

Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important

Palliative Medicine

1–15

© The Author(s) 2016

Reprints and permissions:

sagepub.co.uk/journalsPermissions.nav

DOI: 10.1177/0269216316673547

pmj.sagepub.com



Claudia Virdun¹, Tim Lockett¹, Karl Lorenz^{2,3,8},
Patricia M Davidson^{1,4,5} and Jane Phillips^{1,2,6,7}

Abstract

Background: Despite most expected deaths occurring in hospital, optimal end-of-life care is not available for all in this setting.

Aim: To gain a richer and deeper understanding of elements of end-of-life care that consumers consider most important within the hospital setting.

Design: A meta-synthesis.

Data sources: A systematic search of Academic Search Complete, AMED, CINAHL, MEDLINE, EMBASE, PsycINFO, PubMed, Google, Google Scholar and CareSearch for qualitative studies published between 1990 and April 2015 reporting statements by consumers regarding important elements of end-of-life hospital care. Study quality was appraised by two independent researchers using an established checklist. A three-stage synthesis approach focusing on consumer quotes, rather than primary author themes, was adopted for this review.

Results: Of 1922 articles, 16 met the inclusion criteria providing patient and family data for analysis. Synthesis yielded 7 patient and 10 family themes including 6 common themes: (1) expert care, (2) effective communication and shared decision-making, (3) respectful and compassionate care, (4) adequate environment for care, (5) family involvement and (6) financial affairs. Maintenance of sense of self was the additional patient theme, while the four additional family themes were as follows: (1) maintenance of patient safety, (2) preparation for death, (3) care extending to the family after patient death and (4) enabling patient choice at the end of life.

Conclusion: Consumer narratives help to provide a clearer direction as to what is important for hospital end-of-life care. Systems are needed to enable optimal end-of-life care, in accordance with consumer priorities, and embedded into routine hospital care.

Keywords

Palliative care, hospital, terminal care, consumer participation, qualitative

What is already known about the topic?

- In high-income countries, the majority of people dying from expected deaths die in hospital.
- Optimal care for all those who require end-of-life care in hospitals cannot be assured.

What this paper adds?

- A synthesis of published primary qualitative (interview/focus group) data to identify what dying inpatients and their families consider to be important elements of end-of-life care within the hospital setting.

¹Faculty of Health, University of Technology Sydney (UTS), Ultimo, NSW, Australia

²Center for Innovation to Implementation, VA Palo Alto Health Care System, USA

³The RAND Corporation, USA

⁴School of Nursing, Johns Hopkins University (JHU), Baltimore, MD, USA

⁵St. Vincent's Hospital, Sydney, NSW, Australia

⁶School of Nursing, Sydney, The University of Notre Dame Australia, Sydney, NSW, Australia

⁷Sydney Medical School, The University of Sydney, Sydney, NSW, Australia

⁸Stanford School of Medicine, USA

Corresponding author:

Claudia Virdun, Faculty of Health, University of Technology Sydney (UTS), PO Box 123, Ultimo, NSW 2007, Australia.

Email: claudia.virdun@uts.edu.au

- An in-depth understanding of the elements that ought to inform future hospital-based end-of-life care policy reform and quality improvement agendas.
- An overview of the areas that policy makers, hospital administrators and clinicians ought to focus on in order to improve the provision of patient-centred end-of-life care in hospitals.

Implications for practice, theory or policy

- Studies asking patients with palliative care needs and their families what they need in relation to end-of-life care in the hospital setting have yielded consistent findings for over 25 years. The synthesis of such data directly informs policy and practice development aimed at ensuring experience can match identified need.
- This work provides consumer-centred information to inform policy development in relation to systems and processes of care to support optimal end-of-life care within the hospital setting.

Introduction

In high-income countries, the hospital remains the most common place for expected deaths.^{1,2} Despite the expansion of specialist palliative care services, promotion of a palliative approach and other reforms, dying inpatients cannot be guaranteed optimal end-of-life care^{3–5} and continue to have unmet needs.^{6–8} Basing reforms on what dying inpatients and their families ('consumers') consider most important for optimal end-of-life hospital care values the uniqueness of living with a terminal illness,⁹ upholds a person-centred approach to care¹⁰ and is central to improving care outcomes.¹¹

Since 1995, numerous studies have described what consumers feel is important for optimal end-of-life hospital care.^{10,12–35} Despite the emphasis placed on person-centred care, little attention has been given to integrating these findings into practice, partly because these data have not been previously synthesised. In an attempt to address this gap, a recent systematic review of quantitative studies,¹⁰ completed by this authorship team, identified key themes of importance to patients and families (Box 1).

Box 1. Themes of importance for end-of-life hospital care identified in a recent systematic review of quantitative data.¹⁰

Themes identified by both patients and families	Additional themes identified by patients only	Additional themes identified by families only
Effective communication and shared decision-making Expert care (incorporating good physical care, symptom management and integrated care) Respectful and compassionate care Trust and confidence in clinicians	Adequate environment for care Minimising burden	Financial affairs

While the recent systematic review¹⁰ provides valuable insights from survey responses, there are opportunities to gain deeper insights from patient and family narratives. A meta-synthesis of existing consumer narratives was undertaken to add to the evidence and help improve care of the dying in hospitals through policy and practice change at the systems, health professional and consumer levels.

Aim

To gain a richer and deeper understanding of elements of end-of-life care that consumers consider most important within the hospital setting.

Method

A meta-synthesis of consumer narratives reporting important elements of end-of-life hospital care. In this review,

'hospital' 'refers to all acute inpatient care excluding psychiatric, hospice or inpatient specialist palliative care, and alcohol and drug treatment centres'.¹⁰ Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) method³⁶ guided the sourcing, inclusion and quality review of all papers.³⁷ The reporting of results adheres to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) criteria.³⁸

Eligibility criteria

Manuscripts generating empirical qualitative data were included if they met the inclusion criteria (Table 1). Limiting the inclusion to primary qualitative studies allowed thematic synthesis of verbatim consumer narratives. Qualitative studies were defined as those aimed at providing in-depth exploration of the experience of people dying in hospital and/or their families. The starting date

Table 1. Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Peer reviewed articles from 1990 to 2015	Focus only on one explicit area of care (not broadly asking about end-of-life care)
English language	Examples include advance care planning/communication/site of care preference
Focus on end-of-life care in the hospital setting	No primary patient and/or family data
Focus on experience/satisfaction/importance in relation to end-of-life care	Little or no focus on end-of-life care in the hospital setting
Report original patient and/or family data	Conference/poster abstract
Raw data provided to illustrate themes	Focus of study does not answer research question
Qualitative methodology	Quantitative methodology
Patient sample have an expected prognosis of 1 year or less	Re-reporting raw data in a synthesised form

Table 2. Search terms used.

1. dying, death, 'end of life', terminal, 'terminal care', terminally ill, palliative, 'final day*' (combine with OR)
2. 'good death', 'consumer satisfaction', 'patient satisfaction', perspective*, important, experience (combine all with 'or')
3. Hospital, acute care, intensive care, emergency, inpatient* (combine all with 'or')
4. Patient*, family, families, consumer*, carer* (combine all with 'or')
5. Adult*
6. Qualitative or quantitative
7. 1 and 2 and 3 and 4 and 5 and 6
8. Limit '7' with 1990 – current and English language

was determined by a large US-based study focusing on care preferences for seriously ill hospitalised adults published in 1995.³⁹ Hand searching of reference lists enabled relevant studies to be included as appropriate.

Search

The Medical Subject Headings (MeSH) and key words (Table 2) were developed (C.V. and J.P.) with support from a librarian and informed by key terms from publications. This search focused on identifying what patients and/or families (next-of-kin, significant others, surrogates and/or informal caregivers), when asked about their experiences, perceived to be important elements of hospital end-of-life care. Search terms varied slightly to account for differences required across multiple electronic databases and to identify articles for inclusion in either the quantitative or qualitative review. The search was undertaken during the first quarter of 2014¹⁰ and updated in April 2015.

Information sources

Databases were chosen for their focus on multidisciplinary health care and included the following: Academic Search Complete (EBSCO), AMED (OVID), CINAHL (EBSCO), MEDLINE (EBSCO), MEDLINE (OVID), EMBASE (OVID), PsycINFO (OVID), PubMed and Cochrane. Key Internet search engines were searched (Google, Google Scholar and CareSearch) along with handsearching.

Reference lists of all included studies were searched manually to identify other potentially relevant papers.

Study selection

Articles returned were managed through Endnote (version X5). Titles and abstracts were examined (C.V.) according to inclusion criteria. Uncertainty regarding inclusion was resolved through consensus discussion (C.V., J.P. and T.L.).

Data collection and items

Data were extracted into an electronic proforma (Table 3). The raw data (consumer quotes) reported in each study were extracted for synthesis.

Bias rating

Quality appraisal of potential studies was completed independently by two researchers (C.V. and T.L.) using predefined criteria noted to enhance transfer of findings to practice⁴⁰ (Online Appendix 1).

Synthesis

The three-stage thematic analysis approach developed by Thomas and Harden⁴¹ facilitated (1) line-by-line coding (C.V.), (2) descriptive theme development (C.V., J.P. and T.L.); and (3) analytical theme generation (C.V., J.P. and T.L.).^{37,41} Critical analysis of data allowed key areas to

Table 3. Summary of articles included in meta-synthesis.

Source, country	Aim	Design and method	Participants and hospital setting	Participant details	Results/findings
Bussman et al., ²⁰ Germany	To analyse family members' suggestions for improvement in end-of-life care in general hospitals	Cross-sectional survey with one open-ended question. Free text analysis of responses made	Randomly chosen family members (N=633) of inpatients who were hospitalised during the last 4 weeks of life	Participants (n=270); 52% female	Seven main categories concerning improvement suggestions and reported deficiencies generated from the 270 responses, namely, (1) medical care and nursing; (2) care before and during dying; (3) interpersonal humane interaction; (4) support for families; (5) psychological and spiritual welfare; (6) consultation, information and communication; and (7) structural aspects in hospital management
Steinhauser et al., ²¹ USA	To define the relevant aspects of quality of experience for families of hospitalised patients	Focus groups (n=2) using semi-structured interviews. In-depth interviews with two members of each group to provide additional detail. Content analysis used open and axial coding	Family members (n=14) of patients who had died 6–12 months prior in one of the two large hospitals	Age range: 46–83 years, mean: 62 years; 100% female; 64% Caucasian, 21% African American, 14% did not report ethnicity	Participants were asked what was important, most needed and what constituted quality of experience. Content analysis yielded 64 attributes within 8 domains: (1) completion, (2) symptom impact, (3) decision-making, (4) preparation, (5) relationship with healthcare providers, (6) affirmation of the whole person, (7) post-death care and (8) supportive services
Kongsuwan et al., ²² Thailand	To describe a peaceful death from the perspective of Thai Buddhist family members of people dying in ICU	Descriptive qualitative study informed by a phenomenological approach using interviews and transcript analysis	Family members (n=9) of Buddhist people who died peacefully in an ICU in one hospital from southern Thailand	Age range: 30–62 years, mean: 47 years; 78% female; five daughters, two sons, two wives	Five core qualities of a peaceful death: (1) knowing death was impending, (2) preparing for a peaceful state of mind, (3) not suffering, (4) being with family members and not alone and (5) family members were not mourning
Mossin and Landmark, ²³ Norway	To gain an in-depth understanding of family experience of a loved one dying in hospital	Grounded theory using in-depth semi-structured interviews. Data analysis via coding and use of memos	Family members (n=15) of patients who died of cancer in a nine-bed oncology/palliative care ward in 2006. Interviewed 10–15 weeks after death	Age range: 55–82 years, mean: 66 years; 100% female; all long-term relationships	Participants (n=8, RR=53%) with seven people declining participation. After five interviews, only a few nuances were seen. After the eighth interview, theoretical saturation was considered to have been achieved. Core category = maintaining presence for the other and for one's own sake. Including four categories: (1) to find one's place, (2) to know, (3) to support each other and (4) to terminate
Dzul-Church et al., ²⁴ USA	To describe experiences of serious illness including concerns, preferences and perspectives on improving end-of-life care in underserved inpatients	Qualitative analysis of I-h semi-structured interviews, with thematic analysis to enable development of themes	Patients (n=20) with a terminal illness in an American hospital with an estimated prognosis of <1 year	Age range: 38–78 years, mean: 54.5 years; 30% female; 30% Black, 25% White, 35% Hispanic, 5% American Indian and 5% other	Data themed into three categories: (1) a description of the participants' lives, (2) how their past histories influenced end of life and (3) suggestions about how to improve end-of-life care (centred around improved relationships with providers (healthcare professionals), accessible chaplaincy and community support, feeling welcome in the hospital and the need for a humanist approach)
Nelson et al., ²⁵ USA	To understand how patients and families, who have experienced care in the ICU for at least 5 days, define high-quality palliative care	Focus groups (n=9) with open-ended questions and scripted probes. Content coding and domain development	Randomly selected patients who survived the ICU (length of stay >5 days), families of survivors and families of patients who died in one of the three hospitals in 2007–2008	Patients – age range: 34–87 years, mean: 58.5 years; family – age range: 24–86 years, mean: 60.4 years; female – patients: 46.7%; family: 78.8%; patients – race: 73.3% White, 6.7% Black, 6.7% Hispanic; family – race: 60.6% White, 21.9% Black, 12.5% Hispanic; family relationship to patient: 43.8% spouse, 21.9% adult child, 34.4% other	Participants (n=48; patients=15, family members=33). A shared definition emerged from the data in relation to important domains of high-quality ICU palliative care: (1) communication by clinicians about the patient's condition, treatment and prognosis; (2) patient-focused medical decision-making; (3) clinical care of the patient to maintain comfort, dignity, personhood, and privacy; (4) care of the family: providing access, proximity and support. Furthermore, participants endorsed important care processes and structural aspects of high-quality ICU palliative care: (1) regular family meetings with attending physician and nurse; (2) flexible, liberal policy on visiting; (3) Early identification of surrogate decision-maker/advance directive/resuscitation status; (4) frequent assessment of pain and titration of analgesia to maximise comfort and achieve desired level of consciousness; (5) offer of pastoral care with sensitivity and without mandate; (6) offer of practical and emotional (social work) support; (7) printed information about ICU for families; (8) offer of bereavement support to families of patients dying in the ICU; (9) waiting room affording comfort and privacy to families

Table 3. (Continued)

Source, country	Aim	Design and method	Participants and hospital setting	Participant details	Results/findings
Spichiger, ²⁶ Switzerland	To explore terminally ill patients' and their families' experiences of hospital end-of-life care	Interpretive phenomenology including participant observations, conversations with patients and interviews with family members	Terminally ill patients from a general medical ward within a Swiss public tertiary care hospital (1000 beds) and their designated family member	Patients – age range: 38–85 years, mean: 62.7 years; 30% female; family – age range: 41–82 years, mean: 64.6 years; 70% female; relationship to patient: four spouses, three partners, one mother, one brother, one sister-in-law	Participants (n = 20; patients = 10, family members = 10) Key findings: (1) leading a unique life with a terminal illness – people continue to live; (2) hospital was experienced differently by patients – prison, heaven, necessary sojourn; (3) providers' commitment and caring is crucial to quality of experience; and (4) patients' and family members' experiences with care interventions affects quality of life inclusive of the need for valuing the individual
Payne et al., ²⁷ England	To explore the experiences of patients and carers of end-of-life care in community hospitals	Qualitative semi-structured interviews analysed using principles of Grounded Theory	Participants were patients and carers admitted for end-of-life care in one of the six community hospitals	Patients – age ranges: 65–69 years (3), 70–79 years (10), >80 years (3), unknown (2); 55.5% female; family – 82% female; relationship to patient: six spouses; five child	Participants: patients (n = 18) and family carers (n = 11). The following was valued within a community hospital setting: flexibility, locality (facilitating visiting) and personalised care. Most preferred community hospitals over district general hospitals and considered them to be acceptable places for end-of-life care
Hawker et al., ²⁸ England	To obtain retrospective carer views about the nature and quality of end-of-life care in community hospitals	Qualitative case study approach using semi-structured interviews followed line-by-line coding to inform results	Next of kin for all patients aged above 65 years who died in one of the six hospitals. Hospitals chosen to reflect variance in size, rurality and medical model	Participants – age range: 68–99 years, mean: 80.2 years; 78.4% female; relationship to patient: 17 wives, 14 daughters, 7 sons; 4 husbands; 4 friends; 3 sisters; 1 niece; 1 daughter-in-law	Participants (n = 51; RR = 51%). Overall, bereaved carers were positive about care received and specifically noted the following areas as advantages of receiving end-of-life care in a community hospital: locality, environment, familiarity, nursing staff. Issues of concern noted: unpredictability of death for older patients, staffing, noise
Ogasawara et al., ²⁹ Japan	To examine how families of patients with cancer, in a large university hospital, perceive and are satisfied with terminal care and to identify barriers to best care for patients and families	Descriptive survey study using a 23-item questionnaire where the last three questions were open-ended. This review reports on these last three questions only that asked about expectations of doctors and nurses and noted areas for change in care	Family members who had cared for a patient with cancer treated at the university hospital between April 1996 and October 1998	Age range: 26–87 years, mean 56.1 years; 57% female; relationship: 69% spouse, 18% child, 6% sibling, 6% parent, 3% no response	Participants (n = 73; RR = 55%). Five categories to be involved in terminal care: (1) pain control and symptom management, (2) spiritual care, (3) reduction in medical treatment of the cancer itself, (4) support for family members, (5) appropriate information about diagnosis and prognosis. Five categories regarding expectation of nurses: (1) patient and family-oriented nursing, (2) improvement of bedside manner and techniques, (3) concern for psychological care and support, (4) quick responses, (5) individualised care. Seven categories regarding expectation of doctors: (1) appropriate informed consent for the family, (2) psychological support for the patient and family, (3) desire for satisfactory treatment, (4) minimal medical tests, (5) patient-centred treatment, (6) treatment corresponding to palliative and home care instead of research and treatment-based care, (7) appropriate timing of treatment
Kirchhoff et al., ³⁰ USA	To obtain a detailed overview of the experience of family members whose loved one dies in the ICU	Qualitative semi-structured focus group design followed by content analysis	Patients (>55 years) who had died in the previous 6–18 months in one of the eight ICUs of two large American hospitals	Age range: 38–84 years, mean: 59 years. 75% female; relationship: six spouses, one son, one granddaughter	Participants (n = 8; RR = 19.5%). Communication or lack of it was a common theme. Families talked about the need for contact and targeted communication with a physician, and those who had this, felt the best possible outcome was achieved
McGrath, ³¹ Australia	To document the experience of the dying trajectory for patients with haematological malignancies and their families	Qualitative open-ended interviews focused on the caregiver's description of the experience of illness for the patient and his or her family. Data analysed via coding and thematic analysis	Relatives who were known to the grief support service of the Leukaemia Foundation of Queensland	90% female; relationship: five spouses, three mothers, two sisters	Participants (n = 10; RR = 100%). The following themes were found: caregiver demands; caregiver-patient relationship and the need to be there; patient advocate; the need for information; doctor communication; nurse communication

(Continued)

Table 3. (Continued)

Source, country	Aim	Design and method	Participants and hospital setting	Participant details	Results/findings
Dunne and Sullivan, ³² Northern Ireland	To gain understanding and insights into the lived experience of families who journeyed with their loved one during the palliative phase of illness in the acute hospital setting	Husserlian phenomenology using unstructured interviews. Analysis via Colaizzi's (1978) seven-stage process for the analysis of phenomenological data	Family members involved in the end-of-life care of a loved one who was an inpatient in a medical or surgical ward between September 1998 and February 1999, who lived in a local post-code area and had been bereaved 1–2 years	Details not provided	Participants (n=8), (RR=60%, n=15). Eight interviewed (not the full 15 who responded) as data saturation met at this time. Four core themes emerged from analysis of the data: (1) the hospital environment as a place to deliver palliative care; (2) needs and feelings expressed by family members, (3) the family's experience of the patient in pain, (4) communication as experienced by family members
Rogers et al., ³³ England	To examine causes of dissatisfaction with hospital-based end-of-life care	Analysis of data obtained from 14 open-ended questions within a post-bereavement survey (VOICES). Content analysis used where data was organised into categories and themes	Two-thirds of a random sample of deaths of people who had died from cancer between July 1995 and June 1996 from a particular health authority	Details not provided	Participants (n=138) who answered free text questions from 229 surveys returned. Dissatisfaction arose from (1) feeling devalued, dehumanised and/or disempowered; (2) a breaking of the expectation of the health professional–patient relationship. Suggestion that the palliative care approach could reduce dissatisfaction
Pierce, ³⁴ USA	To describe family members' reactions to experiencing death of a loved one within a tertiary care setting	Qualitative in-depth interviews. Data analysed via thematic analysis using the constant comparative method	194 deceased people from 4 countries identified with 75 randomised into the study. The next-of-kin for these 75 people contacted	Age range 30–80, Mean 53 yrs. Female 72%	Participants n=29 (RR 39%) Common, recurrent experiences: Impact of individual caregivers; Persistence of regrets and sadness Concerns and suggestions: The routinised nature of a complex system; The impact of a routinised system on patients and families; Ameliorate the negative impact of systems on people; Facilitate improved interaction between the dying patient and the family; Improve interactions between caregivers and patients/families; Create a more conducive setting/milieu Participants (n=8) Four major categories: (1) maintaining pain control; (2) living an ordinary life; (3) hoping for improvement of physical condition; (4) having family nearby
Tanaka et al., ³⁵ Japan	To clarify how terminally ill patients think and feel while hospitalised to inform improvements in the quality of palliative care	Qualitative semi-structured interviews. Analysis included coding to lead to the development of themes	Patients with terminal cancer within a large (502 beds) hospital in Japan	Age range: 51–93 years, mean: 63.3 years; 50% female	

emerge within each theme. The analytical framework was informed by domains identified in the systematic review¹⁰ (Box 1). Data included for theming were led by the research question³⁷ and limited to patient and family quotes (raw data). Privileging the raw data ensured the consumer voice was central to analytical theme generation and limited bias due to secondary interpretation of themes generated by others.

Quotes were extracted and imported into EPPI-Reviewer 4.⁴² Initial coding (C.V.) was audited for accuracy and consistency (T.L. and J.P.), with disagreements resolved through discussion. Original coding was transferred into a word document for development of descriptive themes (C.V., J.P. and T.L.). C.V. commenced theming and met with team members (J.P. and T.L.) to ensure agreement. Finally, descriptive themes were examined to generate analytical themes (C.V., J.P. and T.L.) informed by the aforementioned analytical framework.¹⁰ Where qualitative data did not fit a domain, new themes were developed in accordance with an inductive approach. All data contributed to theme development irrespective of number of studies or times reported.

Results

Study selection

Of 1922 articles returned by searches, 16 eligible studies (Table 3) were included in the meta-synthesis, providing patient and family data for analysis (Figure 1).

One article⁴³ was excluded based on poor quality of reporting (Online Appendix 1). Included articles ($n=16$) all provided a clear aim and data collection techniques, 15 outlined their data analysis approach and 13 were informed by theory relevant to practice and/or policy. However, more than three-quarters ($n=12$) failed to provide a rationale for their research design and/or detail researcher reflexivity.

Study characteristics

Study location. Countries represented include the following: USA ($n=5$),^{21,24,25,30,34} England ($n=3$),^{27,28,33} Northern Ireland ($n=1$),³² Japan ($n=2$),^{29,35} Norway ($n=1$),²³ Switzerland ($n=1$),²⁶ Germany ($n=1$),²⁰ Australia ($n=1$)³¹ and Thailand ($n=1$).²²

Study design. Data collection occurred through 1:1 interviewing ($n=7$),^{22,24,26-28,31,32,34,35} focus groups ($n=3$)^{21,25,30} and survey with open-ended questions ($n=3$).^{20,29,33} Approaches to data analysis included content analysis ($n=11$),^{20,21,24,25,28-31,33-35} Husserlian ($n=1$)³² and Interpretive Phenomenology ($n=2$),^{22,26} and Grounded Theory ($n=2$).^{23,27}

Sample characteristics. Overall, 11 studies^{20-23,28-34} focused on family participants, 3²⁵⁻²⁷ included both patients and families and 2^{24,35} included patients only.

In total, 57% of patient participants^{24-27,35} were male, with a mean age across papers reporting age ranging between 54.5 and 63.3 years.^{24-26,35} Only the US papers^{24,25} reported ethnicity with one study recruiting predominately White patients (73.3%)²⁵ and the other²⁴ recruiting a broader patient sample (Table 3).

A total of 14 papers included family participants,^{20-23,25-34} with a larger proportion of females represented (75.6%). Eight papers^{21-23,25,26,28,30,34} reported family participants' mean ages ranging from 47 to 80.2 years. Two US papers^{21,25} described ethnicity showing a majority Caucasian family sample (>60%). Six papers²⁶⁻³¹ described family participants' relationship to the patient, with the most common relationship being spousal (60%) or offspring (20%).

Synthesis. Overall, 100% of patient ($n=71$) quotes ($n=74$) were relevant to the research question and analysed, while 99% of family ($n=672$) quotes ($n=278$) were relevant and analysed. The patient data generated 32 codes, 10 descriptive themes and 7 analytical themes, while the family data generated 72 codes, 21 descriptive themes and 10 analytical themes (Figure 2). Key areas emerged within each theme, with exemplar quotes included, while all themed quotes are detailed in Online Appendix 2 (patient data) and Online Appendix 3 (family data).

Patient data

Synthesis of patient data generated seven themes: expert care; effective communication and shared decision-making; respectful and compassionate care; an adequate environment for care; family involvement in care provision; financial affairs; and maintenance of sense of self/identity.

Expert care. Three sub-themes were identified within the broad theme of 'expert care' – good physical care, symptom management and integrated care – and are used within both the patient and family results.

Good physical care. One study³⁵ noted the importance of good physical care including maintaining hygiene: *I'm thankful for my hair being shampooed*³⁵ and independence: *I can eat at a table when I wear a corset*.³⁵

Symptom management. Patients noted the importance of regular, person-centred pain assessment and management and enabling a rapid response when analgesia is required:²⁵

How can they expect the doctors and the nurses to know what your pain is? They do not know, unless you tell them ...²⁵

And the one thing I used to hate, when it's coming on and you're pressing the button, and they do not come, and you're in a lot of pain.²⁵

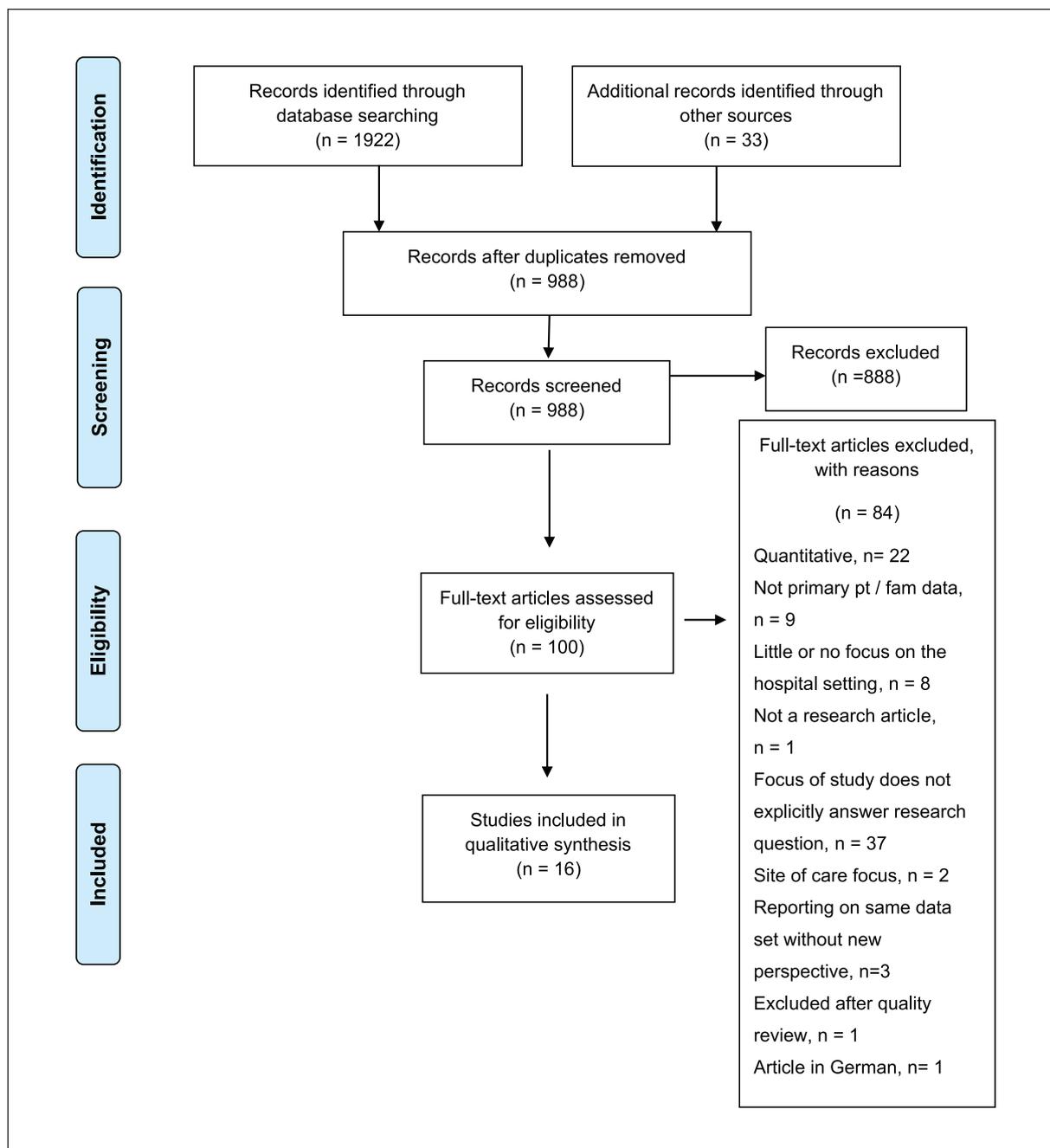


Figure 1. Qualitative PRISMA.

Patients described the negative impact of poorly managed pain both in hospital^{25,35} and at home, and how hospital admission enabled profound and rapid relief.²⁶ Clinicians demonstrating they cared about patients' symptoms was also important:²⁶

They almost suffered themselves. One told me that the whole unit was preoccupied with me. That's good.²⁶

Finally, a patient described the importance of sufficient pain assessment and management for a person with a known opioid dependency:²⁴

They ain't got it under control. They keep thinking because I'm a heroin addict I'm trying to get more pills.²⁴

Pain was the key symptom discussed with mention also of vomiting and restless legs. Of note is the need for prompt individualised assessment and management delivered through a caring approach.

Integrated care. The importance of staff working as a team was highlighted and contributed to patients receiving safer care and better outcomes.^{24,25}

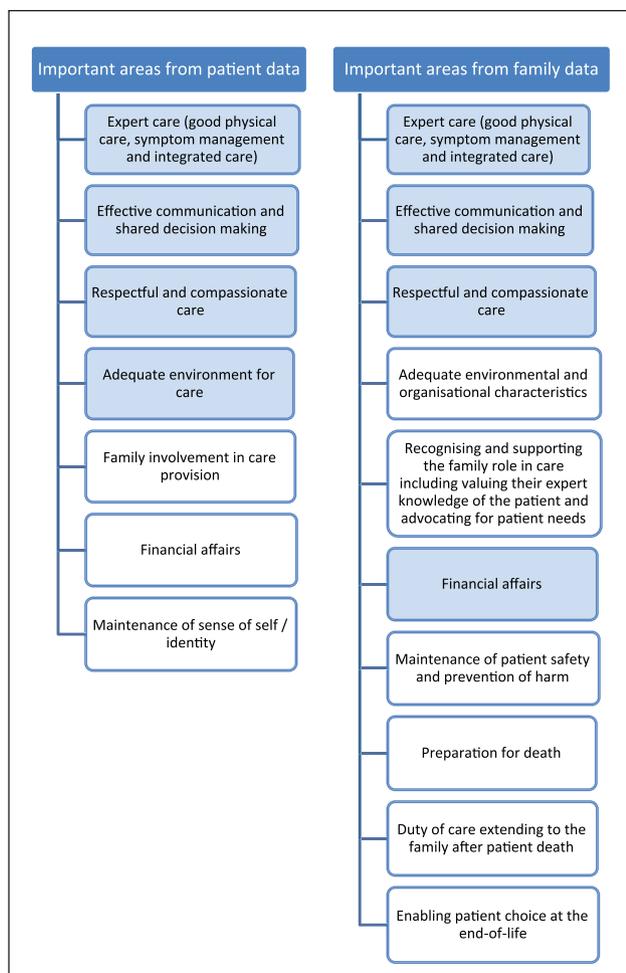


Figure 2. Summary of themes from both patient and family data. Shaded boxes refer to themes from the analytical framework used (themes from a previous systematic review¹⁰). Unshaded boxes are new themes that have developed from this meta-synthesis.

It's like a team effort. If you're a team and they're all together working with the patient itself, it's going to work out really good.²⁴

Effective communication and shared decision-making. There are three areas within this theme. First, the need for honest and clear information to enable a shared understanding, noting the need for layman's language and communication delivered with compassion:²⁵

Using terms that a person that's not a doctor could understand ...²⁵

Communication, with compassion ... because, being in the dark is like being in oil.²⁵

Second, patients detail the importance of adequate information throughout a hospitalisation, inclusive of family members, to support decision-making, decrease stress and prevent surprises:

Knowledge is power, and if my family is informed, then they could have comfort knowing what my status is and how I am progressing or not progressing, day to day, what to expect in the near future.²⁵

Third, patients described their need to be engaged in care planning, inclusive of advance care planning,^{24,25} to remove the burden for decisions from family members:²⁵

One patient thought it was crucial for the ICU to 'know what I prefer' so that her family 'would never feel guilty about having to make a decision'.²⁵

Respectful and compassionate care. This theme encompasses three areas: first, patients feeling welcomed and deserving of a hospital admission:²⁴

I can see where the wheels are turning and people are thinking should he be here? Is he costing us too much?²⁴

Second, patients being treated with care, respect and with a focus on dignity:²⁴⁻²⁶

What really made it different was she treated me with respect and dignity, and the dignity was what made it above and beyond ...²⁵

Third, staff anticipating patient/family needs, being responsive and demonstrating cheerfulness and care for their work:^{26,27}

So I can only speak good really, you know, I've got no complaints whatsoever. They are so attentive, they're so cheerful, they don't mind how many times you ring your buzzer ...²⁷

An adequate environment for care. The concept of space was personal; one patient described the importance of having their own quiet space, while another said the opposite was true.²⁷ Patients described the positive impact of community-based hospitals in preference to tertiary hospitals, which was attributed to a nicer atmosphere, feeling closer to home, more accessible parking and an increased feeling of safety:²⁷

It's [community hospital] such a nice atmosphere, you feel so safe.²⁷

However, lower levels of nursing availability in smaller hospitals were noted with patients having to readjust expectations as a result.²⁷

Family involvement in care provision. Company and family connection, including family support, is indispensable in providing comfort and emotional healing:^{24,25,35}

My friends and, more importantly, my family played a very, very big part in my, in my comfort level, and my emotional healing.²⁵

Financial affairs. Patients in a Japanese study³⁵ outlined concerns about the financial implications of a hospital admission:

I'm concerned about my hospital and living expenses for my family as I have been in hospital for a long time.³⁵

Maintenance of sense of selfidentity. Two areas emerged within this theme, namely, the profound impact of a terminal illness: *It is always there, it is never again not there.*²⁶ Having a terminal illness was likened to being in prison, and the need to maintain independence, to live well in the context of disease and for some, to maintain a focus on work:³⁵

'I will make an effort to maintain this improved condition' ...
'I'm not going to look backwards; I want to live with this disease with all my strength and maintain my quality of life as a human being'.³⁵

Family data

A total of 10 themes emerged from the synthesis of family data: expert care; effective communication and shared decision-making; respectful and compassionate care; adequate environmental and organisational characteristics; recognising and supporting the family role in care including valuing their expert knowledge of the patient and advocating for patient needs; financial affairs; maintenance of patient safety and prevention of harm; preparation for death; duty of care extending to the family after patient death; and enabling patient choice at the end-of-life.

Expert care

Good physical care. Families noted expert provision of core nursing care alongside more specialist nursing competencies:²⁸

They really were fantastically caring and you know, the process of turning and mouth care, all that was done in an exemplary fashion.²⁸

I'm not sure how well trained they were for when he needed his bag changing ...²⁸

Symptom management. Families identified the importance of symptom management generally²⁹ and specifically effective pain management,^{20,29,32} timeliness of interventions^{21,31} and management of breathlessness.²² Sub-optimal pain management was most commonly referred to as a source of distress:^{21,32}

Symptom management is the highest priority.²⁹

Integrated care. Families referred to provision of care to the whole person physically, emotionally and/or spiritually²⁰

and to the importance of one's physician being in charge.²⁵ Challenges in treating the person as a 'whole',²⁰ receiving conflicting information and lack of clarity about who is in charge²⁵ were all attributed to medical sub-specialisation. Multidisciplinary care that included social work and pastoral care input was valued.^{25,34}

The specification of professions involves that everyone treats only one aspect. Man as a whole is falling by the wayside.²⁰

Effective communication and shared decision-making. There are three areas within this theme. First, effective communication leading to a shared understanding was important and dependent upon the compassionate delivery of understandable and honest information:^{20,21,25,32}

The doctor did come in and tried to explain to us what it was, but I really wasn't understanding it. It was kind of over my head because we're not doctors.²¹

Second, having the necessary information was important as end-of-life decision-making is affected by medical complexity, emotional and financial factors:^{25,30}

The doctor would tell you, you can do this or this or this ... And, it's a medical decision, but it's also an emotional decision and a financial decision, and ... I did not know what was best.²⁵

Third, sufficient, timely and proactive information provision,^{20,23,34} involvement in day-to-day care planning^{25,32} and regular planned discussions with the healthcare team²⁵ are all important. Given the complexities experienced generally in accessing information,^{32,33} families valued discussions with physicians.^{25,27,30} However, they noted how hard this was to arrange^{32,33} and that a family meeting assisted them greatly:²¹

... that would be the very best thing that I can say all day today. If they would just say, okay, we're real busy, but we can be there at 10:20, then the family member can make it there.²⁵

Respectful and compassionate care. Three areas were found within this theme. First, approaches to care that are respectful, compassionate and preserve dignity are important:^{20,21,25,33,34}

Everything matters-what people say, how they touch the patient-and you-how they look at you- whether or not you matter.³⁴

Second, patients identified a number of staff attributes they valued in addition to necessary task-oriented care. These included being helpful, empathic, affectionate, appreciative, comforting, gentle, considerate and capable.^{20,28,29,33} The need to distinguish between nursing and

technical care was outlined.³³ Competence in care was noted in terms of care of the dying (noting a need to increase capability in this area)²⁰ and managing a specialised need such as a colostomy:²⁸

First and foremost employment of capable nursing staff characterized by the qualities: helpful, empathic, affectionate, appreciative, comforting.²⁰

Finally, individualised care valuing the patient and their family is important:

[That] they don't become a 'number' but stay a human being and person.²⁰

Adequate environmental and organisational characteristics. Three areas are noted within this theme. Hospital rules and processes need to make sense and should not detract from optimal patient care.^{20,25,29,33,34} Examples were provided where a patient experienced symptomatic distress awaiting formal 'admission',³³ a distressed relative was asked to move her car,³⁴ poor process management of an Advance Care Directive²⁵ and visiting hours restrictions for dying patients:²⁰

... that shouldn't happen to people. Rules need to make sense.³⁴

Environmental characteristics contribute to quality end-of-life care, particularly noting the need for privacy,^{20,32,34} cleanliness^{28,33} and quietness.^{27,28} The need for privacy was noted by numerous family members across several studies with a lack of privacy leading to a feeling of simply 'watching' and not being with their loved one or able to talk openly:

I just wanted to be alone with him-that seemed so hard in the ICU. They let us come in and all, but it wasn't like being with him-it was watching.³⁴

Space for cultural practices such as congregating family members, chanting or other important rituals is also important.²²

Recognising and supporting the family role in care including valuing their expert knowledge of the patient and advocating for patient needs. There are three areas within this theme. Family members want their expertise as 'carer' to be recognised and respected.³¹ They want to be involved both in care provision and care planning^{23,31,32,34} and value their role as patient advocates:^{25,31}

One nurse, one time, asked me to help turn Barbara, while she made the bed ... I got to hold her, and touch her. It was the only time-the only time that I felt like I was able to do something for her. I wanted to do so much to help her-there seemed to be nothing I could do.³⁴

Failure to be welcomed as a partner in care leaves carers feeling like an observer and out of place:^{31,32}

As caregiver, quite often, they didn't talk to me. So you felt like you were the third person watching the events ... I found that difficult.³¹

Given family desire to being involved in care, removing them from distressing situations, especially if the patient dies, may cause long-term harm:³¹

I believe (the patient) would have known that I left the room and that hurts me to this day.³¹

Financial affairs. A UK study³³ noted the importance of proactively supporting patients and families with information about financial supports to enhance comfort and decrease stress:

I am an 83-year-old pensioner not in the best of health ... had we been told of attendance allowance before Graham died his last few months may have been a bit more comfortable.³³

Maintenance of patient safety and prevention of harm. Three areas were found within this theme. Families noted that hospitalisation did not always provide improved care compared with the care they provided at home.^{32,33} Indeed, one family member explicitly stated they feel the inpatient care received made the patient's condition worse:³³

I think the 'care' he received made him worse not better.³³

Sub-optimal care adversely impacts patient safety affecting care outcomes and leading to patient harm.^{26,28,31,33,34} Patient safety at the end of life was perceived to have been compromised by poor communication,^{31,33} not considering a palliative approach,³⁴ not considering a patient's unique care needs,³⁴ families not feeling aware of how to best support the patient,^{26,34} poor nursing care^{28,33} and lack of timely attention:³¹

Henry couldn't hear and the nurse just stood at the bottom of the bed and asked if he wanted anything, when he didn't answer she just left him, if we hadn't asked for drinks he would have died of dehydration.³³

Families in one study³⁴ noted a need for support to 'speak up' about care to ensure patient safety without repercussions:

I'm so glad for this opportunity to say something- and not have it tied to me or my husband in any way. These things need to be said; but you can't when you so desperately need their help.³⁴

Preparation for death. Families noted the importance of being prepared for the patient's death to ensure they

Table 4. Comparison of themes from meta-synthesis (this study) with systematic review.¹⁰

Theme/domain	Identified by meta-synthesis – patient data	Identified by meta-synthesis – family data	Identified by systematic review – patient data	Identified by systematic review – family data
Expert care (good physical care, symptom management and integrated care)	✓	✓	✓	✓
Effective communication and shared decision-making	✓	✓	✓	✓
Respectful and compassionate care	✓	✓	✓	✓
Adequate environment for care ^a	✓	x	✓	x
Adequate environmental and organisational characteristics ^a	x	✓	x	x
Family involvement in care provision ^b	✓	x	x	x
Recognising and supporting the family role in care including valuing their expert knowledge of the patient and advocating for patient needs ^b	x	✓	x	x
Financial affairs	✓	✓	x	✓
Maintenance of sense of self/identity	✓	x	x	x
Trust and confidence in clinicians	x	x	✓	✓
Minimising burden	x	x	✓	x
Maintenance of patient safety and prevention of harm	x	✓	x	x
Preparation for death	x	✓	x	x
Duty of care extending to the family after patient death	x	✓	x	x
Enabling patient choice at the end of life	x	✓	x	x

^aSeparated themes despite similarity due to the addition of organisational characteristics evident in the family data.

^bSeparated themes due to additional information available for the family theme.

were able to say goodbye and to assist with their bereavement:^{21,25,30,34}

And, I believe I would have benefited greatly, if previous to this, I had been told by the doctor that this is the possibility, you need to start thinking about this. I just wasn't ready for it ...²⁵

Duty of care extending to the family after patient's death. One study²⁵ noted the need for the family members to be followed up after the patients' ICU death to prevent them feeling disconnected and rushed away from the hospital at such a profound time:

... they just came and closed his eyes, started doing whatever they do when somebody dies, and basically just said to move. And, I just left. I did not know what else to do ... I would've liked a piece of follow-up, somehow. A call ...²⁵

Enabling patient choice at the end of life. There are two areas within this theme. First, the importance of following established Advance Care Directives,^{20,25,30} and second, a German study noted the need for legalised euthanasia for critically ill patients:²⁰

Physicians: should comply with existing patient advance directive and not prolong the suffering and dying for a few months.²⁰

Discussion

This meta-synthesis validates and adds deeper insights into themes identified in a recent systematic review.¹⁰ It also highlights additional areas of importance including the need for care and involvement of family, the maintenance of self-identity for patients and factors affecting patient safety. Additional insights into environmental needs emerging from the meta-synthesis suggest privacy is of greater importance to families^{20,27,32,34} than patients.²⁷ Table 4 provides an overview of congruent data across the studies included in the systematic review¹⁰ and meta-synthesis, as well as highlighting new themes emerging from this study.

The congruence of areas of importance (themes) across patients and families and across the systematic review¹⁰ and meta-synthesis is noteworthy. This alignment both validates and emphasises the importance of effective communication and shared decision-making, respectful and compassionate care and expert care (encompassing good physical care, symptom management and integrated care) at the end of life. Collectively, the systematic review¹⁰ and the meta-synthesis emphasise the need for practice change. The themes generated from this work ought to inform future patient-centred palliative care delivery, policy frameworks, education and research. However, the challenge is how to best enact this within a system dominated by the

medical paradigm and focused on acute and episodic care.⁴⁴ Given the complexity of care, a whole of system approach is required to enable real change with consideration of positive policy reform (macro); appropriate policy, structure and processes at each local hospital (meso); and a focus on adequate processes and measurement of outcomes to inform ongoing quality review alongside locally relevant improvement strategies (micro). Similar to the systematic review,¹⁰ the insights generated by this meta-synthesis largely reflect findings detailed in publications dating back to 1999.^{34,35} The fact that consumers today continue to echo earlier patient and family perceptions confirms that urgent hospital end-of-life reform is required.

Globally, key policy initiatives have recently been released⁴⁵⁻⁴⁷ and are in various stages of being actioned. Countries vary in their approaches with the English government revising guidelines⁴⁵ and recommending change based within a continuous improvement methodology; the Australian government has redrafted national hospital accreditation standards⁴⁸ to include end-of-life care requirements; while the USA does not have a national policy framework for palliative care, a recent report from a non-government agency⁴⁷ provides recommendations in order to improve care of the dying both within and outside hospital settings; in Europe, the discussion on how to best measure quality end-of-life care to inform improvement efforts has commenced.^{49,50} However, concise and readily implementable hospital end-of-life care measures, that both support service assessments and guide local improvement efforts, remain elusive. The European Association of Palliative Care has published a guidance statement on the development and implementation of patient reported outcome measures,⁵¹ providing a useful first step in progressing this agenda. Having adopted a person-centred approach, the results of this meta-synthesis provide an ideal foundation for the development of hospital end-of-life care measures.

Recommendations for future practice

This meta-synthesis, when considered in conjunction with the partnering systematic review,¹⁰ provides a comprehensive overview of what patients with palliative care needs and their families state as important to enable optimal end-of-life hospital care. This work provides information to guide policy development for the hospital setting and provides useful reading for practitioners working within this setting to guide everyday practice. It also offers a framework for the development, piloting and refining of a suite of measures that assess quality end-of-life care provided by hospitals to assist improvement efforts and future research.

Strengths and limitations

The systematic approach taken to source and analyse the available qualitative data is a considerable strength of this

meta-synthesis. Adopting the same search strategy as the earlier systematic review¹⁰ has enabled direct comparison for a more in-depth understanding.

While focusing analysis on raw data as opposed to full published results increased the likelihood that our findings represent the perspectives of patients and families rather than article authors;^{52,53} this approach is limited by the fact we only had access to raw data reported by original researchers. There may have been selection bias when authors' chose quotes to illustrate their codes and themes. Also, the decision to analyse raw quotes only and exclude author narrative resulted in loss of meaning generated through their interpretations. These interpretations were excluded to bring the patient/caregiver perspectives into sharper relief. The large number of quotes informing this meta-synthesis, and the congruence of qualitative data with the quantitative data,¹⁰ confers confidence that this review has captured the voice of a wide range of patients and families receiving hospital-based end-of-life care. A further limitation of this review is that the quality of reporting across included papers was variable (Online Appendix 1), and we could not confirm with the primary authors whether the data reviewed are representative of the full sample. We excluded studies that focused purely on one aspect of end-of-life care to generate greater insight into which aspects were perceived by consumers as most important. However, this may have resulted in some lost data for analysis. Patient/family perspectives and structural healthcare differences across studies have been highlighted but did not contribute to the synthesis; caution should be exercised when reviewing and extrapolating this study's results. Finally, results are presented based on data from across all ward settings (generalist wards, intensive care and speciality wards). This could mean some themes are relevant to one setting more than another.

Conclusion

Patients with palliative care needs and their families have been consistent in what they consider to be most important in relation to end-of-life care within the hospital setting. The need for expert care (inclusive of physical care, symptom management and integrated care), optimal communication, respectful and compassionate care, valued family involvement in care planning and delivery, maintenance of self-identity for patients, environmental privacy for families, ensuring patient safety, supporting patient choices, preparing families for death and providing contact for families after a patient has died, cannot be over stated. This research adds depth of information and understanding and should be used in conjunction with a recent systematic review¹⁰ to provide a base for clinicians and policy makers to move forward from. We know what is important for patients and families and now need to act to ensure all receive care in line with such areas of identified need.

Acknowledgements

All authors contributed to defining the search aims and methodology used for identification and analysis of all included data; C.V. conducted the focused search for this study; study selection and quality rating were completed by C.V. and T.L.; data extraction was completed by C.V.; and synthesis was completed by C.V, T.L. and J.P. All authors contributed to the writing of this manuscript.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

References

- Broad J, Gott M, Kim H, et al. Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *Int J Public Health* 2013; 58: 257–267.
- Tang ST and Chen C-H. Place of death and end-of-life care. In: Cohen J and Deliens L (eds) *A public health perspective on end of life care*. New York: Oxford University Press, 2012, pp. 21–34.
- Hillman KM. End-of-life care in acute hospitals. *Aust Health Rev* 2011; 35: 176–177.
- Clark D, Armstrong M, Allan A, et al. Imminence of death among hospital inpatients: prevalent cohort study. *Palliat Med* 2014; 28: 474–479.
- Gott M, Ingleton C, Bennett MI, et al. Transitions to palliative care in acute hospitals in England: qualitative study. *BMJ Support Palliat Care* 2011; 1: 42–48.
- Robinson J, Gott M and Ingleton C. Patient and family experiences of palliative care in hospital: what do we know? An integrative review. *Palliat Med* 2014; 28: 18–33.
- To T, Greene A, Agar M, et al. A point prevalence survey of hospital inpatients to define the proportion with palliation as the primary goal of care and the need for specialist palliative care. *Intern Med J* 2011; 41: 430–433.
- Gott CM, Ahmedzai SH and Wood C. How many inpatients at an acute hospital have palliative care needs? Comparing the perspectives of medical and nursing staff. *Palliat Med* 2001; 15: 451–460.
- Teno JM. Putting patient and family voice back into measuring quality of care for the dying. *Hosp J* 1998; 14: 167–176.
- Virdun C, Lockett T, Davidson PM, et al. Dying in the hospital setting: a systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. *Palliat Med* 2015; 29(9): 774–796.
- Leape L, Berwick D, Clancy C, et al. Transforming health-care: a safety imperative. *Qual Saf Health Care* 2009; 18: 424–428.
- Osborn TR, Curtis JR, Nielsen EL, et al. Identifying elements of ICU care that families report as important but unsatisfactory: decision-making, control, and ICU atmosphere. *Chest* 2012; 142: 1185–1192.
- Heyland DK, Cook DJ, Rocker GM, et al. Defining priorities for improving end-of-life care in Canada. *CMAJ* 2010; 182: E747–E752.
- Young AJ, Rogers A, Dent L, et al. Experiences of hospital care reported by bereaved relatives of patients after a stroke: a retrospective survey using the VOICES questionnaire. *J Adv Nurs* 2009; 65: 2161–2174.
- Rocker GM, Dodek PM and Heyland DK. Toward optimal end-of-life care for patients with advanced chronic obstructive pulmonary disease: insights from a multicentre study. *Can Respir J* 2008; 15: 249–254.
- Heyland D, Dodek P, Rocker G, et al. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ* 2006; 174: 627–633.
- Baker R, Wu A, Teno J, et al. Family satisfaction with end-of-life care in seriously ill hospitalized adults. *J Am Geriatr Soc* 2000; 48: S61–S69.
- Steinhauser K, Christakis N, Clipp E, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; 284: 2476–2482.
- Kristjanson LJ. Quality of terminal care: salient indicators identified by families. *J Palliat Care* 1989; 5: 21–30.
- Bussmann S, Muders P, Zahrt-Omar CA, et al. Improving end-of-life care in hospitals: a qualitative analysis of bereaved families' experiences and suggestions. *Am J Hosp Palliat Med* 2015; 32: 44–51.
- Steinhauser KE, Voils CI, Bosworth H, et al. What constitutes quality of family experience at the end of life? Perspectives from family members of patients who died in the hospital. *Palliat Support Care* 2014; 13: 945–952.
- Kongsuwan W, Chaipetch O and Matchim Y. Thai Buddhist families' perspective of a peaceful death in ICUs. *Nurs Crit Care* 2012; 17: 151–159.
- Mossin H and Landmark BT. Being present in hospital when the patient is dying: a grounded theory study of spouses experiences. *Eur J Oncol Nurs* 2011; 15: 382–389.
- Dzul-Church V, Cimino JW, Adler SR, et al. 'I'm sitting here by myself ...': experiences of patients with serious illness at an urban public hospital. *J Palliat Med* 2010; 13: 695–701.
- Nelson JE, Puntillo KA, Pronovost PJ, et al. In their own words: patients and families define high-quality palliative care in the intensive care unit. *Crit Care Med* 2010; 38: 808–818.
- Spichiger E. Living with terminal illness: patient and family experiences of hospital end-of-life care. *Int J Palliat Nurs* 2008; 14: 220–228.
- Payne S, Hawker S, Kerr C, et al. Experiences of end-of-life care in community hospitals. *Health Soc Care Community* 2007; 15: 494–501.
- Hawker S, Kerr C, Payne S, et al. End-of-life care in community hospitals: the perceptions of bereaved family members. *Palliat Med* 2006; 20: 541–547.
- Ogasawara C, Kume Y and Andou M. Family satisfaction with perception of and barriers to terminal care in Japan. *Oncol Nurs Forum* 2003; 30: E100–E105.

30. Kirchhoff KT, Walker L, Hutton A, et al. The vortex: families' experiences with death in the intensive care unit. *Am J Crit Care* 2002; 11: 200–209.
31. McGrath P. Caregivers' insights on the dying trajectory in hematology oncology. *Cancer Nurs* 2001; 24: 413–421.
32. Dunne K and Sullivan K. Family experiences of palliative care in the acute hospital setting. *Int J Palliat Nurs* 2000; 6: 170–178.
33. Rogers A, Karlsen S and Addington-Hall J. 'All the services were excellent. It is when the human element comes in that things go wrong': dissatisfaction with hospital care in the last year of life. *J Adv Nurs* 2000; 31: 768–774.
34. Pierce SF. Improving end-of-life care: gathering suggestions from family members. *Nurs Forum* 1999; 34: 5–14.
35. Tanaka A, Iwamoto T, Kaneyasu H, et al. Thoughts and feelings of in-patients with advanced terminal cancer: implications for terminal care improvement. *Nurs Health Sci* 1999; 1: 189–193.
36. Moher D, Liberati A, Tetzlaff J, et al. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: the PRISMA statement. *Ann Intern Med* 2009; 151: 264–269.
37. Popay J, Roberts H, Sowden A, et al. Guidance on the conduct of narrative synthesis in systematic reviews: a product from the ESRC methods programme, version 1, 2006, http://www.lancaster.ac.uk/shm/research/nssr/research/dissemination/publications/NS_Synthesis_Guidance_v1.pdf
38. Tong A, Flemming K, McInnes E, et al. Enhancing Transparency in Reporting the Synthesis of Qualitative Research: ENTREQ. *BMC Med Res Method* 2012; 12(1): 1–8.
39. Connors AF Jr, Dawson NV, Desbiens NA, et al. A controlled trial to improve care for seriously ill hospitalized patients: the study to understand prognoses and preferences for outcomes and risks of treatments (support). *JAMA* 1995; 274: 1591–1598.
40. Kitto SC, Chesters J and Grbich C. Quality in qualitative research. *Med J Aust* 2008; 188: 243.
41. Thomas J and Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Method* 2008; 8: 45.
42. Thomas JBJ and Graziosi S. *EPPI-Reviewer 4: software for research synthesis*. EPPI-Centre Software. London: Social Science Research Unit, UCL Institute of Education, 2010.
43. Czerwiec M. When a loved one is dying families talk about nursing care. *Am J Nurs* 1996; 96: 32–36.
44. Bloomer MJ, Endacott R, O'Connor M, et al. The 'dis-ease' of dying: challenges in nursing care of the dying in the acute hospital setting. a qualitative observational study. *Palliat Med* 2013; 27: 757–764.
45. National Health Service (NHS) England. *Transforming end of life care in acute hospitals: the route to success 'how to' guide* (ed Medical). London: NHS, 2015.
46. Australian Commission on Safety and Quality in Health Care. National consensus statement: essential elements for safe and high-quality end-of-life care in acute hospitals. Consultation draft, January 2014, [//safetyandquality.gov.au/wp-content/uploads/2014/01/Draft-National-Consensus-Statement-Essential-Elements-for-Safe-and-High-Quality-End-of-Life-Care-in-Acute-Hospitals.pdf](http://safetyandquality.gov.au/wp-content/uploads/2014/01/Draft-National-Consensus-Statement-Essential-Elements-for-Safe-and-High-Quality-End-of-Life-Care-in-Acute-Hospitals.pdf)
47. Institute of Medicine (IOM). *Dying in America: improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press, 2015.
48. Australian Commission on Safety and Quality in Health Care. National safety and quality health service standards: version 2. Consultation draft, July 2016, <https://www.safetyandquality.gov.au/wp-content/uploads/2016/07/DRAFT-National-Safety-and-Quality-Health-Service-Standards-version-21.pdf>
49. Radbruch L and Payne S. White paper on standards and norms for hospice and palliative care in Europe: part 1. *Eur J Palliat Care* 2009; 16: 278–289.
50. Leemans K, Cohen J, Francke A, et al. Towards a standardized method of developing quality indicators for palliative care: protocol of the Quality indicators for Palliative Care (Q-PAC) study. *BMC Palliat Care* 2013; 12: 6.
51. Bausewein C, Daveson BA, Currow DC, et al. EAPC white paper on outcome measurement in palliative care: improving practice, attaining outcomes and delivering quality services – recommendations from the European Association for Palliative Care (EAPC) Task Force on outcome measurement. *Palliat Med* 2016; 30: 6–22.
52. Heaton J. Secondary analysis of qualitative data: an overview. *Hist Soc Res* 2008; 33: 33–45.
53. Szabo V and Strang VR. Secondary analysis of qualitative data. *Adv Nurs Sci* 1997; 20: 66–74.