

## Family experiences of in-hospital end-of-life care for adults

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## SPECIAL ISSUE ARTICLE

# Family experiences of in-hospital end-of-life care for adults: A systematic review of qualitative evidence

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**Abstract**

**Aim:** To systematically identify, appraise, aggregate and synthesise qualitative evidence on family members' experiences of end-of-life care (EoLC) in acute hospitals.

**Methods:** A systematic review and qualitative evidence synthesis based on the Joanna Briggs Institute methodology. Primary research, published 2014 onwards was identified using a sequential strategy of electronic and hand searches. Six databases (CINAHL, Medline, Embase, EMCare, PsycINFO, BNI) were systematically searched. Studies that met pre-determined inclusion/exclusion criteria were uniformly appraised using the Critical Appraisal Skills Programme checklist for qualitative research, and synthesised using a meta-aggregative approach. The ENTREQ statement was used as a checklist for reporting the review.

**Results:** Sixteen studies of European, Australasian and North American origin formed the review. The quality of each study was considered very good in view of a 'yes' response to most screening questions. Extracted findings were assembled into 12 categories, and five synthesised findings: Understanding of approaching end of life; essential care at the end of life; interpersonal interactions; environment of care; patient and family care after death.

**Conclusion:** Enabling and improving peoples' experience of EoLC must remain part of the vision and mission of hospital organisations. Consideration must be given to the fulfilment of family needs and apparent hallmarks of quality care that appear to influence experiential outcomes.

**Relevance to clinical practice:** This review of qualitative research represents the first-stage development of a family-reported experience measure for adult EoLC in the hospital setting. The synthesised findings provide a Western perspective of care practices and environmental factors that are perceived to impact the quality of the care experience. Collectively, the review findings serve as a guide for evidence-informed practice, quality improvement, service evaluation and future research. A developed understanding of the families' subjective reflections creates reciprocal opportunity to transform experiential insights into practical strategies for professional growth and practice development.

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## KEYWORDS

end-of-life care, family, hospital care, quality of care, systematic review

## 1 | INTRODUCTION

In recent years, end-of-life care (EoLC) has become a policy priority in many countries around the world (Hunter, 2018). A person's preferred location of care and place of death is a key feature of evidence-based national policy reform (The Choice in End of Life Care Programme Board, 2015; Saurman et al., 2022; Ziway et al., 2017) and are advocated outcomes of quality care (De Roo et al., 2014). Importantly, personal preference includes the choice to die in hospital, and may be decided upon by some patients and their caregivers for reasons of safety and familiarity with the care setting (Henson et al., 2016). It has been argued that a hospital death is not a negative outcome if it represents the best interests of the individual (Pocock et al., 2016). Indeed, the hospital can be the right place of care for people with an uncertain prognosis or difficult to manage symptoms (Public Health England, 2019), or the essential place of care following an unexpected life-threatening critical illness or event. Despite evidence of a decrease in the number of people dying in hospital (Cross & Warraich, 2019; PHE, 2019), forecasters predict that ageing of the population and the provision of community-based health and social care are likely to influence future nationwide trends (Finucane et al., 2019; Gomes & Higginson, 2008). In a historical review of EoLC in the Western world, Guilbeau (2018) also questions the ideology of a de-institutionalised death in light of contemporary community characteristics and values. Consideration must therefore be given to the availability and quality of end-of-life service provision in a variety of settings, including institutional hospital care.

Most EoLC in acute hospitals is provided by generalists, and existing standards emphasise the contribution of palliative care services to supporting the usual treating team (Masso et al., 2016). Further, a recent study concluded that the presence of hospital-based specialist palliative care could lead to improvements in the quality of EoLC (Binda et al., 2021). Even so, for example, in the United Kingdom (UK), which ranked highest for palliative care development in countries of the European Union (2007 and 2013) (Woitha et al., 2016), there are variations in care for those dying in hospitals (Royal College of Physicians London, 2016). In a qualitative systematic review of hospital healthcare provider views and experiences, several factors, including poor communication structures affected the provision of non-specialist palliative care (Nevin et al., 2020). Barriers to optimal EoLC in hospitals are known to exist (Chan et al., 2020) and poor communication is a common complaint (Anderson et al., 2019).

Some twenty years ago, the quality of EoLC was recognised as an important concept in industrialised countries and a global public health concern (Singer & Bowman, 2002). While quality improvement applies to all care settings, particular attention has been paid to improving the provision of EoLC in acute hospitals (Australian Commission on Safety and Quality in Health Care, 2013; European

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

- Demonstrates use of a meta-aggregative approach to the synthesis of qualitative evidence reporting family experiences of in-hospital end-of-life care for adults.
- Five synthesised findings: Understanding of approaching end of life; Essential care at the end of life; Interpersonal interactions; Environment of care; Patient and family care after death provide a developed, in-depth understanding of care practices and environmental factors that are perceived to impact the family experience of end-of-life care.
- Reveals a knowledge gap in the understanding of patient and family care after death and subsequent bereavement follow-up support.
- Informs the design of an end-of-life care experience measure, to be empirically validated.

Society for Emergency Medicine, 2017; National Health Service England, 2015). Similarly, attention has been paid to the importance of measuring the quality of EoLC, although how best to achieve this is yet to be understood (Virdun et al., 2018). Experiential information is recognised as a valuable metric in healthcare. This is reflected in the development and use of patient-reported experience measures (PREMs) that serve as an indicator of quality and the perceived impact of care processes (Kingsley & Patel, 2017).

This systematic review represents the first-stage development of a family-reported experience measure (FREM) for adult EoLC in the hospital setting, based upon synthesised qualitative research findings derived from the literature. It forms part of a larger study designed to develop and test the FREM in the context of health care in England, and associated national ambitions and recommendations for quality EoLC (Leadership Alliance for the Care of Dying People, 2014; National Institute for Health and Care Excellence, 2017a, 2021; National Palliative and End of Life Care Partnership, 2021).

## 2 | AIM

The purpose of this systematic review was to generate propositions of what counts as a positive experience of EoLC in acute hospitals, as perceived by families of adult patients, in order to create a preliminary pool of statements for an innovative EoLC FREM for use in the hospital setting. Sociologists suggest 'family' is a complex concept with no single definition (Thompson, 2016). For this reason, we

opted to accept authors/researchers' conceptualisation of family rather than imposing a pre-conceptual requirement. 'Acute hospital' was conceptualised as an in-patient facility providing treatment and care for acute and critically ill hospitalised patients. Our working definition of EoLC represented the pre- and post-death practical care delivered to the dying person in the final days and hours of life, together with the information, care and support provided to their family (LACDP, 2014; Royal College of Nursing, 2021). Specifically, we aimed to answer the following review questions:

1. How do families of adult patients describe their experiences of EoLC in acute hospitals?
2. What counts as a positive experience of EoLC, as perceived by experiencing families?

### 3 | METHODS

#### 3.1 | Design

The study employed a systematic review and qualitative evidence synthesis based on the Joanna Briggs Institute (JBI) methodology (JBI, 2020). This type of review was selected for its meta-aggregative approach to synthesis in which the primary authors' findings are the main units of analysis. This implies that the authors' original intended perspective or context is embedded in the extraction, and thus, allows for a range of qualitative research methodologies to form the review. A systematic process was enabled by the development of a review protocol. The guideline, Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) (Tong et al., 2012) was used to report the stages of this review (see Supporting Information File S1).

#### 3.2 | Search strategy

As advocated by Aveyard (2019), we adopted an eclectic approach to search for relevant literature involving a combination of academic databases, general search engines and the hand-searching of reference lists. A focused and uniformed search of six academic databases was carried out with the support of a medical librarian (PC). The Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, Embase, EMCare, PsycINFO and British Nursing Index (BNI) databases were selected for their scope of content in relation to the topic of interest. Consistent with JBI guidance, database searching comprised three phases. First, a limited search of the CINAHL database was undertaken using keywords that corresponded to the population (family), phenomena of interest (experiences, end-of-life care) and context (acute, hospital, adult, in-patient). Relevant natural language terms were selected and combined, that is, family-reported experience, end-of-life care and acute hospitals. An initial step was to search via the keywords to identify appropriate MeSH (Medical Subject Headings) and indexed terms. These terms were then

mapped with the CINAHL Thesaurus, and other relevant terms were added to ensure possible sources were identified. The search results were filtered by Adult, English Language and published since 2014. Second, these terms were rerun in the remaining five electronic databases via the Healthcare Databases (HDAS) platform, using the advanced search option and with slight adjustments for thesaurus mapping. (See Supplementary File S2 for the search strategy used in each database). The date range for the search was informed and justified by our knowledge of published systematic reviews with a similar focus to the review questions. Of particular relevance was a meta-synthesis of qualitative research published between 1990 and April 2015, identifying the elements of EoLC that patients and their families described as being important (Virdun et al., 2017). Our decision to include research published 2014 onwards also meaningfully corresponded with the launch of new guidance for adoption by health and care organisations and staff caring for dying people in England (LACDP, 2014).

We also searched for online resources on Microsoft Bing and Google using the search string 'family experiences of end-of-life care AND hospital'. The first 50 results were screened online; a decision determined by recurring citations, non-research materials and pre-2014 publications. In the third and final phase of the process, the electronic search was supplemented by hand-searching the reference lists of relevant literature reviews identified during the search, and references in the research articles that formed the review. The final search was carried out in March 2021.

#### 3.3 | Screening and study selection

After de-duplication of database records, the combined search strategy yielded 89 candidate records; 72 identified by databases and 17 by other methods. Our initial intention was to review primary qualitative research originating in the UK. However, due to the apparent small amount of relevant UK-based research, we opted to include research originating in the Western world that would allow for potentially comparable experiential findings, that is, Europe, North America and Australasia. By paying attention to contextual factors, we sought to maximize the content validity of a novel experience measure that formed the basis of this review. Study selection involved a two-level screening process (JBI, 2020) based on eligibility criteria (Table 1). First, the title and abstract of 89 records were independently screened for relevance by two reviewers (WW/NE). Of these, 28 records were retained for second-level independent full-text assessment by the same two reviewers. Screening decisions were documented, and consensus meetings were held to discuss and agree the research articles that met the inclusion criteria. A member of the review team (HJ) was available for third-person consultation; however, consensus was reached without the need for arbitration. Twelve studies were excluded; 16 studies formed the review. A flow diagram of the literature search and research article selection process is presented in Figure 1., based on an updated PRISMA reporting guideline (Page et al., 2021).

TABLE 1 Eligibility criteria

Criteria	Inclusion	Exclusion
Population	Family members of deceased adult patients, i.e., aged 16 and over	Patients, healthcare staff, family members of deceased children
Phenomena of interest	Experiences of end-of-life care	General care of the acute and critically ill patient/family
Context	Acute hospital, adult in-patient care settings	All out-of-hospital care, care homes (Nursing/Residential), the home environment
Type of publication	Primary research	Grey literature, doctoral theses and dissertations, conference abstracts/proceedings, letters, commentaries, literature reviews, discussion papers
Country of origin	Western world, i.e., Europe, North America and Australasia	All other countries
Language	English	Any other language
Date range	2014-2021	Prior to 2014

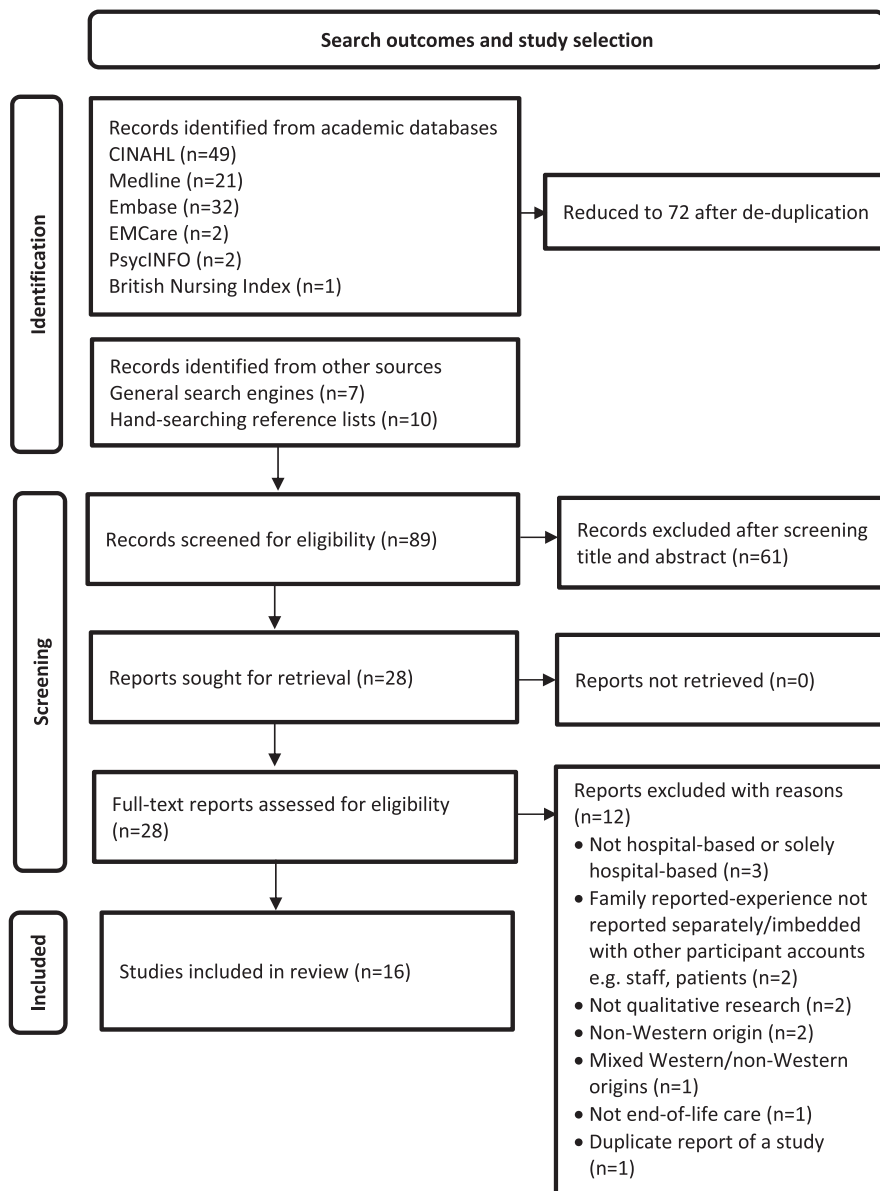


FIGURE 1 PRISMA flow diagram of the literature search and research article selection process

### 3.4 | Study characteristics

The 16 studies, published between 2014–2021, were of European ( $n = 9$ ), Australasia ( $n = 4$ ) and North American ( $n = 3$ ) origin. While all of the studies investigated hospital-based EoLC, research was carried out in various hospital settings including an emergency department, general acute wards/units and intensive care. Most were single hospital site studies. Qualitative methodologies included generic qualitative ( $n = 4$ ), grounded theory ( $n = 3$ ), hermeneutic phenomenology ( $n = 2$ ) and interpretative phenomenological analysis ( $n = 1$ ). There were also two mixed methods' studies, a photo elicitation study comprising qualitative interviews and three questionnaire surveys comprising qualitative analysis of open-ended questions. The most used study methods were purposive or convenience sampling strategies ( $n = 9$ ), interview ( $n = 13$ ) and thematic analysis ( $n = 8$ ). With the exception of the three questionnaire surveys, the number of study participants ranged from 10–55. Of the twelve studies that reported gender characteristics, more female than male participants took part in the research. In all but one study, participants were bereaved, and referred to as either family members, family carers, or relatives of the deceased person. Where stated within the research reports, details of participant characteristics suggested most were related by either blood or marriage. An overview of each study that formed the review is presented in Table 2.

### 3.5 | Quality appraisal

Two reviewers (WW/JJ) independently assessed the 16 studies using the Critical Appraisal Skills Programme checklist for qualitative research (CASP, 2018). The checklist was not used to either accept or reject studies; rather, the questions helpfully supported evaluative judgements about the methodological quality of the research that formed the review. The results were compared and agreement reached through discussion and with reference to the original full-text. The quality of each study was considered very good in view of a 'yes' response to most screening questions (see Table 3). An area of weakness in ten of the 16 studies was under-reporting of the researcher-participant relationship.

### 3.6 | Data extraction

Using the JBI (2020) qualitative data extraction tool, two reviewers (WW/NE) independently documented relevant information about each study. This standardised tool directed the extraction of specific and similar data across all 16 studies including the phenomena of interest, study aim(s)/purpose, methodology, methods, population and setting, and the author(s) summary conclusions. In addition, reported findings in each study (primary themes, subthemes and supporting quotations) of relevance to the focus and purpose of the review were assembled under the descriptive thematic labels used by the authors. We extracted both positive and negative perceptions

of EoLC; the premise being that negative perceptions can convey a message of what is important to families, and as such, provide insight into what counts as a positive experience of EoLC. A meeting was held to compare and agree data extraction before applying the JBI principles and processes of qualitative synthesis.

### 3.7 | Data synthesis

Two reviewers (WW/NE) were involved in data synthesis, consistent with a meta-aggregative approach (JBI, 2020). Meta-aggregation involves allocating a level of plausibility for each extracted finding, developing categories of findings based on similarity of meaning and the aggregation of categories into synthesised findings that are representative of the evidence being brought together (JBI, 2020).

First, we assigned a level of credibility for each extracted finding (unequivocal, credible or unsupported) based on the congruency of the finding with supporting quotations. Almost all of the findings were assessed as unequivocal or credible when supported by a direct quote. A selective highlighting technique was used to identify key words and phrases appropriate to the review questions and central to understanding the family experience of care. For ease of reference, discrete findings were assembled on the basis of similarity in meaning. This assisted the development of categories with at least two qualitative findings per category, and the subsequent aggregation of categories to produce synthesised findings of the review.

## 4 | RESULTS

A total of 99 discrete findings were identified from the included studies. Sufficiently similar findings were integrated to form 12 categories, followed by the development of five synthesised findings (Table 4): Understanding of approaching end of life; essential care at the end of life; interpersonal interactions; environment of care; patient and family care after death. In this section, the synthesised findings in each category are described with reference to the original source. At the end of each category, illustrative participant quotes (mostly one positive and one negative) have been added to provide further insight into families' experiences of care.

### 4.1 | Understanding of approaching end of life

#### 4.1.1 | Clear, factual and truthful information

Family members spoke of a need for clear, factual and truthful information and the role this played in understanding the reality of the situation, and preparation for the possibility of death. The findings suggested a preference to be pre-warned (Berbis-Morelló et al., 2019; Caswell et al., 2015) and a need for information that was objective (Bussmann et al., 2015), upfront (Dose et al., 2015), truthful (Donnelly & Psirides, 2015; Moon et al., 2021), timely (Bussmann

TABLE 2 Overview of studies that formed the review.

Study No. Author(s)/ Year/Country	Aim or research question	Methodology/Methods	Environment of care	Sampling/N° participants	Main themes or categories
Berbis-Morelló et al. (2019) Spain	To identify which are the needs arising from feelings, perceptions and experiences of the family members during any time within the death process in an emergency service of an acute care hospital, with regard to the assistance received.	Qualitative, drawing on grounded theory. Semi-structured interview. Iterative data collection/ analysis; Three types of codification was carried out: open, axial and selective.	Emergency department.	Convenience and theoretical n = 10	The power of information/ communication; Decisions taken by professionals within the dimension of caring; The humanisation of death in emergency services.
Bussmann et al. (2015) Germany	To analyse family members' suggestions for improvement in general hospital EoLC.	Cross-sectional survey using a questionnaire that included open-ended questions/ free-text answers. Qualitative content analysis.	General hospital ward or an ICU.	Random n = 633 n = 270 re: suggestions regarding improvement in hospital care.	Medical care and nursing; Care before and during dying; Interpersonal humane interaction; Support for families; Consultation, information, and communication; Structural aspects in hospital management.
Caswell et al. (2015) England	To understand the factors and processes which affect the quality of care provided to frail older people who are dying in hospital and their family carers.	Mixed-methods using an ethnographic approach. Semi-structured interview with bereaved carers. Constant comparative method.	Four wards in a university teaching hospital.	Not explicit n = 13	Receiving bad news: Clarity; Lacking clarity; Seeking a hearing; Misdirection from external cues; Feeling abandoned.
Clark et al. (2014) Australia	To improve the understanding of the experiences of family members whose relatives had died on an acute medical ward.	Mixed-methods. Semi-structured interview. Thematic analysis.	General medical ward.	Not explicit n = 10	Communication with family; around goals of care; that death was imminent; Place of death; Families concerns around loss of dignity; Symptom control; Support for the family and follow up.
Coombs (2015) UK	To understand the experiences and needs of bereaved families during and after treatment withdrawal in adult intensive care.	Interpretative qualitative design. In-depth interviews. Thematic analysis using an interpretative phenomenological analysis approach.	Tertiary adult ICU.	Purposive. n = 21	Meeting family need; Alleviating further suffering; Re-establishing the identity of the person; Re-connecting relationships with the person.
Donnelly & Psirides (2015) New Zealand	To explore the experience of relatives and staff of patients dying in an ICU.	Qualitative - following grounded theory approach. Face-to-face interview. Thematic analysis.	A tertiary ICU.	Not explicit. n = 14	Excellence of care; Personal/ professional qualities of nursing/ medical staff; Environment; Communication; Pastoral care; Limited access.

TABLE 2 (Continued)

Study No. Author(s)/ Year/Country	Aim or research question	Methodology/Methods	Environment of care	Sampling/N° participants	Main themes or categories
Donnelly et al. (2018) Republic of Ireland	An analysis of bereaved relatives or friends care experience during the patient's last admission to hospital.	Quantitative descriptive post-bereavement postal survey comprising four open-ended free-text questions. Template analysis framework approach.	Two large adult acute university teaching hospitals.	Not explicit. n = 268	Communication; Meeting care needs; Dignity and respect; Hospital environment; Support for family members.
Dose et al. (2015) USA	To explore hospital death from the perspective of patients' family members.	Qualitative. Semi-structured telephone interviews. Content analysis.	Four US hospitals affiliated with a large, multisite tertiary referral centre.	Purposive. n = 30	Before death - A beginning sense that things are not right; The picture as painted by health care providers; Milestone events; Time of death - It's time; Being with the patient. After death - Time with the deceased; Care of the body.
Hajradinovic et al. (2018) Sweden	To explore experiences of the acute-care environment as a setting for EoLC from the perspective of family members of a dying person.	Qualitative, inductive. Participant-produced photographs in conjunction with follow-up interviews (photo-elicitation). Interpretive description.	Two acute-care units providing care for patients with lung diseases.	Purposive. n = 9	Aesthetic and un-aesthetic impressions; Space for privacy and social relationships; Need for guidance in crucial times.
Johnson et al. (2019) USA	What are the EoL priorities of bereaved family members after EoLC experiences in an acute care hospital?	Qualitative, interpretive. Semi-structured telephone interviews. Thematic analysis.	Tertiary referral/ urban medical centre. One death occurred in inpatient hospice, after the patient had received EoLC at the hospital.	Convenience. n = 18	Positive aspects of the in-hospital experience; Negative aspects of the in-hospital experience.
Moon et al. (2021) Australia	To explore bereaved families' experiences of EoL decision making for general medicine patients.	Qualitative exploratory framed by social constructionism. Semi-structured Interviews. Thematic analysis.	General medicine units in a major public hospital network.	Purposive. n = 28	Four subthemes characterised the themes shaping families' experience during end-of-life decisions: power and trust; establishing authority; asserting patients' preferences; and rights and responsibilities.
Noome et al. (2016) Netherlands	To examine the experience(s) of the family with nursing EoLC in ICUs after a decision to end life-sustaining treatment.	Phenomenological approach. Semi-structured interview. Inductive thematic analysis.	One university hospital and three general hospitals.	Purposive. n = 26	Communication between ICU nurses, ICU patients and family; Nursing care for ICU patients; Nursing care for family of ICU patients; Preconditions.
Odgers et al. (2018) Australia	To explore the family's experience of EoLC for their relative during the dying process.	Interpretive. Semi-structured interview. Thematic analysis.	Acute ward of a large regional health service.	Convenience. n = 12	Guidance for family member's role in end of life care; The families' preparation for death; The dying experience; The hospital care experience; The follow-up after death.

(Continues)



TABLE 2 (Continued)

Study No. Author(s)/ Year/Country	Aim or research question	Methodology/Methods	Environment of care	Sampling/N <sup>o</sup> participants	Main themes or categories
Venkatasalu (2017) England	To investigate older British South Asians' views on dying at acute hospital settings.	Constructivist grounded theory approach to data collection and analysis. Focus groups and individual interviews.	Acute hospital settings.	Not explicit. n = 55	Mistrust; Let him not be alone; Family as a protective shield.
Wiegand (2016) USA	To understand the experience of families when a family member had an unexpected life-threatening illness or injury and who died after life-sustaining therapy was withdrawn.	Hermeneutic Phenomenology. Face-face or telephone interview. Thematic analysis.	3 ICUs in an academic teaching hospital.	Purposive. n = 22	Preparing for the dying process; The dying environment; Family perceptions of patient comfort; The death vigil; Essential aspects of care; Together as a family.
Witkamp et al. (2016) Netherlands	To explore the involvement of relatives in the hospital during the patient's last phase of life as experienced by relatives.	Retrospective questionnaire study- qualitative content analysis of responses to open-ended questions.	Non-intensive care wards.	Not explicit. n = 451	Information and communication; Involvement in decision making; Acknowledgment; Trust; Rest and privacy.

et al., 2015; Clark et al., 2014; Donnelly et al., 2018; Odgers et al., 2018; Witkamp et al., 2016) and without false hopes (Berbis-Morelló et al., 2019; Bussmann et al., 2015; Moon et al., 2021). In one study however, family members reported a tension between their need for prognostic information and hope (Odgers et al., 2018).

The clarity of information was the most frequently mentioned factor that appeared to influence family members' understandings, interpretations and expectations (Bussmann et al., 2015; Clark et al., 2014; Donnelly & Psirides, 2015; Johnson et al., 2019; Noome et al., 2016; Odgers et al., 2018; Witkamp et al., 2016). Communication issues of concern were the use of euphemisms (Odgers et al., 2018), and vague information (Clark et al., 2014; Dose et al., 2015) and responses to questions (Hajradinovic et al., 2018). Understanding was also affected by contradictory information (Hajradinovic et al., 2018; Witkamp et al., 2016), misinterpreted cues (Caswell et al., 2015), conflicting projections and differing opinions among staff (Dose et al., 2015). Of importance was alignment between staff and family perspectives (Caswell et al., 2015). Death was perceived as sudden and unexpected in the absence of clear communication (Caswell et al., 2015; Odgers et al., 2018).

I liked that it was all very straightforward talking and no whispered 'we're going to let him pass over' or any crappy talk like that. The nurses were just very straight up, no fluffy, wishy-washy language at all and I really liked that there wasn't any doubt that he was going to die'.

(Donnelly & Psirides, 2015, p. 937)

I was called in the morning when I was at my office, and they asked whether I could come that day, because her saturation was decreasing. Being a lay person, I cannot be expected to understand that; I would have wanted them to be more clear, more pressing.

(Witkamp et al., 2016, p. 237)

## 4.2 | Essential care at the end of life

### 4.2.1 | Care of the dying person

Quality care of the dying person involved the relief of suffering and what family members referred to as a peaceful and/or comfortable death (Coombs, 2015; Johnson et al., 2019; Venkatasalu, 2017; Wiegand, 2016). Some comments were specific to symptom management (Berbis-Morelló et al., 2019; Bussmann et al., 2015; Clark et al., 2014; Johnson et al., 2019; Venkatasalu, 2017; Wiegand, 2016), and concerned the relief of agitation and pain. A perceived lack of patient rest (Witkamp et al., 2016) and heightened suffering (Johnson et al., 2019) were attributed to unnecessary clinical interventions. The option of an alternative place of care and place of death was not always achieved (Clark et al., 2014; Odgers et al., 2018) or desired (Johnson et al., 2019; Venkatasalu, 2017).

TABLE 3 Quality appraisal of studies (Critical Appraisal Skills Programme (CASP) Qualitative Checklist, 2018)

CASP questions	Study															
	Berbis-Morelló et al. (2019)	Bussmann et al. (2015)	Caswell et al. (2015)	Clark et al. (2014)	Coombs (2015)	Donnelly and Psirides (2015)	Donnelly et al. (2018)	Dose et al. (2015)	Hajradinovic et al. (2018)	Johnson et al. (2019)	Moon et al. (2021)	Noome et al. (2016)	Odgers et al. (2018)	Venkatasalu (2017)	Wiegand (2016)	Witkamp et al. (2016)
1. Was there a clear statement of the aims of the research?	Y	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y
2. Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Was the research design appropriate to address the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
4. Was the recruitment strategy appropriate to the aims of the research?	Y	CT	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	CT
5. Was the data collected in a way that addressed the research issue?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
6. Has the relationship between researcher and participants been adequately considered?	CT	CT	CT	CT	N	Y	Y	Y	Y	CT	CT	CT	N	Y	Y	CT
7. Have ethical issues been taken into consideration?	Y	Y	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	Y	Y	Y
8. Was the data analysis sufficiently rigorous?	Y	Y	Y	CT	Y	CT	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
9. Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
10. Is the research valuable?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Abbreviations: CT, cannot tell; N, no; Y, yes.

While some family members described a sense of undue responsibility for the care of their dying relative (Johnson et al., 2019) and expressed concern about staff capacity to care for the dying patient (Berbis-Morelló et al., 2019; Bussmann et al., 2015; Donnelly et al., 2018; Hajradinovic et al., 2018), the findings contained examples of trust and confidence in staff capabilities and skills (Donnelly et al., 2018; Donnelly & Psirides, 2015; Johnson et al., 2019; Moon et al., 2021; Witkamp et al., 2016). Conversely, Venkatasalu (2017) reported older British South Asian adults' mistrust in the EoLC provided in acute hospitals. Feelings of confidence were also affected by disagreements about medical decisions within the medical team and between physicians and the patients or their relatives (Witkamp et al., 2016). There were very few findings that referred to the involvement of a specialist palliative care team (Clark et al., 2014; Donnelly et al., 2018) and family members' accounts contained contrasting experiences. With regard to the latter study, some family members valued the unique skills that this team could offer.

When the palliative care team in the hospital joined forces with it all, it was even better. They got her back into pyjamas she was less a patient, more cared for as a human being who was very ill.

(Donnelly et al., 2018, p. 7)

On the day before my husband died, when we went back from home [to hospital], he was in such a state. There was no one there, the screen was left open and everybody could see that he was in discomfort. The nurses and doctors don't give them their attention, which they should when they care for this type of patient. I had (this) bad experience. I have seen with my eyes.

(Venkatasalu, 2017, p. 435)

#### 4.2.2 | Emotional family care and support

Family members remarked on the availability and conduct of staff who were attentive to their needs (Berbis-Morelló et al., 2019; Bussmann et al., 2015; Donnelly & Psirides, 2015; Johnson et al., 2019) and in one study, this was a hallmark of excellence in care (Donnelly & Psirides, 2015). Affective care requirements included the provision of guidance, support and advice (Berbis-Morelló et al., 2019; Donnelly et al., 2018; Hajradinovic et al., 2018; Odgers et al., 2018), being with/being there for the dying person (Bussmann et al., 2015; Coombs, 2015; Dose et al., 2015; Hajradinovic et al., 2018; Johnson et al., 2019; Noome et al., 2016; Odgers et al., 2018; Venkatasalu, 2017), an opportunity to perform rituals during the dying process (Noome et al., 2016), presence at the time of death (Coombs, 2015; Odgers et al., 2018) and the chance to say goodbye (Berbis-Morelló et al., 2019; Coombs, 2015; Noome et al., 2016). The timeliness of information (Berbis-Morelló et al., 2019; Bussmann et al., 2015; Clark et al., 2014; Hajradinovic et al., 2018; Odgers

et al., 2018; Witkamp et al., 2016) and flexible visiting arrangements (Bussmann et al., 2015; Donnelly et al., 2018; Hajradinovic et al., 2018; Johnson et al., 2019) helped to achieve these goals. Organisational arrangements that allowed the extended family and close friends to visit was found to be helpful and supportive to family members of the dying person (Wiegand, 2016). Dissatisfaction was apparent when confronted with regulations that limited family members' access to the dying patient (Donnelly & Psirides, 2015; Odgers et al., 2018). Positive depictions of family members' experience included the provision of pastoral (Bussmann et al., 2015; Donnelly & Psirides, 2015; Wiegand, 2016) and spiritual care (Donnelly et al., 2018; Johnson et al., 2019), although the availability of a psychologist and spiritual advisor was desired as well (Bussmann et al., 2015).

The nurse got in touch with Father R. We had the final blessing with him too. But to be able to get that priest to come was just so wonderful at the end.

(Donnelly & Psirides, 2015, p. 937)

That woman in ED, I couldn't believe it. She nearly tackled us to the ground. Like we were in a rugby team. We've just been told mum is dying and we're going out to see her and she said, 'Two at a time'.

(Odgers et al., 2018, p. 27)

#### 4.2.3 | Person-centred values

The importance of person-centred EoLC was reflected in values such as privacy (Berbis-Morelló et al., 2019; Bussmann et al., 2015; Donnelly et al., 2018; Hajradinovic et al., 2018; Witkamp et al., 2016), dignity (Bussmann et al., 2015; Clark et al., 2014; Donnelly et al., 2018; Donnelly & Psirides, 2015; Odgers et al., 2018; Venkatasalu, 2017), respect (Bussmann et al., 2015; Clark et al., 2014; Donnelly et al., 2018; Hajradinovic et al., 2018; Moon et al., 2021; Noome et al., 2016; Wiegand, 2016; Witkamp et al., 2016), and in the provision of individualised (Bussmann et al., 2015; Hajradinovic et al., 2018) and holistic care (Bussmann et al., 2015). Coombs (2015) found that personal items around the bedside and meaningful recollections played a role in re-establishing the identity of the hospitalised patient and re-connecting the family with the dying person.

A further perspective of personalisation among the study findings involved taking the wishes of the patient into consideration (Bussmann et al., 2015; Clark et al., 2014) and staff-family communication that reflected partnership in care. Some family members reported involvement in decisions (Caswell et al., 2015; Hajradinovic et al., 2018; Johnson et al., 2019; Witkamp et al., 2016), whereas others described feelings of being ignored (Clark et al., 2014; Moon et al., 2021), neglected (Witkamp et al., 2016), not listened to (Johnson et al., 2019; Moon et al., 2021; Witkamp et al., 2016) or peripheral to important discussions (Odgers et al., 2018). In one study, family members described negative feelings when their views were devalued, and their advocacy role disregarded (Moon et al., 2021).

TABLE 4 Synthesised findings and categories

Study	Berbis-Morelló et al. (2019)	Bussmann et al. (2015)	Caswell et al. (2015)	Clark et al. (2014)	Coombs (2015)	Donnelly and Psirides (2015)	Donnelly et al. (2018)	Dose et al. (2015)	Hajradinovic et al. (2018)	Johnson et al. (2019)	Moon et al. (2021)	Noome et al. (2016)	Odgers et al. (2018)	Venkatasalu (2017)	Wiegand (2016)	Witkamp et al. (2016)	
<b>Understanding of approaching end of life</b>																	
Clear, factual and truthful information	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
<b>Essential care at the end of life</b>																	
Care of the dying person	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Emotional family care and support	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Person-centred values	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
<b>Interpersonal interactions</b>																	
Contact with nurses and doctors	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Communication needs	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Staff demeanour	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
<b>Environment of care</b>																	
Facilities	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Provisions	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Organisational issues	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
<b>Patient and family care after death</b>																	
Final acts of caring	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Guidance, support and follow-up care	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Bold = Synthesised finding.

The doctors asked what his wishes were and tried to honor them.

(Clark et al., 2014, p. 4)

I understood what they said but I found they were not listening to me.

(Moon et al., 2021, p. 4)

### 4.3 | Interpersonal interactions

#### 4.3.1 | Contact with nurses and doctors

Most of the studies contained findings that related to relational aspects of care. It was important for family members to have contact with nurses and doctors, but this appeared dependent on staff being accessible and available (Bussmann et al., 2015; Caswell et al., 2015; Clark et al., 2014; Donnelly et al., 2018; Donnelly & Psirides, 2015; Johnson et al., 2019; Noome et al., 2016). The suggested positive impact of opportunity to form a therapeutic relationship (Donnelly et al., 2018), already being acquainted (Caswell et al., 2015) and consistent nurses (Wiegand, 2016) contrasted with negative perceptions in situations of little or no relationship with the staff (Berbís-Morelló et al., 2019). Meeting a lot of staff members was said to be problematic in a variety of ways (Hajradinovic et al., 2018). Some family members felt abandoned when their relative came close to death (Caswell et al., 2015), and others said they lacked contact with staff (Berbís-Morelló et al., 2019) and felt alone (Bussmann et al., 2015) once the patient had died.

Because he spent nine weeks on the ward, from the end of April, we knew them (staff) so well and I was going at lunchtime to help with feeding him and... we just knew the staff so well and they were so caring.

(Caswell et al., 2015, p. 8)

I am shocked, how one is left alone (...).

(Bussmann et al., 2015, p. 48)

#### 4.3.2 | Communication needs

The findings reflected family members' expressed need to be kept informed and updated (Berbís-Morelló et al., 2019; Donnelly et al., 2018; Donnelly & Psirides, 2015; Johnson et al., 2019), and for staff to communicate with compassion (Berbís-Morelló et al., 2019; Donnelly et al., 2018; Dose et al., 2015; Johnson et al., 2019; Witkamp et al., 2016). Respect for privacy (Dose et al., 2015) and communication with affection and empathy (Berbís-Morelló et al., 2019) was particularly important when reporting bad news. The use of culture-specific respectful words also influenced perceptions of good EoLC (Venkatasalu, 2017).

The doctors and nursing staff were very sensitive when telling us the difficult news that my mother was going to die...

(Donnelly et al., 2018, p. 8)

Um, the one thing that I did not appreciate so much was when they were telling me he probably was not going to survive. They did that in the hallway and I really was not appreciative of that... I know they took me out of the room, I know, so dad would not hear because he could hear... I understand that, ... however, the middle of the hallway was really not a good thing for me... it felt like there were 50 people looking at me while somebody was telling me my dad was going to die.

(Dose et al., 2015, p. 16)

#### 4.3.3 | Staff demeanour

Cumulative findings across several studies contained synonyms that emphasised the importance of compassionate care at the end of life. Family members remarked on staff qualities such as kind (Bussmann et al., 2015; Donnelly et al., 2018; Donnelly & Psirides, 2015; Dose et al., 2015), caring (Berbís-Morelló et al., 2019; Caswell et al., 2015; Johnson et al., 2019) and empathic (Berbís-Morelló et al., 2019; Bussmann et al., 2015; Donnelly et al., 2018; Donnelly & Psirides, 2015). The findings also depicted positive staff attributes of humanity (Bussmann et al., 2015; Donnelly & Psirides, 2015), commitment (Bussmann et al., 2015), dedication and patience (Donnelly et al., 2018), and being helpful (Bussmann et al., 2015; Johnson et al., 2019), considerate (Hajradinovic et al., 2018), supportive (Caswell et al., 2015) and attentive (Johnson et al., 2019). Several family members in the study by Hajradinovic et al. (2018) talked about humour and the need for joy and laughter in encounters with staff.

Well, they are so considerate in a really nice way and they really show compassion and concern and they are comforting, and can have a good laugh and well, they ask how we are. They are really great.

(Hajradinovic et al., 2018, p. 8)

...very, very caring, (elaborating) it made us feel like Dad really mattered to them as well, and not just to us.

(Johnson et al., 2019, p. 5)

### 4.4 | Environment of care

#### 4.4.1 | Facilities

Family members described a number of facilities that impacted their experience of EoLC, such as a single patient room (Bussmann et al., 2015; Donnelly et al., 2018; Hajradinovic et al., 2018; Johnson

et al., 2019; Witkamp et al., 2016), a private area for the grieving family (Berbis-Morelló et al., 2019; Donnelly et al., 2018; Donnelly & Psirides, 2015), overnight accommodation (Bussmann et al., 2015; Clark et al., 2014; Donnelly et al., 2018; Hajradinovic et al., 2018; Johnson et al., 2019; Witkamp et al., 2016), requirements at the bedside such as additional chairs and more space (Johnson et al., 2019) and the ambience of the environment where EoLC was provided (Donnelly et al., 2018; Hajradinovic et al., 2018; Johnson et al., 2019; Wiegand, 2016). A lack of attention to cleanliness and overall orderliness in the care environment led families to question the quality of care (Hajradinovic et al., 2018).

...it is very important, what is the lighting like? What are the colours like? What are the pictures like? The aesthetics of the environment around you, that can make you feel, feel at ease. It's common knowledge that intense lighting, bare walls, white, ... the classic hospital environment... can be pretty scary.

(Hajradinovic et al., 2018, p. 4)

We argued that she as a person deserved her dignity and privacy around herself in the last hours of her life. We also felt that it was not fair to either her large family or the other ward patients that my mother's final hours be lived out on a hospital ward.

(Donnelly et al., 2018, p. 7)

#### 4.4.2 | Provisions

Provisions such as refreshments for the family (Clark et al., 2014; Donnelly et al., 2018; Hajradinovic et al., 2018), bedside television and internet access (Hajradinovic et al., 2018) were meaningful aspects of EoLC in the acute care environment. Staff gestures of hospitality, for example, the offer of food and beverages in the dayroom were regarded as a sign of consideration (Hajradinovic et al., 2018) and opportunity to have a meal at the patient's bedside was important to some (Hajradinovic et al., 2018; Witkamp et al., 2016). An identified stress for family members was the financial cost of hospital car parking (Donnelly et al., 2018).

Internet is as important as air and water.

(Hajradinovic et al., 2018, p. 6)

The cost of parking was outrageous. Given that we were there for 11 weeks, it would be nice if family members could get some help with this cost.

(Donnelly et al., 2018, p. 8)

#### 4.4.3 | Organisational issues

A family member in the study by Bussmann et al. (2015) spoke of a high priority given to documentation and bureaucracy in hospital

wards over treatment and patient care. Concerns were also expressed about the availability of and access to a hospital bed for those receiving EoLC (Berbis-Morelló et al., 2019; Donnelly et al., 2018), and the emotional impact this had on experiencing families (Berbis-Morelló et al., 2019). Bussmann et al. (2015) also identified a family-reported need for staff to respond to verbal complaints.

It was clear that day was hectic... I told them politely to take care of him, as my husband was in a very bad condition. I guess people go there when they are sick, not to spend their holidays there... Nobody goes there for the love of it! We must wait, there are no beds... don't you understand? I think that they didn't pay attention they should... it was outrageous!

(Berbis-Morelló et al., 2019, p. 2796)

...With a lack of personnel, documentation has high priority instead of treatment or care of the patient (...).

(Bussmann et al., 2015, p. 47)

### 4.5 | Patient and family care after death

#### 4.5.1 | Final acts of caring

Care after death requirements of apparent importance to family members included spending time with their relative (Dose et al., 2015), and the personal care of and respect for the deceased person (Donnelly & Psirides, 2015; Dose et al., 2015; Donnelly et al., 2018; Wiegand, 2016) that included small acts of caring (Wiegand, 2016). Dose et al. (2015) found that some family members wanted to participate in personal care and gained comfort from seeing the deceased person without medical tubes or devices.

The nurse went in after my mother had passed and put her teeth in and put her socks on before we went to see her, which I thought was wonderful.

(Wiegand, 2016, p. 163)

...on one hand, they say, 'You can take as much time as you want, you know,' a little while later... 'Okay, the funeral home is on the line... they want to know if they can come now.' Well, no, because we are not ready.

(Dose et al., 2015, p. 17)

#### 4.5.2 | Guidance, support and follow-up care

The findings highlighted the provision of family support and follow-up care in the form of bereavement counselling (Donnelly et al., 2018) and a follow-up meeting, as described by Noome et al. (2016). It was also suggested that family members appreciated the gestures of a condolence letter or card (Donnelly et al., 2018; Noome et al.,

2016) and a remembrance service (Donnelly et al., 2018). However, these findings contrasted with accounts of insufficient information (Bussmann et al., 2015), support (Bussmann et al., 2015; Clark et al., 2014; Donnelly et al., 2018; Johnson et al., 2019; Odgers et al., 2018) and guidance (Johnson et al., 2019) in the post-mortem period.

We received a condolence card a few days later, so thoughtful. And if we wanted to schedule a follow up meeting, this was possible. That was also written in the card. And I was called for a follow up meeting twice, yes, we appreciated that.

(Noome et al., 2016, p. 62)

I didn't know what to do... I was blindsided by all of it... maybe some numbers to contact... Maybe like a 'What to Do Next'.

(Johnson et al., 2019, p. 6)

## 5 | DISCUSSION

This systematic review of qualitative evidence presented family experiences of in-hospital EoLC prior to and following the death of a family member. The 16 studies adequately answered the review questions and provided insights into aspects of care that were meaningful to grieving families. A wide range of relational and functional issues pervaded the synthesised findings and contained both positive and negative perceptions of EoLC. While positive descriptors helped to identify the characteristics of quality care, negative accounts arguably represented aspects of care of importance to families, and from which we can learn.

Communication was a common thread across the studies, particularly within the context of approaching end of life and during the dying process. Family members recounted a myriad of situations where the nature, frequency, timing and availability of information, together with the effectiveness of staffs' communication skills appeared to influence the quality of the care experience. Nurses' competence in EoLC requires skill in communication (Buller et al., 2019) and their contribution to equipping families for end of life through information provision and communication is evidenced in the literature (Coombs et al., 2017). While the value of communication skills training in EoLC for generalists has shown to be somewhat beneficial (Lord et al., 2016), Pfeifer and Head (2018) suggest that effective EoLC discussions involve more than the relaying of difficult information, and several discussions from multiple disciplines are often necessary. This is reflected in the review findings that highlighted the perceived value of initial and on-going interactions with staff in preparing family members for loss and grief.

Essential care at the end of life was both patient and family-need orientated, and contained descriptors of met and unmet care expectations and requirements. Despite the acknowledged role and contributions of a hospital-based palliative care team (Paes et al., 2018), just two studies referred to the provision of specialist palliative care. This

indicated that generalist hospital clinicians were the main providers of care in the studies we reviewed, and the findings raised questions about generalist staff capability (skills, competences and behaviours) and capacity issues previously identified as necessary for quality EoLC (NHSE, 2015). The intradisciplinary contributions of hospital doctors, nurses and chaplains were apparent, as opposed to an interprofessional approach that may have helped to navigate the complexities of EoLC (Pfeifer & Head, 2018). There was also a notable absence of findings relating to social care concerns in contrast to physical, psychological, pastoral and spiritual care. It has been asserted that social, psychological, and spiritual care is as important as physical care at the end of life (Perkins, 2016), yet in practice, evidence suggests that the physical care may take precedence (Blaževičienė et al., 2020). In an audit of in-hospital EoLC delivery and practices, Bloomer et al. (2019) identified low rates of referral to specialist palliative care and pastoral care personnel, despite their availability in the hospital to support EoLC.

Several studies contained findings that signified the importance placed on person-centred EoLC, such as being treated with dignity, compassion and respect; recognised guiding principles that help to put the interests of the individual at the centre of care and support (The Health Foundation, 2016). However, the findings also revealed a lack of concordance between family members and staff, as reflected in concerns about participation in decision-making and acknowledgement of respective views. Good communication and involvement play an important role in identifying, respecting and addressing the needs of patients and families, and in developing an individualised plan of care (LACDP, 2014). The use of structured communication tools such as the huddle model may contribute to patients receiving timely and/or evidence-based assessments and care (Pimentel et al., 2021).

The synthesised finding of environment of care reflected family members' perceptions of organisational issues and the availability of facilities and provisions that were characteristic of what Kingsley and Patel (2017) classify as the functional or more practical indicators of quality care. In a recent national audit of care at the end of life, 80% of participants felt that the hospital was the 'right' place for the person to die. However, 20% remarked there was a lack of peace and privacy, and 157/316 narrative responses referenced practical areas of care consistent with our review findings, that is, refreshments/food, parking, family accommodation and provision for overnight stays (Healthcare Quality Improvement Partnership, 2020). Further, discrete review findings such as patient-family-staff interactions, privacy, personalisation and the ambience of the setting mirrored critical components of the physical environment previously identified as either supporting or detracting from the holistic needs of patients and their families (Sagha Zadeh et al., 2018). Collectively, these findings draw attention to the apparent contributions of environmental design interventions in end-of-life settings (Sagha Zadeh et al., 2018) and the interdependency between relational and functional aspects of EoLC.

The two categories that informed patient and family care after death contained the fewest discrete findings for synthesis. This seemed to prioritise care of the dying person and their family over patient and family care in the immediate aftermath of death, and

subsequent bereavement follow-up support. Of course, this could have been a less explored phase of EoLC in the studies that formed the review. Good EoLC includes pre- and post-death bereavement care for those important to the dying person (NPEoLCP, 2021). In addition to sensitive, honest and informed conversations that help to prepare families for loss and grief, quality standards for EoLC recommend the availability of immediate and ongoing support appropriate to the needs and preferences of people closely affected by a death (NICE, 2017b). Death in the hospital (vs. home) is among identified key risk factors for the development of complicated grief (Neimeyer & Burke, 2012). This warrants greater attention to the provision of bereavement support as an integral part of hospital service provision and improved understanding of families' experience of bereavement care in the design of future research topic guides. The evidence-based bereavement standards and accompanying pragmatic care pathway developed by Hudson et al. (2018) could be used as a platform to enhance the bereavement care agenda in the context of palliative care.

## 6 | STRENGTHS AND LIMITATIONS

We believe there are both strengths and limitations to this review. The review team comprised scholars with knowledge and experience of EoLC in the hospital setting, and research skills that individually and collectively assisted the review. We rigorously followed a recognised qualitative systematic review methodology involving double citation screening, quality appraisal and data extraction, and the synthesis and reporting of findings deemed unequivocal or credible. Our three-step search strategy (JBI, 2020) and combined search methods (Aveyard, 2019), resulted in the identification of research that adequately answered the review questions.

The challenges of searching for, retrieving and synthesising qualitative studies have been recognised (Thomas & Harden, 2008), and we acknowledge the possibility that we may have missed some studies, and/or misinterpreted authors' narrative representation of the findings. The selection of studies in accordance with specified eligibility criteria also confined the range of literature we reviewed. While this allowed for specificity in relation to the purpose of the review, we recognise that factors such as the countries represented and localised contextual variations in the provision of EoLC places limits on the generalisability of our findings. We are also acutely aware and acknowledge the fact that the research in this review represented family-reported experiences of EoLC prior to the COVID-19 pandemic. The pandemic has undoubtedly affected dying, death and bereavement, and further qualitative research has a role to play in understanding what we can learn from these extraordinary circumstances.

## 7 | CONCLUSION

Despite the current orthodoxy for EoLC in a non-institutional setting, and home as the preferred place of death (Pollock, 2015), it

is likely that the hospital will remain the place of care and death for some people, whether in respect of personal choice, demand, unpredictable deterioration or following a fatal life-threatening illness or event. In view of this fact, enabling and improving peoples' experience of EoLC must remain part of the vision and mission of hospital organisations. This systematic review of qualitative evidence provided an aggregated perspective of what counts as a positive experience of care, as perceived by experiencing families. Relational aspects of care dominated the synthesised findings, and underlined the essential contribution of effective staff-patient-family communication. Consideration must be given to the fulfilment of family needs and apparent hallmarks of quality care that appeared to influence experiential outcomes. Bereaved family participation in research serves as a reminder of their valuable contribution to experiential knowledge, and their role as allied partners in our quest to provide high quality EoLC for adults who are approaching the end of their life, and to ensure their priorities for care are achieved.

## 8 | RELEVANCE TO CLINICAL PRACTICE

Knowledge synthesis is critical to advancing policy, practice and research, and the methods used can enhance the quality, scope and applicability of the review results (Whittemore et al., 2014). This qualitative systematic review affirms the acknowledged role and contribution of qualitative methods in evidence-based health care research (JBI, 2020). Relevant studies of very good quality have been synthesised to provide a Western perspective of care practices and environmental factors that are perceived to impact the quality of in-hospital EoLC. The meta-aggregation culminated in five synthesised findings, revealing of both positive and negative family-reported experiences of care for the dying person in their final days and hours of life. While the positive care encounters should be commended, the fact remains that gaps and shortcomings in care provision remain, despite the known external drivers and evidence for change. This clearly has on-going implications for clinical practice, education initiatives and research agendas. A developed understanding of the families' subjective reflections of EoLC creates reciprocal opportunity to transform experiential insights into practical strategies for professional growth and evidence-based practice development for improved quality of care. With regard to education, Rawlings et al. (2019) provide direction and inspiration for translating essential elements for safe and high-quality EoLC (ACSQHC, 2015) into e-learning modules. However, whether this learning effects sustainable change in practice warrants further investigation (Rawlings et al., 2019). Herein lies the role and contribution of a new and valid EoLC experience measure for routine survey administration. We foresee relevant and functional uses of the experiential data set in practice; principally for service evaluation of hospital-based care and the redesign of services that are responsive to patient and family needs. A recommendation going forward is to embrace the value



of patients and families as the co-creators of research knowledge, not forgetting the lessons that can be learnt from the COVID-19 pandemic for improving end of life experience in the future.

### CONFLICT OF INTEREST

There is no conflict of interest to declare.

### AUTHOR CONTRIBUTIONS

The conception of the review: WW/NE; Review protocol: WW/NE; Literature searching: PC/WW; Screening and study selection: WW/NE; Quality appraisal: WW/JJ; Data extraction and synthesis: WW/NE; Manuscript writing and editing: WW/NE; Critically reviewing the manuscript for important intellectual content and critical revisions: WW/NE/PC/JJ/HJ; Approval of the final manuscript: All authors.

### DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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