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Rapid review of the literature on end-of-life care

To inform an update to the National Consensus Statement: essential elements for safe and high-quality end-of-life care

This report has been prepared by the Research Centre for Palliative Care, Death & Dying, Flinders University, Adelaide, South Australia
for the Australian Commission on Safety and Quality in Health Care.

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Preface

The Australian Commission on Safety and Quality in Health Care (the Commission) is continuing to build on work to deliver improvements in safe and high-quality end-of-life care. The Commission has produced a multi-layered suite of resources to support implementation of the strategies to promote safe and high-quality end-of-life care. The suite includes:

- *Safety and Quality of End-of-Life Care in Acute Hospitals: A Background Paper* (2013) (the Consensus Statements)
- *National Consensus Statement: essential elements for safe and high-quality end-of-life care* (2015)
- *National Consensus Statement: essential elements for safe and high-quality paediatric end-of-life care* (2016)
- End-of-Life Care Audit Toolkit (the toolkit).

In 2015 the Commission developed the Consensus Statements which describes the key clinical and organisational requirements that are essential for delivering excellent end-of-life care in Australia. It sets out suggested practice for the provision of end-of-life care in settings where acute care is provided, however the principles apply to situations where patients who are deteriorating are being cared for in other settings – for example, remote clinics, hospital-in-the-home or aged care facilities. The elements and principles of the Consensus Statements can be used by clinicians, health service executives and managers, policy-makers, educators and training providers to improve the safety and quality of end-of-life care.

The Commission engaged Flinders University's Research Centre for Palliative Care, Death and Dying to undertake a rapid review of the literature to provide an update of the current evidence base that could inform a revision of the Consensus Statement. The review sought to:

- Understand best practice processes for end-of-life care and organisational prerequisites for implementation and delivery in the Australian health context
- Recognise new and emerging issues related to delivery of excellent end-of-life care
- Identify end-of-life care delivery considerations during a pandemic.

The authors developed a research methodology protocol for searching and extracting relevant literature from the last five years including standard key words and using PICO framework to determine inclusion and exclusion criteria. Extracted information was synthesised and analysed using NVivo 12 and findings reported.

Fifty-six articles were included in the main review and ten additional papers were included that specifically related to end-of-life care during a pandemic. Five broad themes relating to best practice processes and organisational prerequisites for implementation and delivery of end-of-life care in the Australian health context were determined. Four additional themes relating to delivery of end-of-life care during a pandemic were also identified. As a result of the rapid literature review, the authors made five recommendations for consideration by the Commission to improve delivery of safe and high-quality end-of-life care.

The Commission will consider these recommendations, and will work with key stakeholders to develop and / or adapt appropriate information and resources required to support health service organisations to deliver safe and high-quality end-of-life care.

Flinders UNIVERSITY | Research Centre for Palliative Care, Death & Dying

Rapid review of the literature on end-of life care

A report prepared for the Australian Commission on Safety and Quality in Health Care

Prepared: September 2020

This report has been prepared by the Research Centre for Palliative Care, Death & Dying, Flinders University, Adelaide, South Australia
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Acronyms and abbreviations

AACODS	Authority, Accuracy, Coverage, Objectivity, Date and Significance
ACP	Advance Care Planning
CADTH	Canadian Agency for Drugs and Technologies in Health
CALD	Culturally and Linguistically Diverse
CASP	Critical Appraisal Skills Programme
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COVID-19	Coronavirus Disease 2019
CPD	Continuing Professional Development
GOC	Goals of Care
GP	General Practitioner/Practice
H1N1	Swine Influenza A virus subtype
ICU	Intensive Care Unit
Medline	Medicine's Medical Literature Analysis and Retrieval System Online
MERS	Middle East Respiratory Syndrome
MeSH	Medical Subject Headings
NGO	Non-government Organisation
NP	Nurse Practitioner
NSQHS	National Safety and Quality Health Service
OECD	Organisation for Economic Co-operation and Development
PPE	Personal Protective Equipment
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT	Randomised Controlled Trial
RePaDD	Research Centre for Palliative Care, Death & Dying
SARS	Severe Acute Respiratory Syndrome
UK	United Kingdom
USA	United States of America
VAD	Voluntary Assisted Dying

Executive Summary

Background

The Australian Commission on Safety and Quality in Health Care (the Commission) developed a *National Consensus Statement: essential elements for safe and high-quality end-of-life care (*the Consensus Statement*)* in 2015. The purpose of the Consensus Statement was to describe the elements that are essential for delivering safe and high-quality end-of-life care in Australia. The Consensus Statement sets out recommended practice for the provision of end-of-life care in settings where acute care is provided. In 2017 the National Safety and Quality Health Service (NSQHS) Standards (2nd edition) were released which included six end-of-life care actions in the Comprehensive Care Standard.

Scope

The Commission engaged the Research Centre for Palliative Care, Death and Dying (RePaDD) based at Flinders University to undertake a rapid review of the literature from 2015–2020 to update the knowledge on which the Consensus Statement was built. Specifically, the rapid review sought to:

- Understand best practice processes for end-of-life care and organisational prerequisites for implementation and delivery in the Australian health context
- Recognise new and emerging issues related to delivery of excellent end-of-life care
- Identify end-of-life care delivery considerations during a pandemic.

A grey literature review was also included to identify current practices and influences such as key policies, palliative care projects and initiatives, key organisations and agencies.

Findings

The main literature review included 56 papers. Five key themes were identified:

- Environment of care
- Person-centred care
- Clinician capacity
- Caring for family
- Bereavement support.

The pandemic literature review (no date parameters) included 20 papers and from these, four themes were generated:

- Technological innovation
- Delivery of care
- Person-centred care
- Family grief.

The grey literature review included 18 documents and summarised relevant initiatives from state and territory-based departments of health.

Limitations

We acknowledge that the findings are not exhaustive and that potentially relevant literature may not have been included due to rapid nature of the review. Only articles in English were included. The grey literature search was restricted to Australia. Conclusions and recommendations should therefore be considered within these limitations.

Recommendations

The review generated the following five recommendations which are detailed in the body of the report:

- **Recommendation 1**: That the Commission consider revising the *National Consensus Statement: essential elements for safe and high-quality end-of-life care* to include four new elements.
- **Recommendation 2**: That the Commission consider a new strategy to support health service organisations to understand the importance of, and implement, the National Consensus Statement, including the development of resources to support health service organisations.
- **Recommendation 3**: That the Commission consider development of a clinical care standard for bereavement care.
- **Recommendation 4**: (from the pandemic review): That the Commission consider assessing the contribution of innovative digital technology and equipment in end-of-life care processes, and provide the sector information to support best practice for the utilisation of technology in the delivery of end-of-life care.
- **Recommendation 5**: That the Commission examine the review findings for implications for the audit toolkit and consider liaising with stakeholders to identify gaps in the End-of-Life Care Audit Toolkit and possible opportunities for new components.

Conclusion

With a growing, ageing population that will continue to die in hospitals, there are several implications for policy and end-of-life care practices in this context. Recognition of the importance of end-of-life care is required as an important first step to enable improvements in the quality of care delivered to patients and their families. Organisational readiness to deliver safe and culturally appropriate quality end-of-life care is pivotal to the success of these initiatives. The findings in both the main review and the pandemic review show that without this level of organisational engagement, the required changes in the way in which care is delivered (such as person-centred care, care of family, technological innovation) at both the team and individual level will mean that safe and quality care will be harder to achieve. Increasing pressures on care delivery and a need to provide responsive person-centred end-of-life care places the spotlight on health service organisations to ensure that teams and individuals are supported and enabled to provide care. This is especially true now that end-of-life care is subject to quality assurance mechanisms of the NSQHS Standards (2nd edition): Comprehensive care.

Introduction

Hospitals provide end-of-life care to many people every year. It has been estimated that on average, a person will have four admissions to acute hospitals in the last 12 months of life[1], and up to 75% of Australians will present at least once to the emergency department in the last two years of life[2]. Furthermore while many people say they would prefer to die at home, over 50% of Australians die in hospitals.[3] As a result of our ageing population, it is estimated that the number of Australians who die each year will double by 2040, making the need for safe and quality end-of-life care in hospitals an ongoing concern.[4] Healthcare professionals who work in acute hospitals are attuned to the needs of those acutely unwell, with the aim of improving their condition, and do not always recognise the needs of those who are deteriorating at end of life, and may not recognise dying.[5] End-of-life care and care for those dying in acute hospitals is therefore a core role for hospitals and needs to be considered in terms of the quality of care delivered, along with the experiences of patients and families.

The Australian Commission on Safety and Quality in Healthcare (the Commission) leads and coordinates key improvements in safety and quality of health care across Australia. Three pivotal pieces of work from the Commission inform this review:[6-8]

- *Safety and Quality of End-of-Life Care in Acute Hospitals: A Background Paper* (2013)
- The *National Consensus Statement: essential elements for safe and high-quality end-of-life care* (2015)
- National Safety and Quality Health Service (NSQHS) Standards (2nd edition)
- End-of-Life Care Audit Toolkit.

The National Consensus Statement 2015 (the Consensus Statement) was developed for:

- Clinicians who are involved in the provision of acute health care
- Health service executives and managers who are responsible for developing, implementing and reviewing systems for delivering patient care, including end-of-life care in individual health services or groups of health services
- Providers of clinical education and training, including universities and professional colleges who are responsible for the teaching and training of undergraduate and postgraduate courses for a range of healthcare disciplines
- Health professional registration, regulation and accreditation agencies
- Planners, program managers and policymakers who are responsible for developing state and territory, or other strategic programs dealing with the delivery of end-of-life care.

Based on the Consensus Statement guiding principles, 10 essential elements were derived that ‘are required in systems to ensure safe and high-quality care’.[7] These are illustrated in Figure 1.

Figure 1: Overview of the 10 essential elements in the Consensus Statement

In 2017 the NSQHS Standards (2nd edition) were released. Recognising the ongoing need to provide guidance and suggest practice around safe and quality end-of-life care all eight NSQHS Standards now incorporate elements relevant to end-of-life care. This work articulates recommended end-of-life care in terms of safety and quality and lays a foundation for improvement and accreditation going forward.

Approach to developing the evidence summary

The scope of this rapid review of the literature was determined by the Commission and is intended to capture relevant research on end-of-life care since the development of the Consensus Statement.

The review was undertaken by the Research Centre for Palliative Care, Death and Dying (RePaDD), Flinders University. The knowledge, skills and experience of those involved in the review are detailed in Appendix 1. The Chief Investigator and Associate Investigators were responsible for the conceptualisation of the study, the review processes, the structural elements of the rapid review, as well as for the quality of the project activity and report. The investigators worked with the review research staff to develop the review protocol including the parameters for searching, the inclusion and exclusion criteria and in any decision making in relation to the evidence base. New and emerging needs have been identified through literature review, grey literature review and an environmental scan (Appendices 2–4).

Specifically, key objectives of the review were to:

- Understand best practice processes for end-of-life care and organisational prerequisites for implementation and delivery in the Australian healthcare context
- Recognise new and emerging issues related to delivery of excellent end-of-life care
- Identify end-of-life care delivery considerations during pandemic.

End-of-life care and palliative care

The concepts behind the two terms, palliative care and end-of-life care, intersect a great deal. However, many clinicians who work in acute hospitals and who provide care to patients at the end of life may not define the care they provide or identify their professional skills as palliative. End-of-life care is a common term often used in the literature, as is palliative care, with both used interchangeably at times. In 2015 the Consensus Statement provided definitions of end-of-life care and palliative care that still remain highly relevant to current context.[7, 33-34] This report recognises the Commission's definitions as described in the Consensus Statement.

Table 1: Consensus Statement definitions

Consensus Statement	Definition
End-of-life care	Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death. People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with: • advanced, progressive, incurable conditions • general frailty and co-existing conditions that mean that they are expected to die within 12 months • existing conditions, if they are at risk of dying from a sudden acute crisis in their condition • life-threatening acute conditions caused by sudden catastrophic events.
Palliative care or palliative approach	An approach to treatment that improves the quality of life of patients and their families facing life-limiting illness, through the prevention and relief of suffering. It involves early identification, and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual).

End-of-life care in Australia occurs in a broad context, provided in many settings and delivered by many health and social care professionals. The Australian healthcare system is complex, with two tiers of government (one federal and eight state or territory-based) that share responsibility for funding and regulation. Public hospitals are predominantly funded by the Australian, state and territory-based governments, while managed by the state and territory governments.[9] Private hospital services are provided by private organisations but licensed and regulated by the relevant state and territory governments.[10] Further, specialist palliative care services are funded and managed by the states and territories, and include hospices, palliative care wards in hospitals and hospital-based palliative care teams.[11] Community palliative care teams on the other hand may operate out of hospitals or hospices with a variety of models in place. Care in the last year of life may also be delivered by primary care practitioners in the home or in residential aged care settings with intermittent or emergency acute care use.[11]

Key policies in the current Australian context include the National Palliative Care Strategy[12], the National Palliative Care Standards (edition 5)[13], and the Comprehensive Palliative Care in Aged Care measure.[1]. All these policies acknowledge the significant role that palliative care plays and guide the development and delivery of high-quality patient-centred care. The inclusion of end-of-life care in the NSQHS Standards, is also foundational to ensuring that a quality mechanism exists that enables assessment of care standards beyond specialist palliative care services.[8]

Most Australians with a life-limiting illness die in an acute healthcare service, after receiving a range of care from several different services.[3] Evidence shows when safe and high-quality end-of-life care is delivered, distress and grief associated with death and dying for the individual, and for their family, friends and carers is reduced.[15] The Commission recognises that the acute hospital multidisciplinary healthcare workforce plays an important part in providing care for Australians at the end of their lives.[7] Given that people at the end-of-life transition between complex network of services and operating care models, ensuring quality and communication for safety between clinicians is often difficult but vital. The NSQHS Standards can provide guidance to hospital systems and workforce in assessing and responding to patients with deteriorating health concerns.[8]

With an exponentially growing ageing population in the current climate of voluntary assisted dying, COVID-19 and the Royal Commission into Aged Care Quality and Safety,[16] the processes, systems and infrastructure for end-of-life care in acute settings need to be addressed.

Methodology

To ensure focus in the retrieved literature, we restricted the search to the two most relevant and significant biomedical databases, Medline (Ovid) and CINAHL (Ebsco). Items included were restricted to those with the highest levels of evidence, namely, randomised controlled trials and systematic reviews. No hand searching of references was undertaken, no authors were personally contacted. This rapid review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines 2015.[17]

This rapid review comprises a main search undertaken to understand best practice processes for end-of-life care and organisational prerequisites for implementation and delivery in the Australian health context; a secondary search related to end-of-life care delivery considerations during the pandemic; as well as a grey literature search to look to other relevant Australian sources.

Main review

Data sources and search strategies

The research librarian (SH) in consultation with the investigators built the search strategy using text words and MeSH headings to find research papers, which include the three concepts: acute hospitals, end-of-life care, and safety and quality of healthcare delivery. To limit to the highest level of evidence, we adapted and applied two Canadian Agency for Drugs and Technologies in Health (CADTH) search filters to retrieve only RCTs or Systematic Reviews from the international literature.[18] To prevent the loss of contextually relevant evidence, all articles reporting Australian research were reviewed regardless of study design.

Once the search was finalised in Medline, it was translated into CINAHL using the equivalent subject headings, and text words. All papers were limited to 2015 and English language but the search was not restricted to any country of publication. The searches were run on 8 July 2020. The full search strategies are included in Appendix 2.

Inclusion and exclusion criteria

Papers were deemed eligible for inclusion if they detailed end-of-life care or palliative care in the context of the acute hospital system, were published in English and were within the last five years. The term *specialist palliative care service* was out of scope for inclusion in search construction as the focus was on the non-specialist end-of-life care within acute settings. A full list of specific inclusion and exclusion criteria applied to title and abstract screening, and full-text review is outlined in Table 2 below.

Table 2: Inclusion and exclusion criteria for title, abstract and full-text screening

No.	Criterion	Inclusion	Exclusion
1	**Population of interest**	Patients and their carers/ families of any ages with palliative care needs; hospital based, and hospital employed specialists or non-specialised clinicians	Still birth children; visiting specialists or non-specialised clinicians
2	**Intervention/ phenomenon of interest**	End-of-life care including withdrawal of life sustaining therapy and conversations regarding resuscitation	Specific medical treatment decision making including efficacy of treatment therapies, and diagnostic or prognostic focus (i.e. clinical trials)
3	**Outcome of interest**	Safety and quality in end-of-life and palliative care	Cost-benefits, hospital length of stay or hospital readmission
4	**Setting of interest**	Acute hospital care; and transition/outreach to community care (for example, discharge to residential aged care, outpatient clinic, home) for care initiated at the acute care setting	Primary health care, hospice, specialist palliative care wards within hospital, or visiting specialist palliative care team
5	**Study design of interest**	International articles were included if their study design was either a RCT or experimental and quasi experimental study Articles on the Australian healthcare context of any study design were included	Study protocol, expert commentary/opinion, editorial, letter to the editor, conference abstract and dissertation

Selection of papers

The search results for each database were uploaded to Endnote X9.2 reference management software and duplicates were removed.[19] Journal articles were then imported into web-based Covidence systematic review management system for title, abstract and full-text screening, and data extraction.[20] Four reviewers (DR, KD, AC and PT) independently assessed titles and abstracts of papers against the *priori* inclusion criteria (Table 2). Where eligibility was unclear based on the *title and abstract* screening, the full text was retrieved and assessed. Any disagreements on eligibility for inclusion were resolved by discussions within the review team as necessary.

The full-text papers identified from the title and abstract screening were independently reviewed by four reviewers (DR, KD, AC and PT), before inclusion for final data extraction and synthesis. Due to time constraints, reference lists of the included papers were not examined, nor were any authors personally contacted to obtain further relevant information to identify additional papers.[21]

Data extraction

A data extraction tool was developed in consultation with the review team (DR, PT) using Microsoft Excel and trialled (AC) with three randomly selected articles. The following descriptive data were extracted by two of the reviewers (DR, KD) and independently assessed by a third reviewer (AC) for accuracy and to capture any missed items: (1) study characteristics; and (2) summary description. Study characteristics pertained to author, year of publication, country, study design, study population and study setting. Summary description included brief information on what the study contains including objectives of the study, key findings and conclusion. Comparison of studies in terms of similarities and differences was guided by these descriptive characteristics enabling robust appraisal and synthesis of findings.

Synthesis of data

Synthesis of data were conducted in four sequential steps using a systematic open coding text condensation technique[22], and based on some of the research team members prior experience of using this method.[23] First, two researchers (AC and PT) independently read the full text papers and established a preliminary list of themes. Second, guided by the aim of the study the researchers systematically reviewed full text of the included papers, line by line, to identify relevant component in each sentence and assign a meaning unit. Meaning unit is defined as a text fragment, containing information regarding the best practices and organisational prerequisites in end-of-life care focusing on safety and quality. Identified meaning units were then labelled with codes. Third, through comparison of similarities and differences between selected papers, common meaning units were hierarchically assigned into relevant code groups – defined as sub-themes. Fourth, applying the reflective interpretive process, the individually coded meaning units and sub-themes were then mapped onto related themes. Two researchers (AC and PT) independently coded and assigned labels to the meaning units to ensure appropriate synthesis of data. The results were combined by consensus. An overview analysis of the coded meaning units by individual researchers (AC and PT) determined that a high degree of inter- and intra-group thematic homogeneity existed, suggesting the data could be combined with minimal bias. Data were inductively analysed using the qualitative data analysis software NVivo 12.[24] Findings are reported in narrative form supported with figures and tables.

Assessment of level of evidence

The assessment of level of evidence employed an adaptation of the Johns Hopkins Model of Evidence-Based Practice.[25] The levels of evidence in papers were organised into five categories where Level I represents the strongest level (Table 3).[25]

Table 3: Evidence type used in appraising quality of the evidence of included papers

Evidence Level	Description
Level I	Experimental, randomised controlled trial (RCT), systematic review of RCTs with or without meta-analysis
Level II	Quasi-experimental studies, systematic review of a combination of RCTs and quasi-experimental studies, or quasi-experimental studies only, with or without meta-analysis
Level III	Nonexperimental, systematic review of RCTs, quasi-experimental with/without meta-analysis, qualitative, qualitative systematic review with/without meta-synthesis
Level IV	Respected authorities' opinions, nationally recognised expert committee or consensus panel reports based on scientific evidence
Level V	Literature reviews, quality improvement, program evaluation, financial evaluation, case reports, nationally recognised expert(s) opinion based on experiential evidence

Quality appraisal

Two reviewers (KD, DR) independently read and appraised the included papers to determine the quality of the papers using the Critical Appraisal Skills Programme (CASP) appraisal checklists.[26] However, no papers were excluded based on the quality assessment outcomes, rather quality appraisal was used to provide robust review including additional insights into the strengths and limitations of the individual studies.[27]

Pandemic review

Data sources and search strategies

A specific search for the pandemic concept was developed and combined with the acute hospital and the palliative care/end-of-life care concepts. Searches were run in Medline (Ovid) and CINAHL (Ebsco) on 28th July 2020 by a medical research librarian (SH). The full search strategies are included in Appendix 3.

Inclusion and exclusion criteria

This pandemic review followed the same inclusion criteria outlined in Table 2. The literature search for the pandemic review intended to capture the setting and context as same as that of the main review search. For relevancy three additional terms were added to this search, which were coronavirus, respiratory infections (SARS, MERS, H1N1) and pandemic. No date and country limits were set. The search was narrowed by English language articles.

Selection of papers

The search results for each database were uploaded to Endnote X9.2 reference management software and duplicates were removed.[19] Journal articles were then imported into web-based Covidence systematic review management system for title, abstract and full-text screening, and data extraction.[20] Four reviewers (DR, KD, AC and PT) assessed titles and abstracts of retrieved papers against the *priori* inclusion criteria (Table 2). At least one of the reviewers (DR, KD, AC and PT) assessed each paper and one other reviewer voted to include or exclude a paper. At all times, the review team negotiated any conflicts in the title, abstract and full-text screening process and consensus was reached.

Data extraction

Two reviewers (DR, KD) extracted the following data items and a third reviewer (AC) independently assessed the data for accuracy and to capture any missed items: (1) study characteristics; (2) summary description. Study characteristics included information on study author, year and country of publication. The summary description included brief information on the study itself, and what the study contains including objectives and key findings.

Synthesis of data

Applying the same procedures described earlier in the main literature review, synthesis of data were conducted in four sequential steps utilising the systematic open coding text condensation technique.[22] In summary, two researchers (AC and PT) first independently read the full text papers establishing a preliminary list of themes. Guided by the study objectives, the researchers then systematically reviewed full text of the included papers, line by line, to identify relevant component in each sentence and assign a meaning unit. Meaning unit in this instance is defined as a text fragment, containing information regarding the end-of-life care delivery considerations during pandemic. Through comparison of similarities and differences between selected papers, common meaning units were then hierarchically assigned into relevant code groups – defined as sub-themes. Finally, the individually coded meaning units and sub-themes were mapped onto related themes. An overview analysis of the coded meaning units by individual researchers also determined a high degree of inter- and intra-group thematic homogeneity, suggesting the data could be combined with minimal bias. Data were inductively analysed using the qualitative data analysis software NVivo 12.[24]

Quality appraisal

For this part of the review, with so few papers retrieved, all were considered against the inclusion and exclusion criteria. Of the final included papers some were fast tracked to publication as there was deemed an immediate need for the results to be made available. Quality appraisal process was applied. Given the small number of papers retrieved and the importance of the pandemic context, no papers were excluded based on the quality assessment outcomes.

Grey literature search

Data sources and search strategies

We searched the Australian grey literature to identify key current practices and influences such as key policies, palliative care projects and initiatives, key organisations and agencies. The Commission was approached for information on relevant safety and quality organisations that should be searched. Searches were run in Google (Advanced) using an Australian limit and using keywords for selected key organisations and guidelines. The full search strategies are included in Appendix 4.

Inclusion and exclusion criteria

Initial searches included palliative/hospital/end of life and were restricted to PDF documents over the past three years (i.e. 2017–2020). Secondary searching was conducted in the CareSearch grey literature database, with the parameters of 'Hospital' '2017–2020'. Two searches were conducted – one searching the general grey literature and one specific to conference abstracts. Searching was also undertaken of State based health department websites.

Inclusion

Documents and abstracts were included if they were relevant to the hospital setting and useful for clinical context. They may also represent or highlight a practice or model that had not been included in the main review, but is a known clinical issue.

Exclusion

Documents and abstracts were excluded if:

- The setting was not a hospital, was unknown or not clearly stated
- There was no outcome or results reported (for example, work in progress to be reported at the time of the conference)
- A clinical case study, clinical symptoms or personal reflections are described
- It has been included in the main review or is representative of what is included (for example, similar to included papers)
- There was no clear methodology.

Selection of documents

More than 30 organisations were manually searched for relevant content with 12 relevant documents found in the initial search (Tables A3a–A3c in Appendix 8). These include care plans, guidelines, position statements, policy statements, service development guidelines and clinical support documents. Secondary searching in the CareSearch Grey Literature database found a further document that was included (x) and five relevant conference abstracts (xiv–xviii) out of the 133 retrieved (search by 'Hospital' '2017–2020' and 'conference abstracts').

Quality appraisal

The documents retrieved in the grey literature search have been summarised. Quality appraisal was conducted according to the AACODS (Authority, Accuracy, Coverage, Objectivity, Date and Significance) checklist designed to evaluate and critically appraise grey literature.[28] When considering the documents retrieved via the grey literature search (with the exception of the conference abstracts) the majority of those included met the requirements of the checklist. Two documents (xi, xii) do not meet the criteria fully as they were flow charts and tables. They pertain to clinical practice in COVID-19 but do have the authority of the South Australian Government.

Results

Results of the main literature review

Selection of papers

Figure 2 in Appendix 5 shows search results in a PRISMA Flow Diagram and the findings are reported following the PRISMA checklist.[17] A total of 1,564 citations were retrieved in Medline (n=976) and CINAHL (n=588) databases and deduplicated. This left 1,158 articles for screening. Following screening, 343 studies were selected for the full text review. Upon full-text review, 287 articles were excluded, leaving 56 papers to be included in the thematic analysis. Table A1 in Appendix 8 presents further characteristics of the selected papers.

Twenty-three systematic reviews and 10 randomised control trials were identified in the search. The remaining 23 studies included relevant Australian Studies, of any study design. Papers discussed end-of-life care in Organisation for Economic Co-operation and Development (OECD) countries including: Australia (n=31), USA (n=13), UK (n=5), the Netherlands (n=2), Canada (n=2) and with one each from Belgium, Portugal and Ireland. Among the non-Australian papers 14 were classified into Level III of the evidence hierarchy (see Table A1 in Appendix 8) and 11 into Level I, whereas, almost all (n=28) Australian studies were classified into Level III of the evidence hierarchy, followed by two into Level II, and one into Level V.

Study characteristics

A total 17 papers focused solely on healthcare professionals including volunteer support[29-45], 12 papers on the patients[46-57], two focused on the family[58, 59], and the remainder studying how these three groups interact.[15, 27, 60-82] Also, there were two sets of papers[31, 32, 34, 35] identified as each presenting on the same study focusing on nursing staff engagement in end-of-life care practices. Most studies were conducted in inpatient acute hospital settings.

Identification of themes

Five broad themes relating to best practice processes for end-of-life care and organisational prerequisites for implementation and delivery in the Australian health context were determined (see Table 4).

Table 4: Themes identified for the delivery of end-of-life care

Theme no.	Emerging theme	Description of theme
1.1	Organisational readiness	The space where care is provided, such as privacy and spaces to provide culturally responsive care; organisational systems such as presence of policies and guidance, organisational readiness to managing care of the dying
1.2	Person-centred care	Specific needs groups such as culturally and linguistically diverse (CALD), poor health literacy; tailored care
1.3	Clinician capacity	Clinician factors such as bias, readiness and attitude towards delivering end-of-life care; training and education in end-of-life care
1.4	Caring for family	Involvement of family in care, including valuing their knowledge of the person
1.5	Bereavement support	Routine bereavement practices including creating memories, formal counselling, and follow-up care

Organisational readiness

Physical spaces offered throughout hospitals – ward and shared spaces alike – contribute to the quality of care offered at the end of life.[15, 34-36, 39, 43, 79, 81] Physical spaces in the acute ward area, emergency departments and intensive care units (ICUs) can make privacy challenging; clinicians describe this as less than ideal for the care of dying patients and for supporting families immediately post death.[36, 40, 58, 72] Furthermore, nurses actively modify the environment, for example, by pulling curtains around the person as they provide end-of-life care.[35]

While papers report similar perspectives from patients and family, an adequate environment of care was also found to be less important when compared to other aspects of care.[15, 81] Family members have associated lack of space and privacy with a feeling of being 'watched' and not being able to 'talk openly' with their loved ones.[15, 39, 79] One paper extends the issue to include spaces for cultural practices such as family congregations, chanting or other important rituals associated with end of life.[15]

Seven papers describe the influence of organisational culture – including the presence of guidelines and team communication – as foundational to how clinicians approach end-of-life care.[35, 36, 42, 53, 62, 70, 80] Health service organisations that focus on curative health, urge clinicians to concentrate on using futile therapies even when they were in conflict with the preferences of patients, in end-of-life care.[72, 80] In regards to team communication, the attitude of individual clinicians has been shown to influence the care patients receive.[7.2] For example, one paper noted, junior medical officers ignoring messages in their pagers during ward rounds, left nurses feeling increasingly worried, frustrated, and anxious about patients who were deteriorating.[42]

Bloomer et al. reported an audit into the implementation of the Consensus Statement recommendations at two Victorian hospitals.[63] They identified two clear gaps. The first related to challenges for clinicians in recognising dying patients and thus changing the clinical focus of care. The second related to the significant variation in how end-of-life care is delivered.[63] These gaps encompassed multifactorial issues, including:[63]

- Early communication with the patient and family
- Good teamwork
- Identification of clear goals of care
- Embedding of triggers into routine care
- Developing processes that assist clinicians in identifying deteriorating patients.

Other papers reinforced the need for standardisation of documentation on patient care plans; standardisation helps to identify and support patient and family preferences, and increase engagement in good end-of-life care practices.[33, 34] Conversely, a lack of relevant guidelines contributed to poor end-of-life care, including poor bereavement support.[35, 36] Shared assessment and decision making procedures reinforces communication between all clinicians, the patient and their family.[33, 70] Changes led from the organisations' leadership have been shown to increase workforce familiarity and understanding of organisational policies and protocols relating to communication and end-of-life care. [80]

While hospital rules and processes were described as important, they also needed to make sense and should not undermine the delivery of patient care.[15] Several patient safety concerns linked to poor organisational readiness were identified, including:[15, 81]

- Poor communication
- Not considering a palliative approach to care
- Applying a one size fits all approach
- Families feeling uninformed of how to best support the patient
- Poor nursing care
- Lack of timely attention
- Fragmented care.

Fragmented team dynamics – including unequal power relationships between professional groups – becomes a significant obstacle to initiating and developing end-of-life conversations.[80]

Person-centred care

Important elements of person-centred care at the end-of-life identified, include:[15, 31, 63]

- Honest communication
- Focus on preparing for life's end
- Ensuring availability of someone to listen to and being aware of what to expect about their physical condition
- Compassionate care.

Importantly, care provided with the involvement of the family unit, focusing not only on physical care but also treating the patient as a 'whole person', was found to be essential.[15, 36, 80, 81] An integrated care approach involved documentation of the person's social circumstances, including cultural, religious and spiritual needs.[57, 75, 77]

The review noted the impact of population diversity on access to end-of-life care practice and service delivery.[15, 31, 39, 42, 51, 59, 60, 62, 71, 73, 80, 82] Several papers identified the needs of person-centred clinical and non-clinical decision making. It considered the personal values of the patient and family such as allowing access to traditional or culturally significant foods during the hospital stay, where appropriate.[59, 62, 71] In the acute setting communication plays a significant part in personalised approach through identification and documentation of a person's wishes, including how their wishes are enacted by the healthcare team and the family.[15, 51, 71, 80, 82] This was particularly important for people from underserved communities – such as from a culturally and linguistically diverse (CALD) background, veterans or those diagnosed with dementia – as extra considerations are required.[15, 51, 60, 71, 73] Furthermore, some papers highlighted specific challenges in providing end-of-life care to underserved population groups, including finding equivalent words in the person's language to describe key terms (for example, cancer) and tension in the consultation with the addition of an interpreter in the facilitation of the discussion.[31, 39, 42, 71]

Communication was further complicated where someone has multiple co-morbidities with increased likelihood that many clinicians – from different organisations – are involved in a patient's care.[75, 80] Poor communication has led to inconsistency between teams, insufficient sharing of information, as well as failure to discuss overall health status and prognosis.[39, 71, 76] Conversely, effective communication with patients, taking into consideration health literacy, cultural taboo and faith around death and dying improved satisfaction with the quality of health care provided and influenced treatment decisions.[62, 63, 71, 80] Furthermore, positive language to describe treatment limitations encouraged patients to talk openly and resulted in sharing of preferences for future care.[32, 41, 82]

Non-clinical care tailored to and based on individual patient needs was identified as good practice in end-of-life care.[27, 32, 59, 60, 71] Examples of this included washing hair, reading stories, and telling jokes, even when the patients were sedated.[59] Five papers highlighted the importance of trust, hope and dignity among patients and their families.[27, 32, 59, 60, 71] Volunteer involvement contributed to the care of dementia patients by reducing pressure from the nurses while delivering one-to-one care.[60] Positive and compassionate communication from clinical teams can facilitate maintaining such patient-centred care.

Clinician capacity

Clinician capacity emerged as a key theme with papers describing both harmful and protective factors for the delivery of good end-of-life care. Several papers discussed clinician confidence in dealing with their own emotional concerns such as anxiety, angst, worries and frustration, when managing their patients approaching the end of life.[31, 34, 42] Absence of effective communication and engagement skills were a major hindrance for dealing with emotional concerns when managing deteriorating patients, including communicating with peers from non-English speaking backgrounds.[31, 34, 39, 42, 48, 58]

Evidence suggested that reduced experience in caring for people with end-of-life care needs also increased clinician anxiety.[34] Personal behaviours, which influenced how clinicians deliver end-of-life care can include:[31, 41, 80]

- An expectation that family would lead discussions
- Misunderstanding of terminology (such as applying the term 'palliative' only to those people in the last days of life)
- Focusing only on curative or other medical goals over the consideration of patient wishes
- Preferences and fear of not being able to answer the patient's questions.

Conversely, positive clinician attitude towards engaging families in the treatment and goals-of-care discussions supported conversations about prognosis and treatment expectations.[31, 41, 48]

Clinician knowledge and training needs emerged as a significant tool in improving clinician confidence in delivering end-of-life care. Continuing professional development and post-registration training were reported as important ways to enhance clinician knowledge and improve the end-of-life care experiences for both health services, and patients and families.[30, 32, 41, 69] Palliative care education in the intensive care unit (ICU) setting also improved clinician experience and attitude towards palliative care principles including feeling less guilt or depression after a patients' death.[45] Several papers highlighted the need for formal and informal education to improve clinician knowledge on palliative and end-of-life care. Potential components identified include:[29, 34, 39-41, 45, 50, 59-62, 66-68]

- Symptom management
- Resuscitation outcomes
- How to present prognosis
- Cultural awareness
- Identifying bereavement supports
- Communication principles
- Legal and ethical issues in end-of-life care, including withdrawal of life support.

Six papers discussed a wide variety of clinical practice issues required to provide good end-of-life care [31-33, 37-39, 41-43, 46, 47, 52, 56, 59, 62, 63, 65, 77, 78] including:

- Advocating on behalf of patients
- Developing an advance care plan which describes triggers for when to stop, start or withdraw 'futile' life-prolonging treatment
- Conducting and documenting of any formal clinical assessments
- Establishing referral pathways for pastoral and bereavement support
- Providing practical assistance (e.g. assisting with transport, organising a place for family to sleep and personalising the hospital room)
- Identifying and using triggers for re-evaluating end-of-life care
- Making referrals to pastoral care and social workers to improve care for the dying patients
- Being emotionally prepared.

Studies suggest safe and high-quality end-of-life care requires access to and collaboration between qualified and skilled multi/inter-disciplinary team of clinicians involved in decision making.

A team-based approach is identified as being crucial in delivering quality end-of-life care.[39, 42, 48, 57, 76] Silos within the healthcare team contribute toward communication disparity and misunderstanding between disciplines and various hospital teams.[42, 72] For example, senior medical officers discuss issues with other senior medical officers because they share the same understanding of priorities, shared terminology, and increased respect for one another.[42] Effective collaboration with patient and their family can result in multidisciplinary team consensus, open communication, and the treating team being aware of patient's goals, while enabling families to feel supported.[39, 48, 62] Furthermore, structured communication processes between clinicians and implementing these into practice reduce clinician anxiety and decrease the reliance for assistance from broader hospital supports such as Rapid Response Teams (RRTs).[42]

A formalised inpatient palliative care referral system and assessment scores provide several benefits including:[33, 44, 53, 55, 63]

- Guidance for non-palliative care trained staff
- Standardised multidisciplinary collaboration
- Consistent patient clinical assessment
- Improved development of key clinical indicators relating to quality of life and depression.

There is also good evidence beyond the hospital system where inpatient specialist palliative care teams work together with the home team to facilitate patient transfer to home, with appropriate supports in place.[44, 57] Evidence indicated that patients who received an inpatient palliative care review were less likely to be readmitted into the acute care sector within 30 days of discharge.[44]

Caring for family

It is important to recognise that in Australia, a diverse population means family can be interpreted differently by people based on lived experience and culture. As such, the term family must be interpreted within the context of the individual.[13] Caring for family was identified as an essential 'quality' in the provision of end-of-life care; respect for family preferences and involvement of family members in direct care for the patient was considered vital.[34, 64, 74] Families have a major role in supporting patients throughout end-of-life care, including medication management.[31, 32, 34, 40, 43, 58, 59, 63, 77] As such, involvement of family can inform care in the acute care setting.

Involvement of family in direct end-of-life care was found to be strongly preferred among patients and family from non-English speaking and culturally diverse backgrounds.[31, 32] Nurses learnt a lot about the patient and the family dynamics when family was encouraged to share their perspective.[31, 32] However some papers described circumstances where patients or family caregivers were not willing to talk about death and dying due to cultural beliefs.[71] Addressing this issue through early communication was identified as critical to care. Good communication with the family includes:[31, 59]

- Providing an update and explaining the patient condition to family members using simple and non-technical terminologies
- Paying close attention to and understanding family needs and concerns
- Clinicians being contactable and available to provide relevant information in a timely and appropriate manner.

Critical care nurses support for patient- and family-centred care during the provision of end-of-life care influenced their engagement in practices that share control with, and support inclusion of, families at this time.[34]

Practical examples of family-centred care include:

- Giving family the opportunity to be present at the bedside to spend time with the dying patient
- Providing information about the dying process
- Ensuring emotional support and reassurance is provided.[36]

Engaging family members in direct patient care is perceived as 'indispensable' in providing comfort and emotional healing to patients[15], and understanding of family concerns related to pain, agitation and symptom management.[81] This approach ensures the family feels supported in clinical decision making and has a sense of reassurance that their loved ones are treated with dignity.[15, 81] Family feel prepared for the death with reduced bereavement stress when clinicians:

- Recognise and support the family
- Value their knowledge of the patient
- Advocate for patient needs
- Arrange structured family meetings.[15, 77]

Loss of income due to hospital admission has been ranked highly for family as a concern. Providing families with information about financial supports has been shown to reduce the family's level of distress.[15, 81]

Bereavement support

Several papers advocated for appropriate bereavement support as fundamental for a good end-of-life care experience encountered by family members of a loved one in the acute hospital setting.[40, 43, 58] Bereavement needs of families differed according to the clinical settings across the hospital system (e.g. paediatric ICU versus adult ICU). The literature recommended early assessment and supportive measures be taken to address complex bereavement needs of families, thereby minimising adverse physical and emotional responses.[43] Several papers discuss examples of clinical and non-clinical staff involvement in end-of-life care and bereavement care, including:[40, 43, 49, 58]

- Creating memories of a deceased person using photographs and handprints
- Sending sympathy cards and bereavement packs
- Assisting with memorial services
- Establishing a support group for bereaved parents
- Providing ongoing help and support from hospital staff
- Referring to professional counselling services, such as a social worker
- Offering for the family an opportunity to view the body
- Supporting bereaved families to access community bereavement services
- Organising follow-up appointments.

Some of the papers also highlighted the need for pastoral care to support bereaved family members spiritually and emotionally.[40, 63, 77] Routine referrals to pastoral care were recommended, assisting in the response to family concerns.[63] Staffing and management models of bereavement practices post-loss differed between country contexts. For example, in Australian ICU settings bereavement follow-up services have been managed by allied health (e.g. social workers), whereas in the New Zealand ICU setting such services were primarily managed by nurses.[43] In addition, studies noted that duration of ongoing support for bereaved families varied consisting from several days after the death, to years.[40, 58, 67] An Australian paper described the challenges of bereavement follow up including lack of bereavement coordination roles within the acute care system, as well as financial and logistical constraints.[67]

Results of the pandemic literature review

Selection of papers

Figure 3 in Appendix 6 shows search results in a PRISMA Flow Diagram with the findings reported following the PRISMA checklist.[17] A total of 212 citations were retrieved in Medline (n=126) and CINAHL (n=86) databases and deduplicated. The remaining 165 studies were exported into Covidence and initially reviewed for eligibility by title and abstract. Following the screening process, 20 were found initially to be eligible for inclusion for the full-text review. Subsequently 10 papers were included after full text review (Table A2 in Appendix 8).

The selected papers are from the USA (n= 4), with one each from India, Italy, Singapore, France, England and Canada. Eight out of 10 papers relate to the COVID-19 pandemic, with one related to SARS, and one to influenza. Among the selected papers eight were classified as Level V of the evidence hierarchy, while the remaining two were classified as Level III. Most papers (n=6) were deemed of poor quality as they were not fully described, not necessarily studies and mostly descriptive/a summary of interventions.

Identification of themes

Four broad themes relating to end-of-life care delivery considerations during a pandemic were determined (see Table 5).

Table 5: Pandemic themes

Theme no.	Themes	Sub-themes
2.1	Technological innovations	Benefits and risks to using technology; strategies to implement technology into practice
2.2	Delivery of care	Clinician stress including burnout, high workloads; difficulties faced by changes in hospital guidelines, such as limiting visitors; strategies to innovatively deliver care considering the obstacles
2.3	Person-centred care	Providing person-centred care when the impact of the pandemic is unknown; understanding and documenting goals of care conversations, including how to conduct them
2.4	Family grief	Challenges in connecting with the patient and their care team can lead to a range of tricky issues for families to navigate

Technological innovation

Technological innovation emerged as a major theme in relation to safety and quality in end-of-life care delivery during pandemic. Utilisation of innovative technologies (such as telehealth):[83-88]

- Reduces the risk of infection transmissions between patients, carers and healthcare workforce, through providing physical spacing between clinicians and the people they are caring for and avoidance of unnecessary hospital visits
- Eases the pressure on the healthcare system, by freeing up workforce and resources to manage those patients most in need of acute care
- Improves patient outcomes when used for communication, counselling, and disease monitoring
- Provides better access to palliative services through reaching out to vulnerable patients, and building rapport with family and relatives
- Prevents illness across the clinical workforce, enabling them to provide continued care as a 'first responder or bedside provider' during crisis
- Enhances workflow by involving clinical staff and family in interactive virtual care planning meetings
- Provides the only medium for many families to remain connected with people admitted to hospital, in the face of restricted visits to the hospital during pandemic.

Considering the increase in people with palliative care needs during pandemic, hospital tele-palliative programs were quickly adopted by health service organisations.[84, 87, 88] Tele-palliative consultations included triage assessments of patients, chart-based e-consultations for patient symptom management, and remote consultations with hospitalised patients. Use of free wi-fi as well as technologies with audio-visual functions – such as smart phones, tablets, and computers – made the care process more dynamic and effective. For example, smart tablets are used by outpatient palliative care clinical teams to conduct 'video visits' remotely with their hospitalised patients, supporting continuity of care.[87]

Providing support for family during a pandemic is also essential through the use of smart phone applications (apps), online webinars, e-family meeting and video support groups such as 'virtual hubs'.[84-86] For example, instant messaging apps and video conferencing apps were used to engage family members in a 'three way conversation' between family, clinician and patient to share progress updates and to support end-of-life clinical decision making.[84-86]

Application of technology during pandemic posed some unique challenges. Communicating with patients and families via technology was profoundly different from face-to face consultations. One article discussed the distress for families at seeing a 'loved one' actively dying or in a critical condition online[83]; for family at home connecting to technologies in the hospital setting, their memory of the patient may be different to the view on the screen. Long waiting lists for tele-palliative appointments, technological glitches, and poor technological literacy of patients and families presented significant barriers in patient care.[88] Further, clinicians who would normally rely on 'nonverbal cues' to guide end-of-life conversations, struggled to connect emotionally in tele-palliative consultations.[87] For families needing to make decisions remotely, comprehension of information about disease processes and treatment options was more challenging when discussions could not be conducted face-to-face.[83]

Strategies documented in the literature to overcome these challenges include:[83, 87, 88]

- Working closely with patients and families to understand their needs
- Incorporation of technologies early in care to help the family to become used to it prior to deterioration of the patient
- Ensuring a well-lit environment
- Providing a good internet connection during the consultations.

Strategies that specifically support the healthcare workforce include:[84, 85, 87, 89]

- Making equipment (with WiFi enabled plans) available to families
- Creating (or repurposing of) information leaflets to introduce family members and the patient to the concept of videoconferencing and suggestions of when this technology may be used
- Developing guidance and 'real-time' training aimed to improve tele-palliative skills of clinicians
- Having a dedicated clinical staff member contact families
- Integrating interpreter services into communication via video technology
- Adopting technology into the clinical workflow processes.

Care delivery

Pandemics created significant challenges for delivering person-centred and family-centred care in the acute hospital system. The major challenges highlighted in the literature include:

- Disruption in continuity of care
- High workloads
- Staff working in areas in which they are unfamiliar
- Staff stress and burnout
- Rationing of resources such as personal protective equipment (PPE)
- Uncertain nature of the pandemic's impact on people with multimorbidity.[83, 84, 86, 87, 89-91]

These challenges are overlayed with a high intensity of emotion from patients, families and health care professionals.[89] During the pandemic, multidisciplinary teams can be fragmented, working in different teams from different locations.[90]

Provision of good end-of-life care becomes difficult during pandemic due to restrictions on how clinicians can interact and communicate with patients and families. This may include prohibiting touch, limiting opportunities to connect with families and introduction of risk containment measures for providing routine care (for example, mouth care) to dying patients.[85, 90] The wearing of PPE, making staff unrecognisable, augmented many of the communication and interaction issues.[90] Such restrictions to human interactions highlight the sense of patient isolation.[83, 87] This sense of isolation drove earlier discharge from the acute sector than planned in some jurisdictions.[86] Furthermore, during pandemics clinicians were uncertain about treatment options due to limited availability of information.[87] Reports of patients dying alone without any relatives present – due to restrictions in visiting hospitals – meant that care for both patients and their families was particularly challenging during a pandemic.[86, 90]

Given the shift in workload during pandemic a quick and innovative clinical approach was often needed, particularly in the screening and triaging of patients. Some papers identified the need to have a surge plan (for example, Palliative Pandemic Plan) to help with symptom control, comfort care, staffing and prioritisation of anticipated increases in patient demand.[88, 89, 91] Lack of equipment (such as ventilators) was reported in some overseas studies leading to forced decisions around access to certain intensive care measures.[89]

Part of the ‘surge plan’ a ‘4S’ model of pandemic preparedness included considerations for:

- **S**tuff (for example, quarantining of essential mediations and equipment)
- **S**taff (for example, training of acute health care workers on palliative care)
- **S**pace (for example, expansion of ICU capacity)
- **S**ystem (for example, triaging of patient care).[91]

Additionally, development of the workforce through training for improved communication skills with dying patients, programs to promote self-care, standardised clinical protocols for communicating needs, and provision of palliative care and symptom management, were identified as crucial elements in end-of-life care for pandemic.[88] Also, upskilling of staff who are redeployed and additional training covering infection control, legal arrangement after death, and bereavement support is essential for appropriate end-of-life care in pandemic.[85]

A number of papers highlighted that streamlined processes of care were essential in managing critical patients in hospitals during pandemic.[84, 85, 89, 92] This included:

- Delegating one person to communicate with the patient’s family
- Coordinating with bedside nurses to determine optimal time for a ‘remote visit’ by family
- Using electronic support and decision aids to assist clinicians less familiar with palliative care to adopt new skills and workflow
- Task shifting from highly trained to less trained clinicians and use of trained volunteers to provide companionship and psychosocial support.

Three papers described new models that facilitated good end-of-life care with improved communication, better patient outcomes enabling rapid identification of patient needs, and developing new skills and knowledge base.[85, 89, 92] These models include:

- A dedicated ‘link nurse’ provided palliative care training to general acute care team and linked them to their local specialist palliative care team for advice and referral where necessary[85]
- A centralised, multidisciplinary geriatric evaluation unit – comprising a geriatrician, an emergency specialist, infectious diseases specialist and a palliative care specialist – where telephone support was provided to a range of generalist teams across the acute care a primary care sectors[92]
- Providing a palliative care presence in the emergency departments and intensive care units to encourage goals of care conversations.[89]

Person-centred care

Individualising care for people living with a life-limiting illness during a pandemic was discussed in detail throughout the literature. People living with a life-limiting illness were described as more vulnerable to contracting the pandemic-specific illness and were more prone to complications (including death).[88] This was compounded by the presence of unique diagnostic challenges. Patients with infection commonly presented with nonspecific symptoms such as fever, cough, and shortness of breath – with similarities to symptoms associated with life-limiting illnesses, including lung cancer and Chronic Obstructive Pulmonary Disease.[88]

For people contracting the pandemic-specific illness, articles described a range of measures to assist in individualising care, including:[89-91]

- Identifying patients at risk of dying
- Understanding the risk factors of infection associated morbidity
- Documenting goals of care (GOC).

The literature described significant challenges in conducting and documenting GOC discussions and how to manage deteriorations in health and possible withdrawal of intervention. This was particularly apparent when outcomes were either unknown or uncertain.[83, 89] In some circumstances, family expectations of treatments (despite poor evidence) significantly affected how the person's wishes were enacted.[89] A range of techniques were encouraged to describe the options for care in an environment of uncertainty including scripting of challenging conversations and use of innovative resources (for example, Vital Talk COVID Communication Resources) to convey information to families repeatedly and using plain language during shared decision making.[83, 89]

Some of the papers identified mechanisms for completing advance care plans with patients in isolation. This involved starting conversations early in the admission (for example, in the emergency department) and identifying patients for formal palliative care consult.[89]

Grief

Several papers discussed the impact of a pandemic on grief experienced by the family caring for someone with life-limiting illnesses.[89, 90] Grief in the context of a pandemic is complicated by: [83-87, 90]

- Restrictions on the number and length of time visitors could access the acute hospital setting
- Emotional burden of care
- Ongoing trauma when forced to be absent from the patient's bedside
- A 'disruption to connectedness' – infection control precautions getting in the way of how families could touch or hold their loved one
- Immediate cremation or burial of bodies ruling out the opportunity for culturally appropriate rituals
- Knowing that the person is alone in the last days or weeks of life, with unfamiliar people and surroundings
- Family not being present as the person dies
- Families making treatment decisions remotely.

To support families to cope with unexpected deterioration in their loved one, a paper described a process of clinicians describing the patient's current 'visual condition' to the family before videoconferencing with the patient.[89] In doing so, the health care teams needed to be prepared to deal with the intensity of emotional responses from family members who were unable to be at the bedside when patients entered the terminal phase.[89] Given the unexpected and confusing situations surrounding pandemics, families needed the healthcare team to be personable, vulnerable, and present.[83]

Results of the grey literature review

Selection of documents

From the structured searches 18 documents were retrieved and have been included (see Tables A3a–A3c in Appendix 8). Ten of the documents were relevant to end-of-life care generally and three were related to end-of-life care during COVID-19. The rest (n=5) were conference abstracts. The documents varied and included policies, clinical guidelines, strategies and reports.

Initial search

Care delivery

- *Care Plan for the Dying Person: Health Professional Guidelines*[93]
- *End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients*[94]
- *Pharmacological Management of Symptoms for Adults in the Last Days of Life Clinical Guideline*[95]
- Communication tips for clinicians supporting patients and family facing life-threatening illness / infection (COVID-19)[96]
- Symptom management for adult patients with COVID-19 receiving end-of-life supportive care outside of the ICU[97]
- Palliative Care, Section 20, Clinical Guidelines for the management of COVID-19 in Australasian emergency departments.[98]

Policy and position statements

- Palliative and end-of-life care: position statement, St Vincent's Health Australia[99]
- End of Life and Palliative Care in the Emergency Department Policy.[100]

Guidelines/strategies

- Palliative Care Service Development Guidelines[101]
- WA End-of-Life and Palliative Care Strategy 2018–2028[102]

Reports/white papers

- *Life Before Death: Improving Palliative Care for Older Australians*[103]
- *End of Life Care in a sample of Regional and Rural NSW – what is the current situation and what are the problems?*[104]

Conference abstracts

The conference abstracts represent four conferences: Palliative Care Australia (PCA) 2017, Palliative Care Nurses Australia (PCNA) 2018, Australia New Zealand Society Palliative Medicine (ANZSPM) 2018, Australian Grief and Bereavement Conference 2018, and Palliative Care Australia (PCA) Oceanic Conference 2019.

- Price and colleagues detail a 'Last days of Life toolkit' to improve the care of dying in a NSW hospital. A local initiative that targeted junior medical officers, a group often overlooked[105]
- The work presented by Hughes was in relation to acute bereavement in the mortuary. This unique perspective describes the work of a social worker in this arena and provides a broader application than that of end-of-life care alone[106]

- Rane's abstract also looks to junior medical officers but in respect to their wellbeing in the face of death and dying, describing a pilot program positively evaluated[107]
- Education has been identified as needed across the board in this review and Swensen's abstract describes a successful way of addressing ongoing staff education needs via a Facebook group. This potentially allows attendance by those working across the 24-hour period such as night duty[108]
- Lacey describes a new model of care – that of rapid response services to patients identified as dying provided by an end-of-life care nurse practitioner (NP).[109] Approximately seventy percent of patients who died were referred to the NP, rather than to the traditional ICU-led rapid response teams. This role is akin to that of a hospital palliative care team or palliative care nurse who if hosted onsite may also provide this type of service. Visiting palliative care consult teams may not be able to be as responsive so a role such as this allows immediate support to treating teams.

The grey literature has not been formally peer reviewed necessarily and is heterogeneic in nature.[110] Included here are conference abstracts which may relate to a poster or a paper presentation, and while are peer reviewed will be within the remit of conference aims. Grey literature is useful in this review to build upon the main review and to contribute information (new insights, new models) that have not been captured elsewhere, in this case as a result of the inclusion and exclusion criteria.[110]

State- and territory-level palliative care programs and initiatives

The state and territory government departments of health are responsible for funding specialist palliative care services across Australia. Some recent initiatives relevant to hospitals are included in Table 6.

Table 6: State- and territory-level palliative care programs and initiatives

Government	Key components
State Government of New South Wales **Palliative care programs and initiatives – Palliative care in NSW**[111]	**2018–19 initiatives** • 27 new positions for social workers, allied health and Aboriginal Health Workers to support patients and families • Improved access to palliative care services to support people with a culturally and linguistically diverse background and people with disability • Projects to support service redesign aimed at improving patient care and promoting integrated care • Scope the needs of carers and develop options to leverage existing support programs for carers of people receiving palliative care • Support for volunteer services. **2017–18 initiatives** • An additional 30 palliative care nurses providing care in hospitals, homes and nursing homes • Funding for workforce training and development • NSW Community Pharmacy Palliative Care Initiative to improve medication management for palliative care patients.

Government	Key components
Northern Territory Government **Palliative care programs and initiatives – Territory Palliative Care Services**[112]	Territory Palliative Care (TPC) provides palliative care services to the Northern Territory. Its two teams are based in Darwin and Alice Springs. TPC cares for inpatients (hospital and hospice) and outpatient / community patients. This care is for patients with a life-limiting diagnosis in the last months of their lives. The Top End TPC services operates from the Hospice, which is a 12-bed stand-alone unit within the Royal Darwin Hospital campus. Inpatient and outpatient, including rural and remote, palliative care teams are based here. Central Australian services provide inpatient support to patients in Alice Springs and Tennant Creek Hospitals. It also provides outpatient support to patients at home (urban or remote) or in aged care facilities. This can be supplemented with attendance at the respite day care house based in Alice Springs.
Queensland Government **Palliative care programs and initiatives – The Metro South Palliative Care Service**[113]	• In-reach medical consultancy • Inpatient public palliative care beds at select hospitals.
Government of South Australia **Palliative care programs and initiatives – Palliative Care Services**[114]	Specialist palliative care teams work in a consultative role with general practitioners and other health care providers when these needs cannot be met by primary care teams, across a range of health care services, from hospitals, hospice care, or in the community such as home or residential care.
Tasmanian Government **Palliative care programs and initiatives – Palliative Care Services**[115]	Palliative care services and initiatives in Tasmania include: • Major hospitals • The Palliative Care Service is available in all Tasmania's major hospitals. Specialist doctors and nurses provide advice on pain and symptom management and emotional support. They work with other hospital staff to provide care for the client and family.

Government	Key components
Victoria State Government **Palliative care programs and initiatives – Accessing palliative care**[116]	A range of specialist palliative care services available within Victoria offering advice, information, referral and support for a person with a life-threatening illness, their family, friends, carers and health professionals. These include: • Inpatient palliative care: provides care to patients who require complex symptom and pain management or end-of-life care. Palliative care beds are located within acute hospitals as part of purpose-built subacute units or services, and as stand-alone services • Consultancy teams: provide advice, support, education and training to treating teams in hospitals, across acute and subacute services, to outpatient clinics and to community palliative care services • Outpatient clinics: provide interdisciplinary assessment, care planning and interventions early in the care pathway of a person diagnosed with a life-threatening illness.
Government of Western Australia **Palliative care programs and initiatives – Specialist palliative care services**[117]	• Outpatient clinic comprising: comprehensive assessment, care planning and co-ordination, symptom management, access to multidisciplinary team, psychosocial support for patient and family, and shared care with other care providers • Consultation – facilities (residential care) and hospital – comprising: comprehensive assessment, care planning and co-ordination, symptom management, access to multidisciplinary team, psychosocial support for patient and family, shared care with other care providers, advisory/educational support to doctors, nursing and allied health care workers, terminal care, and bereavement support • Rural and regional services: The WA Country Health Service provides rural and regional specialist palliative care teams across the seven regions of country WA. The service types vary from region to region and include consultation services (nurse-led and visiting palliative care specialist physicians), outpatient clinics in large regional towns and community services.

Other important initiatives

Some other important initiatives include:

- The National Palliative Care Strategy which 'is intended to be used by all Australian governments, as well as organisations and individuals, in guiding the improvement of palliative care across Australia so that people affected by life-limiting illnesses get the care they need to live well'.[12] The document includes vision, guiding principles, goals and information on implementation and evaluation and should be considered and recognised in any service, plan, or policy developments

- The National Palliative Care Program, a group of Australian Government Department of Health national palliative care initiatives and programs. 'These initiatives and programs mostly focus on education, training, quality improvement and advance care planning'.[118] Within these major projects one speaks directly to End of Life Care in Hospitals (End of Life Essentials), but others will have relevance to care provided anywhere including acute settings (for example, palliAGED, Talking EOL for people with an Intellectual Disability, Advance Care Planning Australia, Palliative Care Outcomes Collaboration). Other projects will speak directly to the intersect between and across settings, with relevance to the pathways and journeys that patients often take moving in and out of the hospital setting (such as Greater Choice for at Home Palliative Care Measure, Caring@home project).

There are other relevant organisations providing information and resources on end-of-life care in hospitals and other important considerations:

- The NSQHS Standards, 'which provide a nationally consistent statement of the level of care consumers can expect from health service organisations'.[8] Within this is the Comprehensive Care standard which details comprehensive care at the end of life (Actions 5.15 to 5.20). As an adjunct to this, the End-of-Life Care Audit Toolkit 'is designed to help health service organisations to examine and improve the quality of their end-of-life care'. These initiatives are in place to support those working directly with quality improvement initiatives such as managers, executive staff, and clinical leaders. Also to note, is the development of the 'National consensus statement: essential elements for safe and high-quality paediatric end-of-life care' developed in 2016, in acknowledgement of the differences required in the care of children at the end of life.
- Voluntary assisted dying has emerged in the grey literature in the context of Australian state laws and in clinical practice in Australian hospitals. At the time of this review voluntary assisted dying (VAD) has been legislated only in the Australian state of Victoria (2017)[119], although it is planned to be introduced into Western Australia in 2021 with other states and territories likely to follow. As VAD is introduced into different health care settings including hospitals, each health service will need to decide whether this is something that they could offer. There are implications for all staff involved in the care of someone at the end of life in a hospital that offers VAD, including training for medical practitioners and other health professionals who choose to participate. A State-wide Voluntary Assisted Dying Care Navigator Service has been established 'to provide information and support regarding voluntary assisted dying for the community, health practitioners and health services across Victoria'.[119] This is potentially a model of care that can be adopted elsewhere.

There is a plethora of information and resources in the grey literature relative in some way to end-of-life care in acute hospitals. Some resources will be directly specific to end-of-life care in hospitals and others will have concepts of hospital end-of-life care incorporated in their development or will allude to it. Each organisation will have their own agenda when developing documentation so they are relevant locally and implementation more broadly will need careful consideration.

Discussion

This review of the literature set out to identify contemporary safety and quality issues in the delivery of end-of-life care in the acute care sector, as well as considerations in the provision of end-of-life care in a pandemic, and key documents pertaining to end-of-life care in the Australian grey literature. Overall, nine themes have emerged from this review of the literature. Most of the selected papers were sourced from Australian studies and from other major OECD countries including USA, UK, Canada, France, Italy, Belgium, Portugal, and Ireland.[120] Despite the diversity in healthcare systems[121], themes reflected across this body of literature indicate similar issues relating to the delivery of end-of-life care in acute care both here in Australia and across the globe. The findings of this review can inform understanding and approaches to planning and delivery of end-of-life care in the acute care setting and add to the existing evidence base for Australian healthcare guidance.

The different search approaches identified common and unique evidence and issues, and highlighted the value of a specific pandemic search and environmental scan in retrieving functional considerations as well as research assessments relating to end-of-life care. The organisational readiness in the main review and the technological innovation in the pandemic review emerged as unique categories that complement each other. Organisational readiness comprised of two parts including the physical spaces that care was provided and the organisational elements in place to ensure the workforce was supported to deliver end-of-life care. An urgency in healthcare response during the pandemic, drove technological innovation in clinical service delivery in unprecedented ways. For example, a recent Australian Government initiative extended a number of Medicare items to deliver telehealth services by phone or video conferencing providing protection for patients and health care providers.[122]

Similarities across themes were also observed, particularly aspects of person-centred, and family-centred care delivery were common in both the main review and pandemic review. Some of these commonalities include tailoring care based on individual patient needs, engaging family in clinical decision making and supporting family with grief, loss and bereavement needs.

Many of the studies acknowledge the implications for policy and end-of-life care practice in the acute Australian healthcare context relating to a growing aged population, many of whom will die in hospital. This growing aged population places pressures on care delivery in the acute setting and organisations need to be able to respond to this increased demand while reducing complications. The review highlights responses to these pressures including technology use (for example, as noted in this review in the COVID-19 telehealth initiatives), exploratory (pilot) models of care (for example, outreach), shared care, and the role of individual practitioners in change initiatives (for example, link nurses, social workers in the mortuary, or specialist Nurse Practitioners in hospital response teams). Such examples offer potential solutions to immediate needs for care as well as ways to co-ordinate and integrate end-of-life care over time.

The physical and the organisational environment of the acute care setting influenced end-of-life care. Spaces in which end-of-life care is delivered both at the bedside level and for broader family cultural activity have been identified as a critical element in providing both safety and quality of the care provided. More broadly, the organisational environment in terms of policy and procedures as well as organisational culture influence clinical behaviour and the capability and willingness of health professionals to not only provide comprehensive symptom management clinical care but to engage in complex emotional discussions and interactions. End-of-life care will need to be provided through a whole-of-organisation approach to enable comprehensive responses across the workforce and the care environment with an appropriate focus on implementation and change management.

The evidence also reinforces that the acute care sector is part of a broader more complex healthcare system. As such there are implications on how the acute care workforce communicates with teams in other organisations either in discharge planning or in follow up bereavement supports for the family of the deceased. A public health approach to bereavement support has been emerging in palliative and end-of-life care in recent years that requires working in partnership between tertiary, secondary and primary care health professionals.[123, 124] This partnership can be strengthened building on existing links with community groups and services by providing information about bereavement and making appropriate referrals and follow-up.[123] A range of consumer information resources pertaining to death and dying are currently available by relevant state and territory departments of health in Australia to support this process.[125-130] However, a comprehensive suite of information resources supporting the population health approach to bereavement care in palliative and end-of-life care settings within the acute care setting would be useful.

There is evidence in the literature to emphasise the need for appropriate end-of-life care for underserved populations. This speaks to the themes on person-centred care and care delivery. Person-centred care recognises the need for providing whole of person compassionate care considering their current circumstances and can cover pragmatic issues such as food choices to religious requirements and communication preferences. While this review identified several papers pertaining to end-of-life care needs for people from CALD communities, it is likely that these issues will apply to other underserved communities[131], including:

- Aboriginal and Torres Strait Islander Peoples
- Care leavers and people affected by forced adoption
- People with disabilities
- People experiencing homelessness
- People who identify as lesbian, gay, bisexual, transgender or intersex
- People who are incarcerated
- Refugees
- Veterans.

Organisational support is crucial to expand on the culturally, linguistically and socially appropriate care delivery to the underserved populations in Australia through development and implementation of appropriate protocols and guidelines.

The training and education of the multidisciplinary workforce is paramount, to overcome the biases and lack of understanding that many clinicians exhibit, as articulated in the theme on clinician capacity. Often clinicians lack confidence or are reluctant to initiate early conversations about death and dying due to a knowledge and skills deficit in end-of-life care. Rather, consistent with other studies, this review also noted that clinician focus is mostly on short-term care assuming that active treatments and clinical investigations are always in a patient's best interest.[132] Challenges in open and honest communication have been widely identified as a significant factor for providing quality end-of-life care within hospital.[29, 39, 45, 61, 133] Insufficient experience of clinicians in end-of-life care can also exacerbate delays in referrals of patients with life-limiting illnesses to early palliative care causing distress to both clinical teams, and patients and families.[45] This observation reinforces the need for a comprehensive program of education that acknowledges end-of-life care as a critical component of initial and continuing education.

The family is an important unit of care and systems should consider their perspective both while the patient is alive and into the family's bereavement. Personal beliefs and knowledge about death and dying among family caregivers (as substitute decision makers) influence meaningful conversations between clinicians and family in end-of-life care decision making. This has been particularly prevalent in studies that involved patients and families from non-English speaking and diverse cultural background. Specific issues such as the 'cultural taboo' of death and dying and the view of end-of-life care seen as 'giving up' or 'losing hope' warrants patient and family tailored clinical service delivery. Similar to the findings from other studies, lack of knowledge on death and dying among family caregivers as substitute decision makers highlights the need for public education on end-of-life care.[134] Also, to be considered is the grief of family prior to death, identified as especially relevant in a pandemic where direct personal contact or intimacy may not be allowed, compounding the grief already expected at the impending death of a loved one.

While technology has become useful in the delivery of good end-of-life care, particularly in the current COVID-19 pandemic, organisations will need to ensure that processes and standards are in place to ensure effective integration of technology into processes and systems. There may also be specific issues and considerations in implementing technology in end-of-life care processes. For example, remote communication using smart tablet/video conferencing may be applied as a temporary measure during emergencies, but should not substitute the bedside presence and personalised face-to-face care.[86]

The grey literature has highlighted some of the gaps that were not in the main literature review and include the issue of hospital rapid response teams and their role in end-of-life decision making in instances where inter-team communication has failed. The grey literature has also identified a wide range of end-of-life care resources including clinical evidence, communication modules, training resources, information on population diversity, and patient and family resources. These can be readily taken up as part of change processes within the hospital setting.

National audit tools in alignment with the actions of the NSQHS Standards would be of benefit. Change needs to be supported at an organisational and even regional level. For example:

- To introduce and embed resources aimed at supporting the multidisciplinary workforce to work collaboratively through standardised processes (auditing tools) would require support from senior managers
- Education and training for the workforce demands a whole-of-organisation approach
- Strengthening linkages between community, hospice and hospital palliative care teams would support continuation of care for patients with life-limiting illnesses but would require agreements between disparate service approaches.

Finally, several papers reviewed discussed the challenges of implementing change.[39, 48, 61, 63, 64] The studies recognise that the value of evidence is in its use. With hospitals funded predominantly at the state or territory level, implementing, and embedding evidenced based practice consistently across Australia can be challenging. Even with extensive resources devoted to research, the published literature is filled with examples of delayed and disorganised transfer of research findings into practice.[135] Given a lack of translation, patients and their families can be subjected to ineffective or harmful behaviours and treatments.[135]

Strategies and tactics arising described within the Knowledge Translation literature can inform implementation while addressing the local context to which it is being applied. Collaboration between the researchers and the implementers is important in supporting translation.[135, 136] Leaders have an important role in supporting a culture that addresses effective change and the use of evidence to guide care.[137]

Limitations

This review was a resource limited and time bound analysis. While the construction of the searches was robust and informed by content and research experts in the field, the literature review search was only applied within two electronic databases (although we used the databases that contain by far the largest number of health and medical journals). The decision to limit retrievals to systematic reviews, RCTs and Australian studies may have prevented relevant studies being considered. Restricting to English only articles may also have eliminated relevant evidence.

It should be noted that given the urgent need to share studies during the pandemic, study quality has been affected. Many were of poor quality with study details not fully described, and most being only descriptive in nature. The pandemic studies also only described what was critical at the time rather than being considered pieces about end-of-life care in acute settings during a pandemic situation.

Most Australian papers retrieved were graded to Level III in evidence hierarchy and no Australian papers were graded at Level I. Hence caution needs to be exercised in considering transferring and scaling findings from Australian studies given types of studies being reported. Future research should consider well designed intervention studies in end-of-life and palliative care in the Australian acute health care setting.

The rapid review methodological approach therefore requires the conclusions and recommendations to be approached with caution, acknowledging that the findings are not exhaustive, and that some appropriate, relevant literature may not have been included. For example, the review included only a few papers that provide information on models of care such as the end-of-life care provided by hospital rapid response teams, end-of-life care provided in shared care models and the role of hospital based palliative care teams. This is possibly due to the lack of published systematic reviews or randomised controlled trials captured in this rapid review.

Recommendations

The following recommendations have been developed from the review of evidence presented in this report in the context of the Commission's extensive work relating to the delivery of safe and quality care for people approaching the end of their life in the context of health service organisations.

Recommendation 1

That the Commission consider revising the *National Consensus Statement: essential elements for safe and high-quality end-of-life care* to include:

- The addition of four new elements:
    - Processes of care
        - communication, including using plain language when updating family on someone's condition
        - bereavement, including paying attention to the family's own unique needs (not as proxy for patient)
    - Organisational prerequisites
        - organisational culture, including facilitating cultural change about the role and priority of end-of-life care in health service organisations
        - physical space to meet the individual needs of the patient (privacy) and the family (including spaces were families can gather)

- Cultural sensitivity and diversity
- A definition of family, for example, Relationships Australia define family as:

    > made up of anyone a person considers to be their family. A family shares emotional bonds, common values, goals and responsibilities. Family members contribute significantly to the wellbeing of each other.

- Minimum standards for the delivery of end-of-life care services across different health service organisations
- Addressing variability in health literacy and understanding the needs of underserved communities in the Education and Training element
- Strengthening the Person-Centred Communication and Shared Decision Making element by emphasising the importance of the role of the family, and their needs, in end-of-life discussions and:
    - Promotion of early referrals and utilisation of existing support services within the acute sector such as interpreters and pastoral care workers in end-of-life care to actively engage with families throughout the dying process
    - Development and facilitation of meaningful communication strategies to support the multidisciplinary workforce in engaging with patients and their families when providing care at end of life
- Strengthening the Systems to Support High-quality Care element through shared care models with palliative care teams and incorporating on-site (not visiting) specialist palliative care liaison teams or an organisation-wide reference point (for example, an end-of-life care NP role)
- Strengthening the Leadership and Governance element to support increased visibility of end-of-life and palliative care services
- Consideration of care of the body after death.

Recommendation 2

That the Commission consider a new strategy to support health service organisations to understand the importance of, and implement, the Consensus Statement.

In doing so the Commission may consider as part of their dissemination strategy, development of resources to support health service organisations to:

> Update local policies and procedures to strengthen the understanding of the role of family in end-of-life care

- Include appropriate training and support for the multidisciplinary healthcare workforce by articulating expectations and role in end-of-life care in ongoing Continuing Professional Development
- Access nationally recognised education and training opportunities including:
    - End-of-Life Essentials
    - The Program of Experience in the Palliative Approach (PEPA) project
    - The Palliative Care Curriculum for Undergraduates (PCC4U) project
    - palliAGED
    - CareSearch
    - End of Life Law for Clinicians
- Identify patient areas with high death rates to target quality and safety improvements appropriately
- Tailor end-of-life models of care, with the support of specialist palliative care services (where available)
- Promote liaison with specialist palliative care where available
- Promote bereavement support resources for both families and the multidisciplinary healthcare workforce

- Recognise the importance of incorporating cultural sensitivity and diversity awareness into training and processes which support the multidisciplinary clinical workforce in engaging with patients and their families when providing care at the end of life
- Promote whole-of-organisation integrated approaches to end-of-life care into governance structures
- Promote the Communicating for Safety portal to improve uptake of existing resources that support the sharing of information via standardised clinical handover, shared decision making and facilitating multidisciplinary family meetings
- Support the development of organisational-wide policies, procedures, and guidelines to improve consistency of end-of-life care across specialties
- Implement appropriate education programs
- Promote early discussions on end-of-life care
- Promote development of clear referral criteria or pathways for referral to specialist palliative care
- Promote use of advance care planning tools.

Recommendation 3

That the Commission consider development of a clinical care standard for bereavement care.

Consideration should be given to how health service organisations:

- Identify local community support resources for bereavement referrals
- Develop partnerships with NGOs to provide ongoing bereavement care
- Co-develop bereavement models of care according to clinical settings, for example, paediatric and adult ICU models.

Recommendation 4 (from the pandemic review)

That the Commission consider assessing the contribution of innovative digital technology and equipment in end-of-life care processes, and provide the sector information to support best practice for the utilisation of technology in the delivery of end-of-life care.

Consideration should be given to how health service organisations:

- Embed ways to capture the patient experience using technology to improve communication with the patient's family
- Provide patient and family information on the use of technology
- Provide training for the multidisciplinary healthcare workforce on how to use technology
- Use video conferencing when patients are rapidly deteriorating and family are unable to be present at the bedside
- Introduce technology to the family early in the admission.

Recommendation 5

That the Commission examine the review findings for implications for the End-of-Life Care Audit Toolkit and consider liaising with stakeholders to identify gaps in the audit toolkit and possible opportunities for new components.

Additional modules for consideration could include:

- Review within hospital place of death and cause of death to identify priority areas
- Assessing patient, family and decision-maker satisfaction and experience

- Integration of bereavement support for families and carers
- Enabling inclusive care of diverse groups
- Facilitating family and carer participation thorough technology.

Conclusion

With a growing, ageing population that will continue to die in hospitals, there are several implications for policy and end-of-life care practices in this context. Recognition of the importance of end-of-life care is required as an important first step to enable improvements in the quality of care delivered to patients and their families. Organisational readiness to deliver safe and culturally appropriate quality end-of-life care is pivotal to the success of these initiatives. The findings in both the main review and the pandemic review show that without this level of organisational engagement, the required changes in the way in which care is delivered (such as person-centred care, care of family, technological innovation) at both the team and individual level will mean that safe and quality care will be harder to achieve. Increasing pressures on care delivery and a need to provide responsive person-centred end-of-life care places the spotlight on health service organisations to ensure that teams and individuals are supported and enabled to provide care. This is especially true now that end-of-life care is subject to quality assurance mechanisms of the NSQHS Standards (2nd edition): comprehensive care.

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Appendix 1: The research team

- Ms Deb Rawlings (Chief Investigator) is a senior lecturer with over 30 years' experience in palliative care and end-of-life care. She is an experienced researcher and educator and a chief investigator on the End-of-life Essentials project at Flinders University.
- Professor Jennifer Tieman (Associate Investigator) is the RePaDD director and has research leadership and expertise in Palliative and end-of-life care and in bibliometrics, search filter development, health retrieval processes, and in complex reviews and appraisal.
- Associate Professor Kim Devery (Associate Investigator) is the Clinical Lead for the academic postgraduate studies program with research leadership and expertise in Palliative and end-of-life care. She is lead investigator on the End-of-life Essentials project.
- Mr Paul Tait (Project Manager) has 30 years' experience working in a variety of roles across the Australian acute healthcare system. Mr Tait is a Project Officer for the CareSearch and ELDAC (End of Life Directions for Aged Care) Projects at Flinders University. He is also the Lead Palliative Care Pharmacist at the Southern Adelaide Palliative Services (SAPS) at Flinders Medical Centre.
- Dr Amal Chakraborty (Research Assistant) has almost 20 years of experience working in Australia and overseas in research and evaluation of projects, quality improvement initiatives, reporting, and community health and education programs development. He is a research assistant with the CareSearch and ELDAC projects at Flinders University.
- Ms Sue Hammond (Health Research Librarian) is a reference librarian and works as a health research librarian with the ELDAC and CareSearch project at Flinders University.
- Ms Wendy Jansen (Clinical Reviewer) is Nurse Practitioner, NHMRC Fellow and a Senior Clinician in Palliative Care at Northern Adelaide Palliative Services and she provided clinical expertise and support.

Professor Tieman and Associate Professor Devery provided in-kind support to the rapid review study. As Chief Investigator, Ms Rawlings was responsible for the oversight of the entire project and for the management of university processes. Ms Rawlings liaised with the Commission during the review process. Mr Paul Tait, Dr Amal Chakraborty, Ms Deb Rawlings, and Assoc Professor Devery screened and identified the selected papers with inputs from Ms Sue Hammond. Mr Tait and Dr Chakraborty extracted qualitative data and synthesised findings. All research team members contributed to drafting and finalising the report.

Appendix 2: Peer reviewed search strategy – Main review

Database(s): Ovid MEDLINE(R) and Epub Ahead of Print, In-Process and Other Non-Indexed Citations, Daily and Versions(R) (Search conducted 8 July 2020).

Search #	Query
1	exp hospitals/ or hospital*.tw,kf.
2	((acute or intensive or emergency or critical or coronary or respiratory) adj (care or ward* or department* or unit* or room*)).mp.
3	Outpatient Clinics, Hospital/
4	(inpatient* or outpatient* or icu or icus).tw,kf.
5	1 or 2 or 3 or 4
6	(Terminal care or life support care or end of life or palliative or terminally ill or advance care plan* or advance directive* or grief or bereavement or resuscitation order*).tw,kf.
7	Palliative care/ or Terminal care/ or Terminally ill/ or Resuscitation Orders/ or exp Advance care planning/
8	6 or 7
9	*Quality of health care/ or *Advance directive adherence/ or *Clinical competence/ or *Guideline adherence/ or *"Outcome and Process Assessment, Health Care"/ or *Outcome Assessment, Health Care/ or *patient outcome assessment/ or *critical care outcomes/ or *Process Assessment, Health Care/ or *Program evaluation/ or *Benchmarking/ or *Quality Assurance, Health Care/ or *Clinical audit/ or *Medical audit/ or *nursing audit/ or exp *guidelines as topic/ or *near miss, healthcare/ or *time out, healthcare/ or *total quality management/ or *quality improvement/ or *quality indicators, health care/ or *Standard of care/ or *Drug utilization review/
10	*Delivery of health care/ or *Delivery of health care, Integrated/ or *Culturally Competent Care/ or *Health Services Accessibility/ or *Health Facility Environment/ or *"Health Services Needs and Demand"/ or *Professional Practice Gaps/ or *"Facility Regulation and Control"/ or *Patient handoff/ or exp *Patient Care Management/ or *Documentation/ or *Continuity of care/ or *Patient-centered care/ or exp *Evidence based practice/ or *Reference standards/ or *Patient care/ or *Patient care planning/ or *Critical pathways/ or *Clinical protocols/

Search #	Query
11	*Safety/ or *Patient harm/ or *Patient safety/ or *Safety management/ or *Risk/ or exp *Risk assessment/ or *Risk factors/ or *Risk adjustment/ or *Risk reduction behavior/ or *Medical errors/ or *medication errors/ or *Time-to-treatment/ or *Organizational culture/ or *Efficiency, organizational/ or *Professional competence/ or *Professional practice/ or *"Personnel staffing and scheduling"/ or *Unnecessary procedures/ or *Clinical decision making/ or *hospital bed capacity/ or *case management/ or *health facility administration/ or *infection control/ or *Cross Infection/pc
12	*Nursing process/st or *Nursing care/st or exp *Personnel, hospital/st or *decision making, organizational/ or *Patient care team/st or *Models, organizational/ or exp *communication/st or *Inservice training/ or *Capacity building/ or *Education, Medical, Continuing/ or *Education, Nursing, Continuing/ or *Workflow/ or *Clinical alarms/ or *Health facilities/st or *medication systems, hospital/ or *Checklist/ or *Hospital records/ or exp *medical records/ or *nursing records/ or *Organizational policy/ or *Data accuracy/ or *Decision support systems, clinical/ or *decision support techniques/ or *health information systems/ or *Resource allocation/ or *Health care rationing/
13	(quality or standard* or indicator* or consensus or audit* or barrier* or benchmark* or plan or improv* or adherence or guideline* or pathway* or protocol* or assess* or evaluat* or standard* or accessib* or facilit* or professional or regulation* or continuity or patient cent* or safety or safe or efficien* or organisation* or organization* or capacity or administrat* or process* or procedure* or system or systems or ration* or data or record* or delivery or model* or accreditation or implement* or document*).ti.
14	(Outreach or quality improvement or evidence based or quality indicator* or quality of health care or standard of care or quality assurance or best practice* or accreditation or audit* or health care delivery or health service* delivery or organizational prerequisite* or organisational prerequisite*).tw,kf.
15	9 or 10 or 11 or 12 or 13 or 14
16	5 and 8 and 15
17	meta-analysis.pt.
18	meta-analysis/ or systematic review/ or meta-analysis as topic/ or "meta analysis (topic)"/ or "systematic review (topic)"/
19	((systematic* adj3 (review* or overview*)) or (methodologic* adj3 (review* or overview*))).ti,ab,kf,kw.
20	((quantitative adj3 (review* or overview* or synthes*)) or (research adj3 (integrati* or overview*))).ti,ab,kf,kw.
21	((integrative adj3 (review* or overview*)) or (collaborative adj3 (review* or overview*)) or (pool* adj3 analy*)).ti,ab,kf,kw.
22	rapid review*.ti,ab,kf,kw.

Search #	Query
23	17 or 18 or 19 or 20 or 21 or 22
24	(Randomized Controlled Trial or Controlled Clinical Trial or Pragmatic Clinical Trial or Equivalence Trial or Clinical Trial, Phase III).pt.
25	Randomized Controlled Trial/ or exp Randomized Controlled Trials as Topic/ or "Randomized Controlled Trial (topic)"/ or Randomization/ or Random Allocation/ or Double-Blind Method/ or Double Blind Procedure/ or Double-Blind Studies/
26	Single-Blind Method/ or Single Blind Procedure/ or Single-Blind Studies/ or Placebos/ or Placebo/ or Control Groups/ or Control Group/
27	(random* or sham or placebo*).ti,ab,hw,kf,kw.
28	((singl* or doubl*) adj (blind* or dumm* or mask*)).ti,ab,hw,kf,kw.
29	((tripl* or trebl*) adj (blind* or dumm* or mask*)).ti,ab,hw,kf,kw.
30	(control* adj3 (study or studies or trial* or group*)).ti,ab,kf,kw.
31	(Nonrandom* or non random* or non-random* or quasi-random* or quasirandom*).ti,ab,hw,kf,kw.
32	24 or 25 or 26 or 27 or 28 or 29 or 30 or 31
33	exp Australia/ or Australia*.ti,ab,in. or au.in. or Northern Territory.ti,ab,in. or Tasmania*.ti,ab,in. or New South Wales.ti,ab,in. or Victoria*.ti,ab,in. or Queensland*.ti,ab,in.
34	23 or 32 or 33
35	16 and 34
36	limit 35 to yr="2015 -Current"
37	limit 36 to english language

Database: Cinahl (Ebsco) (Search conducted 8 July 2020).

Search #	Query
S1	(MM "Quality of Health Care") OR (MM "Accountability") OR (MM "Clinical Governance") OR (MM "Clinical Effectiveness") OR (MM "Guideline Adherence") OR (MM "Outcomes (Health Care)") OR (MM "Medical Futility") OR (MM "Nursing Outcomes") OR (MM "Outcome Assessment") OR (MM "Patient-Reported Outcomes") OR (MM "Treatment Outcomes") OR (MM "Treatment Termination") OR (MM "Treatment Failure") OR (MM "Process Assessment (Health Care)") OR (MM "Program Evaluation") OR (MM "Utilization Review") OR (MM "Drug Utilization") OR (MM "Quality Improvement") OR (MM "Benchmarking") OR (MM "Quality Management, Organizational") OR (MM "Quality of Nursing Care")
S2	(MM "Professional Competence") OR (MM "Clinical Competence")
S3	(MM "Decision Making, Clinical") OR (MM "Decision Making, Organizational") OR (MM "Consensus")
S4	(MM "Personnel Staffing and Scheduling")
S5	(MM "Nursing Care Delivery Systems") OR (MM "Case Management")
S6	(MM "Workflow")
S7	(MM "Medical Records+")
S8	(MM "Decision Support Systems, Clinical") OR (MM "Decision Support Systems, Management") OR (MM "Decision Support Techniques")
S9	(MM "Health Resource Allocation") OR (MM "Resource Allocation+") OR (MM "Health Resource Utilization")
S10	(MM "Organizational Culture")
S11	(MM "Infection Control")
S12	(MM "Risk Assessment")
S13	TI (Outreach or “quality improvement” or “evidence based” or “quality indicator*” or “quality of health care” or “standard of care” or “quality assurance” or “best practice*” or accreditation or audit* or “health care delivery” or “health service* delivery” or “organizational prerequisite*” or “organisational prerequisite*”) OR AB (Outreach or “quality improvement” or “evidence based” or “quality indicator*” or “quality of health care” or “standard of care” or “quality assurance” or “best practice*” or accreditation or audit* or “health care delivery” or “health service* delivery” or “organizational prerequisite*” or “organisational prerequisite*”)
S14	(MM "Health Care Delivery") OR (MM "Health Resource Allocation") OR (MM "Health Resource Utilization") OR (MM "Health Services Accessibility") OR (MM "Management") OR (MM "Audit") OR (MM "Decision Making, Organizational") OR (MM "Documentation") OR (MM "Medical Records")

Search #	Query
S15	(MM "Patient Safety") OR (MM "Medication Errors") OR (MM "Health Care Errors") OR (MM "Treatment Errors")
S16	(MM "Continuity of Patient Care") OR (MM "Health Care Errors")
S17	(MM "Hand Off (Patient Safety)")
S18	TI quality or standard* or indicator* or consensus or audit* or barrier* or benchmark* or plan or improv* or adherence or guideline* or pathway* or protocol* or assess* or evaluat* or standard* or accessib* or facilit* or professional or regulation* or continuity or “patient cent*” or safety or safe or efficien* or organisation* or organization* or capacity or administrat* or process* or procedure* or system or systems or ration* or data or record* or delivery or model* or accreditation or implement* or document*
S19	(MM "Nursing Practice, Evidence-Based") OR (MM "Medical Practice, Evidence-Based") OR (MM "Professional Practice, Evidence-Based")
S20	S1 OR S18 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19
S21	TI (“Terminal care” or “life support care” or “end of life” or palliative or “terminally ill” or “advance care plan*” or “advance directive*” or grief or bereavement or resuscitation order*) OR AB (“Terminal care” or “life support care” or “end of life” or palliative or “terminally ill” or “advance care plan*” or “advance directive*” or grief or bereavement or resuscitation order*)
S22	(MH "Advance Care Planning") OR (MH "Advance Directives") OR (MH "Palliative Care") OR ((MH "Resuscitation Orders") OR (MH "Terminal Care")) OR (MH "Terminally Ill Patients")
S23	S21 OR S22
S24	TI (((acute or intensive or emergency or critical or coronary or respiratory) W1 (care or ward* or department* or unit* or room*))) OR AB (((acute or intensive or emergency or critical or coronary or respiratory) W1 (care or ward* or department* or unit* or room*)))
S25	TI (inpatient* or outpatient* or icu or icus or hospital*) OR AB (inpatient* or outpatient* or icu or icus or hospital*)
S26	(MH "Hospitals") OR (MH "Hospitals, Private") OR (MH "Hospitals, Public") OR (MH "Hospitals, Federal") OR (MH "Hospitals, Veterans")
S27	S24 OR S25 OR S26
S28	S20 AND S23 AND S27
S29	(MH "Randomized Controlled Trials+")

Search #	Query
S30	(MH "Clinical Trials+")
S31	(MH "Placebos")
S32	(MH "Control Group")
S33	(random* or sham or placebo*) OR ((singl* or doubl*) N1 (blind* or dumm* or mask*)) OR ((tripl* or trebl*) N1 (blind* or dumm* or mask*)) OR (control* N1 (study or studies or trial* or group*))
S34	Nonrandom* or “non random*” or non-random* or quasi-random* or quasirandom*
S35	S29 OR S30 OR S31 OR S32 OR S33 OR S34
S36	(MH "Systematic Review")
S37	(MH "Meta Analysis")
S38	((systematic* N3 (review* or overview*)) or (methodologic* N3 (review* or overview*)))
S39	((quantitative N3 (review* or overview* or synthes*)) or (research N3 (integrati* or overview*)))
S40	((integrative N3 (review* or overview*)) or (collaborative N3 (review* or overview*)) or (pool* adj3 analy*))
S41	rapid review*
S42	S36 OR S37 OR S38 OR S39 OR S40 OR S41
S43	(MH "Australia+")
S44	australia* OR northern territory OR tasmania* OR new south wales OR victoria* OR queensland*
S45	S43 OR S44
S46	S35 OR S42 OR S45
S47	S28 AND S46
S48	Limiters - Published Date: 20150101-20201231 Narrow by Language: - english

Appendix 3: Peer reviewed search strategy – Pandemic review

Database(s): Ovid MEDLINE(R) and Epub Ahead of Print, In-Process and Other Non-Indexed Citations, Daily and Versions(R) (Search conducted 28 July 2020).

Search #	Searches
1	exp hospitals/ or hospital*.tw,kf.
2	((acute or intensive or emergency or critical or coronary or respiratory) adj (care or ward* or department* or unit* or room*)).mp.
3	Outpatient Clinics, Hospital/
4	(inpatient* or outpatient* or icu or icus).tw,kf.
5	1 or 2 or 3 or 4
6	(Terminal care or life support care or end of life or palliative or terminally ill or advance care plan* or advance directive* or grief or bereavement or resuscitation order*).tw,kf.
7	Palliative care/ or Terminal care/ or Terminally ill/ or Resuscitation Orders/ or exp Advance care planning/
8	6 or 7
9	exp Coronavirus/
10	exp Coronavirus Infections/
11	(severe acute respiratory syndrome or SARS or Middle East respiratory syndrome or MERS or 2009 H1N1 or H1N1pdm09 or swine flu).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
12	(coronavirus* or corona virus* or covid* or ncov* or sarscov* or 2019ncov).mp.
13	pandemic*.mp.
14	9 or 10 or 11 or 12 or 13
15	5 and 8 and 14
16	limit 15 to english language

Database: Cinahl (Ebsco) (Search conducted 28 July 2020).

Search #	Query
S1	TI (“Terminal care” or “life support care” or “end of life” or palliative or “terminally ill” or “advance care plan*” or “advance directive*” or grief or bereavement or resuscitation order*) OR AB (“Terminal care” or “life support care” or “end of life” or palliative or “terminally ill” or “advance care plan*” or “advance directive*” or grief or bereavement or resuscitation order*)
S2	(MH "Advance Care Planning") OR (MH "Advance Directives") OR (MH "Palliative Care") OR ((MH "Resuscitation Orders") OR (MH "Terminal Care")) OR (MH "Terminally Ill Patients")
S3	S1 OR S2
S4	TI (((acute or intensive or emergency or critical or coronary or respiratory) W1 (care or ward* or department* or unit* or room*))) OR AB (((acute or intensive or emergency or critical or coronary or respiratory) W1 (care or ward* or department* or unit* or room*)))
S5	TI (inpatient* or outpatient* or icu or icus or hospital*) OR AB (inpatient* or outpatient* or icu or icus or hospital*)
S6	(MH "Hospitals") OR (MH "Hospitals, Private") OR (MH "Hospitals, Public") OR (MH "Hospitals, Federal") OR (MH "Hospitals, Veterans")
S7	S4 OR S5 OR S6
S8	pandemic*
S9	coronavirus* or "corona virus*" or covid* or ncov* or sarscov* or 2019ncov)
S10	“severe acute respiratory syndrome” or SARS or “Middle East respiratory syndrome” or MERS or “2009 H1N1” or H1N1pdm09 or “swine flu”
S11	S8 OR S9 OR S10
S12	S3 AND S7 AND S11
S13	S3 AND S7 AND S11 Narrow by Language: - english

Appendix 4: Grey literature search

Search terms	Guidelines
palliative, end of life, hospital	• Australia's Clinical Practice Guidelines Portal (NHMRC) – searched https://www.clinicalguidelines.gov.au/ • Royal Australian College of General Practitioners Clinical Guidelines https://www.racgp.org.au/clinical-resources/clinical-guidelines

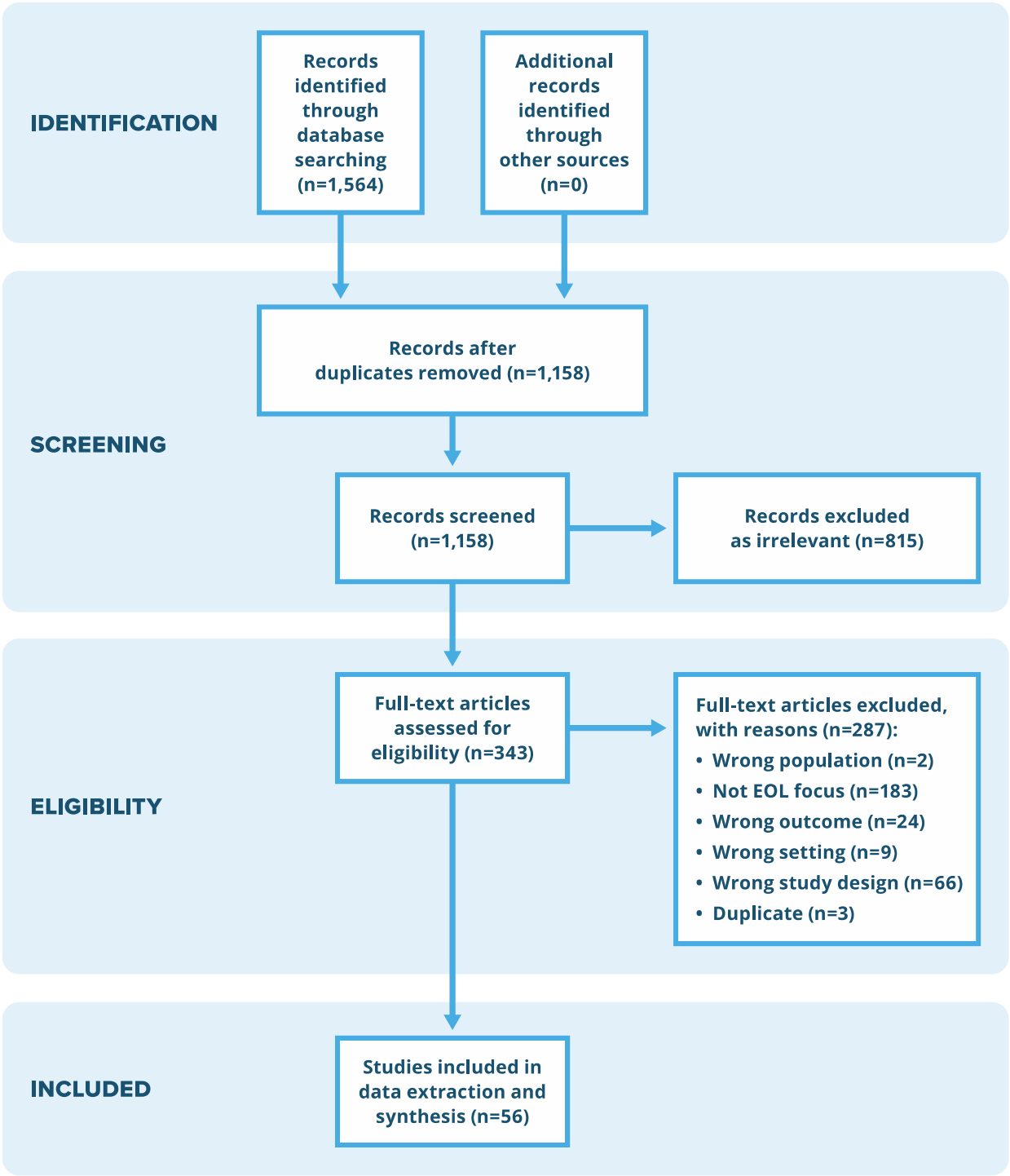
Search terms	Organisations
The websites of organisations browsed and searched by keywords: palliative, end of life, hospital	• HealthyWA • SA Health • Health Victoria • NSW Health • Queensland Health • Northern Territory Health • Tas Health • The Australian and New Zealand Intensive Care Society (ANZICS) • Palliative Care Social Work Australia • Palliative Care Australia • CareSearch • PalliAged • ANZSPM The Australian & New Zealand Society of Palliative Medicine Inc. • The Palliative Care Outcomes Collaboration Outcomes • Centre for Clinical effectiveness, Monash Health • Australian Government Department of Health • Cardiac Society of Australia & New Zealand • Australian Cardiovascular Health and Rehabilitation Association • National Heart Foundation • Lung Foundation Australia • The Society of Hospital Pharmacists of Australia (SHPA) • Cancer Council Australia • Australian Society of Anaesthetists • Australian Anaesthesia Allied Health Practitioners • Palliative Care Nurses Australia • Australian College of Critical Care Nurses (ACCCN) • Australian College of Operating Room Nurses (ACORN) • Australian Medical Association (AMA) • Allied Health Professions Australia (AHPA) • The Australasian College for Emergency Medicine • National Stroke Foundation.

Google advanced search

Search terms
palliative AND (hospital* OR patient*) filetype:pdf – limit to Australia
“end of life” AND (hospital* OR patient*) filetype:pdf – limit to Australia
“end of life” AND medicine filetype:pdf

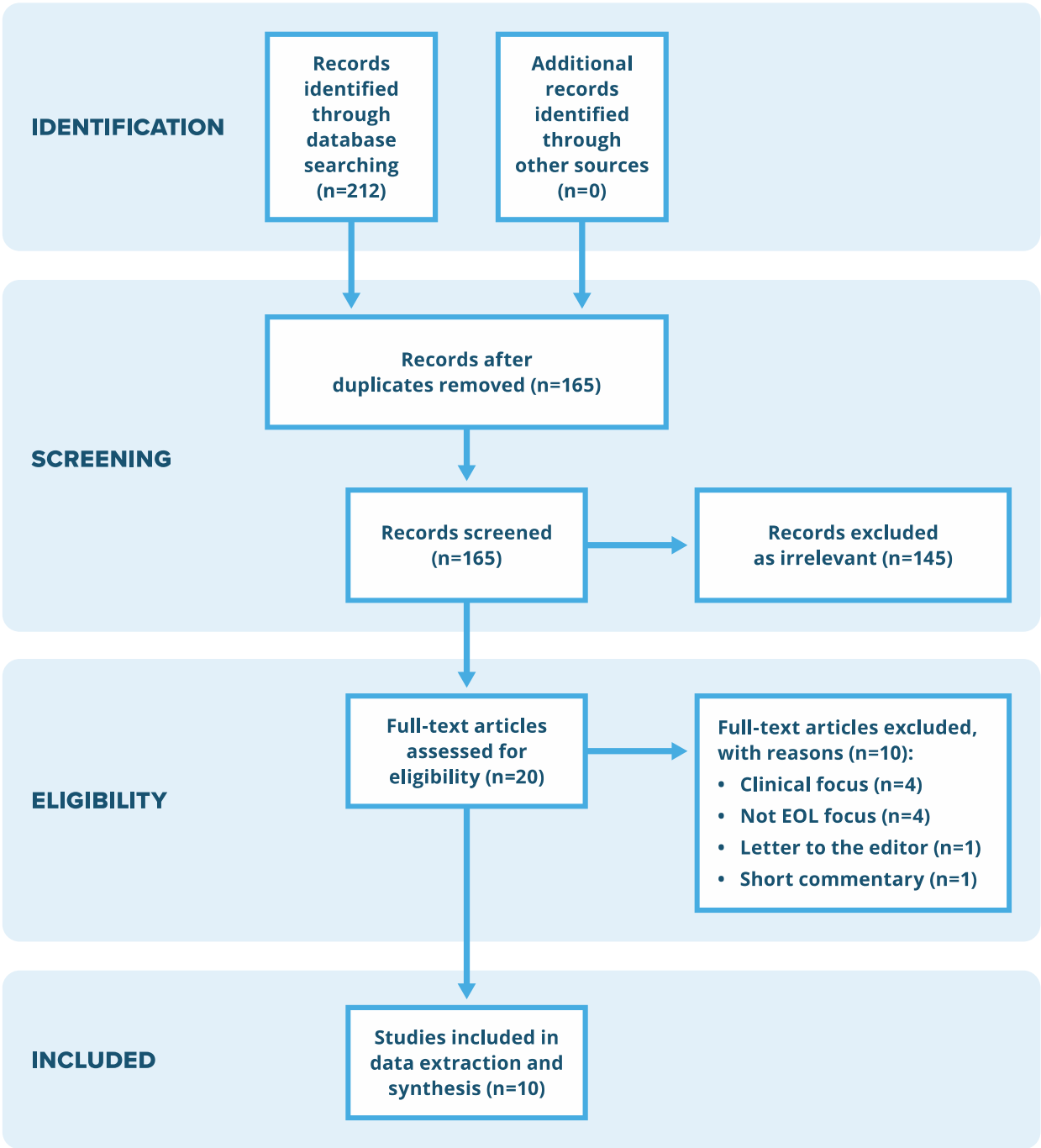
Appendix 5: PRISMA Flow Diagram – Main review

Figure 2: PRISMA Flow Diagram of selection process in the main review



Appendix 6: PRISMA Flow Diagram – Pandemic review

Figure 3: PRISMA Flow Diagram of study selection process in the pandemic review



Appendix 7: Personal communication

Jeannette Lacey

End of Life Care Nurse Practitioner, John Hunter Hospital NSW.

In email correspondence with Jeanette Lacey (known to the research team) she says that:

> the role commenced in 2015. John Hunter Hospital had no onsite specialist pall care service at that time, palliative care consults were provided by the Calvary Mater Hospital staff specialists “once a week”. My role was introduced as it was recognised that there was no expert care for the dying. There has since been the introduction of specialist palliative care TNP and CNC who are responsible for care of pall care patients likely to be discharged from hospital or transferred to hospice. Together our services saw 700 people last year. I now see between 250-300 people a year who are acutely or actively dying at JHH. I see 99.9% of patients within a few hours of referral, and 58% of patients are deceased within 24 hours of introduction, some within 10 minutes!! Last year less than 5% of the patients that I saw were known to palliative care, therefore deaths from the families perspective could be considered “sudden and unexpected”. I do not consider myself to be a specialist pall care staff member, but rather an experienced nurse practitioner with care of the dying as a priority and compassionate patient and family centred care at the centre of all I do. I provide pain and symptom assessment, and management, bio-psychosocial support to patient and family. Spiritual care, and needs assessment and management, fulfilling last wishes, place of care discussions, preparation for the family of dying and care of the deceased and after care, bereavement follow up and support, time, and a compassionate presence. For the staff I provide support, education, reassurance, guidance, and as one nurse described it, “help” when escalation and support from medical teams may be challenging, as well as assistance with recognition of dying, communication assistance for difficult conversations regarding reversibility, best interests and dare I say futility. I also have the luxury of time to spend with staff and families that allows for other team members to focus on other patients if needed

Wendy Jansen

Palliative Care Nurse Practitioner, Northern Adelaide Palliative Services, SA.

Collated comments:

> Environment
>
> - Consider how older hospitals have been designed. Even if you had a great environment with privacy etc what does it mean if the clinical care isn’t there?
>
> Communication and EOL goal planning
>
> - Ultimately how is the result of the communication displayed eg how are goals of care demonstrated eg ACDs and Resus pathways
>
> Education and training
>
> - I think many people have the expectation that their workplace should provide this.
>
> Information and Support
>
> - This is what is lacking for the acute hospital system is a way that clinicians can access in a timely manner the info they need.

The main issues

- Communication and skills to negotiate goals of care discussions
- Diagnosis of dying
- Knowledge how to write end of life orders and confidence to give the medications whilst supporting the emotional needs of the patient and significant others
- How to support those people in bereavement
- How to support staff in acute care providing this care.

This is where high end research needs to focus to improve end of life care! On the main aspects of care delivery.

I have never seen the national consensus statement. I'm pretty sure that a hospital clinician has never heard of it either. Perhaps the safety and quality department have. They are good at making things look great on paper but where is the clinician involvement in the process?

The consensus statement is big. Condense it into main points and add some clinical guidelines about end of life care and prescribing and get it put on each ward. Get the education team of each facility to provide education.

We have the knowledge but it's the implementation of anything is where we fall down.

The academics and researchers provide great work but how does it get into practice? The majority of the time the hospital itself does not want to consider a sustainable implementation plan. Perhaps they think that one discussion will lead to a miraculous transfer of information by osmosis!

Appendix 8: Study characteristics

Table A1: Study characteristics – Main review

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Bakke 2018 (USA)[45]	To identify articles describing end-of-life communication training available to surgeons and anaesthesiologists, and to assess their methodological rigor to inform future curricular design and evaluation	Health care professionals including surgeons, residents, fellows, or a mix thereof	Systematic review	Academic hospital	There are few quality studies evaluating end-of-life communication training for surgeons and anaesthesiologists. These programs frequently use role-playing to teach and assess end-of-life communication skills.	Level III

Bateman 2016 (Australia)[60]	To address the challenges faced by staff in an acute rural hospital in Australia when providing person-centred care for patients with dementia and/or delirium	Patients with cognitive impairment (delirium or dementia) or delirium risk, nurses and volunteers	Quasi experimental pre–post design	Rural acute hospital	A significant reduction over time in length of stay for patients, and an increase in the use of analgesic medications. No effects on the stress of nursing staff or their attitudes to dementia. Volunteers gained significantly in confidence and attitudes to dementia. The program has continued and is now being expanded to other rural sites.	Level II

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Beernaert 2017 (Belgium)[61]	To assess the effectiveness of the Care Programme for the Last Days of Life (CAREFuL) at improving comfort and quality of care in the dying phase in elderly people	Patients, families and hospital staff	Cluster randomised controlled trial	Acute geriatric wards in hospital	Implementation of CAREFuL compared with control significantly improved comfort. No significant differences for the CAD-EOLD assessed by family carers or the SM-EOLD assessed by nurses or by family carers.	Level I

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Bloomer 2019a (Australia)[62]	To explore the impact of cultural factors on the provision of end-of-life care in a geriatric inpatient rehabilitation setting	Deceased in-patients, and multidisciplinary health care professionals	Mixed methods using retrospective patient medical record audit, and interviews with clinicians	Geriatric inpatient rehabilitation facility	Patients' and families' cultural needs were not always recognised or facilitated in end-of-life care, resulting in missed opportunities to tailor care to the individual's needs. Clinicians identified a lack of awareness of cultural factors, and how these may influence end-of-life care needs; and expressed a desire for education opportunities to improve their understanding of how to provide patient-specific, culturally sensitive end-of-life care.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Bloomer 2019b (Australia)[63]	To map end-of-life care in acute hospital settings against Elements 1–5 of the ACSQHC Essential Elements for Safe and High-Quality End-of-Life Care	Deceased in-patients	Retrospective patient medical record audit	Private and public metropolitan health services	Most patients had a limitation of medical treatment. In 91.97% of cases, a written entry indicating poor prognosis preceded a documented decision to provide end-of-life care, with a documented decision noted in 81.1% of cases. Evidence of pastoral care involvement was found in 41.6% of cases, with only 33.1% of non-palliative care patients referred to specialist palliative care personnel. An end-of-life care pathway was used in 51.1% of cases.	Level III
Bond 2018 (Australia)[58]	To identify which strategies are most valued by parents regarding care following stillbirth in order to improve the support and management of grieving families	Bereaved parent	Mixed methods cross-sectional survey	Metropolitan tertiary maternity centres, two large private hospitals and one district hospital	Three key themes relating to hospital management of stillbirth were identified: the emotional response to grief, the educational importance of being guided through the grief process, and the environmental aspects of adequate time and appropriate physical space. Families preferred not to be seen in an antenatal setting for follow-up.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Brooks 2017 (Australia)[39]	To explore the perspectives and experiences of physicians and nurses providing end-of-life care in the ICU. In particular, perceived barriers, enablers and challenges to providing end-of-life care were examined.	Physicians and nurses	Interpretative qualitative inquiry via focus groups	Major referral ICU in tertiary metropolitan hospital	The themes are presented as barriers, enablers and challenges. Barriers include conflict between the ICU physicians and external medical teams, the availability of education and training, and environmental limitations. Enablers include collaboration and leadership during transitions of care. Challenges include communication and decision making, and expectations of the family.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Butler 2018 (Australia)[59]	To explore bereaved parents' judgements of healthcare providers, as part of a larger study examining their perceptions of the death of a child in the paediatric intensive care unit	Bereaved parent	Qualitative interviews	Paediatric ICUs in four hospitals across three Australian states	Bereaved parents judged healthcare providers as 'good' or 'poor' based on behaviours they exhibit. 'Good' behaviours were further subdivided by parents into four categories: 'Better than others', 'good', 'very good', and 'fantastic'. Common behaviours identified as 'good' included provision of practical assistance, facilitation of parental presence, and sharing of information. In contrast, the concept of 'poor' had no subdivision: all identified behaviours, including diminishing parental concern, mishandling hope, adopting an unprofessional demeanour, judging the child's worth, and mishandling communication, were equally detrimental.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Coombs 2017a (Australia)[40]	To describe the type of bereavement care provided in intensive care units across Australia and New Zealand	Nurse practitioners	Inductive qualitative content analysis on free-text responses to a web-based survey	Paediatric and neonatal ICUs in tertiary hospitals in Aust and NZ	Bereavement care practices described use of memory boxes, cultural specificity, annual memorial services and use of community support services. Educational provision identified local in-service programmes, and national bereavement courses for specialist bereavement nurse coordinators. Organisational challenges focused on lack of funding, especially for provision of bereavement follow-up.	Level III
Coombs 2017 (Aust NZ)[64]	To conduct an integrative review on how nurses prepare families for and support families during withdrawal of life-sustaining treatments in intensive care	Patients, families and health care professional	Integrative literature review	ICUs in tertiary hospitals	Thematic analysis revealed the nurses: equipped families for end of life through information provision and communication; managed the withdrawal of life sustaining treatments to meet family need; and continued care to build memories.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Curtis 2016 (USA)[66]	To determine if an ICU communication facilitator reduces family distress and intensity of end-of-life care	Patients and family members	Randomised controlled trial	ICUs located in academic level-one trauma centre and community-based hospital	The intervention was associated with decreased depressive symptoms at six months, but there were no significant differences in psychological symptoms at three months or anxiety or PTSD at six months. The intervention was not associated with ICU mortality but decreased ICU costs among all patients and particularly among decedents. Among decedents, the intervention reduced ICU and hospital length of stay.	Level I

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Curtis 2018 (USA)[65]	To evaluate the efficacy of a patient-specific pre-conversation communication priming intervention (Jumpstart-Tips) targeting both patients and clinicians and designed to increase goals-of-care conversations compared with usual care	Physicians or nurse practitioners, and patients with serious illness	Multicentre cluster-randomised trial	Academic and community hospitals, comprehensive cancer centre, and extensive outpatient network	The intervention was associated with significant increase in a goals of care discussion at the target visit, increased medical record documentation, and increased patient-rated quality of communication. Patient-assessed goal-concordant care did not increase significantly overall but did increase for patients with stable goals between three-month follow-up and last prior assessment. Symptoms of depression or anxiety were not different between groups at three or six months.	Level I

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
da Silva Soares 2016 (Portugal)[46]	To examine the effectiveness of ED-based PC interventions on hospital admissions (primary outcome), length of stay (LOS), symptoms, quality of life, use of other health care services, and PC referrals for adults with advanced disease	Patients with cancer and non-cancer conditions	Systematic review	Major academic tertiary medical centres	There is yet no evidence that ED-based PC affects patient outcomes except for indication from one study of no association with 90-day hospital readmission but a possible reduction in LOS if integrated PC is introduced early at ED rather than after hospital admission. Evidence is very scarce of impact on symptom control, QoL, and referrals to specialist PC services and use of other health care services.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Donovan 2015 (Australia)[67]	To identify services offered to bereaved families in perinatal, neonatal, and paediatric hospital settings and summarize the psychosocial impact of these services and published recommendations for best practice hospital-based bereavement care	Bereaved parents, family and health care professionals	Systematic review	Six settings including perinatal, neonatal; and paediatric intensive care units (PICU)	Qualitatively, family members described feeling cared for and supported by staff, a reduction in sense of isolation, and improved coping and personal growth. Quantitatively, bereavement services have most effect for parents experiencing more complex mourning. It is recommended that bereavement services be theoretically driven and evidence based, offer continuity of care prior to and following the death of a child, and provide a range of interventions for the 'whole family' and flexibility in service delivery.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Gibson 2018 (Australia)[29]	To critically appraise the existing qualitative literature regarding nurses' experiences when caring for infants during end of life in the NICU and to identify barriers and enablers to provide quality end-of-life care	Nursing professionals	Systematic review of qualitative studies	Neonatal intensive care units (NICU)	Five major themes emerged: (1) advocating for the dying infant; (2) building close relationships with the family; (3) providing an appropriate care environment; (4) nurses' emotional responses to dying or death; and (5) professional inadequacy in end-of-life care.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Gloss 2017 (Australia)[68]	To review the literature on the barriers to providing end-of-life care in EDs	Emergency department health care professionals	Systematic review	Emergency department in hospital	Specialist training and education in end-of-life care as a holistic practice, including ethical and legal considerations, should be made available to ED staff. Staff should have access to education to enhance their communication techniques, and initiatives that encourage effective professional communication across all specialties should be introduced. Innovative models of care that support individualised, holistic end-of-life care for patients and their families, in their final days and hours, should be developed. ED executive teams should consider the appropriate allocation of patients who are receiving end-of-life care in EDs, for example, ensuring a single room is available with appropriate staffing. Research and consideration of the effect of ED design on patients receiving end-of-life care should be undertaken.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Griffiths 2019 (UK)[30]	To explore qualitative studies in which nurses discussed the challenges they face when delivering end-of-life care in intensive care units (ICUs)	Nursing professionals	Systematic review of qualitative studies	Intensive care unit (ICU)	Four main themes emerging from analysis. The themes were a lack of nurse involvement in end-of-life care decision-making, a lack of nursing knowledge in providing end-of-life care, the dilemma of prioritising care between the patient and family, and the nature of providing end-of-life care within an ICU environment.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Grudzen 2016 (USA)[47]	To compare quality of life, depression, health care utilisation, and survival in ED patients with advanced cancer randomised to ED-initiated palliative care consultation vs care as usual	Patients with a known advanced cancer	Randomised controlled trial	Emergency department in hospital	Quality of life, as measured by a change in FACT-G score from enrolment to 12 weeks, was significantly higher in patients randomised to the intervention group, who demonstrated a mean (SD) increase of 5.91 (16.65) points compared with 1.08 (16.00) in controls. Median estimates of survival were longer in the intervention group than the control group, although this did not reach statistical significance. There were no statistically significant differences in depression, admission to the intensive care unit, and discharge to hospice.	Level I

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Howes 2015 (UK)[69]	A systematic review of the literature focusing on the provision of end-of-life care on Paediatric Intensive Care Units (PICUs) and the options available to children and families within contemporary clinical practice	Patient, family and health care professionals	Systematic review	Paediatric Intensive Care Units (PICUs)	Key themes identified included family views, staff views, decision-making, medico-legal issues and resources. Although the number of relevant articles is limited, a wide range of challenges facing children, parents and staff are highlighted, whilst generally supporting the facilitation of transferring children to their homes or hospice for withdrawal of intensive care and continuing end-of-life care.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Johnstone 2016a (Australia)[32]	To explore and describe nursing roles and strategies in end-of-life decision making and their possible link to enabling a good death for elderly immigrants admitted to hospitals in the Australian state of Victoria	Nursing professionals	A qualitative exploratory descriptive approach via in-depth interviews	Four different metropolitan health services	Despite feeling underprepared for their role, participants fostered culturally meaningful care by 'doing the ground work,' 'facilitating families,' 'fostering trust,' and 'allaying fear.' The Australian nursing profession has a significant role to play in leading policy, education, practice, and consumer engagement initiatives aimed at ensuring a culturally responsive approach to end-of-life care for Australia's ageing immigrant population. Enabling elderly immigrants to experience a 'good death' at the end of their lives requires highly nuanced and culturally informed nursing care.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Johnstone 2016b (Australia)[31]	To explore and describe the strategies nurses use to facilitate engagement with families of older immigrant Non-English-Speaking Background (NESB) patients hospitalised for end-of-life care	Nursing professionals	A qualitative exploratory descriptive approach via in-depth interviews	Four different metropolitan health services	Five key strategies were identified: listening and understanding families, encouraging family members to speak first, dealing with angst, redressing naive views about the dying process, and managing intergenerational differences. Underpinning these strategies was a profound ‘‘will to engage’’ with the families and their cultural worldviews.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Kerckhoffs 2019 (Netherlands)[70]	To identify strategies that can be used to optimise the decision-making process for continuing versus limiting life sustaining treatment of ICU patients	Family and health care professionals	Systematic review	Intensive care units (ICU)	Five categories of decision-making strategies were identified: (1) integrated communication; (2) consultative communication; (3) ethics consultation; (4) palliative care consultation; and (5) decision aids. Many different outcome measures were used and none of them covered all aspects of decisions on continuing versus limiting life sustaining treatment. Integrated communication strategies had a positive effect on multiple outcome measures. Frequent, predefined family-meetings as well as triggered and integrated ethical or palliative consultation were able to reduce length of stay of patients who eventually died, without increasing overall mortality.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Kirby 2018 (Australia)[71]	To develop a critical, evidence-based understanding of the experiences of people from Culturally and Linguistically Diverse (CALD) backgrounds, and their caregivers, in a palliative care setting	Patients and their caregivers	Qualitative study using semi-structured interviews	Public and private hospital inpatient and outpatient	Four prevalent themes were identified: (1) Terminology in the transition to palliative care; (2) Communication, culture and pain management; (3) (Not) Talking about death and dying; and (4) Religious faith as a coping strategy: challenging the terminal diagnosis.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Levinson 2019 (Australia)[41]	To explore practitioner perspectives on goals of care discussions for adult Emergency Department (ED) patients nearing end of life	ED doctors	Qual component of mixed methods study (interview)	ED in a Catholic, not-for-profit (private) network of metropolitan	Emergency doctors perceive goals of care discussions to be relevant to their practice and occurring frequently. They aim to ensure appropriate care is provided prior to review by the admitting team, focusing on limitations of treatment and clarity in the care process. ED doctors felt they could recognise end of life and that ED visits often prompt consideration of end-of-life care planning. They wanted long-term practitioners to initiate discussions prior to patient deterioration. There were numerous interpretations of palliative care concepts.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Martland 2016 (Australia)[42]	To develop a substantive grounded theory related to the communication process between clinicians that preceded the activation of an RRT when general concern criterion was used	Health care professionals	Qualitative focus groups	Large tertiary metropolitan referral centre	The strongest theme contributed to a theory of ineffective communication and decreased psychological safety, namely that 'In the absence of effective communication there is a subsequent increase in anxiety, fear or concern that can be directly attributed to the activation of an RRT using the 'general concern' criterion'. The RRT filled cultural and process deficiencies in the compliance with an escalation protocol. Issues such as 'not for resuscitation documentation' and 'inability to establish communication with and between medical or nursing personnel' rated highly and contributed to the debate.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
McCallum 2018 (UK)[72]	To explore the quality of the dying and death experience in the Emergency Department from the perspective of staff and carers	Patients relative and health care professionals	Systematic integrative literature review	Hospital emergency department	Eight themes emerged from the literature: care in the Emergency Department is about living not dying, staff perceive that death is a failure, staff feel underprepared to care for the dying patient and family in this environment, there is limited time for safe standards of care, staff stress and distress, staff use of distancing behaviours, the care of the dying role is devolved from medics to nurses at the end of life, and patients and staff perceive that the Emergency Department is not the preferred place of death.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
McCorkle 2015 (USA)[48]	To evaluate the effects of a multidisciplinary coordinated intervention by advanced practice nurses at the clinic level on outcomes with patients newly diagnosed with late-stage cancer	Patients with newly diagnosed late-stage cancers	Cluster Randomised Trial	Four disease-specific multidisciplinary clinics in a cancer hospital	No differences between the two groups on the primary patient-reported outcomes at one and three months postbaseline were found; however, physical and emotional symptoms remained stable or significantly improved from baseline for both groups. Overall, secondary outcomes remained stable within the groups.	Level I

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Mitchell 2017 (Australia)[43]	To investigate provision of family bereavement support in intensive care units (ICU) across New Zealand (NZ) and Australia	Nursing professionals	Cross-sectional exploratory descriptive web-based survey	All ICUs [public/private, neonatal/ paediatrics/ adults]	Whilst respondents reported common bereavement practices to include debriefing for staff after a traumatic death, there was greater variation in sending a sympathy card to families. Fifty percent of responding New Zealand units had a bereavement follow-up service compared to 28.3% of Australian unit respondents. Of those with follow-up services, 92.3% of New Zealand units undertook follow-up calls to families compared to 76.5% of Australian units. Bereavement follow-up services were mainly managed by social workers in Australia and nursing staff in New Zealand.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Moon 2018 (Australia)[73]	To synthesise literature describing the quality of end-of-life care for patients with dementia dying in hospital	Patients, caregivers and health care professionals	Systematic review	Mainly hospital	Literature reflects a growing awareness of the need to consider a palliative approach to end-of-life care for patients with dementia in hospital. Patients with dementia are less likely to receive aggressive care at the end of life, but provision of palliative care interventions is inconsistent. Health-care professionals highlighted the need for greater education around identification and management of problematic symptoms at the end of life.	Level III
Noome 2016 (Netherlands)[74]	To explore how intensive care unit (ICU) nurses describe their role during end of-life care in the ICU, related to the interaction between patient, family and professionals (care triad)	Nursing professionals	Systematic review	ICUs in hospital	Four categories emerged: care for the ICU patient, care for the family, environmental aspects of end-of-life care and organisational aspects of end-of-life care. Regarding the care triad, a gap exists between theoretical models and the actual care provided by ICU nurses during end-of-life care. The relational aspect of care, like aimed with care triad, is absent.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
O'Donnell 2018 (USA)[49]	To determine if early initiation of goals of care conversations by a palliative care–trained social worker would improve prognostic understanding, elicit advanced care preferences, and influence care plans for high-risk patients discharged after HF hospitalisation	Patients with advance heart failure allocated either to the intervention group or to usual care	Pilot randomised clinical trial	Metropolitan women's Hospital	At enrolment, treating physicians anticipated death within a year for 32 patients (64%), but 42 patients (84%) predicted their life expectancy to be longer than five years. At six months, more patients in the intervention group than in the control group had physician-level documentation of advanced care preferences in the electronic health record. Surviving patients allocated to intervention were also more likely to revise their baseline prognostic assessment in a direction consistent with the physician's assessment. Among the 31 survivors at six months, there was no measured difference between groups in depression, anxiety, or quality-of-life scores.	Level I

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Orford 2019 (Australia)[50]	To describe the effect of a communication skills training programme on patient-centred goals of care documentation and clinical outcomes in critically ill patients with life-limiting illnesses (LLI) referred for intensive care management	Adult patients with life-limiting illness referred to the intensive care unit (ICU)	Prospective before-and-after cohort study	ICUs in a tertiary teaching hospital	The intervention was associated with increased documentation of a patient-centred goals of care discussion (PCD) from 50% to 69% and 43% to 94% in patients deceased by day 90. A significant decrease in critical care as the choice of resuscitation goal was observed. Although there was no decrease in admission to ICU, there was a significant decrease in medical emergency team call prevalence. The cancer and organ failure groups had a significant decrease in 90-day mortality, and the frailty group had a significant decrease in 90-day readmissions.	Level II

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Paladino 2019 (USA)[75]	To evaluate the efficacy of a communication quality-improvement intervention in improving the occurrence, timing, quality, and accessibility of documented serious illness conversations between oncology clinicians and patients with advanced cancer	Clinicians and patients with cancer allocated to interventions and control groups	Cluster randomised clinical trial	Outpatient oncology clinic in a large national cancer institute	Medical record review after patients' death demonstrated that a significantly higher proportion of intervention patients had a documented discussion compared with controls and intervention conversations occurred a median of 2.4 months earlier. Conversation documentation for intervention patients was significantly more comprehensive and patient centred, with a greater focus on values or goals, prognosis or illness understanding and life-sustaining treatment preferences. Documentation about end-of-life care planning did not differ between arms. Significantly more intervention patients had documentation that was accessible in the electronic medical record.	Level I

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Patel 2018 (USA)[51]	To determine whether a Lay Health Worker (LHW) program can increase documentation of patients' care preferences after cancer diagnosis	Patients with stage 3 or 4 or recurrent cancer. Six-month program with an LHW trained to assist patients with establishing end-of-life care preferences vs usual care.	Randomised clinical trial	Veterans Affairs Palo Alto Health Care System	Within six months of enrolment, patients randomised to the intervention had greater documentation of goals of care than the control group and larger increases in satisfaction with care on the Consumer Assessment of Health Care Providers and Systems 'satisfaction with provider' item. The number of patients who died within 15 months of enrolment did not differ between groups. In the 30 days before death, patients in the intervention group had greater hospice use, fewer emergency department visits, fewer hospitalisations and lower costs than patients in the control group.	Level I

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Picker 2017 (USA)[52]	To determine whether an Early Warning System could identify patients wishing to focus on palliative care measures	Patients 18 years old or older generating early warning system on a study unit	Prospective, randomised pilot trial study	Adult inpatient general medicine units of metropolitan hospital	Advanced directive documentation was significantly greater prior to discharge in the intervention group as were first-time requests for advanced directive documentation. Documentation of resuscitation status was also greater prior to discharge in the intervention group. There was no difference in the number of patients requesting a change in resuscitation status between groups. However, changes in resuscitation status occurred earlier and on the general medicine units for the intervention group compared to the control group. The number of patients transferred to an ICU was significantly lower for intervention patients. The median (interquartile range) ICU length of stay was significantly less for the intervention group. Hospital mortality was similar.	Level I

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Pringle 2015 (UK)[27]	To examine international evidence relating to dignity and person-centred care for people with palliative care needs in the acute hospital setting	Patients, family and health care professionals	Systematic review	Mainly hospital setting, i.e. ED. ICU, palliative care unit within acute hospital	Papers highlighted the many and varied potential threats to dignity for people with palliative care needs in acute settings, including symptom control and existential distress, approaches and models in care provision and healthcare settings and design.	Level III
Quinn 2016 (USA)[76]	To answer the clinical question: In neonatal intensive care, what evidence can be used to guide implementation of palliative care protocols?	Studies were based on traditional research protocols and description of implementation Neonatal palliative care (NPC) in clinical practice settings	Systematic review	Neonates, neonatal intensive care unit	Approaches to NPC implementation were varied, and outcome data were inconsistently reported. Healthcare team members cited a need for education and consistent, ethical delivery of NPC. Common barriers were identified as lack of NPC education, poor communication, and lack of adequate resources such as staff and space.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Rabbetts 2016 (Australia)[33]	To evaluate the implementation of an assessment process for general nurses involved in providing end-of-life care	Nursing professionals	Mixed-method, three-phased study (Survey, audit, focus groups)	Medical ward of a regional hospital in a rural setting	Nurses were able to integrate the use of the assessment process into the care of patients. The author concludes, while nurses working in rural settings require general clinical knowledge of a wide range of patient groups, validated assessment scales can assist them in the provision of evidence-based palliative care.	Level III
Rajamani 2015 (Australia)[77]	To evaluate the process of end-of-life care practice and to assess family and staff satisfaction with the care provided	ICU patients who had 'withdrawal' of life-sustaining treatment. In addition, family members and healthcare staff were involved in the survey.	Prospective observational study	Adult general ICU in an urban hospital	Problems identified included poor documentation of family meetings and symptom management. Emotional/spiritual support was not offered to families or ICU staff. The overall level of end-of-life care was good. The overwhelming majority of families and healthcare staff were highly satisfied with the care provided. Problems identified related to communication documentation and lack of spiritual/emotional support.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Ranse 2016a (Australia)[34]	To identify factors associated with critical care nurses' engagement in end-of-life care practices	Nursing professionals	Multivariable analysis of data on responses to an online self-report survey	ICUs and ED in tertiary hospital	Stronger agreement with values consistent with a palliative approach, and greater support for patient and family preferences were associated with higher levels of engagement in end-of-life care practices. Higher levels of preparedness and access to opportunities for knowledge acquisition were associated with engagement in the interpersonal practices of patient and family centred decision making and emotional support.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Ranse 2016 (Australia)[35]	To identify the end-of-life care practices of critical care nurses	Nursing professionals	A national cross-sectional online survey	Australian critical care nurses	Exploratory factor analysis identified six domains of end-of-life care practice: information sharing, environmental modification, emotional support, patient and family centred decision-making, symptom management and spiritual support. Descriptive statistics identified a high level of engagement in information sharing and environmental modification practices and less frequent engagement in items from the emotional support and symptom management practice areas.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Raymond 2017 (Australia)[36]	To investigate nurses' roles and responsibilities in providing bereavement care during the care of dying patients within acute care hospitals	Nursing professionals	Systematic review of mixed-method studies	Acute care hospitals	Nurses' role in bereavement care included patient-centred care, family-centred care, advocacy and professional development. Concerns about bereavement roles included competing clinical workload demands, limitations of physical environments in acute care hospitals and the need for further education in bereavement care.	Level III
Sahlollbey 2020 (Canada)[53]	To examine the impact of palliative care on acute care hospitalisations, survival, symptoms, and quality of life (QOL) in patients with advanced heart failure	Patients with advanced heart failure	Systematic review of RCTs	Acute hospital	Compared with usual care, palliative care interventions were associated with a substantial reduction in hospitalisations, modest improvement in QOL, and modest reduction in symptom burden. There was no clear adverse impact on mortality. Most studies had methodological limitations that increased the risk of biases.	Level I

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Scott 2016 (Australia)[54]	To develop, implement and explore the effects of a program in advance care planning (ACP) within a tertiary hospital general medicine service	Consecutive patients admitted acutely in hospital	Before–after exploratory mixed-methods evaluation	Tertiary referral hospital	Major barriers to ACP perceived by at least 30% of questionnaire respondents included the reluctance of patients and family to discuss ACP, insufficient time to initiate or complete ACP, patient and/or family factors that rendered ACP impractical, inadequate communication skills around end-of-life issues, confusion about who was primarily responsible for conducting ACP and difficulty using ACP documentation forms. Enabling factors included dedicated ACP workshops, facilitator and resource packages for staff, and ACP brochures for patients and family.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Scott 2020 (Canada)[44]	To appraise available research on the impact of inpatient palliative care consultations on transitions from hospital to community settings.	Inpatient palliative care consultation teams	Systematic review	Acute hospital, hospice and nursing home	Studies reported that inpatient palliative care consultations are associated with high rates of discharge to community settings, greater provision of services post-discharge, improved coordination and lower rates of rehospitalisation.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Shepherd 2018 (Australia)[37]	To determine in a sample of nurses working in acute and critical care hospital wards: (1) their knowledge of ACP; (2) their own participation in ACP decision-making practices; and (3) associations between nurses' socio-demographic characteristics; clinical expertise; and knowledge and behaviour in relation to ACP practices.	Nursing professionals	Questionnaire-based, cross-sectional study	Acute and critical care wards of metropolitan hospitals	Nurses were least knowledgeable about items relating to the authority of medical and financial substitute decision-makers. Few nurses had prepared advance directives or appointed medical or financial decision-makers, when compared to discussing end-of-life wishes or organ donation. Overall, 15% of nurses had not engaged in any advance care planning practices. Nurses who had cared for 11–30 dying patients in the last six months were more likely to have an increased knowledge score. Older nurses were more likely to participate in a greater number of advance care planning practices and an increase in shifts worked per week led to a significant decrease in nurses' participation.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Sidebottom 2015 (USA)[55]	To assess if inpatient palliative care for heart failure patients is associated with improvements in symptom burden, depressive symptoms, QOL, or differential use of services	Patients with heart failure allocated to intervention and control group over a 10-month period	Randomised controlled trial	Tertiary-care facility	Improvements were greater at both one and three months in the intervention group for primary outcome summary measures after adjusting for age, gender, and marital status differences between study groups. QOL scores increased by 12.92 points in the intervention and eight points in the control group at one month. Improvement in symptom burden was 8.39 in the intervention group and 4.7 in the control group at one month. Advance care planning (ACP) was the only secondary outcome associated with the intervention.	Level I

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Smith 2017 (Australia)[78]	To evaluate the introduction of the 'Acute Resuscitation Plan' (ARP)	All admissions to the hospital from January to June 2014 (Not for CPR period) and January to June 2015 (ARP period)	Retrospective case note audit	Tertiary metropolitan hospital	Resuscitation plans were present for 453 of 23,325 (1.9%) admissions in the Not for CPR period versus 1,801 of 24,037 (7.5%) in the ARP period. A total of 42% of ARP specified 'care of the dying' in the event of arrest. Acknowledgement of the views of the patient (or representative) was indicated on 37% of ARP and of a senior physician on 28%.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Starr 2019 (USA)[56]	To describe associations among end-of-life discussions, health-care utilisation and place of death, and costs in persons with advanced cancer and explore variation in study measures	Patients with advance cancer conditions	Systematic review	Hospital and hospice care	End-of-life discussions are associated with lower health-care costs in the last 30 days of life; lower likelihood of acute care at end of life; lower likelihood of intensive care at end of life; lower odds of chemotherapy near death; lower odds of emergency department use and shorter length of hospital stay; greater use of hospice; and greater likelihood of death outside the hospital. Earlier end-of-life care discussions (30+ days before death) are more strongly associated with less aggressive care outcomes than conversations occurring near death.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Timmins 2018 (Ireland)[79]	To explore the issues surrounding privacy during death in ICU	Patients, families and health care professionals	Systematic review or qualitative and quantitative studies	ICUs in acute hospital setting	The analysis of the studies revealed eight themes, and this study presents the three key themes that were found to be recurring and strongly interconnected to the experience of privacy and death in ICU: 'Privacy in ICU,' 'ICU environment' and 'End-of-Life care'. Research has shown that patient and family privacy during the ICU hospitalisation and the provision of the circumstances that lead to an environment of privacy during and after death remains a significant challenge for ICU nurses. Family members have little or no privacy in shared room and cramped waiting rooms, while they wish to be better informed and involved in end-of-life decisions. Hence, death and dying for many patients takes place in open and/or shared spaces which is problematic in terms of both the level of privacy and respect that death ought to afford.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Travers 2016 and Taylor (UK)[80]	To explore the literature identifying what is known about the barriers to initiating end-of-life conversations with patients from the perspective of doctors and nurses in the acute hospital setting, and to propose recommendations	Health care professionals (doctors or nurses)	Systematic review	Acute hospital setting	Recurrent themes of barriers within the literature related to a lack of education and training, difficulty in prognostication, cultural differences and perceived reluctance of the patient or family	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Urban 2019 (Australia)[57]	To explore the quality of deaths in an acute hospital under a nephrology service at two teaching hospitals in Sydney with renal supportive care services over time	All end stage renal deaths under the nephrology team in 2004, 2009 and 2014 at St George Hospital (SGH) and in 2014 at the Concord Repatriation General Hospital	Retrospective chart review	Nephrology service in acute metropolitan hospital	Rates of interventions in the last week of life were low and did not differ across the three years. There was a significant increase in the prescription of anti-psychotic, anti-emetic and anti-cholinergic medication over the years at St George Hospital (SGH). Use of end-of-life-care plan was significantly higher at SGH, and their use improved several quality domains. Of all deaths, 68% were referred to palliative care at SGH and 33% at Concord Repatriation General Hospital (not significant). Cessation of observations and non-essential medications and documentation of bereavement information given to families was low across both sites in all years, although this significantly improved when end-of-life care plans were used.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Vasquez 2019 (Australia)[38]	To describes the Time is Precious (TiP) project, and reports findings of an evaluation of TiP	Nursing professionals	Literature review, and development, implementation, and evaluation of a palliative care decision making framework (tool)	ED in a metropolitan hospital	Conclusion: The TiP tool enables ED staff to identify a specific group of patients with the sole intention of providing palliative care and comfort at a time of great distress while supporting EOL palliation for patients and their families/carers	Level V
Virdun 2015 (Australia)[81]	To ascertain the five most important elements of inpatient end-of-life care as identified by patients with palliative care needs and their families	Patients and family caregivers	Systematic review	ICUs in acute hospital	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.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Virdun 2017 (Australia)[15]	To gain a richer and deeper understanding of elements of end-of-life care that consumers consider most important within the hospital setting	Patients and family	Systematic review (meta-synthesis)	Various acute settings in hospital (e.g. inpatient, ICU, oncology ward)	Synthesis yielded seven patient and 10 family themes including six common themes: (1) expert care; (2) effective communication and shared decision-making; (3) respectful and compassionate care; (4) adequate environment for care; (5) family involvement; and (6) financial affairs. Maintenance of sense of self was the additional patient theme, while the four additional family themes were as follows: (1) maintenance of patient safety; (2) preparation for death; (3) care extending to the family after patient death; and (4) enabling patient choice at the end of life. Conclusion: Consumer narratives help to provide a clearer direction as to what is important for hospital end-of-life care. Systems are needed to enable optimal end-of-life care, in accordance with consumer priorities, and embedded into routine hospital care.	Level III

Author, year, country	Study purpose	Study population/ participants	Design/ methods	Setting	Relevant key findings	Evidence hierarchy
Williams 2020 (USA)[82]	This integrative review seeks to understand whether targeting patients with episodic disease trajectories in the acute care setting will increase their willingness to participate in advance care planning (ACP) discussions	Patients with heart failure or COPD, and health care professionals	Systematic review (integrative review)	Acute hospital setting	Four themes emerged from the literature: (1) improved patient attitudes toward ACP; (2) effective communication surrounding care preferences; (3) strengthened connection between preferred and delivered care; and (4) increased patient involvement in ACP. Conclusion: Chronic diseases such as heart failure and COPD have a high symptom burden punctuated by exacerbations, making it difficult to know when introduction of ACP discussions would be most beneficial. Future research should focus on a deeper evaluation of when to introduce ACP conversations in this population and which ACP interventions are effective to facilitate these discussions.	Level III

Table A2: Study characteristics – Pandemic review

Author, year, country	Study design	Summary	Pandemic focus	Findings	Fast tracked paper (Y/N)	Evidence hierarchy
Adams 2020 (USA)[89]	Narrative, descriptive. Not a study.	Development of a framework to mobilise palliative care workforce re goals of care	COVID-19	Proposed a framework for proactively mobilising the palliative care workforce to aggressively address goals of care in all patients, with the aim of reducing the need for rationing of resources	Y	Level V
Downer 2010 (Canada)[91]	Narrative, descriptive. Not a study.	Development of a pandemic palliative care plan	H1N1 Influenza	Although all triage systems have guaranteed palliative care for those who are denied critical care, no jurisdiction has yet developed a plan to accommodate the anticipated ‘‘surge’’ in demand for palliative care. The authors presented a thematical and ethical justification for a palliative care surge plan and outline some of the key elements that should be included in such a plan.	Unsure	Level V

Author, year, country	Study design	Summary	Pandemic focus	Findings	Fast tracked paper (Y/N)	Evidence hierarchy
Humphreys 2020 (USA)[87]	Narrative, descriptive. Not a study.	Development of pandemic telemedicine consult plan	COVID-19	The need for tele palliative medicine in the inpatient setting emerged in the face of decreased provider availability because of quarantine and redeployment and seek to reach increasingly isolated hospitalised patients. Authors describe a rapid and ongoing implementation of tele palliative medicine consultation for inpatient palliative care teams and discuss lessons learned and recommendations for programs considering similar care models.	Y	Level V
Knights 2020 (UK)[85]	Narrative, descriptive. Not a study.	Lessons learned from resource limited settings	COVID-19	The study article explored how the field can contribute by ensuring that PC principles and practices are woven into everyday healthcare practice. Alternative ways of providing care under such pressure and discuss three areas of learning from resource-limited settings are presented: (1) integration of palliative medicine into everyday practice; (2) simplification of biomedical management plus multidisciplinary teamwork; and (3) effective use of volunteers.	Y	Level V

Author, year, country	Study design	Summary	Pandemic focus	Findings	Fast tracked paper (Y/N)	Evidence hierarchy
Koeberle 2020 (France)[92]	Narrative, descriptive. Quality improvement report.	Organisation of care model	COVID-19	In COVID-19 endemic situation, with massive flows of patients requiring holistic management including specific and intensive care, the appropriate assessment of each patient's level of care and the organisation of specific networks is essential. To that end, a territorial organisation of health care, favouring communication between all actors is proposed. This organisation meets the urgent health needs of all stakeholders, facilitating its deployment and allows the sustainable implementation of a coordinated geriatric management dynamic between the stakeholders on the territory.	Y	Level V
Kuntz 2020 (USA)[84]	Evaluation of family meetings	Implementation of telemedicine to facilitate electronic family (e-family) meetings to facilitate in-patient palliative care	COVID-19	Implemented and evaluated the use of telemedicine on one aspect of palliative care consultation, the family meeting. The overall ratings of the e-family meetings were high. On a five-point Likert-type scale, the average clinician rating of the e-family meeting overall quality was 3.18.	Y	Level V

Author, year, country	Study design	Summary	Pandemic focus	Findings	Fast tracked paper (Y/N)	Evidence hierarchy
Leong 2004 (Singapore)[90]	Qualitative study using semi structured interviews of palliative care workers	Understanding the perspective use of a hospital-based palliative care service (PCS), the spiritual and psychosocial impact of a novel and potentially fatal viral epidemic on patients, their families and health care workers	SARS	Dealing with a novel viral epidemic creates spiritual and psychosocial issues similar to those encountered in a palliative care practice. Palliative care workers would do well to be aware of such issues and act proactively when such epidemics arise.	Y	Level III
Mercadante 2020 (Italy)[86]	Short report on a study of 16 interviews	Adopting ‘‘WhatsApp’’ to get family members to participate in clinical rounds. Family members of patients admitted to the acute palliative care unit and hospice were screened for a period of two weeks.	COVID-19	Some of the problems related to government restrictions could be overcome with simple technology available to most population, proposing a temporary, hopefully, communication model of adaptation to this crisis. However, as expected, this modality of communication cannot substitute the real presence bedside and should be considered as a temporary measure.	Y	Level III

Author, year, country	Study design	Summary	Pandemic focus	Findings	Fast tracked paper (Y/N)	Evidence hierarchy
Mishra 2020 (India)[88]	Narrative, descriptive. Not a study.	Recognising the unique palliative care needs of cancer patients during pandemic and formulate the plan to maintain continuity of services	COVID-19	Triaging systems are essential tools for proper resource allocation during a pandemic. Therefore, we suggest triaging tools for emergency in hospital palliative care services: community-based palliative care and end-of-life care for cancer patients. Incorporation of newer technologies and identifying the potential resources are the other key components of the preparedness strategy.	Unsure	Level V
Montauk 2020 (USA)[83]	Commentary	ICU providers can take several steps (provided) to help mitigate the trauma experienced by these families	COVID-19	ICU families face additional barriers in fully understanding the complex medical needs of their loved ones (and hence being able to make informed care decisions on their behalf); establishing rapport and bonding with nurses and other members of the ICU treatment team; and, in the event that a loved one passes, achieving closure. ICU health care providers can take steps to mitigate these outcomes by being mindful of the unique stressors ICU families face during pandemic and tailoring their communication and behaviour accordingly.	Y	Level V

Table A3a: Grey literature included documents – End-of-life care focus

No.	Document	Description	Implications for hospitals	URL
i	Care Plan for the Dying Person: Health Professional Guidelines Published by the State of Queensland (Queensland Health), February 2019. Clinical Excellence Division	The Care Plan for the Dying Person is a Queensland Health state-wide clinical tool that supports multidisciplinary care in the last hours and days of life in hospital settings. The website also provides accompanying materials e.g. assessment tools, audit tools.	Specific to end-of-life care in hospitals	https://www.health.qld.gov.au/__data/assets/pdf_file/0023/833315/cpdp-care-plan-hp-guidelines.pdf
ii	End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients, Guidance for health professionals, January 2018. Clinical Excellence Division.	Includes decision making flowchart, criteria for assessing decision making capacity, legal considerations, ethical considerations	Specific to end-of-life care in hospitals	https://www.health.qld.gov.au/__data/assets/pdf_file/0033/688263/acp-guidance.pdf
iii	Palliative and end-of-life care: position statement, St Vincent's Health Australia, April 2017	Position statement	Specific to end-of-life care in hospitals under the auspices of St Vincent's Health Australia	https://www.svha.org.au/newsroom/position-statements

No.	Document	Description	Implications for hospitals	URL
iv	End of Life and Palliative Care in the Emergency Department Policy (P455), Australasian College for Emergency Medicine May 2020	This policy aims to promote discussion and awareness of end-of-life care (end-of-life care) planning, and to ensure that emergency department (ED) staff are confident in providing quality end-of-life care. The policy also describes ED systems and processes for recognising and appropriately caring for patients at the end of life (EoL). This policy applies to all Australian and New Zealand EDs. It pertains to the treatment of adults at the EOL.	Specific to end-of-life care in hospital emergency departments in Australia and NZ	https://acem.org.au/getmedia/d55cb8ce-2d26-49d5-823a-f7f07b5c19cc/P455-PolicyonEoLandPalliativeCareinED-Jul16.aspx
v	Pharmacological Management of Symptoms for Adults in the Last Days of Life Clinical Guideline, SA Health, February 2019	Clinical guideline: 'The Pharmacological Management of Symptoms for Adults in the Last Days of Life Clinical Guideline gives recommendations for initial prescribing practices for adult patients assessed as being in the last days of their lives and likely to die in a general hospital ward. The recommendations may also be useful in other care settings'	Specific to end-of-life care in hospitals.	https://www.sahealth.sa.gov.au/wps/wcm/connect/303827804a23c94db3fdf390d529bdaa/Clinical_Guideline_Pharmacological_Management_of_Symptoms_for_Adults_v2.0_12.04.19.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-303827804a23c94db3fdf390d529bdaa-n5hD7iy
vi	Palliative Care Service Development Guidelines (2018) Palliative Care Australia, 2018	These guidelines have been developed to articulate Palliative Care Australia's expectations for the palliative care system and service design through a population-based approach.	A guideline for palliative care service development. This includes the development of hospital based palliative care teams.	https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf

No.	Document	Description	Implications for hospitals	URL
vii	Life Before Death: Improving Palliative Care for Older Australians, Dr Jessica Borbasi, Research Report, Centre for Independent Studies November 2017	A document detailing the requirements to improve palliative care for older Australians. It articulates the need for changes across the board.	A report re: palliative care for older Australians. This includes care in all settings with a description of care in hospitals.	https://www.cis.org.au/app/uploads/2017/11/rr34.pdf
viii	*End of Life Care in a sample of Regional and Rural NSW – what is the current situation and what are the problems?* Centre for Innovation in Regional Health, 2019.	A white paper developed to support the work of NSW Regional Health Partners. (Copyright NSW Regional Health Partners, Newcastle, Australia 2019).	A white paper detailing end-of-life care in regional and rural NSW that includes some hospital/specialist palliative care outreach examples such as telehealth	https://www.crrmh.com.au/content/uploads/end-of-life-white-paper.pdf
ix	WA End-of-Life and Palliative Care Strategy 2018–2028, WA Department of Health	The strategy informs public, private, community and non-government health sectors of the priority areas within end-of-life and palliative care over the next 10 years	A strategy for end-of-life care in WA across all settings	https://ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf
x	Palliative Care in the Catholic Sector, Catholic Health Australia, 2019. A report by Catholic Health Australia.	The aim of the report is to contribute to the quality and quantity of information that PC organisations including Catholic Health Australia (CHA), policy makers and decision makers have available	A comprehensive snapshot of palliative care in the Catholic sector that includes the state of play in its over 80 hospitals	https://www.cha.org.au/images/Media_Releases/2019/CHA030_PalliativeCareInTheCathSector_A4REPORT_15March_LR.pdf

Table A3b: Grey literature included documents – Pandemic (COVID-19) specific

No.	Document	Description	Implications for hospitals	URL
xi	Communication tips for clinicians supporting patients and family facing life-threatening illness / infection (COVID-19). The Commission for Excellence and Innovation in Health (CEIH). SA Government.	Covid-19 Communication tip sheet	Specific to end-of-life care in hospitals (as the likely setting for care) but can be relevant to any health professional	https://www.sahealth.sa.gov.au/wps/wcm/connect/458de9fd-79d7-48c3-adb7-953548b618fe/20200515+-+COVID-19+Palliative+Care+Communications.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-458de9fd-79d7-48c3-adb7-953548b618fe-n8S2fbU
xii	Symptom management for adult patients with COVID-19 receiving end-of-life supportive care outside of the ICU. The Commission for Excellence and Innovation in Health (CEIH). SA Government.	Covid-19 Clinical prescribing flowchart and guidelines	May not be specific to end-of-life care in hospitals (although this is the most likely setting for care)	https://www.sahealth.sa.gov.au/wps/wcm/connect/88aa1465-c179-444d-a900-6e6fa90ec8c7/20200515-+COVID-19+Pharmacological+Guidelines_Palliative+Care.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-88aa1465-c179-444d-a900-6e6fa90ec8c7-n8R-7c7

No.	Document	Description	Implications for hospitals	URL
xiii	Palliative Care, Section 20, Clinical Guidelines for the management of COVID-19 in Australasian emergency departments, Australasian College for Emergency Medicine 02 July 2020 Version 4.1	Pandemic modelling guidelines: 'These Guidelines are a framework for all in EDs to work from as we plan and respond to the pandemic. With our states, countries, metropolitan, rural and regional emergency care facilities all at different stages of community impact, and with markedly different workforce, infrastructure and resources available, local implementation of these guidelines will differ.'	Specific to end-of-life care in hospitals	https://acem.org.au/getmedia/78105c4b-5195-43f6-9c91-25dda5604eaf/Clinical-Guidelines-for-the-management-of-COVID-19-in-Australasian-emergency-departments

Table A3c: Grey literature included documents – CareSearch conference abstracts 2017–2020

No.	Author	Title	Relevance to hospital / Conclusion
xiv	Price et al. (Hunter New England Health) Oceanic Palliative Care Conference 2019 (19OPCC)	Quality care in the last days of life; can the 'Last Days of Life Toolkit' (LDOLT) improve care of dying patients at a NSW District Hospital? A before and after audit (n=58 and n=54) was performed using medical records of patients who died during their admission at a NSW regional hospital.	The rollout of the LDOLT and JMO (junior doctors) education sessions have had a positive correlation with improving the quality care of dying patients at this NSW regional hospital. We are confident that this represents the beginnings of a positive cultural and clinical change.
xv	Hughes (Tasmanian Health Service) Australian Grief and Bereavement Conference 2018	Acute bereavement in the setting of the mortuary: a social work perspective. Highlights the role of social worker, providing bereavement support to people specifically in the acute stage of bereavement, who are summonsed by the police or a coroner's associate to visually identify someone they know personally or may wish to view	Understanding grief and bereavement in the context of the mortuary is limited to those that work in the area or by those whose lives have been irrevocably changed by the death of a significant person. This presentation highlights a topic that is rarely discussed in public conversation, given that no body visits a mortuary unless they must.
xvi	Rane et al. (Uni of Melbourne) Biennial Conference 2018 (ANZSPM)	Lessons from the dying: a novel approach to improve junior doctor wellbeing in the face of death and dying. A novel pilot program that aimed to assist junior medical staff to recognize and manage difficult emotions such as grief, guilt and anxiety in a small group setting, facilitated by a palliative care physician and a psychiatrist.	It was evaluated very positively by the participants and the vast majority found the issues discussed both relevant to their day-to-day work, as well as having an impact on changing their practice in the future. It provides a safe, non-judgmental environment for junior doctors to reflect on their practice and to improve communication skills. Ongoing work needs to be done to continue to support the sessions to enable more participants to attend.

No.	Author	Title	Relevance to hospital / Conclusion
xvii	Swensen. Sydney Adventist Hospital. PCNA 2018, Palliative Care Nurses Australia, 2018	Connecting for education; Extending the reach of traditional ward-based clinical education by embracing digital communication channels. Traditional methods of face-to-face ward in-services were only reaching 19% of staff. A closed Facebook group was created for ward education and training purposes. Traditional face-to-face inservices were recorded using a mobile phone and uploaded to the Facebook page.	Over an eight-month period the percentage of ward clinicians accessing education in-services increased from 19% to 77%. Positive feedback included the ability to access the information many times over at a time of their choosing, with most staff choosing to view the in-service from home. Negative feedback included poor sound quality and not being able to ask questions. Acceptance of the closed Facebook in-service group has grown over time and increased the reach of ward in-service three-fold. The overwhelming majority of staff have expressed their desire for this mechanism of accessing clinical education to continue.
xviii	Lacey (hunter New England LHD) PCNA 2018, Palliative Care Nurses Australia, 2018	Rapid Response End of life Care: a new model of care. Although rapid response teams (RRT) primary goals are escalation of care to prevent mortality, it is also recognised internationally that approximately 30% of all RRT calls relate to end-of-life care situations. A new model of care was developed in a regional tertiary hospital by an End-of-life Care Nurse Practitioner (End-of-Life care NP).	The End-of-Life care NP aims to address throughout the hospital the essential elements of end-of-life care as outlined by the ACSQHC. Patients are seen within 18 hours (weekdays), and referrals were accepted from any health professional within the hospital. The End-of-Life care NP provides individualised psycho-social and spiritual care planning, symptom assessment and management, advocacy for end-of-life decision making in the acute environment, communication support and bereavement follow up to all families supported. After two years of role development in 2017 the End-of-Life care NP had referrals for almost 70% of inpatient deaths within the hospital, with 70% of the deaths occurring within 48 hours of referral.

Appendix 9: Opportunities for development of the Consensus Statement

Opportunities for development stemming from the results of this rapid review include two new elements to the processes of care (communication and bereavement), and two new organisations prerequisites (organisational culture and physical space).

Table A4: Suggested Essential Elements 2020 Format adapted from National Palliative Care Strategy 2018, Australian Government Department of Health

Suggested Essential Elements	What this means for people affected by life-limiting illness	What this means for people providing care
New **Communication**	I am asked if I wish to know or discuss my prognosis, dying and death	I offer to discuss the future with patients and their families[64, 66]
	My personhood, background, beliefs, culture and preferences are respected	I know how to assess and communicate in a holistic and culturally sensitive way with considerations of health literacy, use of interpreters, cultural taboos and specific faiths[12, 50, 61, 77, 81]
	I trust the professionals who provide me service and care are honest with me about my future	I share with patients and families any information about their illness and future to enable and empower them[29, 35, 48, 50]
	Professionals personalise communication to allow me to understand and prepare for the end of my life	I am confident in discussing with patients and families issues concerning prognosis, withdrawal of interventions, end of life and imminent death[12, 68, 77, 80]
	My preferences and hopes for the future are acknowledged and the professionals providing service can explain my health and care in ways I understand	I know how to communicate the specific limitations of health interventions for individuals while also describing the benefits in terms of end-of-life hopes and preferences[48, 51, 81]
Patient Centred Care	I am included in making decisions about my health care	I know how to negotiate and co-plan health care with patients[12, 50, 61, 77, 81]

Suggested Essential Elements	What this means for people affected by life-limiting illness	What this means for people providing care
	My family is informed and respected	I respect the importance of families and can dutifully share information with them about potentially sensitive and emotional topics[12, 68, 77, 80]
	The professionals providing care can continuously engage and care for me when I am fearful, angry, distressed or emotionally fragile.	I know how to compassionately and skilfully engage and provide care in highly emotional situations. I can also recognise the impact in providing end-of-life care on my own emotions and know how to self-care and where to seek support[33, 34, 47, 52, 54, 66].
	My emotional, social, spiritual, physical and financial needs are taken into account.	I appreciate and recognise whole person care and know to arrange structed family meetings to plan support and service[12, 80]
Goals of Care	If I wish my choices inform my health care	In unison with patients I can plan and prioritise care needs and health services[12, 68, 77, 80]
	My hopes, social, physical, financial and spiritual needs, culture and values are acknowledged	I know how to incorporate end-of-life clinical and non-clinical care decision making into my planning[32, 35, 47, 48, 55, 64]
	If I wish I am empowered to prepare for my death	I am respectful of patient's choices and allow them self-determination through adhering to their advance care plan and or wishes[48, 62, 72, 74]
	My end of life is positively supported with various health care options that are discussed with me.	I know my positive and compassionate attitude and approach in providing end-of-life care has a positive effect on dying patients and families[47, 51, 54]
	I trust the professionals who provide my care to know about me.	I share and communicate the goals of care for each patient with my team and service[29, 35, 48, 50]
	My wishes are known and respected no matter where I present for my health care.	I seek out patient views and documentation on goals of care no matter where I work[48, 62, 72, 74]

Suggested Essential Elements	What this means for people affected by life-limiting illness	What this means for people providing care
Teamwork	The professionals who provide my care are consistent in knowing my history and and overall health status.	I communicate and document clearly all goals of care decisions with my colleagues and patient's treatment teams[60, 77]
	I know my family and I can talk openly, if I wish, to any of the professionals who provide service.	I know the importance of inter-professional collaboration where goals of care are clearly articulated, and support can be targeted[31, 34, 54]
Using Triggers	I trust professionals will offer to tell me about the time I have left to live.	I am confident in understanding illness trajectories and using triggers, prognosis tools and being in tune to patient preferences and needs[31, 32, 65]
	When I want to know information about my future, I trust professionals will engage with me and honestly answer my questions.	I am confident in prognostication and understand the uncertainties, high emotion and complexity involved[47, 51, 54]
New **Bereavement**	My anticipatory losses are acknowledged by the professionals who provide care	I realise, that while death is a normal part of life, feelings of loss and grief are profound and require my acknowledgement, support and care[33, 36, 55]
	My family and I are kept informed during my hospitalisation	I recognize that my knowledge of the patient, delivery of personalised care and family meetings are impactful in terms of bereavement[33, 36, 55]
	My family will be cared for immediately after I die	I know how to provide emotional and practical support for newly bereaved people[32, 55]
	No matter how complex my needs, my family and I can receive tailored care	I recognise and know when and to whom to refer when complex grief, emotional and psychological needs arise[55]

Suggested Essential Elements	What this means for people affected by life-limiting illness	What this means for people providing care
Responding to Concerns	Professionals caring for me are protective and able.	I realize end-of-life care can escalate to an emergency situation. My professional capacity, end-of-life care knowledge, calmness in clinical crisis and compassion allow me to deliver excellent care[47, 52, 66].
New **Organisational Culture**	I am provided end-of-life holistic care when needed.	I know the end-of-life care processes and policies in my organisation. I also know my values, practices and thinking138 and that of my organisation about end-of-life care align[31, 49, 52, 67-69, 77].
	My health care is adaptable and responds to my changing needs.	End-of-life care is a priority where I work. I am aware my organisation at every level is committed to prepare people for the end of life with established KPI's, specific objectives and measurable outcomes[77].
Leadership and Governance	My opinions and preferences matter to my health care organisation. My viewpoints are sought to enhance health care generally and end-of-life care specifically.	End-of-life care is clearly embedded in the governance structure of my organisation. I know who leads our organisational approach, the governance structure, my role and responsibility in delivering safe and quality end-of-life care[7].
Education and Training	My care is provided by skilled and capable professionals	I am encouraged to access quality evidence-based education and training on physical, emotional, psychosocial and spiritual dimensions of end-of-life care[29, 35, 43, 51]
Supervision and Support	My care and health service are delivered by empathetic professionals	I know how and when to access peer support, mentoring clinical supervision and debriefing[7]
	My distress, pain or existential do not deter professionals from engaging in the delivery of my care	I know where I can access quality education and supports regarding my teams and my own self-care[7]
Evaluation and Feedback	I am offered a variety of services and care with explanation of what may or may not be beneficial for me	My organisation and I evaluate and audit the effectiveness of end-of-life care and this is clinician lead[7]

Suggested Essential Elements	What this means for people affected by life-limiting illness	What this means for people providing care
Supporting Systems	My family and I trust that systems are in place to share information about my preferences, prognosis, advance care plans and my health situation with my GP and other key professionals to enhance my care.	I trust my organisation has up-to-date IT, clinical handover and communication systems as I know when well used these enhance quality care[7]
New **Physical Space**	I am provided privacy and quality care so my family and I can talk openly and feel safe.	I can make use of space wherever I work to provide privacy for myself, patients and families[12, 34, 55, 66-68, 76, 80]
	My family and I have access to an environment where my cultural and spiritual practices can be practiced	I am confident I can facilitate and or modify environments to enhance patient care[53, 67]