AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

TRIM: D22-45978

October 2022

Rapid review of the literature on end-of-life care in aged care and community settings

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

Report 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.

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

Published by the Australian Commission on Safety and Quality in Health Care

Level 5, 255 Elizabeth Street, Sydney NSW 2000
Phone: (02) 9126 3600
Email: mail@safetyandquality.gov.au
Website: www.safetyandquality.gov.au

ISBN: 978-1-922880-27-7

© Australian Commission on Safety and Quality in Health Care 2022

All material and work produced by the Australian Commission on Safety and Quality in Health Care (the Commission) is protected by copyright. The Commission reserves the right to set out the terms and conditions for the use of such material.

As far as practicable, material for which the copyright is owned by a third party will be clearly labelled. The Commission has made all reasonable efforts to ensure that this material has been reproduced in this publication with the full consent of the copyright owners.

With the exception of any material protected by a trademark, any content provided by third parties and where otherwise noted, all material presented in this publication is licensed under a Creative Commons Attribution–NonCommercial–NoDerivatives 4.0 International licence.

Enquiries about the licence and any use of this publication are welcome and can be sent to communications@safetyandquality.gov.au.

The Commission's preference is that you attribute this publication (and any material sourced from it) using the following citation:

> Rawlings D, Damarell R, Chakraborty A, Devery K, Tieman J. Rapid review of the literature on end-of-life care in aged care and community settings. Sydney: ACSQHC; 2022.

Disclaimer

This document includes the views or recommendations of its authors and third parties. Publication of this document by the Commission does not necessarily reflect the views of the Commission, or indicate a commitment to a particular course of action. The Commission does not accept any legal liability for any injury, loss or damage incurred by the use of, or reliance on, this document.

The content of this document is published in good faith by the Commission for information purposes. The document is not intended to provide guidance on particular healthcare choices. You should contact your healthcare provider for information or advice on particular healthcare choices.

Table of Contents

List of tables

-

List of figures

List of appendices

Acronyms and abbreviations

Term	Definition
ACP	Advance care planning
AIHW	Australian Institute of Health and Welfare
ANZSPM	Australian and New Zealand Society of Palliative Care
CALD	Culturally and linguistically diverse
CINAHL	Cumulative Index to Nursing and Allied Health Literature
Commission	Australian Commission on Safety and Quality in Health Care
COVID-19	Coronavirus disease 2019 (pandemic)
ED	Emergency department of a hospital
EoL	End of life
GoC	Goals of care
GP	General practitioner
HCP	Healthcare professional
Medline	Medicine’s Medical Literature Analysis and Retrieval System Online
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
OoH	Out of hours
PCA	Palliative Care Australia
PHN	Primary Health Network
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PLwD	People living with dementia
RAC	Residential aged care
RACF	Residential aged care facility

Term	Definition
RCT	Randomised controlled trial
RePaDD	Research Centre for Palliative Care, Death & Dying
SPC	Specialist palliative care
UK	United Kingdom
USA	United States of America

Executive summary

Background

The Australian Commission on Safety and Quality in Health Care (the Commission) has produced foundational work regarding the quality and safety of end-of-life care since 2012. The Commission released the *National Consensus Statement: Essential elements for safe and high-quality end-of-life care* (Consensus Statement) in 2015.[1] The Consensus Statement sets out suggested practice for the provision of end-of-life care in settings where acute care is provided. In 2020 the Commission engaged the Research Centre for Palliative Care, Death & Dying (RePaDD) based at Flinders University to undertake a rapid review of the literature within acute care to update the knowledge on which the Consensus Statement was built.[2] However, the principles articulated within the consensus statement also apply to other settings where patients who are deteriorating receive care, such as in the community and in residential aged care. The need for quality and safety in end-of-life care beyond hospitals has also been in the spotlight with the recent findings of the Royal Commission into Aged Care Quality and Safety which highlighted the vulnerability of older Australians living in residential aged care or receiving aged care services in the community.[3]

Scope

The Commission engaged the Research Centre for Palliative Care, Death & Dying (RePaDD) based at Flinders University to undertake a second rapid review of the literature (rapid review) to further update the knowledge on which the consensus statement was built. The aim of the rapid review is to provide the current evidence base in response to the following questions:

1. What does the evidence show about best practice principles, processes, and organisational prerequisites for delivering safe and high-quality end-of-life care in aged care and community settings?
2. Are there new and emerging issues related to delivery of safe and high-quality end-of-life care in aged care and community settings?
3. What additional considerations should be made to ensure safe and high-quality end-of-life care in aged care and community settings 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, and key organisations and agencies. A standalone supplementary report was produced to address question 3 titled *Rapid review of the literature on end-of-life care in aged care and community settings. Supplementary Report: COVID-19*. This Supplementary Report is available as an attachment to this report.

Findings

The main literature review includes 130 papers, with 10 key themes and eight subthemes identified. The grey literature review identified a further 40 documents. Extracted data from included papers were coded and compared to identify the major themes across studies.

The themes from the main review are:

1. Collaborative or integrated care initiatives, with subthemes of
    - Community-based programs
    - Home-based care

- Residential aged care

Many of the studies identified investigated the benefits of care partnerships that traverse health sectors**.** These multidisciplinary pairings ranged from self-described 'collaborations' between service providers to more fully integrated models of care. Care coordination is vital for seamless transitions between care settings and our findings suggest that care partnerships that traverse health sectors with inter-organisational, inter-sector, and inter-professional collaborations are effective mechanisms for improving end-of-life care provision.

2. Structured approaches to end-of-life goals of care discussions and advance care planning.
   Advance care planning (ACP) and systematic approaches to communicating changing goals of care are prevalent concerns in the end-of-life care literature. A whole of organisation approach incorporating ACP into routine standardised practice has also shown increases in rates of ACP completion and documentation. Not having goals of care discussions or planning has seen increases in hospital transfers and dying in hospital.

3. Interventions to reduce community-hospital transfers
   While the focus of this review is beyond the hospital setting, care is inevitably experienced within a health and social care system. Older people living in the community or residential aged care are frequently transferred to the acute setting near the end of their life.

4. Primary care involvement in end-of-life care
   Having the support of a general practitioner emerged as a key positive factor in quality end-of-life care across all community settings. However, studies identified that a lack of GP skills in identifying the end of life can potentially lead to late discussions around goals of care. Interventions targeted at addressing this include structured approaches using prognostication tools, frameworks, education, and care pathways. Bereavement care (including treatment of complicated grief) has been identified as important by GPs, but it is often challenging to provide.

5. Dementia-specific interventions, with subthemes of:
   - Namaste Care
   - Other dementia -focused interventions

   The review identified many advanced dementia-specific intervention studies, most taking place in residential care, with Namaste Care by far the most prevalent. Staff and families have positively evaluated the program with benefits seen in the improvement of behaviour and psychological symptoms resulting in medication reductions as well as better pain management.

6. Interventions with a positive effect on communication
   In addition to the many formal ACP or goals of care studies already described, a range of interventions were found to have a positive effect on communication between the various people involved in a person's end-of-life care.

7. Interventions for symptom control and patient quality of life
   Some interventions were primarily concerned with improving patient symptoms or quality of life in the end-of-life phase, perhaps with additional effects such as reducing the likelihood of ED or hospitalisations. There is limited evidence of an association between the use of validated pain assessment scales in care and the likelihood of patients finding relief from pain or shortness of breath.

8. Practices to reduce aged care staff stress
   Residential aged care staff distress or burnout when confronted with intense symptoms such as those of pain or agitation, or the death of patients has been identified. Factors that strengthen staff capacity include excellent symptom control for the resident and support from supervisors.

9. Digital innovations
   A few studies identified digital health innovations such as teleconsultation

10. Other considerations, with sub-themes of:
    - Special populations
    - Access to medicines, anticipatory prescribing, and deprescribing

    Many studies focused on the unique end-of-life care needs or challenges associated with specific population groups, including people with non-malignant conditions, people experiencing incarceration or homelessness, the bereaved, and informal carers and families of someone at the end of life. The careful procurement and administration of medicines to people at the end-of-life emerged as an important consideration during the review across all settings. Organisational readiness for change was also identified as an important consideration supporting the importance of both communication and bereavement and in some areas has also highlighted organisational culture as an important consideration.

Limitations

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

Recommendations

The following 10 recommendations have been developed from the review of evidence presented, and which are detailed in the body of the report. They relate to the delivery of safe and quality care for people approaching the end of their life in community and residential aged care settings. We are highlighting higher level guidance, that can be interpreted at different levels in different ways, and across different landscapes. A further seven recommendations pertaining to pandemic preparedness are provided in the Supplementary Report.

- **Recommendation 1:** Integrated care – Facilitate and promote integrated care to improve end-of-life care in all settings
- **Recommendation 2**: Organisational readiness –Organisational readiness is considered across all sectors and settings as a pre-requisite for quality and safety in end-of-life care
- **Recommendation 3:** Keeping people at home –Promote strategies and interventions that focus on enabling people to remain at home at the end of life
- **Recommendation 4:** Bereavement The inclusion of bereavement care that traverses inpatient and community settings including residential aged care (RAC) in the Consensus Statement be considered

- **Recommendation 5:** Communication –Consider how to escalate the need for competent communication skills
- **Recommendation 6:** Structured approached to goals of care and advance care planning – Promote structured approaches to advance care planning that include end-of-life goals of care discussions
- **Recommendation 7**: Dementia care –Reinforce the importance of Dementia care as an important issue in all settings (i.e. acute, community and RAC)
- **Recommendation 8:** Medication management to optimise symptom control – Highlight the importance of medication management at the end of life with a focus on anticipatory prescribing and deprescribing in order to optimise symptom control
- **Recommendation 9:** Specific populations - Promote the work of palliative care programs and organisations that focus on the needs specific populations to address access and equity issues.
- **Recommendation 10:** Healthcare professionals – Highlight the need for ongoing support of healthcare professionals providing end-of-life care in all settings (e.g., prevention of burnout by addressing staff grief / bereavement by promoting self-care and clinical debriefing)

Conclusion

This rapid review of the literature set out to identify best practice principles, processes, and organisational prerequisites for delivering safe and high-quality end-of-life care in aged care and community settings. Recognition of the context in which end-of-life care is provided in the community is required to understand the complexity that lies therein. For example, while the focus of this review is the out of hospital setting, care is inevitably experienced within the whole health and social care system. with admissions to hospital potentially interspersed with care in the community. Transitions across settings at different timepoints require seamless care which can be achieved via attention to collaboration, communication, structured approaches, appropriate interventions for those at the end of life with organisational readiness for changes.

Health professionals in all settings need to be supported in order to enhance the quality of care provided.

Introduction

Australia has an increasingly ageing population with the number of expected deaths predicted to double by 2040.[4] The majority of the last year of a person's life is spent at home, interspersed with visits to their doctor (general practitioner and/or hospital specialist), visits to hospital (emergency department or an admission) and potentially, admission to residential aged care or to hospice. They may or may not see Specialist Palliative Care (SPC) services. Between 60% and 70% of Australians would prefer to die at home, but the reality is that half will die in hospital, and about a third in residential care (although this may be considered home for many).[5] To support more people to die at home, a considerable investment is required beyond the acute sector, to provide appropriate service and support for patients and their families who take on a considerable amount of caregiving. End-of-life care in the broad community, beyond hospital settings where care is provided continuously, is delivered via systems comprising a conglomeration of services and settings – a disparate landscape. Prisons, homeless shelters, aged care facilities, care in private homes, primary health networks, educational settings and more are often governed by various government sectors/portfolios, have different staffing profiles, different core objectives and various cultures and bureaucracies. This often makes planning and coordination of care difficult. There are also cost implications associated with care in the community not necessarily seen in hospital, such as medications and oftentimes home care arrangements.

In residential aged care (RAC), the complexity of care needs has risen steadily over the past 10 years, driven by admissions of those who are older, sicker and very frail. This has been in tandem with a decrease in palliative care provision.[6] Investment in end-of-life care via integrated care models in RAC could see a reduction in the number of emergency department (ED) presentations and less time spent in hospital if admitted.[6] For those older Australians living at home, there has been an emphasis on 'ageing in place' which sees older people living independently in their own home and receiving any required care in a familiar environment, with the aim of avoiding admission to RAC.[7] The need for quality and safety in end-of-life care has also been in the spotlight with the recent findings of the Royal Commission into Aged Care Quality and Safety which highlighted the vulnerability of older Australians living in residential aged care or receiving aged care services in the community.[3] The advent of the COVID-19 pandemic across the country has additionally created significant challenges for care delivery in all settings, but with a high rate of infection and subsequent deaths noted in residential aged care settings. The pandemic created a crisis across the aged care and community settings leading to increased workloads, changes to care guidelines such as the introduction of isolation and restricted visiting, the need for technological innovation, management of staff stress and burnout, and the need to respond to family grief and bereavement when family and friends have been isolated.[2] This has meant a changed landscape of needs and care across community settings and a requirement to consider how end-of-life care is being delivered under these circumstances. This review has produced a separate (supplementary) report detailing quality and safety considerations for aged care and community settings during a pandemic.

Palliative care is the responsibility of all healthcare professionals (including nurses, doctors and allied health professionals) with care taking place in all settings (hospital, community), organisations and cultures. Health professionals in the community and in aged care facilities will provide service to people who are dying. In such circumstances, many professionals will not consider themselves to be providing 'palliative care' but simply appropriate health care. Palliative care is often seen as services delivered by specialist palliative care providers; however, the reality is that the majority of those who are dying will be cared for outside of specialist palliative care by their general practitioner (GP) and community health care/residential aged care staff.

In the context of care in the community there is also an emerging consideration of a public health approach to palliative care or ‘compassionate communities.’ This approach sees the mobilisation of a network of (non-professional) social and practical support around the dying person and their family/caregivers.[8] Communities are also reclaiming death, dying and grief as social concerns.[9]

The Australian Commission for Safety and Quality in Health Care (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:

- *Safety and quality of end-of-life care in acute hospitals: A background paper* (2013)[10]
- *National Consensus Statement: Essential elements for safe and high-quality end-of-life care* (2015)[1] (Consensus Statement)
- *National Safety and Quality Health Service (NSQHS) Standards* (2nd ed.)[11]
- *End-of-life care audit toolkit*.[12]

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’s guiding principles, 10 essential elements were derived that ‘are required in systems to ensure safe and high-quality care’.[1] These are illustrated in Figure 1. The Commission has engaged the Research Centre for Palliative Care, Death & Dying (RePaDD) based at Flinders University to undertake a rapid review of the literature focused on the broader community context to update the knowledge on which the Consensus Statement was built (See Appendix 1: The research team).

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

Approach to developing the evidence summary

The remit of this rapid review is to identify research studies that provide evidence of the effectiveness of end-of-life care interventions and practices delivered to people residing in a community or residential aged care setting. The review also identifies new and emerging issues for safe and high-quality end-of-life care delivery in these settings with a specific consideration of issues arising during a pandemic. In doing so, the review will provide the current evidence base in response to the following questions:

1. What does the evidence show about best practice principles, processes, and organisational prerequisites for delivering safe and high-quality end-of-life care in aged care and community settings?
2. Are there new and emerging issues related to delivery of safe and high-quality end-of-life care in aged care and community settings?
3. What additional considerations should be made to ensure safe and high-quality end-of-life care in aged care and community settings during a pandemic? (Addressed in a separate report.)

Aged care settings include residential aged care facilities, aged care homes, nursing homes, retirement villages and hostels.

Community settings includes private homes, general practices, primary care, community-located outpatient specialist clinics, correctional facilities, community group homes for people living with severe mental illness or disabilities, people who are homeless or vulnerably housed, refugees living in detention centres, and workplace settings.

End-of-life care and palliative care

There are key policies in the current Australian context relevant to end-of-life care in community settings, which include the:

- *National Palliative Care Strategy 2018*[13]
- *National Palliative Care Standards* (Edition 5)[14]
- *Comprehensive Palliative Care in Aged Care Measure*[15]
- *NSQHS Standards* (2nd ed.).[11]

End-of-life care in Australia occurs in a broad context and is provided in many settings and 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.[2] Non-government organisations (NGOs) also contribute to care at the end of life, as do community pharmacies, general practices, and aged care service providers, with people at the end of life often transitioning between settings (such as the hospital and the community). Outreach services into the community from hospitals may also exist (e.g. outpatient clinics) and shared care models have evolved where specialist palliative care teams or individual clinicians (either inhouse or visiting) will work collaboratively to provide care at the end of life for patients and families in hospitals and at home.[2]

Definitions

There is ongoing complexity and opacity on the context and definition of both end-of-life care and palliative care. The terminology used to describe the care of the dying is not straightforward and a hotly contested area. Terms such as ‘end-of-life care’ and ‘palliative care’[16], as well as ‘generalist and specialist palliative care’ are used in practice and in the literature often without agreement on what they mean. They are also used interchangeably, with the same inconsistencies found in the literature.

Palliative Care Australia (PCA) has provided definitions of specialist and generalist palliative care:

- People with more complex needs should be able to access care provided by specialist palliative care services comprising multidisciplinary teams with specialised skills, competencies, experience and training in palliative care. PCA refers to this type of care that is provided by specialist palliative care services as ‘specialist palliative care’
- All health professionals who provide care to people living with a life-limiting illness, their families and carers should have minimum core competencies in the provision of palliative care. PCA refers to this type of care that is provided by other health professionals, including general practitioners, as ‘palliative care’ (although it is also sometimes known as ‘generalist palliative care’).[17]

It is important to note that specialist palliative care services are funded to deliver specialist palliative care according to specific criteria and deliverables. Further to this, healthcare professionals (HCP) working in healthcare settings such as in general practice, community health centres or RACs would not refer to themselves as generalist palliative care providers, nor necessarily consider what they do to be palliative care or even end-of-life care, but simply caring for someone who is at the end of life (

Figure 2).

As a body of work undertaken for the Commission, this review uses the same definition of **‘end of life’** as the Consensus Statement[1] (Table 1).

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).

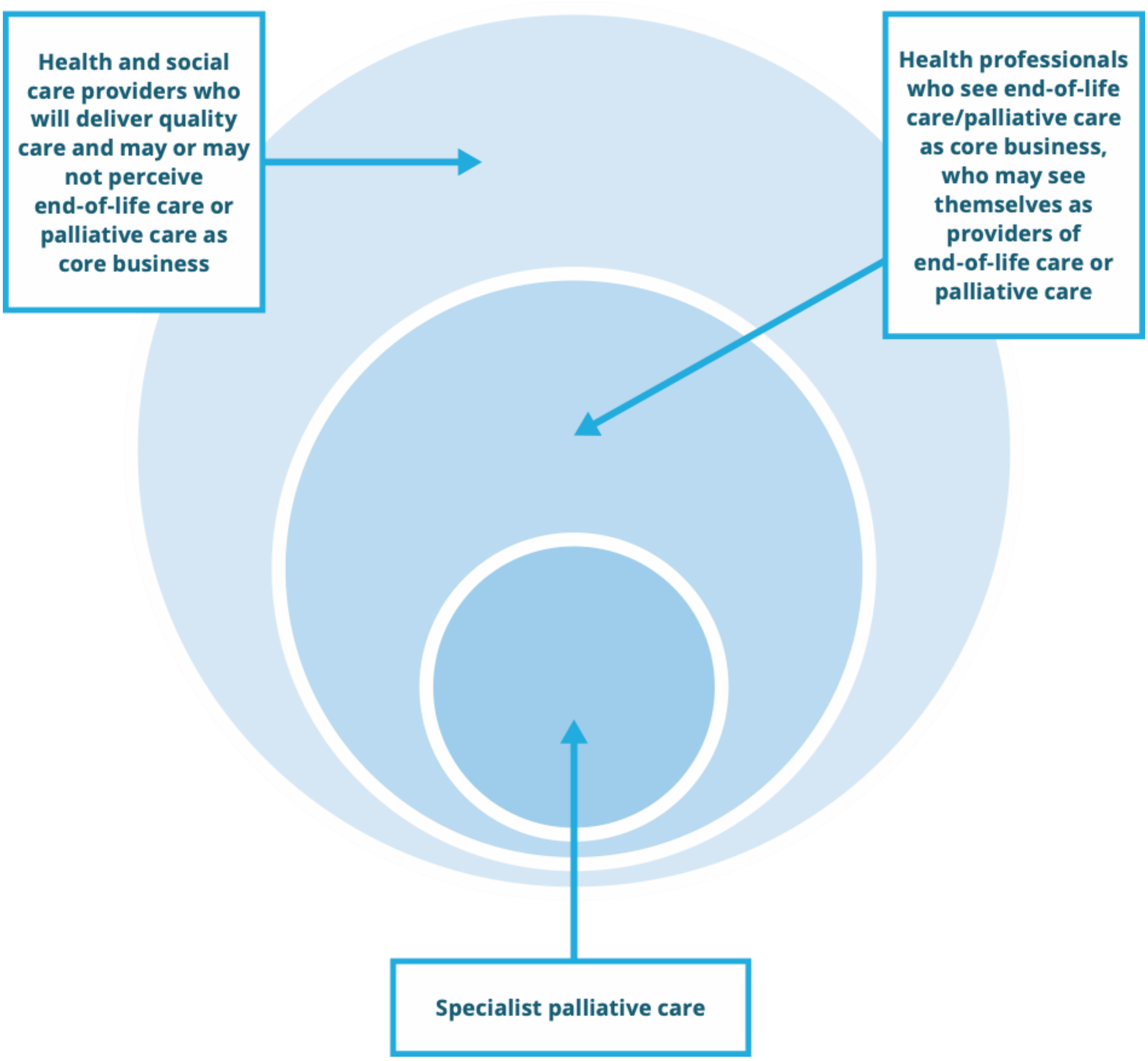
Terminology

- Advanced, progressive, incurable chronic conditions are also described in the literature and elsewhere as 'life-limiting' conditions
- The term 'patient' is often indicative of someone admitted to hospital, with the terms 'resident' or 'client' used to describe someone in the community. However, some papers have used 'patient' across all settings, including the community.

Workforce: What is palliative care? What is end-of-life care?

While palliative care has been promoted as 'everyone's business'[17] there is not a consistent understanding of this core business across the whole healthcare workforce.

Figure 2: Overview of palliative care and end-of-life care



During the period within which this rapid review was undertaken, the Report of the Lancet Commission on the Value of Death titled *Bringing death back to life* was released.[9] The report sets out five principles of a realistic utopia – a new vision of how death and dying could be. In this utopia:

- The social determinants of death, dying, and grieving are tackled (poor deaths often follow poor lives)
- Dying is understood to be a relational and spiritual process rather than simply a physiological event. Relationships are prioritised and made central, including those with HCPs
- Networks of care lead support for people dying, caring, and grieving, including those within the wider community
- Conversations and stories about everyday death, dying, and grief become common with death acknowledged as a part of life
- Death is recognised as having value and spending time with the dying is understood and valued.[9]

The report also provides recommendations to governments and policy makers pertinent to this review:

- Families and communities should not be impoverished by **out-of-pocket expenditure** for treatments at the end of life, and governments should identify ways to support and manage spending at this time
- Policies to **support informal carers** should be created and **paid compassionate or bereavement leave** promoted in all countries
- National programs should be initiated to ensure that everyone can make an **advance care plan** and mechanisms should exist to share these plans **across** health and social care services, alongside access for patients and carers.

Plans, policies, strategies, and reports on health and social care and wellbeing more broadly should always include consideration of death, dying, and grieving.[9]

Methodology

The search for literature capable of answering the review questions involved a targeted selection of citation databases and the grey (or unpublished) literature. Search strategies for both sources of literature comprised a broad range of terms and their synonyms representing two concepts:

1. The community setting
2. End-of-life care.

Results were restricted to a publication/production date of 2015 and onwards and only resources in English were eligible. The methods for the main review and a grey literature search are described in more detail in the following sections of the report. A Supplementary Report relevant to the COVID-19 pandemic has also been developed and is available separate to this report.

Main review search

Data sources and search strategies

The research librarian (SH) in consultation with the investigators built the search strategy using text words and Medical Subject Headings (MeSH). Three databases were selected for use in the review based on their prime relevance to the topic. These were Ovid Medline, the Cumulative Index to Nursing and Health Literature (CINAHL), and AgeLine. A fourth database, the Cochrane Central Register of Controlled Trials (CENTRAL), was scanned for unique studies rather than searched. The database search strategies are provided as Appendix 2.

Inclusion and exclusion criteria

Papers were eligible for inclusion if they detailed end-of-life care (last 12 months) in a community rather than hospital setting (Table 2). Community settings include people‘s homes, residential aged care, accommodation for people living with a disability or mental illness, correctional facilities, shelters/hostels for homeless people or the vulnerably housed, general practices, and community palliative care clinics and day centres.[17]

Other eligibility criteria included:

- Original primary studies or systematic reviews reported in full (i.e. not conference abstracts, posters, editorials or letters)
- Studies conducted in health systems of countries categorised as high-income by the World Bank.[18] This restricted the search to countries with healthcare systems like that of Australia, for example, England, Canada, The Netherlands, and New Zealand
- A publication date of 2015 onwards (the date of the original Consensus Statement)
- English language only.

Exclusion criteria:

- This review does not include care is that provided by **palliative care specialist services** (for example, community hospices) except where these services are working with community (including residential aged care) healthcare providers.

Table 2: Scope of the rapid review

	In scope	Out of scope
Populations	• People of all ages approaching the end-of-life phase (i.e. last 12 months) • Bereaved populations where the loved one died under the care of a regulated service	• Older people and those with a life-limiting condition (e.g. dementia) where it is not clear if they are in or approaching the end-of-life phase • Well populations (e.g. intervention studies testing people's engagement in end-of-life care discussions) • Public health palliative care initiatives (e.g. Compassionate Communities)
Settings	• Home-like settings: residential aged care, retirement villages, hostels, prisons, supported accommodation for people with a disability or mental illness, and private homes • High-income countries only	• Hospitals and emergency departments ***unless*** related to transitions to or from the home/community setting • Hospices where care is delivered by specialist palliative care clinicians
Care providers	• Care delivered by non-palliative care specialists. • Primary care (e.g. GPs, pharmacists, practice nurses, paramedics) • Secondary care providers (e.g. oncologists, cardiologists) ***providing*** they work in outpatient clinics • Hospital-at-home if it is clear that care is not being provided by specialist palliative care • Home health care provided by primary care providers or as part of aged care provision (e.g. Australian Home Care Packages) • Social care provision by social workers or aged care providers (e.g. non-health services funded as part of Australian Home Care Packages) • Community volunteers if linked to a health service (e.g. GP clinic or aged care service) • Nurse practitioners advising, supporting, or educating nursing home staff on palliative care	• Specialist palliative care providers, including those working in 'community/home palliative care' • Hospice-at-home provided by specialist palliative care • Generalist palliative care/secondary care specialists working in a hospital, rather than community outpatient setting

	In scope	Out of scope
Intervention types	• Interventions, initiatives, practices, or programs with demonstrable and measured outcomes to patients • Studies demonstrating the risks associated with the ***non-practice*** of a specific task/function in a community setting • Tool studies investigating usability or accuracy of prognostication tools in clinical practice (at the systematic review level only)	• Specific drug trials or clinical procedure interventions • Educational or training interventions for residential or home-based aged care staff • Interventions aimed at teaching informal or family caregivers how to provide care • Curriculum programs for health professional students or postgraduate health professionals • Tool development studies for determining reliability and validity
Study designs	• Not restricted *a priori* but likely to be systematic reviews, randomised controlled trials (RCTs), cohort studies, pre-post intervention surveys or testing • Qualitative studies providing evidence of care recipient satisfaction with or acceptability and useability of an intervention	• Prevalence or case studies • Qualitative studies exploring patient or clinician experiences • Editorials, letters, conference abstracts or posters and commentaries • Non-systematic literature reviews • Conference posters and abstracts, study, or systematic review protocols • Feasibility and pilot studies

Selection of papers

Citations retrieved from database searches were first imported into an EndNote library (version X9) where duplicates were removed. The remaining unique citations were then uploaded into Covidence for screening. The first round of screening was by title and abstract only and involved two reviewers working independently. Eligibility disagreements were resolved through discussion or by a third reviewer. Studies that passed this process were rescreened, this time by the full text article. Two reviewers were also required for this stage and disagreements were again discussed and resolved.

Data extraction

A data extraction template was set up in the Covidence program for the extraction phase of the review. The information to be extracted was discussed and agreed upon by the review team. It includes the following:

- Author, year and country of study
- Healthcare setting
- Study purpose
- Study design
- Population
- Intervention(s) studied
- Comparison
- Outcome(s)
- Healthcare professionals delivering the intervention
- Key findings
- Levels of evidence.

Each study was assigned one of five evidence rankings from the Johns Hopkins Nursing Evidence-Based Practice evidence level and quality guide[19] (Table 3). These levels reflect the study's research design or the source of evidence underlying the study (e.g. expert opinion).Their hierarchical arrangement assumes that Level I evidence has stronger processes in place for controlling bias than Level II, and so on. However, this does not preclude a well conducted Level II study from being of better quality that a less rigourously conducted Level I study. The quality appraisal results (Appendix 6, Table A8) provide more information on the rigour of execution and quality of reporting associated with individual studies.

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

Evidence level	Description
Level I	Experimental, randomised controlled trials (RCT), systematic reviews of RCTs with or without meta-analysis
Level II	Quasi-experimental studies, systematic reviews of a combination of RCTs and quasi-experimental studies, or quasi-experimental studies only, with or without meta-analysis
Level III	Non-experimental, systematic reviews of RCTs, quasi-experimental with/without meta-analysis, qualitative, qualitative systematic reviews 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

Synthesis of data

Extracted data were exported into an Excel spreadsheet where it was possible to do a cross-comparison of similarities and differences between the studies, their aims, and their outcomes. The investigator group discussed these aspects until themes were agreed upon. These themes are described in the Results section of the report.

Quality appraisal

All included papers were assessed for quality by four researchers (DR, RD, KD, JT) using the quality tool developed by Mackenzie et al.[20] This tool comprises 11 questions to ask of each study, irrespective of design, to assess the study's quality, reliability, and validity. Assessors answer each question by assigning a score in the form: 0 = No; 2 = Yes; 1 = Unsure. Studies are thereby graded according to their score total (Table 4). However, no papers were excluded based on the quality assessment outcomes, rather quality appraisal was used to provide additional insights into the strengths and limitations of the individual studies. This approach was standardised across the team to ensure consistency between reviewers.

Table 4: Quality appraisal grading system[20]

Quality grading system	
0–1	Rejected
2–8	Unreliable
9–12	Weak
13–18	Medium
19–22	Strong

Grey literature search

Data sources and search strategies

Grey literature searches were conducted to identify end-of-life care interventions and emerging issues of importance to the aged care sector. These searches, restricted to Australia only, were undertaken in four phases (Appendix 3):

1. An examination of the published reports from the 2020 Royal Commission into the Quality and Safety of Aged Care[3]
2. Targeted searches of 41 key aged care government, organisational, and research websites
3. General Google web searches using the added functionality of the advanced search option. This enabled searching on 10 different search variants. These searches were restricted to Australian websites and the PDF document type. For each search variant, the first 50 websites returned were checked for relevance (i.e. total n=500)
4. Consultation with RePaDD colleagues who have their own areas of knowledge of resources in the palliative care sector.

Inclusion and exclusion criteria

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

Documents were included if they described:

- Interventions, program evaluations, resources such as guidelines focused on providing quality care or improving the safety and quality of care at the end of life in the community setting (home, nursing home)
- Government and organisational strategies, frameworks, and policies for approaching end of life and palliative care in these settings.

Documents and abstracts were excluded if:

- The setting was 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 where clinical symptoms or personal reflections are described
- They were included in the main review or represent what is included (i.e. similar to included papers)
- There was no clear methodology reported.

Results

Results of the main literature review

Selection of papers

All database searches were conducted on 22 September 2021. Together a total of 9,490 citations remained after duplicate citations were removed. After first-round screening by title and abstract, 1,005 full text reports were left for review by full text article. While this number of citations undergoing full text review could be considered large for a rapid review, it reflects the multifaceted nature of the review topic. It also highlights difficulties in relying on titles and abstracts to identify a person's place in the dying trajectory, the nuances of different regional models of home and specialist palliative care, and the work locations of vaguely described 'generalist' or 'primary' palliative care providers. A final set of 130 studies were accepted as relevant to the review. Appendix 4 (PRISMA flow diagram of review inclusion and exclusion decisions[21]) provides a diagrammatic overview of this selection process.

Study characteristics

The characteristics of the 130 included studies are shown in Table 5.

Table 5: Study characteristics by country, setting, study design and level of evidence

Study characteristics		**No. of associated studies**
Country	England	25
	United States	24
	Australia	14
	Netherlands	12
	Canada	9
	Belgium and Japan	6
	Norway and Sweden	5
	Denmark	4
	Hong Kong, Italy, Scotland	3
	Finland, Ireland, Israel, New Zealand, Northern Ireland, Poland, Portugal, Singapore, Spain, Taiwan, and Wales	1 each
Setting	Residential aged care	53
	Private homes	29

Study characteristics		**No. of associated studies**
	Community (Including oncology centres, day respite centres, correctional facilities, and hostels caring for people experiencing homelessness)	23
	Multiple settings	6
Study designs	Cross-sectional (Including mortality follow-back design)	24
	Randomised controlled trials	20
	Cohort	14
	Mixed methods	14
	Program evaluation	13
	Qualitative	11
	Non-randomised controlled trials	9
	Systematic reviews	9
	Clinical audit	5
	Realist review	3
	Economic studies	2
	Action research, case-control, clinical practice guideline, co-design (appreciative inquiry), quality improvement study, and rapid assessment review	1 each
Level of evidence[19]	I	20
	II	9
	III	75
	IV	1
	V	25

Identification of themes

Extracted data were coded and compared to identify the major themes across studies. These themes and their subthemes are described here (Table 6).

Table 6: Themes from the main literature review

Themes	
1	Collaborative or integrated care initiatives: • Community-based programs • Home-based care • Residential aged care
2	Structured approaches to end-of-life goals of care discussions and advance care planning
3	Interventions to reduce community-hospital transfers
4	Primary care involvement in end-of-life care
5	Dementia-specific interventions: • Namaste care • Other dementia-focused interventions
6	Interventions with a positive effect on communication
7	Interventions for symptom control and patient quality of life
8	Practices to reduce aged care staff stress
9	Digital innovations
10	Other considerations: • Special populations • Access to medicines, anticipatory prescribing, and deprescribing • Organisational readiness for change

1. Collaborative or integrated care initiatives

Many of the studies identified investigated the benefits of care partnerships that traverse health sectors**.** These multidisciplinary pairings ranged from self-described ‘collaborations’ between service providers to more fully integrated models of care. The following are examples from the community, home care, and residential aged care contexts.

Community-based programs

Six studies investigated the effectiveness of integrated or collaborative programs between different sectors of care conducted in the community, but not necessary solely within a private home setting. Of these, four were specifically designed to support the end-of-life care of people with the non-malignant conditions of dementia[22,23], COPD[24], and Parkinson’s disease.[25] The remaining two studies focused on special populations: children[26], and people living in homeless hostels.[27]

These interventions varied in their workforce composition and models of care. They included:

- The integration of specialist palliative care teams within homeless hostels[27]
- A partnership between hospice and children’s community nursing teams[26]
- Integrated care processes between hospital and primary care clinicians[23-25] with selective involvement of specialist palliative care.[26]

Across these studies, models of integrated care could show better symptom control in COPD and Parkinson’s disease[24,25,28], a decrease in the use of acute care[23,24,26], and/or reduced length of inpatient hospital stay[22,28], with an increase in the use of other services such as general practice for COPD care[24], and hospice in the last six months of life for dementia.[22,23] Jennings[22] also found a decreased likelihood of a person with dementia requiring admission to a long-term care facility with the support of an integrated comprehensive care program in the community. Another positive outcome was the increased rate of ACP completions for non-malignant conditions[23,25], and better recognition by hostel managers of the end-of-life care needs of the homeless people living within their facility.[27]

Home-based care

Fifteen studies focused on integrated or collaborative models of care delivered in the home setting. Most of these models had the general practitioner at the centre of the person’s care team. However, two focused on the use of community paramedics/emergency medical services to manage urgent end-of-life problems successfully at home on a 24-hour basis with support from the person’s primary or specialist care provider.[29,30]

Examples of this type of integrated model serving people in their homes include:

- Home visitation programs of integrated primary and specialist palliative care[31-36]
- A collaborative urgent home service between emergency medical services or paramedics and either community/primary care services[29], or a dedicated hospital end-of-life care ward which bypasses the emergency department[30]
- Initiatives between primary care and other generalist palliative care providers[28,37,38] perhaps with additional support from specialist palliative care when needed.[39,40]

Studies of home-based integrated care models were predominately concerned with rates of home versus hospital deaths. Most found intersectoral collaboration improved rates of home death[28,32,34,35,40], with two studies able to demonstrate a dose-response relationship based on the number of home visits made.[34,35] Integrated care models were also associated with reduced acute care use[35,37,38], especially when emergency medical personnel with extended skills were involved.[29,30] However, this finding was not universal. One study found an inverse relationship between home care and length of hospital stay for COPD exacerbations, but no effect on hospitalisations[28], while another reported an increase in ED visits but reduced hospitalisations at 30 days.[41]

Studies also reported improved symptom control through integration of services, especially for non-cancer conditions[28,33,38], although one study found improvement only in the emotional and not the physical domain.[31] Others reported patient or family satisfaction with home care services.[29,42] Another set described positive benefits for health professionals through integrated initiatives involving SPC support for end-of-life care. These gains include bolstered confidence of visiting nurses in caring for patients at the end of life,[40] and stronger GP-SPC physician collaboration with greater role delineation arising from joint participation in synchronous teleconsultations.[36]

Residential aged care

Nine studies described the benefits of collaborative or integrated approaches to providing end-of-life care in the residential aged care setting. Most of these studies involved a mentorship or consultative model whereby visiting clinicians from a SPC service worked alongside aged care staff, providing them with advice, as needed, on how to identify and manage residents approaching the end of life. These models included:

- Specialist palliative care 'needs rounds' comprising monthly triage meetings between RAC and SPC staff to identify residents at risk of dying with a high symptom burden[43-45]
- A reciprocal clinical coaching and knowledge exchange program (SHARE) involving RAC and hospice staff[46]
- Integrated telemedicine and/or onsite mentorship programs[47,48]
- The engagement of an Interdisciplinary Care Leader charged with facilitating integrated care and holistic assessments for people living with dementia (PLwD) while modelling family discussions and providing RAC staff with training on palliative care for PLwD[49]
- Family case/care conferencing involving people at the end of life, their nursing home caregivers, family members, and a specialist palliative care facilitator.[50,51]

The three Australian studies investigating specialist needs rounds (Levels I–II evidence) all reported increased rates of ACP completion as an outcome.[43,44,51] However, while one study found the intervention reduced hospitalisations by 23% and decreased length of stay[43], another identified no significant changes in hospitalisation rates nor the number of in-hospital deaths when rounds took place in a rural Australian setting.[45] Staff-perceived improvements in the quality of resident death and dying were reported in the third study on this model.[44] Two of the other models aimed at providing SPC mentorship for RAC staff similarly reported mixed findings. The 'PCTeams' model found no significant changes in acute care use, nor pain relief, despite end-of-life training from a gero-palliative NP.[48] Conversely, the GeroCare Palliative Care Program, which incorporated on demand RAC-SPC teleconsultations in addition to onsite clinical coaching and mentorship, reported a significant reduction in ED visits.[47]

The two case conferencing studies (Levels I and III evidence) reported on a range of beneficial outcomes between them.[50,51] These included an increased rate of symptom assessment and documentation by RAC staff, greater physician involvement in the final month of life[50] and increased rates of ACP completion.[51] Prescribing behaviour was also observed to change. Medication initiation was more likely to be triggered by symptoms rather than diagnoses[50] with more attention now given to proactive, anticipatory prescribing.[51]

Two qualitative studies in this category identified RAC staff improvement in communicating with resident family members as an outcome of communication role-modelling by SPC staff.[46,49] One also identified closer attention by staff on the individual resident's symptoms, although there remained discontent with general practitioner care quality.[46] The issue of some staff having difficulty communicating in English with family members about sensitive issues was also raised as problematic.[49]

Together, these findings suggest that inter-organisational, inter-sector, and inter-professional collaborations can be effective intervention mechanisms for improving end-of-life care provision in the residential care setting.

2. Structured approaches to end-of-life goals of care discussions and advance care planning

Advance care planning and systematic approaches to communicating changing goals of care are prevalent concerns in the end-of-life care literature. This review identified 28 studies exploring ways to improve patient, resident, or family member involvement in structured planning discussions or describing consequences of poor advance planning. Most took place in residential aged care (n=16), followed by the community (n=7) and primary care (n=5). These studies fall into three groups:

1. Those reporting whether rates of goals of care conversations or documentation increased after an intervention[23,44,45,51-59]
2. Studies investigating the outcomes associated with having a plan in place at the end of life[47,60-69]
3. Data linkage studies that propose a likely association between lack of clear end-of-life care discussions or planning and adverse outcomes without definitive evidence of causality.[32,70-73]

Beneficial outcomes reported in association with efforts to improve end-of-life care planning include:

- Increased congruence between patient-family[62], patient-health professional[57], or family-health professional[63], end-of-life care preferences or goals and reduced decisional conflict[62]
- Increased likelihood of a person dying in their preferred place, usually outside the hospital setting[61,64,65,74]
- Reduced rate of hospital transfers at the end of life[47,63,67], although one study had inconclusive findings on this outcome[66]
- Increased documentation of symptoms, and consequently better symptom control[60]
- Higher rates of anticipatory[51] and PRN symptom medication prescribing[60]
- Increased family satisfaction with care provision.[69]

Initiatives to improve the rate of structured conversations around end-of-life care goals often formed one component of a multicomponent intervention designed to impact on a range of outcomes. Such programs include the implementation of the Gold Standards Framework in Care Homes Program[64], the ‘Steps to Success’ program[65], the ‘Serious Illness Care Program[54], and the GeriCare Palliative Care Program.[47]

Several interventions involved the engagement of health professionals or trained lay workers to advocate for, model practice, or provide training on advance care planning. Examples of positive care planning outcomes deriving from a professional-driven initiative include:

- Specialist palliative care needs rounds[44,45]
- A nurse-led post-discharge ACP program[62]
- A trained lay ‘patient navigator’ working with Latino cancer patients[53]
- One-on-one guided counsellor interventions with chronically homeless persons[55]
- A nurse practitioner-led comprehensive dementia care management program.[23]

Conversely, some interventions relied on improving ACP rates by providing patients and their families with information, with or without more structured follow-up.[53,59,66,68] Of these, those studies describing passive transfer of information in the form of a video[66,68] or information pamphlets[59] reported non-significant changes in ACP rates and acute care use. However, when people were given a video[63] or package of written information[53] providing ACP information with some form of active follow up, significant improvements in these same outcomes were observed. It should be noted that Sussman et al.[59] found residents and families with higher educational levels reacted more positively to written information compared to those with lower levels of education.[60] This may highlight the importance of considering differences in levels of information literacy when designing interventions of this kind.

Two studies attempted to implement whole-of-setting cultural changes to improve ACP, one across multi-site primary care clinics[58] and another within a residential care home.[57] These studies sought to identify barriers to integrating ACP into daily practice and then adopted standardised processes involving training, guidance, ongoing supervision, and continuing support for staff to address them. Both studies reported sustained increases in the rate of ACP form completion and documentation.

Possible consequences of not sharing goals and preferences for care at the end of life with a health professional were also reported across several studies. These include:

- An increased likelihood of being transferred to the hospital[70] or the ED[73] at the end of life, particularly out of hours[71]
- Dying in the hospital[32]
- A lack of anticipatory prescribing for symptom management.[71]

3. Interventions to reduce community-hospital transfers

While the focus of this review is beyond the hospital setting, care is inevitably experienced within a health and social care system. Older people living in the community or residential aged care are frequently transferred to the acute setting near the end of their life. This may be experienced as disruptive, distressing and not always necessary. Furthermore, the act of transfer itself carries a high risk of complications and mortality, especially when outside regular business hours.

Twenty-eight studies investigate interventions for reducing the likelihood of late transfers. In addition to the integrated models of care and ACP interventions already discussed, interventions specifically showing beneficial outcomes include:

- Community or extended skills paramedics primed to provide acute care to older patients in the home setting.[29,75-77] However, a systematic review found limited high-quality evidence supporting their involvement in the delivery of end-of-life care to RAC facilities.[77]
- A community-based palliative care day respite centre providing culturally appropriate care to Aboriginal and Torres Strait Islander patients[78]
- Provision of home death planning and symptom management kits to home care nurses[79]
- An ICT-based communication system linking rural RAC to secondary care specialists for reporting acute changes in conditions[80]
- Home-based nursing care with an explicit end-of-life intent.[81,82]

A further intervention (Level I evidence) was not able to demonstrate a reduction in acute transfers. This was a 13-page, large print decision aid for RAC residents called *Go to the Hospital or Stay Here?*[83]

One Japanese retrospective matched cohort study looked for an association between receiving home care services, both medical and non-medical in nature, and the likelihood of dying at home. It concluded that home care itself may be a protective factor against hospital death.[84] A second Japanese study of home care provision at the end of life, however, elaborated on institutional factors impacting a home care agency's ability to provide this sort of care. For those services providing medical care in the home, the agency's size and level of interagency collaboration were positively associated with the likelihood of end-of-life care provision while institutional preparedness was key for non-medical home help services.[85] A third study focused on the Japanese residential aged care setting was able to demonstrate an association between increased rates of people dying in the care home rather than hospital and a government financial incentive given to care homes in the form of an end-of-life care bonus.[86]

Another set of studies used linked datasets to suggest that unnecessary transfers occur when community settings do not have safe or quality processes in place. These studies, which predominantly focus on the residential aged care setting, describe the following risk factors:

- Uncontrolled symptoms, especially severe breathlessness[70] infections[73,87], or altered mental state[73]
- Lack of advance care planning or communication of care preferences with a health professional[70,71,73]
- Pressure on residential care staff from relatives[73]
- Poorer quality of communication between care home staff and resident/family members[88]
- Not having an identified key health provider[70]
- GP unavailability in RAC[73] or home setting[89]
- Lack of medical review in RAC setting in the last 24 hours[71]
- Poor communication of a person's palliative care status between the usual GP and an out-of-hours service in the community[90]
- Lack of home-based palliative care[91] or case management[92]
- Lower intensity home visits by integrated primary-SPC at the end of life.[34,35]

These findings may suggest that some services are reliant on acute care settings to provide end-of-life care rather than investing in practices to reduce this dependence.[70] Overall, these studies highlight the need for primary palliative care providers to quantify and justify transitions between settings at the end of life.

4. Primary care involvement in end-of-life care

Having the support of a general practitioner emerged as a key positive factor in quality end-of-life care across all community settings. A substantial number of studies were able to demonstrate a relationship between access to primary palliative care, particularly in the form of GP home visits, and people dying in their own homes rather than a hospital.[89,91,93-97] In fact, one study found the odds of a hospital death to be nine times higher if no GP was directly involved in the palliative phase.[94]

Some studies could also demonstrate a dose-response relationship between the intensity of home visits by a GP and the likelihood that a home death would take place.[34,93] However, this relationship did not hold when GP care was provided in the clinic or the out-of-hours setting.[93] Conversely, another study found it only took one general practitioner home visit to decrease the odds of dying in hospital by 47%[96], leading the authors to question why GP home visits were not offered more widely. GP frequency of home visits was also positively associated with bereaved family members' level of satisfaction with their end-of-life care provision.[98] Furthermore, increased frequency of visitations was positively associated with the GP's ability to recognise a resident's terminal phase within the RAC setting.[99]

While they appear to increase the home death rate, GP home visits may not reduce the likelihood of being hospitalised in general, although there is some evidence that they reduce the hospital length of stay.[97] Where adolescents with cancer were concerned, one study found having a usual source of primary care led to an increase in end-of-life transitions to acute or inpatient hospice care, as well as overall healthcare use.[100]

Several studies investigated service provision by out-of-hours primary care.[90,101-103] These found deficits in communication at handover between the regular general practice and the after-hours service as to patients with end-of-life needs.[102,103] This could jeopardise care quality and safety[103], lead to an increased risk of hospitalisations[90] and cause emotional and psychological distress to patients and their families.[103]

One barrier to effective general practitioner end-of-life care provision identified in the review was the GP's ability and willingness to identify where a patient may be on an illness trajectory, especially for non-cancer conditions.[39,104] A discussion around end-of-life goals of care may therefore come too late, if at all, depriving patients and families of opportunities to prepare for the last months of life.[104] Interventions attempting to help GPs overcome these barriers include:

- The Think Ahead end-of-life care planning tool for GPs[52]
- OPT (Outcomes Prioritisation Tool), which provides GPs with a structured approach to conducting goals of care discussions with advanced cancer patients[105]
- The PaTz program (modelled on the Gold Standards Framework) for improving systematic identification of patients with palliative/end-of-life care needs[106]
- Validated prognostication tools tested for applicability in general practice[107]
- A structured palliative care framework for general practice involving training, proactive follow-up, the use of prognostication tools, documentation of palliative care needs and discussion of EoL preferences[94]
- An integrated care pathway supporting better recognition by GPs of end-of-life care needs in people with non-malignant conditions[39]
- Scotland's Palliative Care Directed Enhanced Service care which has demonstrated improved GP prognostication skills.[104]

The primary care setting might also contribute to bereavement care, including treatment of complicated grief, although a randomised controlled trial of a cognitive narrative crisis intervention could only demonstrate a significant improvement in the emotional numbing domain and not depression or traumatic stress.[108] Despite viewing bereavement support as part of their role, GPs report finding this type of care challenging and express uncertainty as to the appropriate scope of their involvement.[109] Overall, the contribution of GPs to care in the last stage of life appears to be critical if people wish to die in a preferred place, especially if that place is home.[95]

5. Dementia-specific interventions

The review identified 23 advanced dementia-specific intervention studies, most taking place in residential care (n=18). Namaste Care is by far the most prevalent, with nine articles describing the program and examining its effectiveness and acceptability.

Namaste Care

Namaste Care is a multi-component physical, sensory, and emotional intervention developed in the United States from a practitioner evidence base to improve the quality of care of people living with advanced dementia. It involves aromas, lighting, sensory experiences such as massage, and music, with frequently offered fluids and high caloric food treats.[110] The intervention is designed to be delivered twice a day for two hours at a time, seven days a week within groups of six to 12 residents.[111,112] The program suggests benefits for both care home staff and PLwD. For staff and the organisation:

> Namaste Care [provides] a structured access to social and physical stimulation, equipping care home staff to cope effectively and responsively to complex behaviours, and providing a framework for person-centred care delivery within the care home.[111]

The frequency of the Namaste Care sessions provide staff with ongoing opportunities to interact and engage with residents, developing interpersonal trust and equipping carers to cope more effectively with the challenging behavioural and psychological symptoms of dementia.[111] By focusing care staff attention on the PLwD as an individual, Namaste Care may also provide a framework for a person-centred culture of care within the residential care setting.[111] Staff reported finding the changes in care brought by the program enjoyable and rewarding.[110] Family caregivers also found their involvement a positive experience, especially their engagement with their relatives.[113] For the PLwD, Namaste Care increases their level of structured social interaction time with others[114], including family and friends who choose to participate.

Several studies have investigated the evidence supporting Namaste Care. Bray et al.[115] found few research studies at the randomised controlled trial level, however a good (albeit inconsistent) body of evidence to support each of the activities making up Namaste Care. The program has also been linked to improvements in the behavioural and psychological symptoms of dementia such as agitation[114,116], with a subsequent reduction in medication use. Staff proxy ratings of resident quality of life also provided evidence of statistically significant improvements within 12 weeks of implementation which were maintained.[116] In other studies, the intervention was found to be cost-effective compared to usual care[117], required no additional resources[114], and had no adverse effects.[116] According to Stacpoole et al.[114], the program's focus on comfort supported good pain management in four out of five care homes in their study. Namaste Care delivered in the private home setting was also evaluated, where it was found to promote engagement and reduce social isolation while providing carers with an opportunity for respite.[118]

Other dementia-focused interventions

The review identified several controlled trials (Levels I-II evidence) investigating means of improving the end-of-life care for people living with advanced dementia in the residential aged care setting. Those demonstrating beneficial outcomes involved:

- The application of an eight-week individual pain treatment approach according to a Systematic Pain Treatment Protocol (SPTP) which reduced staff distress at the symptoms of dementia[119]
- Individualised, facilitated case conferences involving residents, their families, and multidisciplinary staff which increased physician input close to death and led to higher rates of nurse-documented pain and restlessness and focused attention on symptom management[50]
- A goals of care decision aid (video and structured discussion) for family decision maker/resident dyads which increased the palliative care content in treatment plans and reduced hospital transfers[63]
- A multifaceted intervention to improve quality of end-of-life care through training, clinical monitoring of pain and a mouth care routine (amongst other components) which found significantly higher family satisfaction with end-of-life care as well as higher scores on perceived quality of care and quality of dying.[120]

A further intervention study (Level I) sought to determine if the European multi-component palliative care quality improvement initiative, PACE Steps to Success, could demonstrate differences in outcomes for people with and without dementia. This study found the program improved the quality of care and quality of dying for both groups equally but had no effect on either group's level of comfort in the last week of life.[121] It is noted that most of these RAC-based dementia interventions require a high level of organisational support and the ongoing dedication of a trained facilitator or coordinator. For example, each of the 10 facilities participating in the case conference study required a specially training registered nurse to devote two days per week over 18 months to the role of Palliative Care Planning Coordinator.[50] As another study concluded, the effectiveness of these programs largely hinges on having the continuous involvement of a highly trained person in this role.[120]

The review also retrieved several non-experimental studies (Levels III–V) on dementia end-of-life care in residential aged care. A study by White et al.[122] investigated if exposure to nature in the form of a garden had any impact on the PLwD's mood. It asked caregivers to subjectively assess resident mood during the intervention and found that mood improvements were noted at the 20-minute exposure mark with a ceiling effect at 80 minutes duration. This positive finding and those relating to the sensory components of Namaste Care, raise important questions for policy about the design of dementia care facilities and programs.

The UK Evidence-based Interventions in Dementia (EVIDEM) research and development program found a novel way to address the quality of end-of-life care of PLwD in care homes.[123] It used a co-design approach called 'appreciative inquiry' to first examine the problems in care resulting from inadequate collaboration between the care home and its visiting primary care providers. It then brought these two groups together to: (1) identify pathways to death of PLwD; and (2) design tools that promote integrated working between providers and help to resolve common frustrations. The appreciative inquiry intervention proved successful across a range of outcomes. Care home staff became more confident in their own roles and responsibilities towards residents and gained a greater appreciation for the difficulties confronted by general practitioners in this setting. Documentation processes improved with a consequential increase in the rate of completed care plans and Do Not Attempt Cardiopulmonary Resuscitation forms. Communication processes with out-of-hours GPs were revised and improved with a flow-on reduction in hospital transfers. Regular ongoing meetings with district nurses were also established. Although the same number of people continued to die in hospital as in the care home after the introduction of this approach, there was a reduction in emergency transports, length of hospital stays, and hospital and community care costs (although not primary care costs).[123]

Only four studies[22,23,81,118] and one Australian clinical practice guideline[124] addressed end-of-life care for PLwD outside the residential aged care setting. Two studies examined the effectiveness of a community nurse practitioner dementia care co-management program, finding this model reduced acute care use and stimulated higher engagement in ACP for PLwD.[22,23] Another study investigated patterns of acute care transitions for PLwD receiving home health care and found this care to be associated with an increased risk of multiple hospitalisations in the last 90 days of life but a decreased risk of acute care visits or admissions in the last three days of life.[81]

6. Interventions with a positive effect on communication

In addition to the many formal ACP or goals of care studies already described, a range of interventions were found to have a positive effect on communication between the various people involved in a person's EoL care. For many of these studies, however, improving communication did not appear to be the primary objective but was, nevertheless, a necessary requirement for improving some other aspect of care. This includes improving the quality of end-of-life care in general, symptom management, and reducing unnecessary hospital transfers. The following are several examples of interventions *intentionally aimed* at improving communication processes between care providers – an identified risk factor for late transitions:

- A USA study researched the impact of quality of communication between care home staff on transfers at the end of life. It found communication to be a statistically significant factor in risk-adjusted measures of EoL transitions with better communication resulting in less acute transfers but more referrals to hospice[88]
- A successful cancer care transition program in Japan reduced late hospital transfers for terminal cancer patients by establishing processes facilitating two-way communication between hospital specialist staff and community providers before and after hospital discharge. General practitioners and community nurses were supported in their home cancer care by access to oncologists and SPC staff via a 24-hour hotline and periodic phone calls while providing patient reports back to the hospital[125]
- A Level I study examined the impact of a patient information handover form between the regular GP and out-of-hours primary care providers to effect better identification of people with end-of-life care needs.[102] It resulted in moderate increases in communication transfer although the palliative care status of a substantial proportion of patients requiring OoH care remained unreported.[102]

The review also identified structured programs for facilitating communication around end-of-life care between GPs and patients and their families:

- The Serious Illness Care Program equipped GPs with a range of tools for conducting conversations with their patients on EoL issues, resulting in more conversations taking place and in greater depth. This information was subsequently also more accessible in the medical record[54]
- Similarly, the PaTz palliative care at home program also targeted the GP's ability to recognise the EoL and initiate conversations with patients on their life expectancy and possibilities of end-of-life care. It led to increased recognition of palliative care needs by GPs and more conversations on life expectancy, symptoms and possibilities for care.[106]

One study stood apart in measuring the somewhat indirect effect of a palliative care educational intervention for nursing home staff on resident next of kin involvement in care.[126] Using a bespoke instrument, the researchers ascertained that next of kin perceived a post-intervention improvement in their ability to communicate with staff and increased levels of trust. However, this did not necessarily translate to increased participation in caring for their family member.[126]

The following studies report improvements in communication as incidental findings:

- The work processes of community paramedics providing urgent symptom care to people in their own homes ensured timely communication of acute events and their outcomes to families and the treating family physician[77]

- A multi-component community-based palliative care project seeking to improve patient symptoms had a significantly beneficial effect on patient concerns around communicating symptoms with others at the one-month follow-up point. This concern was described as distressing for the patient; possibly due to the Chinese population sample and Chinese cultural taboos on discussing issues relating to death[31]
- Joint consultations between GPs and Hospice Nurse Consultants as part of the Hospice Assist at Home program were reported to give patients greater opportunity to express their end-of-life care preferences leading to better congruence between patient wishes and care outcomes[32]
- The implementation in Scotland of a GP-based Palliative Care Directed Enhanced Service resulted in greater recognition by GPs that recognising early palliative care needs is a form of anticipatory care planning. GPs appear to feel enabled to act more promptly and communicate more effectively with patients although communication with secondary care professionals remained challenging[104]
- A case manager working with GPs in the community improved GPs' awareness of their patients' preferred place of death.[92]

Across those studies addressing GP communication with patients at the EoL, the ability to identify patients with palliative care needs was always presented as a prerequisite. Therefore, a range of tools might also be considered interventions for improving GP-initiated EoL conversations. These include the OPT tool[105], the Think Ahead EoL planning tool[52], and the diagnostic/prognostic tools identified in two systematic reviews.[107,127]

Satisfaction with care provision appears to be closely associated with the amount and quality of communication between families/patients and health providers. In the care home setting, Baranska et al.[128] found that relatives of deceased residents retrospectively rated quality of EoL communication with physicians higher when the treating physician visited the resident at least three times in the last week of the resident's life or provided palliative care. This study also found an association between higher emotional burden in the bereaved person and a perception of EoL communication as having been of lower quality. Similarly, another study reported higher care satisfaction scores among family members with a greater frequency of discussion of EoL treatment wishes between care home staff and the resident/family.[69] This was particularly marked when the subject of discussion was artificial hydration. Furthermore, 90% of family members who attended formalised palliative care case conferences in the care home setting felt their issues had been heard and addressed to their satisfaction and they now had an increased understanding of their relative's current and future care.[129]

As shown by the interventions for improving dementia care, efforts to make lasting changes to practices in the care home setting often require a dedicated role working across professions and staff categories in providing training or facilitating and/or modelling communication practices to care providers. The Interdisciplinary Care Leader (ICL) role is a key example.[49] In examining practices relating to end-of-life care discussions with family members of residents with dementia, this study determined that such conversations cannot be rushed or completed in one encounter. Unlike care staff, the ICL role has the appropriate time required to conduct these sensitive discussions.[49]

Two studies, both focused on out-of-hours palliative care provision by primary care, provide an insight into the consequences of poor communication between health professionals.[90,103] A mixed methods analysis of a national incident reporting database in Wales has set out quality improvement priorities for safer out-of-hours palliative care provided by primary care.[103] It identified inefficient information processes between providers as one of four major areas of unsafe care. Documented consequences included actual physical harm to patients as well as emotional and psychological distress to patients, families, and carers.[103] A second study highlights the importance of flagging a patient's palliative care needs in their medical record. It found that general practice patients registered as 'palliative' in their record were significantly more likely to receive a home visit by the OoH GP clinician for assessment and less likely to be managed solely via phone. Furthermore, these patients were less likely to be admitted to hospital after assessment and more likely to be referred for community input or require no further follow-up.[90]

A further study in the residential aged care setting found that when EoL discussions were well documented, a higher prevalence of symptoms was reported, and the patient also received better symptom relief. Furthermore, prescribers gave more attention to prescribing drugs PRN (or as required) for symptom relief rather than for prevention.[60] The RAC case conferencing intervention by Agar et al.[50] supports the finding that improved symptom documentation can lead to improved symptom management by focusing staff attention.

7. Interventions for symptom control and quality of life

Eighteen interventions were primarily concerned with improving patient symptoms or quality of life in the end-of-life phase. However, this outcome had additional effects such as reducing the likelihood of ED or hospitalisations. For example, in the community setting:

- The Integrated Care Model reduced the number of COPD exacerbations, thereby reducing acute care costs.[24] A similar integrated community model targeting non-cancer conditions demonstrated the same outcomes[33]
- The Life Rainbow Program significantly improved quality of life and well-being of patients with end-stage non-malignant chronic diseases and their caregivers while also reducing hospital bed days[130]
- A Symptom Response Kit left in the home for the use of home care nurses reduced the likelihood of a hospital transfer in the last six months of life and facilitated a home death[79]
- The Care Choices home palliative care service reduced symptom burden resulting in fewer ED and hospital admissions[38]
- Weekly tailored integrative care sessions (i.e. coordinated complementary and conventional treatment approaches) in addition to palliative/supportive care led to improvements in fatigue and depression at six weeks and sleep at 12 weeks. Global health status and quality of life also improved, and hospital visits and length of stays reduced.[131]

In the residential aged care setting, a controlled Level II study investigated the impact of the Liverpool Care Pathway for the Dying Patient on late-stage symptom distress in residents.[132] It found this adapted intervention significantly reduced shortness of breath and nausea in the last few days of life, although it had no effect on pain and anxiety. However, a subsequent systematic review investigating the adaptation of this pathway for the nursing home setting was critical that the tool had not been used without prior validation within non-cancer populations, including people living with dementia.[133]

A further intervention that has been adopted widely in Europe is the PACE (Palliative Care for Older People) 'Steps to Success' program, a one-year multicomponent palliative care programme aiming to integrate general palliative care into day-to-day routines in RAC facilities.[134] PACE has been implemented in seven European countries using a train-the-trainer approach based on the UK's 'Route to Success in Long-term Care Facilities' (in turn based on the Gold Standards Framework). Three other studies related to PACE are included in this review, but the work of Miranda et al.[121] examined whether the program improved the comfort of dying in the last week of life. It determined that while the program did not improve comfort of dying, it improved the quality of care in the last month of life.

The symptomatic benefits of Namaste Care in both the residential and home care settings have already been reported. Two further studies suggest that interventions designed to support the comfort of PLwD and enhance their engagement with external stimuli can reduce symptoms associated with dementia. First, residents demonstrated improvements in mood when accompanied into an outside garden setting.[135] Secondly, families are shown to perceive the resident's quality of life to be higher when the primary goal of care is known to be comfort and the person is offered enhanced activities and social engagement opportunities, including outings beyond the care home.[136]

Retrospective studies of association, rather than prospective studies of an intervention, were also identified. In their study, Andersson et al.[137] drew on administrative data for deceased patients to identify a significant positive association between the use of validated pain assessment scales in care and the likelihood of patients finding relief from pain or shortness of breath. This same study also found a significant correlation between PRN (as required) injections for pain, nausea, and anxiety and symptomatic relief from those concerns.

8. Practices to reduce aged care staff stress

A further theme identified is residential aged care staff distress or burnout when confronted with intense symptoms such as those of pain or agitation, or the death of patients. Three studies addressed practices to reduce nursing home staff distress or highlight where a change in practice is required. Firstly, in a Level I study, staff were shown to be less distressed when PLwD were provided with individualised pain relief, thereby easing the behavioural and psychological symptoms of dementia.[119] In another study, nurse assistants initially experienced stress, a lack of job satisfaction, and held a negative view of management when a palliative care approach was first introduced into the care home via study circles and workshops with practical tasks to complete.[138] Findings of a third study suggest that grief over patient death plays an overlooked role in direct care worker burnout.[139] Supervisory support and awareness of caregiving benefits were consistently associated with lower levels of burnout dimensions. Conversely, the support of co-workers led to higher levels of depersonalisation and emotional exhaustion.[128] It is not known whether this counter-intuitive finding indicates staff with burnout reach out more to their colleagues, or if sharing distress with colleagues leads to more widespread disillusionment in the workplace.[139]

9. Digital innovations

The review identified fewer digital health innovation studies than what might be expected. Five studies used a digital tool to deliver end-of-life care in some way:

- One focused on the benefits of online grief support communities for the bereaved[140]
- Two addressed the benefits of teleconsultation[36,47]
- A Japanese ICT system was able to facilitate timely patient communication between the care home and clinic settings[80]

- The final study from Scotland found that cancer patients were more likely to have a Key Information Summary (KIS) in their shared electronic care coordination record by the time of death documenting their preferences and care plan. This KIS strengthened their likelihood of dying in the community.[72]

10. Other considerations

Many studies focused on the unique end-of-life care needs or challenges associated with specific population groups. These groups include people with non-malignant conditions, people experiencing incarceration or homelessness, children and adolescents, people from ethnic and racial minorities (including Aboriginal and Torres Strait Islander peoples), the bereaved, and informal carers and families of someone at the end of life.

Special populations

People with non-malignant conditions

The literature describes differences in the quality of the end-of-life care received by people with terminal cancer and people with advanced non-malignant conditions. A disparity in service provision was noted across several studies[72,101,104], alongside challenges of identifying the end-of-life phase for this population. In addition to the interventions already outlined for dementia, the following studies were designed specifically for people with non-malignant conditions:

- Integrated care programs and pathways specifically for people with COPD[24,28] and other non-malignant diseases[39]
- A home-based nurse-led COPD psycho-educative intervention[141]
- An integrated outpatient palliative care service for people with Parkinson disease[25]
- A community-based intervention for non-cancer end-stage conditions called The Life Rainbow Programme (LRP)[130]

It is noteworthy that the review did not identify any studies focused on heart failure or end-stage chronic kidney disease that were within scope.

Prisoners

The review did not identify any intervention studies conducted in the ageing and often chronically unwell prisoner population, although several descriptive studies were retrieved. However, one current systematic review has explored the perceptions of palliative care held by the incarcerated population, as well as the perceived barriers and facilitators to care provision in this setting.[142] The review found that prisoners expected to have their basic palliative care needs met, however, access was limited or delayed by internal prison procedures and policies. Furthermore, they were often reliant on the compassion of individual correctional officers and clinicians. Pain could be left unmanaged, particularly when protocols restricted opioid use, and clinicians might be perceived as apathetic or unwilling to form a therapeutic connection with the prisoner. Compassionate release was seen as a long process and some people died before their application was processed. The review concludes that there is a critical need to improve this care by identifying ‘jurisdictionally specific best practice care strategies’ specifically designed for the prison context which address systemic policy, organisational and structural barriers.[142]

People from ethnic and racial minorities

One study examined the effect of a culturally tailored lay patient navigator service on the palliative care of US Latino people with advanced cancer. The service increased ACP and improved physical symptoms but had no effect on overall quality of life.[53]

Aboriginal and Torres Strait Islander peoples

The review found only one study addressing the unique end-of-life care needs of Aboriginal and Torres Strait Islander peoples. Carey et al.[78] designed and evaluated a community-based, culturally appropriate respite service for the high proportion of Aboriginal and Torres Strait Islander peoples with terminal non-cancer conditions living in Alice Springs who often required hospitalisation. This study found that providing medical services as part of this service reduced the hospitalisation rate and, importantly, facilitated death in the community setting.[78]

Children and adolescents

Most of the paediatric palliative care intervention studies identified were situated in the inpatient setting or delivered by specialist palliative care services and were therefore outside the scope of this review. We found only two studies based on a paediatric population.[26,100] One described an integrated model of care employing a hospital-based specialist palliative care nurse to work alongside a children's community nursing team.[26] The model strengthened joint support for children with end-of-life needs and reduced unnecessary hospital admissions. The second study examined if there was a relationship between the end-of-life care provided to adolescents and whether the adolescent had a usual source of primary care.[100] It found that having a usual primary care provider was associated with an increase in hospice enrolment, hospice length of stay, and end-of-life transitions. However, it may be that adolescents with severe symptom experiences requiring intense medical regimens maintained more contact with their primary care provider, signifying a reverse association.

People experiencing homelessness

Two studies addressed end-of-life care for chronically homeless people. One used a trained counsellor to provide one-on-one counselling sessions to guide homeless people in the preparation of an advance directive.[55] The other study qualitatively evaluated a model of care which used palliative specialists as 'homelessness champions' to work in hostels for two half-days a month to give support to hostel staff and residents.[27] Hostel staff reported being empowered by their increased knowledge and understanding and felt better equipped to advocate for their residents' needs with external services.

Bereaved persons

Four studies addressed bereavement care outside the specialist palliative care setting. One examined online grief support networks and found that membership can reduce psychological distress and continue to bring psychosocial benefits over time.[140] A second study assessed the effectiveness of a cognitive narrative crisis intervention for bereavement delivered by primary care psychologists. It found participants in both the intervention and control groups had lowered depressive and traumatic stress symptoms at six months but there were no significant between-group differences.[108] The third study investigated the work-related consequences of grief reactions by aged care workers on the death of a patient.[139] It found that stronger supervisor support and belief in the benefits of caregiving benefits were protective against depersonalisation and emotional exhaustion and positively associated with a sense of personal accomplishment. These findings press the importance of organisational factors in preventing care worker burnout. Supervisors are urged to provide support and direct workers to grief counselling if needed.

The final study was a realist review of support for bereavement and complicated grief in primary care[109], the purpose of which was to identify what works, how, and for whom.
The review found that while GPs and nurses view bereavement support as part of their role, they experience uncertainty over the appropriate extent of their involvement. Patients may also differ in their view of how involved a primary care practitioner should be in providing this form of care. Training in bereavement, local systems for reporting deaths, practitioner time, and resources could facilitate or hinder bereavement care provision.

Informal carers

Providing care for carers and families as well as the patient is an important tenet of specialist palliative care. While training and educational interventions designed to support carers to provide care were out of scope for this review, studies including a concern for carer health and wellbeing (for example, the 'burden of care') were not. However, only three studies included an objective measure of carer outcomes to understand the impact of an intervention on the carer, as well as on the care recipient. All three studies evaluated the effectiveness of an integrated program of care (two for non-malignant conditions), and each used a different tool to evaluate carer burden. These tools were a Chinese version of the Caregiver Strain Index[130], the German EDIZ scale[37], and the Zarit Burden Interview.[25]

Across an additional 10 studies, carers were asked to provide proxy ratings of the quality of life, care, dying, or death experienced by the care recipient. This approach, often used in program evaluation studies, relied upon a recently bereaved person's recall of events or a carer's perceptions of another person's symptom burden. Specific questionnaires were applied for standardisation of responses and analysed quantitatively. These included:

- Quality of Death and Dying Questionnaire[143]
- Edmonton Symptom Assessment System[38,132]
- Views of Informal Carers: Evaluation of Services (VOICES)[132]
- QUALYCARE[70,89]
- Family Perception of Care Scale[120]
- Family Perception of Physician-Family Communication scale (FPPFC)[128]
- End-of-Life Care in Dementia (EOLD) scales:
    - Symptom Management for End-of-Life Care in Dementia (SM-EOLD)[120]
    - Comfort Assessment in Dying with Dementia (CAD-EOLD)[120]
- FAMCARE[37]
- Quality of Dying in Long-Term Care (QOD-LTC)[37]
- Alzheimer's Disease-Related Quality of Life (ADRQOL)[136]
- Satisfaction with Care at End-of-Life in Dementia Scale[69]
- End-of-Life Dementia Scales.[50]

Several of these studies required the carer to focus in on a specific timeframe in the deceased person's life such as the last 48 hours[120], last three days[132], last three months[74,98], or the final year of life.[70] The questionnaires were also administered to carers at different times across the bereavement trajectory ranging from two weeks[37] to twelve months post-death.[89]

A further set of studies used *qualitative methods* to explore carer satisfaction with a service or program of care. Examples of these interventions include:

- The Italian ANT home care model which provides free medical and nursing support 24 hours/seven days per week, a psychological service, bereavement support, and practical social home assistance to cancer patients and their families[42]
- Australia's free-of-charge Palliative Care Home Support Program in which community workers support carers by providing non-clinical patient care, domestic tasks, and day/night respite service[143]

- The unique Medical Foster Home model that provides end-of-life care to USA veterans residing in the private homes of nonfamilial informal caregivers[144]
- A nurse-led home self-management support intervention for people with cancer[145]
- District nurse service accessibility and quality of care[101]
- Namaste Care delivered in the home[118] or RAC facilities.[110,112-114,116]

In contrast, only a few studies included in this review directly sought the perspectives and opinions of people facing the end of life. Those that did were all from the home care setting. They include:

- An evaluation of Care Choices, a home care visiting nurse service[38]
- A nurse-led structured self-management intervention for home-dwelling cancer patients[145]
- A four-day multidisciplinary residential palliative care programme for patients with high-grade glioma and their family caregivers[146]
- Paramedic-provided acute care in the home[29,75,76]
- A home-based COPD psychoeducation program[141]
- A teleconsultation service for integrated palliative care at home.[36]

Access to medicines, anticipatory prescribing, and deprescribing

The careful procurement and administration of medicines to people at the end-of-life emerged as an important consideration during the review across all settings. One study examined the availability of symptomatic palliative medicines from community pharmacies, identifying numerous factors impeding their timely accessibility.[147] Pharmacists report practical difficulties in supplying palliative medicines including stock ordering processes and inadequate storage space and tended to obtain them in a reactive fashion. Some of the problems were alleviated when there was two-way communication between the GP and pharmacist. Pharmacists might also be encouraged to alert practices to pharmacy opening times and cut-off times for same-day delivery of medicines.[147]

A Spanish study examined the use a goal-oriented prescribing model for optimising medication use by frail nursing home residents.[148] Investigators conducted a pharmacotherapy review using the ‘patient-centred prescription’ (PCP) model to focus medication decisions on the resident’s global assessment and personal goals for care. An audit of medications first identified that 92% of residents had at least one inappropriate prescription. The PCP model, however, reduced the number of chronic medications proposed by 25% and polypharmacy from 72.55% to 52.94%.[148]

A systematic review of the barriers to deprescribing for people with a life-limiting illness was also identified.[149] This found the most prominent facilitators to deprescribing to be:

1. Organisational support for standardised medication reviews and an awareness of the overmedication of residents, especially PLwD who demonstrate behavioural and sleep disturbances
2. Involving the person’s multidisciplinary team in medication review and coming to a joint decision
3. Involving the patient and family in the decision-making process.

Barriers included staff shortages and perceived resistance from the patient or family. The review concludes that deprescribing interventions require a whole system approach for success.[149]

Organisational readiness for change

Three studies focused on organisational barriers or facilitators to implementing end-of-life care programs or practices with demonstrated effectiveness in the residential aged care setting.[150-152] A mixed methods study investigated the characteristics of successful implementation of the Gold Standards Framework in Care Homes program.[151] It identified as best practice a proactive 'being present' facilitation style 'supported by multi-layered learning' at the individual, organisational and systems levels. Although this approach to getting staff through the program to accreditation took a larger investment in time and energy than other styles, Kinley et al.[151] assessed the additional costs involved as being outweighed by cost savings in care.

Two realist reviews examined studies describing successful interventions for the mechanisms and contexts contributing to their success (i.e. asking *how* it worked).[150,152] Both reviews acknowledged the fundamental implementation issue – that innovative approaches in residential care settings are mostly multicomponent, localised, often unsustained, and therefore unlikely to be implemented at scale. Successes could be undermined by contextual factors such as high staff turnover, waning interest from management, or a staff skill mix imbalance. However, several actions showed more resistance than others to implementation barriers.

Strengthening and maintaining relations with visiting health professionals

It is not sufficient for clinicians such as GPs to merely attend a residential aged care facility and provide medical care. According to Goodman et al.[150], residents were more likely to achieve benefits from visits when there were strong relations established between care home staff and the visiting health professional. Furthermore, a good working relationship was dependent on the following conditions being met:

- The relationship had been established over a long period of time
- There was good continuity of contact between the clinician and home staff
- Rather than being task-oriented, the visiting clinician engages staff in action learning on issues of interest to them, drawing the connection between new knowledge and existing practices
- The care home establishes a dedicated link-worker role, backed by policy, who liaises with all visiting clinicians.

Staff involvement in change

Staff motivation did not emerge as a strong contextual barrier to organisational readiness for, and acceptance of, change. On the contrary, the Spacey et al.[152] review identified staff as highly motivated and passionate in their care responsibilities. Intervention implementation and fidelity were more often influenced by:

- Organisational incentives or sanctions
- Staff having allocated time for discussion and reflection during shifts, especially with visiting clinicians
- Staff involvement in developing protocols and structured care plans
- Staff ability to contribute to identifying priorities of mutual concern to them and the organisation, thereby creating a common sense of purpose.[150]

Organisational support for change

Care home organisational factors could also influence the successful acceptance and implementation of a practice change. Success was more likely if management showed visible commitment to end-of-life care provision as a priority area through attendance at training or meetings relating to it and by allowing the time required for the system to evolve and self-organise around any changes. Creating time for staff to engage with an intervention, rather than forcing them to carve time out of their work (or non-work) schedule was also identified as a key factor to success.[152]

Results of the grey literature review

Selection of documents

The 500 websites returned from the Google searches and the 41 organisational websites targeted for close review were initially screened by a medical librarian (SH) for content potentially in scope, duplicates, and resource accessibility. Two researchers (AC, DR) then checked the 56 retained resources against the inclusion criteria. Subsequently, 40 documents were included (see Table A9 in Appendix 6).

There is a plethora of information and resources in the grey literature relating in some way to end-of-life care in the community and in RAC. These are categorised to date as:

- Reviews of literature
- Reports by or for government
- Documents
- Evaluation
- Research
- Position statement
- The Royal Commission into Aged Care Quality and Safety.

Reviews of literature

- Comprehensive Palliative Care in Aged Care Measure
- Exploratory analysis of barriers to palliative care: Literature Review
- Advance care planning for people with cancer: A rapid review of the literature
- Exploratory review of palliative care assessment tools
- Improving palliative and end-of-life care for rural and remote Australians*.*

Reports by or for government

- *Research into awareness, attitudes and provision of best practice advance care planning, palliative care and end-of-life care within general practice*
- *Aged care, end-of-life and palliative care.* Report No. 33, 56th Parliament Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee
- *Issues overview: Palliative care within aged care.* Prepared for the Royal Commission into Aged Care Safety and Quality by Palliative Care Australia
- *Exploratory analysis of barriers to palliative care: Issues report on Aboriginal and Torres Strait Islander peoples*
- *Exploratory analysis of barriers to palliative care: Issues report on care leavers and people affected by forced adoption*

- *Exploratory analysis of barriers to palliative care: Issues report on people with disabilities*
- *Exploratory analysis of barriers to palliative care: Issues report on people experiencing homelessness*
- *Exploratory analysis of barriers to palliative care: Issues report on people who identify as lesbian, gay, bisexual, transgender, or intersex*
- *Exploratory analysis of barriers to palliative care: Issues report on people who are incarcerated*
- *Exploratory analysis of barriers to palliative care: Issues report on refugees*.

Documents

General practitioner specific

- GP-led palliative care in rural Australia. Position statement by RACGP
- GP Palliative Shared Care Program Framework: For general practitioners. By GP partners Australia and SA Health
- Workbook for general practice: End-of-life care. By North Western Melbourne PHN.
- Quality improvement toolkit for general practice: Patient population groups. A palliative care/end-of-life module by Brisbane South PHN.

Community specific

- Dying at home is a choice. Fiona Onslow, District Nurse, describes the Tasmanian hospice@HOME program.
- The District Nurses 2017–18 Pre-Budget Submission to the Australian Government by The District Nurses hospice@HOME Tasmania
- *The role of paramedics in palliative and end-of-life care: Scoping report*. Developed by Safer Care Victoria.

RAC and dementia specific

- Principles for Palliative and End-of-Life Care in Residential Aged Care
- Residential Aged Care End-of-life care Pathway (RAC EoLCP) by the Brisbane South Palliative Care Collaborative
- The experience of Punjabi Indians with palliative care at residential aged care facilities: A regional perspective
- Aged care staff training needs analysis report. Greater Townsville Region – Connecting End-of-life care in Townsville (CELC-T) Project by Palliative Care Queensland
- *Content and quality assessment of advance care planning policies in Australian health and residential aged care services: Implications for future policy development*
- Dying well: Improving palliative and end-of-life care for people with dementia

Other

- *Achieving Victoria's best end of life experience for people in Latrobe. Progress Report September 2021* by LaTrobe Health Advocate
- *Concordance between instructional directions in advance care planning documentation versus medical orders*
- The Victorian Councils: Supporting Communities Around End of Life Project
- Advance care planning: Aged care implementation guide. Developed by Advance Care Planning Australia.

Evaluation

- Palliative Care Conversations: Project evaluation. Conducted by Southern Metropolitan Palliative Care Consortium
- *Evaluation of the End of Life Directions for Aged Care (ELDAC) Program: Final Evaluation Report – Summary*. Undertaken for the Australian Government Department of Health by HealthConsult, November 2020
- Building 'end-of-life care' capacity in community pharmacy Supporting community pharmacists to enhance patient care. Information by South Eastern NSW PHN.

Research

- *End of life at home: Co-creating an ecology of care*. A research report by Horsfall D et al. and published by Western Sydney University.

Position statement

- End-of-life care and advance care planning for rural and remote communities. Position statement by the Australian College of Rural and Remote Medicine.

The Royal Commission into Aged Care Quality and Safety

- *Final report: Care, dignity and respect - Volume 1 summary and recommendations*
- Review of international systems of long-term care of older people. Research paper 2
- Review of innovative models of aged care. Research paper 3
- Review of innovative models of aged care: Appendix 3.

Discussion

This rapid review of the literature set out to identify best practice principles, processes, and organisational prerequisites for delivering safe and high-quality end-of-life care in aged care and community settings. It also aimed to provide considerations in end-of-life care in a pandemic, as well as to explore the Australian grey literature. Overall, 10 themes and eight subthemes were identified from the review of 130 included papers in the main review.

The context in which care is provided in the community (including RAC) is inherently more complex than in a hospital environment where care is provided continuously, usually with no direct costs to patients, except for private health payments. Care in the community can be disparate and fragmented, with a patient and family moving through a health and social care system where gaining access to services and having care needs met is complex, and where care, consumables, equipment and medication costs can be incurred. Throughout the last year of a person's life, they will often move between settings. They may begin being at home or in a home-like setting such as a RAC facility, supported accommodation, or a prison. They could also be homeless. At some stage they may visit an emergency department, be admitted as an inpatient in hospice or hospital, or enter respite care. Throughout these transitions they often experience care as discrete rather than continuous and coordinated episodes.

This review took an inductive approach in identifying the issues of concern and the outcomes of attempts to address them. It found that outside the controlled environment of the hospital, end-of-life care can be provided by myriad services across multiple settings, with the risk being that no one service takes responsibility for coordinating it all for the care recipient. Despite this variability, attempts to improve the quality and safety of end-of-life care in community settings appear to focus on achieving a particular set of beneficial outcomes and reducing the likelihood of a narrow range of adverse ones. Benefits targeted by interventions include improved symptom control, timely identification of people with palliative care needs, gaining an explicit and shared understanding of care goals, and supporting informal and formal caregivers in their roles. Equally, interventions commonly sought to reduce the risk of symptom exacerbations leading to late ED visits, hospital transfers, and hospitalisations. Medication safety was also targeted through interventions to reduce inappropriate polypharmacy or to encourage anticipatory prescribing. As this body of evidence has shown, these avoidable outcomes might arise from poor communication between sectors of care, lack of primary care involvement during the end-of-life phase, clinician inability to recognise this phase and, consequently, a hesitation to initiate conversations with patients and their families on changing goals of care.

Collaborative or integrated care initiatives

Care coordination is vital for seamless transitions between care settings and our findings suggest that care partnerships that traverse health sectors with inter-organisational, inter-sector, and inter-professional collaborations are effective mechanisms for improving end-of-life care provision. For example, dementia, multimorbidity and frailty require an integrated social and healthcare response.[9] These range from local collaborations between service providers to more fully integrated models of care.[22-28] Integrated models appear to confer particular symptomatic management benefits to patients with non-malignant conditions such as COPD.

Some models include the involvement or integration of SPC in community settings. Demonstrated benefits of these models include a reduction in inappropriate hospital admissions, reduced use of acute care, as well as increases in the rate of home deaths.[30-42] Additionally, several studies showed improved symptom control, higher family satisfaction, and a more confident workforce with integration. In RAC, successful models of end-of-life care appear to engage an SPC clinician in a mentoring, consultation, or coaching role, preferably working alongside RAC staff and gradually reducing their presence with staff gains in competence and confidence over time. These models emphasise the importance of identifying residents with palliative care needs, formal assessment, documenting symptoms, and engaging with families and residents in conversations around care goals. Telehealth appears to foster these collaborations, allowing SPC clinicians to engage with patients and a GP or RAC staff in real time about acute problems or as part of regular case conferences. This finding was also a feature of our previous report.

Structured approaches to end-of-life goals of care discussions and advance care planning

Advance care planning, or systematic approaches to communicating changing goals of care, are a prevalent concern in end-of-life care. More recent innovations in goals of care planning are seeing well-being promoted, asking how you would wish to be cared for or supported until death?[9] In some studies, planned conversations were incorporated into multicomponent programs. Health professionals' have also taken on an ACP advocacy or facilitating role with positive effect; however, role sustainability does need to be considered. Other approaches targeted at patients and families via the provision of information (video, pamphlet) have shown little effect unless they are actively followed up, in which case significant improvements were seen, although to be noted health literacy does need to be considered. A whole of organisation approach incorporating ACP into routine standardised practice has also shown increases in rates of ACP completion and documentation. Not having goals of care discussions or planning has seen increases in hospital transfers and dying in hospital.

Interventions to reduce community-hospital transfers

Older people living in the community or RAC are frequently transferred to hospital near the end of their life sometimes with a high risk of complications and mortality, especially during out-of-hours. This may be experienced as disruptive, distressing and not always necessary, with dying on a ventilator, looked after by masked and gowned staff, and only able to communicate with family through screens, viewed as the ultimate medicalised death.[9] Models developed to prevent these transfers include paramedics providing at home care, day respite, home death education /symptom control kits available to community nurses, use of technology to connect rural RAC to specialists, community nursing specific to end-of-life care. However, these types of interventions are not always adopted successfully in RAC with precursor risk factors often making transfer inevitable. These include uncontrolled symptoms, lack of ACP or goals of care (GoC) conversations, pressure of RAC staff from families, poor communication between RAC and families and with the GP, GP unavailability (also a factor at home), and no medical review in the last 24 hours. Also noted in the community setting were a lack of community palliative care and few visits by integrated primary/SPC at the end of life.

Primary care involvement in end-of-life care

Having the support of a general practitioner emerged as a key positive factor in quality end-of-life care across all community settings, with this access related to people dying in their own homes rather than a hospital. Home visits by a GP were seen to help enable a home death (by 47% in one study[96]), with GPs more able to recognise imminent dying in RAC. The frequency of visits was also positively reported on by bereaved families. Out of hours care provision in primary care was reliant on good communication from the usual GP re: the patients' status, and when lacking, jeopardised care quality and safety, increased hospitalisations and caused patient and family distress. Studies identified that a lack of GP skills in identifying the end of life can potentially lead to late discussions around GoC. Interventions targeted at addressing this include structured approaches using prognostication tools, frameworks, education, and care pathways. Bereavement care (including treatment of complicated grief) has been identified as important by GPs, but it is often challenging to provide.

Dementia-specific interventions

Dementia-specific interventions were identified with Namaste Care (predominantly provided in RAC) the most prevalent, providing benefits for both PLwD and staff via continuing opportunities for social interaction and engagement. Staff and families have positively evaluated the program with benefits seen in the improvement of behaviour and psychological symptoms resulting in medication reductions as well as better pain management. Another study[117] used exposure to nature as an intervention with resulting mood improvements, which along with those relating to the sensory components of Namaste Care, raises important questions for policy about the design of dementia care facilities and programs. Other dementia-focused studies in RAC include individual pain approaches, facilitated case conferences, GoC decision-aids and training, which in turn reduced staff stress (when symptoms managed), increased GP input and nurse documentation, increased palliative care focus with reduced hospitalisation, and higher family satisfaction. However, most of these RAC-based dementia interventions require a high level of organisational support and the ongoing dedication of a trained facilitator or coordinator. Fewer studies looked to dementia-specific care outside of RAC. A home-based Namaste intervention provided family respite,[113]while two other studies described a community NP dementia co-management program which reduced acute care use and increase ACP.[22,23]

Interventions with a positive effect on communication

In addition to the ACP or GoC studies already described, a range of interventions were found to have a positive effect on communication between the various people involved in a person's end-of-life care, often not the primary intent but a requirement for improving another aspect of care. This includes improving the quality of end-of-life care in general, symptom management, and reducing unnecessary hospital transfers. The review also identified structured programs for facilitating communication around end-of-life care between GPs and patients and their families, with satisfaction with care provision closely associated with the amount and quality of communication. Efforts to make lasting changes to practices in RACs often requires a dedicated role working across professions and staff categories in providing training or facilitating and/or modelling communication practices to care providers. Studies have also reported improvements in communication as incidental findings, including paramedics providing urgent symptom control and ensuing communication of acute events to families and GPs, joint consultations between GPs and hospice staff with improved communication with patients, a case manager working with GPs improved awareness of preferred place of death.

Interventions for symptom control and quality of life

Eighteen interventions were primarily concerned with improving patient symptoms or quality of life in the end-of-life phase with additional effects such as reducing the likelihood of ED or hospitalisations and facilitating a home death. In RAC settings examples include the Liverpool Care Pathway (reduction in some symptoms but needs validation in RAC settings) and the PACE program which has been shown to improve quality of life in one study. The symptomatic benefits of Namaste Care in both the residential and home care setting have already been reported, such as enhance their engagement with external stimuli and reduce symptoms associated with dementia. A further study identified a significant positive association between the use of validated pain assessment scales in care and the likelihood of patients finding relief from pain or shortness of breath.[137]

Practices to reduce aged care staff stress

A further theme identified is residential aged care staff distress or burnout when confronted with intense symptoms such as those of pain or agitation, or the death of patients. This includes less distress when PLwD receive individualised pain relief[114], and support from supervisors and caregiving benefits were associated with lower levels of burnout dimensions[127] It is suggested that grief over patient death also plays an overlooked role in direct care worker burnout.

Digital innovations

The review identified fewer digital health innovation studies than what might be expected with five studies using a digital tool to deliver end-of-life care in some way. These include online grief support communities for the bereaved[128], teleconsultation[36,47], timely patient communication between a care home and a clinic[78], and a shared electronic care coordination record with place of death preferences and care plan embedded which strengthened a person’s likelihood of dying in the community.[72]

Other considerations

Specific population groups

Many studies focused on the unique end-of-life care needs or challenges associated with specific population groups. These groups include people with non-malignant conditions, people experiencing incarceration or homelessness, children and adolescents, people from ethnic and racial minorities (including Aboriginal and Torres Strait Islander peoples), the bereaved, and informal carers and families of someone at the end of life.

People with non-malignant conditions

The literature describes differences in the quality of the end-of-life care received by people with terminal cancer and people with advanced non-malignant conditions including disparities in service provision as well as prognostication challenges.

Prisoners

The review did not identify any intervention studies conducted in the ageing and often chronically unwell prisoner population; however, one current systematic review has explored the perceptions of palliative care held by the incarcerated population, and perceived barriers and facilitators to care provision in this setting. The review recommends improvement of care via identification of best practice specifically designed for the prison context which address systemic policy, organisational and structural barriers.[142]

People from ethnic and racial minorities

One study examined the effect of a lay patient navigator service on the palliative care of US Latino people with advanced cancer, resulting in increased ACP and improved physical symptoms.[52]

Aboriginal and Torres Strait Islander peoples

One study addressed the unique end-of-life care needs of Aboriginal and Torres Strait Islander peoples which found that providing medical services as part of a respite service reduced the hospitalisation rate and facilitated death in the community setting.[78]

Children and adolescents

Two studies were based on paediatric and adolescent populations. One described an integrated model of care employing a hospital-based specialist palliative care nurse to work alongside a children's community nursing team which strengthened joint support for children with end-of-life needs and reduced unnecessary hospital admissions.[26] The second study with adolescents found that having a usual primary care provider was associated with an increase in hospice enrolment, hospice length of stay, and end-of-life transitions.

People experiencing homelessness

Two studies addressed end-of-life care for chronically homeless people. One used a trained counsellor to provide one-on-one counselling sessions to guide homeless people in the preparation of an advance directive.[55] The other study looked at a model of care which used palliative specialists as 'homelessness champions' to work in hostels for two half-days a month to give support to hostel staff and residents.[27] Hostel staff reported being empowered by their increased knowledge and understanding and felt better equipped to advocate for their residents needs with external services.

Bereaved persons

Four studies addressed bereavement care outside the specialist palliative care setting including the benefits of online grief support networks, the benefits of an intervention delivered by primary care psychologists, the consequences of grief reactions by aged care workers on the death of a patient. It found that stronger supervisor support and belief in the benefits of caregiving benefits were protective against depersonalisation and emotional exhaustion and positively associated with a sense of personal accomplishment.

Supervisors are urged to provide support and direct workers to grief counselling if needed.[127] The final study was a realist review of support for bereavement and complicated grief in primary care[109] which found that while GPs and nurses view bereavement support as part of their role, they experience uncertainty over the appropriate extent of their involvement. Patients may also differ in their view of how involved a primary care practitioner should be in providing this form of care. Training in bereavement, local systems for reporting deaths, practitioner time, and resources could facilitate or hinder bereavement care provision.

Informal carers

Providing care for carers and families as well as the patient is an important tenet of specialist palliative care. To note, training and educational interventions designed to support carers to provide care were out of scope for this review. Across 10 studies, carers were asked to provide proxy ratings of the quality of life, care, dying, or death experienced by the care recipient, reliant upon a recently bereaved person's recall of events or a carer's perceptions of another person's symptom burden.

Access to medicines, anticipatory prescribing, and deprescribing

Medication for people at the end-of-life emerged as an important consideration across all settings. One study escribed numerous factors impeding the timely availability of palliative medicines from community pharmacies.[147] Some of the problems were alleviated when there was two-way communication between the GP and pharmacist.

A Spanish study examined a ‘patient-centred prescription’ (PCP) model to focus medication decisions on the resident’s global assessment and personal goals for care, reducing the number of chronic medications prescribed and polypharmacy.[148] A systematic review of the barriers to deprescribing for people with a life-limiting illness was also identified.[149] This found the most prominent facilitators to deprescribing to be:

1. Organisational support for standardised medication reviews and an awareness of the overmedication of residents
2. Involving the person’s multidisciplinary team in medication review and coming to a joint decision
3. Involving the patient and family in the decision-making process.

Barriers included staff shortages and perceived resistance from the patient or family. The review concludes that deprescribing interventions require a whole system approach for success.[149]

Organisational readiness for change

Considerations within organisations providing care for those at the end of life include barriers and facilitators to change in the first instance, as any intervention required a change in the way care is provided. A main factor emerging in RAC was management commitment to end-of-life care that facilitates education initiatives and provides staff time to participate, staff incentives, and staff involvement facilitating a common sense of purpose. Barriers include high staff turnover, skill mix imbalance and less interest form management.

The first rapid review undertaken in 2020[2] provided an overview of care in an acute hospital setting which can be viewed as a discrete episode in a patients end-of-life journey. The initial rapid review resulted in recommendations to the Commission to include four new elements to the essential elements in the consensus statement:

- Within processes of care, to add in **communication (**including using plain language when updating family on someone’s condition) and **bereavement** (including paying attention to the family’s own unique needs, not as proxy for patient)
- Within organisational prerequisites add in **organisational culture** (including facilitating cultural change about the role and priority of end-of-life care in health service organisations) and **physical space** to meet the individual needs of the patient (privacy) and the family (including spaces where families can gather).

This current review requires a different more realist view of care provided in multiple care settings but has supported the importance of both communication and bereavement and in some areas has also highlighted organisational culture as an important consideration.

Limitations

This review was a resource-limited and time-bound analysis covering a broad and diffuse topic. To minimise the potential of missing relevant studies, the search strategy was kept intentionally broad. However, for practical purposes, it was restricted to English language publications arising from high-income countries only. We cannot discount the possibility that this approach eliminated some high-quality and edifying studies from the results set.

Secondly, most of the studies identified and included in the analysis were cross-sectional in design, linked data sets retrospectively, or combined an available data source with a cross-sectional survey of bereaved family members (a ‘mortality follow-back’ design). The findings from these studies should be interpreted with caution as they can only suggest an association and cannot draw conclusions around causation, nor infer the direction of a relationship between variables. They also tend to look for associations between outcomes of interest such as late hospitalisations and non-modifiable variables such as gender and age. There is clearly a need for high-quality prospective studies to investigate some of the issues identified in this review.

This review also excluded pilot and feasibility studies to focus on more established evidence. This decision may have eliminated promising interventions, especially in the digital health realm, which have not yet been tested in larger populations.

Several studies measured quality of care based on bereaved family or formal caregiver perceptions. It should not be assumed that perceived quality of care is a proxy measurement of quality of life as experienced by the care recipient. Bereaved family members may have their own interpretative lens based on several factors and potential confounders that do not appear to have been accounted for in many of the studies reviewed. Furthermore, most studies relied on proxy respondents and their retrospective evaluations of their loved one’s experiences of dying. Only eight of the 130 studies directly sought the voice or opinions of the person facing the end of life. Thus, there is the potential for bias in reporting or recall.

Recommendations

The following recommendations have been developed from the review of evidence presented in this report. They relate to the delivery of safe and quality care for people approaching the end of their life in community and residential aged care settings. We are highlighting higher level guidance that can be interpreted at local levels in different ways, and across different landscapes.

Recommendation 1: Integrated care

Facilitate and promote integrated care to improve end-of-life care in all settings.

Care is experienced within a broad health and social care system, with separate episodes of care in different settings experienced throughout the last year of life. Care coordination is vital for seamless transitions between care settings and our findings suggest that care partnerships that traverse health sectors with inter-organisational, inter-sector, and inter-professional collaborations are effective mechanisms for improving end-of-life care provision. Mechanisms by which people work together could include the multidisciplinary care team at a case conference, intersectoral collaboration via Primary Health Networks, and interdisciplinary care via the use of a patient navigator. Notably, clear role delineation is needed, particularly around activities such as ACP and setting goals of care, else it can be easy to assume that someone else with take responsibility.

Recommendation 2: Organisational readiness

Organisational readiness is considered across all sectors and settings as a pre-requisite for quality and safety in end-of-life care.

In implementing end-of-life care programs or practices, organisational factors can serve as barriers or facilitators to uptake. Successful acceptance and implementation of a practice change requires:

- That health and social care organisations caring for people at the end-of-life recognise and consider this care to be core business
- Adoption of change management practices as any intervention is in itself a change (such as in the way in which care is provided)
- That there is managerial commitment, governance, leadership and visible engagement including staff involvement and ongoing support such as approaches to prevent burnout, and support for ongoing learning
- The ability and willingness to work with and across other organisations and sectors
- Recognising that roles that are embedded into an organisation (facilitator, coordinator) stand more chance of success than a time-limited role where sustainability of the intervention is then questionable
- Involvement in palliative care and end-of-life care data collection (*National Palliative Care Strategy 2018*, National Palliative Care and End-of-Life Care Information Priorities 2022) to aid in service planning. An example could see PHNs providing local data regarding numbers of those considered to be at the end of life.

Recommendation 3: Keeping people at home

Promote strategies and interventions that focus on enabling people to remain at home at the end of life

Many papers were focused on avoiding inappropriate hospitalisation with interventions aimed at keeping people at home, especially if that is where they wish to die. Considerations to address this include:

- Upskilling HCPs to recognise dying and when not to transfer someone who is at the end of life. This is an important skill that can facilitate this goal with an example seen in the ‘needs rounds’ and community paramedic interventions. Conversely, it is also important to recognise and facilitate appropriate an appropriate need for hospitalisation.
- Acknowledging that some services may be reliant on acute care settings to provide end-of-life care, so to highlight the need for primary care providers to quantify and justify transitions between settings at the end of life
- Considering the role of home visits by primary healthcare professionals (including locum GP services) which can help people to remain at home. Also, that communication within services will help facilitate an optimal outcome.

A further important consideration is the availability of a family carer able to provide the support needed for a person to die at home.

Recommendation 4: Bereavement

The inclusion of bereavement care that traverses inpatient and community settings including residential aged care (RAC) in the Consensus Statement be considered.

Everyone should be provided with access to bereavement care wherever their family member or loved one died. While GPs and nurses view bereavement support as part of their role, they experience uncertainty over the appropriate extent of their involvement. Patients may also differ in their view of how involved a primary care practitioner should be in providing this form of care. Training in bereavement, local systems for reporting deaths, practitioner time, and resources could facilitate or hinder bereavement care provision. With the disproportionate impact of COVID-19 on residents in RAC, staff are having to consider more fully their responses to family grief and bereavement. These staff and those in community settings are often without access to grief and bereavement support themselves.

Recommendation 5: Communication

Consider how to escalate the need for competent communication skills.

Patient-centred communication is an essential element in the Commission's Consensus Statement, incorporated into actions as part of the NSQHS standards and as a separate consideration 'Communicating for Safety'. The issue of communication emerged from the 2021 rapid review as a vital part of health care and is supported in this second review, alongside the need for communication between care providers and advance care planning and goals of care discussions. The review has also shown that satisfaction with care provision is closely associated with the amount and quality of communication between families/patients and health providers. Efforts to make lasting changes to practices in the RAC setting often require a dedicated role working across professions and staff categories in providing training or facilitating and/or modelling communication practices to care providers.

Recommendation 6: Structured approaches to goals of care and advance care planning

Promote structured approaches to advance care planning that include end-of-life goals of care discussions The benefits of ACP are well documented and have been supported in this study.

Benefits to goals of care discussions include improved communication overall, with a common understanding of plans, an increased likelihood of dying in preferred place, a reduction in hospital transfers, higher rates of anticipatory medication prescribing and increased family satisfaction. A whole of organisation approach incorporating ACP into routine standardised practice has also shown increases in rates of ACP completion and documentation. Not having goals of care discussions or planning has seen increases in hospital transfers and dying in hospital. The training and support of staff in how to approach this is an important consideration, as is the role of the GP in prognostication to facilitate timely discussions around goals of care and ACP.

Recommendation 7: Dementia care

Reinforce the importance of Dementia care as an important issue in all settings (i.e. acute, community and RAC).

The numbers of those dying with dementia and dying from dementia will increase exponentially over the coming years. Considerations in the care of people living with dementia include:

- Making available comprehensive community care packages that enable people to stay at home longer, deferring admission to RAC
- The value of Namaste Care in improving the care of people living with dementia
- That ACP and goals of care discussions are facilitated in a timely way, while people still have capacity
- That policies based on best evidence direct the design of dementia care facilities and programs
- That RAC-based dementia interventions usually require a high level of organisational support and the ongoing dedication of a trained facilitator or coordinator
- Family caregivers require support in their role in end-of-life care.

Recommendation 8: Medication management to optimise symptom management

Highlight the importance of medication management at the end of life with a focus on anticipatory prescribing and deprescribing in order to optimise symptom control.

Community pharmacies and RACs should be aware of the importance of stocking the required medications to allow easy access when needed. Furthermore, pharmacists and GPs may have a role in modelling approaches to reducing inappropriate medication administration (deprescribing) via medication reviews and through establishing effective GP-pharmacist communication channels.

While optimal management of symptoms at the end of life is difficult to mandate, recommendations relevant to quality and safety aspects of care can be promoted in relation to symptom control. For example, people receiving end-of-life care are often hospitalised due to poor symptom control and may not be able to die at home. Avenues to address this include:

- Models of integrated care can contribute to improved symptom control especially those that involve SPC
- Early identification and documentation of symptom burden can be achieved, for example, via ‘needs rounds’, case conferencing, and Namaste Care. Community paramedics with extended skills in addressing symptom burden in the home setting without hospital transfer are also a promising development.
- Improvements in communication can raise the quality of symptom control and end-of-life care overall
- Improvement in the ability of HCPs to recognise dying and proactively plan care through, for example, anticipatory prescribing or ACP
- Symptom assessment tools can be useful in standardising approaches to symptom management.

Recommendation 9: Specific populations

Promote the work of palliative care programs and organisations that focus on the needs specific populations to address access and equity issues.

Many studies focused on the unique end-of-life care needs or challenges associated with specific population groups. These groups include people with non-malignant conditions, people experiencing incarceration or homelessness, children and adolescents, people from ethnic and racial minorities, Aboriginal and Torres Strait Islander peoples, the bereaved, and informal carers and families of someone at the end of life. The following evidence needs to be considered.

- Improvement of care can be made via identification of best practice and a focus on person-centred care
- Culturally appropriate care can improve ACP uptake and symptom control
- Integrated care can improve care (i.e. between specialists such as neurologists and palliative care)
- Support for staff such as grief counselling is important
- Providing care for carers and families is part of care.

Recommendation 10: Healthcare professionals

Highlight the need for ongoing support of healthcare professionals providing end-of-life care in all settings (e.g., prevention of burnout by addressing staff grief / bereavement by promoting self-care and clinical debriefing).

Healthcare professionals are the mainstay of the healthcare workforce and require ongoing support to continue working. There are personal considerations in this support (for example self-care awareness) and professional ones (such as workforce development). For example, this review has found that:

- Residential aged care staff experience distress or burnout when confronted with a resident’s intense symptoms such as those of pain or agitation, or the death of someone to whom they provided care. These findings press the importance of organisational factors in preventing care worker burnout. While this research evidence is based on nurses, further research may identify that this is also an issue for allied health professionals and primary care professionals. This may also be a recognised need outside of aged care settings.
- The contribution of GPs to care in the last stage of life appears to be critical if people wish to die in a preferred place, especially if that place is home. Across those studies addressing GP communication with patients at the end of life, the ability to identify patients with palliative care needs was always presented as a prerequisite to end-of-life care provision but GPs may require support to increase their confidence in prognosticating. Therefore, promotion of available and validated prognostication tools might serve to facilitate GP-initiated end-of-life conversations.

Implementation strategy

The depth and breadth of this review may require the Commission to consider an implementation strategy detailing how to take these recommendations forward. This could cover considerations of:

- The broader context in which care for those who are dying is delivered. This includes multiple settings with different services, sectors/portfolios, staffing profiles, objectives, cultures and bureaucracies
- Other work documented in this space such as that developed by Palliative Care Australia, the Commonwealth Department of Health, and various state-based and local palliative care organisations (for example, strategic planning documents and clinical pathways)
- Whether consultation occurs across sectors, with consumers, with HCPs, and other stakeholders
- What needs to be developed into a clinical standard such as bereavement, or whether an overarching clinical standard that encompasses end-of-life care is required
- The impact of this report on the Consensus Statement and the NSQHS Standards (see Appendix 9: Opportunities for development of the Consensus Statement)
- Dissemination pathways/messaging of these findings across multiple settings and to multiple providers.

In the 2021 rapid review we recommended revision of the Consensus Statement to include communication, bereavement, organisational culture and physical spaces. With the exception of the latter, these recommendations are also supported in the findings from this review.

Conclusion

This study highlights many of the difficulties in relying on titles and abstracts in the literature to identify a person’s place in the dying trajectory, the nuances of different regional models of home and specialist palliative care, and the work locations of vaguely described ‘generalist’ or ‘primary’ palliative care providers.

Recognition of the context in which end-of-life care is provided in the community is required to understand the complexity that lies therein. While the focus of this review is the out of hospital setting, end-of-life care is inevitably experienced within the whole health and social care system. For the most part, the last year of life person’s life is spent in the community at home (which may be a personal residence, a prison, residential aged care, supported accommodation) or in fact on the streets where many of them would like to remain to die. Interspersed with care in the community will potentially be admissions to hospital, trips to the ED and specialist appointments. These transitions between community and /or residential aged care and hospital demand but do not necessarily achieve seamless care transitions. End-of-life care in the community is provided by many primary health care and aged care health professionals and the quality of care provided needs be enhanced, with the COVID-19 pandemic adding layers of complexity.

Appendices

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 co-lead 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 a longstanding member of the academic postgraduate studies program with research leadership and expertise in Palliative and end-of-life care. She is co-lead investigator on the End-of-life Essentials project.
- Dr Raechel Damarell is a Research Associate with RePaDD. As a former medical librarian, she has extensive experience in evidence retrieval, appraisal, and synthesis, having collaborated on numerous systematic reviews across the medical and health sciences disciplines at Flinders University.
- 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 projects at Flinders University.
- Ms Marg Adams (Clinical Reviewer) RN, NP, MNP (Chronic Disease Management) MCN (Palliative Care). Marg is Manager, Research and Innovation (Anglicare Southern Queensland).

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. Dr Damarell, Dr Chakraborty and Ms Rawlings screened and identified the selected papers with inputs from Assoc Professor Devery and Ms Hammond. Dr Damarell and Dr Chakraborty extracted qualitative data and synthesised findings. All research team members contributed to drafting and finalising the report.

Appendix 2: Peer-reviewed literature search strategies: Main review

Table A1: Summary of retrieved citations

Database	No. of citations retrieved
Ovid Medline	8,086
CINAHL	4,411
AgeLine	1,335
Total before duplicates removed	17,844
Total after duplicates removed	9,489

A hand search of Cochrane Central Register of Controlled Trials (CENTRAL) for Embase original content did not identify additional studies.

Table A2: Ovid Medline search strategy

(Includes Epub Ahead of Print, In-Process, In-Data-Review and Other Non-Indexed Citations, Daily and Versions(R) <1946 to September 20, 2021>)

Search number	Query	Results
1	advance care planning/ or advance directives/ or living wills/	10,224
2	(advance care plan* or advance directive* or living will*).tw,kw.	8,141
3	Attitude to Death/	16,526
4	(dying or end of life).tw,kw.	58,067
5	bereavement/ or grief/	14,000
6	(bereave* or grief or grieving).tw,kw.	14,425
7	Terminal Care/ or Terminally Ill/	34,827
8	((terminal care or (terminal* or end stage or endstage or late stage* or last stage* or final stage* or advanced)) adj1 (ill* or disease* or cancer* or heart failure or chronic obstructive or chronic kidney or chronic liver or dementia or alzheimer* or parkinson*)).tw,kw.	62,707
9	Palliative Care/	57,872
10	palliat*.tw,kw.	84,194

Search number	Query	Results
11	or/1-10	238,662
12	General practice/ or family practice/ or general practitioners/ or physicians, family/ or physicians, primary care/	100,291
13	(primary care or general practi* or family practi* or GP or GPs or family physician*).tw,kw.	256,423
14	((primary or primary-level or generalist* or nonspecialist* or non-specialist*) adj2 (palliative or end of life)).tw,kw.	559
15	Primary Health Care/	83,875
16	primary health*.tw,kw.	39,717
17	Community pharmacy services/	5,160
18	((community or clinical or home retail*) adj (pharmacy* or pharmacies or pharmacist* or drugstore* or drug store* or dispens*)).tw,kw.	13,128
19	((communit* or home* or residential* or primary care) and (Allied health or dental or dentist* or speech patholog* or speech language patholog* or nutritionist* or dietician* or occupational therap* or physical therap* or physiotherap* or psychologist* or social worker* or paramedic*)).mp. or doula*.tw,kw.	45,797
20	community health services/ or adult day care centers/ or child health services/ or maternal-child health services/ or community health nursing/ or home health nursing/ or parish nursing/ or community networks/ or community participation/ or foster home care/ or home care services/ or hemodialysis, home/ or home nursing/ or respite care/	137,363
21	(Homecare or day care or daycare or “hospital at home“ or “hospital in the home” or ((home or respite or domicil* or district or communit*) adj1 (care or caring or based or dwelling or health or healthcare or health care or setting* or health service* or nursing))).tw,kw.	212,851
22	(Community adj2 (palliative or “end of life” or setting* or organization* or organisation* or support* or service* or network* or led)).tw,kw.	44,456
23	Compassionate communit*.tw,kw.	68
24	residential facilities/ or assisted living facilities/ or group homes/ or homes for the aged/ or nursing homes/ or intermediate care facilities/ or skilled nursing facilities/	53,854

Search number	Query	Results
25	(residential* or aged care or nursing home* or skilled nursing facilit* or retirement village* or longterm care or long term care or institutionali* or hostel* or group home*).tw,kw.	105,308
26	((assisted or supported) adj2 (living or home* or accommodation or residential)).tw,kw.	3,314
27	(care setting* or setting* of care).tw,kw.	50,671
28	(Caregivers/ or terminally ill/) and (workplace/ or employment/ or occupational health/)	716
29	(((carer* or caregiver* or terminally ill or dying or bereave* or grief or grieving) adj1 (employee* or employment or work* or cowork* or co-work* or colleague*)) and (workplace* or work environment*)).tw,kw.	83
30	Correctional facilities/ or prisons/ or prisoners/	23,826
31	(Prison* or incarcerat* or correctional facilit* or penitentiar* or detention or detainee*).tw,kw.	31,696
32	Homeless persons/	8,598
33	(homeless* or ((transitional* or supportive or vulnerab* or stable or unstable or instabilit* or insecur*) adj1 (house* or housing))).tw,kw.	13,819
34	or/12-33	832,317
35	11 and 34	22,878
36	limit 35 to (english language and yr="2015 -Current")	8,465

Search number	Query	Results
37	exp Developing Countries/ or caribbean region/ or west indies/ or cuba/ or dominica/ or dominican republic/ or grenada/ or haiti/ or jamaica/ or saint lucia/ or “saint vincent and the grenadines”/ or americas/ or central america/ or belize/ or costa rica/ or el salvador/ or guatemala/ or honduras/ or nicaragua/ or panama/ or “gulf of mexico”/ or latin america/ or mexico/ or south america/ or argentina/ or bolivia/ or brazil/ or colombia/ or ecuador/ or guyana/ or paraguay/ or peru/ or suriname/ or venezuela/ or asia/ or asia, central/ or kazakhstan/ or kyrgyzstan/ or tajikistan/ or turkmenistan/ or uzbekistan/ or asia, northern/ or russia/ or siberia/ or asia, southeastern/ or cambodia/ or east timor/ or indonesia/ or laos/ or malaysia/ or myanmar/ or philippines/ or thailand/ or vietnam/ or asia, western/ or bangladesh/ or bhutan/ or india/ or afghanistan/ or iraq/ or jordan/ or lebanon/ or syria/ or turkey/ or yemen/ or nepal/ or pakistan/ or sri lanka/ or china/ or “democratic people‘s republic of korea”/ or mongolia/ or europe, eastern/ or albania/ or bosnia-herzegovina/ or bulgaria/ or kosovo/ or “macedonia (republic)”/ or moldova/ or montenegro/ or “republic of belarus”/ or romania/ or serbia/ or ukraine/ or fiji/ or papua new guinea/ or vanuatu/ or micronesia/ or guam/ or palau/ or samoa/ or american samoa/ or tonga/ or africa/ or africa, northern/ or algeria/ or egypt/ or libya/ or morocco/ or tunisia/ or “africa south of the sahara”/ or africa, central/ or cameroon/ or central african republic/ or chad/ or congo/ or “democratic republic of the congo”/ or equatorial guinea/ or gabon/ or africa, eastern/ or burundi/ or djibouti/ or eritrea/ or ethiopia/ or kenya/ or rwanda/ or somalia/ or sudan/ or tanzania/ or uganda/ or africa, southern/ or angola/ or botswana/ or lesotho/ or malawi/ or mozambique/ or namibia/ or south africa/ or swaziland/ or zambia/ or zimbabwe/ or africa, western/ or benin/ or burkina faso/ or cape verde/ or cote d‘ivoire/ or gambia/ or ghana/ or guinea/ or guinea-bissau/ or liberia/ or mali/ or mauritania/ or niger/ or nigeria/ or senegal/ or sierra leone/ or togo/	1,176,376
38	36 not 37	8,086

Table A3: CINAHL (EBSCOhost) search strategy

Search number	Query	Results
1	((MH “Advance Care Planning” OR (MH “Advance Directives”) OR (MH “Living Wills”)) OR TI (“advance care plan*” or “advance directive*” or “living will*”) OR AB (“advance care plan*” or “advance directive*” or “living will*”)	10,982
2	(MH “Attitude to Death”) OR TI (dying or “end of life”) OR AB (dying or “end of life”)	40,607
3	((MH “Bereavement”) OR (MH “Grief”)) OR TI (bereave* or grief or grieving) OR AB (bereave* or grief or grieving)	18,994
4	((MH “Terminal Care”) OR (MH “Terminally Ill Patients”)) OR TI (((“terminal care” or (terminal* or “end stage” or endstage or “late stage*” or “last stage*” or “final stage*” or advanced)) N1 (ill* or disease* or cancer* or “heart failure” or “chronic obstructive” or COPD or “chronic kidney” or “chronic liver” or dementia or alzheimer* or parkinson*))) OR AB (((“terminal care” or (terminal* or “end stage” or endstage or “late stage*” or “last stage*” or “final stage*” or advanced)) N1 (ill* or disease* or cancer* or “heart failure” or “chronic obstructive” or COPD or “chronic kidney” or “chronic liver” or dementia or alzheimer* or parkinson*)))	70,612
5	(MH “Palliative Care”) OR TI palliat* OR AB palliat*	54,407
6	1 OR 2 OR 3 OR 4 OR 5	146,146
7	((MH “Family Practice”) OR (MH “Physicians, Family”)) OR TI (“primary care” or “general practi*” or “family practi*” or GP or GPs or “family physician*”) OR AB (“primary care” or “general practi*” or “family practi*” or GP or GPs or “family physician*”)	132,874
8	TI (((primary or “primary-level” or generalist* or nonspecialist* or “non-specialist*”) N1 (palliative or “end of life”))) OR AB (((primary or “primary-level” or generalist* or nonspecialist* or “non-specialist*”) N1 (palliative or “end of life”)))	399
9	(MH “Primary Health Care”) OR TI “primary health*” OR AB “primary health*”	76,032

Search number	Query	Results
10	((MH “Community Health Centers”) OR (MH “Senior Centers”) OR (MH “Home Health Agencies”) OR (MH “Home Nursing”) OR (MH “Home Dialysis”) OR (MH “Home Health Care”) OR (MH “Community Health Nursing”) OR (MH “Family Nursing”) OR (MH “Home Nursing, Professional”) OR (MH “Occupational Health Nursing”) OR (MH “Child Health Services”) OR (MH “Health Services for the Aged”) OR (MH “Community Networks”) OR (MH “Parish Nursing”)) OR TI ((Homecare or “day care” or daycare or “hospital at home” or “hospital in the home” or ((home or respite or domicil* or district or communit*) N0 (care or caring or based or dwelling or health or healthcare or “health care” or setting* or “health service*” or nursing)))) OR AB ((Homecare or “day care” or daycare or “hospital at home” or “hospital in the home” or ((home or respite or domicil* or district or communit*) N0 (care or caring or based or dwelling or health or healthcare or “health care” or setting* or “health service*” or nursing))))	213,738
11	TI ((Community N1 (palliative or “end of life” or setting* or organization* or organisation* or support* or service* or network* or led))) OR AB ((Community N1 (palliative or “end of life” or setting* or organization* or organisation* or support* or service* or network* or led))) OR TI “Compassionate communit*” OR AB “Compassionate communit*”	29,316
12	((MH “Residential Facilities”) OR (MH “Nursing Homes”) OR (MH “Skilled Nursing Facilities”) OR (MH “Housing for the Elderly”) OR (MH “Community Living”) OR (MH “Assisted Living”)) OR TI (residential* or “aged care” or “nursing home*” or “skilled nursing facilit*” or “retirement village*” or “longterm care” or “long term care” or institutionali* or hostel* or “group home*”) OR AB (residential* or “aged care” or “nursing home*” or “skilled nursing facilit*” or “retirement village*” or “longterm care” or “long term care” or institutionali* or hostel* or “group home*”) OR TI (((assisted or supported) N1 (living or home* or accommodation or residential))) OR AB (((assisted or supported) N1 (living or home* or accommodation or residential))) OR TI (“care setting*” or “setting* of care”) OR AB (“care setting*” or “setting* of care”)	126,767
13	(MH “Pharmacy, Retail”)	7,338
14	TI (((community or clinical or home or retail*) N0 (pharmacy* or pharmacies or pharmacist* or drugstore* or drug store* or dispens*))) OR AB (((community or clinical or home or retail*) N0 (pharmacy* or pharmacies or pharmacist* or drugstore* or drug store* or dispens*)))	7,265

Search number	Query	Results
15	TI (((communit* or home* or residential* or “primary care”) and (“Allied health” or dental or dentist* or “speech patholog*” or “speech language patholog*” or nutritionist* or dietician* or “occupational therap*” or “physical therap*” or physiotherap* or psychologist* or “social worker*” or paramedic*))) OR AB (((communit* or home* or residential* or “primary care”) and (“Allied health” or dental or dentist* or “speech patholog*” or “speech language patholog*” or nutritionist* or dietician* or “occupational therap*” or “physical therap*” or physiotherap* or psychologist* or “social worker*” or paramedic*))) OR TI doula* OR AB doula*	22,643
16	(MH “Home Visits”) OR (MH “Community Health Services”) OR (MH “Respite Care”)	30,158
17	(MH “Correctional Health Services”) OR (MH “Correctional Facilities”) OR (MH “Prisoners”) OR (MH “Correctional Health Nursing”)	14,841
18	TI (Prison* or incarcerat* or “correctional facilit*” or penitentiar* or detention or detainee*) OR AB (Prison* or incarcerat* or correctional facilit* or penitentiar* or detention or detainee*)	15,052
19	((MH “Caregivers”) OR (MH “Caregiver Support”) OR (MH “Terminally Ill Patients”)) AND ((MH “work environment”) OR (MH “work engagement”) OR (MH “job accommodation”) OR (MH “work redesign”) OR (MH “occupational health”) OR (MH Employment))	636
20	TI ((((carer* or caregiver* or “terminally ill” or dying or bereave* or grief or grieving) N0 (employee* or employment or work* or cowork* or “co-work*” or colleague*)) AND (workplace* or “work environment*”))) OR AB ((((carer* or caregiver* or “terminally ill” or dying or bereave* or grief or grieving) N0 (employee* or employment or work* or cowork* or “co-work*” or colleague*)) AND (workplace* or “work environment*”)))	53
21	(MH “Homeless Persons”) OR TI ((homeless* or ((transitional* or supportive or vulnerab* or stable or unstable or instabilit* or insecur*) N0 (house* or housing)))) OR AB ((homeless* or ((transitional* or supportive or vulnerab* or stable or unstable or instabilit* or insecur*) N0 (house* or housing))))	12,178
22	7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21	506,665
23	6 AND 22	19,277

Search number	Query	Results
24	(MH “Africa+”) OR (MH “Central America+”) OR (MH “Mexico”) OR (MH “Bolivia”) OR (MH “Brazil”) OR (MH “Colombia”) OR (MH “Ecuador”) OR (MH “French Guiana”) OR (MH “Guyana”) OR (MH “Paraguay”) OR (MH “Peru”) OR (MH “Suriname”) OR (MH “Venezuela”) OR (MH “Cuba”) OR (MH “Dominica”) OR (MH “Dominican Republic”) OR (MH “Haiti”) OR (MH “Jamaica”) OR (MH “Asia, Central+”) OR (MH “Borneo”) OR (MH “Cambodia”) OR (MH “East Timor”) OR (MH “Indonesia”) OR (MH “Laos”) OR (MH “Malaysia”) OR (MH “Myanmar”) OR (MH “Philippines”) OR (MH “Thailand”) OR (MH “Timor”) OR (MH “Vietnam”) OR (MH “Bangladesh”) OR (MH “Bhutan”) OR (MH “India”) OR (MH “Afghanistan”) OR (MH “Iran”) OR (MH “Iraq”) OR (MH “Jordan”) OR (MH “Lebanon”) OR (MH “Turkey”) OR (MH “Yemen”) OR (MH “Nepal”) OR (MH “Pakistan”) OR (MH “Sri Lanka”) OR (MH “China+”) OR (MH “Mongolia”) OR (MH “North Korea”) OR (MH “Developing Countries”) OR (MH “Armenia”) OR (MH “Azerbaijan”) OR (MH “Albania”) OR (MH “Estonia”) OR (MH “Bosnia-Herzegovina”) OR (MH “Bulgaria”) OR (MH “Byelarus”) OR (MH “Macedonia (Republic)”) OR (MH “Moldova”) OR (MH “Romania”) OR (MH “Russia”) OR (MH “Serbia”) OR (MH “Ukraine”) OR (MH “Georgia (Republic)”) OR (MH “Madagascar”) OR (MH “Low and Middle Income Countries”) OR (MH “Papua New Guinea”) OR (MH “Independent State of Samoa”)	379,302
25	23 NOT 24	18,431
26	23 NOT 24 Limiters – Published Date: 20150101-20211231; English Language; Peer Reviewed; Research Article	4,411

Table A4: Cochrane Central Register of Controlled Trials (CENTRAL) search strategy

Search number	Query
1	(“advance care” NEXT plan* OR advance NEXT directive* OR living NEXT will* OR dying OR “end of life” OR bereave* OR grief OR grieving OR “terminal care” OR palliat*) OR (((terminal* or “end stage” or endstage or late NEXT stage* or last NEXT stage* or final NEXT stage* or advanced) NEAR/1 (ill* or disease* or cancer* or “heart failure” OR “chronic obstructive” or COPD OR “chronic kidney” or “chronic liver” or dementia or alzheimer* or parkinson*)))
2	(“primary care” or general NEXT practi* or family NEXT practi* or GP or GPs or family NEXT physician* OR primary NEXT health* OR ((primary or “primary-level” or generalist* or nonspecialist* or “non-specialist*”) NEAR/2 (palliative or “end of life”))):ti,ab,kw
3	((community or clinical or home) NEAR/1 (pharmacy* or pharmacies or pharmacist* or drugstore* or drug NEXT store* or dispens*))

Search number	Query
4	((communit* or home* or residential* or “primary care”) and (“Allied health” or dental or dentist* or speech NEXT patholog* or “speech language” NEXT patholog* or nutritionist* or dietician* or occupational NEXT therap* or physical NEXT therap* or physiotherap* or psychologist* or social NEXT worker* or paramedic*)) or doula*
5	(Homecare or “day care” or daycare or “hospital at home” or “hospital in the home” or ((home or respite or domicil* or district or communit*) NEAR/1 (care or caring or based or dwelling or health or healthcare or “health care” or setting* or health NEXT service* or nursing)))
6	(Community NEAR/2 (palliative or “end of life” or setting* or organization* or organisation* or support* or service* or network* or led))
7	Compassionate NEXT communit*
8	residential* or aged care or nursing NEXT home* or “skilled nursing” NEXT facilit* or retirement NEXT village* or “longterm care” or “long term care” or institutionali* or hostel* or group NEXT home*
9	((assisted or supported) NEAR/2 (living or home* or accommodation or residential))
10	care NEXT setting* or “settings of care” OR “setting of care”
11	(((carer* or caregiver* or “terminally ill” or dying or bereave* or grief or grieving) NEAR/1 (employee* or employment or work* or cowork* or co NEXT work* or colleague*)) AND (workplace* or work NEXT environment*))
12	Prison* or incarcerat* or correctional NEXT facilit* or penitentiar* or detention or detainee*
13	homeless* or ((transitional* or supportive or vulnerab* or stable or unstable or instabilit* or insecur*) NEAR/1 (house* or housing))
14	#2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13
15	#1 AND #14

Table A5: AgeLine (EBSCOhost)

Search number	Query	Results
1	(“advance care plan*” or “advance directive*” or “living will*”) OR (dying or “end of life” or palliat*) OR (bereave* or grief or grieving) OR (((“terminal care” or (terminal* or “end stage” or endstage or “late stage*” or “last stage*” or “final stage*” or advanced)) N1 (ill* or disease* or cancer* or “heart failure” or “chronic obstructive” or COPD or “chronic kidney” or “chronic liver” or dementia or alzheimer* or parkinson*)))	13,293
2	(“primary care” or “general practi*” or “family practi*” or GP or GPs or “family physician*”) OR (((primary or “primary-level” or generalist* or nonspecialist* or “non-specialist*”) N1 (palliative or “end of life”))) OR “primary health*” OR ((Homecare or “day care” or daycare or “hospital at home” or “hospital in the home” or ((home or respite or domicil* or district or communit*) N0 (care or caring or based or dwelling or health or healthcare or “health care” or setting* or “health service*” or nursing)))) OR ((Community N1 (palliative or “end of life” or setting* or organization* or organisation* or support* or service* or network* or led)) OR “Compassionate communit*”)	58,197
3	(residential* or “aged care” or “nursing home*” or “skilled nursing facilit*” or “retirement village*” or “longterm care” or “long term care” or institutionali* or hostel* or “group home*”) OR (((assisted or supported) N1 (living or home* or accommodation or residential))) OR (“care setting*” or “setting* of care”)	35,981
4	((community or clinical or home or retail*) N0 (pharmacy* or pharmacies or pharmacist* or drugstore* or drug store* or dispens*))	907
5	(((communit* or home* or residential* or “primary care”) and (“Allied health” or dental or dentist* or “speech patholog*” or “speech language patholog*” or nutritionist* or dietician* or “occupational therap*” or “physical therap*” or physiotherap* or psychologist* or “social worker*” or paramedic*))) OR doula*	3,668
6	(Prison* or incarcerat* or “correctional facilit*” or penitentiar* or detention or detainee*) OR ((((carer* or caregiver* or “terminally ill” or dying or bereave* or grief or grieving) N0 (employee* or employment or work* or cowork* or “co-work*” or colleague*)) AND (workplace* or “work environment*”))) OR ((homeless* or ((transitional* or supportive or vulnerab* or stable or unstable or instabilit* or insecur*) N0 (house* or housing))))	1,149
7	2 OR 3 OR 4 OR 5 OR 6	68,174
8	1 AND 7	5,514

Search number	Query	Results
9	1 AND 7 Limiters – Publication Year: 2015-2021; Publication Type: Journal Article	1,335

Appendix 3: Grey literature review search strategies

A grey literature search was conducted for the following:

1. Interventions, program evaluations, and resources such as guidelines focused on providing quality care or improving the safety and quality of care at the end of life in the community setting (i.e. home, nursing homes)
2. Government and organisational strategies, frameworks and policies for approaching end of life and palliative care in these settings.

Google Advanced Searches

General community end-of-life care intervention searches

Variation 1. (50 items)

- All these words: “end of life”
- Any of these words: home OR community OR communities OR “aged care” OR “primary care” OR “general practice” OR “general practices” OR “general practitioner” OR “general practitioners” OR GPs
- Limit to Australia and PDFs

Variation 2. (50 items)

- All these words: palliative
- Any of these words: home OR community OR communities OR “aged care” OR “primary care” OR “general practice” OR “general practices” OR “general practitioner” OR “general practitioners” OR GPs
- Limit to Australia and PDFs

Variation 3. (50 items)

- All these words: “bereavement”
- Any of these words: home OR community OR communities OR “aged care” OR “primary care” OR “general practice” OR “general practices” OR “general practitioner” OR “general practitioners” OR GPs
- Limit to Australia and PDFs

Variation 4. (50 items)

- All these words: “advance care plan”
- Any of these words: home OR community OR communities OR “aged care” OR “primary care” OR “general practice” OR “general practices” OR “general practitioner” OR “general practitioners” OR GPs
- Limit to Australia and PDFs

Strategies, frameworks, and policies searches

Variation 1. (50 items)

- All these words: “aged care” AND “end of life”
- Any of these: “strategy” “policy” “framework”
- site: .gov.au

Variation 2. (50 items)

- All these words: “aged care” AND “end of life”
- Any of these: strategy policy framework
- site: .gov.au – *PDF format*

Variation 3. (50 items)

- All these words: “aged care” AND “end of life”
- Any of these: strategy policy framework
- site: .org.au

Variation 4. (50 items)

- All these words: “home care” AND “end of life”
- Any of these: “strategy” “policy” “framework”
- site: .gov.au

Variation 5. (50 items)

- All these words: “home care” AND “end of life”
- Any of these: “strategy” “policy” “framework”
- site: .org.au

Variation 6. (50 items)

- All these words: “home care” AND “end of life”
- Any of these: strategy policy framework
- site: .gov.au – *PDF format*

Website searches

The following 41 Australian websites were browsed, or a search was conducted in the search box using the following terms singly or in combination: palliative care, end of life, aged care, nursing home, general practice, community.

Organisations:

- Aged and Community Services Australia
- Aged Care Quality and Safety Commission
- Australian Aged Care Quality Agency (AACQA)
- Australian Alzheimer’s Research Foundation
- Australian Association of Gerontology
- Royal Commission into Aged Care Quality and Safety
- Australian Research Council (ARC)
- Centre of Excellence in Population Ageing
- UNSW Ageing Futures Institute
- Centre for Education and Research on Ageing (University of Sydney)
- Centre for Research on Ageing, Health & Wellbeing (ANU)
- COTA Australia
- Dementia Australia

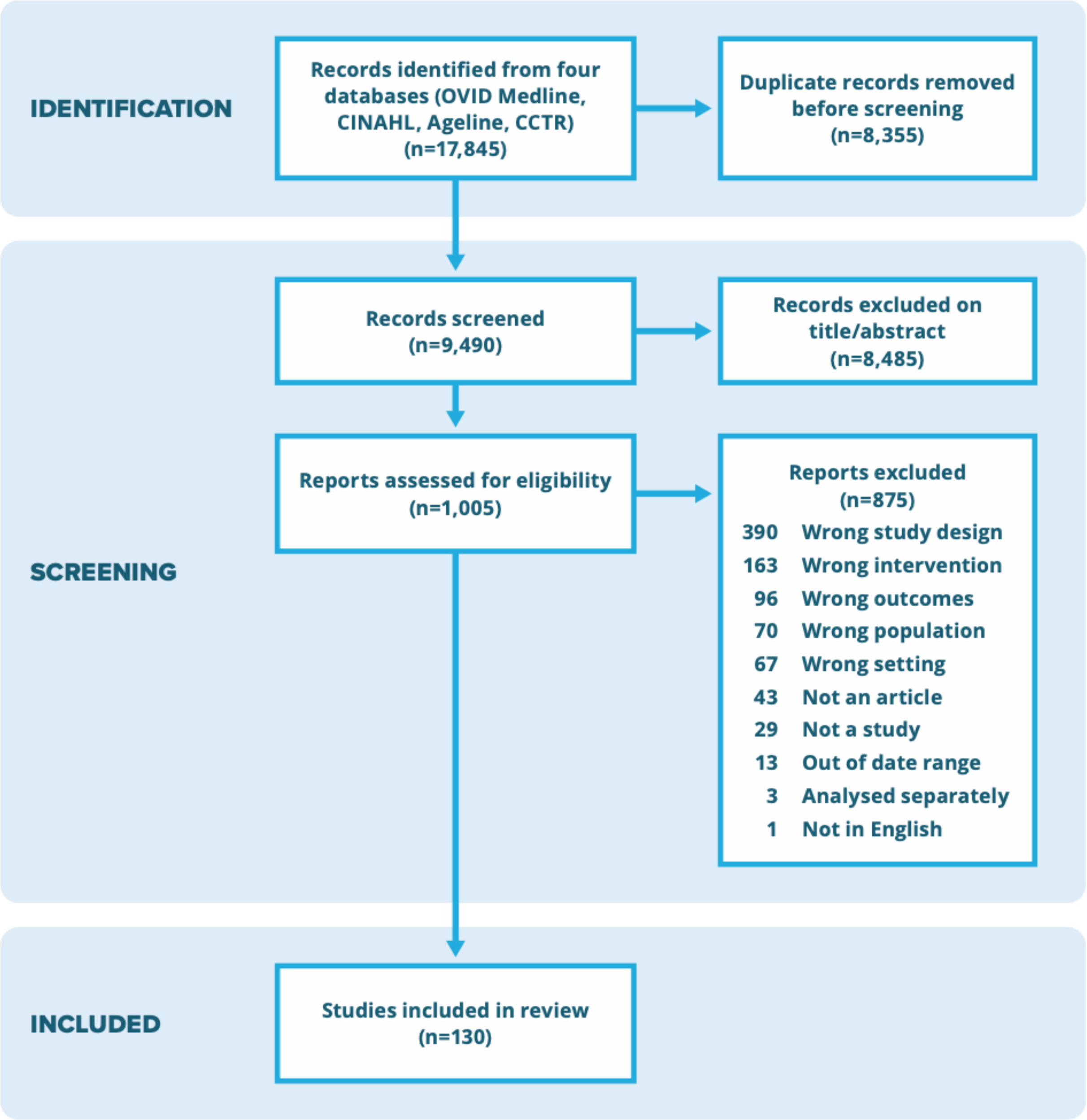
- Department of Health Australia
- Monash Ageing Research Centre (MONARC)
- National Ageing Research Institute Limited
- Australian COVID-19 Palliative Care Working Group (ACPCWG)
- Palliative Care Australia
- CareSearch grey literature database
- Australian and New Zealand Society of Palliative Medicine.

Major palliative care projects (as identified by CareSearch www.caresearch.com.au/tabid/6450/Default.aspx):

- Advance Care Planning Australia
- The Advance Project
- CarerHelp
- CareSearch
- caring@home
- Comprehensive Palliative Care in Aged Care Measure
- End of life Directions for Aged Care (ELDAC)
- End-of-Life Essentials
- End of Life Law for Clinicians
- Gwandalan Project
- Improving Palliative Care Services for People With and Intellectual Disability
- Palliative Care Self-Assessment Online (PaCSA)
- palliAGED
- Palliative Care Education and Training Collaborative
- Palliative Care in Prisons
- Palliative Care Online Training Portal
- Palliative Care Outcomes Collaboration (PCOC)
- Psychosocial and Existential Wellbeing in Palliative Care
- Quality of Care Collaborative in Paediatric Pall Care (QuoCCA)
- Talking End of Life ...With People with an Intellectual Disability (TEL)
- The National LGBTI Health Alliance Palliative Care Project

Appendix 4: PRISMA flow diagram: Main review

Figure A1: PRISMA flow diagram of review inclusion and exclusion decisions[21]



Appendix 5: Clinical review

Marg Adams provided feedback on the preliminary report submitted to the Commission in November 2022:

> My only query/comment relates to the connection between end-of-life care and palliative care, particularly in the background section. In the opening background we mention end-of-life care, however don't discuss or define palliative care. We then continue to refer to palliative care and palliative care providers throughout the review. As we all know, the services, and MDT professionals providing end-of-life care in acute care and primary and community care context are recognised as 'palliative care services' or 'palliative care professionals' providing end-of-life care.

Marg then provided feedback on findings from the draft final review submitted on 21 January 2022. Considerations were around:

Palliative care is provided in the community / palliative care as a philosophy of care / palliative care as a service:

> Care in the community is complex – it can be difficult for people to find services if they don't fit into the '12 months left to live' category e.g. people living with dementia, neurodegenerative disorders such as Motor Neuron Disease. I think the issue of coordination and engagement of relevant stakeholders to be on the same page is paramount and not often achieved forcing the wish for place of care back into acute care setting

Conflation around terminology/nomenclature/understanding of what we mean:

> palliative care when we are speaking about end-of-life care / Palliative Care provision / Investment in end-of-life care – What's the difference?
>
> Palliative care and End-of-life care need to be teased out. What is the context surrounding the choice of using End-of-life care over Palliative Care. When we refer to Community, Primary Care and Residential Aged Care, Palliative Care is used.

Bereavement:

> In reality, staff respond to family grief and bereavement on a daily basis as part of normal business, however during the pandemic, staff have needed to adapt usual practice to connect family and loved ones to work through this grief, loss and bereavement. Business continuity was interrupted and required organisations to be agile and responsive to ever changing directions for best practice management.

Medication management:

> Most RACs will have imprest systems – supply of medications to support symptoms in unstable deteriorating and terminal phase of illness would be onsite. However there are RACs that don't. Clients living in other settings such as Prisons may have different clinical protocols

COVID-19:

> Yes, this statement is very relevant – particularly when lockdowns in progress and family unable to engage in the usual face to face way.
>
> Yes, many organisations had challenges accessing IT hardware and software with supply reduced across the country

Discussion:

> I don't this we can generalise that the hospital environment is without cost to the patient – some people are not eligible for a Medicare Card e.g. visitors, refugee/migrants
>
> I don't totally agree with this statement – rather than Care in the community is disparate and generally fragmented it should read 'Can be'
>
> Costs are not just associated with medications but consumables and equipment. If a client is ineligible to access funding support from the palliative care program, they are relying on funding this themselves or through agencies such as Cancer Council

The Royal Commission recommendations consistently refer to palliative care – end-of-life care is not referred to

The use of end-of-life and dementia care training is incorrect. The correct wording is palliative care and dementia care training.

Recommendations:

Public Hospitals in Queensland have Nurse Navigators to support transition in and out of Acute

This is huge – The role of Public Health Units, HHS as members of the extended team have been vital. There has also been an impact on Community NGO service provision with workforce shortages, particularly OMICRON wave

Symptom control – This is going to be dependent on the workforce / Skillmix. Assessment of deterioration and escalation of care is a major area of need and focus – that notion of knowing who the phone a friend is

Pharmacist role is becoming more visible in its importance as team member. Safe medicines – use of the most appropriate therapy in consultation. Focus has been on reducing use of psychotropics

Appendix 6: Study characteristics

Tables for main and grey literature review searches.

Table A6: Evidence type used in appraising quality of the evidence of included papers[19]

Level	Description
I	Experimental, systematic reviews of RCTs (+/- meta-analyses)
II	Quasi-experimental, systematic reviews of RCTs or quasi-experimental studies
III	Non-experimental studies, other systematic reviews
IV	Expert opinion, consensus statements by experts
V	Review, quality improvement, evaluation, costs

Table A7: Quality appraisal grading system[20]

Quality grading system	
0–1	Rejected
2–8	Unreliable
9–12	Weak
13–18	Medium
19–22	Strong

Table A8: Study characteristics: Main review

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Chan (2018) **Hong Kong SAR, China**	**Effects of a nurse-led post-discharge advance care planning programme for community-dwelling patients nearing the end of life and their family members: A randomised controlled trial**	To examine the effects of a structured, nurse-led post-discharge advance care planning programme on congruence between the end-of-life care preferences of the patient and family members, decisional conflicts and the documentation of care preferences.	Community-based	Structured advance care planning programme administered by a training nurse during three weekly home visits following hospital discharge.	This study showed that a nurse-led structured advance care planning programme could effectively improve dyadic congruence regarding end-of-life care preferences, reduce patients' decisional conflict and increase the documentation of care preferences in the form of advance directives and electronic medical record documentation of do-not-attempt CPR orders.	I	19

Author (year) Country	**Article title**	**Study aim/ purpose**	**Setting**	**Intervention, exposure, risk factor**	**Key findings**	**Evidence ranking**	**Quality appraisal**
Fischer (2018) **USA**	**Effect of Apoyo con Carino (Support with Caring) trial of a patient navigator intervention to improve palliative care outcomes for Latino adults with advanced cancer: A randomized clinical trial**	To investigate if a culturally tailored patient navigator intervention can improve palliative care outcomes for Latino adults with advanced cancer.	Community-based	Culturally tailored patient navigator intervention. Bicultural patient navigators (trained laypersons empowering and activating patients to seek improved primary palliative care from their oncologists) who made at least five home visits and provided a culturally tailored packet of written information about ACP, pain management, hospice use, and a study-specific advance directive.	The intervention increased advance care planning and improved physical symptoms; however, it had no effect on pain management and hospice use or overall quality of life.	I	21

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Kluger (2020) **USA**	**Comparison of integrated outpatient palliative care with standard care in patients with Parkinson disease and related disorders: A randomized clinical trial**	To determine if outpatient integrated palliative care is associated with improvements in patient-centred outcomes compared with standard care among patients with Parkinson disease and related disorders (PDRD) and their caregivers.	Community-based	Integrated outpatient palliative care involving a neurologist, social worker, chaplain, and nurse using palliative care checklists and guidance and selective involvement from a palliative medicine specialist.	Participants receiving the palliative care intervention had better QoL, but no significant difference was observed in caregiver burden, except at the 12-month mark. Other significant differences favouring the intervention included non-motor symptom burden, motor symptom severity, completion of advance directives, and caregiver anxiety. No outcomes favoured standard care alone. Secondary analyses suggested that benefits were greater for persons with higher palliative care needs. This study supports efforts to integrate palliative care into PDRD care.	I	21

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Ben-Arye (2021) **Israel**	**Impact of combined integrative oncology and palliative care program on quality of life of patients with advanced cancer**	To examine the impact of the integrative oncology (IO)-palliative patient-tailored program on quality of life among patients with advanced cancer.	Community-based	Weekly patient-tailored IO treatment sessions of 30–45 minutes, with one or more of the following modalities: guidance on herbal/dietary supplement use; manual therapies (e.g. acupuncture/acupressure, reflexology, anthroposophic manual methods); movement therapies (e.g. Qi Gong, Feldenkrais, and Paula methods); and mind-body-spirit therapies (e.g. guided imagery, music therapy, spiritual care). All patients were treated throughout with conventional palliative/ supportive care, including consultations and medications administered by their oncologist and/or palliative care specialist, nurse-provided care, and psycho-oncology interventions.	The high adherence integrative care group reported greater improvement on ESAS scores for fatigue and, depression at six weeks, and sleep at 12 weeks. They had significantly improved EORTC global health status/QoL at six weeks, cognitive functioning, and social functioning. They also had reduced rates of hospitalisations at 12 weeks, length of hospital stays, and opioid use.	II	18

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Jennings (2020) **USA**	**The effects of dementia care co-management on acute care, hospice, and long-term care utilization**	To examine the impact of nurse practitioner dementia care co-management on costs of care for fee-for-service Medicare beneficiaries, including acute care utilisation, long-term care admissions, and hospice use.	Community-based	The ADC program is a co-management program with nurse practitioner dementia care managers and partnering physicians. It consists of five key components: structured needs assessments of patients and their caregivers; creation and implementation of individualised dementia care plans; monitoring and revising care plans; referral to community organisations for dementia-related services and support; and access to a clinician 24 hours/seven days a week for assistance and advice.	Comprehensive nurse practitioner dementia care co-management patients had fewer ED visits and shorter hospital length of stay. There were no significant differences between groups for hospitalisations or ICU stays. Program participants were less likely to be admitted to a long-term care facility and more likely to receive hospice services in the last six months of life.	II	19
Armstrong (2021) **England**	**The benefits and challenges of embedding specialist palliative care teams within homeless hostels to enhance support and learning: Perspectives from palliative care teams and hostel staff**	To evaluate a model embedding palliative specialists, trained as ‘homelessness champions’ into hostels for two half-days a month to provide support to staff and residents and facilitate a multidisciplinary approach to care.	Community-based	A model embedding palliative care specialists (nurses or social workers) for two half-days a month into homeless hostels providing in-reach support.	A palliative approach supported hostel staff to take a more person-centred approach to care and to recognise when more health or social care input was needed. Hostel staff were empowered by their increased knowledge and understanding, which enabled them to advocate for what their residents required from external services.	III	19

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Bannon (2018) **Northern Ireland**	**Insights into the factors associated with achieving the preference of home death in terminal cancer: A national population-based study**	To investigate the factors associated with cancer patients achieving their preference to die at home.	Community-based	Factors associated with achieving a desired home death.	Factors positively associated with achieving a home death were living in an affluent area, receipt of good and satisfactory district nurse care, discussing the place of death with health professionals, and the caregiver's preference for a home death. Further, communication, care satisfaction, and caregiver preferences were all associated with home death.	III	22

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Bone (2016) **England**	**Factors associated with transition from community settings to hospital as place of death for adults aged 75 and older: A population-based mortality follow-back survey**	To identify carer-reported factors associated with end-of-life (EoL) transition from the usual place of care to the hospital as a place of death for people aged 75 and older.	Community-based	Factors associated with EoL transition to hospital as place of death.	More than one-third of patients transitioned to the hospital at the EoL and died there, even though only 2.0% wished to do so. There is an apparent reliance on hospitals to provide EoL care for older people, particularly those living at home, who accounted for 71.9% of those who transitioned. Irrespective of their usual place of care. The likelihood of transition to the hospital was greater for people with respiratory and circulatory diseases and with severe breathlessness. The likelihood of transition was lower for people who had discussed EoL care preferences with a health professional and those with an identified key healthcare professional.	III	21

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Brettell (2017) **England**	**What proportion of patients at the end of life contact out-of-hours primary care? A data linkage study in Oxfordshire**	To establish the proportion of patients seen by an OOH service within the last 30 days of life, whether they were documented in a palliative phase of care, and the demographic and clinical features of these groups.	Community-based	Out-of-hours (OoH) primary care services including home visits and telephone contacts.	OoH GP services are at the forefront of end-of-life care provision, seeing almost a third of people who died during the study period. Patients documented as palliative were seen more frequently by the OoH service in 30 days prior to death, and their final contact with the service was closer to the point of death. However, most patients at the end of life were not documented as palliative by OoH services and were less likely to receive ongoing care at home. Patients not documented as palliative had a much higher rate of acute hospital admission.	III	21
Hartig (2016) **USA**	**Online grief support communities: Therapeutic benefits of membership**	To determine if membership in online bereavement support communities provides positive psychosocial benefits, and if those benefits accrue over the length of their involvement.	Community-based	Online grief support communities hosted via Facebook or accessed via organisational website.	Members of online grief support networks report less psychological distress as a result of joining these groups, and this psychosocial benefit increased over time. Individuals who were members for a year or more characterised their grief as less severe compared with those who had a shorter tenure in the community.	III	12

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Jennings (2019) **USA**	**The effect of a comprehensive dementia care management program on end-of-life care**	To describe the end-of-life care preferences and acute care and hospice use in the last six months of life for persons enrolled in a comprehensive, integrated dementia care management program.	Community-based	Dementia care co-management model using nurse practitioners partnered with primary care providers and community organisations to provide comprehensive dementia care, including advance care planning.	Enrolees in a comprehensive dementia care co-management program had high engagement in advance care planning, high rates of hospice use, and low acute care utilisation near the end of life.	III	17
Leung (2015) **Canada**	**Chronically homeless persons' participation in an advance directive intervention: A cohort study**	To determine the rate of advance directive completion by chronically homeless individuals after a one-on-one counsellor-guided intervention, identify characteristics associated with advance directive completion, and describe end-of-life care preferences.	Community-based	A one-on-one counsellor guided intervention.	Half of all participants were willing to complete an advance directive with the assistance of a trained counsellor. Completion of an advance directive was not associated with any socio-demographic characteristics but was significantly associated with knowing one's wishes for end-of-life care and not having told anyone about these wishes. The vast majority (94%) of participants who completed an advance directive wished to receive CPR in the event of a cardiorespiratory arrest if CPR provided a chance of returning them to their current state of health.	III	18

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Manheim (2016) **USA**	**Allowing family to be family: End-of-life care in Veterans Affairs Medical Foster Homes**	To learn about facilitators and barriers to coordinating end-of life-care using foster caregivers in place of familial caregivers in a VHA MFH program and specifically how this model of care impacted the Veteran, their family, and the MFH caregiver and their family at the Veterans' end of life.	Community-based	The Medical Foster Home program, a long-term care program coordinated by the Veterans Health Administration which airs Veterans with private, 24-hour-a-day community-based caregivers who often care for Veterans until the end of life.	(a) Medical Foster Home program supports Veterans' families; (b) Medical Foster Home program supports the caregiver as family; (c) Veterans' needs are met socially and culturally at the end of life; and (d) the changing needs of Veterans, families, and caregivers at Veterans' end of life are addressed.	III	18

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Miller (2019) **England**	**How timely is access to palliative care medicines in the community? A mixed methods study in a UK city**	To investigate timely access to palliative medicines/drugs from community pharmacies to inform palliative care service delivery.	Community-based	Barriers to the timely access to palliative medicines in the community pharmacy setting.	One in five people had to travel to more than one pharmacy to access palliative medicines. The range of medicines stocked by pharmacies was the key facilitating factor. Pharmacists reported practical issues causing difficulty keeping these medicines in stock and playing a reactive role with palliative prescriptions. Confidentiality concerns were cited by other HCPs who were reluctant to share key patient information proactively with pharmacy teams. Inadequate information transfer, lack of community pharmacy integration into the care of palliative patients and poor HCP knowledge of which pharmacies stock palliative medicines meant patients and their families were not always able to access medicines promptly.	III	21

Author (year) Country	**Article title**	**Study aim/ purpose**	**Setting**	**Intervention, exposure, risk factor**	**Key findings**	**Evidence ranking**	**Quality appraisal**
Schaefer (2021) **Australia**	**Palliative care needs and experiences of people in prison: A systematic review and meta-synthesis**	To identify the: (i) perceptions of palliative care provision and dying in custody by people in prison; and (ii) perceived barriers and facilitators of person-centred palliative care provision in prison.	Community-based	Palliative care provision in prisons.	People in prison expect to receive high-quality palliative care, but their experiences often do not match their expectations. Numerous structural and organisational challenges complicate the provision of palliative care in prisons, limiting accessibility of care.	III	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
van Vuuren (2021) **Australia**	**Reshaping healthcare delivery for elderly patients: The role of community paramedicine; a systematic review**	To identify evidence of the community paramedicine role in care delivery for elderly patients, with an additional focus on palliative care, and the possible impact of this role on the wider healthcare system.	Community-based	Community/extended skills paramedic programs.	Most studies saw a reduction in emergency calls, transport to ED, ED visits, or hospitalisation. The CPN programs were seen as a safe and effective option for responding and treating older adults at home and reducing the strain on Paramedic Services and ED by moving care from ED and inpatient to outpatient and medical home-based care. CPs were able to bridge the communication gap between the family physician and family, and effective communication was seen as important to the building of relationships with Long-Term Care (LTC) staff. Satisfaction with service was high and there is evidence of positive patient health outcomes. There is limited high-quality evidence to support CPN involvement in the care delivery in RACFs and EOL care specifically, although there was high quality evidence for the role of CPN in care of elderly patients.	III	22

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Bandurska (2017) **Poland**	**Impact of Integrated Care Model (ICM) on direct medical costs in management of advanced chronic obstructive pulmonary disease (COPD)**	To estimate COPD costs and to analyse the impact of introducing integrated care (IC) on the public budget.	Community-based	The Integrated Care Model (ICM) involving general and specialist care, combined with home support for patients, and intensive education of patients and their relatives. All actions in the ICM are synchronised by the program coordinator, who is also responsible for supervising the proper use of drugs by the patients and coordinating their visits to GPs and pulmonologists.	ICM reduced the number of COPD exacerbations. Integrated care caused a decrease in costs and in the number of hospitalisations and ED visits, with a simultaneous increase in the number of GP visits.	V	19
Bennett (2016) **England**	**Partnership working between hospice and children's community nursing teams**	To evaluate an innovative integrated model of paediatric palliative care that implements a nurse to work alongside and between a core hospice community team and a children's community nursing team.	Community-based	The Alexander's Nurse (AN) role provides respite and end-of-life care while working closely with the community nursing team and the wider hospice team. The ANs support the community team to develop a greater awareness of children's palliative care and to standardise care delivery.	The introduction of the role of the AN has been valuable in meeting the needs of children and families in community-based palliative care. Many of the aims of the service have been met, including an increase in the number of families supported, reduction of unnecessary hospital admissions, and joint support for children at the end of their lives.	V	11

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Broadhurst (2019) **England**	**Advance care planning: The impact of ceiling of treatment plans in patients with Coordinate My Care**	The aims of this service evaluation were: (1) to identify the numbers of patients willing to engage in urgent care planning; (2) the factors associated with and the numbers patients completing ceiling of treatment (CoT) plans; and (3) to undertake a comparison of the outcomes of patients with and without CoT plans.	Community-based	Factors differentiating those who create a ceiling of treatment plan within their digital integrated Coordinate My Care record and those who do not. The optional ceiling of treatment plan captures patient and clinician decisions about how aggressive medical intervention should be in case of emergency or deterioration and where that care should be provided.	A substantial proportion of patients were willing to engage in urgent care planning as part of the Coordinate My Care program. Those with a CoT plan were more likely to die in their preferred place of death, most frequently outside the hospital setting. Seventy-eight percent of patients included in this analysis had a documented decision about resuscitation.	V	15
Carey (2017) **Australia**	**Reducing hospital admissions in remote Australia through the establishment of a palliative and chronic disease respite facility**	To assess the impact of a community-based culturally appropriate respite service for Aboriginal and Torres Strait Islander peoples on the use of hospital resources.	Community-based	A referral-based respite service where patients can have some medical needs attended to or participate in various unstructured leisure and social activities such as cooking, watching television, or socialising with the staff and other patients.	The respite service produced a mean cost saving of $1,882.50 per episode for hospital admissions with a reduction in hospital admissions, mean length of stay, Intensive Care Unit hours, and ventilator hours.	V	18

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Law (2021) **Hong Kong SAR, China**	**Empowering families facing end-stage non-malignant chronic diseases with a holistic, transdisciplinary, community-based intervention:** **3 months outcome of the Life Rainbow Program**	To report on the three-month outcomes of the Life Rainbow Program using a single-group, pre-post comparison.	Community-based	The Life Rainbow Program which provides holistic, transdisciplinary, community-based end-of-life care. Comprises four components: (1) Empowering patient self-management and optimising function; (2) psycho-social-spiritual support; (3) family-oriented advance care planning; and (4) connection with informal networks and community resources.	After receiving three months' LRP services, patients with end-stage non-malignant chronic diseases and their caregivers experienced significant improvements in their quality of life and well-being, and their hospital bed-days were reduced.	V	17
Neubauer (2015) **USA**	**Improving incidence of code status documentation through process and discipline**	To describe the implementation and outcomes of an ACP program aimed at increasing code status documentation in the electronic health record.	Community-based	The ACP program, My Choices, My Wishes, which provides a systematic approach for learning about and documenting a patient's values and goals for care in the electronic health record.	Before implementation of the My Choices, My Wishes program, all sites reported zero or nominal incidence of code status documentation. Through the described ACP process, there were notable incremental improvements in code status documentation, however documentation was highly variable across participating clinics.	V	10

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Nordentoft (2021) **Denmark**	**Evaluation of a multimodal rehabilitative palliative care programme for patients with high-grade glioma and their family caregivers**	To explore patient and caregiver experiences of high-grade glioma and evaluate the relevance of and patient and caregiver satisfaction with a multimodal rehabilitative palliative care programme for this condition.	Community-based	A four-day multimodal rehabilitative palliative care residential programme and a two-day follow-up programme three months later.	Participants found completing the REHPA-HGG programme feasible and rated all sessions highly for relevance and satisfaction. Three themes emerged in the evaluation group interviews: (1) meeting peers strengthens social well-being; (2) the value of information and focusing on individual needs; and (3) accepting life as an unpredictable passage.	V	20
Abe (2020) **Japan**	**Place of death associated with types of long-term care services near the end-of-life for home-dwelling older people in Japan: A pooled cross-sectional study**	To assess the association between each type of long-term care service (non-residential) that home-dwelling older individuals utilised at their end of life and place of death.	Home-based care	Decedent receipt of non-medical and medical services via in-home services, day services, and short-stay services.	Home-dwelling older persons who used non-residential LTC services near end-of-life had a higher probability of home deaths as compared to those who did not.	III	22

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Abrashkin (2019) **USA**	**Community paramedics treat high acuity conditions in the home: A prospective observational study**	To explore whether high acuity conditions that would typically result in transport to the emergency department in a conventional 911 system can be effectively treated at home using a physician extender community paramedic model within an advanced illness management (AIM) program.	Home-based care	Community paramedic responses including telephonic triage, evaluation by the community paramedic in the home, and video or telephonic conference with the online medical control physician. If patient is not transported, follow-up care is provided telephonically by registered nurses within six hours of the response or by AIM staff telephonically or in-person as needed.	Community paramedics, operating within a multidisciplinary AIM program and with direct access to medical control, can treat high acuity conditions that would otherwise result in transport to the ED. Patient/carers reported high levels of satisfaction with the program.	III	14
Bove (2017) **Denmark**	**Home-based COPD psychoeducation : A qualitative study of the patients' experiences**	To explore the patients' experiences of a minimal home-based psychoeducative intervention aimed at reducing symptoms of anxiety.	Home-based care	The COPD psychoeducative intervention: A single, home-based, one-hour dialogue based on cognitive behaviour theory and psychoeducation. This was followed by a 20-minute telephone booster session after two weeks. The intervention was nurse-led and conducted according to a manual.	The intervention was appreciated by patients because it strengthened their internal resources. Further, it was perceived as a relief that the intervention insisted on talking about anxiety and thereby invited patients to verbalise worries related to end-of-life. The intervention was perceived as comprehensible and applicable in the patients' everyday life and contributed to the patients' ability to self-manage their condition.	III	17

Author (year) Country	**Article title**	**Study aim/ purpose**	**Setting**	**Intervention, exposure, risk factor**	**Key findings**	**Evidence ranking**	**Quality appraisal**
Carter (2019) **Canada**	**Paramedics providing palliative care at home: A mixed-methods exploration of patient and family satisfaction and paramedic comfort and confidence**	To evaluate patient/family satisfaction and paramedic comfort and confidence with the Paramedics Providing Palliative Care at Home program. The primary objectives of this study were to deter-mine the impact of the program in two parts: Part A examined patient and family/ caregiver satisfaction; and Part B measured paramedic comfort and confidence with the delivery of palliative care support.	Home-based care	The multifaceted Paramedics Providing Palliative Care at Home Program. Includes a clinical practice guideline specific to palliative care, adding new medications, and care in the home without transport to the ED. Paramedics were trained and a database was expanded and upgraded to include individualised care plans, including goals of care to make them accessible to paramedics.	Patients expressed more confidence in fulfilling wishes for a preferred location of care and peace of mind that paramedics would respect care wishes. Families expressed relief at having emergency help available 24 hours/seven days a week. Quality of care was rated highly by most families with a focus on the professionalism and compassion of paramedics and their ability to manage symptoms and provide psychosocial support. Paramedics showed an increase in comfort in providing palliative care and confidence in doing so without transport to ED.	III	19

Author (year) Country	**Article title**	**Study aim/ purpose**	**Setting**	**Intervention, exposure, risk factor**	**Key findings**	**Evidence ranking**	**Quality appraisal**
Chan (2021) **Hong Kong SAR, China**	**Community palliative care services on addressing physical and psychosocial needs in people with advanced illness:** **A prospective cohort study**	This study aims to evaluate the effects of a community interdisciplinary palliative care program (palliative care integrated with primary health care) on the symptom experience of patients with advanced disease.	Home-based care	A community-based palliative care project comprising a comprehensive assessment using Integrated Palliative Care Outcome Scale (IPOS), medication review, and various non-pharmacologist strategies for symptom management and health maintenance such as aromatherapy, massage and oral supplements, home-based occupational therapy and dietitian consultation. The project team also provided psychosocial support through psychoeducation, counselling, advance care planning, coordination of financial, home care or funeral services, wish fulfilment and bereavement care.	Improvement in emotional symptoms was statistically significant at one-month follow up ($p<0.001$). Improvements in communication/practical issues were also significant at the one-month ($p<0.001$) and two-month ($p=0.005$) follow-up. However, changes in symptom experiences in the subsequent months were not apparent.	III	17

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Chen (2020) **Taiwan**	**The association between home healthcare and burdensome transitions at the end-of-life in people living with dementia: A 12-year nationwide population-based cohort study**	To investigate the impact of home healthcare (i.e. patterns and characteristics of home healthcare) on transitions and hospital/intensive care unit (ICU) utilisation nearing the end-of-life for people living with dementia at a national level.	Home-based care	People in receipt of home healthcare. This comprises services that rehabilitate after an illness or injury or help to manage chronic diseases and their complications. Various programs are included in this category, such as Medicare skilled home healthcare, home-based primary care, physician house calls, or hospital at home. These vary in terms of acuity, type of care provided, and the degree of physician involvement.	Home healthcare has differential effects on early and late transitions. Receiving home healthcare was associated with an increased risk of multiple hospitalisations in the last 90 days (ET) but a decreased risk of hospitalisation or ED visits in the last three days of life (LT). Furthermore, those receiving home healthcare over a longer duration, more frequently or closer to the time of death were associated with a much lower risk of hospitalisation in the last 90 days (ET).	III	16

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Coldrick (2020) **England**	**Family members' and carers' perceptions of palliative care provided by district nurses**	To analyse the available evidence from families and carers of patients with life-limiting conditions to identify any inconsistencies in the provision of palliative care by district nurses.	Home-based care	Palliative care provided by district nurses.	There was often suboptimal coordination of district nursing palliative care services and significant variations in access to these services. While family members' and carers' perceptions of palliative care provided by district nurses were frequently positive, out-of-hours palliative care was often regarded as inadequate. The findings also suggest that palliative care is not always available to people with life-limiting diseases other than cancer, such as COPD.	III	9
Dalkin (2020) **England**	**Namaste care in the home setting: Developing initial realist explanatory theories and uncovering unintended outcomes**	To develop initial programme theories detailing if, how and under which circumstances Namaste Care works when implemented at home.	Home-based care	Namaste Care: A program designed to provide holistic and personalised care to people with both moderate and advanced dementia in the home. Two-hour visits once a week by a consistent volunteer.	Individualised NC activities led to positive outcomes for people with dementia, volunteers and family members, especially in promoting engagement and reducing social isolation. However, NC may not work in the same way in the person's own home, as it does in care homes. Carers often chose to use NC sessions as respite.	III	17

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
de Graaf (2016) **Netherlands**	**Hospice assist at home: does the integration of hospice care in primary healthcare support patients to die in their preferred location – A retrospective cross-sectional evaluation study**	To explore whether hospice assist at home service enables patients at home to express end-of-life preferences and die in their preferred location. In addition, this study provides insight into symptom burden, stability and early referral.	Home-based care	Hospice assist at home (HaHo service) facilitates: (1) general practitioner (GP)-initiated home visit and consultation by Hospice Nurse Consultant (HNC); (2) fortnightly interdisciplinary consultations led by a hospice GP and supported by two HNC; (3) 24 hours/seven days per week hospice care telephone backup for patients, caregivers and professionals; and (4) one healthcare professional selected by patient responsible for coordination of care.	If the preferred place of death was known, 92/101 (91%) patients died in their preferred place of death. Therefore, Hospice assist at home service supports patients to die in their preferred place of death. Shared responsibility of proactive care in primary care collaboration enabled patients to express preferences.	III	21
Ferroni (2016) **Italy**	**Intensity of integrated primary and specialist home-based palliative care for chronic diseases in Northeast Italy and its impact on end-of-life hospital access**	To examine the impact of intensity (number of home visits) of integrated primary and specialist Home-based Palliative Care for Chronic Diseases (HPCCD) plan of care on place of death and length of hospital stay over the last 30 days of life.	Home-based care	An integrated primary and specialist Home-based Palliative Care for Chronic Diseases (HPCCD) plan of care involving home visits by GPs, nurses, out-of-hours clinicians, and occasionally palliative care specialists.	Integrated primary and specialist palliative care can be provided to terminally ill patients with non-oncological diseases in a population-based way to reduce the risk of inappropriate hospital stay and death. The intensity of integrated HPCCD plans of care was associated with a reduction in EOL hospital stay and in-hospital death. Hospital death and prolonged EOL hospital stay for medical reasons were reduced at increasing intensity of homecare visits, with a dose-response relationship.	III	21

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Igarashi (2015) **Japan**	**Factors related to the provision of home-based end-of-life care among home-care nursing, home help, and care management agencies in Japan**	To clarify institution-related factors associated with the provision of home-based EOL care cases, and to compare them among three different types of home-care agencies.	Home-based care	Home-based EoL care of three types (home care nursing, home help, or care management).	The agency's size and the inter-agency collaborative system seemed most important among home care nursing agencies and care management agencies, while institutional preparedness for EOL (including accepting EoL patients) was most important for home help agencies.	III	16
Maetens (2019) **Belgium**	**Impact of palliative home care support on the quality and costs of care at the end of life: A population-level matched cohort study**	To evaluate the impact of palliative home care support on the quality of care and costs in the last 14 days of life.	Home-based care	Receiving the allowance for palliative home patients, multidisciplinary palliative home care team visit, or palliative nurse or physiotherapist visit at home.	People receiving palliative home care support had more family physician contacts, more chance of home death, and lower risk of hospital, ICU or ED admission.	III	19
Pivodic (2016) **UK**	**Home care by general practitioners for cancer patients in the last 3 months of life: An epidemiological study of quality and associated factors**	To determine the degree of and factors associated with bereaved relatives' satisfaction with home end-of-life care delivered by general practitioners to cancer patients.	Home-based care	Home care delivered by GPs at the end of life.	Bereaved relatives' satisfaction with GP EoL home care provision was considerably lower than satisfaction with home care by district/ community/private nurses or specialist palliative care providers. The odds of reporting high satisfaction with GP home care increased with more frequent home visits by the GP and halved if the patient died in hospital rather than at home.	III	21

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Seow (2016) **Canada**	**Does increasing home care nursing reduce emergency department visits at the end of life? A population-based cohort study of cancer decedents**	To examine the temporal association between home care nursing rate on emergency department (ED) visit rate in the subsequent week during the last six months of life.	Home-based care	Generalist home care nursing.	An increasing home care nursing rate was associated with a decreasing ED rate but only in the last month of life. Moreover, home care nursing with an explicit end-of-life intent in the last six months, but especially in the last month of life, also was associated with a reduced ED rate in a subsequent week.	III	19

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Surakka (2021) **Finland**	**Preplanned participation of paramedics in end-of-life care at home: A retrospective cohort study**	To evaluate a protocol for end-of-life care at home including pre-planned integration of paramedics and end-of-life care wards.	Home-based care	Integration of paramedics into municipal end-of-life care at home on 24 hours/seven days per week basis. All patients admitted to the protocol requested to be cared of at home at the end of their lives. Daily palliative care was provided by a home care team or by a nursing home staff. They informed patient details (name and address) to Fire and Rescue Department. Patients had a written end-of-life care plan available at their homes including information of a pre-planned end-of-life care ward in a community hospital where they could have been transferred.	Over half of all the visits were outside of office hours. Problems were resolved at home in 31% of the visits. The patient was transferred to a pre-planned end-of-life care ward for 48% of patients and to an emergency department for 16%. More patients died in end-of-life care wards in areas without (54%) than with (33%) 24 hours/seven days a week home care services. Integration of paramedics into end-of-life care at home is reasonable especially in rural areas without 24 hours/seven days per week palliative care services and outside of office hours. Most patients can be managed at home or with the help of an end-of-life care ward without an emergency visit.	III	14

Author (year) Country	**Article title**	**Study aim/ purpose**	**Setting**	**Intervention, exposure, risk factor**	**Key findings**	**Evidence ranking**	**Quality appraisal**
Takashima (2015) **Japan**	**Usefulness of a collaborative home visit program between hospital and visiting nurses**	To provide a basis for appropriate home care for cancer patients by clarifying the usefulness of home visits in a collaboration program between visiting and certified hospital nurses.	Home-based care	Collaborative community nurse home visit program with support from specialist palliative care personnel when required (e.g. advice, lectures, and technical guidance for the visiting nurse).	The proportion of home deaths increased after the initiation of collaborative home visits; this increase was not significant. However, visiting nurses' sense of difficulty in providing palliative care was significantly reduced in comparison between those with and without experience of such visits.	III	15
Tanuseputro (2018) **Canada**	**Associations between physician home visits for the dying and place of death: A population-based retrospective cohort study**	To determine whether receiving a physician home visit near the end of life is associated with lower odds of death in a hospital.	Home-based care	Health services received near the end of life, including end-of-life designated primary physician home visits and those by specialist palliative care physicians.	Receiving at least one physician home visit from a non-palliative care physician was associated with 47% decreased odds of dying in a hospital. When a palliative care physician specialist was involved, the overall odds declined by 59%. Location of death is strongly associated with end-of-life health care in the home. Less than one-third of the population, however, received end-of-life home care or a physician visit in their last year of life, revealing large room for improvement.	III	22

Author (year) Country	**Article title**	**Study aim/ purpose**	**Setting**	**Intervention, exposure, risk factor**	**Key findings**	**Evidence ranking**	**Quality appraisal**
van Gurp (2016) **Netherlands**	**Teleconsultation for integrated palliative care at home: A qualitative study**	To describe: (1) whether and how teleconsultation supports the integration of primary care, specialist palliative care, and patient perspectives and services; and (2) how patients and (in)formal caregivers experience collaboration in a teleconsultation approach.	Home-based care	Specialist palliative care team-patient teleconsultation and ability for home-based patient to consult both his/her primary care physician (PCP) (generalist care) and, digitally, hospital-based palliative care experts. For this study, synchronous audio-visual teleconsultation between a hospital based SPCT and home-based palliative care patients was added to the existing community care model. PCPs were invited to attend the teleconsultations at the patient's home to build tripartite consultations between patient, PCP, and SPCT.	Teleconsultation between a home-based patient and a hospital-based specialist palliative care team stimulates integration of care between primary care practitioners and specialist palliative care clinicians. Health professionals were observed defining responsibility as a consequence of (1) reshaping of specialist palliative care and palliative home-care collaboration and (2) building interprofessional rapport.	III	19
Webber (2019) **Canada**	**Community palliative care initiatives to reduce end-of-life hospital utilization and in-hospital deaths: A population-based observational study evaluating two home care interventions**	To evaluate the impact of interventions aimed at planning for a home death (Yellow Folder) and managing symptoms in the home (Symptom Response Kit) on place of death and hospital utilisation among palliative home care patients.	Home-based care	(1) Yellow folder: materials to help home care providers, patients and families plan for an expected home death (e.g. a DNR form and home-death planning tool). (2) Symptom Response Kit: medications and supplies customised to patients' conditions, for home care nurses to use if the patient's condition changes suddenly.	Patients who received the Yellow Folder (a home death planning tool) or Symptom Response Kit were less likely to visit a hospital in the last six months of life and more likely to die at home. This association was stronger when these interventions were used together. When provided in conjunction with palliative homecare, these interventions can help support patients' preferences to remain at home at the end of life.	III	19

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Winthereik (2018) **Denmark**	**Propensity for paying home visits among general practitioners and the associations with cancer patients' place of care and death: A register-based cohort study**	To analyse associations between general practitioners' propensity to pay home visits and the likelihood of hospitalisation and dying out of hospital among their cancer patients.	Home-based care	GP home visits.	There was a significant positive association between general practitioners' propensity to pay home visits and their patients' likelihood of being hospitalised, being hospitalised for a short time only, and dying out of hospital.	III	19
Zavagli (2020) **Italy**	**The ANT home care model in palliative and end-of-life care. An investigation on family caregivers' satisfaction with the services provided**	To measure caregivers' satisfaction with the home care services of Italy's National Tumor Assistance (ANT) and determine what types of support services are associated with greater satisfaction.	Home-based care	The ANT home care interdisciplinary model which provides free medical and nursing support 24 hours/seven days per week, a psychological (including bereavement) service, and practical social home assistance to cancer patients and their families.	Family caregivers expressed a high level of satisfaction with the home care assistance received, particularly that provided by healthcare professionals (physicians, nurses, and psychologists). The most appreciated aspects were the global nature of care to the patient and family and service availability. The least was the continuity of care provided.	III	13

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Garner (2017) **England**	**An analysis of the economic and patient outcome impact of an integrated COPD service in east London**	To investigate the impact of the Acute COPD Early Response Service (ACERS) team on: (1) Management of COPD in primary care; (2) Hospital admissions due to COPD; (3) Time spent in hospital for COPD admissions; (4) Readmissions following discharge from hospital; (5) Patient outcomes; (6) Place of death for patients with COPD; and (7) Healthcare usage costs for COPD patients.	Home-based care	ACERS team service including a full home oxygen service, four pulmonary rehabilitation groups, nurse-led clinics and a full range of intermediate care services. ACER also works with primary care to improve rates of diagnosis, helping with case finding and education and providing a responsive early discharge service to patients admitted, Hospital at Home, acute exacerbation management within the community (to prevent acute admissions and to reduce future exacerbation frequency, to improve patient quality of life) and end-of-life care service.	The ACER integrated care model did not reduce the number of COPD hospital admissions nor the readmission rate. However, it significantly reduced hospital length of stay and the number of people dying within a hospital. There was also a clinically significant improvement in CAT scores. Economic benefits of the service were almost equal to the cost of the service.	V	13
Montgomery (2017) **Canada**	**Innovative urgent care for the palliative patient at home**	Describes an innovative strategy to provide urgent collaborative palliative and end-of-life care to patients in their homes to avoid transport to an Emergency Department during symptom crisis.	Home-based care	A collaborative community approach to palliative care between emergency medical services and community care services.	Most patients had their symptoms managed at home with the additional resources and collaboration. Patients and families were very satisfied with the initiative, which avoided unnecessary visits and admissions to the ED.	V	10

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Pellizzari (2017) **Italy**	**Impact of intensity and timing of integrated home palliative cancer care on end-of-life hospitalization in Northern Italy**	To examine the impact and timing and intensity of a novel integrated home-based palliative cancer care (HBCC) program on the quality of end-of-life care.	Home-based care	Intensity of exposure to an integrated home-based palliative cancer care program 90 to 16 days before death.	A greater HPCC program intensity reduces the risk of hospital death and hospital stay in the end-of-life. A late activation (greater than 30 days before death) of HPCC was also associated with increased hospital stay and hospital stay greater than seven days.	V	18
Poulos (2018) **Australia**	**Can specially trained community care workers effectively support patients and their families in the home setting at the end of life?**	To describe the self-reported impact of the Palliative Care Home Support Program (PCHSP) on family carers, with triangulation of findings from community palliative care teams and community care workers.	Home-based care	Specialist supportive community care workers providing free of charge non-clinical patient care, domestic tasks, and respite (day or night).	Support provided by community care workers was valued by carers for: enabling choice (i.e. to realise end-of-life care in the home); providing practical assistance (‘hands-on’); and for emotional support and reassurance. This was corroborated by community palliative care teams and community care workers. Carers also indicated that in the last week of life, effective control of symptoms was occurring, and quality of life was being maintained.	V	19

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Shimada (2017) **Japan**	**Cancer transitional care for terminally ill cancer patients can reduce the number of emergency admissions and emergency department visits**	To evaluate the effectiveness of cancer transitional care by analysing the frequency and characteristics of emergency admissions and emergency department visits.	Home-based care	A cancer transitional care system to monitor and manage patients with cancer at home after hospital discharge. The system consisted of at least one or more following components: (1) a 24-hour hotline for general physicians or home care nurses to reach hospital-based physicians; (2) periodic phone calls from an expert hospital-based oncology nurse to home care medical staff; and (3) reports sent to the palliative care department from home care medical staff.	The cancer transitional care system reduced the number of emergency admissions and ED visits made by cancer patients in the last 30 days of life, appearing to replace them with planned admissions.	V	19
Pouliot (2017) **USA**	**First-year analysis of a new, home-based palliative care program offered jointly by a community hospital and local visiting nurse service**	To evaluate the effectiveness of Care Choices, a new in-home palliative care program provided by the Visiting Nurse Services of Northeastern New York and Ellis Medicine-community hospital serving New York's Capital District.	Home-based care	Care Choices: An in-home palliative care program offered jointly by a visiting nurse service and a community hospital. Home visits offer education about pain and symptom management, psychosocial and spiritual support, anticipatory guidance for problem solving at home to avoid unnecessary hospitalisations, management of medications, communication among caregivers and providers, and facilitation of conversations related to serious illness, goals of care, and advance directive planning.	Patients were highly satisfied (72.7%–100%) with their initial care and reported greater satisfaction and stable symptom management over time. Fewer emergency department and inpatient hospital admissions occurred among enrolees while on the palliative care service.	V	20

Author (year) Country	**Article title**	**Study aim/ purpose**	**Setting**	**Intervention, exposure, risk factor**	**Key findings**	**Evidence ranking**	**Quality appraisal**
Ernecoff (2021) **USA**	**Evaluation of a home-based, nurse practitioner-led Advanced Illness Care Program**	To investigate the effect of the Advanced Illness Care Program on hospital encounters, hospice conversion, and mortality.	Home-based care	The Advanced Illness Care Program provides nurse practitioner-led, home-based care for people with serious or complex chronic illnesses that specifically targets palliative care needs and coordinates with patients' primary care and specialty healthcare providers. It provides social work, and case management and is tailored to support patients and families as they navigate serious illness.	Compared with matched controls, AIC enrolees had a higher likelihood of ED visits at 30 and 90 days yet decreased likelihood of hospitalisation at 30 days; and a higher likelihood of converting to hospice. There was no between-group difference in mortality. The AIC Program provides care and coordination that the home-based serious illness population may not otherwise receive.	III	19
de Veer (2020) **Netherlands**	**Assessment of a structured self-management support intervention by nurses for patients with incurable cancer**	To gain an understanding of the perceptions of patients with incurable cancer regarding a new nurse-led self-management support intervention with an integrated eHealth application (Oncokompas) and its potential effectiveness.	Home-based care	(1) Face-to-face contact with a nurse providing self-management support according to the steps of the 5A's model. (2) An optional eHealth component (Oncokompas) which is a web-based self-management instrument for monitoring various QoL aspects by means of PROMs, tailored feedback and personalised advice about supportive care services.	85% of patients were satisfied with the assessment of their needs and the advice received. They valued nurses' expertise and the assistance provided in their homes. Twenty-five percent of the patients used Oncokompas. However, no statistically significant changes in patient activation and quality of life were found.	III	18

Author (year) Country	**Article title**	**Study aim/ purpose**	**Setting**	**Intervention, exposure, risk factor**	**Key findings**	**Evidence ranking**	**Quality appraisal**
Keim-Malpass (2017) **USA**	**End-of-life transitions and hospice utilization for adolescents: Does having a usual source of care matter?**	To elucidate the relationship between a usual source of primary care and end-of-life care delivered to adolescents (including hospice utilisation and end-of-life transitions).	Primary health care setting	A usual source of primary care such as the provided through the medical home model.	Rather than decreasing end-of-life transitions, having a usual source of primary care was associated with an increase in hospice enrolment, hospice length of stay, and end-of-life transitions (includes inpatient stays, outpatient visits, and clinic visits). Adolescents with a cancer diagnosis were more likely to enrol in hospice services.	III	16
Pearce (2021) **England**	**Supporting bereavement and complicated grief in primary care: A realist review**	To identify what works, how, and for whom, in the management of complicated grief in primary care.	Primary healthcare setting	General practitioner support for complicated grief.	GPs and nurses view bereavement support as part of their role yet experience uncertainty over the appropriate extent of their involvement. Patients and clinicians often have differing views on the role of primary care in bereavement. Training in bereavement, local systems for reporting deaths, practitioner time, and resources can assist or hinder bereavement care provision. Practitioners find bereavement care can be emotionally challenging. Understanding patients' needs can encourage a proactive response and help identify appropriate support.	III	12

Author (year) Country	**Article title**	**Study aim/ purpose**	**Setting**	**Intervention, exposure, risk factor**	**Key findings**	**Evidence ranking**	**Quality appraisal**
Andrade (2017) **Portugal**	**Randomized controlled trial of a cognitive narrative crisis intervention for bereavement in primary healthcare**	To assess the effectiveness of an intervention manual developed to aid primary care psychologists to prevent bereavement problems such as depressive or psycho-traumatic symptoms.	Primary healthcare setting	A manualised cognitive narrative program for complicated grief delivered by trained primary psychologists in four hour-long weekly sessions. These sessions cover: recall, cognitive and emotional subjectification, metaphorising, and projection.	Depressive symptoms: Lowering of depressive symptoms observed in both groups but between group difference was not statistically significant. Traumatic stress symptoms: Both groups had lower levels of traumatic stress at six months post-loss. A significant positive difference was only observed in Emotional Numbing for the experimental group.	I	20
Evans (2021) **England**	**Community-based short-term integrated palliative and supportive care reduces symptom distress for older people with chronic noncancer conditions compared with usual care: A randomised controlled single-blind mixed method trial**	To evaluate the impact of the short-term integrated palliative and supportive care intervention for older people living with chronic noncancer conditions and frailty on clinical and economic outcomes and perceptions of care.	Primary healthcare setting	Integrated person-centred palliative care delivered by community-based multidisciplinary palliative care teams working with general practitioners and community healthcare services, including district and community nurses.	The intervention is an effective and cost-effective approach to reduce symptom distress for older people severely affected by chronic noncancer conditions. It is a clinically effective way to integrate specialist palliative care with primary and community care for older people with chronic conditions. The study demonstrated reduced symptom distress between the intervention compared with usual care and medium effect size. Symptom distress reduced with decreased costs from the intervention compared with usual care, demonstrating cost-effectiveness.	1	21

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Schweitzer (2016) **Netherlands**	**Writing information transfers for out-of-hours palliative care: A controlled trial among GPs**	To evaluate the effect of implementing an information handover form regarding patients receiving palliative care for the use of GPs in an out of hours co-operative.	Primary healthcare setting	GPs in the intervention group received an information handover form containing essential information about palliative care patients and an invitation for a one-hour training.	The number of contacts in the experimental group in which information was available increased significantly after intervention while decreasing in the control group. The training had no additional effect. The introduction of a handover form resulted in a moderate increase of information transfers to the GP co-operative. However, the percentage of palliative contacts remained low in cases where information was available.	I	19
Groenewoud (2021) **Netherlands**	**Effects of an integrated palliative care pathway: More proactive GPs, well timed, and less acute care: A clustered, partially controlled before-after study**	To present an integrated, proactive palliative care pathway covering the full care cycle and evaluate its effects using three types of outcomes: (1) physician-reported outcomes; (2) outcomes reported by family; and (3) (utilisation of) healthcare outcomes.	Primary healthcare setting	A multidisciplinary integrated palliative care pathway encompassing (among others) early identification of the palliative phase, timely conversation about EoL wishes and care plan, multidisciplinary consultation and coordination, and continuous monitoring of outcomes.	Patients in the pathway received more (intensive) primary care, less unexpected care during out-of-office hours, and more often received hospital care in the form of day care. Therefore, an integrated palliative care pathway improves a variety of clinical outcomes important to patients, their families, physicians, and the healthcare system.	II	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Dalkin (2016) **England**	**Reducing inequalities in care for patients with non-malignant diseases: Insights from a realist evaluation of an integrated palliative care pathway**	To find whether, how, and under what circumstances palliative care registrations are made for patients with non-malignant diseases in primary care.	Primary healthcare setting	An integrated care pathway implemented in primary care by multidisciplinary teams.	Qualitative analyses indicate that healthcare professionals find registering patients with non-malignant diseases stressful yet feel that their confidence in treating this population is increasing. The integrated care pathway began to enable the reduction in inequalities in care by identifying, registering and managing an increasing number of palliative patients with non-malignant diseases.	III	15
Dunphy (2016) **Ireland**	**End-of-life planning with frail patients attending general practice: An exploratory prospective cross-sectional study**	To ascertain the feasibility of improving the identification of patients at high risk of dying in general practice and the acceptability of providing patients identified with an end-of-life planning tool.	Primary healthcare setting	Think Ahead – an end-of-life planning tool.	Provision of Think Ahead to a purposive sample of preterminal patients identified by GPs was feasible, acceptable to most patients, and somewhat effective in increasing discussion among families and in practice on end-of-life planning.	III	22

Author (year) Country	**Article title**	**Study aim/ purpose**	**Setting**	**Intervention, exposure, risk factor**	**Key findings**	**Evidence ranking**	**Quality appraisal**
Kjellstadli (2020) **Norway**	**General practitioners' provision of end-of-life care and associations with dying at home: a registry-based longitudinal study**	(1) To investigate deceased patients' contacts with GPs, GPs' interdisciplinary collaboration, out-of-hours services and hospitalisations in the last 13 weeks of life and associations with dying at home. (2) To investigate whether GP contacts were associated with fewer out-of-hours contacts or days hospitalised.	Primary healthcare setting	Contact with GPs (office and home visits) and GPs' interdisciplinary collaboration.	General practitioner (GP) home visits and interdisciplinary collaboration were associated with home death in a dose-dependent relationship. However, people leaving their home for GP consultations or OOH contacts or those who were hospitalised were less likely to die at home (also dose-dependent). GPs play an important role in enabling people to die at home by performing home visits and collaborating with other healthcare personnel but only for a small minority of dying people.	III	15

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Mason (2015) **Scotland**	**Improving primary palliative care in Scotland: Lessons from a mixed methods study**	To investigate the impact of a GP-based Palliative Care Directed Enhanced Service initiative introduced in Scotland in 2012.	Primary healthcare setting	Palliative Care Directed Enhanced Service care.	GPs were more likely to identify patients for the palliative care register if they had cancer, although small increase in non-malignant numbers occurred during the study. GPs largely associate palliative care with terminal care and therefore find it challenging to 'break bad news' to patients. They also report issues with prognosticating for non-cancer patients and are therefore reluctant to add these patients to the palliative care register. GPs also struggle to communicate with secondary care professionals about their patients, especially around hospitalisation and discharge. Workload pressures and a complicated electronic palliative care summary also serve as barriers to patient identification and registration. By recognising that early palliative care is a form of anticipatory care planning it appears that GPs feel enabled to act more promptly and communicate more effectively with patients.	III	19

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
van der Plas (2015) **Netherlands**	**Involvement of a case manager in palliative care reduces hospitalisations at the end of life in cancer patients: A mortality follow-back study in primary care**	To compare cancer patients with and without additional support from a nurse case manager on: (1) general characteristics; (2) characteristics of care and support given by the GP; and (3) palliative care outcomes.	Primary healthcare setting	Palliative care from GP and nurse case manager.	With additional support from a case manager, the patient's GP is more likely to know the preferred place of death, the place of death is more likely to be at the home and less likely to be the hospital, and there are fewer hospitalisations in the last 30 days of life.	III	21
Walsh (2015) **Australia**	**What diagnostic tools exist for the early identification of palliative care patients in general practice? A systematic review**	To identify and assess existing diagnostic tools that can be used for the early identification of palliative care patients in a general practice setting.	Primary healthcare setting	Evaluated tools for diagnosing palliative care needs.	The four tools identified stimulate consideration of potential illness trajectories; their prompts can encourage discussions between clinicians and patients about life-limiting illness and help diminish the potential awkwardness of such discussions. However, their impact on relevant outcomes should now be studied.	V	17

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Finucane (2020) **Scotland**	**Electronic care coordination systems for people with advanced progressive illness: A mixed-methods evaluation in Scottish primary care**	(1) To estimate the proportion of people with an advanced progressive illness who have a Key Information Summary (KIS) by the time of death documenting their preferences and a care plan; and (2) to examine when planning information is documented and suggest improvements for electronic care coordination systems.	Primary healthcare setting	Having a KIS at the time of death.	Most people who died with an advanced progressive illness had a KIS but people with cancer were more likely to have one than people with organ failure. Most people who died with frailty and/or dementia had a KIS that was typically started more than one year before death. The existence of a KIS was positively associated with dying in the community.	V	17

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Lakin (2017) **USA**	**A systematic intervention to improve serious illness communication in primary care**	To describe the implementation and evaluation of the Serious Illness Care Program in a high-risk primary care population.	Primary healthcare setting	The Serious Illness Care Program: a multicomponent intervention designed to support best practices in serious illness communication by clinicians who lack specialty-level palliative care training in outpatient care settings. Includes four core elements: (1) a population approach to identifying patients; (2) training and coaching for clinicians to use a structured Conversation Guide; (3) reminders to conduct conversations; and (4) a documentation system.	Patients enrolled in clinics participating in the program who died had more serious illness conversations with their clinicians, and these conversations were both more comprehensive and more accessible in the medical record. The intervention did not have an effect on the timing of conversations in relation to death. There were no statistically significant differences in hospice use between the two groups, although numbers were small. Clinicians who participated also reported high satisfaction with training they received as part of the program, which they regarded as effective.	V	18

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Larsen (2020) **Denmark**	**Increased rate of home-death among patients in a Danish general practice**	To investigate whether the home-death rate was higher than the Danish average in a general practice with a systematic approach to palliative care and to examine if the number of clinical contacts between the practice and its patients was associated with place of death.	Primary healthcare setting	Palliative care provided by general practitioners using a structured framework involving training, proactive follow-up, the use of prognostication tools, documentation of palliative care needs and discussion of EoL preferences.	Compared with regional data (but not municipal or national data), the proportion of home-deaths was higher in the study population. The odds of death in hospital were nine times higher if no GP was directly involved in the palliative phase, indicating the importance of GP involvement. The home death group had a similar amount of contact with the GP clinic as those who died elsewhere.	V	16
Sandoval (2019) **USA**	**Increasing advance care planning in primary care practices: A multi-site quality improvement initiative**	(1) To develop and implement standardised processes to address common barriers and integrate ACP into daily practice across nine primary care clinics. (2) To increase the percentage of adult primary care patients with an ACP form in their electronic health record (EHR).	Primary healthcare setting	Interventions targeting barriers to obtaining ACP forms in clinic sites. Components include: (1) Establishing ACP as a priority across practices; (2) Normalising ACP discussion and educating patients about ACP; (3) Creating an electronic reminder if ACP forms are absent; (4) Identifying appropriate patients for ACP discussion prior to visit; (5) Referring patients to community resources when needed; (6) Performing adoption audits at the site level; and (7) Providing financial incentives to physicians.	A quality initiative targeting common barriers to ACP in primary care was associated with sustained increases in the rate of ACP form completion across nine primary care clinic sites.	V	13

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
van der Plas (2018) **Netherlands**	**Improving palliative care provision in primary care: A pre- and post-survey evaluation among PaTz groups**	To study the effects of the implementation of PaTz (modelled after the Gold Standards Framework), and provide additional analyses on two important elements: the PaTz register and patient discussions.	Primary healthcare setting	Exposure to the PaTz palliative care at home program.	Identification of patients with palliative care needs was done systematically for more patients after implementation of PaTz than before. Compared with patients not included on the PaTz register, preferred place of death was more likely to be known. GPs were more likely to have considered a possible death sooner and conversations on life expectancy, physical complaints, existential issues, and possibilities of care occurred more often.	V	19
Williams (2019) **Wales**	**Quality improvement priorities for safer out-of-hours palliative care: Lessons from a mixed-methods analysis of a national incident-reporting database**	To explore the nature and causes of unsafe care delivered to patients receiving palliative care from primary-care services outside normal working hours.	Primary healthcare setting	Out of hours primary care services.	Unsafe palliative care occurred in four main areas: errors in medication provision; securing access to timely care; inefficient information processes between providers; and non-medication-related treatment provision including staff minimum basic skills, and confidence, and availability of equipment for common procedures. Actual harm was a feature of almost two-thirds of patient safety incident reports with many citing emotional and psychological distress to patients, families, and carers.	V	14

Author (year) Country	**Article title**	**Study aim/ purpose**	**Setting**	**Intervention, exposure, risk factor**	**Key findings**	**Evidence ranking**	**Quality appraisal**
Stegmann (2020) **Netherlands**	**Prioritization of treatment goals among older patients with non-curable cancer: The OPTion randomized controlled trial in Dutch primary care**	To assess the utility of the Outcome Prioritisation Tool (OPT), designed to aid discussion with a patient in regard to their treatment goals, to empower patients with cancer through structured conversations about generic treatment goals with GPs.	Primary healthcare setting	Outcome Prioritisation Tool (OPT). The OPT is a decision aid with four visual analog scales, each representing a generic treatment goal: extending life, maintaining independence, reducing pain, and reducing other symptoms. The intervention consisted of a conversation with the GP during which treatment goals were explored with the aid of the OPT.	An OPT-facilitated conversation about generic treatment goals between patients and their GPs is associated with less anxiety and fatigue but did not show statistically significant improvements in patient empowerment. Adding the OPT to routine care might ensure more patient-tailored care.	I	15
Aasmul (2016) **Norway**	**Staff distress improves by treating pain in nursing home patients with dementia: Results from a cluster-randomized controlled trial**	To investigate the association between neuropsychiatric symptoms (NPSs) and the impact of individual pain treatment on distress in nursing home staff	Residential aged care	Care provider half-day specific training in the clinical assessment of pain, cognition, NPSs, activities of daily living, and functional assessment staging. Individual pain treatment for eight weeks according to a Systematic Pain Treatment Protocol (SPTP), followed by a four-week washout period.	Individual pain treatment reduced staff distress in the intervention group compared to control group, especially regarding agitation-related symptoms and apathy. Staff experienced less distress related to patients with higher cognitive functioning and less pain compared to patients with lower cognitive functioning and more reported pain. Staff distress was especially provoked by agitation and disinhibition, whereas euphoria was least distressing for the carers.	I	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Agar (2017) **Australia**	**Effects of facilitated family case conferencing for advanced dementia: A cluster randomized clinical trial**	To compare the efficacy of facilitated case conferencing versus usual care in improving end-of-life (EOL) care for persons with advanced dementia living in nursing homes.	Residential aged care	Individualised, facilitated case conferences involving residents, their families, and multidisciplinary staff. Conference model includes shared agenda-setting, facilitation by the Palliative Care Planning Coordinator, and a follow-up communication summarising actions and the plan arising from the case conference.	The intervention resulted in higher rates of nurse-documented pain and restlessness, more pharmacological and non-pharmacological changes to care relating to symptom management, and greater physician input during the month prior to death. Intercurrent illness was associated with lower family-rated End-of-life Care in Dementia (EOLD) Satisfaction with Care and lower staff-rated EOLD Comfort Assessment with Dying. There were also positive relationships between EOLD and staff hours to bed ratios, the proportion of residents with dementia, and staff attitudes.	I	22
El Alili (2020) **Netherlands**	**Cost-effectiveness of the Namaste care family program for nursing home residents with advanced dementia in comparison with usual care: a cluster-randomized controlled trial**	To assess the societal cost-effectiveness of Namaste Care Family program in comparison with usual care in nursing home residents with advanced dementia.	Residential aged care	The Namaste Care Family program: a multidimensional care program with psychosocial, sensory and spiritual components that incorporates tailored and personalised care until death for people living with advanced dementia. Ideal frequency: two two-hour sessions seven days per week.	Study found no statistically significant differences in costs and clinical outcomes between the Namaste Care Family program and usual care, although overall clinical outcomes improved, and costs were lower.	I	21

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Forbat (2020) **Australia**	**Reducing time in acute hospitals: A stepped-wedge randomised control trial of a specialist palliative care intervention in residential care homes**	To determine whether a model of care providing specialist palliative care in care homes, called Specialist Palliative Care needs rounds, could reduce length of stay in hospital.	Residential aged care	Specialist Palliative Care needs rounds: monthly one-hour triage meetings involving care home staff and specialist palliative care clinicians (two nurse practitioners and a clinical nurse consultant), focusing on residents at risk of dying with a high symptom burden and without a plan in place.	Specialist Palliative Care needs rounds led to reduced length of stay in hospital for people living in care homes approaching the end of life. The number of hospitalisations reduced by 23% which is a saving of approximately A$1,759,011.	I	19
Hanson (2017) **USA**	**Effect of the goals of care intervention for advanced dementia: A randomized clinical trial**	To test a goals of care (GoC) decision aid intervention to improve quality of communication and palliative care for nursing home residents with advanced dementia.	Residential aged care	A goals of care video decision aid plus a structured discussion with nursing home healthcare providers.	Family decision makers reported better quality of communication and end-of-life communication with the GoC intervention. They also reported greater goal concordance by nine months or death. The GoC intervention also resulted in more palliative care content in treatment plans and half as many hospital transfers.	I	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Liu (2020) **Australia**	**Improved quality of death and dying in care homes: A palliative care stepped wedge randomized control trial in Australia**	To examine the impact of providing specialist palliative care on care home residents' quality of death and dying	Residential aged care	Palliative Care needs rounds: monthly hour-long staff triage meetings to discuss residents at risk of dying without a plan in place. A checklist is followed to guide discussions and outcomes, focused on anticipatory planning.	Needs rounds are associated with staff perceptions that residents had a better quality of death and dying, particularly in the 10 facilities that complied with the intervention protocol. Staff self-reported perceptions of capability increased. Rates of advance care planning and appointment of medical POA increased following implementation of needs rounds.	I	20
Martin (2019) **Australia**	**Introducing goals of patient care in residential aged care facilities to decrease hospitalization: A cluster randomized controlled trial**	To determine whether 'Goals of Patient Care' (GOPC) medical treatment orders were more effective than ACP alone in preventing emergency department (ED) visits (no hospitalisation), ED visits (with hospitalisation), and deaths outside the residential aged care facility.	Residential aged care	Completion of GOPC process by a geriatrician, following a shared decision-making process, incorporating ACP documents of residents' preferences.	A statistically significant difference was reached at 12 months with a 40% reduction in ED visits and hospitalisations compared to the control group. In the RACF population, GOPC medical treatment orders were more effective than ACP alone for decreasing hospitalisation and likelihood of dying outside the RACF.	I	21

Author (year) Country	**Article title**	**Study aim/ purpose**	**Setting**	**Intervention, exposure, risk factor**	**Key findings**	**Evidence ranking**	**Quality appraisal**
Miranda (2021) **Belgium**	**No difference in effects of ‘PACE steps to success’ palliative care program for nursing home residents with and without dementia: A pre-planned subgroup analysis of the seven-country PACE trial**	To investigate whether the ‘PACE steps to success’ palliative care program effects differ between nursing home residents with advanced, non-advanced, and no dementia.	Residential aged care	PACE Steps to Success intervention. This involved: (1) advance care planning with residents and families; (2) assessment, care planning, and review of resident needs and problems; (3) coordination of care via monthly multidisciplinary palliative care review meetings; (4) high-quality palliative care with a focus on pain and depression; (5) care in the last days of life; and (6) care after death.	Dementia subgroups demonstrated no differences in comfort in the last week of life nor in quality of care and dying in the last month of life. The program did not improve comfort in the last week of life for those with or without dementia, however, it improved quality of care and dying equally for both groups at this time.	I	20
Mitchell (2020) **USA**	**Advance care planning video intervention among long-stay nursing home residents: A pragmatic cluster randomized clinical trial**	To test the effect of an ACP video program on hospital transfers, burdensome treatments, and hospice enrolment among long-stay nursing home residents with and without advanced illness.	Residential aged care	Five six- to 10-minute ACP videos made available on tablet computers or online. Designated champions (mostly social workers) in intervention facilities were instructed to offer residents (or their proxies) the opportunity to view a video(s) on admission and every six months.	There was no significant reduction in hospital transfers per 1,000 person-days alive in the intervention vs control groups. Furthermore, outcomes did not significantly differ between residents with and without advanced illness. Therefore, the ACP video program was not effective in reducing hospital transfers, decreasing burdensome treatment use, or increasing hospice enrolment amongst long-term stay residents with or without advanced illness. However, implementation fidelity was low.	I	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Saevareid (2019) **Norway**	**Improved patient participation through advance care planning in nursing homes: A cluster randomized clinical trial**	To improve patient participation in advance care planning in nursing homes where most patients have some degree of cognitive impairment.	Residential aged care	Whole-ward approach to ACP with patients and next of kin. Regular ward staff are supported by a guide, pocket card and ACP training.	Intervention group patients participated more often in EoL treatment conversations. Patients' preferences, hopes and worries were more often documented, and concordance between provided treatment and patient preferences and next of kin participation in ACP with the patient increased.	I	19
Tappen (2020) **USA**	**Evaluation of a novel decision guide 'Go to the Hospital or Stay Here?' for nursing home residents and families – randomized trial**	To conduct a randomised trial of a newly developed decision aid, 'Go to the Hospital or Stay Here?' designed to support resident and family member involvement in the transfer decision when an acute change in condition occurs.	Residential aged care	Decision aid (guide) 'Go the Hospital or Stay Here?' intervention was applied to impart knowledge regarding the decision to remain in the nursing home or transfer to acute care. The full colour, 13-page, large print guide, contains an exploratory narrative and a list of assessments and interventions that can be provided in most nursing homes.	Use of the Decision Guide was found to increase residents' and family members' knowledge and decrease decisional conflict, but it did not increase decisional preparation. No reduction in transfers was found. Residents and families rated the guide as very helpful.	I	17

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Temkin-Greener (2018) **USA**	**Impact of nursing home palliative care teams on end-of-life outcomes: A randomized controlled trial**	To test the impact of palliative care teams (PCTeams) on end-of-life outcomes in nursing homes	Residential aged care	PCTeams: implementation of facility-based palliative care teams and staff palliative and EOL geriatric training.	The intervention demonstrated no statistically significant effect; however this was attributed to 6/14 facilities not implementing the intervention consistently during the study period. Homes with teams still reported reductions in the odds of in-hospital deaths and reduced rates of depressive symptoms, however not reduced rates of pain or hospitalisations.	I	19
Loomer (2021) **USA**	**Impact of an advance care planning video intervention on care of short-stay nursing home patients**	To assess whether an advance care planning video intervention impacts care among short-stay nursing home patients.	Residential aged care	Five short videos in English or Spanish covering general goals of care, goals for advanced dementia, hospice, hospitalisation and ACP for health patients.	An ACP video program did not significantly reduce hospital transfers, burdensome treatment, or hospice enrolment, among short-stay patients.	I	18

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Beck (2015) **Sweden**	**Applying a palliative care approach in residential care: Effects on nurse assistants' work situation**	To investigate the effects of an intervention that applies a palliative care approach in residential care upon nurse assistants' level of strain, job satisfaction, and view of leadership.	Residential aged care	Seven two-hour study circle sessions with three six-hour workshops in between. Each study circle meeting involved discussions and reflections based on texts or practical tasks carried out prior to the meeting, such as reading about the topic or interviewing a resident. The workshops were based on nurse assistants' discussions during previous study circle sessions and focused on how practices could be changed in line with the discussions.	Nurse assistant job satisfaction decreased after the intervention, and they perceived the leadership team more negatively than before the intervention. However, six months after completion of the intervention, nurse assistants' strain and perceived criticism from superiors and residents decreased.	II	18
Brannstrom (2016) **Sweden**	**Effectiveness of the Liverpool care pathway for the dying in residential care homes: An exploratory, controlled before-and-after study**	To compare the effects of the Liverpool Care Pathway for the Dying Patient and usual care on patients' symptom distress and well-being during the last days of life in residential care homes.	Residential aged care	Liverpool Care Pathway for the Dying Patient (LCP) adapted for Sweden. Intervention contact nurses participated in an approximately 35-hour web-based LCP train-the-trainer course. Each contact nurse then taught staff at their respective workplace and acted as a resource person for LCP implementation.	Shortness of breath and nausea were significantly reduced in the intervention group according to both objective and subjective assessment measures. The Liverpool Care Pathway for the Dying Patient may be a useful tool for providing end-of-life care for elderly people at the end of life in non-cancer settings when implemented with adequate staff training and support.	II	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Ohta (2021) **Japan**	**Improvement in palliative care quality in rural nursing homes through information and communication technology-driven interprofessional collaboration**	To investigate whether the application of ICT-based communication in rural nursing homes can reduce the number of emergency transportations to, and death in, hospitals.	Residential aged care	Local government-initiated ICT system called Mamenet that works between the nursing home and clinic. Using this system, the clinic and nursing home share information on a patients' medical and care conditions, as well as acute and chronic changes in these conditions. After posting patient information via the ICT, a computer-generated notification mail is automatically sent to all medical and care professionals involved in a patient's care. If any patient shows emergency symptoms, the nursing home nurses are required to call the physicians directly by phone, rather than use the system.	The rate of emergency transportation was significantly higher in the control group than the intervention group while the rate of end-of-life care delivered in the nursing home was higher for the intervention group. ICT-driven nursing home care can therefore reduce emergency transportation from nursing homes and enables residents to remain in the home at the end of life.	II	18
Rainsford (2020) **Australia**	**The impact of introducing palliative care needs rounds into rural residential aged care: A quasi-experimental study**	To examine the impact of introducing palliative care needs rounds into rural residential aged care on hospitalisations (emergency department presentations, admissions and length of stay) and documentation of advance care plans.	Residential aged care	Palliative care needs rounds: monthly onsite triage/risk stratification meetings led by palliative medicine physician where case-based education and staff support help care staff to identify residents most at risk of dying without an adequate plan in place.	Documented advance care plans increased. There were no statistically significant changes in hospitalisations or in-hospital deaths.	II	17

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Verreault (2018) **Canada**	**Quasi-experimental evaluation of a multifaceted intervention to improve quality of end-of-life care and quality of dying for patients with advanced dementia in long-term care institutions**	To evaluate the impact of a multidimensional intervention to improve quality of care and quality of dying in advanced dementia in long-term care facilities.	Residential aged care	(1) Training program to physicians and nursing staff; (2) clinical monitoring of pain using an observational pain scale; (3) implementation of a regular mouth care routine; (4) early and systematic communication with families about end-of-life care issues with provision of an information booklet; and (5) involvement of a nurse facilitator to implement and monitor the intervention.	The Family Perception of Care, Comfort Assessment, and Symptom Management scores were significantly higher in the intervention group. This multidimensional, interdisciplinary program therefore improves family satisfaction with end-of-life care, quality of care and quality of dying in long-term care facilities for patients with terminal dementia. However, continuous involvement of a well-trained nurse facilitator from the institution is a key component of an effective program.	II	18
Westergren (2021) **Sweden**	**Next of kin participation in the care of older persons in nursing homes: A pre-post non-randomised educational evaluation, using within-group and individual person-level comparisons**	To evaluate the participation of next of kin in care following a palliative care educational intervention directed towards nursing home staff members.	Residential aged care	Staff educational intervention (five two-hour seminars) focused on palliative care knowledge and skills.	The intervention seems to have a positive impact on next of kin participation in care in nursing homes for communication and trust but less so for collaboration. Some next of kin reported decreased participation in care after the intervention.	II	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Iliffe (2015) **England**	**Changing practice in dementia care in the community: developing and testing evidence-based interventions, from timely diagnosis to end of life (EVIDEM)**	One of several studies in this multi-study project focuses on the development of a toolkit for palliative care for people living with dementia.	Residential aged care	Intervention is use of Appreciate Inquiry as a context-sensitive tool for improving interprofessional and interagency collaboration and communication for addressing problems in the end-of-life care for PLwD. Aim of the intervention is to co-designing a range of tools and revised practices to address common frustrations between care home staff and visiting primary care professionals.	Distinct trajectories of dying were identified (anticipated, unexpected and uncertain), tools were co-designed between NHS primary care and care home staff. Improvements seen in staff confidence in roles and responsibilities, documentation of care plans, Do Not Attempt CPR form completion, communication with OOH GPs, increased and regular communication with district nurses. Also observed reduction in emergency transports, length of hospital stays, and hospital and community care costs (but not primary care costs).	III	22
Andersson (2018) **Sweden**	**Factors associated with symptom relief in end-of-life care in residential care homes: A national register-based study**	To explore the presence of symptoms and symptom relief and identify factors associated with symptom relief of pain, nausea, anxiety, and shortness of breath among residential care home residents in end-of-life care.	Residential aged care	Factors associated with symptom relief of pain, nausea, anxiety, and shortness of breath during end-of-life care.	Use of a validated pain assessment scale, assessment of oral health, and prescribed PRN injections for pain, nausea, and anxiety were significantly associated with a higher probability of relief from pain, nausea, and anxiety. Likewise, the use of a validated pain assessment scale and assessment of oral health were significantly associated with a higher probability of relief from shortness of breath.	III	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Andersson (2021) **Sweden**	**End-of-life discussions in residential care homes improve symptom control: A national register study**	To examine the correlation between documented EOL discussions with a physician and symptom occurrence, symptom relief, and prescriptions of PRN drugs against symptoms for care home residents.	Residential aged care	Documented resident-physician and family-physician EOL discussions.	Documented EOL discussions are correlated with a higher prevalence of symptoms (i.e. pain, nausea, anxiety, death rattles, and shortness of breath) as well as better symptom relief and prescription of symptom drugs PRN when symptomatic.	III	19
Baranska (2020) **Poland**	**Factors associated with perception of the quality of physicians' end-of-life communication in long-term care facilities: PACE cross-sectional study**	To examine factors associated with perceived quality of communication with physicians by relatives of dying residents of long-term care facilities (LTCFs).	Residential aged care	Factors associated with quality of end-of-life communication with physicians as perceived by relatives.	The quality of EoL communication with physicians was perceived to be higher when the relative spent more than 14 hours with the resident in the last week of the residents' life, and when the treating physician visited the resident at least three times in the last week of the resident's life or provided the resident with palliative care. Relatives with a higher emotional burden perceived the quality of EoL communication with physicians as lower.	III	15

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Bray (2021) **England**	**What is the evidence for the activities of Namaste Care? A rapid assessment review**	To assess the quality of research evidence for the different activity components for the psycho-social Namaste Care intervention for care home residents with advanced dementia.	Residential aged care	Namaste Care: A multi-component intervention delivered daily to people living with advanced dementia or people at end of life with dementia. Trained in-house Namaste Care workers deliver several activities to a group of residents with similar high dependency needs. The Namaste Care workers focus on touch, music, nature, sensory experience, aromas, and interactions with objects delivered in a way to enhance feelings of enjoyment and wellbeing.	Most Namaste Care activity interventions yielded between 10 and 20 peer-reviewed papers of total included articles (n=127). The use of smells and aromas, interacting with animals and dolls, the use of various forms of music (e.g. background music, singing, personalised music), nature, lighting, various forms of touch/massage, and sensory interventions (including Snoezelen) all appear to have proven efficacy with people living with advanced dementia.	III	17

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Brownstein (2021) **Australia**	**Care to the end: A retrospective observational study of aged care facility residents transferred to a hospital in the last day of life**	To explore the characteristics of aged care facility (ACF) residents transferred to a hospital in the last 24 hours of life and factors that might influence this decision, including access to medical review, advance care planning (ACP), and pre-emptive symptom management prescribing.	Residential aged care	Factors associated with resident transfer to hospital in the last 24 hours of life.	Of the small, but significant number of RACF residents transferred, most were transferred out of hours and were without a medical review in the previous 24 hours. A majority (58%) required injectable opioid for symptom management in hospital, but this had only been pre-emptively prescribed for 8%. Less than half had an advanced care plan in place. For residents to die in place, aged care facilities need skilled and timely assessment of deterioration; skilled management of dying; skilled communication with family; and timely access to medications for the management of symptoms.	III	21

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Frey (2020) **New Zealand**	**Palliative care delivery in residential aged care: Bereaved family member experiences of the Supportive Hospice Aged Residential Exchange (SHARE) intervention**	To describe bereaved family members' experiences of palliative care for their relative in RAC facilities implementing SHARE.	Residential aged care	The supportive hospice aged residential exchange (SHARE)-a mechanism to support knowledge exchange between hospice staff and residential aged care staff to improve palliative care within residential aged care facilities and to improve specialist palliative care nurses' knowledge and skill to care for frail older people. Comprises (1) weekly visits by a hospice nurse specialist over one year; (2) clinical coaching and reciprocal role modelling of palliative care and gerontology skills and knowledge; (3) identifying RAC staff learning needs and developing a program of teaching; (4) guidance and role modelling of advance care planning conversation with RAC nurses; (5) debriefing with RAC staff surrounding resident deaths.	According to families, SHARE benefited them (improved communication and hospice support) through the end-of-life journey of their relatives, but challenges remained including relationship with GP, staff shortages and turnover.	III	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Goodman (2016) **England**	**Effective health care for older people living and dying in care homes: a realist review**	To explore the evidence for how different service delivery models for care home residents support and/or improve well-being and health-related outcomes in older people living and dying in care homes.	Residential aged care	Differing models of healthcare delivery to care homes.	Healthcare interventions were accepted and embedded into care home practice more readily when there were strategies to support and sustain the relational working between care home staff and visiting healthcare professionals (especially general practitioners). Visiting healthcare professionals and care home staff should be encouraged to jointly identify, plan and implement care home appropriate protocols for care.	III	17
Harrison (2021) **USA**	**Does integration of palliative care and infection management reduce hospital transfers among nursing home residents?**	To evaluate the association between nursing home integration of the goals of palliative care and infection management at the end of life and: (1) all-cause hospital transfers; and (2) hospital transfers due to infection.	Residential aged care	Integration intensity (degree to which nursing homes follow best practices for integration).	Integration intensity was inversely associated with all-cause hospital transfer and transfer due to infection for patients with advanced dementia but only all-cause hospital transfer for people with advanced COPD. There was no association between intensity and either hospital outcome for people with heart failure. This perhaps indicates alternative strategies are needed to promote best practices for infection management at end of life for this group of patients.	III	22

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Ho (2021) **Singapore**	**Does an integrated palliative care program reduce emergency department transfers for nursing home palliative residents?**	To describe and examine the impact of the GeriCare Palliative Care Program, which comprises telemedicine, on-site clinical preceptorship, palliative care education program, and Advance Care Planning (ACP) advocacy in reducing emergency department (ED) transfers from nursing homes.	Residential aged care	GeriCare Palliative Care Program aimed to provide nursing homes with greater access to quality geriatric and palliative care, upskill NH staff and reduce potentially inappropriate ED transfers. Included scheduled or urgent teleconsultations, weekly onsite mentorship and coaching by specialist palliative care nurses, early (on admission) discussions of ACP by NH staff, supported by SPC nurses and an education program.	82% of urgent telemedicine consultations successfully averted ED transfers. Completion of an ACP significantly reduced the likelihood of an ED transfer.	III	15
Husebo (2017) **Norway**	**The Liverpool Care Pathway: Discarded in cancer patients but good enough for dying nursing home patients? A systematic review**	To investigate whether the Liverpool Care Pathway has been adapted and validated for use in nursing homes and for dying people living with dementia.	Residential aged care	Any adapted version of the Liverpool Care Pathway.	The review could not identify studies describing or evaluating an evidence-based adaption of LCP to nursing home patients and people living with dementia. It concludes that LCP has not been adapted to nursing home patients and people with dementia.	III	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Kaasalainen (2019) **Canada**	**Launching 'Namaste Care' in Canada: Findings from training sessions and initial perceptions of an end-of-life programme for people with advanced dementia**	To explore early experiences associated with the implementation of a new programme called 'Namaste Care' in two Canadian long-term care homes.	Residential aged care	Namaste Care program training (two-day session or a public lecture) and program implementation after three months.	Initial perceptions of the Namaste Care program by LTC staff and residents' family members were positive; they felt that it improved the quality of life for residents. However, staff involvement in both the implementation and decision making around it is recommended, in order to facilitate a collaborative approach.	III	18
Kinley (2018) **England**	**Facilitation of an end-of-life care programme into practice within UK nursing care homes: A mixed-methods study**	To identify the type, role, impact and cost of facilitation when implementing the Gold Standards Framework in Care Homes (GSFCH) programme into nursing care home practice.	Residential aged care	The GSFCH programme.	'Being present' proactive facilitation supported by multi-layered learning (individual, organisational and systems level learning), most effectively enabled staff completion of the programme, through to accreditation, even though this took time, commitment and energy. The cost savings in the study outweighed the cost of providing a 'being present' approach to facilitation.	III	19

Author (year) Country	**Article title**	**Study aim/ purpose**	**Setting**	**Intervention, exposure, risk factor**	**Key findings**	**Evidence ranking**	**Quality appraisal**
Latham (2020) **England**	**The impact of implementing a Namaste Care intervention in UK care homes for people living with advanced dementia, staff and families**	To elucidate the implementation processes of Namaste Care within six UK care homes that had made a positive decision to introduce the intervention as part of regular practice. This paper reports on the impact of a manualised Namaste Care Intervention for UK care homes (NCI-UK) delivered to five care homes over 12–24 weeks.	Residential aged care	Namaste Care Intervention for UK care homes. This includes providing a calming environment, expressive touch, food and drink treats, tactile stimulation, personalised music, family involvement, and significant items to the individual. Homes assigned to once or twice daily sessions of two hours duration delivered by care staff.	Statistically significant improvement in quality of life achieved within 12 weeks and henceforth maintained rather than advanced further. Similarly, reduction of agitation was achieved, with the verbal agitation sub-score continuing to reduce after 12 weeks. Staff perceived improvements in resident physical wellbeing (e.g. eating better and weight gain), mental wellbeing (e.g. reduced displays of anxiety and frustration), and responsiveness/connection. They also reported feeling an increased sense of purpose and wellbeing and had developed positive relationships with residents and their families. Families reported a positive difference in their relationship with the resident and felt involved and useful.	III	18

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Lemoyne (2019) **Belgium**	**Appropriateness of transferring nursing home residents to emergency departments: A systematic review**	To define the characteristics of emergency department transfers of nursing home residents, to describe definitions of appropriateness and to identify factors associated with a reduction in inappropriate transfers.	Residential aged care	Emergency department transfers.	Across all studies, 4–55% of ED transfers were considered inappropriate. The most common reasons for transfer were trauma after falling, altered mental status and infection. Transfers were associated with a high risk of complications and mortality, especially during out-of-hours. Advance directives were usually not available, and relatives often urge nursing home staff to transfer patients to an ED. The lack of availability of GPs was a barrier to organise acute care in the NH in order to prevent admission to the hospital.	III	18

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Nishiguchi (2017) **Japan**	**End-of-life care bonus promoting end-of-life care in nursing homes: An 11-year retrospective longitudinal prefecture-wide study in Japan**	To identify whether the EoL care bonus promotes EoL care in nursing homes, by using retrospective longitudinal data	Residential aged care	The Japanese government's financial incentive for improving ACP and end-of-life care in nursing homes. This requires a facility to meet five criteria: (1) employing a full-time registered nurse onsite; (2) having a 24-hour call system for nurses; (3) having a basic policy for EoL care that needs to be explained to residents and/or their families on admission; (4) organising training courses on EoL for the staff; and (5) having an individual room for EoL care.	The availability of the EoL care bonus and years of usage of the EoL care bonus were significantly associated with increased numbers of residents dying in nursing homes. Our analysis revealed that the EoL care bonus has the potential to increase the number of residents receiving EoL care in nursing homes over several years. EoL care conferences, physician support for emergency care during off-time, and the presence of an adjacent affiliated hospital may also increase the number of residents receiving EoL care in nursing homes. These results suggest that a government financial incentive may contribute to effective EoL care among nursing home residents in other developed countries with rapidly aging populations.	III	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Oosterveld-Vlug (2019) **Belgium**	**Physician visits and recognition of residents' terminal phase in long-term care facilities: Findings from the PACE Cross-Sectional Study in 6 EU countries**	To describe the relationship between physician visits and physicians' recognition of a residents' terminal phase in long-term care facilities (LTCFs) in Belgium, England, Finland, Italy, the Netherlands, and Poland.	Residential aged care	Practitioner visits to RAC residents.	There were positive associations between the number of physician visits to the LTCF and the recognition of the residents' terminal phase and between the number of physician visits and the resident having palliation as main treatment goal in the last week of life. LTCFs should be encouraged to work collaboratively with physicians to involve them as much as possible in caring for their residents.	III	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Parker (2016) **Australia**	**Palliative care case conferences in long-term care: Views of family members**	To examine the use of structured Palliative Care Case Conferences in long-term care, the issues families bring to the conference, their prior level of distress, the extent to which issues are addressed by staff, and family satisfaction with this process.	Residential aged care	A structured palliative care case conference in long-term care.	A formalised Palliative Care Case Conference process ensured issues relating to end-of-life care planning, pastoral care, pain and comfort and physical and medical needs were well documented by staff. Issues relating to care processes and the family role in care were less well documented. All families, interviewed post intervention, recommended Palliative Care Case Conferences; and over 90% of families felt their issues were addressed to their satisfaction. Families also reported an increased understanding of the residents' current and future care.	III	17

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Rainsford (2021) **Australia**	**Strengthening advance care planning in rural residential aged care through multidisciplinary educational case conferences: A hybrid implementation-effectiveness study**	To implement and evaluate the effectiveness of multidisciplinary educational case conferences in end-of-life planning in two Australian rural residential aged care facilities.	Residential aged care	Multidisciplinary Educational Case Conferences (MuDECC) consisting of Medicare compliant one-hour meetings, attended by residents, family caregivers, and healthcare providers. The MuDECC was to coordinate current care and plan for end-of-life care. Key issues discussed in the case conferences included the resident's health issues (symptoms, social/psychological/ spiritual needs, and prognosis), medications and deprescribing, goals of care (including preferred place of care and death), and advance care planning (including anticipatory prescribing). The intervention also comprised of *a priori* Residential Medication Management Review (RMMR) and documented outcomes and action lists.	Multidisciplinary educational case conferences (MuDECC) were acceptable and effective in facilitating advance care planning and prescribing of anticipatory medications. However, MuDECCs were time-consuming to organise with disproportionate responsibilities or time commitments borne by several key individuals. The necessary personal and professional capital to implement MuDECCs may be limited or unavailable in some rural locations.	III	16

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Reinhardt (2015) **USA**	**The positive association of end-of-life treatment discussions and care satisfaction in the nursing home**	To examine the frequency of discussions family members reported with healthcare team members regarding specific life-sustaining treatments and pain and symptom management for their relatives with advanced dementia over a six-month period and explored the unique association of having these particular discussions with care satisfaction at the six-month time point.	Residential aged care	An in-depth conversation with a palliative care physician and social worker that covered multiple types of EOL treatments.	A greater frequency of discussion of EOL treatment wishes was positively associated with higher care satisfaction scores among family members of nursing home residents with dementia. When considered together, greater frequency of discussion of artificial hydration was uniquely associated with greater care satisfaction and increased care satisfaction over time.	III	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Saini (2016) **England**	**An ethnographic study of strategies to support discussions with family members on end-of-life care for people living with advanced dementia in nursing homes**	To examine practices relating to end-of-life discussions with family members of people living with advanced dementia residing in nursing homes and to explore strategies for improving practice.	Residential aged care	Interdisciplinary Care Leader (ICL) embedded in two NHs to implement the Compassion Intervention. This comprises: (i) facilitation of integrated care for people with advanced dementia and (ii) training and support for those working with and caring for people with advanced dementia. The ICL completed holistic assessments of residents which included discussions with family members and staff, review of the care plan, and discussions with or observations of residents. Staff training sessions covered behavioural symptoms, pain management, and EOL, and family sessions covered the trajectory of dementia, common EOL symptoms, and the personal experiences of care.	Despite the existence of barriers to discussions, families recognised the importance of having discussions to reassure, support, and educate them. This study suggests EOL discussions should be ongoing rather than a one-off task-driven conversation. Conversations cannot be rushed and require appropriate time and space to develop sensitively. Having a coordinator similar to the ICL role, who has the time, knowledge, and communication skills to have EOL discussions with family and train and support staff, offers a way forward to promoting these discussions in the NH setting.	III	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Spacey (2020) **England**	**Systematic critical realist review of interventions designed to improve end-of-life care in care homes**	To describe and explain the effectiveness of interventions designed to improve end-of-life care in care homes.	Residential aged care	All included interventions contained mechanisms related to education, including: • EoL discussions with residents and relatives and advance care planning • Leadership and communication with external services • Overarching principles, such as person-centred and dignified EoL care • Education on identifying the signs and symptoms of EoL • Dementia education • Symptom and pain management.	While most of the evidence identified in this review was not strong, there was evidence to suggest that education and inter-professional collaboration can be effective intervention mechanisms for improving end-of-life care in care homes. High staff turnover was a significant contextual mechanism impacting the sustainability of interventions.	III	21

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Stacpoole (2015) **England**	**The Namaste Care program can reduce behavioral symptoms in care home residents with advanced dementia**	To evaluate the effects of the Namaste Care program on the behavioural symptoms and pain management of residents with advanced dementia and the work life of care staff.	Residential aged care	Namaste Care is a multi-dimensional intervention seeking to engage people with advanced dementia and enrich their quality of life through sensory stimulation, shared activity, and increased social interaction. Comfort is a primary aim of the care program, which includes formal pain assessment, as well as increasing care staff awareness and responsiveness to distress. The program takes place seven days a week with two two-hour sessions, morning and afternoon.	Strong leadership and good nursing and medical care enabled the Namaste Care programme to significantly decrease behavioural symptoms of residents with advanced dementia. The focus on comfort in Namaste Care supported good pain management in four out of five care homes. However, Namaste Care cannot be a substitute for good clinical care. The Namaste Care program requires no extra resources and has the potential to transform care for residents with advanced dementia in care homes. There was a slight reduction in the effectiveness of the intervention towards the end of the research period.	III	17

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Stacpoole (2017) **England**	**Implementing the Namaste Care Program for residents with advanced dementia: Exploring the perceptions of families and staff in UK care homes**	To establish whether the Namaste Care program can be implemented in UK care homes; and what effect Namaste Care has on the quality of life of residents with advanced dementia, their families, and staff.	Residential aged care	Namaste was developed for care home residents with advanced dementia that combines compassionate care with meaningful activity in a dedicated, peaceful environment together with a 'loving touch'. Namaste is a seven-day/week program that runs for two hours in the morning and two hours in the afternoon. Residents are welcomed into a calm environment with gentle music and the space/room scented with lavender. Ideally, Namaste Care has a dedicated room/space, but may also take place in a screened-off area, or a dining room otherwise only used at mealtimes. Namaste residents are assessed for pain and discomfort and treated if necessary. The Namaste Care worker offers personal care as meaningful activity alongside individualised interventions. Fluids are offered frequently during Namaste along with high caloric food treats. A meeting with family/friends is a key element of the program and explores specific sources of comfort and pleasure for their relative, creating an individual sensory biography to guide the Namaste Care worker.	Namaste Care can enrich the quality of life of older people living with advanced dementia in care homes. The program was welcomed by care home staff and families and was achieved with only modest expenditure and no change in staffing levels. The positive impact on residents' quality of life influenced the well-being of family carers. Care staff found the changes in care enjoyable and rewarding. Namaste Care was valued for the benefits seen in residents; the improvement in relationships; and the shift towards a person-centred, relationship-based culture of care brought about by introducing the program.	III	19

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Sussman (2017) **Canada**	**'Now I don't have to guess': Using pamphlets to encourage residents and families/friends to engage in advance care planning in long-term care**	To explore whether access to illness trajectory pamphlets for five conditions with high prevalence in long-term care (LTC) can encourage residents and families/friends to openly engage in advance care planning (ACP) discussions with one another and with health providers.	Residential aged care	Access to illness trajectory pamphlets for five conditions.	Access to pamphlets with information about EOL care provides important and welcome opportunities for reflection for both residents in LTC and their families/ friends. Moving residents and families/friends from reflecting on issues to discussing them together could require staff support through planned care conferences or staff-initiated conversations at the bedside.	III	16

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Tasseron-Dries (2021) **Netherlands**	**Family involvement in the Namaste care family program for dementia: A qualitative study on experiences of family, nursing home staff, and volunteers**	To examine experiences of family caregivers, staff and volunteers with family caregiver participation in the Namaste Care Family program, a psychosocial intervention to increase the quality of life for people living with advanced dementia that may help family caregivers to connect with their relatives. Further, the study aimed to examine facilitators of and barriers to family participation.	Residential aged care	Namaste Care Family program: a program based on a palliative and person-centred care approach that aims to increase the quality of life of nursing home residents with advanced dementia at low costs. It involves two daily group sessions of two hours in which 8–10 residents per group participates. Sessions are held in a quiet and homely room with nice smells, soft music and no outside distractions. Namaste Care consists of psychological, social and spiritual components, including five important psychological needs of people living with dementia: comfort, attachment, identity, being involved in the process of life (occupation), and feeling part of a group (inclusion).	Family caregivers experienced their involvement as positive, particularly the meaningful connections with their relatives. To optimise family involvement, it is important to adopt a family-centred approach and provide training and guidance. Making a personal, comprehensive plan with family caregivers and offering them guidance can help them overcome their uncertainty and remove barriers to being more involved with a care program.	III	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Temkin-Greener (2016) **USA**	**End-of-life care in nursing homes: From care processes to quality**	To examine the association between communication – among nursing home providers and providers and residents/families – and in-hospital deaths and hospice use at the end of life.	Residential aged care	Quality of communication between nursing home staff and between staff and residents and their families.	Communication is a statistically significant factor in explaining variations in risk-adjusted measures of EOL transitions in NHs. Better communication with residents/family members (especially by a facility palliative care team) was significantly associated with fewer EoL hospital transfers and deaths. However, better communication among providers appears to reduce, rather than increase, referrals to hospice.	III	17
White (2018) **England**	**Exposure to nature gardens has time-dependent associations with mood improvements for people living with mid- and late-stage dementia: Innovative practice**	To investigate specifically the associations between duration of exposure to nature and changes in mood for people at any stage of dementia.	Residential aged care	Carer-mediated exposure to a nature-rich garden.	Increasing duration of time spent outside was associated with increasing positive change in mood score but in a non-linear fashion. Marked improvements in mood were associated with outdoor time of only 20 minutes' duration and the greatest benefits were associated with an outdoor time of 80 minutes' duration. After this point, the extent of positive change in mood score declined with greater time spent outside.	III	13

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Ernecoff (2019) **USA**	**Quality of life with late-stage dementia: Exploring opportunities to intervene**	(1) To describe temporal trends in quality of life in late-stage dementia; and (2) To explore associations between patient characteristics, care interventions, and quality of life.	Residential aged care	Hospital transfers, treatment plans, and hospice enrolment.	ADRQL at nine months was associated with later dementia stage and referral to hospice. Subscales Enjoyment of Activities and Awareness of Self were rated lower than the other subscales and scores decreased significantly over nine months. Lower nine-month ADRQL was also independently associated with a higher likelihood of being referred to hospice. A primary goal of comfort, enhanced activities and social engagement was associated with a larger increase in ADRQL.	III	17

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Bunn (2018) **England**	**Improving living and dying for people with advanced dementia living in care homes: A realist review of Namaste Care and other multisensory interventions**	To understand how the Namaste Care intervention might achieve particular outcomes, and in what circumstances. The focus was on the contextual conditions and mechanisms that influence how end-of-life care for people living with advanced dementia is effectively managed in care homes.	Residential aged care	Interventions drawing on similar principles to Namaste Care or including components of Namaste Care such as music therapy, massage, or aromatherapy.	The key mechanisms that Namaste Care triggers for residents are feelings of familiarity, reassurance, engagement and connection, which in turn lead to a reduction in agitation and behavioural symptoms. For staff, it gives permission and awareness to engage with residents in a more person-centred way by focusing attention on residents' biography and preferences. The creators of Namaste Care proposed that it is delivered regularly and intensively, ideally twice a day, seven days a week. However, the evidence to support this is limited.	V	18
Hockley (2016) **Scotland**	**A practice development initiative supporting care home staff deliver high quality end-of-life care**	To implement the Gold Standards Framework in Care Homes Programme and audit outcomes within nursing care homes across five Clinical Commissioning Groups over a seven-year period using a research-based model of facilitation.	Residential aged care	Gold Standards Framework in Care Homes Programme.	Nursing Care Homes that participated in the GSFCH programme improved their end-of-life care practice and documentation over time. This is evidenced by increased number of residents dying in the home rather than hospital, an increase in advance care planning, as well as last days of life and CPR decision documentation.	V	12

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Kinley (2017) **England**	**Developing, implementing and sustaining an end-of-life care programme in residential care homes**	To implement an end-of-life care programme, namely the 'Steps to Success' programme, in residential care homes, and collect measurable outcomes through audit.	Residential aged care	The 'Steps to Success' programme involving (amongst other elements): monthly review meetings and debriefing meetings after a resident's death, training in use of a prognostication tool and tools for pain and depression, a framework for coordinating care with district nurses and general practitioners, familiarisation with ACP discussions.	The programme was associated with an increase in care home deaths, ACP plans, and 'Do not attempt CPR' forms.	V	8
Molist-Brunet (2021) **Spain**	**Therapeutic optimization through goal-oriented prescription in nursing homes**	To (i) study the baseline situation and calculate the frailty index (FI) of the residents; (ii) assess the results of routine clinical practice to do a pharmacotherapy review (patient-centred prescription (PCP) model); and (iii) study the relationship between inappropriate polypharmacy and frailty, functional dependence, advanced dementia and end-of-life situation.	Residential aged care	Assessment of each patient's medications using the PCP model which centres therapeutic decisions on the patient's global assessment and personal therapeutic goals.	At least one inappropriate prescription was identified in 92.2% of home residents. As a final result, the number of chronic medications proposed decreased by 25.15%. Polypharmacy decreased from 72.55% to 52.94% and excessive polypharmacy from 18.62% to 5.88%. The application of the PCP model in clinical practice therefore considerably optimises pharmacological prescription in frail nursing home patients.	V	19

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Wichmann (2020) **Netherlands**	**Decreased costs and retained QoL due to the ‘PACE Steps to Success’ intervention in LTCFs: Cost-effectiveness analysis of a randomized controlled trial**	To assess the cost-effectiveness of the ‘PACE Steps to Success’ intervention.	Residential aged care	PACE (Palliative Care for Older People) Steps to Success: a one-year palliative care programme aiming at integrating general palliative care into day-to-day routines in LTCFs via a train-the-trainer approach, throughout seven EU countries.	Costs decreased and QoL was retained due to the PACE Steps to Success intervention. The programme realised significant cost savings and improved quality of end of life (care) in the last month of life (QOD-LTC), meaning it strengthened sense of personhood, closure and preparatory tasks. Outcomes on the EQ-5D-5L were unchanged. Cost savings mainly resulted from decreased hospitalisation-related costs	V	20

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Boerner (2017) **USA**	**Burnout after patient death: Challenges for direct care workers**	(1) To investigate staff, institutional, patient, and grief factors as predictors of burnout dimensions among direct care workers who had experienced recent patient death; (2) to determine which specific aspects of these factors are of particular importance and establish grief as an independent predictor of burnout dimensions.	Residential aged care, home-based care	Support from supervisors and care workers, and training regarding a patient death.	Findings suggest that grief over patient death plays an overlooked role in direct care worker burnout. Supervisory support and caregiving benefits were consistently associated with lower levels of burnout dimensions. In contrast, co-worker support was associated with a higher likelihood of depersonalisation and emotional exhaustion.	III	19

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Gomes (2015) **England**	**Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study**	To determine the association between place of death, health services used, and pain, feeling at peace, and grief intensity.	Home-based care, hospital-based care	Death in the home and health services used at the end of life.	Likelihood of death at home increased when the relative was aware of incurability and the patient discussed his/her preferences with family. Dying in hospital was associated with more hospital days, fewer general practitioner (GP) home visits, and fewer days taken off work by relatives. Adjusting for confounders, patients who died at home experienced similar pain levels but more peace in their last week of life. Grief was less intense for their relatives than for those of patients who died in hospital.	III	19
Paque (2019) **Belgium**	**Barriers and enablers to deprescribing in people with a life-limiting disease: A systematic review**	To identify the barriers/enablers to deprescribing of medications in people with a life-limiting diseases.	General practice, hospice, RAC, academic medical centres, specialist palliative care units.	N/A	The most prominent barriers/facilitators to deprescribing in the specific context of a life-limiting disease were: organisational support; Interdisciplinary communication and collaboration; communication with the patient and family.	III	19

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Raijmakers (2018) **Netherlands**	**Which patients die in their preferred place? A secondary analysis of questionnaire data from bereaved relatives**	To provide insight into the extent to which patients with various diseases die in their preferred place and into factors associated with dying in the preferred place.	Various	Factors associated with people dying in their preferred place.	Preference for home death is negatively associated with the likelihood of dying in the preferred place, even more for people with dementia. Continuity of care by different professionals and general practitioner contact in the last week before death are positively associated with dying in the preferred place. The involvement of GPs in the last stage of life is crucial in helping people die in their preferred place, especially if at home.	III	21
Simmons (2017) **Norway**	**Prognostic tools in patients with advanced cancer: A systematic review**	To examine and compare prognostic tools in patients with advanced cancer and make recommendations for their use.	Various (unspecified)	Prognostic tools that have been validated in two or more independent data sets.	Seven tools were identified varying in the complexity, subjectivity, and clinical utility. These are: Palliative Prognostic Score, Delirium-PaP, B12/C-Reactive Protein Index, Prognosis in Palliative Care Study, Palliative Prognostic Index, Palliative Performance Scale, and the Glasgow Prognostic Score. The Glasgow Prognostic Score would seem the most favourable as it uses only two parameters (both objective) and has prognostic value complementary to the gold standard measure, which is performance status.	III	19

Author (year) Country	Article title	Study aim/ purpose	Setting	Intervention, exposure, risk factor	Key findings	Evidence ranking	Quality appraisal
Laver (2016) **Australia**	**Clinical practice guidelines for dementia in Australia**	The purpose of the guidelines is to provide recommendations for an agreed standard of practice for the diagnosis and management of people living with dementia in Australia.	Community-based, residential aged care, hospital		Care for people living with advanced dementia should be based on a palliative approach and involve a palliative care service if indicated. Treatment and care should be provided as per the persons' advance care plan.	IV	20

Table A9: Document characteristics: Grey literature review

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
1	**Comprehensive Palliative Care in Aged Care Measure** Prepared for the Australian Department of Health by the Nous Group	Australian Government Department of Health 2021 Australia	Literature review summary report. The Comprehensive Palliative Care in Aged Care Measure (the Measure) aims to help older Australians living in residential aged care, nearing the end of their life. The evaluation of the comprehensive palliative care measure will determine in what extent the aims of the measure have been achieved. Whereas the literature review report summarises the outcomes of a review of peer-reviewed and grey literature on international and domestic approaches to palliative care in residential aged care facilities.	Four key questions guided the literature review: 1. What are the palliative care needs of residents, families/carers, staff and the system in RAC facilities? 2. What models of care exist that have proven successful? 3. What evidence exists on best practice approaches to funding and delivery arrangements? 4. How have palliative care initiatives in RAC facilities sought to address health interface issues?	Findings from the literature review provide a basis for understanding the context in which RAC facilities participating in the measure operate and have implications for the evaluation.	www.health.gov.au/initiatives-and-programs/comprehensive-palliative-care-in-aged-care-measure

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
2	**Research into awareness, attitudes and provision of best practice advance care planning, palliative care and end-of-life care within general practice** GP best practice research project, 2016 for the Australian Department of Health	Colton C, and Boekel C 2017 Australia	The study reported in this document was undertaken with general practitioners, allied health professionals and medical specialists in August and September 2016, informed by a literature review and stakeholder interviews.	The primary objectives of this study were to understand: 1. The awareness, knowledge, and attitudes about ACP, palliative and end-of-life care within general practice 2. How health professionals in general practice describe their role and scope of practice in relation to ACP, palliative and end-of-life care, and which aspects of best practice palliative care they are currently providing 3. The perceived enablers and barriers in the provision of ACP and best practice palliative and end-of-life care within general practice and report on the system changes that are needed to support best practice 4. The awareness and utilisation of currently available palliative care and ACP tools and training by health professional working in general practice, and perceived barriers to accessing these tools and educational resources.	The study findings report that, GPs are doing more palliative care than previously thought. The findings also suggest that GPs are ready to engage with SPC nurses, and that only a small proportion of GPs are outright rejectors of palliative care. Further, the study identified that GPs require more resources in relation to educational and practical supports. The findings also highlight the importance of tailored interventions that consider different attitudes towards palliative care as well as preferences for doing medicine by the GPs.	www.health.gov.au/sites/default/files/gp-best-practice-research-project_0.pdf

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
3	**Aged care, end-of-life and palliative care. Report no. 33, 56th Parliament** Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee	Parliamentary Committees, Queensland Parliament, Queensland Government 2020 Australia	In November 2018, the Legislative Assembly ordered the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee to undertake a major inquiry into the delivery of aged care, end-of-life care and palliative care, and community and health practitioners' views on voluntary assisted dying.	This report presents the committee's findings and recommendations covering aged care, end-of-life care and palliative care. The committee has resolved to report findings on voluntary assisted dying separately.	The Committee provides a comprehensive review of the Australian aged care, palliative care and end-of-life care sector as well as 89 recommendations in regard to the system, workforce, programs and funding.	documents.parliament.qld.gov.au/tableOffice/TabledPapers/2020/5620T466.pdf
4	**Issues overview: Palliative care within aged care** Prepared for the Royal Commission into Aged Care Safety and Quality	Palliative Care Australia 2019 Australia	This issues overview highlights five key structural and policy-based issues that must be addressed if the needs of older Australians living with a life-limiting illness are to be adequately met by the aged care sector.	The report outlines the following five structural and policy issues that needs attention: 1. 'Palliative care' should inform structures and policy not just 'end-of-life care' 2. The Aged Care Quality Standards do not include the provision of palliative care as an outcome for consumers regarding requirement for providers 3. Commonwealth Home Support Program (CHSP) and Home Care Package (HCP) 'versus' palliative care – impact on the choice to stay at home 4. Palliative care is not appropriately recognised for funding in residential care 5. The aged care workforce needs support to make palliative care core business.	There are a number of structural and policy-based issues that contribute to the lack of understanding and attention paid to palliative care in aged care. Palliative care should be recognised as an essential component of quality aged care provision, where there are examples of innovative programs around the country that could guide reform in this area.	palliativecare.org.au/wp-content/uploads/dlm_uploads/2019/07/Palliative-care-in-aged-care_Royal-Commission-Issues-Overview_May-2019.pdf

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
5	**GP-led palliative care in rural Australia**	The Royal Australian College of General Practitioners (RACGP) 2016 Australia	Strategic objective: Important insights from the general practitioner membership were analysed to inform this paper with a number of key principles developed	This RACGP Position Statement recommends policy shifts that are vital for rural-based general practitioners in addressing current need and future demand in palliative care including strengthening access for rural patients. RACGP Rural recommends: 1. Increased investment for GP-led palliative care in rural communities and calls for targeted action in the areas of national planning measures, coordination of care, and access measure 2. More supportive policies which enable increased participation of rural GPs across all services settings 3. Stronger investment in palliative care skills through accessible and flexible training options for rural GPs and across the full multidisciplinary teams.	Provides useful detail for policy makers and health service planners around the particular requirements to enable optimal care and well-integrated rural palliative care services.	www.racgp.org.au/FSDEDEV/media/documents/RACGP/Position%20statements/GP-led-Palliative-Care-in-Rural-Australia.pdf
6	**GP Palliative Shared Care Program Framework**	SA Health, Government of South Australia 2017 Australia	The GP Palliative Shared Care Program Framework outlines the requirements for general practitioners providing GP Palliative Shared Care in metropolitan Adelaide.	The Framework provides a comprehensive guideline for GPs who are involved in shared care arrangement. This includes a description of: 1. GP palliative care shared care program 2. GP participation – orientation and education 3. Specific details of shared care arrangements, e.g. communication, home visits, carer support 4. Patient access to GP palliative shared care 5. GP care planning 6. End-of-life care, including bereavement. Several appendices are also provided to support GPs with tools, forms, and checklists.	GPs who are involved in palliative care shared care arrangements can benefit from the Framework to provide quality palliative and end-of-life care in all care settings.	www.gpaustralia.org.au/wp-content/uploads/2018/04/161201-UPDATE-GP-PALLIATIVE-SHARED-CARE-PROGRAM-FRAMEWORK-2017-accepted-1.pdf

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
7	**Dying at home is a choice: hospice@HOME (h@H)**	Onslow F, for the District Nurses, a Division of Hobart District Nursing Service Inc, Tasmania 2015 Australia	A project entitled hospice@HOME (h@H) commenced through Commonwealth funding to deliver 'Better Access to Palliative Care'. The project is a first in Australia and aims to ensure all Tasmanians who wish to die in their own home are supported and resourced to do so.	The hospice@HOME (h@H) project aimed to shift the delivery of care from a 'clinical approach' to 'individual client driven care' providing a unique wraparound model of care with a focus on meeting the gaps in care and provisions required for in home palliation at end of life. The project team worked with 25 organisations across Tasmania to deliver the in-home care linking to the delivery of consistent practices across the State.	h@H implemented system and partnership approach which required collaboration across varying health and care providers maintaining the focus on the individual who inevitably has complicated issues and challenges.	www.ruralhealth.org.au/13nrhc/images/paper_Onslow%2C%20Fiona.pdf
8	**Principles for palliative and end-of-life care in residential aged care**	Palliative Care Australia, Alzheimer's Australia, COTA Australia, Aged & Community Services Australia, Leading Age Services Australia, Catholic Health Australia and the Aged Care Guild (no date) Australia	Consensus Statement. These principles have been developed collaboratively to present a united commitment in recognising the diverse needs of residential aged care consumers, families, carers, aged care staff and service providers in providing palliative and end-of-life care	The consensus statements include the following eight principles: 1. Consumers physical and mental needs at end-of-life are assessed and recognised 2. Consumers, families and carers are involved in end-of-life planning and decision making 3. Consumers receive equitable and timely access to appropriate end-of-life care within aged care facilities 4. End-of-life care is holistic, integrated and delivered by appropriately trained and skilled staff 5. The end-of-life care needs of consumers with dementia or cognitive impairment are understood and met within residential aged care 6. Consumers, families and carers are treated with dignity and respect 7. Consumers have their spiritual, cultural and psychosocial needs respected and fulfilled 8. Families, carers, staff and residents are supported in bereavement.	The principles reflect the views of Palliative Care Australia, Alzheimer's Australia, COTA Australia, Aged & Community Services Australia, Leading Age Services Australia, and Catholic Health Australia and the Aged Care Guild guiding their work in the areas of aged, palliative cand end-of life care for older Australians.	palliativecare.org.au/consensus-principles-palliative-end-life-care-residential-aged-care/

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
9	**The experience of Punjabi Indians with palliative care at residential aged care facilities: A regional perspective**	Charles Sturt University 2015 Australia	The qualitative study sought to identify barriers to appropriate and equitable palliative care and services for regionally based Punjabi Indians, with important implications for the wider culturally and linguistically diverse (CALD) population.	The findings report that the dominant medical knowledge base does not adequately account for experiences of CALD population groups in the context to palliative care services. There is also lack of adequate account for interrelationships and collective concerns of the CALD population.	The study recommends a human rights framework where stronger ethics of care is conceptualised in terms of proficiency as well as care in terms of cultural respect demonstrated through the palliative care service delivery model.	www.caresearch.com.au/tabid/6241/Default.aspx

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
10	**Aged care staff training needs analysis report. Greater Townsville Region** Connecting End-of-life care in Townsville (CELC-T) Project	Palliative Care Queensland 2018 Australia	Needs analysis (surveys /interviews). To determine needs for training of aged care staff; to overcome the knowledge/skills gaps; and reduce the barriers to provide good palliative care in the aged care facilities in Greater Townsville.	The analysis report identified the top six challenges to providing palliative care in RAC facilities in Townsville as lack of: 1. Communication skills 2. Knowledge 3. Skilled staff 4. Resources 5. Cultural understanding 6. Funding. The analysis report also identified five key reasons for hospital transfer from RAC facilities for residents with palliative care needs: 1. To control pain 2. Perception that hospital has more available responses 3. Family requesting transfer 4. Skill deficit of RAC facility staff 5. Lack of resources to manage complex care needs. Most importantly, self-identified palliative care training needs for residential aged care staff were: 1. Communication skills 2. General training on palliative care 3. Pain management 4. Compassion.	The purpose of this training needs analysis was to understand the training needs of RAC facility staff in the Greater Townsville Region to assist with designing a six-month Practice Development Program for the CELC-T project, which may be generalisable in the wider RAC facility settings in Australia.	palliativecareqld.org.au/wp-content/uploads/2019/05/CELC-T-RACF-TNA-2018-report.pdf

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
11	**Palliative Care Conversations: Project evaluation**	Southern Metropolitan Region Palliative Care Consortium 2017 Victoria, Australia	Project Evaluation. 'Palliative Care Conversation' training across the southern metropolitan region to assist non-palliative care health professionals in the region to gain an improved understanding and skills in referring to palliative care.	The 'Palliative Care Conversation' training resulted into a number of improvements: 1. Significant improvements in each of the training learning objectives and 100% of participants found the session either fully or partially met their training needs and was fully or partially relevant to their work 2. Follow up interviews (four to six weeks post training) were conducted with 29% of participants and of those interviewed, 85% identified a take home message, 73% had integrated the take home message into their practice and 77% identified that they had changed their practice as a result of the training 3. The initiative was delivered beyond scope, under budget and within the timeline. Outcomes exceeded expectations.	The Palliative Care Conversations resource has proven to support Victoria's End of Life and Palliative Care Framework, Priority 4. Implementing the resource enables healthcare professionals improve their confidence and skills in discussing death and dying with clients and their families.	smrpcc.org.au/wp-content/uploads/2020/06/PCC-Evaluation-Report_c.pdf

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
12	**Evaluation of the End-of-Life Directions for Aged Care (ELDAC) Program Final Evaluation Report: Summary** For the Australian Government Department of Health	Health Consult Pty Ltd 2020 Australia	Evaluation report. ELDAC Project aim: to build the capacity of aged and primary care providers to deliver quality palliative care and enhance awareness of the importance of timely and appropriate access to palliative care services.	ELDAC project consisted of four workstreams: • Stream 1: Capacity building resources and advisory services, providing a Helpline, website and series of toolkits to assist with building capacity and capability in advance care planning and palliative care • Stream 2: Technology solutions: developing a Digital Dashboard to standardise basic data collection relevant to end-of-life care into aged care providers' Clinical Care Systems (CCSs) • Stream 3: Policy enablers: a series of six Roundtables to provide policy briefs to inform decision makers about key issues in palliative care and advance care planning policy and planning in aged care • Stream 4: Service and sector development and advisory services: implementing the Working Together Program to facilitate linkages between aged care providers and specialist palliative care services.	Overall, ELDAC was found to contribute to the capacity-building of aged care providers to deliver quality palliative care and enhance community and professional awareness of the importance of timely and appropriate access to palliative care services. This was supported by the governance model, which provided an effective framework to achieve the aims and objectives of ELDAC.	www.health.gov.au/sites/default/files/documents/2020/12/final-evaluation-report-of-the-end-of-life-directions-for-aged-care-program-final-evaluation-report-of-the-end-of-life-directions-for-aged-care-program.pdf

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
13	**End of life at home: Co-creating an ecology of care. Research report** Funded through an ARC Linkage Grant with Western Sydney University, Cancer Council of NSW, CSIRO, QUT, ACU and Calvary Centre for Palliative Care	Horsfall D, Yardley A, Leonard RJ, Noonan K, Rosenberg JP, and Western Sydney University 2015 Australia	Study report. This report documents Stages 2–4 of the Caring at End-of-Life Study, which identified the end-of-life care arrangements that allowed 20% of terminally ill people to be cared for at home.	The study explored: 1. How ordinary people supported each other to care for someone dying at home 2. How their wider community supported the carer 3. Formal support available to carers 4. How those formal and informal networks interacted with each other.	The ecological perspective that 'all living things have a relationship to each other and to what's around them, and those human beings (and human systems) have the capacity to act selectively with the environment to achieve a harmonious relationship' has practical implications in the design of programs and services in the context of an end-of-life care environment.	www.westernsydney.edu.au/__data/assets/pdf_file/0007/966301/EndofLife_Report_Final_14Sept.pdf
14	**Building 'end-of-life care' capacity in community pharmacy: Supporting community pharmacists to enhance patient care** Report of pilot project funded by COORDINARE	PHN South-Eastern NSW 2020 Australia	Pilot project report. By building the capacity of community pharmacists to support patients requiring end-of-life care services, COORDINARE has been able to strengthen the palliative care multidisciplinary team and enhance care coordination.	The Pharmaceutical Society of Australia (PSA) provided targeted training to community pharmacists in three key regional areas within South-eastern NSW. Several resources were developed to highlight how community pharmacists can support people living with a life-limiting illness and their carers	With targeted training and resources, community pharmacists can significantly increase their ability to assist palliative patients and to support GPs and nurse practitioners in providing end-of-life care.	www.coordinare.org.au/assets/End-of-life-care-in-pharmacy-case-study.pdf

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
15	**The role of paramedics in palliative and end-of-life care: Scoping report**	Safer Care Victoria 2021 Australia	Scoping reports on various projects. This scoping report focuses on the increasing role that paramedic staff and their services can play in the provision of palliative and end-of-life care for the Victorian community.	A number of development and changes was reported in the context of palliative and end-of-life care in Victoria, Australia, there are: 1. Legislated recognition for all health practitioners, including paramedics, caring for people who no longer have decision making capacity but have nominated a substitute decision maker or have an advance care directive 2. The Victorian end of life and palliative care framework 3. The Palliative Care Clinical Network 4. The Ambulance Victoria Palliative Care Clinical Practice Guideline 5. The Ambulance Victoria Regional/Rural Local Government Area (LGA) Paramedic Community Support Coordinators (PCSC) 6. The WAVE Project (We are Ambulance Victoria Engaged).	This scoping report supports the opportunity for improvement work commencing with Safer Care Victoria's Centres of Clinical Excellence to explore more deeply and apply their continuous improvement methodology to work towards system change for palliative care and paramedics to collaborate to improve peoples' end-of-life care outcomes.	www.bettersafercare.vic.gov.au/sites/default/files/2021-09/WAVE%20Scoping%20Report.pdf

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
16	**Achieving Victoria's best end of life experience for people in Latrobe. Progress report September 2021**	LaTrobe Health Advocate 2021 Australia	Reports on various projects and initiatives for primary care. For example, the new Progress report on Palliative Care Advanced Skills Post for Gippsland GP registrars	This is the second progress update provided by the Advocate, including recommendations and the following reform priorities: 1. Empowering people in Latrobe to die in their place of choice and offering places to choose from 2. Latrobe communities experiencing a system that works in harmony with their needs 3. Latrobe as the epicentre for those who have the heart for palliative care 4. Latrobe communities benefiting from a public health approach that brings death and dying out from the shadows 5. Contemporary governance brings health services and communities together to share their collective expertise.	The programs undertaken and reported in the progress reports, including commentary about how the recommendations might be implemented and offers suggestions for areas consideration could provide useful insights on developing integrated community-level palliative and end-of-life care facilitating people in Latrobe to die in their place of choice and offering places to choose from.	www.lhadvocate.vic.gov.au/wp-content/uploads/2021/09/J716107-edited.pdf
17	**End-of-life care and advance care planning for rural and remote communities**	Australian College of Rural and Remote Medicine 2015 Australia	Position statement. Sets out the principles for rural doctors to provide the best possible end-of-life experience as defined by the wishes of the patient themselves.	The position statement relates to: 1. Principles of end-of-life care 2. The value of advance care planning 3. Promoting patient awareness of advance care planning options 4. Care for Aboriginal and Torres Strait Islander peoples 5. Discussing end-of-life care and advance care planning with patients 6. Coordinating end-of-life care 7. Establishment of My Health Record.	The principles outlined in the position statements can guide medical practitioners to provide best possible end-of-life care recognising patients' wishes in rural and remote communities in Australia.	www.acrrm.org.au/docs/default-source/all-files/end-of-life-care---nov-2015.pdf?sfvrsn=93419eeb_6

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
18	**The District Nurses 2017–18 pre-budget submission to the Australian Government**	The District Nurses and hospice@HOME 2017 Australia	Snapshot of the hospice@HOME program in Tasmania. Includes survey results from carers and clients.	hospice@HOME includes effective care packages that coordinate and complement other services available in the community, providing clients with the service mix and level they need to enable 'a good death' at home if they so choose.	It is perceived that the Tasmanian hospice@HOME model of care would cut across the aged care, tertiary care, primary health care, and community care systems, complementing other care support streams such as the Commonwealth Home Support Programme (CHSP) and Home Care Packages in providing cost effective and sustainable end-of-life care.	cdn.treasury.gov.au/uploads/sites/1/2017/06/C2016-052_District-Nurses.pdf
19	**Exploratory analysis of barriers to palliative care: Literature review** Prepared for the Australian Government Department of Health	Australian Healthcare Associates (AHA) 2019 Australia	This review is part of a project that analysed barriers to palliative care facing nine population groups in Australia.	The literature reviews were undertaken focusing on the following nine specified under-served populations: 1. Aboriginal and Torres Strait Islander peoples 2. Care leavers and people affected by forced adoption 3. People from culturally and linguistically diverse (CALD) backgrounds 4. People with disabilities 5. People experiencing homelessness 6. People who are incarcerated 7. People who identify as lesbian, gay, bisexual, transgender or intersex (LGBTI) 8. Refugees 9. Veterans.	The report presenting the findings from the literature reviews provides a better understanding of the barriers to and enablers of access to palliative care for nine underserved populations.	www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-literature-review

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
20	**Exploratory analysis of barriers to palliative care: Issues report on Aboriginal and Torres Strait Islander Peoples** Prepared for the Australian Government Department of Health	Australian Healthcare Associates (AHA) 2019 Australia	This report describes key barriers and promising approaches for improving Aboriginal and Torres Strait Islander peoples' experience of palliative care in Australia.	Some of the most common barriers for this population group include: Lack of awareness/understanding of palliative care; language and communication issues; mismatching in beliefs and preferences between individuals and service providers; fear or mistrust of 'Western' medicine and/or healthcare providers and services; preference for family-kinship determined decision making; issues with cultural practices in palliative care settings; lack of/late referral to, or initiation of, palliative care; racism, discrimination and cultural stereotyping; and financial disadvantage. Some of the most promising practices include: community awareness-raising and engagement; Aboriginal and Torres Strait Islander workforce; appropriate resources and professional interpreting services; community capacity-building for palliative care; cultural competence within services; trauma-informed approaches to care; and patient navigator initiatives.	This report describes key barriers and promising approaches for improving Aboriginal and Torres Strait Islander peoples' access to and experience of palliative care in Australia. It also discusses the potential role of advance care planning and provides recommendations for the palliative care and other sectors to improve access and quality of care for Aboriginal and Torres Strait Islander peoples.	www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-aboriginal-and-torres-strait-islander-peoples

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
21	**Exploratory qnalysis of barriers to palliative care: Issues report on care leavers and people affected by forced adoption** Prepared for the Australian Government Department of Health	Australian Healthcare Associates (AHA) 2019 Australia	This report describes key barriers and promising approaches for improving the experience of palliative care for care leavers and people affected by forced adoption in Australia.	Some of the most common barriers for this population group include: lack of awareness/understanding of palliative care; distrust of the health system and government; lack of health providers' understanding of impact of past experiences; impact of past trauma; challenging/dysfunctional family dynamics; and lack of flexibility in institutional settings. Some of the most promising practices include: awareness-raising activities; education and training for health and social care providers; peer and advocacy support; trauma-informed approaches to care; and flexible care options that centre on provision of care at home.	This report describes key barriers and promising approaches to guide programs and services for improving access to and experience of palliative care for people who are care leavers or affected by forced adoption. It also discusses the potential role of advance care planning and provides recommendations for the palliative care and other sectors to improve access and quality of care for this group.	www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-care-leavers-and-people-affected-by-forced-adoption

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
22	**Exploratory analysis of barriers to palliative care: Issues report on people with disabilities** Prepared for the Australian Government Department of Health	Australian Healthcare Associates (AHA) 2019 Australia	This report describes key barriers and promising approaches for improving the experience of palliative care for people with disabilities in Australia.	Some of the most common barriers for this population group include: lack of awareness/understanding of palliative care; communication issues; assumptions about competence of people with disabilities; diagnostic 'overshadowing'; physical barriers (access, mobility, transport); distrust of health services; inadequate support for carers and families; lack of services integration; community living settings and lack of organisational support for dying in place of choice. Some of the most promising practices include: community awareness-raising; education and training for palliative care, disability service staff and people with disability; support for carers and families; advocacy support; collaboration and inter-agency communication; and supportive organisational policies and processes.	This report describes key barriers and promising approaches to guide programs and services for improving access to and experience of palliative care for people with disabilities. It also discusses the potential role of advance care planning and provides recommendations for the palliative care and other sectors to improve access and quality of care for this group.	www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-people-with-disabilities

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
23	**Exploratory analysis of barriers to palliative care: Issues report on people experiencing homelessness** Prepared for the Australian Government Department of Health	Australian Healthcare Associates (AHA) 2019 Australia	This report describes key barriers and promising approaches for improving the experience of palliative care for people experiencing homelessness in Australia.	Some of the most common barriers for this population group include: lack of awareness/understanding of palliative care; prioritising basic day-to-day needs; unstable or unsafe living environments; fear of being displaced from living environment; incompatibility between healthcare services and realities of homelessness; mental health and substance use issues; social and/or family isolation; stigma and judgement; distrust of institutions and authority; lack of access to/use of primary care services; lack of knowledge, training and experience of service providers in homelessness; issues with accurate diagnoses and prognoses. Some of the most promising practices include: education and training in culturally appropriate approaches to care; understanding complex needs of the homeless population; collaboration between services; specialist homeless healthcare organisations; timely engagement; flexible services and care environments; integration and coordination across health and other services; adopting a harm reduction approach; and appropriate funding.	This report describes key barriers and promising approaches to guide programs and services for improving access to and experience of palliative care for people experiencing homelessness. It also discusses the potential role of advance care planning and provides recommendations for the palliative care and other sectors to improve access and quality of care for this group.	www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-people-experiencing-homelessness

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
24	**Exploratory analysis of barriers to palliative care: Issues report on people who identify as lesbian, gay, bisexual, transgender or intersex** Prepared for the Australian Government Department of Health	Australian Healthcare Associates (AHA) 2019 Australia	This report describes key barriers and promising approaches for improving the experience of palliative care for LGBTI people in Australia.	Some of the most common barriers for this population group include: lack of awareness/understanding of palliative care; fear and experience of discrimination and bias; heteronormative assumptions; lack of recognition of LGBTI relationships and family of choice, including legal; service providers' lack of knowledge; issues related to HIV/AIDS. Some of the most promising practices include: awareness-raising, especially around community-based palliative care; strategies to identify inclusive services (e.g. Rainbow Tick certification); visible signifiers of inclusion; language that avoids heteronormative assumptions; recognition and inclusion of partners and chosen family, including legal recognition; access to advocacy services; and LGBTI-specific education and training for care providers.	This report describes key barriers and promising approaches to guide programs and services for improving access to and experience of palliative care for people who Identify as Lesbian, Gay, Bisexual, Transgender or Intersex. It also discusses the potential role of advance care planning and provides recommendations for the palliative care and other sectors to improve access and quality of care for this group.	www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-people-who-identify-as-lesbian-gay-bisexual-transgender-or-intersex

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
25	**Exploratory analysis of barriers to palliative care: Issues report on people who are incarcerated** Prepared for the Australian Government Department of Health	Australian Healthcare Associates (AHA) 2019 Australia	This report describes key barriers and promising approaches for improving the experience of palliative care for people who are incarcerated in Australia.	Some of the most common barriers for this population group include: lack of awareness and understanding of palliative care; attitudes of prison staff and tension between priorities of security and prisoner wellbeing; distrust of health services; lack of access to health services; challenging family relationships; physical and cultural environments of prisons are not conducive to provision of quality palliative care; and lack of effective policies and processes for palliative care. Some of the most promising practices include: education and training for palliative care staff; development of palliative care-specific guidelines and pathways; collaboration and relationship-building between prisons and inpatient/community palliative care services; provision of alternative accommodation options for delivery of care; and prison health literacy programs.	This report describes key barriers and promising approaches to guide programs and services for improving access to and experience of palliative care for people who are Incarcerated. It also discusses the potential role of advance care planning and provides recommendations for the palliative care and other sectors to improve access and quality of care for this group.	www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-people-who-are-incarcerated

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
26	**Exploratory analysis of barriers to palliative care: Issues report on refugees** Prepared for the Australian Government Department of Health	Australian Healthcare Associates (AHA) 2019 Australia	This report describes key barriers and promising approaches for improving the experience of palliative care for refugees in Australia.	Some of the most common barriers for this population group include: lack of awareness/understanding of palliative care; language and communication issues; mismatching cultural, religious and/or health beliefs and preferences; difficulty accommodating cultural practices in palliative care settings; effects of trauma; lack of/late referral; fear or distrust of services; social isolation and family separation; socioeconomic factors; eligibility issues (for publicly-funded care). Some of the most promising practices include: community education and awareness raising; cultural champions; culturally-appropriate and translated resources; access to appropriate professional interpreting services; training for professional interpreters; improved cultural competence within services; taking time to build rapport with individuals, families and communities; access to telehealth; trauma-informed approaches to care; and policy reform and development to support access to health care.	This report describes key barriers and promising approaches to guide programs and services for improving access to and experience of palliative care for Refugees. It also discusses the potential role of advance care planning and provides recommendations for the palliative care and other sectors to improve access and quality of care for this group.	www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-refugees

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
27	**Residential Aged Care End-of-Life Care Pathway (RAC EoLCP)**	Queensland Government 2013 Australia	The End-of-Life Care Pathway (EoLCP) is a consensus based best practice guide to providing care for residents in RACFs during the last days of their lives.	The tool comprises the following five sections with instructions for clinicians for completing the Pathway: • Section 1: Commencing a Resident on the Pathway. Medical Officer to be consulted and documentation can be completed by any of the following: GP, PCMO, PCNS, RN • Section 2: Medical Interventions and Advance Care Planning Medical Officer to be consulted and documentation can be completed by any of the following: GP, PCMO, PCNS, RN • Section 3: Care Staff Interventions ○ Part A – Care Management: To be completed by RN or Enrolled Nurse (EN) ○ Part B – Comfort Care Chart: To be completed by attending Nursing and Care Staff. A new chart is to be commenced daily ○ Part C – Further Care Action Sheet: Nursing and Care Staff are to document any further actions taken to improve comfort care • Section 4: Multidisciplinary Communication Sheet. All members of the multidisciplinary team can document here • Section 5: After Death Care: To be completed upon death of a resident by the attending nurse.	This tool can assist GPs, Palliative Care Medical Officer, Palliative Care Nurse Specialist, RACF Registered Nurse and other multidisciplinary care professionals in providing integrated care pathway for RACF residents' end-of-life care.	metrosouth.health.qld.gov.au/sites/default/files/content/raceolcp_watermark.pdf

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
28	**Advance care planning for people with cancer: A rapid review of the literature**	Rodi H, Sellars M, Todd J, Detering KM, Nolte L. Advance Care Planning Australia, Austin Health 2020 Australia	This rapid literature review identifies and describes Australian academic literature relating to advance care planning for people with cancer. The report focuses on key themes from the literature, including evidence of barriers and facilitators to advance care planning for people with cancer.	The following five main themes were identified from the review: prevalence of ACP in people with cancer; people with cancer and their support people's views of ACP; concordance between people with cancer and their support person's views; oncology healthcare professional views of ACP; and barriers and facilitators of ACP.	The benefits of ACP for people with cancer, their families and the healthcare system are clear. In order to improve ACP participation in people with cancer, interventions should address both personal and healthcare professional factors at a system-wide level. Systems should promote an early and continual discussion of ACP and involve support people.	www.advancecareplanning.org.au/about-us/our-research-and-publications
29	**Advance care planning: Aged care implementation guide**	Advance Care Planning Australia 2021 Australia	This guide aims to support the implementation of advance care planning and Advance Care Directives in aged care as well as compliance with relevant standards.	The guide explains why advance care planning and Advance Care Directives are important, explores Advance Care Directive legislation and standards, and provides guidance for implementing and monitoring advance care planning activities and documents in aged care.	The Advance Care Planning: Aged care implementation guide should ensure that the assessment and planning identify and address the consumer's needs, goals, and preferences, including advance care planning and end-of-life planning, if the consumer wishes in the aged care sector.	www.advancecareplanning.org.au/about-us/our-research-and-publications

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
30	**Content and quality assessment of advance care planning policies in Australian health and residential aged care services: Implications for future policy development**	Macleod A, Detering K, and Nolte L. Advance Care Planning Australia, Austin Health 2020 Australia	This report evaluates existing organisational policies sourced from participating general practices, hospitals and residential aged care facilities. The focus of the evaluation relates to policy content and quality. The strengths and weaknesses of ACP policy documents in hospitals and residential aged care facilities are examined.	The report findings identify the limited number of valid ACP policy documents and a lack of policy in general practices in Australia.	Advance Care Planning Australia provides recommendations for the development of quality ACP organisation-level policy to promote the uptake of ACP and advance care directives (ACD) in Australian multi-sector health service organisations.	www.advancecareplanning.org.au/about-us/our-research-and-publications
31	**Concordance between instructional directions in advance care planning documentation versus medical orders**	Macleod A, Detering KM, Buck K, Sinclair C, Sellars M, Kelly H, and Nolte L. Advance Care Planning Australia, Austin Health 2020 Australia	This report describes the prevalence and concordance of health records containing at least one statutory ACD: preferences for care document or non-statutory ACD: preferences for care document outlining preferences for life-sustaining (also known as life-prolonging) medical treatment and at least one medical order containing treatment instructions related to life-sustaining medical treatment.	In this study, older Australians at risk of deterioration and dying had limited documented instructions available for use by treating health professionals. Health and residential aged care systems should promote advance care planning, palliative care and/or end-of-life care planning, including robust policy, ACP training and education, health practitioners with ACP and medical order responsibilities, a health record inclusive of ACP documentation, and performance monitoring.	The availability of an ACD and/or medical order for those receiving health and residential aged care services, would be an important element of quality medical treatment, palliative care or end-of-life care. Older Australians should be supported to understand and participate in advance care planning, palliative care and end-of-life care planning, when relevant.	www.advancecareplanning.org.au/about-us/our-research-and-publications

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
32	**Exploratory review of palliative care assessment tools**	Australian Commission on Safety and Quality in Health Care 2021 Australia	Exec Summary report. The purpose of this project was to build on the current evidence base of palliative care prognostic tools used by healthcare professionals and increase their application across a range of healthcare settings.	The frequency of use of the tools does not appear to be dependent on the specific resources, knowledge or skills required to use the tool, or the number of benefits of using the tool. It was, however, associated with the amount of time required to complete it; with those tools that were used most frequently also requiring the least time to complete. The three most used tools were the Karnofsky Performance Status Scale (KPSS), the Supportive and Palliative Care Indicators Tool (SPICT), and the Residential Aged Care End-of-life care Pathway (RAC EoLCP) tool. The most frequently used tools were the KPSS, Surprise Question and Active Daily Living (RUG-ADL).	Studies provided limited insight into the operational aspects associated with implementation of these tools in clinical settings and the practical and resource constraints that may influence clinicians' ability to utilise them.	bit.ly/3wP1CBQ

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
33	**Dying well: Improving palliative and end-of-life care for people with dementia**	Dementia Australia 2019 Australia	Dementia Australia is calling on the Victorian State government (in collaboration with the Commonwealth government) to systematise and customise palliative care for people with dementia, acknowledging the contextual complexities of dementia care within the different healthcare and community settings.	The report provides useful recommendations in relation to workforce, advance care planning, flexible and responsive funding models, improved access and service coordination, and better community awareness of dementia and palliative care.	Comprehensive palliative care for people living with dementia should be available when and where it is needed, including community or home-based care, residential aged care, hospice care, and acute care settings. There is a need to improve the provision of palliative care services for people living with dementia in each of these settings, and to increase the ability of health professionals, staff, families and the community to meet the specific palliative care needs of people living with dementia.	www.dementia.org.au/sites/default/files/documents/DA%20Dying%20Well%20Discussion%20Paper%20FINAL%20for%20online.pdf

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
34a	**Review of innovative models of aged care.** **Report for the Royal Commission into Aged Care Quality and Safety**	Flinders University, Bolton Clarke Research Institute, SAHMRI and Stand Out Report 2019 Australia	Research paper 3. To assist the Royal Commission into Aged Care Quality and Safety, a review of innovative international models of aged care was undertaken.	The review identified many different models of aged care including those specific to people living with dementia, lesbian, gay, bisexual, trans and/or intersex (LGBTI) people, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse (CALD) people, people living in rural and remote areas, and young people with disability living in RAC. Most of the approaches described have limited evidence for their impact on recipient outcomes.	The Australian aged care sector could benefit from larger-scale assessments of: • Alternative building models of RAC • Non-pharmacological programs to support PLwD and their carers in the first year post-diagnosis • Community- and neighbourhood-based models of support for older people living in the community • Remote support of independent living through ambient assisted living or health smart homes.	agedcare.royalcommission.gov.au/sites/default/files/2020-01/research-paper-3-review-innovative-models-of-aged-care.pdf

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
34b	**Review of innovative models of aged care: Appendix 3** **Report for the Royal Commission into Aged Care Quality and Safety**	Rehabilitation, Aged and Extended Care Group, Flinders University and THEMA Consulting 2020 Australia	Research paper 3. This Appendix 3 presents innovative models of aged care comprising key examples, countries available, settings and population, key features, extent implemented, delivery, strengths, challenges and weakness, resources impact on inequity, and consumer views.	The Appendix 3 tabulated the following innovative models of aged care: • Table 1 Innovative models of care for residential care • Table 2 Innovative community models of care • Table 3 Innovative models of care for rural/remote living populations • Table 4 Innovative models of care for Aboriginal and Torres Strait Islander peoples • Table 5 Models of care and supports for CALD groups • Table 6 Innovative models of care for younger people (under 65 years) • Table 7 Innovative models of care for LGBTI populations • Table 8 Innovative models of care for homeless populations • Table 9 Selected examples of innovative technologies to support LTC for older people.	These innovative models of aged care provide useful insight which could potentially be used in developing locally adaptable models of care in Australian aged care services.	agedcare.royalcommission.gov.au/sites/default/files/2020-01/research-paper-3-review-innovative-models-aged_care-appendix-3.pdf

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
35	**The Victorian Councils: Supporting Communities Around End of Life Project**	Municipal Association of Victoria (MAV) and La Trobe University 2017 Australia	The overall aim of the Victorian Councils: Supporting communities Around End-of-Life Project is to explore how local government can be involved in building the capacity of communities to actively participate in caring and supporting people in their community around dying, death and bereavement. Information/ communication kit (#1) to support local government staff progress the end-of-life concept and ideas across council.	This information/communication kit provides factual information, ideas and resources to support council staff in beginning the journey of communicating and discussing ‘end of life’ across all of council.	The kit is expected to assist council work in this new area of ‘end of life’ care across all of council.	www.mav.asn.au/__data/assets/pdf_file/0020/7094/EoL-Project-Starting-the-conversation.pdf
36	**Improving palliative and end-of-life care for rural and remote Australians**	Wenham S, Cumming M, Saurman E. Public Health Res Pract., 2020 Australia	Perspective article. This article describes the development and implementation of the Far West NSW Palliative and End-of-Life Model of Care.	Some of the key points reported in this study are: • Palliative care provision is inconsistent, particularly in rural and remote Australia where access is limited, and generalist providers may feel ill-equipped to provide such care. • Everyone should have equitable access to palliative care as they approach and reach the end of their lives. • The Far West NSW Palliative and End-of-Life Model functions with leadership from a Specialist Palliative Care Service which can drive evidence-based care in the generalist space by sharing knowledge and tools to ensure a current, effective and supported palliative approach.	The Far West NSW Palliative and End-of-Life Model of Care is a systematic solution that could drive improvement in the provision of a quality palliative approach to care and support from any clinician in a timely manner, for patients, their families and carers anywhere.	www.phrp.com.au/wp-content/uploads/2020/03/PHRP3012001.pdf

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
37	**Workbook for general practice end-of-life care**	Primary Health Network (PHN) North Western 2020 Australia	A new model for general practice improvement: Our aim is to strengthen primary care to deliver integrated person-centred care that is comprehensive, accessible, safe and coordinated.	The new model has three modules of engagement for general practices: practice improvement, continuous quality improvement, and intensive quality improvement. The Model for Improvement, with activities and resources for end-of-life care is guided by a four-step approach. The four steps are: • Step 1: Understand end-of-life care and chronic complex illness • Step 2: Analyse data, set goals and brainstorm potential improvements • Step 3: Create a plan and act on it, following the 'plan, do, study, act' cycle • Step 4: Evaluate and celebrate.	Using the Model for Improvement, the services can start small with changes to end-of-life care. They can then systematically review, refine and re-test ideas as necessary before broader implementation.	nwmphn.org.au/wp-content/uploads/2020/12/NWMPHN20200124QualityImprovementKit_EndOfLife_FINAL1.pdf
38	**Quality Improvement Toolkit for General Practice Patient Population Groups: Palliative Care/End of Life Module**	Brisbane South Primary Health Network 2019 Australia	The Model for Improvement uses the Plan-Do-Study-Act (PDSA) cycle, a tried and tested approach to achieving successful change.	The topics that are included in this Quality Improvement (QI) toolkit are: • Chronic Complex Illness • Important conversations including interpreter services • Assistance to live at home longer • Teams • MBS items • Resources	Using the QI Toolkit practices can make easy, measurable and sustainable improvements to provide best practice care for patients.	bsphn.org.au/wp-content/uploads/2020/01/QI-Toolkit-Palliative-Care.pdf

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
39	**Review of international systems for long-term care (LTC) of older people** **Prepared for the Royal Commission into Aged Care Quality and Safety**	Rehabilitation, Aged and Extended Care Group, Flinders University and THEMA Consulting 2020 Australia	The aim of this review is to provide learnings for the aged care system in Australia and to situate the Australian aged care system within the appropriate global context.	This review of international LTC systems has highlighted some key areas where care for older Australians may be improved: 1. Support for home-based care and informal carer 2. Level of regulation 3. Professionalism of the workforce 4. Transparency in staffing level 5. Transparency in quality-of-care indicators 6. Integration with the healthcare system 7. Reablement 8. Human rights.	There is a scope for Australian authorities to invest in long-term care sector for improved care. In general, Australia's spending appears to be lower than the Scandinavian countries of Denmark, Norway and Sweden, as well as Japan and the Netherlands, and roughly similar to that of Canada and the UK.	agedcare.royalcommission.gov.au/sites/default/files/2020-09/Research%20Paper%202%20-%20Review%20of%20international%20systems%20for%20long-term%20care%20of....pdf

Doc #	Document title	Author, year, country	Description	Key components (e.g. program/services/ intervention/exposure/risk factors)	Implications for Community/RAC?	URL
40	**Final report: Care, dignity and respect: Volume 1: Summary and recommendations**	Royal Commission into Aged Care Quality and Safety	Final report. In this report, the Commissioners make 148 wide-ranging recommendations for the fundamental reform of the Australian aged care system. Many of these recommendations focus on improving palliative care provision to those in receipt of aged care.	Twelve of the recommendations in this final report of the Royal Commission directly refer to changes needed in the provision of palliative care across home-based and residential aged care settings. The Commissioners first addressed the rights of older people receiving aged care to have fair, equitable and non-discriminatory access to palliative and end-of-life care (Recommendations 2c and 70). They also addressed workforce capacity, processes, staff training and competences, accreditation, clinical governance, and funding models that will be required to make high quality palliative care a reality across aged care. Just as this review found, regular engagement of care recipients with medical care providers, including GPs and palliative care specialists, through coordinated, *integrated,* multidisciplinary outreach models will be central to the success of any new model of aged care.	The final report and recommendations are now in the hands of the Australian Government. The Commission and all stakeholders should call on the Government to implement all recommendations according to the timelines laid out by the Commissioners. This constitutes a once-in-a-lifetime reform of this important sector in time for the growth in the number of people who will be requiring aged care services over the coming years	agedcare.royalcommission.gov.au/publications/final-report-volume-1

Appendix 7: Opportunities for development of the Consensus Statement

In 2021, opportunities for development stemming from the results of the rapid review identified two new elements to the processes of care (communication and bereavement), and two new organisational prerequisites (organisational culture and physical space). In 2022 further development is suggested based on the current findings of evidence and recommendations. These are highlighted in green.

Table A10: Suggested Essential Elements 2021 (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
Identified in 2021 **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[2]
	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[2]
	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[2]
	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[2]
	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[2]
	I am confident that my needs are well understood by the professionals providing care and service	I know that quality well documented communication on all aspects of care needs with patients, families, my team and beyond can uphold quality and safe end-of-life care[32,57,88,97]

Suggested Essential Elements	What this means for people affected by life-limiting illness	What this means for people providing care
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[2]
	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[2]
	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[2]
	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[2]
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[2]
	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[53-58]
	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[56,59-61]
	My end of life is positively supported with various healthcare 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[2]
	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[2]
	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[56,59-61]

Suggested Essential Elements	What this means for people affected by life-limiting illness	What this means for people providing care
	I hope that I will be frequently asked about my preferences and wishes and that my family's needs will be combined in the care and service we receive	I know that increased planning and shared care goals between myself, my team, the patient and family will result in decreased conflict and increased safety and quality in care[61,63,66139]
Teamwork and **Coordination of care**	The professionals who provide my care are consistent in knowing my history and overall health status	I communicate and document clearly all goals of care decisions with my colleagues and patient's treatment teams[2]
	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[2]
	Regardless of location, wherever I am, I know I can access end-of-life care that is appropriate and harmonised to my needs	I know the importance of multi-organisational collaborations beyond my immediate team. The combined power of well-coordinated services and care can improve patient care and staff skillsets.[25,26,29,40,45,50]
	While the options of the place of my care may be unknown to me, I trust that I will be guided well and my wishes, and those of my family, will be central in decision-making	I know that planning for a patient's end of life and death requires coordinated planning for services and family support, 24 hours a day and seven days per week. I understand that transfers to hospitals are not always helpful in terms of whole person care and may prompt unsafe and poorer quality care.[71-72,74,84-88]
	I trust that if home is the place I wish to stay. Those professionals providing my care respect this	In terms of place of care, I understand that my relationships and consultations between general practitioners and other professionals could be key in determining the fulfilment of patient wishes[85,87,89,90-93]
Using triggers and **Planning for the future**	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[2]

Suggested Essential Elements	What this means for people affected by life-limiting illness	What this means for people providing care
	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[2]
	I hope that planning for my future will enhance my care and reduce conflict	I know that structure approaches to end-of-life goals and advance care planning may reduce conflict between family, healthcare teams and the patient and enhance quality care and preferred place of death[59,61,63]
Identified in 2021 **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[2]
	My family and I are kept informed during my hospitalisation/illness journey	I recognise that my knowledge of the patient, delivery of personalised care and family meetings are impactful in terms of bereavement[2]
	My family will be cared for immediately after I die	I know how to provide emotional and practical support for newly bereaved people[2]
	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[2]
	I know the professionals who provide service are capable of assisting myself and my family even at the saddest times	I am skilled and supported in providing bereavement care and I know who can provide me supervision and who I can refer for complex cases beyond my skill set[103-104,128-129]
Responding to concerns	Professionals caring for me are protective and able	I realise 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[2] I know that increasing workforce capabilities and knowledge in quality end-of-life care coupled with supportive work environments are protective practices for professionals[126-127]

Suggested Essential Elements	What this means for people affected by life-limiting illness	What this means for people providing care
Identified in 2021 **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 thinking and that of my organisation about end-of-life care align[2]
	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 KPIs, specific objectives and measurable outcomes[2]
	My healthcare providers are able to talk with me about my future and my dying	I know the importance of integrated and collaborative end-of-life service provision where end-of-life care is core business and professionals are provided training, mentorship and exposure to best practice[44-52]
Leadership and governance	My opinions and preferences matter to my healthcare 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[2]
	All professionals who provide service are knowledgeable about my healthcare needs	My organisation, my service and or my practice liaise and communicate to any service provider about holistic care of patients and work together to ensure quality end-of-life care[23-42]
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[2]
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[2]
	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[2]

Suggested Essential Elements	**What this means for people affected by life-limiting illness**	**What this means for people providing care**
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[2]
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[2]
Identified in 2021 **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[2]
	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[2]

References

1. Australian Commission on Safety and Quality in Health Care. National consensus statement: Essential elements for safe and high-quality end-of-life care [Internet]. Sydney, NSW: ACSQHC; 2015 [cited 2021 Nov 29]. Available from: www.safetyandquality.gov.au/sites/default/files/migrated/National-Consensus-Statement-Essential-Elements-forsafe-high-quality-end-of-life-care.pdf.
2. Rawlings D, Devery K, Tieman J, Chakraborty A. Rapid review of the literature on end-of-life care [Internet]. Sydney: ACSQHC; 2021 [cited 2021 Dec 1]. Available from: www.safetyandquality.gov.au/sites/default/files/2021-06/d21-18901_rapid_review_of_the_literature_on_end-of-life_care_-_final_accessible_word_document_-_18_may_2021.pdf.
3. Royal Commission into Aged Care Quality and Safety. Final report: Care, dignity and respect – volume 1 summary and recommendations [Internet]. Canberra, ACT: Commonwealth of Australia; 2021 [cited 2021 Aug 30]. Available from: agedcare.royalcommission.gov.au/publications/final-report-volume-1.
4. NSW Agency for Clinical Innovation (ACI). Fact of death analysis 2011/12 – use of NSW public hospital services in the last year of life by NSW residents. Sydney: Health Economic and Evaluation Team, ACI Palliative Care Network; 2015.
5. Swerissen H, Duckett S. Dying well [Internet]. Melbourne, Vic.: Grattan Institute; 2014 [cited 2022 Feb 14]. Available from: grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf.
6. Palliative Care Australia, KPMG. Investing to save: The economics of increased investment in palliative care in Australia [Internet]. [Canberra]: Palliative Care Australia; 2020 [cited 2022 Feb 14]. Available from: palliativecare.org.au/download/20649/.
7. Stones D, Gullifer J. 'At home it's just so much easier to be yourself': Older adults' perceptions of ageing in place. Ageing Soc. 2016;36(3):449-481. doi: 10.1017/S0144686X14001214
8. Abel J, Kellehear A, Karapliagou A. Palliative care – the new essentials. Ann Palliat Med. 2018:S3-S14. doi: 10.21037/apm.2018.03.04
9. Sallnow L, Smith R, Ahmedzai SH, Bhadelia A, Chamberlain C, Cong Y, et al. Report of the Lancet Commission on the Value of Death: Bringing death back into life. Lancet. 2022;Jan 31:S0140-6736(0121)02314-X. doi: 10.1016/S0140-6736(21)02314-X.
10. Australian Commission on Safety and Quality in Health Care. Safety and quality of end-of-life care in acute hospitals: A background paper [Internet]. Sydney: ACSQHC; 2013 [cited 2021 Dec 1]. Available from: www.safetyandquality.gov.au/sites/default/files/migrated/SAQ083_End_of_life_care_V15_FILM_REVISED_TAGGED.pdf.
11. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards [Internet]. Sydney, NSW: ACSQHC; 2017 [cited 2022 Feb 14]. Available from: www.health.gov.au/initiatives-and-programs/comprehensive-palliative-care-in-aged-care-measure.
12. Australian Commission on Safety and Quality in Health Care. End-of-life care audit toolkit [Internet]. Sydney: ACSQHC; 2019 [cited 2022 Feb 15]. Available from: www.safetyandquality.gov.au/our-work/end-life-care/end-life-care-audit-toolkit.
13. Department of Health (Australia). National Palliative Care Strategy 2018 [Internet]. Canberra, ACT: Department of Health; 2018 [cited 2022 Feb 14]. Available from: www.health.gov.au/sites/default/files/the-national-palliative-care-strategy-2018-national-palliative-care-strategy-2018.pdf.

14. Palliative Care Australia. National Palliative Care Standards [Internet]. Canberra, ACT: PCA; 2018 [cited 2022 Feb 14]. Available from: palliativecare.org.au/download/21163/.

15. Department of Health (Australia). Comprehensive palliative care in aged care measure [Internet]. Canberra, ACT: Department of Health; 2019 [updated 19 Jan 2022; cited 2022 Feb 14]. Available from: www.health.gov.au/initiatives-and-programs/comprehensive-palliative-care-in-aged-care-measure.

16. Hui D, Mori M, Parsons HA, Kim SH, Li Z, Damani S, et al. The lack of standard definitions in the supportive and palliative oncology literature. J Pain Symptom Manage. 2012;43(3):582-592. doi: 10.1016/j.jpainsymman.2011.04.016.

17. Palliative Care Australia. Palliative care service development guidelines [Internet]. Griffith, ACT: Palliative Care Australia; 2018 [cited 2021 Aug 30]. Available from: palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf.

18. World Bank. World Bank country and lending groups [Internet]. n.d. [cited 2021 Nov 29]. Available from: datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups.

19. Dang D, Dearholt SL. Johns Hopkins nursing evidence-based practice: Model and guidelines. 3rd ed. Indianapolis, IN: Sigma Theta Tau International; 2018.

20. Mackenzie S, Bannister J, Flint J, Parr S, Millie A, Fleetwood J. The drivers of perceptions of anti-social behaviour. Research report [Internet]. London: Home Office; 2010 [cited 2022 Feb 14]. Available from: assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/116592/horr34-report.pdf.

21. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. BMJ. 2021;372:n71. doi: 10.1136/bmj.n71.

22. Jennings LA, Hollands S, Keeler E, Wenger NS, Reuben DB. The effects of dementia care co-management on acute care, hospice, and long-term care utilization. J Am Geriatr Soc. 2020;68(11):2500-2507. doi: 10.1111/jgs.16667

23. Jennings LA, Turner M, Keebler C, Burton CH, Romero T, Wenger NS, et al. The effect of a comprehensive dementia care management program on end-of-life care. J Am Geriatr Soc. 2019;67(3):443-448. doi: 10.1111/jgs.15769.

24. Bandurska E, Damps-Konstanska I, Popowski P, Jedrzejczyk T, Janowiak P, Swietnicka K, et al. Impact of Integrated Care Model (ICM) on direct medical costs in management of advanced chronic obstructive pulmonary disease (COPD). Med Sci Monit. 2017;23:2850-2862. doi: 10.12659/MSM.901982

25. Kluger BM, Miyasaki J, Katz M, Galifianakis N, Hall K, Pantilat S, et al. Comparison of integrated outpatient palliative care with standard care in patients with Parkinson disease and related disorders: A randomized clinical trial. JAMA Neurol. 2020;77(5):551-560. doi: 10.1001/jamaneurol.2019.4992.

26. Bennett H, McCarthy L, McKinnon S. Partnership working between hospice and children's community nursing teams. Nurs Child Young People. 2016;28(9):26-30. doi: 10.7748/ncyp.2016.e752

27. Armstrong M, Shulman C, Hudson B, Brophy N, Daley J, Hewett N, et al. The benefits and challenges of embedding specialist palliative care teams within homeless hostels to enhance support and learning: Perspectives from palliative care teams and hostel staff. Palliat Med. 2021;35(6):1202-1214. doi: 10.1177/02692163211006318.

28. Garner A, Hodson M, Ketsetzis G, Pulle L, Yorke J, Bhowmik A. An analysis of the economic and patient outcome impact of an integrated COPD service in East London. Int J Chron Obstruct Pulmon Dis. 2017;12:1653-1662. doi: 10.2147/COPD.S127843.

29. Montgomery CL, Pooler C, Arsenault JE, Berean C, Sharman R, Cameron CL, et al. Innovative urgent care for the palliative patient at home. Home Healthc Now. 2017;35(4):196-201. doi: 10.1097/NHH.0000000000000526.

30. Surakka LK, Peake MM, Kiljunen MM, Mantyselka P, Lehto JT. Preplanned participation of paramedics in end-of-life care at home: A retrospective cohort study. Palliat Med. 2021;35(3):584-591. doi: 10.1177/0269216320981713.

31. Chan HY, Chung CK, Tam SS, Chow RS. Community palliative care services on addressing physical and psychosocial needs in people with advanced illness: A prospective cohort study. BMC Palliat Care. 2021;20(1):143. doi: 10.1186/s12904-021-00840-0.

32. de Graaf E, Zweers D, Valkenburg A, Uyttewaal A, Teunissen SC. Hospice assist at home: Does the integration of hospice care in primary healthcare support patients to die in their preferred location – a retrospective cross-sectional evaluation study. Palliat Med. 2016;30(6):580-586. doi: 10.1177/0269216315626353.

33. Evans CJ, Bone AE, Yi D, Gao W, Morgan M, Taherzadeh S, et al. Community-based short-term integrated palliative and supportive care reduces symptom distress for older people with chronic noncancer conditions compared with usual care: A randomised controlled single-blind mixed method trial. Int J Nurs Stud. 2021;120:103978. doi: 10.1016/j.ijnurstu.2021.103978.

34. Ferroni E, Avossa F, Figoli F, Cancian M, De Chirico C, Pinato E, et al. Intensity of integrated primary and specialist home-based palliative care for chronic diseases in Northeast Italy and its impact on end-of-life hospital access. J Palliat Med. 2016;19(12):1260-1266. doi: 10.1089/jpm.2016.0158

35. Pellizzari M, Hui D, Pinato E, Lisiero M, Serpentini S, Gubian L, et al. Impact of intensity and timing of integrated home palliative cancer care on end-of-life hospitalization in Northern Italy. Support Care Cancer. 2017;25(4):1201-1207. doi: 10.1007/s00520-016-3510-x.

36. van Gurp J, van Selm M, van Leeuwen E, Vissers K, Hasselaar J. Teleconsultation for integrated palliative care at home: A qualitative study. Palliat Med. 2016;30(3):257-269. doi: 10.1177/0269216315598068.

37. Groenewoud AS, Wichmann AB, Dijkstra L, Knapen E, Warmerdam F, De Weerdt-Spaetgens C, et al. Effects of an integrated palliative care pathway: More proactive GPs, well timed, and less acute care: A clustered, partially controlled before-after study. J Am Med Dir Assoc. 2021;22(2):297-304. doi: 10.1016/j.jamda.2020.10.025.

38. Pouliot K, Weisse CS, Pratt DS, DiSorbo P. First-year analysis of a new, home-based palliative care program offered jointly by a community hospital and local visiting nurse service. Am J Hosp Palliat Med. 2017;34(2):166-172. doi: 10.1177/1049909115617139.

39. Dalkin SM, Lhussier M, Philipson P, Jones D, Cunningham W. Reducing inequalities in care for patients with non-malignant diseases: Insights from a realist evaluation of an integrated palliative care pathway. Palliat Med. 2016;30(7):690-697. doi: 10.1177/0269216315626352.

40. Takashimi R, Tanabe K, Morita T, Amemiya Y, Fukikawa Y, Yasuda H, Kashii T, Murakami N. Usefulness of a collaborative home visit program between hospital and visiting nurses. J Hosp Palliat Nurs. 2015;17(6):524-535. doi: 10.1097/NJH.0000000000000194

41. Ernecoff NC, Altieri-Dunn SC, Bilderback A, Wilson CL, Saxon S, Ahuja Yende N, et al. Evaluation of a home-based, nurse practitioner-led advanced illness care program. J Am Med Dir Assoc. 2021;08:08. doi: 10.1016/j.jamda.2021.05.013.

42. Zavagli V, Raccichini M, Ostan R, Franchini L, Bonazzi A, Varani S, et al. The ANT home care model in palliative and end-of-life care. An investigation on family caregivers' satisfaction with the services provided. Transl Med UniSa. 2020;23:1-6. doi: 10.37825/2239-9747.1022.

43. Forbat L, Liu WM, Koerner J, Lam L, Samara J, Chapman M, et al. Reducing time in acute hospitals: A stepped-wedge randomised control trial of a specialist palliative care intervention in residential care homes. Palliat Med. 2020;34(5):571-579. doi: 10.1177/0269216319891077.

44. Liu WM, Koerner J, Lam L, Johnston N, Samara J, Chapman M, et al. Improved quality of death and dying in care homes: A palliative care stepped wedge randomized control trial in Australia. J Am Geriatr Soc. 2020;68(2):305-312. doi: 10.1111/jgs.16192.

45. Rainsford S, Liu WM, Johnston N, Glasgow N. The impact of introducing palliative care needs rounds into rural residential aged care: A quasi-experimental study. Aust J Rural Health. 2020;28(5):480-489. doi: 10.1111/ajr.12654.

46. Frey R, Barham S, Balmer D, Boyd M, Robinson J, Gott M. Palliative care delivery in residential aged care: Bereaved family member experiences of the supportive hospice aged residential exchange (SHARE) intervention. BMC Palliat Care. 2020;19(1):127. doi: 10.1186/s12904-020-00633-x.

47. Ho P, Lim Y, Tan LLC, Wang X, Magpantay G, Chia JWK, et al. Does an integrated palliative care program reduce emergency department transfers for nursing home palliative residents? J Palliat Med. 2021;07:07. doi: 10.1089/jpm.2021.0241.

48. Temkin-Greener H, Mukamel DB, Ladd H, Ladwig S, Caprio TV, Norton SA, et al. Impact of nursing home palliative care teams on end-of-life outcomes: A randomized controlled trial. Med Care. 2018;56(1):11-18. doi: 10.1097/MLR.0000000000000835.

49. Saini G, Sampson EL, Davis S, Kupeli N, Harrington J, Leavey G, et al. An ethnographic study of strategies to support discussions with family members on end-of-life care for people with advanced dementia in nursing homes. BMC Palliat Care. 2016;15:55. doi: 10.1186/s12904-016-0127-2.

50. Agar M, Luckett T, Luscombe G, Phillips J, Beattie E, Pond D, et al. Effects of facilitated family case conferencing for advanced dementia: A cluster randomised clinical trial. PLoS ONE. 2017;12(8):e0181020. doi: 10.1371/journal.pone.0181020.

51. Rainsford S, Hall Dykgraaf S, Kasim R, Phillips C, Glasgow N. Strengthening advance care planning in rural residential aged care through multidisciplinary educational case conferences: A hybrid implementation-effectiveness study. Prog Palliat Care. 2021;29(4):199-208. doi: 10.1080/09699260.2021.1872136.

52. Dunphy EJ, Conlon SC, O'Brien SA, Loughrey E, O'Shea BJ. End-of-life planning with frail patients attending general practice: An exploratory prospective cross-sectional study. Br J Gen Pract. 2016;66(650):e661-666. doi: 10.3399/bjgp16X686557.

53. Fischer SM, Kline DM, Min SJ, Okuyama-Sasaki S, Fink RM. Effect of Apoyo con Carino (Support with Caring) trial of a patient navigator intervention to improve palliative care outcomes for Latino adults with advanced cancer: A randomized clinical trial. JAMA Oncol. 2018;4(12):1736-1741. doi: 10.1001/jamaoncol.2018.4014.

54. Lakin JR, Koritsanszky LA, Cunningham R, Maloney FL, Neal BJ, Paladino J, et al. A systematic intervention to improve serious illness communication in primary care. Health Aff. 2017;36(7):1258-1264. doi: 10.1377/hlthaff.2017.0219.

55. Leung AK, Nayyar D, Sachdeva M, Song J, Hwang SW. Chronically homeless persons' participation in an advance directive intervention: A cohort study. Palliat Med. 2015;29(8):746-755. doi: 10.1177/0269216315575679.

56. Neubauer MA, Taniguchi CB, Hoverman JR. Improving incidence of code status documentation through process and discipline. J Oncol Pract. 2015;11(2):e263-266. doi: 10.1200/JOP.2014.001438.

57. Saevareid TJL, Thoresen L, Gjerberg E, Lillemoen L, Pedersen R. Improved patient participation through advance care planning in nursing homes-a cluster randomized clinical trial. Patient Educ Couns. 2019;102(12):2183-2191. doi: 10.1016/j.pec.2019.06.001.

58. Sandoval MB, King JG, Hart V, Repp AB. Increasing advance care planning in primary care practices: A multi-site quality improvement initiative. J Gen Intern Med. 2019;34(6):809-811. doi: 10.1007/s11606-018-4800-4.

59. Sussman T, Kaasalainen S, Bui M, Akhtar-Danesh N, Mintzberg S, Strachan P. 'Now i don't have to guess': Using pamphlets to encourage residents and families/friends to engage in advance care planning in long-term care. Gerontol Geriatr Med. 2017;3:2333721417747323. doi: 10.1177/2333721417747323.

60. Andersson S, Martinsson L, Furst CJ, Brannstrom M. End-of-life discussions in residential care homes improves symptom control: A national register study. BMJ Support Palliat Care. 2021;23:23. doi: 10.1136/bmjspcare-2021-002983.

61. Broadhurst HL, Droney J, Callender T, Shaw A, Riley J. Advance care planning: The impact of ceiling of treatment plans in patients with coordinate my care. BMJ Support Palliat Care. 2019;9(3):267-270. doi: 10.1136/bmjspcare-2017-001414.

62. Chan HY, Ng JS, Chan KS, Ko PS, Leung DY, Chan CW, et al. Effects of a nurse-led post-discharge advance care planning programme for community-dwelling patients nearing the end of life and their family members: A randomised controlled trial. Int J Nurs Stud. 2018;87:26-33. doi: 10.1016/j.ijnurstu.2018.07.008.

63. Hanson LC, Zimmerman S, Song MK, Lin FC, Rosemond C, Carey TS, et al. Effect of the goals of care intervention for advanced dementia: A randomized clinical trial. JAMA Intern Med. 2017;177(1):24-31. doi: 10.1001/jamainternmed.2016.7031.

64. Hockley J, Kinley J. A practice development initiative supporting care home staff deliver high quality end-of-life care. Int J Palliat Nurs. 2016;22(10):474-481. doi: 10.12968/ijpn.2016.22.10.474.

65. Kinley J, Stone L, Butt A, Kenyon B, Lopes NS. Developing, implementing and sustaining an end-of-life care programme in residential care homes. Int J Palliat Nurs. 2017;23(4):186-193. doi: 10.12968/ijpn.2017.23.4.186.

66. Loomer L, Ogarek JA, Mitchell SL, Volandes AE, Gutman R, Gozalo PL, et al. Impact of an advance care planning video intervention on care of short-stay nursing home patients. J Am Geriatr Soc. 2021;69(3):735-743. doi: 10.1111/jgs.16918.

67. Martin RS, Hayes BJ, Hutchinson A, Tacey M, Yates P, Lim WK. Introducing goals of patient care in residential aged care facilities to decrease hospitalization: A cluster randomized controlled trial. J Am Med Dir Assoc. 2019;20(10):1318-1324.e1312. doi: 10.1016/j.jamda.2019.06.017.

68. Mitchell SL, Volandes AE, Gutman R, Gozalo PL, Ogarek JA, Loomer L, et al. Advance care planning video intervention among long-stay nursing home residents: A pragmatic cluster randomized clinical trial. JAMA Intern Med. 2020;180(8):1070-1078. doi: 10.1001/jamainternmed.2020.2366.

69. Reinhardt JP, Boerner K, Downes D. The positive association of end-of-life treatment discussions and care satisfaction in the nursing home. J Soc Work End Life Palliat Care. 2015;11(3-4):307-322. doi: 10.1080/15524256.2015.1107805.

70. Bone AE, Gao W, Gomes B, Sleeman KE, Maddocks M, Wright J, et al. Factors associated with transition from community settings to hospital as place of death for adults aged 75 and older: A population-based mortality follow-back survey. J Am Geriatr Soc. 2016;64(11):2210-2217. doi: 10.1111/jgs.14442.

71. Brownstein H, Hayes B, Simadri A, Tacey M, Holbeach E. Care to the end: A retrospective observational study of aged care facility residents transferred to hospital in the last day of life. Intern Med J. 2021;51(1):27-32. doi: 10.1111/imj.15084.

72. Finucane AM, Davydaitis D, Horseman Z, Carduff E, Baughan P, Tapsfield J, et al. Electronic care coordination systems for people with advanced progressive illness: A mixed-methods evaluation in Scottish primary care. Br J Gen Pract. 2020;70(690):e20-e28. doi: 10.3399/bjgp19X707117.

73. Lemoyne SE, Herbots HH, De Blick D, Remmen R, Monsieurs KG, Van Bogaert P. Appropriateness of transferring nursing home residents to emergency departments: A systematic review. BMC Geriatr. 2019;19(1):17. doi: 10.1186/s12877-019-1028-z.

74. Bannon F, Cairnduff V, Fitzpatrick D, Blaney J, Gomes B, Gavin A, et al. Insights into the factors associated with achieving the preference of home death in terminal cancer: A national population-based study. Palliat Support Care. 2018;16(6):749-755. doi: 10.1017/S1478951517000876.

75. Abrashkin KA, Poku A, Ramjit A, Washko J, Zhang J, Guttenberg M, et al. Community paramedics treat high acuity conditions in the home: A prospective observational study. BMJ Support Palliat Care. 2019;04:04. doi: 10.1136/bmjspcare-2018-001746.

76. Carter AJE, Arab M, Harrison M, Goldstein J, Stewart B, Lecours M, et al. Paramedics providing palliative care at home: A mixed-methods exploration of patient and family satisfaction and paramedic comfort and confidence. CJEM. 2019;21(4):513-522. doi: 10.1017/cem.2018.497.

77. van Vuuren J, Thomas B, Agarwal G, MacDermott S, Kinsman L, O'Meara P, et al. Reshaping healthcare delivery for elderly patients: The role of community paramedicine; a systematic review. BMC Health Serv Res. 2021;21(1):29. doi: 10.1186/s12913-020-06037-0.

78. Carey TA, Arundell M, Schouten K, Humphreys JS, Miegel F, Murphy S, et al. Reducing hospital admissions in remote Australia through the establishment of a palliative and chronic disease respite facility. BMC Palliat Care. 2017;16(1):54. doi: 10.1186/s12904-017-0247-3.

79. Webber C, Viola R, Knott C, Peng Y, Groome PA. Community palliative care initiatives to reduce end-of-life hospital utilization and in-hospital deaths: A population-based observational study evaluating two home care interventions. J Pain Symptom Manage. 2019;58(2):181-189.e181. doi: 10.1016/j.jpainsymman.2019.04.021.

80. Ohta R, Ryu Y. Improvement in palliative care quality in rural nursing homes through information and communication technology-driven interprofessional collaboration. Rural Remote Health. 2021;21(2):6450. doi: 10.22605/RRH6450.

81. Chen PJ, Ho CH, Liao JY, Smits L, Hsiung CA, Yu SJ, et al. The association between home healthcare and burdensome transitions at the end-of-life in people with dementia: A 12-year nationwide population-based cohort study. Int J Environ Res Public Health. 2020;17(24):10. doi: 10.3390/ijerph17249255.

82. Seow H, Barbera L, Pataky R, Lawson B, O'Leary E, Fassbender K, et al. Does increasing home care nursing reduce emergency department visits at the end of life? A population-based cohort study of cancer decedents. J Pain Symptom Manage. 2016;51(2):204-212. doi: 10.1016/j.jpainsymman.2015.10.008.

83. Tappen RM, Worch SM, Newman DO, Hain D. Evaluation of a novel decision guide 'Go to the hospital or stay here?' For nursing home residents and families: A randomized trial. Res Gerontol Nurs. 2020;13(6):309-319. doi: 10.3928/19404921-20201002-01.

84. Abe K, Miyawaki A, Kobayashi Y, Watanabe T, Tamiya N. Place of death associated with types of long-term care services near the end-of-life for home-dwelling older people in Japan: A pooled cross-sectional study. BMC Palliat Care. 2020;19(1):121. doi: 10.1186/s12904-020-00622-0.

85. Igarashi A, Kurinobu T, Ko A, Okamoto Y, Matsuura S, Feng M, et al. Factors related to the provision of home-based end-of-life care among home-care nursing, home help, and care management agencies in Japan. BMC Res Notes. 2015;8:434. doi: 10.1186/s13104-015-1418-z.

86. Nishiguchi S, Sugaya N, Sakamaki K, Mizushima S. End-of-life care bonus promoting end-of-life care in nursing homes: An 11-year retrospective longitudinal prefecture-wide study in Japan. Biosci Trends. 2017;11(1):54-61. doi: 10.5582/bst.2016.01183.

87. Harrison JM, Agarwal M, Stone PW, Gracner T, Sorbero M, Dick AW. Does integration of palliative care and infection management reduce hospital transfers among nursing home residents? J Palliat Med. 2021;24(9):1334-1341. doi: 10.1089/jpm.2020.0577.

88. Temkin-Greener H, Li Q, Li Y, Segelman M, Mukamel DB. End-of-life care in nursing homes: From care processes to quality. J Palliat Med. 2016;19(12):1304-1311. doi: 10.1089/jpm.2016.0093.

89. Gomes B, Calanzani N, Koffman J, Higginson IJ. Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study. BMC Med. 2015;13:235. doi: 10.1186/s12916-015-0466-5.

90. Brettell R, Fisher R, Hunt H, Garland S, Lasserson D, Hayward G. What proportion of patients at the end of life contact out-of-hours primary care? A data linkage study in Oxfordshire. BMJ Open. 2018;8(4):e020244. doi: 10.1136/bmjopen-2017-020244.

91. Maetens A, Beernaert K, De Schreye R, Faes K, Annemans L, Pardon K, et al. Impact of palliative home care support on the quality and costs of care at the end of life: A population-level matched cohort study. BMJ Open. 2019;9(1):e025180. doi: 10.1136/bmjopen-2018-025180.

92. van der Plas AG, Vissers KC, Francke AL, Donker GA, Jansen WJ, Deliens L, et al. Involvement of a case manager in palliative care reduces hospitalisations at the end of life in cancer patients: A mortality follow-back study in primary care. PLoS ONE. 2015;10(7):e0133197. doi: 10.1371/journal.pone.0133197.

93. Kjellstadli C, Allore H, Husebo BS, Flo E, Sandvik H, Hunskaar S. General practitioners' provision of end-of-life care and associations with dying at home: A registry-based longitudinal study. Fam Pract. 2020;37(3):340-347. doi: 10.1093/fampra/cmz059.

94. Larsen AMN, Neergaard MA, Andersen MF, Gorlen T. Increased rate of home-death among patients in a Danish general practice. Dan Med J. 2020;67(10):22. Available from: ugeskriftet.dk/files/scientific_article_files/2021-01/a01200054_web.pdf

95. Raijmakers NJH, de Veer AJE, Zwaan R, Hofstede JM, Francke AL. Which patients die in their preferred place? A secondary analysis of questionnaire data from bereaved relatives. Palliat Med. 2018;32(2):347-356. doi: 10.1177/0269216317710383.

96. Tanuseputro P, Beach S, Chalifoux M, Wodchis WP, Hsu AT, Seow H, et al. Associations between physician home visits for the dying and place of death: A population-based retrospective cohort study. PLoS ONE. 2018;13(2):e0191322. doi: 10.1371/journal.pone.0191322.

97. Winthereik AK, Hjertholm P, Neergaard MA, Jensen AB, Vedsted P. Propensity for paying home visits among general practitioners and the associations with cancer patients' place of care and death: A register-based cohort study. Palliat Med. 2018;32(2):376-383. doi: 10.1177/0269216317727387.

98. Pivodic L, Harding R, Calanzani N, McCrone P, Hall S, Deliens L, et al. Home care by general practitioners for cancer patients in the last 3 months of life: An epidemiological study of quality and associated factors. Palliat Med. 2016;30(1):64-74. doi: 10.1177/0269216315589213.

99. Oosterveld-Vlug MG, Pasman HRW, Ten Koppel M, van Hout HPJ, van der Steen JT, Collingridge Moore D, et al. Physician visits and recognition of residents' terminal phase in long-term care facilities: Findings from the PACE cross-sectional study in 6 EU countries. J Am Med Dir Assoc. 2019;20(6):696-702.e691. doi: 10.1016/j.jamda.2018.08.015.

100. Keim-Malpass J, Lindley LC. End-of-life transitions and hospice utilization for adolescents: Does having a usual source of care matter? J Hosp Palliat Nurs. 2017;19(4):376-382. doi: 10.1097/NJH.0000000000000361.

101. Coldrick C, Crimmons K. Family members' and carers' perceptions of palliative care provided by district nurses. Prim Health Care. 2020;30(1):31-36. doi: 10.7748/phc.2019.e1478.

102. Schweitzer B, Blankenstein N, Slort W, Knol DL, Deliens L, Van Der Horst H. Writing information transfers for out-of-hours palliative care: A controlled trial among GPs. Scand J Prim Health Care. 2016;34(2):186-195. doi: 10.3109/02813432.2016.1163036.

103. Williams H, Donaldson SL, Noble S, Hibbert P, Watson R, Kenkre J, et al. Quality improvement priorities for safer out-of-hours palliative care: Lessons from a mixed-methods analysis of a national incident-reporting database. Palliat Med. 2019;33(3):346-356. doi: 10.1177/0269216318817692.

104. Mason B, Buckingham S, Finucane A, Hutchison P, Kendall M, McCutcheon H, et al. Improving primary palliative care in Scotland: Lessons from a mixed methods study. BMC Fam Pract. 2015;16:176. doi: 10.1186/s12875-015-0391-x.

105. Stegmann ME, Brandenbarg D, Reyners AK, van Geffen WH, Hiltermann TJN, Berendsen AJ. Prioritisation of treatment goals among older patients with non-curable cancer: The OPTION randomised controlled trial in Dutch primary care. Br J Gen Pract. 2020;70(696):e450-e456. doi: 10.3399/bjgp20X710405.

106. van der Plas AG, Pasman HRW, Schweitzer B, Onwuteaka-Philipsen BD. Improving palliative care provision in primary care: A pre- and post-survey evaluation among PaTz groups. Br J Gen Pract. 2018;68(670):e351-e359. doi: 10.3399/bjgp18X695753.

107. Walsh RI, Mitchell G, Francis L, van Driel ML. What diagnostic tools exist for the early identification of palliative care patients in general practice? A systematic review. J Palliat Care. 2015;31(2):118-123. doi: 10.1177/082585971503100208.

108. Andrade AS, Moreira M, Sa M, Pacheco D, Almeida V, Rocha JC. Randomized controlled trial of a cognitive narrative crisis intervention for bereavement in primary healthcare. Behav Cogn Psychother. 2017;45(1):85-90. doi: 10.1017/S1352465816000345.

109. Pearce C, Wong G, Kuhn I, Barclay S. Supporting bereavement and complicated grief in primary care: A realist review. BJGP Open. 2021;5(3). doi: 10.3399/BJGPO.2021.0008.

110. Stacpoole M, Hockley J, Thompsell A, Simard J, Volicer L. Implementing the Namaste Care program for residents with advanced dementia: Exploring the perceptions of families and staff in UK care homes. Ann Palliat Med. 2017;6(4):327-339. doi: 10.21037/apm.2017.06.26.

111. Bunn F, Lynch J, Goodman C, Sharpe R, Walshe C, Preston N, et al. Improving living and dying for people with advanced dementia living in care homes: A realist review of Namaste Care and other multisensory interventions. BMC Geriatr. 2018;18(1):303. doi: 10.1186/s12877-018-0995-9.

112. Kaasalainen S, Hunter PV, Hill C, Moss R, Kim J, van der Steen JT, et al. Launching 'Namaste Care' in Canada: Findings from training sessions and initial perceptions of an end-of-life programme for people with advanced dementia. J Res Nurs. 2019;24(6):403-417. doi: 10.1177/1744987119832932.

113. Tasseron-Dries PEM, Smaling HJA, Doncker S, Achterberg WP, van der Steen JT. Family involvement in the Namaste Care family program for dementia: A qualitative study on experiences of family, nursing home staff, and volunteers. Int J Nurs Stud. 2021;121:103968. doi: 10.1016/j.ijnurstu.2021.103968.

114. Stacpoole M, Hockley J, Thompsell A, Simard J, Volicer L. The Namaste Care programme can reduce behavioural symptoms in care home residents with advanced dementia. Int J Geriatr Psychiatry. 2015;30(7):702-709. doi: 10.1002/gps.4211.

115. Bray J, Brooker DJ, Garabedian C. What is the evidence for the activities of Namaste Care? A rapid assessment review. Dementia (London). 2021;20(1):247-272. doi: 10.1177/1471301219878299.

116. Latham I, Brooker D, Bray J, Jacobson-Wright N, Frost F. The impact of implementing a Namaste Care intervention in UK care homes for people living with advanced dementia, staff and families. Int J Environ Res Public Health. 2020;17(16):18. doi: 10.3390/ijerph17166004.

117. El Alili M, Smaling HJA, Joling KJ, Achterberg WP, Francke AL, Bosmans JE, et al. Cost-effectiveness of the Namaste Care family program for nursing home residents with advanced dementia in comparison with usual care: A cluster-randomized controlled trial. BMC Health Serv Res. 2020;20(1):831. doi: 10.1186/s12913-020-05570-2.

118. Dalkin SM, Lhussier M, Kendall N, Atkinson J, Tolman S. Namaste Care in the home setting: Developing initial realist explanatory theories and uncovering unintended outcomes. BMJ Open. 2020;10(1):e033046. doi: 10.1136/bmjopen-2019-033046.

119. Aasmul I, Husebo BS, Flo E. Staff distress improves by treating pain in nursing home patients with dementia: Results from a cluster-randomized controlled trial. J Pain Symptom Manage. 2016;52(6):795-805. doi: 10.1016/j.jpainsymman.2016.07.004.

120. Verreault R, Arcand M, Misson L, Durand PJ, Kroger E, Aubin M, et al. Quasi-experimental evaluation of a multifaceted intervention to improve quality of end-of-life care and quality of dying for patients with advanced dementia in long-term care institutions. Palliat Med. 2018;32(3):613-621. doi: 10.1177/0269216317719588.

121. Miranda R, Smets T, Van Den Noortgate N, van der Steen JT, Deliens L, Payne S, et al. No difference in effects of ‘PACE steps to success’ palliative care program for nursing home residents with and without dementia: A pre-planned subgroup analysis of the seven-country pace trial. BMC Palliat Care. 2021;20(1):39. doi: 10.1186/s12904-021-00734-1.

122. White PC, Wyatt J, Chalfont G, Bland JM, Neale C, Trepel D, et al. Exposure to nature gardens has time-dependent associations with mood improvements for people with mid- and late-stage dementia: Innovative practice. Dementia (London). 2018;17(5):627-634. doi: 10.1177/1471301217723772.

123. Iliffe S, Wilcock J, Drennan V, Goodman C, Griffin M, Knapp M, et al. Changing practice in dementia care in the community: Developing and testing evidence-based interventions, from timely diagnosis to end of life (EVIDEM). NIHR Journals Library Programme Grants for Applied Research. 2015;3(3). doi: 10.3310/pgfar03030.

124. Laver K, Cumming RG, Dyer SM, Agar MR, Anstey KJ, Beattie E, et al. Clinical practice guidelines for dementia in Australia. Med J Aust. 2016;204(5):191-193.

125. Shimada N, Ishiki H, Iwase S, Chiba T, Fujiwara N, Watanabe A, et al. Cancer transitional care for terminally ill cancer patients can reduce the number of emergency admissions and emergency department visits. Am J Hosp Palliat Med. 2017;34(9):831-837. doi: 10.1177/1049909116658641.

126. Westergren A, Ahlstrom G, Persson M, Behm L. Next of kin participation in the care of older persons in nursing homes: A pre-post non-randomised educational evaluation, using within-group and individual person-level comparisons. PLoS ONE. 2021;16(1):e0244600. doi: 10.1371/journal.pone.0244600.

127. Simmons CPL, McMillan DC, McWilliams K, Sande TA, Fearon KC, Tuck S, et al. Prognostic tools in patients with advanced cancer: A systematic review. J Pain Symptom Manage. 2017;53(5):962-970.e910. doi: 10.1016/j.jpainsymman.2016.12.330.

128. Baranska I, Kijowska V, Engels Y, Finne-Soveri H, Froggatt K, Gambassi G, et al. Factors associated with perception of the quality of physicians’ end-of-life communication in long-term care facilities: PACE cross-sectional study. J Am Med Dir Assoc. 2020;21(3):439.e431-439.e438. doi: 10.1016/j.jamda.2019.07.018.

129. Parker D, Clifton K, Tuckett A, Walker H, Reymond E, Prior T, et al. Palliative care case conferences in long-term care: Views of family members. Int J Older People Nurs. 2016;11(2):140-148. doi: 10.1111/opn.12105.

130. Law MC, Lau BH, Kwok AYY, Lee JSH, Lui RNY, Liu KH, et al. Empowering families facing end-stage nonmalignant chronic diseases with a holistic, transdisciplinary, community-based intervention: 3 months outcome of the Life Rainbow Program. Palliat Support Care. 2020:1-10. doi: 10.1017/S1478951520001224.

131. Ben-Arye E, Yakubov Y, Samuels N, Gressel O, Yosipovich A, Schiff E, et al. Impact of a combined integrative oncology and palliative care program on quality of life of patients with advanced cancer. Med Oncol. 2021;38(8):93. doi: 10.1007/s12032-021-01544-4.

132. Brannstrom M, Furst CJ, Tishelman C, Petzold M, Lindqvist O. Effectiveness of the Liverpool Care Pathway for the Dying in residential care homes: An exploratory, controlled before-and-after study. Palliat Med. 2016;30(1):54-63. doi: 10.1177/0269216315588007.

133. Husebo BS, Flo E, Engedal K. The Liverpool Care Pathway: Discarded in cancer patients but good enough for dying nursing home patients? A systematic review. BMC Med Ethics. 2017;18(1):48. doi: 10.1186/s12910-017-0205-x.

134. Wichmann AB, Adang EMM, Vissers KCP, Szczerbinska K, Kylanen M, Payne S, et al. Decreased costs and retained QoL due to the ‘PACE Steps to Success’ intervention in LTCFs: Cost-effectiveness analysis of a randomized controlled trial. BMC Med. 2020;18(1):258. doi: 10.1186/s12916-020-01720-9.

135. White PC, Wyatt J, Chalfont G, Bland JM, Neale C, Trepel D, et al. Exposure to nature gardens has time-dependent associations with mood improvements for people with mid- and late-stage dementia: Innovative practice. Dementia (London). 2018;17(5):627-634. doi: 10.1177/1471301217723772.

136. Ernecoff NC, Lin FC, Wessell KL, Hanson LC. Quality of life with late-stage dementia: Exploring opportunities to intervene. J Am Geriatr Soc. 2019;67(6):1189-1196. doi: 10.1111/jgs.15794.

137. Andersson S, Arestedt K, Lindqvist O, Furst CJ, Brannstrom M. Factors associated with symptom relief in end-of-life care in residential care homes: A national register-based study. J Pain Symptom Manage. 2018;55(5):1304-1312. doi: 10.1016/j.jpainsymman.2017.12.489.

138. Beck I, Jakobsson U, Edberg AK. Applying a palliative care approach in residential care: Effects on nurse assistants’ work situation. Palliat Support Care. 2015;13(3):543-553. doi: 10.1017/S1478951513000783.

139. Boerner K, Gleason H, Jopp DS. Burnout after patient death: Challenges for direct care workers. J Pain Symptom Manage. 2017;54(3):317-325. doi: 10.1016/j.jpainsymman.2017.06.006.

140. Hartig J, Viola J. Online grief support communities. Omega (Westport). 2016;73(1):29-41. doi: 10.1177/0030222815575698.

141. Bove DG, Midtgaard J, Kaldan G, Overgaard D, Lomborg K. Home-based copd psychoeducation: A qualitative study of the patients’ experiences. J Psychosom Res. 2017;98:71-77. doi: 10.1016/j.jpsychores.2017.05.013.

142. Schaefer I, DiGiacomo M, Heneka N, Panozzo S, Luckett T, Phillips JL. Palliative care needs and experiences of people in prison: A systematic review and meta-synthesis. Palliat Med. 2021:2692163211068278. doi: 10.1177/02692163211068278.

143. Poulos RG, Harkin D, Poulos CJ, Cole A, MacLeod R. Can specially trained community care workers effectively support patients and their families in the home setting at the end of life? Health Social Care Community. 2018;26(2):e270-e279. doi: 10.1111/hsc.12515.

144. Manheim CE, Haverhals LM, Jones J, Levy CR. Allowing family to be family: End-of-life care in veterans affairs medical foster homes. J Soc Work End Life Palliat Care. 2016;12(1-2):104-125. doi: 10.1080/15524256.2016.1156603.

145. de Veer AJE, Slev VN, Pasman HR, Verdonck-de Leeuw IM, Francke AL, van Uden-Kraan CF. Assessment of a structured self-management support intervention by nurses for patients with incurable cancer. Oncol Nurs Forum. 2020;47(3):305-317. doi: 10.1188/20.ONF.305-317.

146. Nordentoft S, Dieperink KB, Johansson SD, Jarden M, Piil K. Evaluation of a multimodal rehabilitative palliative care programme for patients with high-grade glioma and their family caregivers. Scand J Caring Sci. 2021;23:23. doi: 10.1111/scs.13019.

147. Miller EJ, Morgan JD, Blenkinsopp A. How timely is access to palliative care medicines in the community? A mixed methods study in a UK city. BMJ Open. 2019;9(11):e029016. doi: 10.1136/bmjopen-2019-029016.

148. Molist-Brunet N, Sevilla-Sanchez D, Gonzalez-Bueno J, Garcia-Sanchez V, Segura-Martin LA, Codina-Jane C, et al. Therapeutic optimization through goal-oriented prescription in nursing homes. Int J Clin Pharm. 2021;43(4):990-997. doi: 10.1007/s11096-020-01206-x.

149. Paque K, Vander Stichele R, Elseviers M, Pardon K, Dilles T, Deliens L, et al. Barriers and enablers to deprescribing in people with a life-limiting disease: A systematic review. Palliat Med. 2019;33(1):37-48. doi: 10.1177/0269216318801124.

150. Goodman C, Dening T, Gordon AL, Davies SL, Meyer J, Martin FC, et al. Effective health care for older people living and dying in care homes: A realist review. BMC Health Serv Res. 2016;16:269. doi: 10.1186/s12913-016-1493-4.

151. Kinley J, Preston N, Froggatt K. Facilitation of an end-of-life care programme into practice within UK nursing care homes: A mixed-methods study. Int J Nurs Stud. 2018;82:1-10. doi: 10.1016/j.ijnurstu.2018.02.004.

152. Spacey A, Scammell J, Board M, Porter S. Systematic critical realist review of interventions designed to improve end-of-life care in care homes. Nurs Health Sci. 2020;22(2):343-354. doi: 10.1111/nhs.12665.

AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

Level 5, 255 Elizabeth Street, Sydney NSW 2000
GPO Box 5480, Sydney NSW 2001

Phone: (02) 9126 3600

Email: mail@safetyandquality.gov.au
Website: www.safetyandquality.gov.au