

PALLIATIVE MEDICINE

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

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Abstract

Background: The majority of expected deaths occur in hospitals where optimal end-of-life care is not yet fully realised, as evidenced by recent reviews outlining experience of care. Better understanding what patients and their families consider to be the most important elements of inpatient end-of-life care is crucial to addressing this gap.

Aim and design: This systematic review aimed to ascertain the five most important elements of inpatient end-of-life care as identified by patients with palliative care needs and their families.

Data sources: Nine electronic databases from 1990 to 2014 were searched along with key internet search engines and handsearching of included article reference lists. Quality of included studies was appraised by two researchers.

Results: Of 1859 articles, 8 met the inclusion criteria generating data from 1141 patients and 3117 families. Synthesis of the top five elements identified four common end-of-life care domains considered important to both patients and their families, namely, (1) effective communication and shared decision making, (2) expert care, (3) respectful and compassionate care and (4) trust and confidence in clinicians. The final domains differed with financial affairs being important to families, while an adequate environment for care and minimising burden both being important to patients.

Conclusion: This review adds to what has been known for over two decades in relation to patient and family priorities for end-of-life care within the hospital setting. The challenge for health care services is to act on this evidence, reconfigure care systems accordingly and ensure universal access to optimal end-of-life care within hospitals.

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Introduction

In high income countries, the hospital remains the most common place for expected deaths².³. 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 care⁴⁻⁶ and continue to have unmet needs⁷⁻⁹. Basing reforms on what dying in-patients and their families ('consumers') consider most important for optimal end-of-life hospital care values the uniqueness of living with a terminal illness¹⁰, upholds a person-centred approach to care¹ and is central to improving care outcomes¹¹.

Since 1995, numerous studies have described what consumers feel is important for optimal end-of-life hospital care^{1, 12-35}. Despite the emphasis placed on person-centred care, little attention has been given to integrating these findings into practice, partly because this data has not previously been synthesised. In an attempt to address this gap, a recent systematic review of quantitative studies¹ completed by this authorship team, identified key themes of importance to patients and families (Refer Box 1).

Box 1 – Themes of importance for end-of-life hospital care identified in a recent systematic review of quantitative data¹

| 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 | Adequate environment for care | Financial affairs |
| Expert care (incorporating good physical care, symptom management and integrated care) | Minimising burden | |
| Respectful and compassionate care | | |
| Trust and confidence in clinicians | | |

While the recent systematic review¹ provides valuable insights from survey responses, there are opportunities to gain deeper insights from patient and family narratives. A metasynthesis 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 metasynthesis 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'¹. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) method³⁶ guided the sourcing, inclusion and quality review of all papers³⁷. The reporting of results adheres to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) criteria³⁸.

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 was determined by a large US based study focusing on care

preferences for seriously ill hospitalised adults published in 1995³⁹. Hand searching of reference lists enabled relevant studies to be included as appropriate.

Table 1: Inclusion and exclusion criteria

| Inclusion criteria | Exclusion criteria |
|---|---|
| <ul style="list-style-type: none"> • Peer reviewed articles from 1990 - 2015 • English language • Focus on end-of-life care in the hospital setting • Focus on experience / satisfaction / importance in relation to end-of-life care • Report original patient and/or family data • Raw data provided to illustrate themes • Qualitative methodology • Patient sample have an expected prognosis of 1 year or less | <ul style="list-style-type: none"> • Focus only on one explicit area of care (not broadly asking about end-of-life care). Examples include advance care planning / communication / site of care preference • No primary patient and/or family data • Little or no focus on end-of-life care in the hospital setting • Conference/Poster abstract • Focus of study does not answer research question • Quantitative methodology • Re-reporting raw data in a synthesised form |

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 2014¹ and updated in April 2015.

Table 2: Search terms used

| |
|---|
| <ol style="list-style-type: none"> 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

Information sources

Databases were chosen for their focus on multidisciplinary health care and included: 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 (CV, JP and TL).

Data collection and items

Data were extracted into an electronic proforma (Table 3). The raw data (consumer quotes) reported in each study was 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 (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, T.L); and 3) analytical theme generation (C.V, J.P, T.L)^{37,41}. Critical analysis of data allowed key areas to emerge within each theme. The analytical framework was informed by domains identified in the systematic review¹ (refer Box 1). Data included for theming was 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 4⁴². 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, T.L). C.V commenced theming and met with team members (J.P, T.L) to ensure agreement. Finally, descriptive themes were examined to generate analytical themes (C.V, J.P, T.L) informed by the aforementioned analytical framework¹. 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 metasynthesis, providing patient and family data for analysis (Figure 1).

Figure 1: Qualitative PRISMA

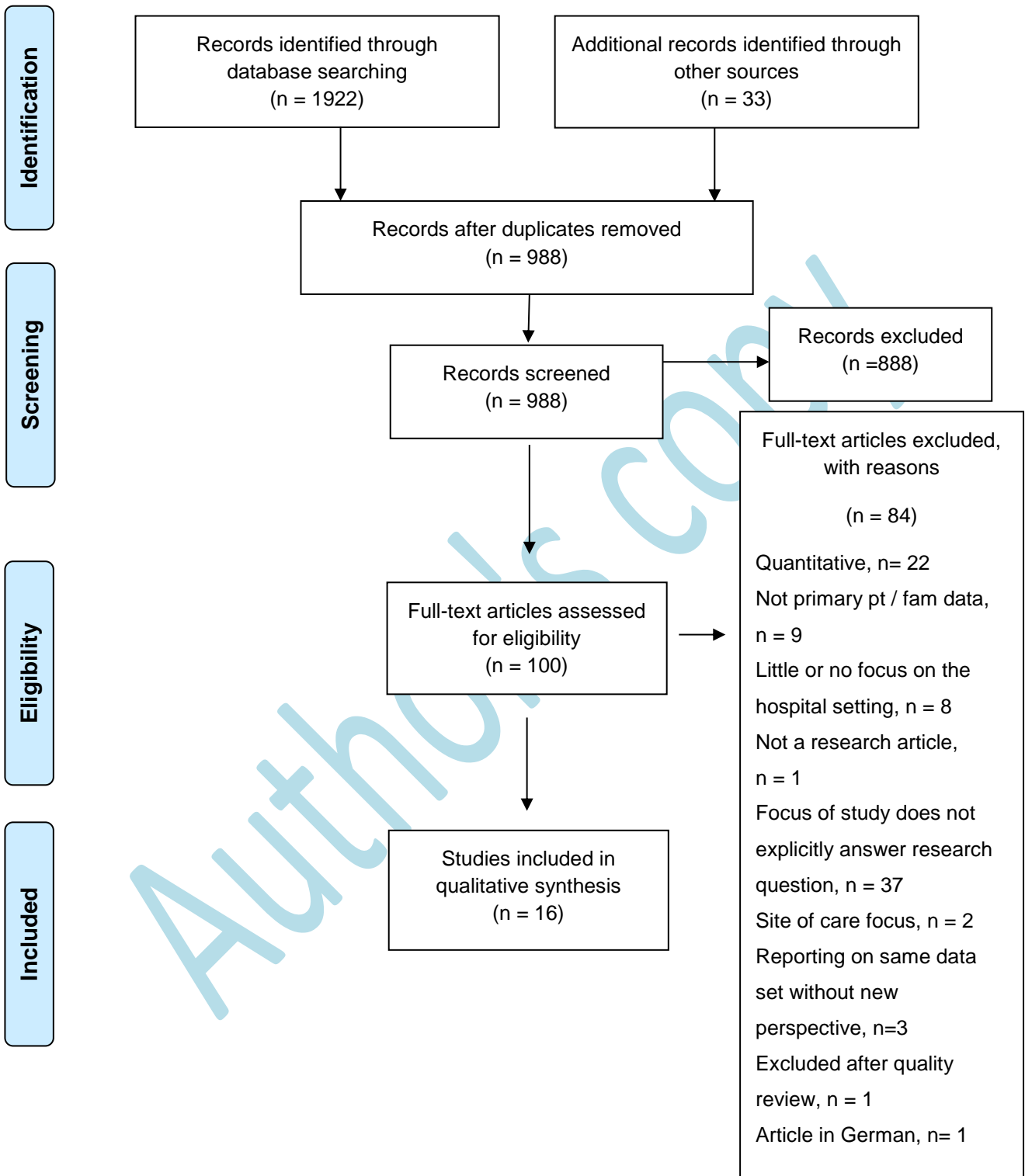


Table 3: Summary of articles included in metasynthesis

| Source / Country | Aim | Design and method | Participants and hospital setting | Participant details | Results / findings |
|-----------------------------------|---|---|--|---|---|
| Bussman et al. 2015 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 hospitalized 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. 2014 USA | To define the relevant aspects of quality of experience for families of hospitalized patients | Focus groups (n=2) using semi structured interviews. In-depth interviews with 2 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 2 large hospitals | Age range: 46-83, mean 62 yrs. 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; 8. Supportive services |
| Kongsuwan et al. 2012 Thailand | To describe a peaceful death from the perspective of Thai Buddhist family | Descriptive qualitative study informed by a phenomenological approach using interviews, | Family members (n=9) of Buddhist people who died peacefully in an ICU in one hospital from | Age range:30-62, mean 47 yrs. 78% female. Daughters 5; sons 2 ; | 5 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 |

| | | | | | |
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| | members of people dying in ICU | and transcript analysis | southern Thailand | wives 2 | |
| Mossin and Landmark 2011 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 memoes | 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, mean 66 yrs; Female: 100% All long term relationships | Participants n = 8 (RR = 53%) with 7 people declining participation. After 5 interviews only a few nuances were seen. After the 8 th interview – theoretical saturation was considered to have been achieved. Core category = Maintaining presence for the other and for one's own sake. Including 4 categories: 1. to find one's place; 2. to know; 3. to support each other; and 4. to terminate. |
| Dzul-Church et al. 2010 USA | To describe experiences of serious illness including concerns, preferences, and perspectives on improving end-of-life care in underserved inpatients | Qualitative analysis of 1 hour 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, mean= 54.5 yrs Female 30% Black 30%; White 25%; Hispanic 35%; American Indian 5%; Other 5% | Data themed into three categories: 1. a description of the participants' lives; 2. how their past histories influenced end of life; 3. suggestions about how to improve end of life care (centre around improved relationships with providers (health care professionals), accessible chaplaincy and community support, feeling welcome in the hospital and the need for a humanist approach). |
| Nelson et al. 2010 USA | To understand how patients and families, who have experienced care in the ICU for at least 5 days, define high-quality | 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 | Age range: patients 34-87, mean= 58.5yrs yrs; family 24-86, mean = 60.4 yrs; Female: patients 46.7%; family 78.8% Race: patients- White | 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, |

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| | palliative care | | in one of 3 hospitals, in 2007 – 2008 | 73.3%, Black 6.7%, Hispanic 6.7%; Family- White 60.6%, Black 21.9%, Hispanic 12.5% Family relationship to patient: Spouse 43.8%; adult child 21.9%; other 34.4% | 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 maximize 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. |
| Spichiger 2008 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; mean = 62.7 yrs. Female 30% Family: Age range 41 – 82; mean = 64.6yrs. Female 70% Relationship to pt: 4 spouses, 3 partners, 1 mother, 1 brother, 1 sister-in-law | Participants n = 20 (10 patients and 10 family members) 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. 2007 England | To explore the experiences of patients and carers of end-of-life care in community | Qualitative semi-structured interviews analysed using principles of Grounded Theory | Participants were patients and carers admitted for end-of-life care in one of six | Patients: Age ranges 65-69 - 3; 70-79 - 10; >80 - 3; unknown -2 Female 55.5%; Family: Female 82%; | 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 |

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| | hospitals | | community hospitals | Relationship to pt: spouse 6; child 5 | considered them to be acceptable places for end-of-life care |
| Hawker et al. 2006 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 by line by line coding to inform results | Next of kin for all patients aged over 65 who died in one of 6 hospitals. Hospitals chosen to reflect variance in size, rurality and medical model | Participants: Age range 68 – 99, Mean 80.2 yrs Female 78.4%; Relationship to pt: wife 17; daughter 14; son 7; husband 4; friend 4; sister 3; niece 1; daughter-in-law 1 | 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. 2003 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 3 questions were open-ended. This review reports on these last 3 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, Mean 56.1 yrs Female 57%; Relationship: spouse 69%, child 18%, sibling 6%, parent 6%, no response 3% | Participants n =73 (RR = 55%) 5 categories to be involved in terminal care: 1. Pain control and symptom management; 2. Spiritual care; 3. Reduction of medical treatment of the cancer itself; 4. Support for family members; 5. Appropriate information about diagnosis and prognosis 5 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 7 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 |

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| Kirchhoff et al. 2002 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 8 ICUs of 2 large American hospitals | Age range 38-84, Mean 59 yrs Females 75% Relationship: spouse 6; son 1; granddaughter 1 | 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 2001 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 | Females 90% Relationship: Spouse 5; Mother 3; Sister 2 | Participants n =10 (RR = 100%) The following themes were found: <ul style="list-style-type: none"> • Caregiver Demands • Caregiver–Patient Relationship and the Need to Be There • Patient Advocate • The Need for Information • Doctor Communication • Nurse Communication |
| Dunne and Sullivan. 2000 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 Sept 1998 and Feb 1999, who lived in a local postcode area and had been bereaved 1-2 yrs | Details not provided | Participants n = 8 (RR = 60%, n= 15). 8 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. 2000 | To examine causes of dissatisfaction with hospital- | Analysis of data obtained from 14 open ended questions within a | Two-thirds of a random sample of deaths of people | Details not provided | Participants n = 138 who answered free text questions from 229 surveys returned Dissatisfaction arose from: |

| | | | | | |
|-----------------------------|---|--|---|--|---|
| England | based end-of-life care | postbereavement survey (VOICES). Content analysis used where data was organised into categories and themes | who had died from cancer between July 1995 and June 1996 from a particular health authority. | | <ol style="list-style-type: none"> 1. feeling devalued, dehumanized and/or disempowered 2. a breaking of the expectation of the health professional-patient relationship <p>Suggestion that the palliative care approach could reduce dissatisfaction</p> |
| Pierce 1999 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 counties 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% | <p>Participants n =29 (RR 39%)</p> <p>Common, recurrent experiences: Impact of individual caregivers; Persistence of regrets and sadness</p> <p>Concerns and suggestions: The routinized nature of a complex system; The impact of a routinized 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</p> |
| Tanaka et al. 1999 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 bed) hospital in Japan | Age range 51 – 93, Mean 63.3 yrs. Female 50% | <p>Participants n = 8</p> <p>4 major categories:</p> <ol style="list-style-type: none"> 1. Maintaining pain control 2. Living an ordinary life 3. Hoping for improvement of physical condition 4. Having family nearby |

One article ⁴³ was excluded based on poor quality of reporting (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: 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}; 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

Eleven studies ^{20-23, 28-34} focused on family participants, three ²⁵⁻²⁷ included both patients and families and two ^{24, 35} included patients only.

Fifty-seven percent of patient participants ^{24-27, 35} were male, with a mean age across papers reporting age ranging between 54.5 – 63.3 years ^{24-26, 35}. Only the USA papers ^{24, 25} reported ethnicity with one study recruiting predominately white patients (73.3%) ²⁵ and the other ²⁴ recruiting a broader patient sample (Table 3).

Fourteen 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 – 80.2 years. Two USA papers ^{21, 25} described ethnicity showing a majority

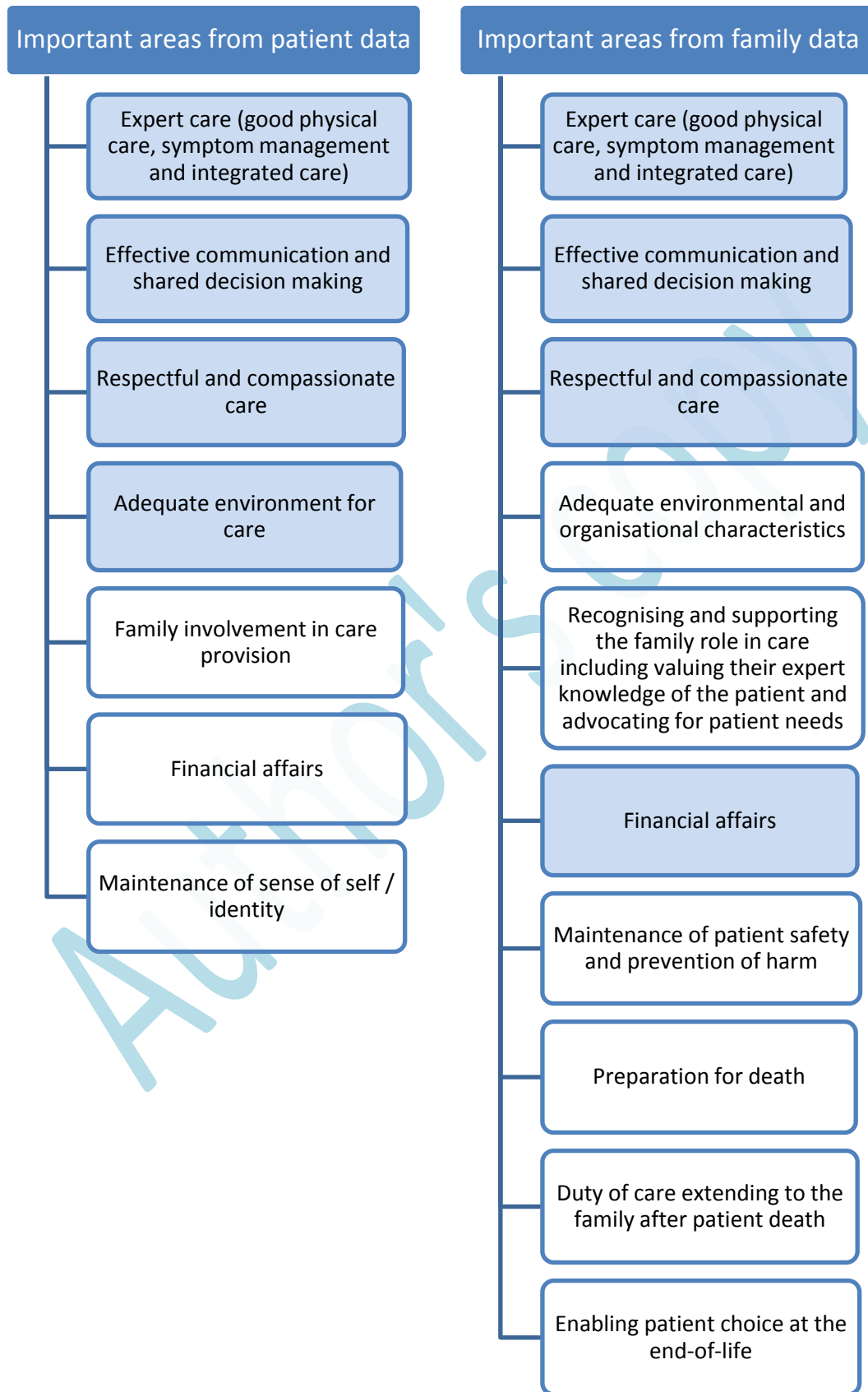
Caucasian family sample (>60%). Six papers²⁶⁻³¹ described family participants' relationship to the patient, with the most common relationship being spousal (60%) or offspring (20%).

Synthesis

One hundred percent 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 theme quotes are detailed in Appendix 2 (patient data) and Appendix 3 (family data).

Author's copy

Figure 2: Summary of themes from both patient and family data



Note: Shaded boxes refer to themes from the analytical framework used (themes from a previous systematic review ¹). Unshaded boxes are new themes that have developed from this metasynthesis.

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 study ³⁵ 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

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 relief²⁶. Clinicians demonstrating they cared about patients' symptoms was also important²⁶.

*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 dependency²⁴.

*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}.

*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. Firstly, the need for honest and clear information to enable a shared understanding, noting the need for layman's language and communication delivered with compassion²⁵.

*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

Secondly, 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

Thirdly, 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 members²⁵.

*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: firstly, patients feeling welcomed and deserving of a hospital admission²⁴.

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

Secondly, patients being treated with care, respect and with a focus on dignity²⁴⁻²⁶.

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

Thirdly, 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 whilst another said the opposite was true²⁷. 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 safety²⁷.

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

However, lower levels of nursing availability in smaller hospitals was noted with patients having to readjust expectations as a result²⁷.

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 healing²⁵

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 time³⁵

Maintenance of sense of self / identity

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 work³⁵.

*'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

Ten 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 competencies²⁸.

*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 breathlessness²². 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 charge²⁵. 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 worker 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. Firstly, 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

Secondly, 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

Thirdly, 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 greatly²¹.

*...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. Firstly, 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

Secondly, 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 outlined³³. 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 colostomy²⁸.

*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 shouldn't 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 car³⁴, poor process management of an Advance Care Directive²⁵ and visiting hours restrictions for dying patients²⁰.

*... 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 quiet^{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 important²².

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 respected³¹. 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 do³⁴

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 difficult³¹

Given family desire to being involved in care, removing them from distressing situations, especially if the patient dies, may cause longer term harm³¹.

I believe (the patient) would have known that I left the room and that hurts me to this day³¹.

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 comfortable³³

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 worse³³.

I think the 'care' he received made him worse not better³³

Sub-optimal care impacts adversely on 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 approach³⁴; not considering a patient's unique care needs³⁴; families not feeling aware of how to best support the patient^{26, 34}; poor nursing care^{28, 33} and lack of timely attention³¹.

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 dehydration³³

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 help³⁴

Preparation for death

Families noted the importance of being prepared for the patient's death to ensure they 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 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. Firstly, the importance of following established Advance Care Directives^{20, 25, 30}, and secondly a German study noted the need for legalised euthanasia for critically ill patients²⁰.

Physicians: should comply with existing patient advance directive and not prolong the suffering and dying for a few months²⁰

Discussion

This metasynthesis validates and adds deeper insights into themes identified in a recent systematic review¹. 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 metasynthesis suggest privacy is of greater importance to families^{20, 27, 32, 34} than patients²⁷.

Table 4 provides an overview of congruent data across the studies included in the systematic review¹ and metasynthesis, as well as highlighting new themes emerging from this study.

Table 4: Comparison of themes from metasynthesis (this study) with systematic review¹

| Theme / Domain | Identified by | Identified by | Identified by | Identified by |
|----------------|---------------|---------------|---------------|---------------|
|----------------|---------------|---------------|---------------|---------------|

| | metasynthesis - patient data | metasynthesis - family data | systematic review - patient data | 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* | ✓ | x | ✓ | x |
| Adequate environmental and organisational characteristics* | x | ✓ | x | x |
| Family involvement in care provision** | ✓ | x | x | x |
| Recognising and supporting the family role in care including valuing their expert knowledge of the patient and advocating for patient needs** | 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 |

*Separated themes despite similarity due to the addition of organisational characteristics evident in the family data **Separated themes due to additional information available for the family theme

The congruence of areas of importance (themes) across patients and families and across the systematic review¹ and metasynthesis 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

review¹ and the metasynthesis 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 care⁴⁴. 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). Similarly to the systematic review¹ the insights generated by this metasynthesis 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; and 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 measures⁵¹, providing a useful first step in progressing this agenda. Having

adopted a person-centred approach, the results of this metasynthesis provide an ideal foundation for the development of hospital end-of-life care measures.

Recommendations for future practice

This metasynthesis, when considered in conjunction with the partnering systematic review,¹ 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 metasynthesis. Adopting the same search strategy as the earlier systematic review¹ has enabled direct comparison for a more in-depth understanding. Whilst 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 metasynthesis, and the congruence of qualitative data with the quantitative data,¹ 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 (Appendix 1) and we could not confirm with the primary authors whether the data reviewed is 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 health care 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 review¹ 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.

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Declaration of conflicting interests

The authors declare that there is no conflict of interest.

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Appendix 1: Overview of quality rating following dual assessment (C.V and T.L) in accordance with published criteria for assessing qualitative research ⁴⁰

| | Clear aim | Clear research question | Appropriate method choice | Outline of why research design chosen | Clear data collection techniques | Transparent data analysis | Clear sampling techniques | Sampling techniques support conceptual generalisability | Conceptual discussion of results and linkage to new or existing theory to explain relevance of findings to targeted audience | Negative case inclusion | Clear statement of effect on the data of researcher's views | Clear evaluation of the relationship between researcher and those under research, addressing any ethical issues | Ethics approval obtained from an appropriate institution | Critical evaluation of application of findings to other similar contexts | Relevance of findings to policy and practice discussed | Include? |
|----|-----------|-------------------------|---------------------------|---------------------------------------|----------------------------------|---------------------------|---------------------------|---|--|-------------------------|---|---|--|--|--|----------|
| 1 | Yes | No | Yes | No | Yes | Yes | Yes | Yes | Yes | No | Yes | No | Yes | No | Yes | Yes |
| 2 | Yes | No | Yes | No | Yes | Yes | Yes | No | Yes | No | No | No | No | Yes | Yes | Yes |
| 3 | Yes | Yes | Yes | Yes | Yes | Yes | No | No | Yes | No | No | No | Yes | Yes | Yes | Yes |
| 4 | Yes | No | Yes | Yes | Yes | Yes | Yes | No | Yes | No | No | No | Yes | Yes | Yes | Yes |
| 5 | Yes | No | No | No | Yes | Yes | Yes | Yes | Yes | No | No | No | Yes | Yes | Yes | Yes |
| 6 | Yes | No | Yes | No | Yes | Yes | Yes | No | Yes | No | No | No | Yes | Yes | Yes | Yes |
| 7 | Yes | No | No | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | No | Yes |
| 8 | Yes | Yes | No | No | Yes | Yes | Yes | Yes | Yes | No | Yes | No | Yes | Yes | Yes | Yes |
| 9 | Yes | No | No | No | Yes | Yes | Yes | Yes | No | No | No | Yes | Yes | Yes | Yes | Yes |
| 10 | Yes | No | No | No | Yes | No | No | No | No | No | No | No | No | Yes | Yes | Yes |
| 11 | Yes | No | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | No | Yes | Yes | Yes | Yes |
| 12 | Yes | No | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | No | Yes | No | Yes | Yes |
| 13 | Yes | No | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | No | Yes | No | Yes | Yes |
| 14 | Yes | No | Yes | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | No | Yes | Yes |
| 15 | Yes | No | Yes | No | Yes | Yes | Yes | No | No | No | No | No | No | No | Yes | Yes |
| 16 | Yes | No | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | No | No | Yes | Yes | Yes |
| 17 | Yes | No | No | No | No | No | Yes | Yes | No | No | No | No | No | No | No | No |

Key for Table 4:

| | Reference | | Reference |
|----|---------------------------|-----|--------------------------|
| 1. | Bussman et al. 2015 | 10. | Ogasawara et al. 2003 |
| 2. | Steinhauser et al. 2014 | 11. | Kirchhoff et al. 2002 |
| 3. | Kongsuwan et al. 2012 | 12. | McGrath. 2001 |
| 4. | Mossin and Landmark. 2011 | 13. | Rogers et al. 2000 |
| 5. | Nelson et al. 2010 | 14. | Dunne and Sullivan. 2000 |
| 6. | Dzul-Church et al. 2010 | 15. | Tanaka et al. 1999 |
| 7. | Spichiger. 2008 | 16. | Pierce. 1999 |
| 8. | Payne et al. 2007 | 17. | Czerwiec. 1996 |
| 9. | Hawker et al. 2006 | | |

Percentage of articles who met the criteria as outlined by Kitto, Chesters⁴⁰

| Quality element as described by Kitto et al. (2008) | % of papers (n=17) who had evidence of this |
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| Clear aim | 100% |
| Clear research question | 12% |
| Appropriate method choice | 65% |
| Outline of why research design chosen | 24% |
| Clear data collection techniques | 94% |
| Transparent data analysis | 88% |
| Clear sampling techniques | 88% |
| Sampling techniques support conceptual generalisability | 65% |
| Conceptual discussion of results and linkage to new or existing theory to explain relevance of findings to targeted audience | 76% |
| Negative case inclusion | 0% |
| Clear statement of effect on the data of researcher's views | 24% |
| Clear evaluation of the relationship between researcher and those under research, addressing any ethical issues | 18% |
| Ethics approval obtained from an appropriate institution | 71% |
| Critical evaluation of application of findings to other similar contexts | 65% |
| Relevance of findings to policy and practice discussed | 88% |

Appendix 2

Themed patient data inclusive of raw quotes (red font denotes quotes also used in-text)

| Theme | Expert Care |
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| <p>Example quotes from included papers</p> | <p><u>Good physical care</u></p> <ul style="list-style-type: none"> • <i>I'm thankful for my hair being shampooed</i>³⁵ • <i>I can eat at a table when I wear a corset</i>³⁵ <p><u>Symptom management</u></p> <ul style="list-style-type: none"> • <i>How can they expect the doctors and the nurses to know what your pain is? They do not know, unless you tell them . . . and it will change . . . Every time they come in the room they should ask, 'How is your pain today, how is your pain tonight, what can we do to help you with it?'²⁵</i> • <i>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</i>²⁵ • <i>[Relief of pain] is very important to your recovery. You do not feel good, you just do not care</i>²⁵ • <i>I am most delighted when the pain is gone</i>³⁵ • <i>At home I kept vomiting, but in the emergency department this was remedied within half an hour, an hour. They probably gave me morphine. And the restless legs didn't bother me any longer, I didn't vomit anymore, I wasn't nauseated. I felt like I was in heaven that afternoon, because I had improved so much</i>²⁶ • <i>They almost suffered themselves. One told me that the whole unit was preoccupied with me. That's good. And it is good that one realizes it</i>²⁶ • <i>I don't see any reason why I should be in pain. They ain't got it under control. They keep thinking because I'm a heroin addict I'm trying to get more pills</i>²⁴ <p><u>Integrated care</u></p> <ul style="list-style-type: none"> • <i>There's good work to be done. 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</i>²⁴ • <i>The communication between doctors and nurses, that's paramount . . . You want to make sure that the chain of communication between doctors, nurses, and patients is not broken, because if it is broken, the patient is gonna get lost</i>²⁵ |
| Theme | Effective communication and shared decision making |
| <p>Example quotes from included papers</p> | <ul style="list-style-type: none"> • <i>Put this in layman's terms for my family to understand. Why are you doing these tests and things that are painful and intrusive? Is there really reason enough to do it?</i>²⁵ • <i>Using terms that a person that's not a doctor could understand . . . You did not need to go get a dictionary to look it up . . . they explained themselves well</i>²⁵ • <i>The lack of communication was so severe that my wife could not even make informed decisions as to my care. She could not find out enough . . . Nobody told her anything, and this went on for eight days. Nothing. The doctors wouldn't come by. If they did, they wouldn't tell her anything. She had no idea what was going on</i>²⁵ • <i>The family's stress level is so high to begin with, and this just adds more stress, not knowing what my condition is</i>²⁵ • <i>Be honest, so, if you do not come out alive, [the family members] are not surprised, they expected that, they are going to be disappointed, but they realized that you might not make it</i>²⁵ • <i>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</i>²⁵ • <i>Communication, with compassion . . . because, being in the dark is like being in oil</i>²⁵ • <i>I think there are a lot of patients who are either not well enough to do anything about [their care], or not smart enough to do anything about [their care], don't voice their opinions and they just take it. But I'm not one to take it</i>²⁴ • <i>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."</i>²⁵ • <i>Another, whose preeminent concern was to avoid "being a burden to my family," stressed that she "would want the ICU to know that . . . at the beginning, absolutely," and when asked if</i> |

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| | <i>investigation of patient preferences should occur on admission to ICU, replied, “they should know before you even get into ICU.”²⁵</i> |
| Theme | Respectful and compassionate care |
| Example quotes from included papers | <ul style="list-style-type: none"> • <i>I can see where the wheels are turning and people are thinking should he be here? Is he costing us too much? Is he an outpatient? Or is he a hospice patient? Don’t make him too comfortable. If he wants to be bathed, cleaned, he’s not supposed to be in a hospital. That’s not what we do—I can feel it from the staff.²⁴</i> • <i>I think every patient deserves to be treated with love and respect . . . think of them not that they’re just kind of specimens, but they’re human beings . . . ask the patient what they feel . . . I want to talk to somebody maybe about what I’m feeling that day, just to have a conversation with them.²⁴</i> • <i>[The nurse did]...just the absolute minimum that she had to do. There was the medications at night. She entered, didn’t say “Good evening”, did something with the equipment and, “Good night”, and out and gone. Didn’t ask, “How are you”, didn’t say, as the others did, “Call me, ring the bell, if you don’t feel well or whatever²⁶</i> • <i>What really made it different was she treated me with respect and dignity, and the dignity was what made it above and beyond. . . And that really contributed to my healing, and getting better²⁵</i> • <i>. . . they could bring the father here more often so you get communion. Because they want people going downstairs [for mass] . . . if you go in a wheelchair, usually you don’t have underwear on— when you get up to get communion . . . everybody’s looking at your rear end²⁴</i> • <i>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 and whether it’s in the middle of the night or whatever.²⁷</i> • <i>One could say that 90% of all who are here anticipate one’s every wish. And are concerned.²⁶</i> |
| Theme | An adequate environment for care |
| Example quotes from included papers | <ul style="list-style-type: none"> • <i>Patient: It’s not so peaceful as the other room. I like it [being in a single room]. I like being on my own. Because they [nurses] all giggle, you know a lot, and I’m glad they do, but it gets on my nerves, that’s me, I mean nothing against the girls laughing, they like a good laugh, ... I’d sooner be quiet ...²⁷</i> • <i>No, I wouldn’t want a room on my own ... I couldn’t be better cared for if I was in a private place with a room of my own, I couldn’t. It’s more fun with other people there to talk to ...²⁷</i> • <i>It’s [community hospital] such a nice atmosphere, you feel so safe. I can see now how necessary they [DGH] are, but it’s a different atmosphere in here.²⁷</i> • <i>I like it because it is near home and my son can get to me conveniently, which is a main plus, I feel nearer home, I feel safer.²⁷</i> • <i>Well, the nursing is quite different and there is hardly any nursing, there are only two or three of them on duty, so the nursing is quite different and you’ve got to tune yourself to that to accept that things that you used to get done at the hospital [DGH] they don’t do here.²⁷</i> • <i>As long as I am in hospital, I feel safe³⁵</i> • <i>It would be more convenient for my family if I was to pass away here [the hospital], because then they could start my funeral arrangements going . . .No [I haven’t talked about these things with them]²⁴</i> |
| Theme | Family involvement in care provision |
| Example quotes from included papers | <ul style="list-style-type: none"> • <i>I’m sitting here by myself. And just like everybody else, I need the company of somebody and to have the family. I need my family, too²⁴</i> • <i>With my family I have always overcome difficult times. My family is the very source of my support³⁵</i> • <i>The presence of my spouse has been indispensable to me. We have lived together through times of difficulties with the disease³⁵</i> • <i>My friends and, more importantly, my family played a very, very big part in my, in my comfort level, and my emotional healing. And for me, the emotional healing is high, right there with physical healing. It’s all one. I would stare at the clock, and wait for visiting hours to come, and that was just very, very crucial for my personal healing, to get better and get out of here²⁵</i> • <i>The mind of the patient is not on himself only; his mind is also toward the family that is beside</i> |

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| | <i>him, that is caring for him. Most times, most of the patients do not care much about themselves. But they care for the family that has been giving them support.</i> ²⁵ |
| Theme | Financial affairs |
| Example quotes from included papers | <ul style="list-style-type: none"> • <i>I'm concerned about my hospital and living expenses for my family as I have been in hospital for a long time. I wouldn't care about the expenses if my stay were shorter.</i>³⁵ |
| Theme | Maintenance of sense of self / identity |
| Example quotes from included papers | <ul style="list-style-type: none"> • <i>'It is always there, it is never again not there.'</i>²⁶ • <i>'I feel like I'm in prison.'</i>²⁶ • <i>'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'</i>³⁵ • <i>I'm concerned if the important documents are kept in order at home</i>³⁵ • <i>I wish I could go back to work even for a short while</i>³⁵ |

Author's copy

Appendix 3

Themed family data inclusive of raw quotes (red font denotes quotes also used in-text)

| Theme | Expert care (good physical care, symptom management and integrated care) |
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| <p>Example quotes from included papers</p> | <p><u>Good physical care</u></p> <ul style="list-style-type: none"> • <i>I'm not sure how well trained they were for when he needed his bag changing. There was mess made then, and stuff like that</i>²⁸ • <i>They really were fantastically caring and you know, the process of turning and mouth care, all that was done in an exemplary fashion</i>²⁸ <p><u>Symptom management</u></p> <ul style="list-style-type: none"> • <i>Symptom management is the highest priority</i>²⁹ • <i>My husband went into hospital because he was in severe pain but I don't think he was any better off. The pain never went away, he was always uncomfortable. I felt annoyed about that because if I had known I wouldn't have let him go to hospital</i>³² • <i>Critically ill people should be free of pain in the terminal phase</i>²⁰ • <i>My husband had secondaries in his spine and he was paralysed. He suffered very severe pain and although he had drugs given for the pain, it never seemed to go away. He had pain right up until he died. The staff tried to do their best. Nobody seemed to be able to get to the bottom of it. It was very distressing for us as a family</i>³² • <i>Want the patient to be free from pain</i>²⁹ • <i>It was important for him to have immediate care because he was very sick, and it hurt to have to wait and see him suffer. And there wasn't anything I could do to relieve that</i>²¹ • <i>He was in obvious pain and they paged the doctor . . . then we just waited and waited and waited and waited and it was getting worse</i>³¹ • <i>I don't agree with allowing the patient to have shortness of breath before death. This is because when we say anything to them, the mind will not receive it. The mind can only receive these ideas when the body is not suffering</i>²² <p><u>Integrated care</u></p> <ul style="list-style-type: none"> • <i>The specification of professions involves that everyone treats only one aspect. Man as a whole is falling by the wayside</i>²⁰ • <i>More psychological support for the ill as well as the families</i>²⁰ • <i>The mentally and emotionally part of a dying person receive too little support</i>²⁰ • <i>If anybody has the story down and the plot and how it is going to turn out, the social worker does. They know what they need to bring to the table and what you are going to need help with . . . especially when you have a family member that is critically ill . . . They say the right things, know what to do . . . It should be an integral part of the care</i>²⁵ • <i>I want to start by giving praises, because I cannot praise the chaplain enough. I can't say enough about Paul Jones. He was just great . . . a great service</i>³⁴ • <i>The power of prayer cannot be outdone, especially in times of crisis, that is when people are looking for some place to go, for help. . . . Having someone that is going to come by and offer you prayers, it should not be forced upon anybody but it should be looked upon as a part of treatment that can help people</i>²⁵ • <i>A lot of times, we did not know who was in charge . . . Do they ever sit down and have somebody leading the discussion that's the patient's main doctor? You had all kinds of specialists</i>²⁵ • <i>If you gotta talk to two or three specialists, they come in with conflicting information</i>²⁵ • <i>So many different teams of doctors and nurses were involved . . . but those people were all communicating . . . were all on the same page</i>²⁵ |
| Theme | Effective communication and shared decision making |
| <p>Example quotes from</p> | <p><u>Effective communication leading to a shared understanding</u></p> <ul style="list-style-type: none"> • <i>'We were all generally happy enough with the information we got. It was understandable and we knew what to expect. The staff seemed concerned about us and were keen to do their best</i> |

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| <p>included papers</p> | <p>for us. I found this particularly in the last day or so.’³²</p> <ul style="list-style-type: none"> • <i>‘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</i> • <i>“I do not have a medical background,” said a family member, “so . . . I would be saying, please, tell me in English.”²⁵</i> • <i>Physicians beat around the bush instead of talking in plain language. What a pity.²⁰</i> • <i>“She’s going to tell you, she’s not going to give you a line, but she’s still sensitive. That’s the key.”²⁵</i> <p><u>Complexity involved in decision making at the end-of-life both in relation to medical complexity but also the fact such decisions also have significant emotional and financial implications</u></p> <ul style="list-style-type: none"> • <i>“Here you are, you are so medically untrained, you have to put your faith and trust in people you have never seen and you don’t know....If they said ‘Should we do this or do that?’ I didn’t know what to tell them to do.”³⁰</i> • <i>‘The doctor would tell you, you can do this or this or 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</i> • <i>The doctor would say, ‘well, I cannot advise you, but these are your options.’ But if I asked, ‘what would you do?’, then he could answer that question. And then I had more information to make my decision on, whereas he was, ‘you’ve got these choices.’²⁵</i> <p><u>Need for sufficient and timely information provision with a particular focus on being informed ahead of time, being included in the day to day care plan outlines and the importance of regular planned discussions with the healthcare team, specifically valuing discussions with medical physicians.</u></p> <ul style="list-style-type: none"> • <i>Family members should be informed ‘early enough’ to support him (. . .).²⁰</i> • <i>Why are they so afraid to talk with you about what they think might be happening? I wish they had told me sooner that they thought my son was dying . . . the sooner the better.³⁴</i> • <i>She was there 45 days. . . . On Friday, the doctors and nurses knew she would die-she probably knew, too- but she wasn’t told. . . . If they had just come out and said it, then we could have all said our goodbyes; we didn’t.³⁴</i> • <i>Doctors need to tell you more about what to expect, though-like how close to the end and what might happen next. You don’t think to ask-they need to say what is likely to happen next . . . like, with her congestive failure, she got very short of breath-but I don’t think she suffered; they gave her morphine on the last day.³⁴</i> • <i>‘When I approached the nurses to say or ask anything I got the impression they were busy. Nobody explained how things were progressing. I mean we weren’t kept informed about daily events. It came as quite a shock to me when I became aware that my wife had only about 2 days to live. I knew this would happen of course but I didn’t realize she was as near to dying as she was at that time.’³²</i> • <i>Even if it is also hard to know, I think it is better than not knowing, just wondering. Yes, it is positive, even if it is hard. To be present and to know what is going on.²³</i> • <i>“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. We’ll go along with their schedule. We know they’re busy, but man, would that be helpful.”²⁵</i> • <i>“ICU has rounds at a certain time in the morning. And after that time, when everybody that works there has met and talked, that would be a good time to arrange a family meeting, so we could find out what are they all thinking, what are their plans, just for today, to know what’s going on, instead of day after day, not being sure, not being able to get a hold of the doctor.”²⁵</i> • <i>“ You sit around waiting for the doctor to come in and tell you something....They say, ‘I will talk to you later,’ and....you don’t know when later is....so you don’t dare leave.”³⁰</i> • <i>“Nothing, nothing was important to me as much as just being able to talk to the doctor and to get the information there.”²⁵</i> • <i>I follow his routine, so I see him when he is here. To see him outside those hours is difficult, he is a busy man, but I thought there would be somebody here who would have a file, some information, so that I wouldn’t need to chase after the doctor ...²⁷</i> • <i>She [sister] felt like I didn’t give him a chance to get better. If they [the medical team] had</i> |
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| | <p>called a family meeting, then everybody would have gotten the same information at the same time.²¹</p> <ul style="list-style-type: none"> • ...we were never invited to discuss his condition...I felt that we were gathering information from several people, squirreling it out of them.³³ |
| Theme | Respectful and compassionate care |
| Example quotes from included papers | <p>Provision of respectful and compassionate care noting this to include the preservation of dignity</p> <ul style="list-style-type: none"> • <i>Everything matters-what people say, how they touch the patient-and you-how they look at you- whether or not you matter</i>³⁴ • <i>They once discharged her back to nursing home at midnight in her nightdress, with no coat – wouldn't even give us a blanket. Didn't inform nursing home</i>³³ • <i>To my mind even a dying man deserves dignity and Henry was not given this during his stay in hospital</i>³³ • <i>That was my mother. They need to realize that that's somebody's loved one in there . . . It's not like they need to have an emotional bond with each and every one of our relatives, but they need to have some compassion for these people</i>²⁵ • <i>Better humane care – affectionate care of patients!!!</i>²⁰ • <i>I did have the sense-sort of a bad experience----of people being cold, inattentive, like all routine stuff to them</i>³⁴ • <i>My brother came to get me and we went over to get my Dad's body released. Everyone was so nonchalant and really cool-like they couldn't care less</i>³⁴ • <i>They came in and stretched him out and put one pillow under his head and wiped his face. They had already come in a little bit earlier and changed him because he was very particular about his hygiene. (. . .) They had shaved him, bathed him, put him in clean pajamas before he died. After he died, the kind of propped him, and told me I could stay with him as long as I wanted to</i>²¹ • <i>No diagnosis like 'You have metastases in the brain, there is nothing that can be done about that' and then leaving the patient without any help</i>²⁰ • <i>To still treat the deceased with dignity</i>²⁰ <p><u>Care was provided by capable staff with key attributes principally centred on approaches to care provision rather than purely skilled task completion.</u></p> <ul style="list-style-type: none"> • <i>First and foremost employment of capable nursing staff characterized by the qualities: helpful, empathic, affectionate, appreciative, comforting</i>²⁰ • <i>More sympathy of hospital staff and physicians, which know what families have to expect</i>²⁰ • <i>speaking gently to the patient</i>²⁹ • <i>approaches with a smile</i>²⁹ • <i>gentle touching</i>²⁹ • <i>want nurses to be constantly considerate of the patient's feelings</i>²⁹ • <i>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</i>³³ • <i>The nurses were very nice and worked very hard, but I think they have become technicians rather than providing what we used to consider 'nursing care'</i>³³ • <i>but no, he was just left in his pyjamas and if he was out sat by his bed or lounging on his bed, he had no help to feed himself and he had no use of his right hand, so he needed all his food cut up and they weren't doing that for him. I'm not sure how well trained they were for when he needed his bag changing. There was mess made then, and stuff like that</i>²⁸ • <i>Better training for the caregivers attending the dying during the last hours</i>²⁰ <p><u>Individualised care provision valuing the patient and their family – 'the little things are the important things'</u>²⁸</p> <ul style="list-style-type: none"> • <i>[That] they don't become a 'number' but stay a human being and person. [That they are] treated humanely and [are] not used as a guinea pig</i>²⁰ • <i>That was my mother. They need to realize that that's somebody's loved one in there . . . It's not like they need to have an emotional bond with each and every one of our relatives, but they need to have some compassion for these people</i>²⁵ |

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| | <ul style="list-style-type: none"> • <i>I think that while their focus is medical and saving lives and, you know, the science, I think also, along with that comes the responsibility of some kind of support to a relative or a family, that patient's loved one or caregiver. Yeah, and they actually did that, and that is part of high-quality care</i>²⁵ • <i>Some were good, and I thought some had a blank face, looking at my mother as just a number, number 35. So what I did, I said, my mother is not just an old lady, my mother had a life, of course now she's hooked up to a million cables. I brought in pictures of my mother when she was born, and when she got married to my father in 1936, and how she looked later on. And they saw her differently. It's not just a piece of meat that is sitting in that hospital bed. It's a life. That is 100% important</i>²⁵ • <i>He sat with us, listened to us, cared about Frank as a person-who he was, what he liked doing, what he meant to us</i>³⁴ • <i>One of the hardest things-that is burned indelibly right in my brain [drawing a line across her fore head]-is what a nurse said to me when I questioned why Ben had a feeding tube. She said: "These patients do better when they are fed early" -these patients!-these patients!-not "Ben" - not "your husband" -but "these patients!"-like he were a number, or one of a herd or something-that hurt a lot-I'll never forget it- I wanted to scream: "He's not a 'these patients!'"- he's Ben-he's my husband</i>³⁴ • <i>The whole atmosphere is very different from the General . . . they ignore you there, you know nobody comes and says "he's done this, he's done that, he's done anything" in the General, whereas when I went to [community hospital] they all recognised me and at least would say "hullo" or "he's such and such today" or make a comment about my husband, you know, even in the corridor for example, so I was connecting with them _ and I mean that helped ever such a lot. It was very homely, if that's the right word, and if he was sitting in the sitting room everyone immediately told you where he was, and where he was sitting, and take you to him and things like that _ which was very, which was nice. And I know they were all little things, but the little things are the important things</i>²⁸ • <i>One time, one of the nurses was clearly doing things her own way; her own routine. I wanted to suggest some things that I knew made Ed more comfortable; but . . . she clearly was moving to her own ways</i>³⁴ • <i>it was very important to my mother to tell her life story . . . it was important to my father to, to relate that, to others-who she was and what she spent her life doing</i>³⁴ |
| Theme | Adequate environmental and organisational characteristics |
| Example quotes from included papers | <p><u>Hospital rules and processes – these need to make sense and ought not to detract from optimal patient care</u></p> <ul style="list-style-type: none"> • <i>Admittance procedure was dreadful and distressing. Charles was in great pain — had eaten nothing since breakfast and was vomiting. He was taken up to a ward at 12 00 and made to sit in a chair for two hours until a doctor could see him and officially admit him</i>³³ • <i>By the time I got to the hospital, he had been moved from the Emergency Room to the ICU, but I didn't know that. I went to the Emergency Room and the person at the desk told me that I couldn't go to the ICU to see him until I moved my car from emergency parking because he was no longer a patient in the Emergency Department. I couldn't believe it! I started crying-I only wanted to go see Carl- finally, another person saw me and said: 'For Pete's sake, let her leave her car there!' but that shouldn't happen to people. Rules need to make sense</i>³⁴ • <i>Visiting hours for the families of dying patients should not be restricted</i>²⁰ • <i>Ease up on hospital rules depending on the patient's situation</i>²⁹ • <i>More assistance concerning questions about care, [and] the options one has. Quicker aid, less bureaucracy; you need certifications and forms for everything!</i>²⁰ • <i>He had esophageal cancer, so we know it's got a very, very low survival rate, so, as soon as he was diagnosed, he got [an advance directive] in place . . . One of the nurses came out and said, 'it's getting to the time where we need to decide' . . . and I said, we're not going to prolong this, and she said, 'do you have paperwork?' I said, yes, I've got paperwork, it's on file here. She called downstairs to medical records, they could not find it, and so I am just panicking, because I'm thinking he's going to code, and they're going to try, and he only weighs 80 pounds, so I sent my husband immediately to get it, and we live in another city. An hour and a half of anguish, and it wasn't necessary</i>²⁵ |

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| | <ul style="list-style-type: none"> • <i>Allowing more time for nursing staff and hospital nurses so that they can care for the patients wholeheartedly</i>²⁰ • <i>. . . with a lack of personnel, documentation has high priority instead of treatment or care of the patient</i>²⁰ <p><u>Environmental characteristics contribute to quality end-of-life care with a particular noting of the need for privacy, cleanliness and quiet</u></p> <ul style="list-style-type: none"> • <i>Dying in a separate room with the possibility of a personal farewell – that would have been important for me</i>²⁰ • <i>And he had a lovely, lovely room, a little doorway out on to a little patio. Yes, gorgeous, as I say he was really happy there</i>²⁷ • <i>One big thing: There needs to be a more private space for family to be when death is imminent. Frank was moved out of ICU on the 24th-when they were sure that he would not recover from that second stroke. I spent the night with him. That next morning-there was a beautiful view out his window-the sun rose right over his bed-it was the most beautiful sunrise I had ever seen. He died that morning-the whole family had come in to be with him. I had wondered what was the purpose of moving him out of the ICU-then, I knew. It was beautiful</i>³⁴ • <i>One should not put up critically ill persons in three- or four-bed rooms without shower and WC</i>²⁰ • <i>In the ward where my husband was there really was no privacy. There didn't seem to be any place in the ward where you could talk in private to the staff or indeed to my husband. I never felt at ease when we were talking because I always thought there was somebody who could hear you</i>³² • <i>I never felt there was any privacy in the ward, there was only a curtain between the beds. I felt I couldn't talk about things that I wanted to because I was aware that others could hear me. We were disappointed that there wasn't a bit more privacy</i>³² • <i>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</i>³⁴ • <i>You hear so much about dirty beds, dirty pillows, things not being changed, my mum's linen was changed every day and she wasn't incontinent, um, I mean I'd go there when they didn't expect me, so it wasn't sort of, oh, she's coming, we'll do it, I remember going there one lunchtime, and they said, you'll have to hang on a minute, we're in the middle of doing your mum's bed, you know, so I was most impressed with the cleanliness I must admit</i>²⁸ • <i>The hospital ward was not up to standard in hygiene (cleaning). I clean a locker and a bath before allowing him to use it</i>³³ • <i>I do not think the standards of hygiene are good in hospital compared to the past. Odd rubbish seems to lie about</i>³³ • <i>I appreciate the staff are working and that, but they do make a clatter sometimes, most of the time there is something going on. Yes, well those last few days we were in a ward directly opposite the nurses' station, and it was a tiny bit on the noisy side I mean you can't expect them to walk around whispering, but there were times when it was noisy. And the bell seemed to ring an awful lot, but I mean, they are patients, they need help. The casualty bell is a very strident bell, you know . . . I'm not complaining about it at all, its just they are constantly busy, it's not a quiet place. It's not a peaceful place</i>²⁸ • <i>They shout from one end to the other. Yes, if they want somebody, they don't go and look for them, they shout for them</i>²⁷ <p><u>Space for cultural practices whether this be congregating family members, chanting or other important rituals to support optimal end-of-life care. This information came from one article only</u>²²</p> <ul style="list-style-type: none"> • <i>At the end, all relatives and cousins have to be there. . .this will help the dying person to leave with happiness and in peace. . .not feeling alone. . .</i>²² • <i>I came to be with him and did some short chanting. I whispered that he should not worry, I will take care of mom. After that my younger brother came in to speak into his ear. Then my mom said to him to have a comfortable sleep, our sons were already grown, not to worry about her and to go to sleep in comfort</i>²² • <i>I knew that my dad was dying soon. . . in the moment of being informed of the impending death by the doctor. He said to me that dad would not survive. Then, I asked the nurse to turn</i> |
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| | <p>on the taperecording of the monk's chanting. When dad heard the chanting voice, he grasped my hand and closed his eyes. He wanted to hold every person's hand. I said to him that please pass peacefully, and prayed for his spirit to depart peacefully, not worrying about anything²²</p> |
| Theme | Recognising and supporting the family role in care including valuing their expert knowledge of the patient and advocating for patient needs |
| Example quotes from included papers | <p>Wanting to be involved, to advocate and for their expertise as 'carer' to be recognised and valued</p> <ul style="list-style-type: none"> From the time my mother went into the hospital and us knowing that she was going to die was an extremely trying time for all of us. I had looked after my mother at home and I still wanted to do that in hospital. I felt I didn't have a lot of contact with the staff. I felt helpless³² 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. They let me help to turn him and hold him-that was important to me-I was helping keep him comfortable³⁴ To me it felt safe to be there, but for him you might say it was a need. And to be able to help I felt was a good thing. Yes, I thought it was very good! (Spouse 2)²³ I went to the doctor and I said that there is something wrong and I know (the patient) . . . and they found fifteen blood clots blocking the urethra . . . all the water was coming in and nothing was going out! I just said 'Sorry, but I know (the patient) better and he is in pain'³¹ I probably made a nuisance of myself, but I really feel that my sister got much better care because I was there every day. I was a decision-maker, and I was a prodder, and I was a nagger, and I was an everything else²⁵ Right from the word go, (the patient) never went anywhere without me. From the time (the patient) got sick and they put in the central line, I stuck by (the patient)³¹ The case seemed to be 'Just shut up. We are the experts; we will do what we think is right. We don't want to hear from you'³¹ There was no attempt to say, 'Are you concerned about it? Do you think things are going OK?' That sort of thing³¹ <p><u>The importance of feeling welcomed as a partner in care so the carer is certain of their role</u></p> <ul style="list-style-type: none"> It almost feels like it wasn't your place there. It was the patients', and they deal with the patient³¹ 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 difficult³¹ I will never forget that time in the hospital with my husband. I had cared for him at home. It was very hard knowing that he was going to die. I wasn't sure how to cope with it. I seemed to be in a panic all the time and when I went to the hospital I wasn't sure what I should do for my husband. I don't think we were helped much. I felt ill at ease and never seemed to be able to settle³² <p><u>It is not necessarily beneficial to remove carers from distressing situations – involvement remains key for some and therefore should be supported</u></p> <ul style="list-style-type: none"> And she just said "Would you like to sit in the lounge?" and I said, "No, I don't want to sit in the lounge; I will stand at the door, thank you." When they came out it was only a matter of a few minutes, I believe, and she said "Sorry (the patient) has gone," and I said "I want to be with (the patient)." I wanted to be with (the patient) all along and they tend to try to shoo you out. I did not see him when he was dying. (The patient) had wires all over his head and everything and that may not look good . . . but I could deal with all that. I would have preferred to be with (the patient) holding hands, even though it might only have been a small time³¹ They tried to get me out of the room saying this is not beautiful for your eyes . . . let's get you out of the room. And I said, "No, I am not going . . . this is someone I care about." And this other nurse said to me (later) that I held (your loved one's) hand and (the patient) breathed four times after everything was turned off and I held (the patients hand) and tried to comfort (the patient). (Crying) That really hurt me because that is my role. It was my role, and I just believe from hearing from people who were unconscious or had those near-death experiences that they know who is with them and know what is going on. I believe (the patient) would have known that I left the room and that hurts me to this day³¹ |

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| Theme | Financial affairs |
| Example quotes from included papers | <ul style="list-style-type: none"> • <i>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</i> ³³ • <i>The advice in completing social security forms and finding out about benefits he was entitled to claim was very poor. Because of this, he lost benefits in the first 8 weeks of illness. It was only through pulling their finances together and by financial assistance from 'Help the Aged' that eased our situation. This initial failure led Dad to worrying about bills being paid. He did not need this sort of additional stress in the last few months of his life</i> ³³ |
| Theme | Maintenance of patient safety and prevention of harm |
| Example quotes from included papers | <p>Families feeling hospitalisation did not provide any improved level of care compared with care at home – hospitalisation is not always the answer</p> <ul style="list-style-type: none"> • <i>My husband went into hospital because he was in severe pain but I don't think he was any better off. The pain never went away, he was always uncomfortable. I felt annoyed about that because if I had known I wouldn't have let him go to hospital</i> ³² • <i>I will never forget that time in the hospital with my husband. I had cared for him at home. It was very hard knowing that he was going to die. I wasn't sure how to cope with it. I seemed to be in a panic all the time and when I went to the hospital I wasn't sure what I should do for my husband. I don't think we were helped much. I felt ill at ease and never seemed to be able to settle</i> ³² • <i>I think the 'care' he received made him worse not better</i> ³³ • <i>From the time my mother went into the hospital and us knowing that she was going to die was an extremely trying time for all of us. I had looked after my mother at home and I still wanted to do that in hospital. I felt I didn't have a lot of contact with the staff. I felt helpless</i> ³² <p>Poor care leads to a lack of patient safety with the following key areas particularly noted: poor communication; not considering a palliative approach as needed; not considering a patient's unique care needs; ensuring families feel aware of how to best support their loved ones; poor levels of core nursing care; lack of timely attention</p> <p><u>Poor communication</u></p> <ul style="list-style-type: none"> • <i>One night I arrived and (the patient) was panicking after a doctor's visit and there was a total misunderstanding and basically what the doctor said was that (the patient) would die. I had to find the doctor and identify what was said. I told the doctors that in the future I want to be there for future meetings. My instructions were ignored by them</i> ³¹ • <i>Edward never wanted to be told he was going to die. It was clear on his hospital notes that he did not want to be told. The doctor at the hospital told him while he was alone. This upset everyone for a long time</i> ³³ • <i>(she) understood enough about her illness to know the prognosis was poor. It was clearly not necessary to spell it out and it undermined my morale at a time when it was important to give Elizabeth encouragement</i> ³³ <p><u>Not considering a palliative approach</u></p> <ul style="list-style-type: none"> • <i>My Dad was alert. He could squeeze my hand- but he had a breathing tube in. He seemed like he wanted to talk-I am regretful that I didn't ask to have that tube removed . . . When it's happening, you do the best that you can . . . it's not a good situation for thinking straight</i> ³⁴ <p><u>Not considering a patient's unique care needs</u></p> <ul style="list-style-type: none"> • <i>One time, one of the nurses was clearly doing things her own way; her own routine. I wanted to suggest some things that I knew made Ed more comfortable; but . . . she clearly was moving to her own ways.</i> ³⁴ <p><u>Ensuring families feel aware of how to best support the patient</u></p> <ul style="list-style-type: none"> • <i>One of the things that is helpful for the family is to know that they have done as much as they can. . . It's not knowing, necessarily, that they have had as much medical treatment as they could, but maybe as much caring as they could-touching, music, listening . . .</i> ³⁴ • <i>I would never want to experience that again, such a New Year. That was the most brutal; New Year's Eve at midnight, that was absolutely unbearable</i> ²⁶ <p><u>Poor nursing care</u></p> <ul style="list-style-type: none"> • <i>Admittance procedure was dreadful and distressing. Charles was in great pain — had eaten</i> |

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| | <p>nothing since breakfast and was vomiting. He was taken up to a ward at 12 00 and made to sit in a chair for two hours until a doctor could see him and officially admit him³³</p> <ul style="list-style-type: none"> • They once discharged her back to nursing home at midnight in her nightdress, with no coat — wouldn't even give us a blanket. Didn't inform nursing home.³³ • Nobody would take responsibility for him, nobody seemed to care. He was discharged before Christmas when they should never have sent him out. Never checked there was anyone there to look after him, they didn't arrange any support for him³³ • To my mind even a dying man deserves dignity and Henry was not given this during his stay in hospital³³ • <i>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 dehydration³³</i> • On visiting Henry one evening we found his breakfast tray on his bed³³ • ...but no, he was just left in his pyjamas and if he was out sat by his bed or lounging on his bed, he had no help to feed himself and he had no use of his right hand, so he needed all his food cut up and they weren't doing that for him. I'm not sure how well trained they were for when he needed his bag changing. There was mess made then, and stuff like that²⁸ <p><u>Lack of timely attention</u></p> <ul style="list-style-type: none"> • He was in obvious pain and they paged the doctor . . . then we just waited and waited and waited and waited and it was getting worse³¹ <p><u>There is a need to support families and patients to 'speak up' about their care to ensure patient safety</u></p> <ul style="list-style-type: none"> • I thought that you weren't supposed to do that- but I was afraid to say anything³⁴ • You just don't want to complain about anything. You are at their mercy; your loved one is at their mercy . . . what would happen if they got mad at you?³⁴ • <i>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 help³⁴</i> |
| Theme | Preparation for death |
| Example quotes from included papers | <ul style="list-style-type: none"> • [We] needed this, our grandchildren especially needed that moment³⁰ • It would have been advantageous for me and my family if, at a point, of the better than 2 weeks that he was in ICU, we could have had some kind of counselling on end of life issues²⁵ • <i>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 . . . We got a call at 5 AM and my brother was gone. And I never had the chance, you know²⁵</i> • She was there 45 days. . . . On Friday, the doctors and nurses knew she would die-she probably knew, too-but she wasn't told. . . . If they had just come out and said it, then we could have all said our goodbyes; we didn't³⁴ • The whole thing about the experience with me was I didn't know he was dying, so it was very hard²¹ |
| Theme | Duty of care extending to the family after patient death |
| Example quotes from included papers | <ul style="list-style-type: none"> • I think that I did get very good attention and my father had the best of care, but . . . <i>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: 'Ms.____, I know your father just recently died, how are you doing? Did you know there's a group? Would you be interested in talking to someone? . . . It's important for people who have recently lost their loved ones,' or something like that²⁵</i> • At 8:00 PM, I went out there and felt like I was going into a war zone. I was put out like, out on the street. No one told me anything. They knew several days beforehand that I had arranged the date [for ventilator withdrawal], but nobody approached me . . . Nothing was addressed at all . . . Nobody asked, 'Are you able to take care of yourself; are you able to find a place to go to, as far as for grief, for death of your mother?' Where do you go, what do you do? . . . Prepare one for it a little bit. Not to walk out into the cold night²⁵ • After he died, they just came in there and pronounced him dead, and started covering him up and moving him, and pulling out all these things. And, I thought, do they need the room right |

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| | <p>now? They do not give me a minute to just kind of get up and grab my stuff and get out? So, I just left. I would have appreciated some follow-up or grief support or social work or anything. Because I did not cry over my father. . . . I did not cry at all, until 2 months ago, I finally had myself a good little fit. I did not know that I was so messed up. I wished that I had spoken with someone. Or someone had reached out to me. In some way²⁵</p> |
| Theme | Enabling patient choice at the end-of-life |
| Example quotes from included papers | <p>The importance of following established Advance Care Directives and for processes to be in place to facilitate this</p> <ul style="list-style-type: none"> • <i>Physicians: should comply with existing patient advance directive and not prolong the suffering and dying for a few months</i>²⁰ • <i>My mother had made a decision against a nourishing probe in advance but everyone (paramedical and nursing staff, some physicians) made me a bad conscience: 'Do you want to let your mother starve?'</i>²⁰ • <i>For patients who had previously expressed preferences in an advance directive, there was agreement among participants that "the ICU needs to know immediately" before major decisions were actually at hand, if possible, "before something tragic happens." "What's the point of making one out if the information's not passed on?" in a timely way, a family member asked, rhetorically</i>²⁵ • <i>He had esophageal cancer, so we know it's got a very, very low survival rate, so, as soon as he was diagnosed, he got [an advance directive] in place. . . . One of the nurses came out and said, 'it's getting to the time where we need to decide'. . . and I said, we're not going to prolong this, and she said, 'do you have paperwork?' I said, yes, I've got paperwork, it's on file here. She called downstairs to medical records, they could not find it, and so I am just panicking, because I'm thinking he's going to code, and they're going to try, and he only weighs 80 pounds, so I sent my husband immediately to get it, and we live in another city. An hour and a half of anguish, and it wasn't necessary</i>²⁵ • <i>One man had told his wife, ". . . [I]f I am physically able, but I have lost my mental facilities, . . . I would choose not to live, . . . [but] I would like to live to see these little kids (grandchildren) grow up (Kirchhoff, 2002 #130)</i> <p><u>The fact decision making at the end-of-life is complex, even when in the context of being guided by an Advance Care Directive</u></p> <ul style="list-style-type: none"> • <i>I knew [he] did not want to be on life support systems. . . . I made us up a living will every year, . . . but when you're actually faced with the reality, [that is] something! You have to go with the decision. . . . [but] I would have taken [him] under any circumstances</i>³⁰ <p><u>The need for legalised euthanasia for critically ill patients</u></p> <ul style="list-style-type: none"> • <i>Critically ill patients should get the legal option to end their lives painlessly and without complications if they wish (. . .)</i>²⁰ |