

A review summary:

Palliative care and end of life in aged care settings

OCTOBER 2022

Key points

- A scoping review identified 78 systematic, integrative, and realist reviews, published since 2012, discussing palliative and end-of-life care for people receiving aged care services in residential and home settings.
- Many of the reviews were concerned with care of the person with advanced dementia, facilitators and barriers to advance care planning, and the appropriateness of transfers from home/residential care to an acute care facility near the end of life.
- What constitutes high quality palliative and end-of-life care and a good death in aged care settings and how to measure quality were also prominent themes.
- The review identified a lack of systematic review evidence on care of the bereaved and the importance of self-care for staff involved in end-of-life care. This is surprising considering the impact of the COVID-19 pandemic on deaths in residential aged care settings and the pressures experienced by staff at that time.

Background

There is evidence to show that people are living longer, and most older people have a preference to die in their usual place of care. [1, 2] Priority, therefore, is for models of palliative and end-of-life care to be designed for residential aged care (RAC) and home settings. [1] Understanding the extent of palliative and end-of-life care being undertaken in aged care settings (RAC and community-dwelling older adults) allows for a mapping of the services currently being undertaken and highlights gaps in practice. Barriers and facilitators to improve practice can then be identified. However, published literature about palliative and end-of-life care programs in long-term care facilities and home settings is sparse, [1] and the majority is anecdotal or observational. [3]

Objectives of this review

We undertook a scoping review of the published systematic review literature on palliative and end-of-life care within the aged care context to gauge the size, breadth, and nature of the research evidence. The major themes across this literature will then inform short 'evidence themes' to support the knowledge and practice of people providing care in this setting.

Methods

A search strategy was created in Ovid Medline and then translated for PsycINFO, CINAHL, Embase (Ovid) and Scopus on 8 September 2022. The strategy included a range of terms covering end of life, terminal illness, palliative care, residential aged care, and non-specialist home care services. The search was limited to English language systematic reviews published since 2012. A librarian assisted by conducting a search for grey literature on the topic, as well as iterative searches of Google Scholar. All citations retrieved were uploaded into Covidence for dual citation and abstract screening, followed by full-text screening for articles thought to be relevant. Where a conflict occurred, authors convened to come to an agreement on eligibility.

Inclusion criteria

Eligible reviews were those that:

- Focussed on the provision of palliative care or end-of-life care (defined as the last 12 months of life). Palliative care included the following domains: advance care planning, bereavement care, inclusive care of the person and their family/informal carers, and the physical, psychosocial, and spiritual care of the dying person.
- Included participants who were receiving aged care services (home care or residential aged care)
- Included participants that were receiving palliative or end-of-life care, their families and/or informal carers, health professionals, and non-clinical aged care workers.

- Included a search strategy and a statement that they have evaluated the quality of included studies and in some way
- Were in the English language
- Were published between 2012 and 8 September 2022

Palliative care included the following multidisciplinary domains:

- Advance care planning
- Bereavement care
- Care of the family and informal carers
- Spiritual and emotional care of the dying person (e.g., psychological services, chaplain services).

Exclusion criteria

Reviews not included were those that:

- Did not include a critical appraisal of studies of some kind
- Included mixed populations where age and/or setting was not clear, or were too mixed to draw generalisable conclusions to aged care
- Did not focus on palliative care or the end of life
- Focussed on:
 - specialist palliative care home outreach programs (not funded by aged care and provided by hospice or hospital service) care
 - national models of palliative care with limited generalisability to Australian aged care
 - hospice care, except if the topic was the transfer of aged care residents to hospice
 - home nursing care if not funded by aged care services.

Keeping the evidence themes current

The evidence themes on this topic will be kept current via regular, scheduled updates. Newly published systematic reviews are routinely identified as part of our process for creating the [ARIIA review collection](#). This involves monthly searches of Google Scholar and the Medline (OVID) and CINAHL databases using a broad search strategy for retrieving reviews set in an aged care context (home care and residential aged care). The [PubMed version](#) of this search strategy is available on the [ARIIA review collection](#) page.

All reviews relevant to our priority topics are checked against the review collection's eligibility criteria. Those that meet these criteria are included in the ARIIA review collection under the appropriate topic heading. In updating the original scoping review, systematic reviews under the heading of palliative care and end of life will be analysed to determine their relevance to the existing evidence themes. If relevant, their findings and conclusions will be mapped against those of the evidence theme. Newer reviews might therefore lead to:

- Additional findings being added to a theme
- Newly included reviews strengthening a theme's existing findings
- The theme's overall conclusions being revised based on a change in the direction or strength of the newer evidence
- A new evidence theme being written.

Results

The systematic search retrieved 2331 papers; after duplicates were removed, 1350 citations were reviewed independently by at least two authors against the inclusion and exclusion criteria. After full text review, 78 systematic reviews met inclusion criteria (see Figure 1 on page 4).

Characteristics of the included reviews

Fifty-one reviews (65%) focussed on older people in residential facilities such as residential aged care homes, nursing homes, or long-term care facilities. Nine reviews (12%) reported on older people living in their own home while the remaining 18 reviews (23%) included people across mixed settings. Nearly one-half (42%) of the reviews examine some aspect of palliative or end-of-life care for people living with advanced dementia and their families.

Data were extracted from each review, initially identifying the following four distinct themes:

- Advance care planning
- Acute care transfers
- Staff training and education
- Communication at end of life.

Additional themes have also been identified and will be summarised and made available on the Hub website soon. Table 1 shows a comprehensive list of all themes, the number of reviews identified that report on that theme, and what each theme covers.

Table 1. Potential themes identified by scoping the palliative and end-of-life care evidence of systematic reviews (2012-2022)

Theme	Description of included evidence	Number of reviews
End-of-life care for people with advanced dementia	Prognostics and quality indicators, Namaste Care, costs of care, and the challenges of surrogate end-of-life decision-making and achieving a home death.	33
Advance care planning	Facilitators and barriers to ACP and the effect of having a plan in place for EoL care.	17
Interventions	Interventions addressing multiple palliative care domains; spiritual needs of care recipients; educational interventions; storage, use and disposal of controlled drugs; increasing primary care; deprescribing and prescribing.	17
Quality of care	Staff and aged care recipient perspectives on what constitutes quality palliative and end-of-life care and a good death, and quality indicators for assessing optimal palliative care for people living with dementia.	17
Acute care transfers	Factors associated with transfers from the home setting to an emergency department or a hospital ward, rates of transfer, and interventions to reduce unnecessary transfers.	13
Staff attitudes and experiences	Attitudes and experiences of care staff towards providing palliative care to people in the home and residential aged care.	9
Dying in place	Predictors and determinants of home death versus hospital death.	9
Staff roles and responsibilities	Expected or perceived roles of specific care workers in providing palliative care.	8
Communication at the end of life	Barriers and facilitators to end-of-life conversations between people with advanced illness, their families, and care providers, as well as the potential outcomes of these conversations.	8
Staff training and education	The impact of training and education on staff confidence and competence in providing palliative and end-of-life care, barriers to training, and the value of guidelines for staff knowledge and competence.	6
Models of care	Effective palliative care models and their components.	3
Surrogate decision making	Barriers and facilitators to, and interventions for, proxy decision-making for people living with dementia	2

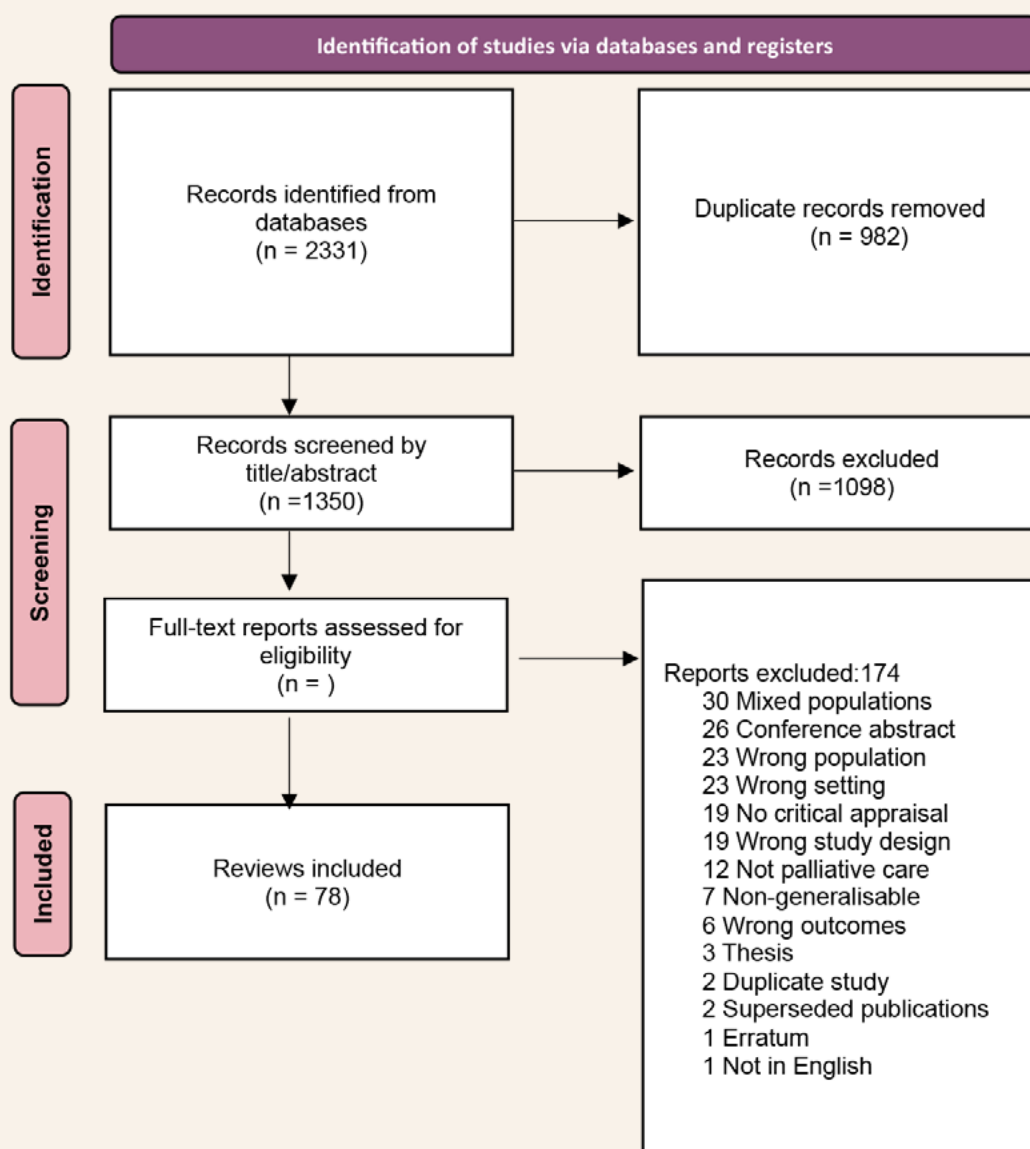


Figure 1. Process for selecting published studies

Conclusion

The themes identified within systematic reviews on this topic from across the past ten years appear to focus predominately on palliative care considerations for people living with advanced dementia and their families, the importance of advance care planning, and what constitutes quality palliative care and a good death within aged care settings. We note a high proportion of qualitative studies which explore staff experiences with, and attitudes towards, providing palliative care. Several reviews also describe educational interventions aimed at improving staff knowledge and confidence in providing this type of care and the flow-on benefits of staff training to residents.

The review identified a lack of systematic review evidence on care of the bereaved and the importance of self-care for staff involved in end-of-life care. This is surprising considering the recent impact of the COVID-19 pandemic on residential aged care settings including the high number of deaths of residents and the unprecedented pressures experienced by staff at that time.



References

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