theorist Martinsen (2003, 15–16) emphasises that care is a three-dimensional concept, consisting of relation, action and morality. The relational dimension means that in care there is interaction between people. Action, or practical tasks, indicates that something is done, what is done depends on the life situation of the person receiving the care, and the expertise of the person providing the care. The moral dimension refers to the care provider's way of being in the relation, and in the way the action is performed (Alvsvåg, 2014, 147-170). Becker (2009, 18-25) claims in his textbook that palliative nursing consists of five skills: communication skills, psychosocial skills, teamwork skills, physical skills, life closure skills and intrapersonal skills. These five core elements could all be included in Martinsen's three dimensions of care. Moreover, as seen in the findings and stated by Martinsen (2003, 15-16), the three dimensions are simultaneously present in care. The relational, practical and moral are intertwined, so to speak. The quality of these three dimensions and how they interact determine whether activities constitute care or if care fails (Martinsen, 2003, 15-16). This shows that health personnel's attitudes and basic values are of great importance and colour the relationship with the patients, as well as their practical work. Saunders (1978, 193-202, 2003) emphasised in different ways just the relational, practical and moral when she described palliative care. The threefold dimensions reveal how nursing is deeply rooted in the concrete situation and sheds light on how demanding it may be to make the invisible work more visible. This, however, does not make the work any less important.

The finding being attentively present and dedicated encompasses, and sheds light on, the nurses' personal competence. Interpersonal skills and qualities, such as kindness, personal involvement, warmth, compassion and genuineness, were essential personal characteristics for the nurses in their role in palliative care, across healthcare services and across continents, even though several studies, as we have seen, show that particularly on acute wards the focus on effective curative treatment gave little room to provide palliative care. Martinsen (2003) emphasises the perspective of caring in nursing and says that although caring goes beyond nursing, it is fundamental to nursing. Caring involves having consideration for, taking care of, and being concerned about the other. The current review does reveal that some nurses are more skilled than others in their ability to create and maintain a relation with their patients and the families, as echoed in other studies as well (Bergdahl, Wikström, & Andershed, 2007; Canning, Rosenberg, & Yates, 2007). Hence, the nurses' personal and professional competence and their dedication to their role as nurses are essential to the quality of palliative care. Nurses described a commitment to care, so to speak. Being there, dedicated and involved, made a difference.

Several studies identified abilities such as creativity, intuition and empathy related to the caring relation. Bergdahl et al. (2007) found in their study that nurses develop in a similar way as artists. Naden and Eriksson (2002) says that nurses' communication may be seen as an aesthetic act and that the art of nursing is connected to the creation of relations. The nurses need to be skilled, as well as open and perceptive, like artists, to create the unique caring relation. This means that art and expertise are interconnected (Naden & Eriksson, 2002) in nursing-oriented competencies. Doing and being are both required, and to be open to and prepared for the journey into the unknown in the encounter (Naden & Eriksson, 2002). Saunders (1978) used the term "total pain" to show the complexity of the patients' suffering when living with severe, life-threatening illness at the end of life. One may ask if this complexity makes the art of nursing more needed in palliative care. The art of nursing is about taking care of the practical, relational and the moral in the encounter in a creative way. Time and creativity are needed to meet the individual patient and the relatives in the concrete situation. However, the findings in this review demonstrate that time has become increasingly scarce and that nurses described their workloads as increased in the field. It is challenging to clearly describe a role that is complex and compounded. Without visibility or a clear description of the role, it is difficult to clarify the art of care, as well.

#### 5 | STRENGTHS AND LIMITATIONS

This review focuses on the registered nurses' own descriptions of their role, not the healthcare team's or the patients' and relatives' descriptions of the role. This does not mean that the nurse's role exists in a vacuum, or is without clear boundaries to other professions or patients and relatives. However, we argue that in interdisciplinary cooperation, each and every professional role in the team needs to be described as clearly as possible. A clear description creates safety for everyone in the team and is important for comprehensive cooperation in patient-centred care. As the nurse's role is very complex, partly invisible, taken for granted and, as such, hard to define, it is even more important to clarify the role.

Although great efforts were put into identifying all relevant articles in the field, there may be studies that were missed. Even though we attempted to include evidence of the experiences of the nurse's role worldwide, 13 of 28 articles were from Europe, and eight of those from UK. It would have been strengthening to have a more even distribution worldwide. Moreover, the majority of the participants in this review worked on different wards in hospitals or in home care. A broader variety of healthcare institutions, such as nursing homes, substance abuse treatment centres and psychiatric care would be warranted. The findings of the current synthesis suggest that the core themes are relevant across institutions, but further research is needed.

### 6 | CONCLUSION

Nurses' availability and overall health expertise govern their position in palliative care. A prominent, but not always valued, role for nurses is acting as a coordinator and liaison between patient and family, other health professions and between different healthcare services. The nurse's role requires knowledge and clinical experience in all core areas of nursing. As such, nurses need to be skilled in fundamental nursing to give individually tailored palliative care to patients and relatives. To fulfil the role in palliative care, they have to go beyond routines, trust intuitive feelings and be guided by a feeling for the situation, professional and person-oriented competencies that are highly intertwined. Moreover, the nurse's role encompasses the threefold dimensions that are independent of culture and context. The relational, practical and moral are all crucial for care and for the nurses' performance of their role. However, culture, place, time, and personal attitude and knowledge, provide a frame which gives unequal opportunities for the practice of palliative care.

## 7 | RELEVANCE TO CLINICAL PRACTICE

Nurses need knowledge of fundamental care, as well as guidance and support, to do what the situation demands to fulfil their role in palliative care. Fundamental care, and the nurses' coordinating role in particular, should be emphasised in education as well as in training. The nurses need to focus on articulating their role, which is often taken for granted and undervalued.

#### CONTRIBUTIONS

Study conception and design: SE, IH, RJTS; literature search and organisation: IH; interpretation of data analysis: SE, RJTS; manuscript drafting: RJTS, SE; and critical revisions for important intellectual content and agreement on the final version: all authors.

#### CONFLICT OF INTEREST

The authors report no conflict of interests.

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