

International Practice Development Journal

Online journal of FoNS in association with the IPDC and PcP-ICoP (ISSN 2046-9292)



CRITICAL REVIEW OF LITERATURE

Barriers and facilitators perceived by registered nurses to providing person-centred care at the end of life. A scoping review

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Submitted for publication: 25th June 2019
Accepted for publication: 7th October 2019
Published: 13th November 2019
<https://doi.org/10.19043/ipdj.92.008>

Abstract

Background: Registered nurses are increasingly expected to provide person-centred end-of-life care. However, there is a gap between patients' needs and the capacity of nurses to meet the existing recommendations on provision of this care. Identifying the relevant barriers and facilitators can inform the development of strategies to support person-centred nursing.

Aim: To identify registered nurses' perceived barriers and facilitators in terms of providing person-centred end-of-life care.

Method: A scoping review was conducted according to the 2005 guidelines proposed by Arksey and O'Malley. The databases Medline, CINAHL, PsycINFO, Cochrane, Web of Science and Embase were searched using the period 2000 to 2018. Empirical studies, literature reviews and studies focusing on the experiences of generalist nurses providing end-of-life care were included. The selected articles were independently reviewed by two researchers.

Results: A total of 2,126 publications were identified, with 26 retained after applying the eligibility criteria. Four barriers to providing person-centred care were identified: knowledge of end-of-life care; communication skills; coping strategies; and teamwork. Three main facilitators were identified: knowing the person in a holistic way; nurses' self-knowledge; and the development of a good nurse-person relationship. Organisational and managerial support also emerged to be important. These findings are reflected in the construct of McCormack and McCance's (2017) Person-centred Practice Framework.

Conclusions and implications for practice: This review provides an overview and an understanding of the key elements that influence the provision of person-centred end-of-life care by registered nurses. These barriers and facilitators point to professional competencies that could improve nurses' ability to provide this care. This scoping review highlights registered nurses' need for more specific education, and the elements identified could be a starting point to design an innovative educational programme for registered nurses focused on person-centred end-of-life care to improve person-centred care-related outcomes.

Keywords: Person-centred care, end of life, generalist nurses, education, scoping review, barriers and facilitators

Introduction

The development of person-centred services is a major concern for healthcare systems around the world (Pelzang et al., 2010). There is evidence that meeting the needs of the individual within a person-centred care approach is imperative for an efficient and effective healthcare service (Kitson et al., 2013). In the UK, the policies and strategies of the NHS and the Health Foundation highlight the need for healthcare to focus more on the needs of the person (Kitson et al., 2013). The philosophy and practice of person-centredness is a key focus of future care delivery frameworks.

The concept of person-centred care lacks a clear consensus definition (Edvardsson et al., 2008). However, it is generally defined as regarding the patient as a person within a biopsychosocial perspective (Slater, 2006; Edvardsson et al., 2008). Therefore, person-centred care focuses on the individual person's expectations, needs, wishes and preferences beyond the medical condition (Woitha et al., 2016). The underpinning ethos of end-of-life care, as developed by Cicely Saunders, strongly reflects a person-centred focus that includes a holistic approach, with relationships and personal values and beliefs as core elements of care (Moreno-Fergusson, 2013; Dobrina et al., 2014; Rahim, 2016). This mirrors the Person-centred Practice Framework developed by McCormack and McCance (2017), which explains the required elements of person-centred practice. Therefore, this framework can inform the development of person-centred end-of-life care in any care setting.

Implementing a person-centred focus of care has a positive impact on staff's attitudes, beliefs and behaviours towards people at the end of life in any setting, including acute care (Wilson and Kirshbaum, 2011). This is vital as, increasingly, end-of-life care is being delivered in the generalist setting.

Research evidence shows that end-of-life care is mainly provided in non-palliative care settings by generalist registered nurses rather than specialist palliative care nurses. For instance, in the UK in 2009, 457,000 people received end-of-life care, despite there being only 507 specialist palliative care inpatient units (National Council for Palliative Care, 2009). Generalist registered nurses are defined as qualified nurses with the capacity and authority to practice primary, secondary and tertiary healthcare competently in all settings and branches of nursing (International Council of Nurses, 2008). Yet most registered nurses who provide end-of-life care lack sufficient knowledge about person-centred care and are thus not always able to apply this approach to support holistic care (Oppert et al., 2018).

Research has described how generalist nurses feel their lack of knowledge about person-centred end-of-life care leaves them unprepared to face the care of dying patients (Andersson et al., 2016). This lack of knowledge and skills may negatively influence the quality of care and the safety of patients and their families (Aiken et al., 2014). In addition, it may result in increased nurse stress when providing care (Grafton and Coyne, 2012). Further, Andersson et al. (2016) outline how nurses working in surgical units feel more anxious and powerless about caring for dying people than nurses who work in palliative care units. These factors (anxiety and feelings of powerlessness) can negatively influence their ability to meet the needs of patients and families and consequently reduce their capacity to facilitate a good death (Tishelman et al., 2004).

Likewise, evidence shows that generalist registered nurses are less able to provide high-quality end-of-life care than palliative care specialist nurses (Andersson et al., 2016). To address this issue it is necessary to identify the barriers and facilitators perceived by non-palliative care specialist nurses in this respect. As such, this article will highlight the contextual elements within practice settings that enable or facilitate such care, and inform the development of relevant education programmes for nurses.

Aim

A systematic scoping review was carried out to identify the barriers and facilitators perceived by registered nurses. The research question framing the review was: What are the barriers and facilitators to providing person-centred end-of-life care for generalist registered nurses?

Method and analysis

Design

A scoping review guided by Arksey and O'Malley's (2005) guidelines was carried out to achieve an overview of this broad field of literature. Scoping reviews serve 'to determine the scope or coverage of a body of literature on a given topic and give clear indication of the volume of literature and studies available, as well as an overview (broad or detailed) of its focus' (Munn et al., 2018, p 2).

This scoping review matches one of the four reasons identified by Arksey and O'Malley for doing such a review of evidence: to summarise and synthesise the available published evidence and grey literature on a given topic and disseminate the findings to policymakers, researchers, practitioners and consumers who otherwise lack time and resources to undertake such work themselves (Arksey and O'Malley, 2005; Pham et al., 2014; Peterson et al., 2017).

The phases involved in this review, as described by Arksey and O'Malley (2005), were:

1. Identification of the research question
2. Identification of relevant studies
3. Study selection
4. Data charting and collating
5. Results summarising and reporting of findings (Moher et al., 2009).

Search methods

Six databases (CINAHL, Medline, PsycINFO, Web of Science, Embase and Cochrane reviews) were searched using the dates 2000 to 2018 – years that were expected to include the main studies related to person-centred care. A search of the grey literature that included repositories, catalogues and websites was also carried out. Additional references were located through an examination of the references from the selected studies identified from the databases search (snowballing).

Articles in English were selected. Both MeSH terms and free text search were used on the individual databases with the following search terms:

(Nurs*) **AND** ('Person centred care' OR 'patient centred care' {Mesh Term} OR 'person centr*' OR 'Patient focused care' OR Patient's beliefs and values OR Engagement OR 'shared decision making' OR Sympathetic presence OR 'Holistic care' OR 'Professional competence' OR Interpersonal skills OR Commitment OR 'Knowing self') **AND** ('Palliative care' OR 'end of life' OR 'advance disease' OR 'advanced illness').

Inclusion and exclusion criteria

The inclusion criteria were:

- Empirical studies, non-empirical studies (not limited to any specific research design) and reviews focusing on experiences of generalist nurses providing end-of-life care in adult populations and in any setting

The exclusion criteria were:

- Empirical and non-empirical studies that focused on experiences of specialist/hospice nurses in providing end-of-life care
- Studies focusing on the experiences of patients/families of end-of-life care
- Research centred on nurses' experiences at the early stages of the illness

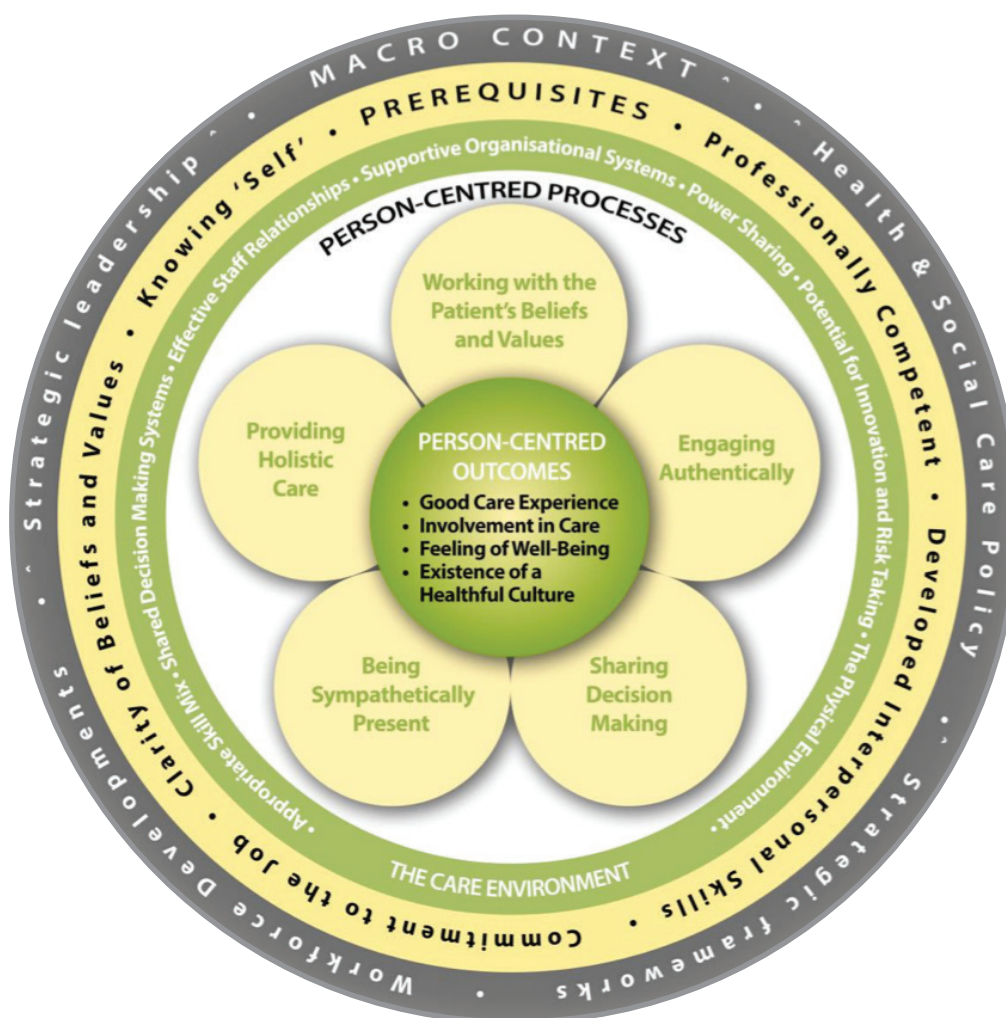
Data abstraction and synthesis

Data were systematically extracted into summary tables including the following information: author, year, country, aim, study population, setting, methodology and findings. Synthesis, analysis and interpretation of the data followed the steps outlined by Arksey and O'Malley (2005). The Person-centred Practice Framework of McCormack and McCance (2017) was used to identify and describe the

barriers and facilitators found in the literature (Figure 1). This framework was chosen because it is the only framework focused on person-centredness that pays attention to all the constructs of a system that need to be considered in order to provide person-centred care. Findings were mapped against the constructs of the framework. Due to the heterogeneity of the included papers, it was not possible to carry out a meta-analysis of data. Rather, the chosen studies are summarised in Table 1.

A formal assessment of methodological quality was not performed as the aim of the scoping review was not to examine the quality of the evidence but to obtain a complete overview of existing evidence (Pham et al., 2014; Peters et al., 2015; Peterson et al., 2017).

Figure 1: Person-centred Practice Framework (McCormack and McCance, 2017)



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Table 1: Features of included studies

	Author/year/country	Aim	Study population	Setting	Methodology	Findings
1	Roche-Fahey et al. (2009) Ireland	Explore experiences of nurses who provide comfort to palliative care patients	12 nurses working in an acute setting (7-40 years' experience)	Urban hospital	<ul style="list-style-type: none"> Qualitative study Hermeneutic phenomenology 	<ul style="list-style-type: none"> Time, emotional cost to the nurse and holistic approach in providing comfort Education and expert team are important to provide comfort
2	Efstathiou et al. (2011) UK	Identify issues with critical care nurses when providing end-of-life care			Literature review based on Clarke et al. (2003) domains	Communication, emotional/spiritual support, patient- and family-centred decision making and support for health professionals help to provide effective end-of-life care
3	Ranse et al. (2016) Australia	Identify the end-of-life care practices of critical care nurses	392 critical care nurses	Critical care	<ul style="list-style-type: none"> Quantitative study Exploratory factor analysis 	Information sharing, emotional support, environmental modification, patient and family-centred decision making, symptom management and spiritual support
4	Andersson et al. (2016) Sweden	Describe nurses' experiences of caring for dying patients	7 RNs (>two years' experience on surgical ward)	University hospital and regional hospital	<ul style="list-style-type: none"> Qualitative study Content analysis 	For nurses, the caring process involves being supportive, being frustrated and being sensitive
5	Hamilton et al. (2004) Scotland	To document the perceptions of nurses and GPs in providing palliative care	4 RNs and two GPs	Two community hospital sites	Qualitative exploratory/descriptive study	The role of the nurse in palliative care in a community hospital setting includes: communication, relationship and teamwork, holistic care, resources and professional role
6	McCourt et al. (2013) UK	To explore nurses' experiences when providing end-of-life care in acute hospital settings			<ul style="list-style-type: none"> Literature review Thematic analysis by Thomas and Harden 	Six themes were found: lack of education and knowledge; lack of time; barriers arising in the culture of the healthcare setting; communication barriers; lack of symptom management; and nurses' personal issues
7	Wai et al. (2016) Hong Kong	To understand emergency nurses' perceptions regarding the provision of end-of-life care	16 nurses with experience with end-of-life care	Acute hospital	<ul style="list-style-type: none"> Qualitative study Content analysis of the interviews 	Four themes were found: doing good for end-of-life patients, in duration of stay, desired environment, providing comfort; facilitating family involvement; improving personal growth and professional skills; and expressing ambiguity to resource deployment
8	Gagnon and Duggleby (2018) Canada	To document the experience of nurses providing end-of-life care			Literature review	It was found that nurses felt a strong commitment to help end-of-life patients, it was a privilege to share experiences with the patients and a challenge to care for them
9	King and Thomas (2013) US	To explore lived experiences of caring for dying patients	14 critical care nurses (2-30 years' intensive care unit experience)	Critical care	Existential phenomenological study	A nursing theme of 'promises to keep' was found. These included: to be truthful, to provide comfort, to be an advocate and to remain connected with the patient or family

Table 1: Features of included studies (*continued*)

	Author/year/country	Aim	Study population	Setting	Methodology	Findings
10	Alasiry et al. (2012) Saudi Arabia	To explore the nurses' experiences of providing palliative care for critically ill patients	9 nurses who work in an intensive care unit (<3 years of experience)	Intensive care unit	<ul style="list-style-type: none"> • Qualitative study • Content analysis 	The themes identified were: care in the intensive care unit is challenging; collaborative work to achieve patient's demands; caring as a comprehensive approach; experiencing language as a barrier or as a support; and providing family- and patient-centred care
11	Johnson and Gray (2013) US	Explore nurses' perspectives within the hospital setting	13 RNs	Academic medical centre and community hospital	<ul style="list-style-type: none"> • Qualitative study • Hermeneutic phenomenological research 	The participants' experiences were: 'confronting challenges', 'coming to understand end of life care' and 'transforming the understanding of end-of-life care into nursing practice'
12	Johanson and Lindahl (2011) Sweden	Experiences of generalist nurses of caring for end-of-life patients	8 RNs (experience ranging from 3-32 years)	Surgical and medical care in acute care settings	<ul style="list-style-type: none"> • Qualitative study • Phenomenological hermeneutics 	Working with end-of-life patients in acute hospitals is interpreted by the nurses as being about contrasts, contradictions and the nurses' varying attitudes as they move between persons' rooms
13	Borhani et al. (2014) Iran	Identify nurses' perception of end-of-life care	12 intensive care nurses	Three intensive care unit teaching hospitals	<ul style="list-style-type: none"> • Qualitative research • Inductive coding approach 	Caring for critically ill end-of-life patients was associated with commitment to care, caring relationship and awareness of dying persons
14	Wallerstedt and Andershed (2007) Sweden	Describe nurses' experiences in caring for end-of-life patients outside palliative care settings	9 nurses (>3 years of experience)	Primary home care, community care and hospital care	<ul style="list-style-type: none"> • Qualitative research • Phenomenological method 	Findings included: ambition and dedication; everyday encounters such as responsibility, experience, cooperation and knowledge; satisfaction through contact with patients and families; dissatisfaction with factors such as a lack of time
15	Kisorio and Langley (2016) South Africa	To explore nurses' experiences of end-of-life care settings	24 nurses from intensive care units	Three academic tertiary hospitals	Exploratory, descriptive qualitative research	Different themes found: 'difficulty that nurses experience', 'discussion and decision making', 'support for patients, families and nurses'
16	Beckstrand et al. (2005) US	To explore nurses' perceptions in providing end-of-life care to patients and their families	864 nurses from members of the American Association of Critical Care Nurses	Critical care	Quantitative study	The highest-scoring difficulties were telephone calls from family members for information, misunderstanding of the term 'lifesaving measures' by families, and disagreement among physicians concerning the aim of treatment at the end of life. The highest-scoring supportive behaviours were to provide family members enough time with patients after death, provide adequate environment after death, and educate to family members on caring for the patient
17	Hopkinson et al. (2005) UK	To explore how nurses cope with caring for patients at the end of life in acute hospital medical wards	28 nurses	Acute hospital trusts	<ul style="list-style-type: none"> • Qualitative study • A cross-sectional interview 	There are different components enabling a nurse to deal with the experience of caring for dying people; relationships, learning, resources, measuring, controlling involvement and revising

Table 1: Features of included studies (*continued*)

	Author/year/country	Aim	Study population	Setting	Methodology	Findings
18	Beckstrand et al. (2009) US	To explore barriers and supportive behaviours perceived by nurses in providing end-of-life care	375 oncology nurses	Inpatient care	<ul style="list-style-type: none"> Quantitative study Survey of oncology nurses' perceptions of end-of-life care 	Barriers: dealing with angry families not accepting patients' poor prognosis; nurses being away from end-of-life patients to care for other patients. Facilitators: allowing families time with patients after death; having social work or palliative care staff as part of the team; and helping family members accept that patients are dying
19	Dong et al. (2016) China	Identify perceptions of physicians and nurses when caring for dying cancer patients	<ul style="list-style-type: none"> 2 nurses 15 physicians 	One cancer hospital	<ul style="list-style-type: none"> Qualitative research Phenomenological approach 	Nurses wanted to provide dying patients high-quality care, and maintain their hopes. They were concerned about physical comfort and wish fulfilment. Health professionals suffered while taking care of dying patients, which helped with their personal growth and allowed greater insight into themselves and their clinical practice
20	Kim and Hwang (2014) South Korea	To explore nurses' knowledge, attitude, coping, and preparedness to practice palliative care for patients with heart failure	90 nurses	Two tertiary university hospitals	<ul style="list-style-type: none"> Quantitative study Cross-sectional descriptive design 	Findings showed that nurses caring for palliative care heart failure patients had low levels of knowledge, coping, attitude, and preparedness to practice
21	Anne et al. (2017) Australia	To explore the perspectives and experiences of physicians and nurses providing end-of-life care in the intensive care unit	<ul style="list-style-type: none"> 11 physicians 17 nurses 	Tertiary metropolitan hospital	<ul style="list-style-type: none"> Interpretative, qualitative study 	Barriers include conflict between the intensive critical unit doctors and external physicians, the availability of training and education, and care environment limitations. Enablers include collaboration and leadership during transitions of care. Challenges include decision making and communication, and hopes of the family
22	Mahiro et al. (2014) Japan	To examine the relationship between work engagement and attitudes toward caring for dying patients and their families	• 184 nurses	Home care	<ul style="list-style-type: none"> Quantitative study 	Work engagement was positively related to the nurses' attitudes toward caring for end-of-life patients and their relatives
23	Attia and Abd-Elaziz (2012) Egypt	To examine critical care nurses' perceptions of barriers and supportive behaviors in providing end-of-life care	70 nurses involved who attend critically ill patients	University hospital	Quantitative descriptive study	The barriers found were related to the intensive care environment, nurses' knowledge and skills, family members, doctors' attitudes and treatment policy. Supportive behaviours included nurses' support for each other, families' support and patient- and family-centered care

Table 1: Features of included studies (*continued*)

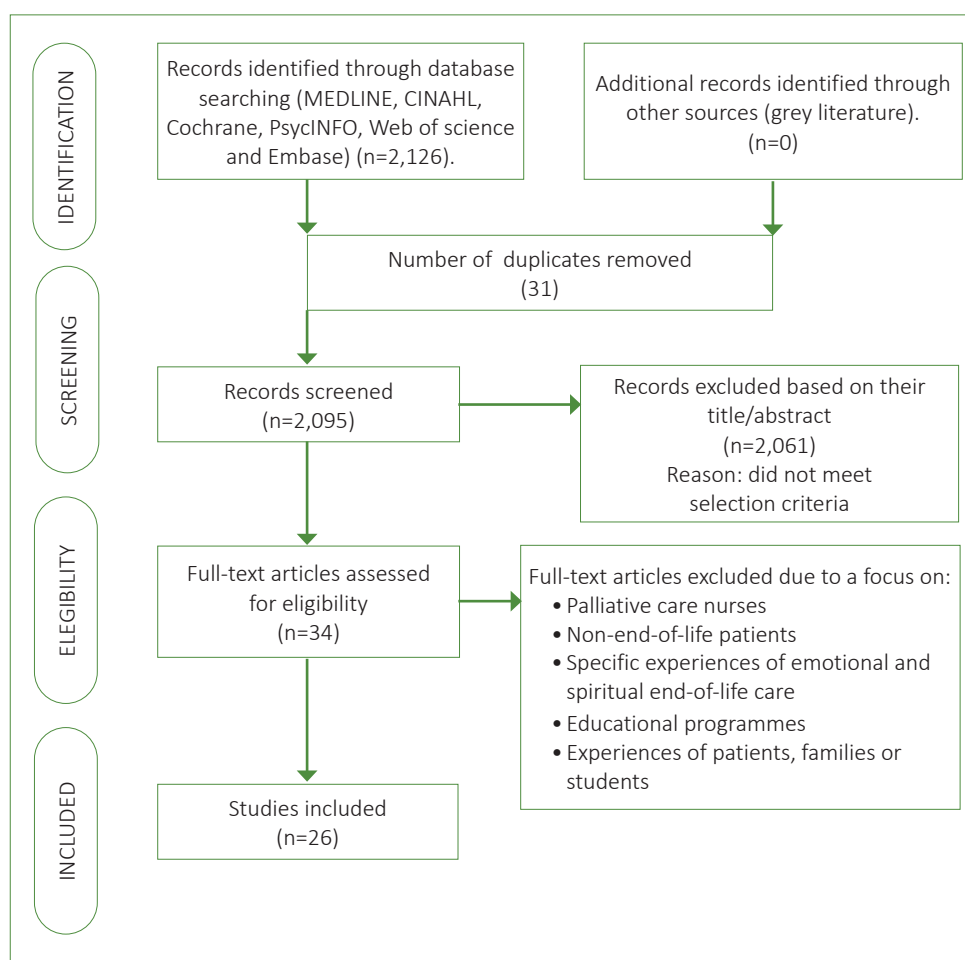
	Author/year/country	Aim	Study population	Setting	Methodology	Findings
24	Thompson et al. (2006) Canada	To develop an understanding of the process nurses undertake in providing quality end-of-life care	10 RNs	Teaching hospitals	<ul style="list-style-type: none"> • Qualitative research • Grounded theory 	'Creating a haven for safe passage' represents a continuum of behaviours and strategies, and comprises 'facilitating and maintain a lane change'; 'getting what's needed'; 'being there'; and 'manipulating the care environment'
25	Andrew and Whyte (2004) Scotland	To explore the experiences of nurses caring for people receiving palliative chemotherapy	10 district nurses	Primary care trust	<ul style="list-style-type: none"> • Qualitative descriptive study 	Nurses saw that their role had relevance at all stages of the illness. Important aspects were knowing the patient and family, communication between primary care and hospital, coping with uncertainty and the provision of comprehensive care based on good interpersonal relationships
26	Espinosa et al. (2008) US	To identify barriers to providing terminal care in intensive care unit			Literature review	The barriers found were: lack of involvement in planning care; disagreement among health professionals; lack of pain relief; unrealistic hopes of the family; nurses' difficulty coping; lack of skills and education; staffing levels; and care environment characteristics

Results

Search results

The search of electronic databases initially retrieved 2,126 references (CINAHL, Medline and PsycINFO: n=673; Web of Science: n=305; Embase: n=1137; Cochrane reviews: n=11; grey literature: n=0). Following the removal of duplicates, the remaining 2,095 titles and abstracts were reviewed, applying the inclusion and exclusion criteria. This resulted in a total of 34 articles for review. Hand searching of the references cited in the articles selected produced five more studies. A review of these 39 full-text articles was done independently by two reviewers (CA and KT). In this process, 13 articles were found not to meet the inclusion criteria. The final 26 included publications were journal articles. Figure 2 shows the PRISMA flowchart (Joanna Briggs Institute, 2015) of the article selection process.

Figure 2: Literature search PRISMA flow diagram



Characteristics of the literature

All articles included were published between 2004 and 2018 – most (n=11) between 2013 and 2016. While the majority of the studies (n=22) were primary research studies, four were literature reviews.

Most of the primary studies (n=10) included nurses from acute care settings. Other studies (n=7) included nurses working in university hospitals, medical and surgical wards, and emergency units. Five studies were conducted with community nurses. The primary studies were carried out in 15 different countries from the five continents: Europe (n=7); North America (n=5); Asia (n=6); Africa (n=2); and Australia (n=2). Summaries of each study are presented in Table 1, above. The final 26 papers include a diverse range of research designs. Sixteen employed qualitative designs (phenomenology, grounded theory and content analysis), four were literature reviews (systematic literature review, narrative review, integrated literature review) and six used quantitative designs (exploratory factor analysis, cross-sectional and descriptive analysis).

Outcomes

From the analysis, the barriers and facilitators to person-centred end-of-life care were mapped and categorised under the constructs of McCormack and McCance's (2017) Person-centred Practice Framework (see Figure 1, above). In this way, the barriers were mapped against two key constructs: prerequisites (professionally competent, developed interpersonal skills, knowing self) and care environment (shared decision making, effective staff relationships, supportive organisational systems, physical environment). The facilitators reflected the same two constructs and in addition were mapped against person-centred processes (sharing decision making, being sympathetically present, providing holistic care), which promote high-quality end-of-life care.

A synthesis of the barriers and facilitators is shown in Table 2.

Table 2: Barriers and facilitators perceived by non-palliative care specialist nurses to the provision of person-centred end-of-life care

Provision of person-centred care at the end of life		
Person-centred Nursing Framework	Barriers	Facilitators
Attributes/prerequisites <ul style="list-style-type: none"> • Professionally competent • Developed interpersonal skills • Knowing self 	Lack of knowledge and experience in palliative care	Educational programmes to provide a holistic knowledge
	Lack of communication skills	Experiential learning of palliative care
	Emotional cost to the nurse when caring for patients	Promotion of nurse's self-reflection for evaluating care procedures and the emotional impact of caring for patients at the end of life
Care environment <ul style="list-style-type: none"> • Effective staff relationships • Shared decision-making systems • Supportive organisational systems • The physical environment 	Lack of coping strategies during caring and after the patient's death	Strategies and ways to cope themselves with end-of-life care Commitment to the job to provide end-of-life care
	Lack of teamwork	Collaboration between physician and nurses
	Undefined nurse's role in decision making and lack of involvement in patient's decision making	Creation of a conducive physical environment
	Heavy workload	Continuity of care at the end of life
	Lack of continuity of care due to great number of staff caring for a single patient	Time to provide comfort to patients and families and to reflect on care process and on self
	Caring simultaneously for acute and terminal patients	
	Lack of time for nurses to provide comfort and support	
	Lack of personal support by the organisation to cope with end-of-life situations	
Unsuitable noise in the physical environment		
Care processes <ul style="list-style-type: none"> • Sharing decision making • Being sympathetically present • Providing holistic care 		Provision of holistic care at all stages of advanced disease
		Sharing decision making and information between patients, families and health professionals to achieve good care and death (better interventions, dignity, place of death)
		Nurse-person (patient/family/health professionals) relationships to provide holistic care during care and after the patient's death

Barriers to providing person-centred end-of-life care by generalist nurses

Barriers related to prerequisites (or attributes) of nurses necessary to providing person-centred end-of-life care

Professionally competent

Six publications highlighted key barriers in relation to the competence of the nurse (Espinosa et al., 2008; Roche-Fahy and Dowling, 2009; McCourt et al., 2013; Kim and Hwang, 2014; Kisorio and Langley, 2016; Andersson et al., 2016). One of the most frequent barriers mapped against this prerequisite was nurses' lack of knowledge and experience in palliative care to support dying persons. It was evident that generalist nurses did not have the knowledge and skills needed to provide holistic care (Espinosa et al., 2008), to assess and manage symptoms (Espinosa et al., 2008; Roche-Fahy and Dowling, 2009; McCourt et al., 2013; Kim and Hwang, 2014), to provide spiritual support (Roche-Fahy and Dowling, 2009; Kisorio and Langley, 2016) or to support existential needs (Kisorio and Langley, 2016). It was evident that nurses provided a partial assessment of the person, focusing mainly on symptom control and use of technical equipment or management of drugs (Andersson et al., 2016) rather than providing care of the whole person (Roche-Fahy and Dowling, 2009). This was due to the lack of knowledge needed to assess other aspects of the person, such as the spiritual (Roche-Fahy and Dowling, 2009; Kisorio and Langley, 2016). There was evidence that generalist nurses need more education in these areas to enable them to be professionally competent in the delivery of high-quality end-of-life care.

Interpersonal skills

Seven papers reported the lack of communication skills as a barrier to person-centred and holistic care for patients and families (Beckstrand and Kirchhoff, 2005; Alasiry et al., 2012; McCourt et al., 2013; Borhani et al., 2014; Dong et al., 2016; Kisorio and Langley, 2016; Brooks et al., 2017). This barrier relates to the framework's prerequisite of developed interpersonal skills. It was evident that general nurses felt they did not have enough experience and confidence to engage in difficult conversations with patients and families (Brooks et al., 2017). A particular challenge was having the skills and confidence to conduct complex conversations while keeping a balance between maintaining hope and truth telling (Dong et al., 2016). In one study, it was also reported that communication relating to language difficulties could be challenging (Dong et al., 2016).

Knowing self

The emotional cost to the nurse of being in close contact with dying people and their relatives was identified as another barrier that makes nurses feel professionally insecure and affects their ability to deliver high-quality end-of-life care (Johansson and Lindahl, 2010; Alasiry et al., 2012; Andersson et al., 2016). This cost was perceived as higher in close nurse-patient relationships (Roche-Fahy and Dowling, 2009), affecting the nurse's identity professionally and personally (Hamilton and McDowell, 2004; Johansson and Lindahl, 2010). For instance, nurses might imagine themselves in the same situation as patients, potentially meaning they are too close to the patients and unable to provide existential support (Johansson and Lindahl, 2010).

It was also evident that the nurses had not developed the resilience needed to provide high-quality end-of-life care. A lack of coping strategies while caring for the person and after their death was reported in eight publications (Wallerstedt and Andershed, 2007; Roche-Fahy and Dowling, 2009; Johansson and Lindahl, 2010; Efstathiou and Clifford, 2011; Alasiry et al., 2012; King and Thomas, 2013; Andersson et al., 2016; Kisorio and Langley, 2016). Feelings of frustration at a patient's death were reported, for example where a patient died suddenly and the nurse was left feeling that the relationship had no proper closure (Wallerstedt and Andershed, 2007). Nurses also experienced coping with multiple deaths within a short period as very challenging and stressful (Wallerstedt and Andershed, 2007).

Barriers related to the care environment in providing person-centred end-of-life care

A total of 18 publications described barriers that could be mapped to the care environment construct, such as those around staff relationships, shared decision-making systems, supportive organisational systems and the physical environment.

Effective staff relationships and shared decision-making systems

Nine papers highlighted a lack of teamwork and this seemed to be a frequent barrier in the generalist setting, which also affected shared decision-making systems (Andrew and Whyte, 2004; Espinosa et al., 2008; Beckstrand et al., 2009; Alasiry et al., 2012; Attia et al., 2012; Gagnon and Duggleby, 2014; Kisorio and Langley, 2016; Ranse et al., 2016; Brooks et al., 2017). This barrier was mostly related to lack of communication within the team (Andrew and Whyte, 2004; Alasiry et al., 2012; Gagnon and Duggleby, 2014; Kisorio and Langley, 2016; Ranse et al., 2016). Lack of communication between hospital and primary care was also evident (Andrew and Whyte, 2004). It was frequently reported that the nurses felt that there was a lack of shared decision making when caring for the patients, reflected in different goals within the care offered (Beckstrand et al., 2009; Attia et al., 2012; Brooks et al., 2017). There was also evidence of disagreements among physicians regarding prognosis (Espinosa et al., 2008) contributing to nurses' confusion about the aims and goals of care. Nurses also felt that their opinions were not included or considered (Attia et al., 2012) and felt excluded from family discussions (Espinosa et al., 2008).

Supportive organisational systems

There were also barriers relating to organisational systems within the care environment construct. Heavy workload (Attia et al., 2012) was identified as an obstacle to delivering high-quality end-of-life care. A lack of continuity of care was also mentioned as a barrier (Efstathiou and Clifford, 2011), while having to provide care for end-of-life patients at the same time as acute care for other patients was identified as a barrier that prevented a closer relationship between the nurse and the patient (Wallerstedt and Andershed, 2007; Beckstrand et al., 2009; Johansson and Lindahl, 2010; McCourt et al., 2013). Nurses found it difficult to combine care of the dying people with care of people in curative treatment in the same unit (Wallerstedt and Andershed, 2007; Johansson and Lindahl, 2010; McCourt et al., 2013).

Five studies found barriers related to a lack of time to provide comfort and support to patients and families, as well as a lack of time to adjust after a patient's death and before admission of a new patient (Espinosa et al., 2008; Roche-Fahy and Dowling, 2009; McCourt et al., 2013; Andersson et al., 2016; Kisorio and Langley, 2016).

Studies also cited a lack of organisational structure to supported nurses in coping with demanding and challenging end-of-life care situations (Roche-Fahy and Dowling, 2009; Efstathiou and Clifford, 2011; Attia et al., 2012). This was especially the case in relation to support for newly qualified nurses (Roche-Fahy and Dowling, 2009).

The physical environment

An unsuitable physical environment was reported in four articles. A lack of privacy, drab decoration and noise were all mentioned in this respect (Espinosa et al., 2008; Roche-Fahy and Dowling, 2009; Efstathiou and Clifford, 2011; McCourt et al., 2013).

Facilitators to providing person-centred end-of-life care by generalist nurses

The facilitators were also mapped and categorised under the constructs of the Person-centred Practice Framework and reflect the same constructs as those already described within the barriers – prerequisites/attributes, care environment, and in addition person-centred processes (McCormack and McCance, 2017). A synthesis of the facilitators is shown in Table 1, above.

Facilitators relating to the prerequisites (or attributes) of nurses in providing person-centred end-of-life care

There were 21 publications that discussed facilitators relating to the prerequisites or attributes nurses need for person-centred end-of-life care. As already alluded to in the barriers section, education is an essential facilitator of nurses' professional competence. Developing education programmes that provide a holistic knowledge of the person was identified as a relevant enabler (Hamilton and McDowell, 2004; Hopkinson et al., 2005; Thompson et al., 2006; Wallerstedt and Andershed, 2007; Roche-Fahy and Dowling, 2009; Johansson and Lindahl, 2010; McCourt et al., 2013; Gagnon and Duggleby, 2014; Dong et al., 2016; Ranse et al., 2016). These programmes need to focus on holistic assessment and care in physical, emotional, spiritual and social dimensions (Wallerstedt and Andershed, 2007; Espinosa et al., 2008; Attia et al., 2012; Kisorio and Langley, 2016). It was also highlighted that nurses need experiential learning in these areas to be able to provide effective care (Wallerstedt and Andershed, 2007; Espinosa et al., 2008; Attia et al., 2012; Kisorio and Langley, 2016).

In relation to the knowing self construct, it was identified that promotion of nurses' self-reflection about the care they provide is essential. Awareness and identification of the emotional impact of caring for people at the end of life is an important facilitator (Hopkinson et al., 2005; Johansson and Lindahl, 2010; Gagnon and Duggleby, 2014; Andersson et al., 2016; Dong et al., 2016). To develop self-awareness and understanding of their emotions, nurses need to reflect on the care they give and their own emotional responses, including on their own and their relatives' mortality as well as existential issues related to their own being in the world (Andersson et al., 2016). This self-reflection helps them to engage in a deeper relationship with patients and their families as a nurse and as a person (Hamilton and McDowell, 2004).

It was also highlighted that nurses need to learn strategies to cope with issues related to end-of-life care (Espinosa et al., 2008; Efstathiou and Clifford, 2011; Andersson et al., 2016; Kisorio and Langley, 2016). Some of the strategies identified as helpful were: humour; a structured approach when talking with dying people and their families (Beckstrand and Kirchhoff, 2005); and balance between engagement and detachment (Hopkinson et al. 2005). These strategies help nurses to provide comfort without unnecessary physical and emotional cost (Hopkinson et al., 2005; Beckstrand et al., 2009). Additionally, obtaining spiritual and emotional support to cope with end-of-life situations was highlighted as an important consideration (Hamilton and McDowell, 2004; Espinosa et al., 2008; Roche-Fahy and Dowling, 2009; Efstathiou and Clifford, 2011; Andersson et al., 2016). Some authors suggested counselling and debriefing sessions following a patient's death may be useful (Beckstrand et al., 2009; Andersson et al., 2016).

Commitment to the job was named as another facilitator of person-centred end-of-life care (Wallerstedt and Andershed, 2007; King and Thomas, 2013; Borhani et al., 2014; Mahiro et al., 2014). Commitment helps nurses maintain a positive attitude towards caring for patients and families until the last moment of life (Wallerstedt and Andershed, 2007; King and Thomas, 2013; Borhani et al., 2014; Mahiro et al., 2014).

Facilitators relating to the care environment for providing person-centred end-of-life care

Seven publications discussed facilitators relating to the care environment (Espinosa et al., 2008; Roche-Fahy and Dowling, 2009; Efstathiou and Clifford, 2011; Alasiry et al., 2012; Attia et al., 2012; Grafton and Coyne, 2012; Ranse et al., 2016)

Positive and effective staff relationships, such as collaboration between physicians and nurses, was a frequent facilitator found in the studies (n=7). Nurses considered that this facilitated patient- and family-centred decision making and enabled shared decision making (Efstathiou and Clifford, 2011). Other facilitators related to supportive organisational systems set out in the Person-centred Practice Framework were identified. These included time to comfort patients and families (Roche-Fahy and

Dowling, 2009; Attia et al., 2012; Grafton and Coyne, 2012); enough staff to provide care; continuity of care at the end of life; and establishing an evidence-based care plan in order to provide standardised care (Efstathiou and Clifford, 2011; Alasiry et al., 2012).

A positive physical environment for providing end-of-life care was another facilitator. Working in a peaceful, relaxing and pleasant environment that affords privacy and comfort to patients was identified as helpful (Espinosa et al., 2008; Ranse et al., 2016). It was seen as important that generalist nurses could allow family members to have adequate time to be alone with the patient during caring and after death of the patient. The ability to create a space for families to rest and to have access to food was also seen as important (Espinosa et al., 2008).

Facilitators relating to person-centred processes

A total of 18 publications discussed facilitators mapped against care processes, including providing holistic care, shared decision making and being sympathetically present. Within the facilitators of person-centred processes, seven papers reported that approaching patients and families in a holistic way, taking into account physical, emotional, spiritual and psychosocial aspects, was an enabler of good-quality end-of-life care at all stages of advanced illness (Hamilton and McDowell, 2004; Roche-Fahy and Dowling, 2009; Efstathiou and Clifford, 2011; Gagnon and Duggleby, 2014; Dong et al., 2016; Kisorio and Langley, 2016; Wai Tse et al., 2016). Supporting and enhancing families' ability to take care of dying persons is also important (Beckstrand and Kirchhoff, 2005; Beckstrand et al., 2009; Alasiry et al., 2012; King and Thomas, 2013; Dong et al., 2016). Nine papers reported the sharing of information and decisions among patients, families and health professionals as facilitators of good care and a good death (better interventions, dignity of care, place of death) (Thompson et al., 2006; Beckstrand et al., 2009; Efstathiou and Clifford, 2011; Attia et al., 2012; King and Thomas, 2013; Gagnon and Duggleby, 2014; Dong et al., 2016; Kisorio and Langley, 2016; Ranse et al., 2016).

The ability to develop effective nurse-person relationships (with patients, families and other health professionals) for holistic care at end of life and after death is an enabler of compassionate care (Wallerstedt and Andershed, 2007; Espinosa et al., 2008; Roche-Fahy and Dowling, 2009; Alasiry et al., 2012; Attia et al., 2012). Such relationships help with physical comfort (Roche-Fahy and Dowling, 2009), emotional support (Hamilton and McDowell, 2004; Thompson et al., 2006; Roche-Fahy and Dowling, 2009; Efstathiou and Clifford, 2011; King and Thomas, 2013; Borhani et al., 2014; Andersson et al., 2016; Dong et al., 2016) and spiritual support (Roche-Fahy and Dowling, 2009; Dong et al., 2016). They also improve shared decision making (Efstathiou and Clifford, 2011). To achieve these results, nurses need to be present, available to the needs of the patient and the family, use positive physical contact, be truthful, and engage in honest communication (Hamilton and McDowell, 2004; Thompson et al., 2006; Roche-Fahy and Dowling, 2009; Efstathiou and Clifford, 2011; King and Thomas, 2013; Borhani et al., 2014; Andersson et al., 2016; Dong et al., 2016).

Discussion

This scoping review provides a comprehensive overview of the research evidence on the key factors that influence the provision of person-centred end-of-life care by generalist nurses. This is also the first study to focus specifically on the barriers and facilitators perceived by generalist nurses in this respect. In this sense, the results of this review could inspire the development of key action points at different levels (educational, practice, organisational, policy and research) where further work could be undertaken to implement person-centred care at the end of life. In this regard, the review highlights nurses' need for adequate education and training.

The primary studies included were from 15 distinct countries, representing five continents. This diversity of settings and widespread interest in the topic across a range of studies adds strength to the results, which are able to offer a broad overview of the barriers and facilitators using an international evidence base.

This scoping review was informed by the Person-centred Practice Framework (McCormack and McCance, 2017) – the first time this framework has been used to identify barriers and facilitators related to person-centred end-of-life care by registered nurses. Other authors (Lannie and Peelo-Kilroe, 2017) have related the assessment and provision of palliative care with the key elements of the framework. They recognised that those elements were equally important and relevant to person-centred palliative care practices and culture. Therefore, this study underlines the relevance of the theoretical framework to person-centred practice in the context of end-of-life and palliative care in all clinical settings.

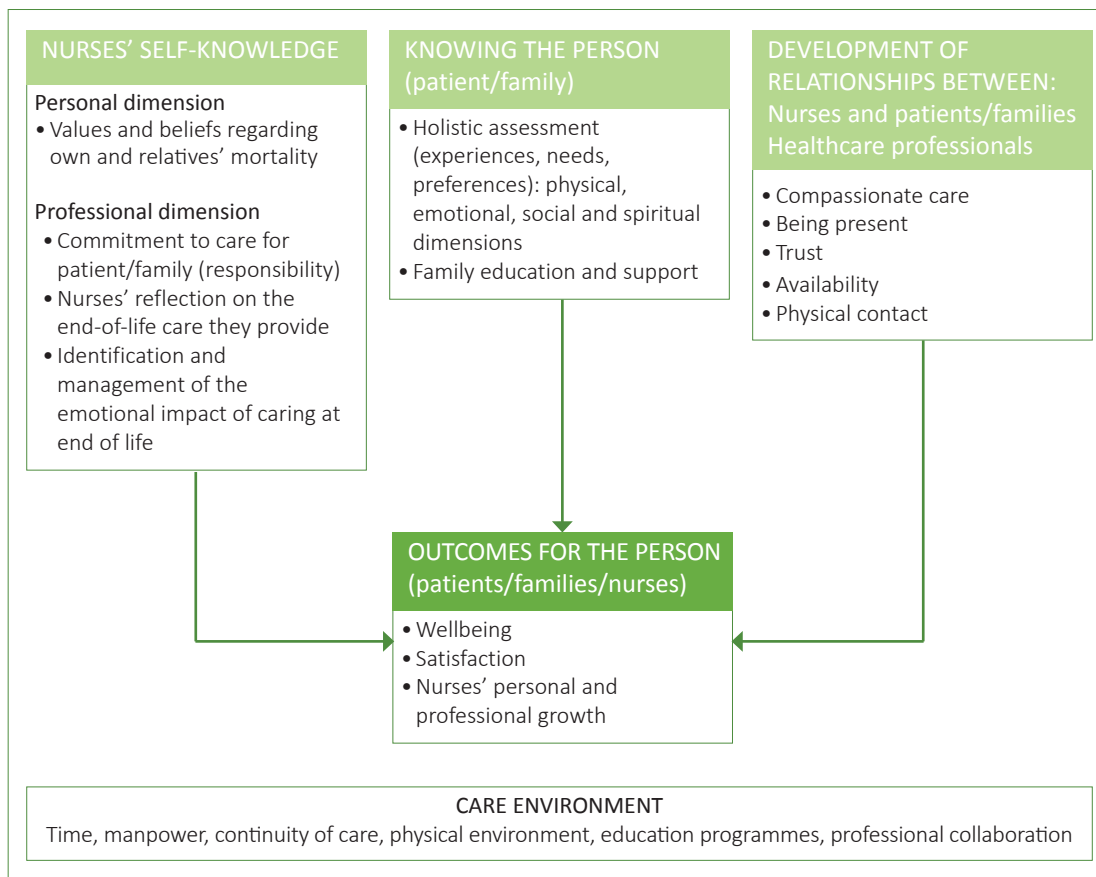
The barriers found in the scoping review pointed mainly to a lack of professional competences (knowledge, skills and attitudes) among generalist registered nurses to provide palliative end-of-life care to relieve suffering and improve the quality of provision for patients and their families. This could be due to a lack of education in the philosophy of palliative care that addresses the breadth of physical, psychological, social and spiritual issues (Gaspard and Roberts, 2009). These barriers could be overcome by the inclusion of the Person-centred Practice Framework in educational programmes for generalist registered nurses (McCormack and McCance, 2017). As such, the framework could inform end-of-life care training courses aimed at generalist registered nurses in acute settings.

The findings of this review are similar to those of a study focusing on older people with cognitive impairment (Edvardsson and Nay, 2009). Those authors showed the need to develop healthcare systems that support person-centred care, including the promotion of friendly environments with competent nurses who provide comprehensive assessments and perform holistic care planning. They proposed that this care be provided by interdisciplinary teams.

From the synthesis of the barriers and facilitators found in this study, essential elements were identified that directly reflect constructs in the Person-centred Practice Framework (see Figure 3):

- Knowing the person (patient and family)
- Self-knowledge of the nurse
- Development of nurse-person relationships

Figure 3: Elements of end-of-life nursing that reflect the Person-centred Practice Framework



In relation to the first element, knowing the person, it is important to point out that this should be achieved through a holistic assessment of the person, considering their experiences, needs and preferences. In this regard, it is worthy of mention that nurses will only be able to do this if they have had appropriate education and are trained in person-centred end-of-life care. Evidence shows that nurses who gain knowledge, improve their skills and have good attitudes towards caring for persons at the end of life provide better palliative care in practice (Kim and Hwang, 2014).

The second aspect, the self-knowledge of the nurse as a professional and as a person, was made evident through evaluation of caring procedures and the identification and management of the emotional impact that caring for people at the end of life may have on nurses. This aspect has also been identified as relevant in palliative care specialist nurses (Arnaert and Wainwright, 2009). In fact, Arnaert and Wainwright's reflections on palliative care nursing highlighted the importance of self-knowledge to recognise one's limitations and humanness, and to cope with emotional demands.

Development of nurse-person relationships entails aspects such as nurses' presence, trust, availability and physical contact. Such relationships enable nurses to be involved with persons and to know them as both a patient and as a person (Errasti-Ibarrondo et al., 2015), but there is a need for the relationship to be reciprocal, and based on values, beliefs and expectations shared by nurses and patients/families (Rumeu-Casares et al., 2017).

This review also has shown that to enact the competences of person-centred care at the end of life, generalist nurses need a care environment supported by the organisation and managers, which pays attention to time, collaboration, continuity of care and the physical environment. The time factor relates to nurses ability to provide comfort to patients and families and to reflect on the caring process.

The evidence suggests that when nurses do not have time to discuss their feelings, experiences and emotions associated with suffering, emotional exhaustion can result, adversely affecting retention of experienced staff (Jezuit, 2002). Another identified need was collaboration and good communication between physicians, nurses and other professionals for person-centred care and shared decision making. This collaboration benefits from pooling the support and wisdom of diverse professionals (Crawford and Price, 2003).

An outcome of providing person-centred end-of-life care is the personal and professional growth of the nurse. Evidence suggests that caring for people at the end of life and their families helps nurses to gain the strength to care and find meaning in what they do (Johansson and Lindahl, 2010). Some authors (Dong et al., 2016; Wai Tse et al., 2016) pointed out how nurses develop professionally and personally when caring for end-of-life patients and families by reflecting on the meaning of death. This is also supported by the literature review of Zheng et al. (2016), which shows how nurses who work with patients at the end of life and their families have the experience of learning and a chance to grow professionally. Likewise, this study also highlights the personal growth that can be experienced by nurses after the death of patients they have cared for. This personal and professional growth experienced can have positive impacts, such as a reduction of burnout-related time off work and improvements in job satisfaction. Understanding this could enable managers to facilitate an effective care environment for providing person-centred end-of-life care.

Study limitations

This scoping review provides a broad, international view of the barriers and facilitators perceived by generalist nurses when providing person-centred care at the end of life. However, this global map could be supplemented by further studies focusing on specific aspects of person-centred end-of-life care, such as compassionate care, the nurse-person relationship or knowing the person. The search and the identification of the literature was based on a combination of keywords and MeSH terms. Although the literature search was conducted using the main healthcare databases, searching in additional databases with a more expansive search of the grey literature may have identified additional publications.

Implications for practice

Person-centredness as it relates to end-of-life care needs to be firmly embedded in education for nurses and the need for further attention to this has been highlighted (O'Donnell et al., 2017). One way to do this is by teaching the key elements of end-of-life care using the Person-centred Practice Framework (McCormack and McCance, 2017). The International Community of Practice for Person-centred Practice (PcP-ICoP) has identified key considerations in its statement Development of a Person-centred Curriculum, set out in eight key themes, one which is the 'review of person-centred concepts, theories and principles' (McCormack and Dewing, 2019). The identification of the barriers and facilitators by this literature review has helped to identify the essential person-centred concepts that are central to end-of-life care in nursing practice. These include knowing the person (patient/family) in a holistic way, self-knowledge of nurses as professionals and as persons, and the development of nurse-person relationships with patients, families and other healthcare professionals. These concepts could be included in an education programme for non-specialist palliative care nurses to promote the provision of person-centred end-of-life care that truly reflects the person-centred curriculum (McCormack and Dewing, 2019). In this way, generalist nurses could obtain the professional competences required to provide this care in an acute setting.

The PcP-ICoP person-centred curriculum statement highlights engagement with stakeholders (McCormack and Dewing, 2019). This study could inform an education programme developed at an organisational level for managers to highlight the key concepts of person-centred care.

Likewise, such an educational programme could take into account the Person-centred Practice Framework (McCormack and McCance, 2017). This intersectionality of end-of-life care with the

framework could form an innovative nursing curriculum that could have an impact in clinical settings and in the wider care environment.

Finally, this review highlights the importance of interprofessional collaboration in clinical practice, such as the value of interdisciplinary sessions and shared decision making to provide optimal person-centred care. This contributes to building relationships and consequently improving the context and culture of person-centredness.

Conclusions

A synthesis of the barriers and facilitators for providing person-centred end-of-life care by registered nurses has identified the key elements needed for implementing the philosophy of person-centred care at the end of life in the general healthcare arena, where most people with end-of-life needs are cared for. This review also points out the professional competences that nurses should have to provide this care.

This scoping review provides evidence that the Person-centred Practice Framework (McCormack and McCance, 2017) can be used to help identify barriers and facilitators influencing person-centred end-of-life care. It reinforces the idea that this framework can be used in the context of clinical practice and to inform education programmes for the purpose of developing person-centredness in palliative and end-of-life care. The identified elements in this scoping review can form a starting point to design an innovative educational programme in end-of-life care for registered nurses, focused on improving person-centred outcomes.

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Acknowledgements

We would like to thank the University of Navarra for enabling us to develop this manuscript. We also thank Ana Choperena for her reviews and comments.

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