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Components of palliative care interventions addressing the needs of people with dementia living in long-term care: a systematic review

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Components of palliative care interventions addressing the needs of people with dementia living in long-term care: A systematic review

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Abstract

Background: People with dementia requiring palliative care have multiple needs, which are amplified in long-term care settings. The European Association for Palliative Care White Paper offers recommendations for optimal palliative care in dementia integral for this population, providing useful guidance to inform interventions addressing their specific needs.

Aim: The aim of this study is to describe the components of palliative care interventions for people with dementia in long-term care focusing on shared decision-making and examine their alignment to the European Association for Palliative Care domains of care.

Design: Systematic review with narrative synthesis (PROSPERO ID: CRD42018095649).

Data sources: Four databases (MEDLINE, CINAHL, PsycINFO and CENTRAL) were searched (earliest records – July 2019) for peer-reviewed articles and protocols in English, reporting on palliative care interventions for people with dementia in long-term care, addressing European Association for Palliative Care Domains 2 (person-centred) or 3 (setting care goals) and ≥ 1 other domain.

Results: Fifty-one papers were included, reporting on 32 studies. For each domain (1–10), there were interventions found aiming to address its goal, although no single intervention addressed all domains. Domain 7 (symptom management; $n = 19$), 6 (avoiding overly aggressive treatment; $n = 18$) and 10 (education; $n = 17$) were the most commonly addressed; Domain 5 (prognostication; $n = 7$) and 4 (continuity of care; $n = 2$) were the least addressed.

Conclusion: Almost all domains were addressed across all interventions currently offered for this population to various degrees, but not within a singular intervention. Future research optimally needs to be theory driven when developing dementia-specific interventions at the end of life, with the European Association for Palliative Care domains serving as a foundation to inform the best care for this population.

Keywords

Dementia, palliative care, intervention, long-term care

What is already known about the topic?

- Dementia is a progressive life-limiting illness, and a palliative approach to care is considered the best practice in its advanced stages.
- The European Association for Palliative Care White Paper offers recommendations for optimal palliative care for people with dementia.
- A review of current palliative care interventions for people with dementia is timely to better understand their design and examine how intervention components align with the European Association for Palliative Care framework domains.

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What this paper adds?

- This study indicates that a range of interventions is being developed for people with dementia receiving palliative care in long-term care.
- This is the first review to use the European Association for Palliative Care White Paper to investigate the content being addressed in interventions for people receiving palliative care for their dementia in long-term care settings.
- No single intervention addresses all 10 considered European Association for Palliative Care domains of interest, but all 10 domains are addressed to some extent across various interventions, and to various degrees.
- The findings indicate that current research is more focussed on developing interventions that provide education and upskilling of health care teams, support optimal treatment of symptoms and comfort care, and those that seek to prevent aggressive treatment at the end of life. Fewer interventions focus on prognostication and continuity of care.

Implications for practice, theory or policy

- This article highlights a shift from prognosis-driven palliative care models to need-based care models for people with dementia in long-term care settings.
- The European Association for Palliative Care framework offers a useful way to structure and consider complex, multi-component interventions for people with dementia and palliative care needs, and to place such interventions in context, thus improving the generalisability and applicability of their findings.
- Future research could highlight the inter-relatedness of domains, and how intervening at one domain may also improve outcomes in others.

Introduction

Dementia is a progressive life-limiting illness, and a palliative approach to care is considered best practice in its advanced stages¹ to help improve people's quality of life, address their physical, psychosocial and spiritual issues, and support their carers.² Cognitive decline, the pattern of physical symptoms, inter-current problems such as infections, and high prevalence of comorbidities require a unique approach for the provision and delivery of optimal palliative care. As dementia progresses, the majority of this population in developed countries will be living in long-term care facilities at the end of life, a setting where palliative care is often suboptimal and/or deterioration precipitates acute hospitalisation (where receiving appropriate care is also limited).^{3,4}

The multidimensional aspect of palliative care necessitates complex, multicomponent interventions to best address the needs of people with life-limiting illnesses. This also applies when considering the needs of specific populations, including those with dementia. Specifically, this requires a more in-depth understanding of how the elements contributing to tailored interventions can be optimally chosen, evaluated, implemented and described, to inform future research and also maximise knowledge translation into clinical practice.¹ A recent Cochrane review highlighted a paucity of high-quality data on the efficacy of palliative care interventions for people with dementia.¹⁰ The review's focus on efficacy limited the type of its included studies, which meant that studies focussing on how interventions have been designed to target dementia palliative care needs were not explored.

In 2014, the European Association for Palliative Care (EAPC) published a White Paper aiming to define optimal

palliative care for people with dementia based on existing evidence and expert consensus.⁶ The proposed framework outlined 11 domains, including 57 recommendations ('subdomains'), with a view to guide clinical practice and policy change. In addition to its practice and policy agenda, the EAPC domains can provide a framework for the development of research in this context. A recent paper by Nakanishi et al.⁵ has applied the EAPC domains to evaluate national dementia strategies and their palliative care content. Our review set out to identify the range of long-term care facility interventions addressing the palliative care needs of people with dementia and investigate their alignment with the domains of care as identified in the EAPC White Paper. In particular, we focused on interventions that fostered inclusiveness of the person with dementia and their families in decision-making and care planning, taking patient-centredness to be an essential pillar for care for people with dementia, who may have less capacity to provide information about their needs and to directly contribute to decision-making to their care.⁷ In order to gain a more comprehensive description of current interventions available for this population, we sought to include a range of studies, including protocols, non-randomised studies and ongoing trials as well as randomised controlled studies. The review aimed to:

1. Describe the components of palliative care interventions that have been, or are being, developed for people with dementia in long-term care facilities, with a particular focus on those which included a focus on shared decision-making.
2. Examine the alignment of components with the EAPC framework domains.⁶

Methods

A systematic review with a narrative approach to synthesis was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)⁸ guidelines.

Protocol and registration

The systematic review protocol was registered on the international prospective register of systematic reviews (PROSPERO) (ID: CRD42018095649).

Eligibility criteria

We included peer-reviewed primary studies, in English, focusing on palliative care interventions that address the needs of people with dementia living in long-term care facilities. Long-term care facilities were defined as settings where care is provided for older people 24 h a day, 7 days a week for an undefined period of time (e.g. care homes, nursing homes and residential aged care facilities).⁹

Study design included qualitative, quantitative and mixed methods. The relevant population were people with any type of dementia in long-term care facilities who required and/or were receiving palliative care (as explicitly reported in the paper). Relevant interventions were those that supported palliative care for people with dementia, as defined by the EAPC White Paper domains as optimal care for this population.⁶

To identify multicomponent interventions focusing on shared decision-making and implemented at a service level, studies were included if they described interventions addressing Domains 2 or 3 and at least one other domain.⁶ Domain 2 (person-centred care and shared decision-making) and Domain 3 (setting care goals) were

selected to capture interventions that included at least one element that acknowledged the review’s focus on the centrality of person with dementia in decision-making and care. In addition, the intervention(s) could address any other domain(s). Domain 11 was not considered as it relates to policy issues, and as such, is aligned with system level rather than service level interventions.

Information sources

Searches on the databases MEDLINE, CINAHL, PsycINFO and CENTRAL were conducted from earliest dates until 25 September 2017. The searches were updated for all databases from 1 September 2017 (or from 25 September 2019 where possible) to 11 July 2019. Collectively, dates searched were from 1946 – current for MEDLINE, 1980 – current for CINAHL, 1806 – current for PsycINFO and in Issue 10 October 2017 for CENTRAL.

Lateral searching was conducted and included: (1) Google Scholar with keywords adapted from Box 1; (2) checking reference lists of two recent systematic reviews,^{10,11} and their included studies; and (3) searching of clinical trials registries for Australia/New Zealand,¹² United States of America,¹³ United Kingdom¹⁴ and the European Union¹⁵ to identify in-progress studies. Reference lists of relevant systematic reviews retrieved during the selection process were also searched. The systematic reviews themselves were not included.

Search terms were informed by a recent Cochrane review,¹⁰ modified to include non-randomised studies, Medical Subject Headings (MeSH) terms and keywords concerning palliative care and dementia, and search terms to capture studies describing interventions, strategies and their implementation. The MEDLINE search strategy is outlined in Box 1, with the modifications highlighted.

Box 1. Search strategy.

Database	Medline
Dates searched	1946 to current (11 July 2019)
Search terms	Murphy et al. ¹⁰
1. exp Dementia/	619
2. Delirium/	
3. Wernicke Encephalopathy/	
4. amnesia/ or cognition disorders/ or delirium/ or dementia/	
5. dement*.mp.	
6. alzheimer*.mp.	
7. (lewy* adj2 bod*).mp.	
8. deliri*.mp.	
9. (chronic adj2 cerebrovascular).mp.	
10. (“organic brain disease” or “organic brain syndrome”).mp.	
11. (“normal pressure hydrocephalus” and “shunt*”).mp.	
12. “benign senescent forgetfulness”.mp.	
13. (cerebr* adj2 deteriorat*).mp.	

(Continued)

Box 1. (Continued)

14. (cerebral* adj2 insufficient*).mp.
15. (pick* adj2 disease).mp.
16. (creutzfeldt or jcd or cjd).mp.
17. huntington*.mp.
18. binswanger*.mp.
19. korsako*.mp.
20. or/1-19
21. exp Palliative Care/
22. "Hospice and Palliative Care Nursing"/
23. Terminal Care/
24. "end of life".ti,ab.
25. palliative.ti,ab.
26. (dying adj3 (care or comfort or relief or strateg* or plan or intervention or pain)).ti,ab.
27. "symptom control".ti,ab.
28. (bereavement adj2 support).ti,ab.
29. or/21-28
30. 20 and 29
31. (strategy or strategies or implement* or intervention*).mp.
32. 30 and 31
33. Animals/
34. 32 not 33
35. limit 34 to English language

Study selection and data extraction

Search results were imported into EndNote X8 and selection criteria were applied independently by three reviewers (S.K., T.L. and M.V.G.). Two reviewers screened titles and abstracts (S.K. and M.V.G.) against inclusion criteria. Full text of potentially relevant studies was assessed for relevance by two reviewers (T.L. and M.V.G.). Any disagreements were resolved through discussion with a third reviewer (S.K.).

Data were extracted by three reviewers (S.K., T.L. and M.V.G.) using a Microsoft Office (2010) electronic pro-forma for EAPC Domains 1-10.⁶ Data were extracted under the following headings: author, year, location, setting, study design, participants, outcomes, results (including efficacy, if evaluated) and conclusions. Intervention data were extracted using the Template for Intervention Description and Replication (TIDieR) reporting checklist.¹⁶ Interventions were categorised based on the Cochrane Effective Practice and Organisation of Care (EPOC) Taxonomy for health interventions.¹⁷

Data were only mapped to an EAPC domain if the intervention explicitly mentioned an aspect of palliative care aligned with the phrasing in that domain. A study had to meet at least one subdomain within the domain of interest, in order for that domain to be addressed. The content could apply to more than one subdomain within the domain of interest.

Synthesis of results

Synthesis of results followed a narrative approach,¹⁸ structured around the aim, content and delivery of the

intervention described in the included studies in relation to the EAPC domains. Results on efficacy were descriptively summarised, if available, to provide context for the content of those interventions.

Risk of bias in individual studies

The main focus of the review was to describe the components of interventions rather than determine their efficacy; thus, papers were not formally assessed for risk of bias.

Results**Study selection**

Of 2221 references identified by database searches and an additional eight citations identified through lateral searching, 51 papers reporting on 32 studies met our inclusion criteria (Figure 1). The PRISMA flow chart details the original and updated search results for the review (Figure 1).

Study characteristics

Table 1 outlines the characteristics of the included studies.

Included studies were quantitative ($n = 22$),^{19–27,30,33,43,44,51,53,58,59,61,65–67} mixed methods ($n = 10$),^{28,30,31,34,38,45,49,54,56,60} qualitative ($n = 2$)^{42,52} and a description of an advance care plan process.⁶⁴ Studies included randomised control trials ($n = 11$)^{21–24,26,28,33,34,43,60,61} and non-randomised studies ($n = 16$).^{27,31,38,42,44,45,49,51,52,54,56,58,64–67}

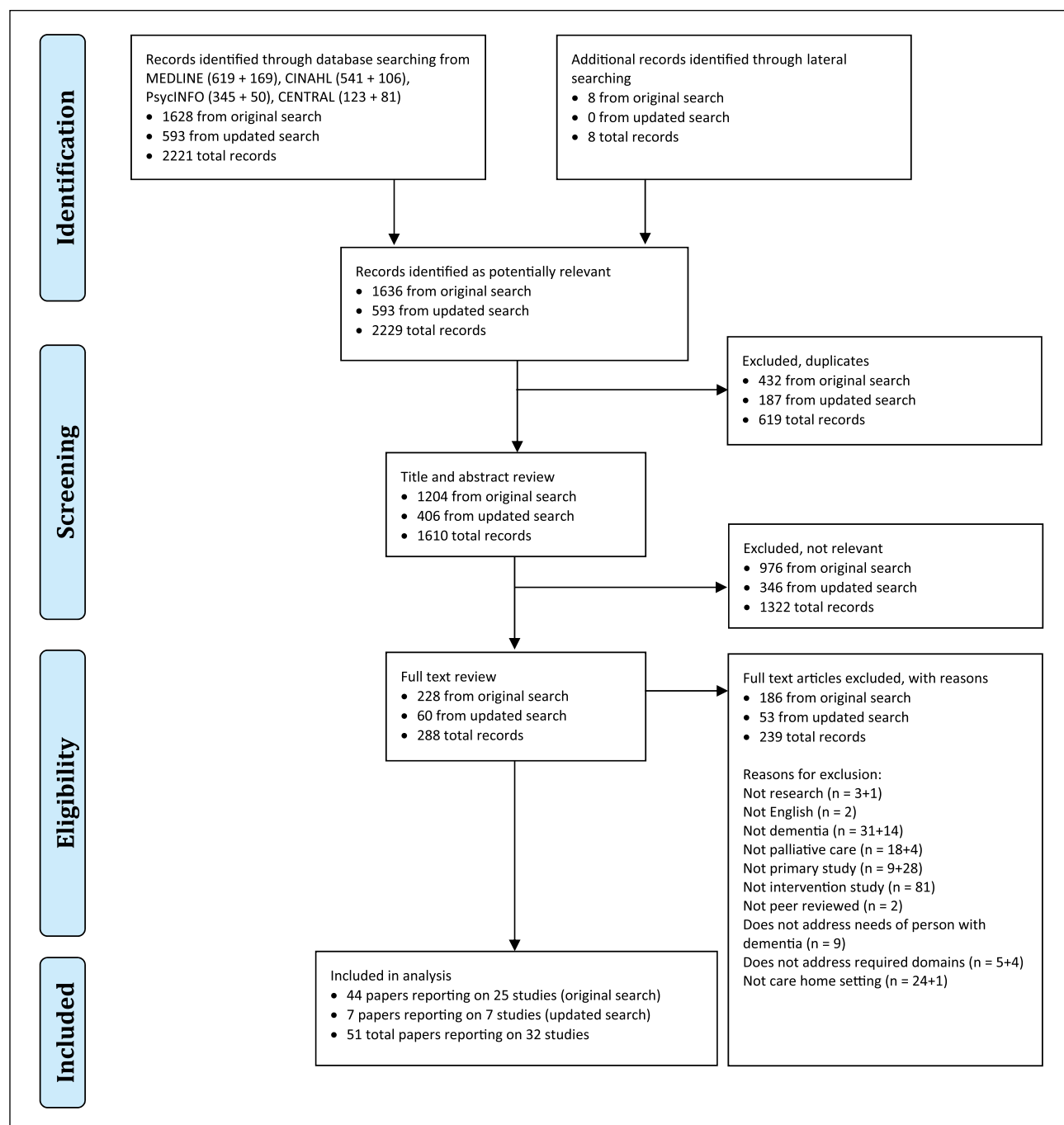


Figure 1. PRISMA flow diagram of included and excluded studies.

Studies originated from the United Kingdom ($n = 7$),^{22,33,38,42,44,45,54} United States ($n = 5$),^{19,23,25,34,61} Australia ($n = 4$),^{28,49,52,64} the Netherlands ($n = 6$),^{21,24,26,43,56,60} Canada ($n = 3$),^{27,56,65} Italy ($n = 2$),^{20,56} and one each from Belgium,³¹ and Japan.⁵⁶ Eighteen interventions were specifically developed for people with advanced dementia.^{19,23,24,27,28,34,38,42,49,51,53,56,58,61,64–67} Number of participants in the studies ranged from 16 to 688, with a median of 136 participants. Type of participants included residents, family members of residents, long-term care

facility staff (clinical and non-clinical) and health professionals external to the long-term care facility.

Interventions specifically targeted long-term care facility staff members ($n = 9$),^{25,44,51,52,54,58,59,66,67} family members ($n = 5$),^{23,34,53,56,61} or a combination of both ($n = 8$).^{21,23,24,26,38,59,60} Three interventions involved long-term care facility staff, family members and external health professionals.^{33,49,60} Two interventions involved long-term care facility staff and external health professionals (general practitioners and district nurses),^{30,45} three involved

Table 1. Summary of included studies.

Author and country	Study design	Aim(s)	Participants	Outcomes and measures	Findings	Domains addressed
Carpenter et al. ¹⁹ United States	Description of the protocol and preliminary findings	- Implement the Partnership Programme at four to six VA CLCs - Enhance implementation of the Partnership Programme using audit with feedback and action planning technique and implementing learning collaboratives - Evaluate the effectiveness of the Partnership Programme in increasing GOCC and documentation of preferences for LST using interrupted time-series analysis	CLC residents with a documented diagnosis of dementia and moderate to severe cognitive impairment	Increased documentation of a GOCC and the resulting LST plan by residents with dementia	Early partnership meetings highlight the importance of addressing project-level goals. Implementation challenges have been identified including arranging a time to hold meetings due to staff schedules and surrogate time restraints	2, 3, 6, 8
Di Giulio et al. ²⁰ Italy	Quality improvement study	Compare EOL care in NH residents with advanced dementia before and after an educational intervention aimed to improving palliative care	20 residents with advanced dementia from each NH: the last 10 who died before the intervention (pre-intervention group, $n = 245$ residents) and the first 10 who died at least 3 months after the intervention (post-intervention group, $n = 237$ residents)	Improving palliative care	- The number of residents receiving a palliative approach for nutrition and hydration increased, though not significantly, from 24% pre-intervention to 31.5% post-intervention - The proportion of tube-fed residents and residents receiving intravenous hydration decreased from 15.5% to 10.5%, and from 52% to 42%, respectively - Cardiopulmonary resuscitations decreased from 52/245 (21%) to 18/237 (7.6%) cases ($p = 0.002$)	1, 3, 6, 7
Boogaard et al. ²¹ The Netherlands	Randomised controlled trial	Test the effects of an audit-feedback strategy on quality of care and of dying in residents with dementia NHs	Family members ($n = 668$)	Family satisfaction with the care (SWC-EOLD) and comfort levels of their relative (CAD-EOLD)	- Generic feedback strategy resulted in lower satisfaction - Patient-specific feedback strategy resulted in increased comfort in unadjusted analyses - Team discussions about EOLD scores were not always feasible	2, 7, 8, 9
Froggatt et al. ²² United Kingdom	Protocol for a feasibility randomised controlled trial	Ascertain the feasibility of conducting a full trial of the Namaste Care intervention	NA (protocol)	Quality of dying (dementia) (CAD-EOLD) and Quality of life (QUALID)	NA (protocol)	2, 3, 8, 9
Mitchell et al. ²³ United States	Randomised controlled trial	Test whether an ACP video has an effect on documented advanced directives, level of care preferences, GOC discussions and burdensome treatments in residents with advanced dementia	Residents-caregiver dyads ($n = 402$)	Proportion of residents with DNH directives by 6 months; comfort care preferences (proxy interview); documented GOC discussions; burdensome treatments (per 1000 resident days)	- There were no significant differences in comfort care or in burdensome treatments between arms - The intervention arm was more likely to have documented GOC discussions at 3 months, and had a significantly higher cumulative incidence for acquiring a decision for no tube feeding - Proxies rated the video as helpful (68%), somewhat helpful (8.5%) or unhelpful (23.6%)	2, 3, 6,

(Continued)

Table 1. (Continued)

Author and country	Study design	Aim(s)	Participants	Outcomes and measures	Findings	Domains addressed
Pieper et al. ²⁴ The Netherlands	Cluster randomised controlled trial	Assess whether implementation of the stepwise multidisciplinary intervention also reduces pain and improves pain management	Residents with advanced dementia (<i>n</i> = 288)	Reduction in pain and improvement in pain management	There was an overall effect of the intervention on observed pain but not on estimated pain; Pain Assessment Checklist for Seniors with Limited Ability to Communicate–Dutch version, mean difference: –1.21 points (95% confidence interval: –2.35 to –0.06); Minimum Dataset of the Resident Assessment Instrument pain scale, mean difference: –0.01 points (95% confidence interval: –0.36 to 0.35)	1, 3, 7, 8
Rodríguez et al. ²⁵ United States	Performance improvement project	Improve care and quality of life for people with dementia	Team staff members (<i>n</i> = 32; certified nursing assistants, charge nurses, nurse manager, social workers, and a recreation therapist) NA (protocol)	Discomfort and intensity of discomfort using observation (breathing, facial expression, negative vocalisations, body language)	There was a significant decrease in the PAINAD scores from initial assessment (mean, 6.06) to follow-up (mean, 1.85) (<i>p</i> < 0.001), suggesting a reduction of patient discomfort	3, 7
Smaling et al. ²⁶ The Netherlands	Protocol of a cluster randomised controlled trial	Examine the effectiveness of the Namaste Care Family programme, an adapted version of the original Namaste Care, on (1) the quality of life of people with advanced dementia living in nursing homes and on (2) caregiving experiences of their family caregiver	NA (protocol)	<i>Primary outcome measures:</i> Quality of life and positive caregiving experiences <i>Secondary outcome measures:</i> Discomfort in person with dementia, quality (comfort) of dying, behavioural symptoms of dementia, medication use and health problems, caregiver burden, guilt and conflict in caregiving, family caregivers' grief	NA (protocol)	2, 3, 7, 8, 9
Verreault et al. ²⁷ Canada	Quasi-experimental study	Evaluate the impact of a multidimensional intervention to improve quality of care and quality of dying in advanced dementia in long-term care facilities	LTC residents with advanced dementia (<i>n</i> = 193)	Quality of care (using the FPCS) and quality of dying (using SM-EOLD and CAD-EOLD)	- The Family Perception of Care score was significantly higher in the intervention group compared to the usual care group (157.3 vs 149.1; <i>p</i> = 0.04) - The Comfort Assessment Score was also significantly higher in the intervention group compared to the usual care (35.8 vs 33.1; <i>p</i> = 0.03) - Symptom Management Score was significantly better in the intervention group compared to usual care (34.7 vs 29.8; <i>p</i> = 0.03)	1, 2, 3, 7, 9

(Continued)

Table 1. (Continued)

Author and country	Study design	Aim(s)	Participants	Outcomes and measures	Findings	Domains addressed
Agar et al., ²⁸ Luckett et al., ²⁹ Agar et al. ³⁰ Australia	Randomised controlled trial	Compare FCC efficacy to usual care in improving EOL care for residents with dementia in NHs	NH residents (<i>n</i> = 131)	Symptom related comfort (CAD-EOLD); family carer satisfaction with care (SWC-EOLD); perception of resident's symptom management (SM-EOLD)	- FCC group had management more consistent with a palliative care approach (<i>p</i> = 0.004) and higher rates of nurse-documented pain and discomfort (<i>p</i> = 0.04) and other symptoms (<i>p</i> > 0.001) - The end-point of quality of EOL care was underpowered due to the small sample size and did not show evidence of effect	1, 2, 3, 10
Ampe et al. ^{31,32} Belgium	Pre-post study	Evaluate the use of an SDM model on the policy and actual practice of ACP in NH dementia care units, and facilitators and barriers to its implementation	ACP audit: long-term care facility staff; management (<i>n</i> = 25), clinical (<i>n</i> = 65). ACP conversations: long-term care facility staff (<i>n</i> = 30)	Compliance with best practice of ACP policy (ACP audit); degree to which ACP was discussed (using ACP criteria); degree of involvement of residents and families in conversations (OPTION scale); views on importance, frequency and competence of realising SDM (IFC-SDM)	- ACP practice was more compliant with policy post-intervention (<i>p</i> = 0.013). There were no significant differences in average OPTION score for admission and crisis conversations, or for pre- and post-test - ACP was not discussed more frequently or at a significantly higher level after the intervention	2, 3, 10
Brazil et al. ³³ United Kingdom	Randomised controlled trial	Evaluate the efficacy of facilitated ACP with family carers in dementia care homes	Family carers (<i>n</i> = 142)	Family carer: Uncertainty in decision-making about resident care (DCS); Satisfaction with NH care (FPCS); psychological distress (GHQ); Quality of Dying in Long-Term Care (QOD-LTC); hospitalisation rates; completion rates (DNR orders); place of death	- There was reduced decision-making uncertainty (<i>p</i> < 0.001) and improved satisfaction (<i>p</i> = 0.01) in carers - There were no significant changes in carer distress, the number of completed DNR orders, hospitalisation reduction or the number of deaths in hospital	1, 2, 3, 6, 7, 8, 9, 10
Hanson et al., ^{34,35} Einterz et al., ³⁶ Rosemond et al. ³⁷ United States	Randomised controlled trial	Test if a GOC decision aid could improve communication and decision-making, quality of care and of dying in advanced dementia	Resident-surrogate dyads (<i>n</i> = 302)	Surrogate knowledge; quality of communication (QOC); surrogate-provider concordance (% of family surrogates who report that their primary goal and the primary goal of the NH staff are the same); number of palliative care domains addressed in the care plan	- There were significantly better rated QOC and EOL communication, and better concordance with providers in GOC in the intervention than in the control group - There was an increase in palliative care domains addressed in the treatment plans of intervention residents (<i>p</i> = 0.02)	2, 3, 6, 7, 10

(Continued)

Table 1. (Continued)

Author and country	Study design	Aim(s)	Participants	Outcomes and measures	Findings	Domains addressed
Moore et al. ³⁸ Jones et al., ³⁹ Saini et al., ⁴⁰ Elliott et al. ⁴¹ United Kingdom	Naturalistic feasibility study	Understand the operation and implementation of the 'Compassion' intervention in practice and collect data on its feasibility, acceptability and economic costs	Long-term care facility staff: trained ($n = 105$), interviewed ($n = 48$) Residents ($n = 9$), family carers (interviews) ($n = 4$)	<i>Resident outcomes:</i> Severity of chronic comorbidities (CCI); functional impairment (FAST); risk for developing pressure sores (Waterlow scale); levels of severe memory impairment (BANS-S); behavioural and psychological symptoms (NPI); agitated and potentially challenging behaviours (CMAI); pain during care tasks and at rest (PAINAD); comfort and pain the last 30 days (SM-EOLD); comfort at the end of life (CAD-EOLD); quality of life in the prior week (QUALID); formal and informal health and social care use Family carer outcomes: Feelings about caring, carer burden (Zarit Burden Interview); symptoms of anxiety and depression (HADS), satisfaction with care in advanced dementia (SWC-EOLD); perception of symptoms and comfort at the end of life, quality-adjusted life years (CAD-EOLD) Care-home level outcome data: no. of – ICL visits to NH and external HCPs; individual assessments completed; discussions with family members; weekly core meetings; individualised assessments (core meetings); individual reviews completed; referrals to external HCPs; monthly team meetings; residents assessed by ICL discussed at monthly team meetings; training sessions and their attendees NA	'Compassion' evoked improvements in advanced care planning, pain management and person-centred care - No harm was observed to occur in participating residents - Feasibility of implementation differed according to NH context, but was dependent on the ICL driving practice change	1, 2, 3, 5, 6, 7, 8, 9, 10
Stacpoole et al. ⁴² United Kingdom	Qualitative study (focus groups)	Report perceptions of families and staff on the implementation of Namaste Care	Long-term care facility staff ($n = 40$), managers ($n = 5$), family members ($n = 11$)	NA	Namaste Care fostered connection and relationship between care staff, residents and family members	2, 3, 8, 9, 10
van der Maaden et al. ⁴³ The Netherlands	Randomised controlled trial	Assess the effects of a practice guideline for the optimal relief of symptoms of pneumonia for residents with dementia	Residents ($n = 367$)	Comfort or lack thereof (DS-DAT, CAD-EOLD); pain (PAINAD); respiratory distress (RDOS); level of sleepiness (6-level scale); use of non-pharmacological measures	- The practice guideline for optimal symptom relief did not relieve discomfort and symptoms in NH residents: DS-DAT: 1.11 (95% CI 0.93–1.31), EOLD-CAD: 1.01 (95% CI 0.98–1.05), PAINAD: 1.04 (95% CI 0.93–1.15), RDOS: 1.11 (95% CI 0.90–1.24) - Lack of comfort and respiratory distress was found to decrease in both intervention and usual care groups	3, 5, 6, 7

(Continued)

Table 1. (Continued)

Author and country	Study design	Aim(s)	Participants	Outcomes and measures	Findings	Domains addressed
Garden et al. ⁴⁴ United States	Pre-post study, service evaluation	Explore the effects and examine the steps of implementing the Bromhead Care Home Service	Long-term care facility staff (<i>n</i> = 250)	Staff: Confidence in recognising, preventing and managing delirium and dysphagia; knowledge of factors associated with development of delirium and dysphagia; carer satisfaction; comparison between desired and actual place of death of residents; hospital admission rates; costs before and after intervention NA	There were high levels of carer satisfaction ACP and residents dying in their preferred place, as well as a reduction in hospital admissions	3, 6, 10
Amador et al., ⁴⁵ Iliffe et al., ⁴⁶ Amador et al., ⁴⁷ Evans and Goodman ⁴⁸ United Kingdom	Qualitative study (semi-structured interviews)	Explore the current need for support and EOL care of residents with dementia and develop evidence-based strategies to address these needs	Phase 1: residents with dementia (<i>n</i> = 133); Phase 2: residents with dementia (<i>n</i> = 74). Long-term care facility managers (<i>n</i> = 3); deputy managers (<i>n</i> = 3); GPs (<i>n</i> = 3); district nurses (<i>n</i> = 4)	NA	All fostered integrated working between care home staff and other health care practitioners, allowing for the development and implementation of context-specific practice changes	3, 5, 6
Toye et al. ^{49,50} Australia	Action research	Examine the effect of a COP on care delivery, staff and family knowledge of a palliative approach to dementia and on practice and care continuity	Long-term care facility staff (<i>n</i> = 72); family members (<i>n</i> = 28)	Staff post-intervention confidence and views (Wilcoxon Signed Ranked Tests); Changes since reconnaissance in areas targeted by action; staff knowledge (Dementia Knowledge Assessment Tool; Palliative Approach Questionnaire); views of practice change (staff and/or family survey responses)	- There was increased recognition of swallowing difficulties and agreement in avoiding hospitalisation, and small improvements in staff knowledge of dementia and a palliative approach - Staff (78%) felt the booklet would assist in decision-making, but some (26%) felt it might be overwhelming for families - All family members found the booklet helpful (<i>n</i> = 9), but some reported anxiety (<i>n</i> = 2) or being overwhelmed and confronted (<i>n</i> = 2)	1, 2, 3, 6, 7, 8, 9, 10
Nakanishi et al. ⁵¹ Japan	Pre-post study	Explore the effect of an adapted Japanese comfort care booklet on NH staff perspectives on palliative care for advanced dementia	Long-term care facility staff (nurses and other care workers) (<i>n</i> = 61)	Perspectives on palliative care for advanced dementia (qPAD)	- There was a significant increase in total qPAD knowledge scores, attitude scores and job satisfaction. There were no significant differences post-test in perceptions, beliefs and work setting support of families - Staff reported that the booklet validated the care they provide, and acknowledged its usefulness for families and the general public	1, 2, 3, 6, 7, 9, 10

(Continued)

Table 1. (Continued)

Author and country	Study design	Aim(s)	Participants	Outcomes and measures	Findings	Domains addressed
Stirling et al. ⁵² Australia	Qualitative study (interviews and written feedback)	Evaluate a tool developed to facilitate conversations about death and dying in LTCFs	Family members participating in meetings (<i>n</i> = 11)	NA	- Families reported clearer discussion and dialogue with staff - Staff reported the tool provided format and structure to discussions - Both staff and families reported more confidence in discussing the relative's dementia trajectory, deterioration, palliative care, and in talking about death	1, 2, 3, 5, 6, 9
Reinhardt et al. ⁵³ United States	Randomised controlled trial	Assess the effect of information and support provided to family members about treatment decisions for their relative with dementia	Surrogates of residents (<i>n</i> = 110)	Resident data regarding resuscitation, intubation, hospitalisation, feeding tube, intravenous lines, antibiotics, and comfort care Surrogate rated: care of resident (SWC-EOLD), perception of resident's symptom control and frequency of symptoms (SM-EOLD), surrogate depressive symptoms (PHQ-9); surrogate life satisfaction (Satisfaction with Life Scale)	- The intervention group: had higher care ratings; was more likely to include advanced directives to their relatives' chart with significant differences in 'Do Not Resuscitate', 'Do Not Intubate', 'Do Not Hospitalise', 'No Feeding Tube'; increase comfort care (not significant); no effect on 'No Antibiotics' or 'No IVs' orders - No significant effects on symptom management, surrogate well-being, satisfaction with life or with relatives' care	2, 3, 6, 7, 9, 10
Livingston et al. ^{54,55} United Kingdom	Pre-post study; interviews	Evaluate a programme designed to enable staff to better document and implement EOL advanced care wishes residents with dementia	Residents (<i>n</i> = 96)	Number of residents with dementia: Dying in care home; documented EOL conversations and/or DNR orders; with other advanced wishes; whose intervention was in line with advanced wishes; days spent in hospital in 3 months prior to death. Family rated: Quality of life of relative with dementia (QOL-AD); family carer stress symptoms; satisfaction with care (after-death bereaved family member interview)	- There was an increase in residents dying in the care home, dying having had an 'EOL conversation' with their families, and in DNR decisions - There was a decreasing trend in number of days spent in hospital, and positive trends for proxy rated QOL-AD (non-significant) post-intervention - All families were satisfied with their input into care decisions; satisfaction with pain control was unchanged; symptom control improved; overall satisfaction increased from 7.5 (SD 1.3) to 9.1 (SD 1.4) - Staff reported more confidence and being more comfortable with EOL planning and communication post-intervention	2, 3, 7, 8, 9, 10

(Continued)

Table 1. (Continued)

Author and country	Study design	Aim(s)	Participants	Outcomes and measures	Findings	Domains addressed
van der Steen et al. ^{56,57} Canada, The Netherlands, Italy	Mixed methods (questionnaires)	Evaluate a booklet on comfort care in dementia from the perspective of bereaved family members from three countries	Family caregivers: Canada (n = 54); the Netherlands (n = 59); Italy (n = 25)	Booklet acceptability (8-item acceptability scale); perceived usefulness of booklet (0–10 scale); preferred way of obtaining booklet	- Families positively rated booklets' quality of information, agreeability and acceptability - Italian families requested more information, and were more likely to score the booklet's acceptability lower than families from Canada and the Netherlands - Families expressed a wish for having the booklet available earlier in their relative's disease trajectory	2, 5, 6
Kuhn et al. ⁵⁸ United States	Pre-post study	Implement a programme of palliative care education, training, consultations and administrative coaching	Residents (n = 31), family caregivers (n = 33), long-term care facility staff (n = 80)	Resident data: use of antipsychotics, monthly blood draws, antibiotics, physical restraints, artificial nutrition, dietary supplements, diets without restrictions, weekly assessment of pain, daily treatment of pain, average body weights, emergency department visits, hospital admissions, use of 'Do Not Resuscitate Orders', 'hospice utilisation, and monthly visits by pastoral care staff; knowledge and attitudes towards advanced dementia of staff members (qPAD); family members (abbreviated qPAD); confidence in staff to provide them and their relatives with good care (5-point Likert-type Scale)	- Sample size was too small to detect any significant changes - NH2 showed more improvement in knowledge and attitudes of family members and staff - Both sites showed more routine pain evaluation for residents post-intervention	1, 2, 3, 6, 7, 8, 9, 10
Elliott et al. ⁵⁹ United Kingdom	Pre-post study	Provide staff with information and education to drive change in care practices	Long-term care facility staff (n = 86)	Attitudes to dementia (ADQ)	- ADQ scores increased in at least one attitude dimension (84% respondents), and in both dimensions in (38%), but decreased in both attitude dimensions in 7% of respondents - The project received positive informal feedback - The project time period was insufficient to collect conclusive data	2, 7, 9, 10

(Continued)

Table 1. (Continued)

Author and country	Study design	Aim(s)	Participants	Outcomes and measures	Findings	Domains addressed
van der Steen et al. ⁶⁰ The Netherlands	Mixed methods	Validate a prognostic risk score to assist in decision-making for residents with dementia and pneumonia	Clinical staff (<i>n</i> = 209); family members (<i>n</i> = 53)	Use and usefulness of the score; families' and nurses' perspectives on being informed of prognosis; nurses' self-reported role in decision-making and informing families; physicians' self-reported decision-making and information-providing behaviour	- Physicians found the score for learning purposes useful, but found it difficult to use a numerical approach for decision-making and prognostication - Most nurses perceived their involvement in informing families in varying degrees ('Always' 52%, 'Often' 38%, 'Sometimes' 10%) - Family members' preferences for being informed were numerical (43%), verbalised (35%), other approach (18%), no preference (5%)	2, 5, 6
Hanson et al., ^{61,62} Ersek et al. ⁶³ United States	Randomised controlled trial	Test the effects of a decision aid in improving the quality of decision-making about feeding options in advanced dementia	Resident-surrogate dyads (<i>n</i> = 256), intervention (<i>n</i> = 127), control (<i>n</i> = 129)	Surrogate decisional conflict (DCS); decisional regret (Decisional Regret Index); Knowledge about dementia and feeding options (Expectation of Benefit Index); surrogate reported: frequency of communication with health care providers; use of feeding treatments; resident variables: feeding problems, use of feeding treatments, orders not to tube feed, weight loss and mortality. Resident variables (MDS ADL Scale)	The decision aid improved surrogate knowledge scores ($p < 0.001$), lowered decisional conflict ($p < 0.001$), and saw more frequent discussions of feeding options with a health care provider ($p = 0.04$)	2, 6
Meller et al. ⁶⁴ Australia	Outline for an ACP service	Describe a process whereby treatment options for residents, who have lost decision-making ability, can be considered in advance of any further episodes of illness	NA	Number of: staff and PRs per facility attending education sessions; facilities with protocol for PR identification, residents with PR documented, enduring guardian appointments documented, ACDs written, discussions held, plans of treatment or other documentation attended, specialty opinions sought (as well as type), documented difficulties and issues, ACDs or PoT that present to acute facilities	The paper discussed the legal context of substitute decision-making; considered issues such as when to broach the topic of ACP and how to approach families regarding this issue	1, 2, 3, 10
Arcand et al. ⁶⁵ Canada	Pre-post study	Assess the impact of an NH pilot educational programme for nursing staff and physicians on comfort care and advance dementia, on family satisfaction with EOL care	Contact persons of residents with advanced dementia (<i>n</i> = 27)	Family member satisfaction with care (after-death bereaved family member interview)	Satisfaction scores were generally higher in the post-intervention group but no statistically significant differences were found	1, 2, 3, 5, 6, 7, 9, 10

(Continued)

Table 1. (Continued)

Author and country	Study design	Aim(s)	Participants	Outcomes and measures	Findings	Domains addressed
Kovach et al. ⁶⁶ United States	Pre-post study	Report the development, use and evaluation of a protocol for the assessment and treatment of discomfort for residents with dementia	Residents (<i>n</i> = 104)	Frequency of: scheduled and 'as needed' analgesic and psychotropic medication administered; use of non-pharmacological interventions to decrease resident's discomfort; demonstration of behavioural symptomatology commonly associated with discomfort	- Use of the protocol increased staff awareness of residents' discomfort and improved assessments - Protocol implementation was hindered by lack of time, staff resistance to change and difficulty to sufficiently educate staff	3, 7, 10
Kovach et al. ⁶⁷ United States	Pre-post study	Investigate the effect of hospice-oriented care on discomfort, physiological complications and behaviours associated with dementia	Residents: intervention (<i>n</i> = 35), control (<i>n</i> = 37)	Measurement of comfort (DS-DAT), behaviour (BEHAVE-AD) and physical complications	- The intervention group had a significantly lower levels of discomfort ($p < 0.001$). No significant effects on physical complications ($p = 0.957$) or behavioural problems ($p = 0.155$) were found - Interviews revealed that the intervention increased feelings of job satisfaction and of sense of empathy and caring in staff, and changed perceptions towards people with dementia - Family members reported perceiving fewer changes	3, 7, 10

ACP: advance care planning; ACD: advanced care directive; ADQ: Approaches to Dementia Questionnaire; AI: Appreciative Inquiry; BANS-S: Bedford Alzheimer Nursing Severity Scale; BEHAVE-AD: Behaviour pathology in the Alzheimer's disease; CAD-EOLD: Comfort Assessment in Dying with Dementia; CCI: Charlson Comorbidity Index; CMAI: Cohen-Mansfield Agitation Inventory; COP: community of practice; DCS: Decision Conflict Scale; DS-DAT: Discomfort Scale for Dementia of the Alzheimer's Type; DNR: Do Not Resuscitate; EOL: end of life; EOLD-CAD: End-of-Life in Dementia-Comfort Assessment in Dying scale; EOLD-SWC: End-of-Life in Dementia-Satisfaction with Care scale; EQ-5D-5L: EuroQol Group measure of health related quality of life; FAST: Functional Assessment Staging Scale; FCC: facilitated case conferencing; FPCS: Family Perceptions of Care Scale; GHQ: General Health Questionnaire; GOC: goals of care; GP: general practitioner; HADS: Hospital Anxiety and Depression Scale; HCP: Health Care Professional; ICL: interdisciplinary care leader; IFC-SDM: Importance, Frequency and Competence in Shared Decision-Making Questionnaire; MDS ADL Scale: Minimum Data Set Activities of Daily Living Scale; MDT: multidisciplinary team; NA: not applicable; NICE: The National Institute for Health and Care Excellence; NH: nursing home; NPI: Neuropsychiatric Inventory Questionnaire; NR: not reported; OPTION: Observing patient involvement in decision-making; PAINAD: Pain Assessment in Advanced Dementia; PCPC: Palliative Care Planning Coordinator; PR: Person(s) Responsible; PoT: Plan of Treatment; QOC: Quality of Communication; QOD-LTC: Quality of Dying in Long-Term Care; QOL-AD: Quality of life in Alzheimer's Disease; qPAD: Questionnaire on Palliative Care for Advanced Dementia; QUALID: Quality of Life in Late-Stage Dementia; RDOS: Respiratory Distress Observation Scale; RN: registered nurse; RUD-LITE: Resource Utilisation in Dementia; SDM: shared decision-making; SM-EOLD: Symptom Management at the End of Life in Dementia; SWC-EOLD: Satisfaction with Care at the End of Life in Dementia; VA: Veterans Affairs; CLC: community living centre; GOCC: goals of care conversation; LST: life-sustaining treatment; DNH: Do Not Hospitalise; LTC: long-term care; PHQ-9: Patient Health Questionnaire-9; LTCF: long-term care facility.

long-term care facility-based physicians^{24,43,45} and one was delivered by an external agent.³⁸

Duration of follow-up to the intervention ranged from 7 days to 36 months (median 6 months) post-intervention implementation. Six studies did not report on the duration of follow-up.

Synthesis of results

Interventions

Table 2 outlines the interventions described in the included studies.

Interventions involved educational material, including booklets (for staff and/or family),^{27,33,49,56,58,65} clinical practice guidelines (for physicians and/or long-term care facility staff),^{24,43,60,66} a communication tool (for staff),⁵² and video decision aids (for family).^{34,61} Other interventions included educational outreach (for staff members),^{19,20,26,33,34,38,44,49,53,54,58,59,65,67} structured family meetings (for long-term care facility staff and family members),^{27,34,53,61} expansion of roles (e.g. training nurses to be case managers⁶⁷ or coordinators),^{28,29} or modification to long-term care facility environments.^{22,24,26,42,67}

Some interventions focused on a particular need related to palliative care in dementia, such as facilitating communication with family members,^{28,31,52,53} advance care planning (ACP),^{28,29,31,33,44,54,64} symptom management^{24,30,49,51,56,58,65} and addressing psychosocial or spiritual needs.^{22,26,42} Other interventions were aimed at improving the overall knowledge regarding dementia and the role of palliative care in both long-term care facility staff^{20,34,49,58,59,67} and family.^{27,49,56,58,65}

EAPC domains

Table 3 maps the interventions in relation to each of the EAPC domains they addressed. On average, the interventions addressed five domains each. Table 4 describes the components of interventions as they relate to the EAPC domains.

All 10 domains were addressed to varying extent: Domain 1 ($n = 12$),^{20,24,27,33,38,49,51,52,56,58,64,65} Domain 2 ($n = 25$),^{19,21–23,26–28,31,33,34,38,42,49,51–54,56,58–61,64,65,67} Domain 3 ($n = 28$),^{19,20,22–28,31,33,34,38,42–45,49,51–54,56,58,64–67} Domain 4 ($n = 3$),^{28,45} Domain 5 ($n = 7$),^{28,38,43,45,52,60,65} Domain 6 ($n = 18$),^{19,20,33,34,38,43,44,49,51–53,56,58,60,61,65,67} Domain 7 ($n = 19$),^{20,21,24–27,33,34,38,43,51,53,54,56,58,59,65,66} Domain 8 ($n = 13$),^{19,21,22,24,26,33,38,42,49,54,56,58,67} Domain 9 ($n = 16$)^{21,22,26,27,33,38,42,49,51–54,56,58,59,65} and Domain 10 ($n = 17$).^{28,31,33,34,38,42,44,49,51,53,54,58,59,64–67}

Studies implemented educational material addressing Domain 1 ($n = 9$),^{24,33,38,49,51,52,56,58,65} Domain 2 ($n = 4$),^{23,34,52,60} Domain 3 ($n = 13$),^{23–25,33,34,51,52,56,58,61,65–67} Domain 6 ($n = 10$),^{23,33,34,49,51,52,56,58,61,65} Domain 7 ($n = 8$),

^{24,25,33,49,51,56,58,65} Domain 8 ($n = 3$),^{33,56,58} Domain 9 ($n = 7$)^{24,33,49,52,56,58,65} and Domain 10 ($n = 4$).^{34,49,58,65}

Clinical practice guidelines addressed Domain 2,⁶⁰ Domain 3,^{43,66} Domain 5,^{43,60} Domain 6,^{43,60} Domain 7^{43,66} and Domain 10.⁶⁶ Thirteen studies used educational outreach visits or educational meetings for long-term care facility staff and/or family members.^{19,27,33,34,38,44,49,53,54,58,59,65,67} These activities addressed Domain 1,^{27,49} Domain 2,^{19,27,31} Domain 3,^{19,27,31,33,44,54} Domain 5,⁶⁵ Domain 6,^{19,44,58,65,67} Domain 7,^{26,27,58,59,65,67} Domain 8^{19,54,67} and Domain 9.^{27,49,54,58,59,65} By virtue of being education and training for staff regarding palliative care in dementia, these interventions also addressed Domain 10.^{28,31,33,34,38,42,44,49,51,53,54,58,59,64–67} Nine studies proposed interventions that facilitate better resident case management addressing Domain 1,⁶⁴ Domain 2,^{28,31,33,53,54} Domain 3,^{23,31,33,44,52–54} Domain 4,^{28,34,64} Domain 7,^{33,34,54} Domain 9⁵³ and Domain 10.^{28,31,44,64}

Five interventions were considered to be resident/family mediated, addressing Domain 2,^{22,26} Domain 3,²³ Domain 5,²⁸ Domain 8⁴² and Domain 9.⁴² Two interventions involved the expansion or the creation of a role addressing Domain 2,⁶⁷ Domain 4²⁸ and Domain 10.²⁸ Four environment modification interventions addressed Domain 8.^{22,26,42,67}

One audit and feedback intervention addressed Domains 2, 7, 8 and 9.²¹ One intervention involved inter-professional communication between health professionals addressing Domains 3–5.⁴⁵ Other interventions involved telemedicine addressing Domain 9,⁵³ and monitoring health care delivery addressing Domain 7.⁵⁹ One intervention was informed by a national consensus process to form a model for end-of-life (EOL) care.³⁸

Domain coverage and theoretical underpinning

None of the studies addressed all ten considered EAPC domains as part of a single intervention. However, all ten EAPC domains were addressed to some extent across the included studies. The degree to which each study addressed each domain varied. The 'Compassion Intervention' had the most comprehensive coverage, supporting nine out of ten EAPC domains.^{38–41}

Apart from Domains 2 and 3, the most commonly addressed domains were Domain 10 ($n = 17$),^{28,31,33,34,38,42,44,49,51,53,54,58,59,64–67} Domain 6 ($n = 15$)^{33,34,38,43,44,49,51–53,56,58,60,61,65,67} and Domain 7 ($n = 14$).^{21,33,34,38,43,49,51,53,54,56,58,59,61,65,66} In contrast, the least commonly addressed domains were Domain 4 ($n = 2$)^{28,45} and Domain 5 ($n = 7$).^{28,38,43,45,52,60,65}

Seven of the included studies reported on the theoretical foundations of their interventions.^{28,31,34,38,42,45,49} Any available findings on intervention efficacy are summarised in Table 1. Included interventions were found to

Table 2. TIDieR table for included interventions.

Author	What	Comparator	Rationale and/or theory	Who provided	How	Where	When and how much	Adherence	Tailoring, Modifications
Carpenter et al. ¹⁹ Partnership programme	Collaborative Care Plans for CLC Residents with Dementia Meetings with staff members dedicated to discussing care preferences and GOCC	NR	Given the challenges in determining Care preferences for CLC residents with dementia, the principles of PCC and the LSTDI were combined to design a clinical innovation centred on building partnerships between CLC staff and family surrogate decision-makers to enhance care planning and LST decision-making	Staff members whom the family member believes know the Veteran well, including nursing assistants, activities directors, dietitians, nurses, psychologists, chaplains, nurse practitioners, physicians, or physician assistants	Face-to-face	Department of Veterans Affairs CLCs	Once off meeting	NA	NA
Boogaard et al. ²¹ 'The Follow-up Project'	Caregivers of people who died with dementia were invited to provide feedback (generic or resident-specific) using established instruments	Control group – no feedback	Audit and feedback was more effective when accompanied by active or passive interventions	A NH staff member sent questionnaires with EOLD instruments to family caregivers	Hard-copy written questionnaires	NHs, where a specially trained elderly care physician is responsible for the care	EOLD scales administered every 10 months for 20 months	Response rates – pre-intervention: 69.8%; intervention: 67.7%	Feedback reports in the generic feedback arm were generated from EOLD scores
Di Giulio et al. ²⁰	A lecture, followed by two meetings consisting of case discussions	Pre-educational intervention versus post-intervention	There is insufficient evidence to determine whether educational interventions really promote better EOL outcomes	The content of the lecture was determined by a panel of experts in palliative care, geriatrics, nursing, psychology, family medicine and bioethics	A lecture followed by two face-to-face meetings	29 NHs	A 7-h lecture, followed by two 3-h meetings	NR	NA
Froggatt et al. ²² 'Namaste Care (NC)'	Programme with sensory, psychosocial and spiritual components to enhance quality of life and of care for people with advanced dementia	Usual EOL care (two nursing homes allocated to this group)	Programme developed to address psychological needs of people with dementia as identified in previous literature	Nursing home staff	Face-to-face	A designated space in the nursing home	2 h twice a day, 7 days a week for 6 months	NR	NA

(Continued)

Table 2. (Continued)

Author	What	Comparator	Rationale and/or theory	Who provided	How	Where	When and how much	Adherence	Tailoring, Modifications
Mitchell et al. ²³ EVINCE – Educational Video to Improve Nursing Home Care in End-Stage Dementia	ACP video for proxies and a form to document their preference of care	Proxies in control facilities were read descriptions of the levels of care and preferences. Their choices were not communicated to clinicians and experienced usual ACP practices	Previous RCTs found proxies who viewed ACP videos were more likely to want comfort-focused care	Research assistants administered the videos on tablets	Videos were viewed on tablets. Preferences for care were documented on a form mailed or emailed to residents' clinicians, nursing units and/or social worker	64 NHs in the Boston area	12-min video, viewed once	NR	NR
Pieper et al. ²⁴ STA OPI	The STA OPI, stepwise, multidisciplinary and multicomponent approach, to improve the assessment and management of pain and challenging behaviour	Residents receiving usual care without a stepwise component	STA OPI has proven to be effective in improving behaviour in advanced dementia in the Netherlands and United States but effects on pain were not studied	Trained research assistants (psychologists, members, physicians, psychologists and physiotherapists)	Face-to-face	12 Dutch NHs	Observed and estimated pain was assessed at baseline and at 3 and 6 months post-intervention	Study had lost to follow-up rate of 50%	NR
Rodriguez et al. ²⁵	A training curriculum for certified nursing assistants for using the Pain Assessment in Advanced Dementia (PAINAD)	Pre-educational intervention versus post-intervention	Studies proposing a short and effective curriculum, primarily for certified nursing assistants (CNAs) on how to use and incorporate the PAINAD in daily patient care, are scarce	Training protocol session was offered by the project leader, a geriatric physician fellow	Face-to-face training session followed by two videos	Dementia unit	Several times across each of the three nursing shifts to capture all staff members. There were a total of five training sessions over a period of 2 weeks	No information is available regarding the 21 cases where the charge nurse was unable to complete the follow-up PAINAD by the shift's end	NA
Smaling et al. ²⁶ 'Namaste Care (NC)'	Programme with sensory, psychosocial and spiritual components that incorporates person-centred and palliative care approaches	Usual care NH	Other psychosocial interventions for people with dementia living in NHs often do not involve family caregivers or lack evaluation of the effects on family caregiving experiences	Nursing staff, volunteers and the primary researcher	Face-to-face	Dutch NHs	7-day-a-week programme, intended to be offered in 2-h sessions, twice a day		
Verreault et al. ²⁷	A training programme to physicians and nursing staff	Usual care	Experts suggest that nurse training could be more effective if followed by coaching in practice by a 'nurse facilitator'	Two nurse facilitators	Face-to-face training of physicians and nursing staff	Two LTC facilities	Training of physicians (3 h) and all nursing staff (7 h for nurses and 3.5 h for nurses' aids)	NA	NA

(Continued)

Table 2. (Continued)

Author	What	Comparator	Rationale and/or theory	Who provided	How	Where	When and how much	Adherence	Tailoring, Modifications
Agar et al. ²⁸	Case conferences, facilitated by a PCPC, elicited by pre-defined-specific clinical triggers	Usual care did not receive staff education, training or support, no restrictions were placed on education programmes, approach to care planning or decision-making	Clinical leadership train-the-trainer models and theoretical frameworks of expected trajectory informed intervention development	RNs from long-term care facilities were trained for PCPC role. Training provided by team of physicians, nurses and consumers	RNs trained face-to-face, supported through teleconference; FCCs conducted face-to-face	20 NHs in two major cities meeting the following criteria: (1) 100 beds, (2) 50% people with dementia and (3) designated as facility providing intensive level of NH care	Case conferences conducted 16 h/week for 18 months, prompted by dementia-specific clinical triggers	69% residents received at least one case conference (FCC arm), compared to 44% residents (usual care arm) ($p = 0.004$)	Discussion topics individualised to what was seen as important for the resident
Ampe et al. ³¹ 'We decide (Discussing End of Life Choices)'	Long-term care facility staff in management and clinical levels were trained to conduct ACP conversations using a three-step SDM model	Control group did not receive the intervention until after data collection	Three-step SDM model-guided intervention and instrument development	Experienced communication trainer conducted workshops	Face-to-face	18 NHs	Three 4 h workshop modules, in 4 weeks	ACP discussed in 7/11 intervention group conversations, and in all control group 10 conversations	Not reported
Brazil et al. ³³	A trained ACP facilitator, family education and meetings, ACP documentation, GP and NH staff orientation	Control group received only usual care	Guidelines suggest a trained facilitator, family education and meetings, documentation of ACP decisions and orientating GPs and long-term care facility staff to the intervention are important elements of ACP	RN was trained as ACP facilitator	Face-to-face family meetings; face-to-face orientation and Internet training for ACP facilitator	24 NHs in Northern Ireland, United Kingdom	Two family meetings and one follow-up	67/80 family carers who responded to the questionnaire also completed the intervention	No modifications were made to the intervention from the pilot phase
Hanson et al. ³⁴	Video decision aid for surrogate decision-makers outlining GOC care choices and a structured NH care plan	Control sites –informational video on interacting with a person with dementia; usual care plan meeting with staff; staff received 45-min training on study procedures	Decision aid section on SDM and discussions were based on established framework for informed decision-making	Nurses, social workers, therapists and nutritionists trained by investigators to conduct GOC discussions; Research staff provided decision aid and discussion guide	Video decision aid; face-to-face GOC discussions; Written discussion guide	22 NHs in North Carolina, which varied in size, profit status and diversity of residents	Decision aid review averaged 20 min. GOC discussion was scheduled several weeks after the viewing	Both components of the intervention were delivered to 90% of the participants. One facility required retraining	NR

(Continued)

Table 2. (Continued)

Author	What	Comparator	Rationale and/or theory	Who provided	How	Where	When and how much	Adherence	Tailoring, Modifications
Moore et al. ³⁸ The 'Compassion (Care of Memory Problems In Stages: Improving Our Knowledge) Programme'	Model of enhanced integrated care delivered by ICL to facilitate integrated care, and provide education, training and support to NH staff	Baseline assessment data were compared with an earlier cohort study but no statistical comparisons were made	Intervention development informed by literature and current policy, workshops and interviews with health and social care professionals and with residents and carers. It was then mapped to sociological theories of process and impact	ICL was an external coordinator with a social care background and experience of working with people with dementia in NHs, and received supervision from clinicians with palliative and dementia expertise	Face-to-face weekly core team meetings and monthly wider interdisciplinary team meetings; online resources	2 NHs in northern London, United Kingdom, operating within different local funding systems for health care and social care services	Weekly core meetings, monthly wider meetings (6-month period). Some assessments were prompted by resident-specific triggers	Many weekly core meetings were cancelled due to staff leave or needs. Monthly immediate resident meetings could not be established in NH2. NH1 saw more attendees for training sessions than NH2	NR
Stacopole et al. ⁴² 'Namaste Care (NC)'	Programme with sensory, psychosocial and spiritual components to enhance quality of life and of care for people with advanced dementia	NA	Programme developed to address psychological needs of people with dementia as identified in previous literature. Implementation underpinned by organisational action research	Research staff conducted NC workshops. Two NC workers were chosen from NH staff	Face-to-face workshops and NC sessions	6 NHs in the United Kingdom; 2 care homes were NHS Specialist Care Units with residents with complex behavioural problems	1-day workshop; NC programme was 2 sessions every day for 7 days, one session each in the morning and in the afternoon	Four NHs achieved the full programme by the end of the implementation period; one NH only held morning sessions with occasional afternoon sessions	NR
Amador et al. ⁴⁵ 'EVIDEM-EOL (Evidence-based Interventions in Dementia at the End of Life)'	Phase 1 tracked care and needs of residents; Phase 2 – AI meetings held to share long-term care facility goals and concerns	Resource use and associated costs were compared between Phase 1 and Phase 2	AI is an organisational development tool used to discover what drives and sustains people and organisations when they are most effective	Palliative care nurse researcher facilitated AI meetings	Face-to-face AI meetings	6 NHs in the East of England	3 meetings over 6 months	NR	EOL tools developed and implemented at each NH were specific to the context of each NH and concerns arising from AI discussions
Garden et al. ⁴⁴ The Bromhead Care Home Service (BCHS)	Educational programme for nurses and staff, on ACP, delirium and eating, drinking and dysphagia	Post-training staff data	Role of anticipatory care in end-stage dementia to reduce hospital admission is lacking in evidence. Delirium, a common trigger for admission, is partially preventable	2 RNs provided service and were supported by a consultant liaison psychiatrist	Face-to-face education session. Additional material was provided in a reference file	7 NHs in Boston (United Kingdom)	Programme offered 6–8 times via small group teaching	250 staff trained, 124 staff completed pre-education evaluation and 90 staff completed post-education evaluation	NR

(Continued)

Table 2. (Continued)

Author	What	Comparator	Rationale and/or theory	Who provided	How	Where	When and how much	Adherence	Tailoring, Modifications
van der Maaden et al. ⁴³	Practice guideline for pneumonia: a symptom checklist; instruments for monitoring pain and respiratory distress; tailored treatment recommendations	Control homes were informed an intervention was introduced into intervention homes but were not informed of its contents	Guideline development was based on existing guidelines, literature and consensus in a Delphi study	Physicians used guideline at their own discretion	NR	32 Dutch NHs, which employ elderly care physicians	Guideline introduced in 1 meeting. Monthly reminders to use guideline through emails, semi-annual newsletters and phone calls	399 pneumonia episodes were reported. An additional 131 pneumonia episodes were reported but observations could not be performed on time	Residents were included upon clinical diagnosis rather than with McGeer's surveillance criteria for pneumonia; RDOs for respiratory distress was used to address respiratory difficulty. Reaction Level Scale was not used to assess coma
Nakanishi et al. ⁵¹ The 'Comfort care at the end of life for persons with Alzheimer's disease or other degenerative diseases of the brain' booklet – Japanese adaptation	Translation and cultural adaptation of booklet on comfort care in dementia for use in Japan was introduced to long-term care facility staff in a seminar	Post-intervention questionnaire scores	Cultural differences exist in EOL care for dementia between Japan and Western countries	RN researchers conducted the seminar and presented the contents of the booklet	Face-to-face seminar	4 long-term care facilities in Japan	30 min seminar; 60 min debriefing meeting	NR	NR
Toye et al. ⁴⁹	COP formed from participating organisations, and implemented education programmes for staff and families	Pre-training questionnaires and scores	COPs facilitate shared understandings and goals. Action research engages community of practice members in a cyclical research process	COP members (6 nurses, case manager, care coordinator, physician) provided staff members with education modules; a counsellor and a medical practitioner delivered an education session for family carers	Face-to-face education sessions; hard-copy version of educational booklets for staff and family	COP members were drawn from various settings (e.g. the local community, residential aged care and mental health and aged care wards in hospitals); intervention phases could only be implemented in LTCFs and community-based care settings	Monthly COP meetings; education session frequency and duration not reported	52 of 132 eligible staff and 9 of 28 family members responded to the staff survey and information evaluation survey, respectively	NR
Reinhardt et al. ⁵³	Structured conversations about EOL options and treatment decisions with family members with telephone follow-up	Usual care group did not receive face-to-face contact and only received telephone support	Having staff specifically trained in palliative care can enable better communication integral for EOL care decisions. Conversations followed an 'ask-tell-ask' model	Physician and social worker conducted structured meetings; palliative care team consisted of two certified palliative medicine physicians and a palliative care social worker	Face-to-face meetings; telephone follow-up	Large skilled nursing facility in the Northeast. Palliative care nurses were not available at this facility	Structured meetings duration mean 47 min; Telephone follow-up every 2 months over 6 months, and calls duration mean 10 min	96/110 initial surrogates completed a Time 2 interview (at 3 months) (12.7% attrition rate) and 90 surrogates completed a Time 3 interview (at 6 months) (15.1% attrition rate)	Telephone follow-up was a continuation of issues discussed in meetings as suggested by family members

(Continued)

Table 2. (Continued)

Author	What	Comparator	Rationale and/or theory	Who provided	How	Where	When and how much	Adherence	Tailoring, Modifications
Stirling et al. ⁵² Talking about Dementia and Dying – a discussion tool for residential aged care facility staff	Discussion tool for long-term care facility staff covering: palliative approach in dementia, communicating with families about death and supporting staff in real-life situations	NA	Tool development – based on clinical practice guidelines on communicating prognosis and EOL issues in advanced stages of life-limiting illnesses, diagnosis disclosure and collaborative communication	Dementia resource nurse (role developed for study) conducted meetings with tool	Face-to-face meetings; hard-copy booklet	Aged care facilities in two Australian states. Number of aged care facilities involved or included aged care facilities was not reported	9 family meetings were conducted	NR	A section that addressed interactions with relatives outside of formal family meetings was added after tool stakeholder review
Livingston et al. ⁵⁴	An interactive training programme aimed at increasing the implementation of advanced care wishes	Pre-intervention data	Communication issues, cultural differences and fear of blame may be barriers to improving EOL care in dementia in long-term care facilities	A consultant physician and long-term care facility senior managers developed the education programme; Education sessions were delivered by members of the research team and other LTCF staff	Face-to-face	120-bed NH for older people, providing care recognising Jewish traditions, beliefs and cultures, for people throughout the religious spectrum	Training programme consisted of 10 sessions	NR	NR
Elliot et al. ⁵⁹	Training sessions based on person-centred dementia care, developing activities centred on reminiscence and life story work, falls causation and prevention	Pre-intervention data	Training sessions were structured around the UK NICE 2010 Dementia Quality Standard. Implementation was based on technical practice development combined with emancipatory practice development	The training team consisted of clinical psychologist, mental health nurses, occupational therapist, mental health workers in psychology and occupational therapy, speech and language therapists, pharmacist and an administrator	Face-to-face	43 care homes expressed interest	Training consisted of five core sessions, each lasting 3 h	NR	NR
Kuhn et al. ⁵⁸	Staff training and administrative coaching, case consultations with a project nurse and information booklet for all participating staff and family members	Pre-intervention data	Based on similar multimodal programme, which incorporated resident life stories into care practices and planning, creating a homelike environment, anticipating needs and empowering caregivers	Who provided training was not reported. Palliative care consultation was delivered by physicians from the hospice; weekly case consultations were conducted with a project nurse	Face-to-face interactive training sessions; web-based education booklet	2 NHs in Chicago with the same parent organisation, selected for their willingness to participate in the pilot project	12 h of training in 6 modules, one palliative care consultation, and weekly case consultations over 1 year	NR	NR

(Continued)

Table 2. (Continued)

Author	What	Comparator	Rationale and/or theory	Who provided	How	Where	When and how much	Adherence	Tailoring, Modifications
van der Steen et al. ⁵⁶	Adaptation and translation of booklet covering topics on course of dementia, expected complications, decision-making, dying and grief	NA	Decision-making is complex in dementia due to lack of evidence for effectiveness of treatment and family members may need support and guidance	Original booklet was translated by local teams in each country, consisting of researchers, ethicists and physicians. Research team provided families with the adapted booklet	NR	Long-term care facilities in French-speaking Canada (5 NHs, 2 of which participated in studies to develop the booklet), and the Netherlands (29 long-term care facilities, employing 23 separate physician teams; 23 NHs and 6 residential homes) and Italy (4 NHs)	Families invited to participate 2 months after the death of relative with dementia, and were given the booklet and evaluation instrument upon consenting to participate	Response rates: 55% (Canada), 69% (the Netherlands), 76% (Italy)	NR
Hanson et al. ⁶¹	Structured decision aid covering: dementia, feeding options, outcomes, advantages/disadvantages of feeding tubes or assisted oral feeding	Control surrogates received usual care, and any information from health care providers. All other study procedures were identical for intervention and control participants	Decision aids designed for surrogates are lacking. A previous study in tube feeding has shown that decision aids can improve knowledge and decisional conflict but randomised controlled studies are lacking	Family decision-makers viewed the decision aid with a research assistant	Print, audio or video format decision aid (format of participants' choice)	24 NHs in North Carolina, with varied organisational characteristics were recruited and randomised in pairs matched on variables associated with tube feeding rates: for-profit or non-profit status, size, and percentage of African-American residents	Surrogates viewed the decision aid once and were given a copy to review at home and were encouraged to use in future discussions	126 of 127 dyads completed a 3-month follow-up assessment; 101 dyads completed a 9-month follow-up (intervention group). 127 out of 129 resident-dyads completed the 3-month follow-up assessment and 100 out of the 127 completed the 9-month follow-up (control group)	Additional brief chart reviews were added to the protocol
van der Steen et al. ⁶⁰	Risk score to estimate mortality risk in patients with dementia and pneumonia, listing risk factors and brief recommendation to communicate risk as a frequency	Control group completed a survey only and did not receive the risk score	Current evidence on the use of risk scores are lacking evidence on clinical impact on decision-making	NHs physicians used the risk score	Face-to-face; hard-copy version of score	Residential care settings in the Netherlands, where NHs employ physicians	NH physicians advised to use score for their next case of pneumonia in any of their dementia patients. Physician focus groups duration: mean 85 min	Physicians only used the score in 21 out of 31 cases	NR

(Continued)

Table 2. (Continued)

Author	What	Comparator	Rationale and/or theory	Who provided	How	Where	When and how much	Adherence	Tailoring, Modifications
Arcand et al. ⁶⁵	Educational programme for NH staff, providing staff with an information booklet that was also optionally available to families	Pre-training data	Palliative care training interventions for long-term care facility staff are not often specific to the challenges of dementia specifically for EOL, and rarely involve physicians	Administrators facilitated implementation. In-house geriatric clinical nurse specialist helped organise educational sessions and facilitate staff participation	Face-to-educational sessions for staff; hard-copy booklet 'Comfort Care at the End of Life'	One NH which cares for a heterogeneous Jewish population, with no palliative care unit	Educational sessions for nursing staff were 45 min (24 sessions); educational sessions for physicians were 60 min	Participation rate: was 60% (post-intervention 27/45, and pre-intervention 21/35). 4/21 recruited contact persons (19%) received the information booklet	NR
Meller et al. ⁶⁴	10-step plan for implementing ACP within Long-term care facilities for residents without decisional capacity	NA	The described ACP programme was developed with consideration to legal context and establishment of a paradigm to determine when ACP should occur	NA	NA	NA	NA	NA	NA
Kovach et al. ⁶⁶	Long-term care facility staff were trained in the use of the protocol to assess and manage pain and discomfort in people with dementia	Pre-test data	Tools are needed that recognise pain and discomfort as having various non-physiological sources and non-verbal cues, as people with dementia may lack the language skills or cognitive capacity to express their pain	RNs and Licenced Practical nurses administered the protocol	Face-to-face	57 Long-term care facilities in Wisconsin were recruited. 32 Long-term care facilities had the ADD Protocol implemented and its use evaluated	An education session (8 h) followed by a second conference (4 h) 3 months later. Use of ADD was triggered when a resident showed signs of possible physical or affective discomfort	NR	Any non-pharmacological interventions were planned around the resident's stress threshold
Kovach et al. ⁶⁷	Developing households NHs, training nurses as case managers, general training of staff regarding hospice concepts, dementia, activity programming and family and spiritual care	Control group received traditional care for the long-term care facility	There was a lack of consensus in defining the essential concepts that relate to hospice care for people with end-stage dementia	Interventions were developed by an interdisciplinary task force which included two nurse consultants. Case managers were chosen from RNs at facilities	Face-to-face	3 Long-term care facilities were chosen by convenience as sites for the study. The long-term care facilities were all geographically close, which facilitated interagency meetings, and coincidentally, all had the same religious affiliation	Training and education given through one all-day conference	NR	NR

TIDieR: Template for Intervention Description and Replication; ACP: advance care planning; AI: Appreciative Inquiry; COP: community of practice; CLC: community living centre; EOL: end of life; GOC: goals of care; GP: general practitioner; ICL: interdisciplinary care leader; MDT: multidisciplinary team; NA: not applicable; NH: nursing home; NR: not reported; PPC: Palliative Care Planning Coordinator; RN: registered nurse; SDM: shared decision-making; RCT: randomised controlled trial; GOC: goals of care conversation; PCC: palliative care clinic; LSTD: life-sustaining treatment decisions initiative; LST: life-sustaining treatment; EOLD: End-of-Life in Dementia; LTC: long-term care; FCC: facilitated case conferencing; RDOS: Respiratory Distress Observation Scale; LTCF: long-term care facility.

Table 3. Intervention mapping to EAPC domains.

Study	Domain 1	Domain 2 ^a	Domain 3 ^a	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10
	Applicability of palliative care	Person-centred care, communication shared decision-making	Setting care goals and advance planning	Continuity of care	Prognostication and timely recognition of dying	Avoiding overly aggressive, burdensome or futile treatment	Optimal treatment of symptoms and providing comfort	Psychosocial and spiritual support	Family care and involvement	Education of the health care team
Carpenter et al. ¹⁹		x	x			x		x		
Di Giulio et al. ²⁰	x		x			x	x			
Boogaard et al. ²¹		x					x		x	
Froggatt et al. ²²		x	x					x	x	
Mitchell et al. ²³		x	x			x				
Pieper et al. ²⁴	x		x				x	x		
Rodriguez et al. ²⁵		x	x			x	x			
Smaling et al. ²⁶		x	x			x	x		x	
Verreault et al. ²⁷	x		x				x			
Agar et al. ²⁸		x	x	x						
Ampe et al. ³¹		x	x		x					x
Brazil et al. ³³	x	x	x			x		x		x
Hanson et al. ³⁴		x	x			x			x	x
Moore et al. ³⁸	x	x	x		x	x	x		x	x
Stacopole et al. ⁴²		x	x					x	x	x
Amador et al. ⁴⁵			x		x					
Garden et al. ⁴⁴			x	x						
van der Maaden et al. ⁴³			x		x	x	x			x
Nakanishi et al. ⁵¹	x	x	x			x	x		x	x
Toye et al. ⁴⁹	x	x	x			x	x		x	x
Reinhardt et al. ⁵³		x	x			x	x		x	x
Stirling et al. ⁵²		x	x			x			x	
Livingston et al. ⁵⁴	x	x	x		x			x	x	x
Elliot et al. ⁵⁹		x					x			
Kuhn et al. ⁵⁸	x	x	x			x	x	x	x	x
van der Steen et al. ⁵⁶	x	x	x			x	x	x	x	
Hanson et al. ⁶¹		x				x				
van der Steen et al. ⁶⁰		x			x	x				
Arcand et al. ⁶⁵	x	x	x		x	x	x		x	x
Meller et al. ⁶⁴	x	x	x							x
Kovach et al. ⁶⁶		x	x				x			x
Kovach et al. ⁶⁷		x	x			x				x
Number of studies addressing each domain	12	25	28	2	7	18	19	13	16	17

EAPC: European Association for Palliative Care.

^aDomains 2 and 3 were inclusion criteria for this systematic review.

Table 4. Mapping of intervention components to EAPC domains.

Study	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10
Carpenter et al. ¹⁹		<i>Educational outreach</i> Partnership programme that uses principles of shared decision-making to engage family members in structured conversations	<i>Educational outreach</i> Partnership programme to build support and trust, improve goals of care discussions and enhance outcomes			<i>Educational outreach</i> Partnership programme considers that limiting oral intake and instead using medical-administered nutrition may not align with the pleasure gained from eating		<i>Educational outreach</i> Partnership programme includes activities such as attending religious services		
Boogaard et al. ²¹		<i>Audit and feedback</i> EOLD-SWC scale asked family how involved family felt in decision-making for resident; asked if health care team was sensitive to needs and feelings of family					<i>Audit and feedback</i> EOLD-CAD scale asked family whether the resident's symptom management and comfort needs were met	<i>Audit and feedback</i> EOLD scale asked family whether the resident's spiritual needs were met	<i>Audit and feedback</i> EOLD scales used by families to rate the quality of care of their relative	
Di Giulio et al. ²⁰	<i>Educational material</i> A 7 h lecture offering training in the appropriateness of EOL interventions		<i>Educational material</i> A 7 h lecture offering training in optimising patient comfort							
Froggatt et al. ²²		<i>Resident/family mediated</i> Meetings with family informed sources of comfort and pleasure for the relative	<i>Environment modification</i> Aims to give comfort and pleasure to people with advanced dementia through engagement, meaningful and creative activities as well as sensory stimulation					<i>Environment modification</i> An environment that is made 'special' and calm and is welcoming and homely, with natural or slightly dimmed lighting	<i>Resident/family mediated</i> Family were encouraged to take part in nursing care and activities with the resident	

(Continued)

Table 4. (Continued)

Study	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10
Mitchell et al. ²³		<i>Educational material</i> • Video decision aid contained information on ACP and comfort care <i>Resident/family mediated</i> • Proxy's preferred level of care was documented	<i>Educational material</i> • Video decision aid presented different levels of care <i>Case management</i> • Documented level of care was shared with clinicians, nursing units and social worker, and placed in medical records			<i>Educational material</i> • Video decision aid provided information about comfort care (e.g. that hospitalisation would be avoided except when needed for comfort)				
Pieper et al. ²⁴	<i>Clinical practice guideline</i> • A tool that focuses on the needs of people with dementia to maximise comfort		<i>Clinical practice guideline</i> • A tool that focuses on the needs of people with dementia to maximise comfort				<i>Clinical practice guideline</i> • A tool to access pain and physical needs; and administration of non-pharmacological comfort treatment	<i>Environment modification</i> • Perform affective needs assessment (environmental stress threshold not excesses, balance between sensory-stimulatory and sensory-calming activity, and meaningful human interaction each day)		
Rodriguez et al. ²⁵			<i>Educational material</i> • The PAINAD to assess discomfort				<i>Educational material</i> • The PAINAD to assess discomfort and intensity of discomfort			
Smaling et al. ²⁶		<i>Resident/family mediated</i> • Meetings with family informed sources of comfort and pleasure for the relative	<i>Environment modification</i> • Aims to give comfort and pleasure to people with advanced dementia through engagement, meaningful and creative activities as well as sensory stimulation				<i>Educational outreach</i> • Programme to ensure resident comfort and screening for signs of pain	<i>Environment modification</i> • A calm environment with soft music or nature sounds and pleasant scents, without external distractions	<i>Resident/family mediated</i> • Family caregivers and volunteers invited to participate in the Namaste sessions	

(Continued)

Table 4. (Continued)

Study	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10
Verreault et al. ²⁷	<i>Educational outreach</i> • Training programme including how to recognise EOL signs	<i>Educational outreach</i> • Training programme including a patient and family-centred approach and teamwork	<i>Educational outreach</i> • Training programme including advance directives and communication with families				<i>Educational outreach</i> • Training programme including the recognition of pain and discomfort, mouth care, signs and controlling symptoms at the end of life		<i>Educational outreach</i> • Training programme including support to families at end of life and following death	
Agar et al. ²⁸		<i>Case management</i> • Facilitated case conferences for resident, family and MDT staff used shared agenda-setting model <i>Educational outreach</i> • Training sessions to train nursing and direct care staff in person-centred palliative care	<i>Case management</i> • PCPCs trained to facilitate case conferences, implement palliative care plan	<i>Expansion of role</i> • Nurses from within care homes were assigned PCPC roles to facilitate case conferences	<i>Resident mediated</i> • Evidence-based triggers were used to identify residents who would benefit from a case conference				<i>Educational outreach</i> • Nurses were trained for the PCPC role • PCPCs were in turn trained to train other fellow staff in person-centred palliative care	<i>Educational outreach; expansion of role</i> • Nurses were trained for the PCPC role • PCPCs were in turn trained to train other fellow staff in person-centred palliative care
Ampe et al. ³¹		<i>Educational outreach</i> • Staff training: SDM framework is the basis of the ACP process	<i>Educational outreach</i> • Staff training modules on conversations: at admission, in daily informal contexts, in crisis situations							<i>Educational outreach; inter-professional education</i> • Clinical and management staff were trained in the implemented ACP protocol

(Continued)

Table 4. (Continued)

Study	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10
Brazil et al. ³³	Educational material Booklet for families highlighted the need for palliative care approach	Case management - ACP meetings with family invited to review ACP Educational material - Booklet for families recommending families to have open discussions with the resident's doctor and that family should be well informed	Educational material Booklet for families informed approach to care that optimises comfort at the end of life			Educational material - Booklet for families outlining risks associated with hospital transfer; discomfort associated with tube feeding - Considerations to be made for antibiotic use in the event of pneumonia	Educational material - Booklet for families recognising non-verbal indications for pain and discomfort - Advises that some medications can be administered to minimise discomfort - Includes importance of nursing care (hygiene and skincare) for comfort and dignity	Educational material - Booklet for families acknowledging religious authorities' stance on bereavement and where to seek support - Information on measures at the end of life that family discuss such concerns with a religious or spiritual representative	Educational material - Booklet was provided to family members before ACP meeting - Information on bereavement and where to seek support were outlined in booklet	Educational outreach A selected ACP facilitator was trained on ACP facilitation and EOL care
Hanson et al. ³⁴		Educational material Decision aid covered elements of shared decision-making	Educational material Decision aid with information on the role of surrogate decision-maker, treatment goals and options consistent with these goals			Educational material Decision aid provided information on comfort care goals (noting that hospital admission is only done if to improve comfort); medicines and fluids should be taken by mouth, contains orders not to use life support	Educational material Decision aid included information on supporting function, treating pain and other symptoms		Educational outreach Training session for nurses, social workers and nutritionists to prepare them for goals of care discussions	
Moore et al. ³⁸	National consensus process Informed complex model of EOL care informed by core competence guidelines for EOL care	Local opinion leaders - ICL met with family carers to ensure needs and wishes were understood Case management - Holistic resident assessment included needs, issues and expectations of resident and family of EOL care	Local opinion leaders - ICL-facilitated use of care plans Case management - Resident assessment included goals of care and well-being, action plan - Documentation and review of status, preferred place of death		Case management: Individual assessments and review included discussion of anticipated needs, plans for 'what if's' and the prescription of 'just in case' medications	Local opinion leaders - ICL provided support to staff to prevent unnecessary transfer Case management - Resident assessment documented resuscitation status, preferred place of death and current medications	Case management Assessment template incorporated observational measures to identify signs of comfort, discomfort, distress and/or pain	Case management Resident assessment incorporated needs or restrictions related to faith and/or culture	Local opinion leader - ICL acted as central resource for family carers Educational outreach - ICL undertook training and education of family carers	Local opinion leader - ICL acted as central resource for HPs and long-term care facility staff Educational outreach - ICL undertook training and education of staff

(Continued)

Table 4. (Continued)

Study	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10
Stacpoole et al. ⁴²		<i>Resident/family mediated</i> Meetings with family informed sources of comfort and pleasure for the relative	<i>Resident/family mediated</i> Meeting provided opportunity to acknowledge dementia progression and establish goals and introduce ACP in positive context	<i>Communication between HPs</i> Development of care plans that used language consistent across care staff and GPs	<i>Communication between HPs</i> Out of Hours Information sheet was developed	<i>Communication between HPs</i> - Meetings with GP and long-term care facility staff led to review of residents who would benefit from treatment plans - Visualisations of what is 'normal' for residents, and what symptoms would be considered significant		<i>Environment modification</i> A calm environment with gentle music and pleasant scents was established in a space in the long-term care facility	<i>Resident/family mediated</i> Family was encouraged to take part in nursing care and activities with the resident	<i>Educational material</i> Long-term care facility managers book covering Namaste Care Teaching huddles to explain Namaste Care to staff
Amador et al. ⁴⁵										
Garden et al. ⁴⁴			<i>Case management</i> ACP conducted as informed by meetings with residents and/or their carers			<i>Educational material</i> Contained information on eating, drinking and dysphagia based on advice from speech and language therapist	<i>Clinical practice guideline (pneumonia)</i> Information for clinicians regarding optimal relief of symptoms for pneumonia residents with dementia	<i>Clinical practice guideline (pneumonia)</i> A symptom checklist, observational instruments for monitoring symptoms and tailored treatment recommendations		<i>Educational outreach</i> The implemented service included education for the health care team
van der Maaden et al. ⁴³		<i>Clinical practice guideline (pneumonia)</i> Physician determines resident's treatment goals			<i>Clinical practice guideline (pneumonia)</i> A prognostic score was used to estimate dying within 2 weeks with antibiotics					

(Continued)

Table 4. (Continued)

Study	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10
Nakanishi et al. ⁵¹	Educational material Booklet for staff highlighted the need for palliative care approach	Educational material Booklet for families recommended they have open discussions with the resident's doctor, and that they should be well informed	Educational material Booklet for families informed approach to care that optimises comfort at the end of life			Educational material Booklet for families with information regarding risks associated with hospital transfer; discomfort associated with tube feeding; considerations to be made for antibiotic use in the event of pneumonia	Educational material Booklet for families with information regarding recognising non-verbal indications for pain and discomfort; the importance of nursing care (hygiene and skincare) for comfort and dignity		Educational material - Booklet was provided to family members before ACP meeting - Information on bereavement and where to seek support are outlined in booklet	Educational outreach Staff were given a seminar on the context of the booklet
Toye et al. ⁴⁹	Educational outreach - For staff and support workers: on the topic of dementia as a terminal illness Educational outreach - For family on the topic of palliative care approach to dementia	Case management - A Personal Life History Booklet helped prompt memories and inform care - A Client Personal Preference Information Form documented resident preferences	Educational material Booklet for families encouraged discussion of likely health events early in disease process			Educational material Booklet for families noted the risks associated with artificial feeding in dementia	Educational material Booklet for families informed family to distinguish between how resident acted in past when in pain and to discuss this with HP involved in their care	Educational material Booklet for staff offered aromatherapy for resident agitation	Educational material Booklet for families provided information on importance of family member to maintain their own physical and emotional health, seek assistance and support for caring and take time away from caring duties	Educational outreach Three core training modules were given to staff covering dementia as a life-limiting condition, palliation and communication
Reinhardt et al. ⁵³	Case management Families asked about what they knew of dementia, their relative's condition and expectations		Case management Discussion of family goals of care for resident and how these goals can be achieved			Case management Meetings covered: resuscitation, hospitalisation, artificial nutrition and hydration	Case management Meetings covered: pain and symptom management		Telemedicine Palliative care social workers performed telephone follow-up to check the family member's level of emotional comfort	

(Continued)

Table 4. (Continued)

Study	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10
Stirling et al. ⁵²	<i>Educational material</i> • Staff communication tool assisted with communicating terminal nature of dementia to resident's family	<i>Educational material</i> • Staff communication tool asked family what they know about their relative in terms of their illness, life and personality	<i>Educational material</i> • Staff communication tool discussed goals of care and family/resident wishes		<i>Educational material</i> • Staff communication tool contained instructions to discuss the prognosis of residents with family, the dementia trajectory, average life span and amount of uncertainty	<i>Educational material</i> • Staff communication tool informed of risks associated with hospitalisation of people with dementia, and burdensome interventions and the poor control of symptoms			<i>Educational material</i> • Staff communication tool contained guidance and instructions for conducting informal conversations with resident's family and friends, informing family of distinctions between life-saving and palliative care	
Livingston et al. ⁵⁴		<i>Case management</i> • Form was completed about relatives' decision regarding advanced care wishes and emergency care plans	<i>Educational outreach</i> • Staff training sessions included care planning				<i>Educational outreach</i> • Staff training sessions included EOL symptoms	<i>Educational outreach</i> • Staff training sessions included religion and spirituality at the end of life	<i>Educational outreach</i> • Staff training sessions included communicating with residents and their relatives	<i>Educational outreach</i> • A training programme for care staff was devised, covering EOL care delivery
Elliot et al. ⁵⁹		<i>Educational outreach</i> • Staff training sessions based on person-centred dementia care					<i>Monitoring delivery of health care</i> • Pharmacist reviewed antipsychotic prescriptions to ensure best practice and reduce over-prescription			<i>Educational outreach</i> • Staff training sessions based on improving basic level understanding of dementia and person-centred approach

(Continued)

Table 4. (Continued)

Study	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10
Kuhn et al. ⁵⁸	<i>Educational material</i> • Booklet for staff highlighted terminal nature of dementia and importance of comfort care	<i>Educational material</i> • Booklet for staff highlighted family and friends' role as a partner in resident's care	<i>Educational material</i> • Booklet for staff covered considerations for a comfort care approach			<i>Educational material</i> • Booklet for staff provided information on warranting hospitalisation, discussing alternatives and making decisions with goals of care in mind • Informed of risks associated with restraints, forced or artificial feeding and hydration and offers alternatives • Offered considerations for antibiotic use in residents with pneumonia	<i>Educational material</i> • Booklet for staff recommended assessment methods for pain in residents, how to manage pain with medication and non-drug interventions (e.g., repositioning, massage, prayer)	<i>Educational material</i> • Booklet for staff noted that religious practices or objects can be incorporated into caring for resident	<i>Educational material</i> • Booklet for staff gave guidance and resources for families to cope with caring for their resident	<i>Educational outreach</i> • All staff in skilled and special care units were given training sessions in dementia care
van der Steen et al. ⁵⁶	<i>Educational material</i> • Booklet for families highlighted the need for palliative care approach	<i>Educational material</i> • Booklet for families noted that families should have open discussions with the resident's doctor and be well informed	<i>Educational material</i> • Booklet for families informed approach to care that optimises comfort at the end of life			<i>Educational material</i> • Booklet for families provided information on risks associated with hospital transfer; discomfort associated with tube feeding; considerations to be made for antibiotic use in the event of pneumonia	<i>Educational material</i> • Booklet for families provided information on recognising non-verbal indications for pain and discomfort; some medications can be administered to minimise discomfort; the importance of nursing care (hygiene and skincare) for comfort and dignity	<i>Educational material</i> • Booklet for families acknowledged religious authorities' stance on refraining from using life-prolonging measures at the end of life • Advised that family discuss such concerns with a religious or spiritual representative	<i>Educational material</i> • Booklet was provided to family members before ACP meeting with information on bereavement and where to seek support	
Hanson et al. ⁶¹		<i>Educational material</i> • Decision aid assisted family members in decision-making regarding feeding tube placement								

(Continued)

Table 4. (Continued)

Study	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10
van der Steen et al. ⁶⁰		<i>Clinical practice guideline</i> (for pneumonia) Considered resident's wishes and best interest: when competent; from living will; and as recalled by family/caregivers			<i>Clinical practice guideline</i> (with prognostic risk score) Prognostic risk score aimed to inform prognosis and support clinician decision-making in residents	<i>Clinical practice guideline</i> (with prognostic risk score) Risk score or estimated 2-week mortality to inform decision-making process of antibiotic use				
Arcand et al. ⁶⁵	<i>Educational material</i> Booklet for families highlighted the need for palliative care approach	<i>Educational outreach</i> Staff training sessions on the importance of patient-focused and family-centred approach	<i>Educational material</i> (booklet for family) Booklet for families informed approach to care that optimises comfort at the end of life			<i>Educational material</i> Booklet for families provided information on risks associated with hospital transfer; discomfort associated with tube feeding; considerations to be made for antibiotic use in the event of pneumonia	<i>Educational material</i> Booklet for families provided information on recognising non-verbal indications for pain and discomfort; some medications can be administered to minimise discomfort;	<i>Educational material</i> Booklet for families acknowledged religious authorities' stance on refraining from using life-prolonging measures at the end of life	<i>Educational material</i> Booklet was provided to family members before ACP meeting with information on bereavement and where to seek support	<i>Educational outreach</i> Nursing staff of all levels were given educational sessions on palliative care for dementia. Physicians were also invited to attend
Meller et al. ⁶⁴	<i>Case management</i> Suggested point in trajectory in which ACP should occur	<i>Educational outreach</i> Staff training sessions covered decision-making, the importance of identifying a 'person responsible' and incorporating them in care planning	<i>Case management</i> ACD should be documented when resident is capable with a witness							<i>Educational outreach</i> Sessions on consent, substitute decision-making and ACD

(Continued)

Table 4. (Continued)

Study	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10
Kovach et al. ⁶⁶			<i>Clinical practice guideline</i> Protocol designed to assess more accurately treat pain and discomfort, and reduce use of 'as needed' psychotropic medication				<i>Clinical practice guideline</i> - Nurses instructed to assume other sources for discomfort when pain is ruled out - Non-pharmacological interventions were implemented to ease discomfort, based on maintaining appropriate balance between sensory calming or stimulating experiences			<i>Clinical practice guideline</i> Staff were trained to be aware of each resident's stress threshold
Kovach et al. ⁶⁷		<i>Case management</i> Case manager led teams with ideology of 'treating the whole patient'	<i>Case management</i> Individualised care plans were developed for residents			<i>Educational outreach</i> Nurses trained to assess and manage possible infections to keep residents out of acute care when possible		<i>Environment modification</i> Households made to be homelike and comfortable through choice of furniture and lighting		<i>Educational meeting</i> Covered topics of hospice concepts, dementia, treatment of behaviours associated with dementia, activity programming and family and spiritual care

EAPC: European Association for Palliative Care; ACP: advance care planning; AI: Appreciative Inquiry; COP: community of practice; EOL: end of life; EOLD: End of life in Dementia; GOC: goals of care; GP: general practitioner; ICL: interdisciplinary care leader; long-term care facility: long-term care facility; MDT: multidisciplinary team; NA: not applicable; NH: nursing home; NR: not reported; PCPC: Palliative Care Planning Coordinator; RN: registered nurse; SDM: shared decision-making; EOL: end of life; EOLD-SWC: End-of-Life in Dementia-Satisfaction with Care scale; EOLD-CAD: End-of-Life in Dementia-Comfort Assessment in Dying scale; ACD: advanced care directive.

improve: staff competencies in various aspects of palliative care in dementia,⁴⁴ relatives' satisfaction with the care,²⁷ symptom management²⁷ or comfort of the resident with dementia^{21,27,54} or observed pain^{24,25} or discomfort levels⁶⁷ in residents, to reduce decision-making uncertainty³³ or conflict,⁶¹ to increase in the number of Do Not Resuscitate (DNR) decisions,⁵⁴ decrease in the number of resuscitations,²⁰ or to result in management more consistent with a palliative care approach.²⁸

There were non-significant trends towards higher effects on symptom management, surrogate well-being, life satisfaction or satisfaction with relatives' care,⁵³ improved staff attitudes to dementia,⁵⁹ more routine pain evaluation,⁵⁸ increased satisfaction with pain control, emotional support, treatment of patient with respect, communication and provided information,⁶⁵ palliative approach to nutrition and hydration and proportion of tube-fed residents,²⁰ and in reduced behavioural problems.⁶⁷ Some interventions found no significant changes to ACP practice,³¹ preferences for comfort care²³ or for withholding burdensome treatments,^{23,33,53} relatives' satisfaction with resident pain control,⁵⁴ estimated pain,²⁴ number of physical iatrogenic problems experienced by residents,⁶⁶ or in overall quality of EOL care.²⁸

Discussion

Main findings

This is the first review to utilise the EAPC White Paper domains on optimal palliative care in dementia to explore the relevance and range of interventions in long-term care facilities. Although none of the interventions addressed all ten considered EAPC domains as part of a single intervention, these ten domains were addressed to some extent across various interventions, and to various degrees. Different domains were addressed by different types of interventions; with some highly focused, and others trying to address multiple aspects of palliative dementia care. Pragmatically, it is expected that no intervention can address all domains because it is difficult to achieve that level of change simultaneously, because of limits posed by finite resources or service model structure and processes, and also, importantly, because different interventions may prioritise different aspects of palliative care needs of people with dementia, and subsequently, relevant EAPC domains and recommendations. Equally, the development of multicomponent interventions is often incremental where one element or a simpler combination is developed and tested initially, and built on in subsequent studies. Our review has highlighted that when reporting on such studies, it is important for researchers to explicitly state why they have chosen specific domains, define the 'active ingredient(s)' within the complex intervention, and how those choices define the scope of the intervention, as well

as its outcomes. Future work also needs to inform our understanding of 'dose' and 'coverage', that is how many components are needed (and at what breadth and depth) to best achieve the EAPC domain goals. The health economic aspect should also be considered when designing and implementing such interventions.

The review indicates that current research is more focussed on developing interventions that provide education and upskilling of health care teams, interventions that support optimal treatment of symptoms and comfort care, and interventions that seek to prevent aggressive treatment at the end of life. At the same time, less research seems to relate to continuity of care and prognostication. The small number of interventions relating to prognostication is consistent with the EAPC White Paper where prognostication was scored as the least important domain of interest. Given the uncertainty and difficulty in predicting survival, and the emphasis on identifying the (unmet) palliative care needs of people with dementia as best practice, it is encouraging that care interventions are focusing on addressing the (unmet) needs for this population rather than on models driven purely by prognosis.

Continuity of care was also less commonly explicitly addressed as a domain of interest. With our focus on long-term care facilities, the major transition from home for the person with dementia may have already occurred prior to this time, is complex to study longitudinally and care pathways may not always be linear. Acknowledging that avoidance of inappropriate hospitalisation is desirable (Domain 6), sometimes transition into the hospital environment will need to occur as it might be in the resident's best interest and such occurrences should not be defined purely as 'failures of the system'. Consideration of what defines continuity of care within the long-term care facility itself is needed and is likely multi-faceted (including continuity of information, continuity of staff and management).⁶⁸

The EAPC domains were proposed to inform clinical practice and policy by defining the relevant aspects of optimal palliative care for people with dementia and to articulate a research agenda. They were not developed to inform quality assessment of conducted research. However, this review supports the EAPC domains as useful guidance on issues critical for this population that new interventions should aim to address (and appropriately measure). This review does not argue for a minimum or maximum number of domains that need to be captured within individual interventions, but highlights the need for greater clarity around the intervention elements and their goals to encourage transparency and help replication and normalisation of the interventions.⁶⁹ In most cases, palliative care interventions for people with dementia will be complex, requiring multiple components. The EAPC framework offers a useful way to structure and consider interventions for people with dementia and

palliative care needs, and to place such interventions in context. Similarly, this review did not set out to provide an optimal number of intervention components nor draw any correlations about types, numbers or combinations of intervention components and outcomes, but rather to conceptualise what current complex interventions are on offer for this population. This review however offers a starting point for informing future work in this field. The updated search identified seven studies for the period of 2018–2019, signalling that this is a research area of growing interest.

This review set out to describe the components of interventions within the framework posed by the EAPC White Paper. It was not in the remit of this review to address if greater domain coverage correlates with better outcomes for people with dementia (and their caregivers). Instead, the review set out to explore how thinking about these domains *a priori* would help inform study design, improve reporting, reduce the risk of duplication and enhance capacity to build systematically from prior intervention studies, as well as adapt or implement interventions in a variety of contexts.⁶⁹ Such approach will help increase generalisability and applicability of study findings in the clinical setting. Future research could highlight the inter-relatedness of domains, and how intervening at one domain may also improve outcomes in others.

This review explored whether proposed interventions were informed by theory. Strengthening the theoretical underpinnings in future research should extend beyond that of development and design of interventions. This may potentially involve using theory to inform the selection of outcomes, the interpretation and analysis of results, as well as to tailor the intervention as exemplified in studies such as FINCH, OPTIMAL and Namaste.^{70–72} Our review did not specifically explore the role of context. This can be a significant element for interventions, as exemplified by the ‘Compassion’ intervention where the impact of context was highlighted as critical to the intervention implementation.³⁸ Developing interventions with strong theoretical foundations would help bring clarity around how interventions are thought to achieve particular outcomes and the role of contextual factors. This, in turn, will help strengthen the evidence base for this population.¹ Theoretical frameworks of behaviour change at the levels of the long-term care facility,⁶⁹ clinician and family would be of particular interest.

Strengths and limitations

This review offers an initial, descriptive synthesis of interventions for people with dementia and palliative care needs using the domains of care proposed in the EAPC White Paper. The review was underpinned by the philosophy that at least one domain of such interventions should focus on shared decision-making or

person-centredness, acknowledging the person with dementia as a partner in care. This may have led to exclusion of studies with a focus purely on a singular domain (e.g. symptom management).

The authors on this review were also investigators on some of the included studies. To minimise bias, decisions of whether or not such studies should be included and how content was to be mapped to EAPC domains was conducted by team members not involved in those studies.

This review used a modified search strategy from a recent Cochrane review¹⁰ to ensure that the review findings build on existing evidence. The modification did not specifically include keywords on shared decision-making or person-centredness, as this could have potentially excluded studies of interest.

Data extraction and mapping of domains relied on the level of reporting in the included studies. To overcome this, content about each intervention was extracted from the primary study findings and then augmented by data reported in supplementary reports on those studies. Study authors were not contacted to provide further details with regard to the content of their interventions. Therefore, it is possible that some interventions may have addressed domains in addition to the ones reported in this review, but these details may have been missed because the information was not reported in the publications, or sufficient detail was not given about the intervention components. This may have affected how data were extracted against the EAPC domains.

Mapping of content to a singular domain for each intervention was difficult due to domain overlap. To maximise coverage within each domain, content was mapped to all relevant subdomains.

All of the included studies were set in long-term care facilities and interventions were set up to answer questions relevant to this setting. Interventions conducted in other clinical settings or in the community may be different, and therefore, may cover different domains.

This review focused on describing interventions rather than evidence for efficacy. Efficacy has been explored by previous reviews;^{10,11} this review sought to include emerging interventions (e.g. in protocols) as well-completed evaluations to ensure an up-to-date overview of the state of the science. Where available, included interventions showed mixed findings for efficacy, including the randomised controlled trials (RCTs) retrieved in this review. Included RCTs showed evidence for efficacy only on measures of process and very little evidence on efficacy on outcomes, highlighting the complex nature of this population and the included interventions, with a number of many interacting contextual factors. As many interventions in this field will require behaviour, attitudinal or system change, the mechanism to achieve this is also critical in intervention development.

What this study adds

The EAPC recommendations were derived from consensus and thus reflect participants' ('experts') knowledge that is grounded in clinical experience and acknowledge the interaction and overlap between both the intent and integrated approach required to achieving the domain outcomes. Such frameworks will need to be responsive as the evidence evolves with further clarity about subdomains evolving as outcomes of different interventions are known. This can be augmented by a theory-driven approach which might articulate the inter-relationship and hierarchy of these subdomains in a more complex way. It may also highlight where there is large 'return on investment', if a singular component can tackle several important elements of care in an integrated manner, or if the degree of effort required to implement is lower and is thus associated with higher incremental gains in outcomes.

Conclusion

The design of complex interventions for people with dementia in long-term care facilities is itself an emerging field, and a primary focus on evaluative methods may stymie innovation through allowing the 'tail to wag the dog'. Palliative care for long-term care facility residents with dementia represents a perfect storm of a complex intervention for a complex population in a complex setting. As such, improvements in care and optimal knowledge translation should be driven by a broader range of qualitative and quantitative methods including, but not exclusively driven by, randomised controlled trials, unified by a shared language of the elements of the intervention, with the EAPC domains informing the complex needs of people with dementia and their family members.

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Authorship

M.R.A., C.G., T.L. and F.B. were responsible for study concept and design and for funding acquisition. S.K., M.V.G., C.G., F.B., T.L. and M.R.A. were responsible for the acquisition of data and for the drafting of the manuscript. All the authors contributed to analysis and interpretation of the data and the critical revision of the manuscript for important intellectual content. All the authors approved this version of the manuscript to be published.

Data management and sharing

All relevant data are within the manuscript. Any other data are available upon request from the corresponding author.

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