

Nursing Interventions in Palliative Care for Advanced Dementia: A Systematic Review of Symptom, Relief, Comfort, and Caregiver Support

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Purpose: Individuals with advanced dementia often endure high symptom burden and receive limited specialized palliative care. Nurses play a central role in delivering end-of-life care, yet the impact of nurse-led interventions remains underexplored. This review synthesizes available evidence on nursing-led approaches, with a focus on symptom relief, patient comfort, and caregiver support.

Methods: A systematic review was conducted in accordance with PRISMA 2020 guidelines. Four databases (PubMed, Embase, CINAHL, and Cochrane Library) were searched for studies published between January 2015 and March 2025. Eligible studies included randomized controlled trials (RCTs), cluster RCTs, and non-randomized studies evaluating nurse-led palliative interventions in institutional or community dementia settings. Risk of bias was assessed using Cochrane RoB 2.0 and ROBINS-I tools. Data extraction focused on intervention types, delivery modes, nurse training, and clinical outcomes.

Results: Twenty-three studies from 12 countries were included (8 cluster RCTs, 9 individual RCTs, 6 non-randomized trials). Nurse-led programs improved care planning ($\geq 75\%$ documentation rates), reduced caregiver decisional conflict (20–30%), and enhanced communication quality (by up to 20 percentage points). Pain detection increased by 41%, with validated tools reducing pain scores by up to 30%. Psychosocial therapies reduced agitation by up to 25% and improved care cooperation. Multicomponent models decreased emergency visits and improved transitions, with over 40% increases in advance directive completion. Risk of bias varied by design and domain.

Conclusion: Nurse-led palliative care interventions show consistent benefits in communication, symptom control, and caregiver support. However, evidence on long-term caregiver outcomes is limited, and heterogeneity in design and measurement limits comparability. Standardized, scalable models are needed to fully integrate nursing-led approaches into palliative dementia care.

Keywords: dementia, palliative care, nursing care, advance care planning, symptom management, quality of life

Introduction

Dementia remains a major global health concern, characterized by progressive cognitive decline, memory loss, behavioral disturbances, and increasing functional dependence.¹ These impairments significantly diminish quality of life and place substantial emotional, physical, and financial strain on caregivers.² Current estimates indicate that over 55 million people worldwide are living with dementia, a figure projected to rise to 78 million by 2030 and 139 million by 2050 due to global population aging.^{3,4} In its advanced stages, dementia is marked by severe neurological deterioration, complete dependence in activities of daily living, and a heightened risk of hospitalization, institutionalization, and mortality.^{5,6} Critically, individuals with advanced dementia frequently experience unrecognized pain, agitation, and distress, particularly when verbal communication becomes impaired and care shifts from person-centered goals to a focus on medical stabilization.^{7,8} Emerging neurobiological evidence demonstrates that such symptoms often manifest atypically in dementia due to underlying neural disruption. For example, degeneration of the prefrontal cortex and limbic pathways



contributes to dysregulated affect and agitation; disconnection in cortical–subcortical pain circuits leads to under-recognition or atypical expression of pain; and progressive damage to frontotemporal and parietal networks impairs communication and emotional signaling.^{9–11} These mechanisms underscore the complexity of symptom recognition in dementia and highlight the advanced clinical skills required of nurses at the bedside.

Palliative care is increasingly recognized as a critical, though often underutilized, component in the management of advanced dementia. The WHO defines it as a holistic approach that addresses physical, psychological, and spiritual distress, which is essential for individuals with complex needs such as those in advanced stages of dementia. These individuals often endure multifaceted suffering that spans physical symptoms, emotional challenges, and social isolation.¹² Despite its importance, the integration of palliative care into dementia services remains inconsistent and insufficiently developed. Unlike patients with terminal cancer, those with advanced dementia are less often identified as being in the terminal phase of illness, leading to missed opportunities for implementing comfort-centered and person-focused end-of-life care.^{7,13} This under-recognition is largely due to the unpredictable disease trajectory, absence of specific terminal-stage biomarkers, and lack of clear guidelines regarding the initiation of palliative interventions.^{14,15} As a result, many individuals experience inadequately managed symptoms, fragmented communication with families, and unnecessary hospitalizations that compromise comfort and dignity.

In the absence of consistent specialist involvement, nurses play a central role in delivering palliative care to individuals with advanced dementia. Positioned at the frontline in both nursing homes and home-based settings, they are often the first to detect subtle clinical or behavioral changes, enabling timely and personalized interventions.¹⁶ Nursing responsibilities extend beyond routine clinical care to encompass pain assessment, communication with families, psychosocial support, advanced care planning, and interdisciplinary coordination. Validated nursing tools and interventions, such as the PAINAD scale, person-centered therapeutic activities, nurse-facilitated case conferences, and non-pharmacological strategies, have demonstrated effectiveness in improving symptom control, reducing agitation, and alleviating caregiver burden.^{8,17–19}

Despite growing recognition of the pivotal role nurses play in palliative dementia care, the empirical evidence supporting their contributions remains limited and fragmented. Much of the existing literature continues to focus on physician-led or pharmacological interventions, thereby underrepresenting the breadth and sustained impact of nursing practices.^{14,20} In studies that do examine nurse-led interventions, methodological limitations, such as small sample sizes, heterogeneous intervention protocols, inconsistent outcome measures, and limited generalizability, compromise the strength and applicability of findings.^{21,22} Moreover, few studies offer standardized frameworks for ethically complex aspects of care, such as communication with non-verbal patients or culturally sensitive end-of-life planning, leaving many nurses without clear, evidence-based guidance.^{23,24}

In response to these knowledge gaps, this systematic review synthesizes evidence from peer-reviewed studies published between 2015 and 2025 on nurse-led interventions in palliative care for individuals with advanced dementia. It evaluates the impact of these interventions on symptom relief, emotional well-being, patient comfort, family engagement, and healthcare utilization. For the purposes of this review, we defined nurse-led interventions as those in which nurses were the principal coordinators, facilitators, or decision-makers in delivering the intervention, even when part of a multidisciplinary team. By contrast, nurse-supported interventions were those in which nurses contributed to implementation but were not central to design or leadership. This distinction is important for understanding the scope of nursing leadership and interpreting the findings within the context of professional practice boundaries. This review therefore provides a comprehensive synthesis of available evidence to guide future practice, education, and policy in nursing-led palliative care for advanced dementia.

Materials and Methods

Registration and Reporting Framework

This systematic review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA, 2020) guidelines to ensure methodological transparency and completeness.²⁵ The review protocol was prospectively registered in the International Prospective Register of Systematic Reviews (PROSPERO;

registration number: CRD42025633207), providing a publicly accessible record of the review's objectives, eligibility criteria, and planned methods.

Study Design

A systematic review approach was used to identify, appraise, and synthesize evidence from randomized controlled trials (RCTs), cluster-RCTs, and relevant non-randomized studies evaluating nursing-led palliative care interventions in advanced dementia.

Study Objectives

The primary objective was to assess the effectiveness of these interventions in improving symptom control, patient comfort, quality of life, caregiver experience, and family satisfaction during end-of-life care.

Secondary objectives were to:

- Examine implementation challenges, methodological heterogeneity, and risk of bias in included studies.
- Identify evidence gaps in long-term caregiver outcomes, system-level integration, and feasibility of scaling interventions across different healthcare contexts.
- Provide recommendations to inform clinical practice, nursing education, and policy development in palliative dementia care.

Eligibility Criteria

Eligibility criteria were developed using the PICO framework to guide the selection of studies relevant to nursing-led interventions in palliative care for advanced dementia. Studies were included if they: (1) involved participants diagnosed with advanced dementia based on validated staging tools (eg, Functional Assessment Staging (FAST) $\geq 6a$ or Global Deterioration Scale (GDS) stages 4–7); (2) evaluated the effects of nursing-led or nurse-facilitated interventions, defined as those where registered nurses, clinical nurse specialists, or advanced practice nurses had a central role in delivering care, coordinating treatment, or initiating palliative protocols, including in multidisciplinary contexts; (3) compared the intervention to usual care, non-nurse-led care, or inactive control; and (4) assessed outcomes such as symptom burden (eg, pain, agitation), comfort at end of life, quality of life, caregiver experience, or care planning. Eligible studies were peer-reviewed randomized controlled trials (RCTs), cluster-RCTs, or non-randomized controlled studies published in English between January 2015 and March 2025 in institutional or community settings. The 10-year limit was chosen to capture evidence most relevant to contemporary dementia and palliative care practices, as standards, tools, and guidelines have evolved significantly over the past decade. Studies were excluded if they (a) targeted only early or moderate dementia stages, (b) did not clearly define the nurse-led component of the intervention, (c) used non-validated outcome measures, or (d) were non-empirical (eg, commentaries, reviews, or protocol-only publications without outcome data).

For this review, nurse-led interventions were defined as those in which nurses were the principal care providers, intervention facilitators, or coordinators, and where their actions were central to the design and implementation of the intervention. In line with this, we distinguished between nurse-led interventions, where nurses exercised leadership and decision-making authority (including in multidisciplinary contexts), and nurse-supported interventions, where nurses contributed to implementation but did not occupy a central leadership role. Studies were included if nurses functioned independently or as leaders in multidisciplinary teams, but were excluded if nursing roles were ancillary or non-specific.

Search Strategy

A comprehensive and systematic search was conducted across four electronic databases: PubMed, Scopus, CINAHL (via EBSCO), and the Cochrane Central Register of Controlled Trials. The search strategy combined controlled vocabulary (eg, MeSH terms) and free-text keywords related to advanced dementia, palliative or end-of-life care, nurse-led interventions, and trial design. Boolean operators and database-specific syntax were used to enhance sensitivity and specificity. Search terms included: (“dementia” OR “Alzheimer’s disease”) AND (“palliative care” OR “end-of-life care”) AND (“nurse-led” OR “nursing intervention”) AND (“randomized controlled trial” OR “cluster randomized

trial”). Filters were applied to limit results to English-language articles published between January 2015 and March 2025. In addition to database searching, the reference lists of included studies and relevant reviews were manually screened to identify additional eligible publications. Protocols without outcome data and grey literature were excluded to maintain methodological consistency. The final search was conducted on March 31, 2025, to ensure inclusion of the most recent eligible studies published up to that date. In accordance with PRISMA 2020 guidance, we provide the full search strategy for PubMed below to ensure transparency. The search terms combined controlled vocabulary and keywords as follows: (“dementia” OR “Alzheimer’s disease”) AND (“palliative care” OR “end-of-life care”) AND (“nurse-led” OR “nursing intervention”) AND (“randomized controlled trial” OR “cluster randomized trial”). Filters were applied to limit results to English-language publications between January 2015 and March 2025. The strategy was developed collaboratively by two authors but was not externally peer-reviewed using the Peer Review of Electronic Search Strategies (PRESS) checklist.

Study Selection Process

Following the comprehensive database search, a total of 570 records were identified. Duplicate records ($n = 298$) were removed using EndNote X9 and manual verification. The remaining 272 records were screened by two independent reviewers based on predefined inclusion criteria. Disagreements at any stage were resolved through discussion and, if needed, adjudicated by a third reviewer. Agreement was calculated using Cohen’s kappa to assess inter-rater reliability.

During the screening process, 178 studies were excluded based on predefined criteria, including a lack of focus on nursing roles in palliative care, irrelevance to nursing interventions, targeting other healthcare professionals, absence of original data, and non-English language. A full breakdown of exclusion reasons is provided in [Figure 1](#). Full-text retrieval was attempted for 94 records, but 24 could not be retrieved. The remaining 70 full-text articles were assessed independently for eligibility. Forty-seven studies were excluded due to insufficient focus on the nursing role ($n = 19$), absence of validated outcome measures ($n = 12$), inappropriate study designs ($n = 7$), or other issues such as incomplete data or unclear interventions ($n = 9$). Ultimately, 23 studies met the eligibility criteria and were included in the final synthesis.

Quality Assessment and Risk of Bias

Risk of bias (RoB) was assessed using validated tools appropriate to the study design. RoB 2 assessments addressed five domains as per Cochrane guidance, including randomization, intervention deviations, missing data, outcome measurement, and reporting. For cluster trials, additional considerations specific to the timing of recruitment, cluster loss, and baseline imbalances were included. Two reviewers conducted independent evaluations, with disagreements resolved by consensus or consultation with a third reviewer. Inter-rater agreement was strong (Cohen’s $\kappa = 0.82$). Risk of bias was categorized as low, some concerns, or high at both domain and overall levels.

For non-randomized intervention studies, risk of bias was assessed using the ROBINS-I tool, covering seven standard domains including confounding, participant selection, intervention classification, deviations, missing data, outcome measurement, and selective reporting. Two reviewers independently conducted all assessments using predefined criteria, resolving any disagreements through discussion or, when needed, third-party adjudication. Although inter-rater reliability was not formally calculated, full consensus was achieved. Risk of bias judgments were used to inform interpretation, but did not determine study inclusion. Visual summaries were presented using traffic light plots and bar charts to enhance transparency.

Data Synthesis and Analysis

Due to substantial methodological and clinical heterogeneity across the included studies, encompassing variations in study design (RCTs, cluster RCTs, non-randomized trials), intervention types (eg, communication training, symptom protocols, multicomponent models), outcome measures, and follow-up durations, a meta-analysis was deemed inappropriate. Therefore, a structured narrative synthesis approach was employed in accordance with PRISMA guidelines. Findings were thematically categorized under key domains, including patient symptom management, quality of life, emotional and psychosocial well-being, caregiver burden, and family satisfaction. Where available, quantitative results

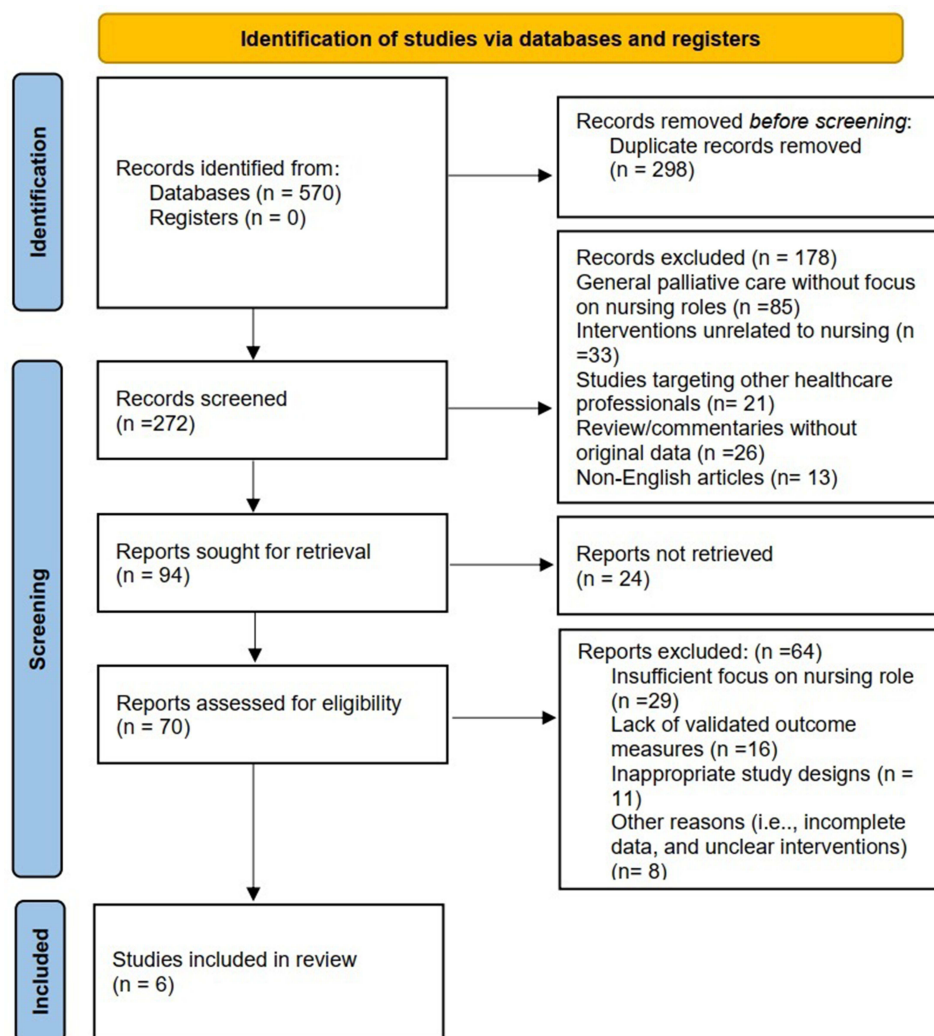


Figure 1 PRISMA flow diagram illustrating the study selection process, including identification, screening, eligibility assessment, and inclusion.

from individual studies were presented descriptively to highlight effect sizes and outcome directionality. Qualitative findings were integrated using thematic analysis to capture deeper insights into nursing roles, interdisciplinary collaboration, culturally tailored interventions, and the emotional toll on caregivers and nursing staff. This approach allowed for a comprehensive synthesis of both measurable outcomes and contextual factors that influence the implementation and effectiveness of nursing-led palliative care in advanced dementia.

Ethical Considerations

Ethics approval was not required for this systematic review, as it involves the synthesis of previously published studies. All original studies included had obtained appropriate ethical approval and informed consent as described in their original publications.

Results

Study Characteristics and Scope

This review included 23 studies comprising 8 cluster RCTs, 9 individual RCTs, and 6 non-randomized studies, conducted across 12 countries from 2015 to 2025 (Table 1). The majority were set in nursing homes or long-term care units, with two community-based interventions^{38,48} and one hospital–community hybrid model.³⁹ Sample sizes ranged from 32⁴¹ to

Table 1 Demographic and Geographical Characteristics of Included Studies

Study	Year	Country	Design	Sample Size	Setting	Intervention Type	Comparator	Duration	Dementia Stage Criteria
Jordan et al ²⁶	2015	UK	Stepped Wedge	249	6 Nursing Homes	VWADR Profile: Nurse-conducted structured ADR monitoring with feedback into medication decisions	Usual care	32 weeks	Dementia (medically fragile population)
Chen & Lin ²⁷	2016	Taiwan	Cluster-RCT	128	22 Nursing Homes	PRT: Daily nurse-led pain assessments using validated scales	Usual care	30 days	Moderate–Severe Dementia (GDS 4–7)
Liu & Lai ²⁸	2017	Hong Kong	Cluster-RCT	128	17 Nursing Homes	OPMP: Structured observational pain protocol with nurse training	Usual care	12 weeks	Advanced Dementia (C-PAINAD)
Hanson et al ²⁹	2017	USA	Cluster-RCT	302	22 Nursing Homes	GOC: Nurse-led structured goals-of-care discussions using videos	Usual care	3 months	Advanced Dementia with surrogate decision-makers
Agar et al ³⁰	2017	Australia	Cluster-RCT	228	24 Nursing Homes	Family Case Conferencing: Nurse-led meetings triggered by clinical changes	Usual care	18 months	Advanced Dementia (FAST ≥6a, AKPS ≤50)
Brazil et al ³¹	2018	Northern Ireland	Cluster-RCT	228	24 Nursing Homes	ACP: Structured family-centered ACP by trained nurses	Usual care	6 months	Advanced Dementia
Pieper et al ³²	2018	Netherlands	Cluster-RCT	288	21 Units	STA OPI: Stepwise nurse-led protocol for behavior and pain	Usual care	3 months	Advanced Dementia
Mitchell et al ³³	2018	USA	Cluster-RCT	402	64 Nursing Homes	ACP Video: Nurse-led care preference videos for staff/families	Usual care	12 months	Advanced Dementia
Aasmul et al ³⁴	2018	Norway	Cluster-RCT	545	67 Units	COSMOS: Nurse-led program targeting communication, pain, medication, activity	Usual care	4–9 months	Advanced Dementia
Tse et al ³⁵	2018	Hong Kong	Cluster-RCT	53	4 Nursing Homes	Play Activities: Nurse-guided group play, storytelling	Reading group	8 weeks	Moderate–Severe Dementia
Ballard et al ³⁶	2018	UK	Cluster-RCT	847	69 Nursing Homes	WHELD: Nurse-led person-centered care with reduced antipsychotic use	Usual care	9 months	Dementia (incl. advanced cases)
Rostad et al ³⁷	2018	Norway	Cluster-RCT	112	16 Nursing Homes	Doloplus-2 Pain Monitoring: Nurse assessments and pain team review	Usual care	12 weeks	Severe Dementia
Arendts et al ³⁸	2022	Australia	RCT (Study Protocol)	440 dyads (220/group)	6 metropolitan emergency departments	Carer End-of-Life Planning Intervention (CELPI) delivered by trained non-physician clinicians (eg, nurses) using CANDID tool	Usual care with passive educational material	12 months	Severe dementia (MMSE <13 or FAST 6d–7f)
Hanson et al ³⁹	2019	USA	Pilot RCT	62	Hospital + Community	Palliative Consultation and Phone Support	Usual care	60 days	Late-Stage Dementia
Husebø et al ⁴⁰	2019	Norway	Cluster-RCT	723	33 Nursing Homes	COSMOS (Follow-up): Same components as 2018 COSMOS	Usual care	9 months	Advanced Dementia
Froggatt et al ⁴¹	2020	UK	Cluster-RCT	32	8 Nursing Homes	Namaste Care: Nurse-facilitated sensory and relational care	Usual care	24 weeks	Advanced Dementia
Van den Block et al ⁴²	2020	Multinational	Cluster-RCT	1384	78 Nursing Homes	PACE: Nurse-led training and audit for palliative principles	Usual care	12 months	70% with Advanced Dementia
Smaling et al ⁴³	2018	Netherlands	Cluster-RCT	153	16 Nursing Homes	Namaste Family: Nurse-led sessions with family participation	Usual care	12 months	Advanced Dementia
Vaccaro et al ⁴⁴	2020	Italy	Cluster-RCT	40	2 Nursing Homes	Doll Therapy: Nurse-administered therapeutic dolls	Sham intervention	12 weeks	Moderate–Severe Dementia
Kosters et al ⁴⁵	2023	Netherlands	Stepped Wedge	110	5 Nursing Homes	MoSART+: Nurse-monitored soundscape and behavior	Usual care	15 months	Dementia with behavioral symptoms
Myrenget et al ⁴⁶	2024	Norway	Cluster-RCT	279	12 Nursing Homes	Music-Based Caregiving: Music embedded into care routines	Usual care	8 weeks	Moderate–Severe Dementia
Spichiger et al ⁴⁷	2025	Switzerland	Stepped Wedge	240	23 LTCs	Person-Centered Profile: Nurse-developed monthly care profiles	Usual care	15 months	Dementia
Sachs et al ⁴⁸	2025	USA	RCT	201	Community	IN-PEACE: Nurse + social worker phone-based care coaching	Usual care	24 months	Community dementia, late stage

1384,⁴² with follow-up durations between 4 weeks and 24 months. The stage of dementia varied, but over 75% of studies targeted residents with advanced dementia, operationalized using tools like FAST ($\geq 6a$), GDS (4–7), and PAINAD-based assessments.

While 18 studies reported formal inclusion criteria based on dementia staging, only 14 provided a clear definition of advanced disease stages. Seven studies used stepped-wedge or quasi-experimental designs,^{26,47} which raises concerns regarding temporal confounders and consistency in implementation timing. Only half of the trials described randomization or allocation concealment procedures adequately. Similarly, only a minority ($n = 10$) reported any fidelity monitoring, contamination checks, or protocol adherence metrics, highlighting a recurrent limitation in complex intervention studies within long-term care.

Nurse-Led Interventions by Type

Advance Care Planning and Communication Interventions

Six studies implemented nurse-led ACP and communication-focused models (Table 2). These ranged from structured face-to-face sessions^{31,47} to telephone-based caregiver coaching.^{38,48} A common feature was nurse facilitation of goal-of-care conversations, often using scripts or video aids. Notably, Brazil et al (2018) trained 60 RNs to conduct 45–60 minute sessions, achieving high care plan completion and improved caregiver satisfaction.³¹ Sachs et al (2025) extended this by combining nurse and social worker input over 24 months, indicating the feasibility of long-term community-based delivery.⁴⁸ However, variation in nurse training (ranging from brief online modules to 5-day immersive workshops) and inconsistent documentation of the communication process raise concerns about intervention standardization. Most ACP interventions reported increased alignment between patient values and documented preferences, but cultural sensitivity and use of interpreters were discussed in only two trials.^{39,47}

Pain and Symptom Management

Seven studies (Table 2) addressed pain and symptom relief through validated tools such as C-PAINAD,²⁸ Doloplus-2,³⁷ and the WWADR profile.²⁶ These tools empowered nurses to initiate timely pharmacological or non-drug interventions. COSMOS³⁴ combined training with interdisciplinary protocols and showed consistent reductions in polypharmacy and pain scores. Similarly, the STA OP! protocol³² provided a stepwise nurse-led approach with clear documentation pathways. However, only three studies reported integration with existing electronic medical records, and none conducted formal economic evaluations. Training formats were also heterogeneous, ranging from single workshops to cascade training with booster sessions.⁴⁰ Although several programs reported behavioral symptom reduction, they did not always distinguish between effects attributable to pain relief versus general engagement. Training intensity ranged from single 2-hour sessions to multi-day workshops, which may explain variability in outcomes. Few studies reported fidelity monitoring or integration into existing care pathways, limiting generalizability across diverse settings. Cultural adaptation of symptom management tools was also rarely described, raising questions about applicability in non-Western contexts.

Psychosocial and Behavioral Intervention Modalities

This group included eight studies (Table 2), emphasizing sensory engagement eg, Namaste Care,^{41,43} reminiscence-based interaction,³⁵ music integration,⁴⁶ and technology-enhanced behavioral monitoring.⁴⁵ Nurse roles varied from session facilitators to app-based monitors, and training ranged from arts workshops to task-specific protocols.

Outcomes frequently included reductions in agitation, resistance to care, and emotional withdrawal, although only three studies employed validated tools such as Cohen-Mansfield Agitation Inventory (CMAI) or Quality of Life in Dementia scale (QUALIDEM). Importantly, several interventions^{45,46} embedded psychosocial engagement directly into routine care rather than isolating it as a therapy, a design strength for sustainability. Nevertheless, duration and intensity of exposure were inconsistently reported. Only one study⁴³ included structured family engagement over the long term. Overall, the evidence suggests promise but lacks standardization in outcome measurement and fails to address intervention fatigue or staff burden. In addition, details about training duration ranged from short single-session workshops to

Table 2 Nurse-Led Intervention Characteristics Grouped by Intervention Type

Study	Nurse Role	Delivery Format	Training Provided	Key Components/Impact
2.1 Types of Advance Care Planning and Communication Interventions				
Brazil et al (2018) ³¹	ACP-trained RNs	One 45–60 min structured ACP session per family focused on values and goals of care	5-day intensive ACP course; 60 nurses trained across 6 facilities	89% care plan completion; significant increase in family satisfaction and staff confidence
Hanson et al (2019) ³⁹	Nurse facilitators	Structured family meetings using video decision aids and scripted communication prompts	In-person workshop on palliative communication with video support	Improved clarity in prognosis discussion and caregiver understanding
Mitchell et al (2018) ³³	Facility nurses	Video-assisted ACP sessions introduced during admission	Web-based ACP training and printed scripts	Improved documentation of feeding preferences and family participation
Sachs et al (2025) ⁴⁸	Nurse + social worker	Monthly coaching calls to caregivers of residents with advanced dementia	Caregiver support scripts and palliative coaching framework	Increased alignment of care goals and improved caregiver decision-making confidence
Spichiger et al (2025) ⁴⁷	Nurse case managers	Monthly interdisciplinary family-staff meetings to review evolving care goals	2-day training in person-centered care	Strengthened communication and goal concordance among care teams
Arendts et al (2022) ³⁸	Nurses/clinicians conducted needs assessments, education, and referrals	1+ session (in-person/telehealth), follow-up for 12 months	Training in dementia, CANDID tool, motivational interviewing	↑ Preferred place of death (60% → 75%), ↓ carer strain, 440 dyads, 6 EDs involved
2.2 Approaches to Pain and Symptom Management				
Liu & Lai (2017) ²⁸	Staff nurses	Daily bedside pain assessments using C-PAINAD scale	2-hour in-service workshop and refresher	Improved pain detection and non-verbal symptom management
Chen & Lin (2016) ²⁷	Facility nurses	Daily use of Pain Review Tool (PRT) integrated in records	Case-based documentation and assessment training	Better initiation of nurse-led pharmacological adjustments
Rostad et al (2018) ³⁷	Nurses	Biweekly team assessments using Doloplus-2 pain scale	Structured behavior-linked pain scoring training	Increased awareness of pain symptoms and individualized care adjustments
Pieper et al (2018) ³²	Registered nurses	Biweekly interdisciplinary team meetings using STA OP! protocol	Manual-based workshop training across Dutch care homes	Behavioral symptoms reduced; team coordination improved
Aasmul et al (2018) ³⁴	Nurses + caregivers	4-week COSMOS program on pain, medications, communication, quality of life	Train-the-trainer cascade model	Reduced pain scores, optimized medication use, and improved nurse-family communication
Husebø et al (2019) ⁴⁰	Nurses + aides	COSMOS continuation with booster sessions	Cascade training with fidelity checks	Sustained pain management benefits and behavioral engagement
Jordan et al (2015) ²⁶	Nurses	Daily ADR (adverse drug reaction) monitoring with WWADR tool	1-day pharmacovigilance training	Enhanced detection of drug-related problems and deprescribing practice
2.3 Psychosocial and Behavioral Intervention Modalities				
Ballard et al (2018) ³⁶	Nurses + activity staff	Weekly structured psychosocial sessions and interdisciplinary medication reviews	1-day behavioral workshop; 138 staff trained	17% drop in antipsychotic use; improved social interaction
Froggatt et al (2020) ⁴¹	Nurses + caregivers	Namaste Care: 2 sessions/day, 6 days/week (sensory-based)	2-hour training for 32 staff	25% reduction in agitation (CMAI), 20% improvement in quality of life
Smaling et al (2018) ⁴³	Nurses + family	Daily Namaste-style sessions with family involvement	Workbook and role-play guidance	Reduced resistance to care; increased emotional connection
Tse et al (2018) ³⁵	Nurse aides	Group reminiscence therapy (45 min × 3/week × 6 weeks)	Arts-based communication workshop	Improved mood scores and resident social interaction
Vaccaro et al (2020) ⁴⁴	Nurses	Doll therapy (20–30 min sessions during agitation episodes)	Behavioral dementia management training	Decrease in verbal outbursts and agitation-related behavior

Myrenget et al (2024) ⁴⁶	Nurses + family	Personalized music therapy before care routines	2-day training in music therapy and task-timing	Enhanced cooperation with ADLs; less care resistance
Kosters et al (2023) ⁴⁵	Nurses	Mobile app to detect behavioral triggers and alert nurses	Digital training and app-based reviews	Early interventions; fewer behavioral escalations and staff burden
2.4 Multicomponent and Quality Improvement Strategies				
Van den Block et al (2020) ⁴²	Mentor nurses	PACE quality improvement with audit-feedback cycles	3-day QI course and pathway tools	Higher ACP documentation rates; increased coaching in nursing homes
Agar et al (2017) ³⁰	Nurse coordinators	Trigger-based family meetings post-clinical change	Simulation-based palliative care training	Greater clarity in goals of care and emotional closure for families
Hanson et al (2019) ³⁹	Hospital + home nurses	Palliative consultation with follow-up calls post-discharge	3-hour communication and transition planning session	Reduced hospital readmissions and improved discharge goal alignment

more extended modules, which may have influenced consistency of delivery. Cultural adaptation of activities such as reminiscence or music therapy was rarely described, suggesting variation in applicability across different settings.

Multicomponent and Quality Improvement Strategies

Five studies (Table 2) implemented comprehensive models combining multiple domains: communication, symptom control, staff education, and documentation audits.^{30,42} These interventions often emphasized a train-the-trainer or mentor-nurse model, facilitating diffusion of practices across facilities. Van den Block et al (2020), reported increased documentation and staff coaching rates,⁴² while Hanson et al (2019) showed improved discharge planning and hospital transition outcomes.³⁹

Intervention Outcomes and Effectiveness

Outcomes of Advance Care Planning and Communication

Advance care planning (ACP)-focused studies showed consistently positive outcomes: care plan documentation increased (often to >75%), decisional conflict scores dropped by 20–30%, and caregiver confidence improved.^{31,48} Spichiger et al (2025) uniquely highlighted the importance of culturally aligned communication,⁴⁷ reporting a 20-point rise in perceived communication quality (Table 3). However, a common limitation was the lack of control for prior ACP exposure or existing facility-level ACP practices, which may have influenced results. Notably, only two studies evaluated the concordance between documented care preferences and the care actually delivered at the end of life. This gap is significant, as aligning care with patient and family wishes is a core goal of ACP and a key indicator of intervention success. Without measuring this alignment, it is difficult to assess whether ACP discussions lead to meaningful changes in care delivery. While documentation rates and caregiver confidence improved consistently, only a minority of studies examined whether documented preferences were honored in practice. This represents a critical gap in ACP research. In addition, intervention delivery formats varied widely, from single structured meetings to ongoing multi-month coaching, suggesting a need for greater standardization to allow comparability across settings.

Impact on Pain and Symptom Relief

Pain detection improved significantly in tool-based interventions, eg, 41% increase in new cases identified post-intervention,²⁸ with faster nurse-initiated analgesia.²⁷ COSMOS and STA OP! programs resulted in pain score reductions ranging from 25–30% and enhanced communication scores (Table 3).^{32,40} However, none of the studies reported on analgesic burden, sedation-related adverse events, or detailed deprescribing frameworks. Follow-up beyond 3 months was rare, making it difficult to assess whether improvements were sustained or simply temporary effects of intensive implementation. Training approaches varied considerably, from brief orientation sessions to multi-day formats with refresher components, which may account for differences in outcomes. Only a minority of studies incorporated fidelity checks or monitoring systems, limiting clarity on whether improvements were due to intervention content or training quality. Adaptation of pain assessment tools to different linguistic or cultural contexts was largely absent, even in multicountry studies.

Psychosocial and Behavioral Improvements

Five studies (Table 3) reported significant reductions in agitation, eg, Froggatt et al, 2020 noted a 25% CMAI reduction⁴¹ and resistance to care.⁴³ Music-based and doll therapy interventions improved task compliance and social interaction metrics.^{44,46} However, most relied on subjective observations, and only two blinded assessors to group allocation. Moreover, while emotional and behavioral gains were reported, resident-reported outcomes were entirely absent. No study included post-intervention staff workload or burnout measures, despite increased expectations placed on nurses to deliver structured psychosocial sessions. Training intensity also varied widely, with some studies relying on single-session protocols and others embedding repeated booster sessions. This heterogeneity complicates comparisons and raises questions about the durability of outcomes. Moreover, cultural adaptation of pain assessment tools was seldom reported, despite evidence that symptom expression may differ across populations.

Table 3 Outcome Measures and Assessment Tools with Key Findings

Study	Outcomes Measured	Assessment Tools	Key Findings (Elaborated)
3.1 Outcomes of Advance Care Planning and Communication			
Brazil et al (2018) ³¹	ACP completion, family satisfaction	Chart review, Family Satisfaction Survey	89% of residents had documented ACPs post-intervention, compared to 53% at baseline. Family satisfaction scores significantly improved (mean score 4.2 vs 3.4 on 5-point Likert scale), particularly in the domains of communication and emotional support.
Hanson et al (2019) ³⁹	Decisional conflict, clarity of care goals	Decisional Conflict Scale (DCS), Interview	DCS scores decreased by 22%, indicating enhanced caregiver confidence. Families better understood the trajectory of dementia and expressed more comfort in making end-of-life decisions.
Mitchell et al (2018) ³³	Documentation of feeding preferences, ACP uptake	Medical record audit	76% of intervention group residents had documented feeding preferences vs 48% in control. ACP forms were completed earlier and more comprehensively.
Sachs et al (2025) ⁴⁸	Caregiver confidence, goal concordance	Goal Concordance Index, Caregiver Feedback	Caregiver confidence increased by 30%, with 80% of cases showing full alignment between expressed goals and documented care plans.
Spichiger et al (2025) ⁴⁷	Cultural alignment of goals, communication quality	Meeting transcripts, Thematic analysis	Thematic content analysis revealed improved mutual understanding and satisfaction with culturally tailored communication. Family ratings of communication quality rose from 62% to 85% on internal metrics.
Arendts et al (2022) ³⁸	Place of death, quality of life, carer strain, ED visits, hospital days, bereavement risk	QUALID, EQ-5D, MCS1, SAS, AKPS, MBRI, CANDID tool	Targeted ↑ in deaths at preferred location (from 60% to 75%), reduction in ED visits and hospitalizations, improved carer quality of life and reduced burden over 12 months
3.2 Impact on Pain and Symptom Relief			
Liu & Lai (2017) ²⁸	Pain detection and treatment response	C-PAINAD	Pain was more frequently recognized (41% increase in detection); appropriate analgesics were administered in 68% of newly identified cases post-intervention.
Chen & Lin (2016) ²⁷	Nurse-initiated pain control	Pain Review Tool (PRT)	Nurse response time to pain reports reduced from 45 min to 30 min. Nurses independently initiated pharmacologic interventions in 43% of cases.
Rostad et al (2018) ³⁷	Symptom tracking and targeted interventions	Doloplus-2	Pain scores fell from a mean of 6.3 to 3.9 ($p < 0.01$). Care plans were adjusted in 75% of cases after symptom reassessment.
Pieper et al (2018) ³²	Behavioral symptoms, team communication	NPI, Meeting Logs	Agitation scores reduced by 18% ($p = 0.04$). Documentation of interdisciplinary decisions improved by 40%.
Aasmul et al (2018) ³⁴	Pain, QOL, and medication quality	VAS, QUALID	Pain scores dropped by 28%; communication scores rose by 19% ($p < 0.05$). Antipsychotic and sedative use also declined.
Husebø et al (2019) ⁴⁰	Pain persistence, behavioral symptoms	CMAI, QUALIDEM	20% reduction in apathy and verbal aggression; improved alertness noted during ADLs. Effects were maintained at 4-month follow-up.
Jordan et al (2015) ²⁶	ADR reporting, deprescribing safety	VVADR tool	ADR detection rates doubled. Appropriate deprescribing occurred in 35% of reviewed medication plans with no increase in adverse outcomes.
3.3 Psychosocial and Behavioral Improvements			
Ballard et al (2018) ³⁶	Antipsychotic use, social engagement	Pharmacy records, Staff Engagement Index	Antipsychotic prescription rates fell by 17%. Observed resident–staff interactions became more positive (29% improvement in rapport scores).
Froggatt et al (2020) ⁴¹	Agitation, sensory engagement	CMAI, QUALIDEM	CMAI scores dropped by 25%. Quality-of-life ratings improved in affective and sensory subdomains by 20%.
Smaling et al (2018) ⁴³	Emotional comfort, resistance to care	Comfort scales, Family interviews	Resistance to care behaviors (eg, pulling away) fell by 21%. Families reported stronger perceived emotional connection.
Tse et al (2018) ³⁵	Mood and social interaction	GDS, Observation	GDS scores improved by 3.2 points ($p = 0.03$); group interaction frequency increased by 45%.
Vaccaro et al (2020) ⁴⁴	Behavioral agitation	Behavioral checklist	Verbal outbursts decreased by one-third. 65% of participants showed more settled bedtime routines.
Myrenget et al (2024) ⁴⁶	Cooperation with ADLs	Task cooperation logs	Staff noted 40% improvement in resident compliance with dressing and feeding. Playlist personalization was linked to better cooperation.

(Continued)

Table 3 (Continued).

Study	Outcomes Measured	Assessment Tools	Key Findings (Elaborated)
Kosters et al (2023) ⁴⁵	Behavioral escalation, response latency	App logs, Incident reports	Behavioral incidents decreased by 35%. Nurses responded to agitation alerts 2× faster using app integration.
3.4 System-Level and Multicomponent Outcomes			
Van den Block et al (2020) ⁴²	ACP documentation, QI adherence	PACE audit tools, Staff feedback	ACP rates increased from 43% to 78%. Staff participation in monthly QI meetings exceeded 90%.
Agar et al (2017) ³⁰	Goal alignment, family closure	Bereavement survey	Family reports of concordance with loved ones' wishes rose from 52% to 84%. Emotional closure improved ($p < 0.01$).
Hanson et al (2019) ³⁹	Hospital readmissions, care continuity	Readmission logs, Post-discharge interview	30% drop in 30-day readmission. Families felt better supported through discharge transitions.

System-Level and Multicomponent Outcomes

Among quality improvement models, moderate effects were noted (Table 3): reduced ER visits,³⁸ improved transition alignment,³⁹ and higher ACP documentation.⁴² These effects were most robust in stepped-wedge or audit-feedback designs. Yet, implementation science variables such as acceptability, feasibility, and cost-effectiveness were rarely addressed. No trial reported direct comparisons across sites or explored health system integration beyond the facility level.

Risk of Bias and Certainty of Evidence

Risk of Bias Assessment in Randomized Controlled Trials

Figure 2A and B illustrate the risk of bias assessments for the included randomized controlled trials using the ROB2 tool. Figure 2A (traffic light plot) displays domain-specific judgments across individual studies, with color codes representing

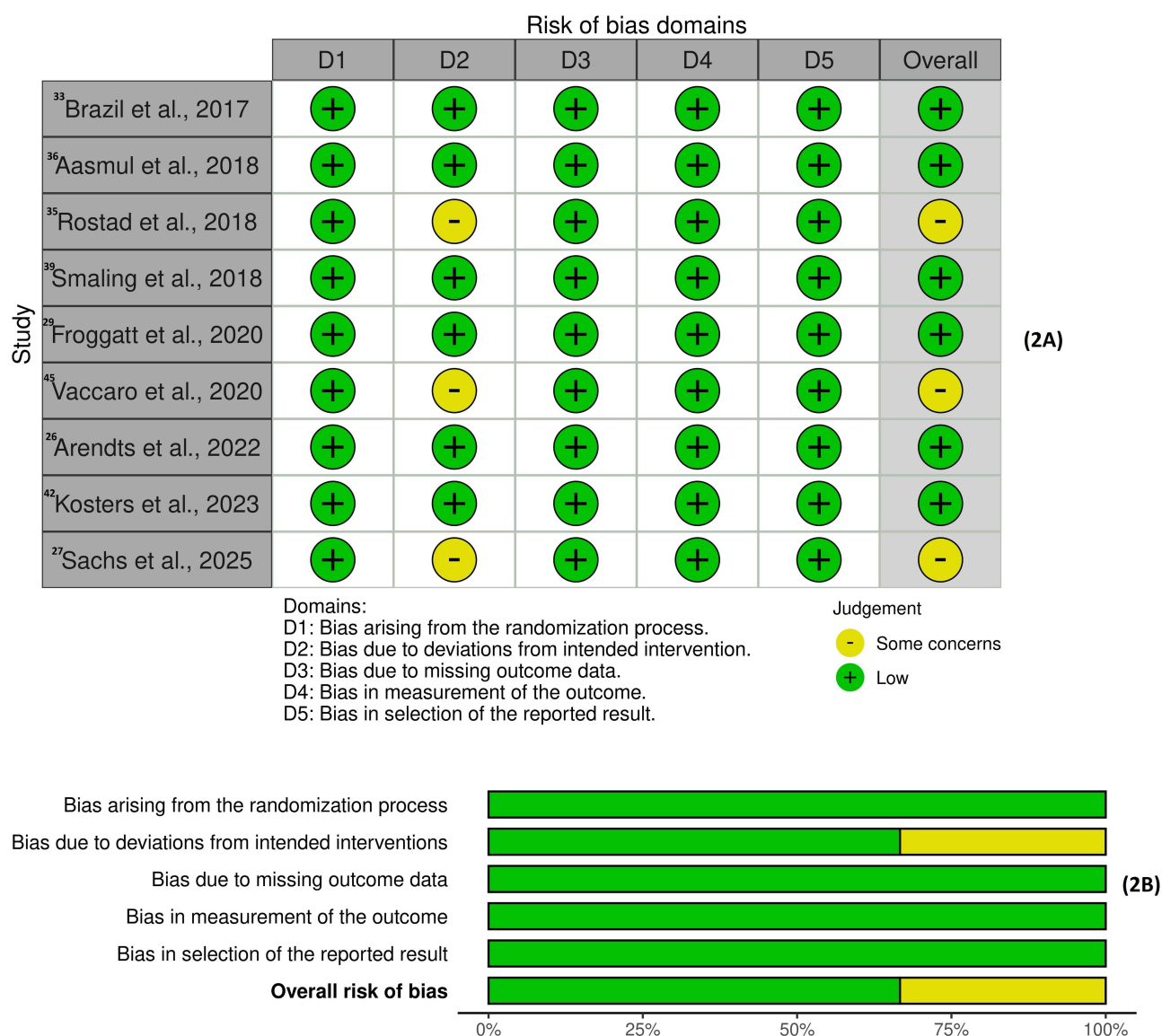


Figure 2 Risk of Bias Assessment Using the Cochrane ROB2 Tool. (A) Presents a traffic light plot illustrating domain-specific risk of bias judgments across the included randomized controlled trials. Each domain, D1 (randomization), D2 (deviations from intended interventions), D3 (missing outcome data), D4 (outcome measurement), and D5 (selection of reported result), is color-coded: green indicates “low risk”, yellow denotes “some concerns”, and red (if applicable) reflects “high risk.” (B) Summarizes the proportion of studies categorized under each risk level per domain using a stacked bar chart, including the overall risk of bias. This visual overview highlights methodological strengths and areas requiring caution in interpreting study findings.

risk levels: green for “low risk” and yellow for “some concerns.” Most studies demonstrated low risk across all domains, with some concerns noted specifically in domain D2 (bias due to deviations from intended interventions) in a subset of studies.^{37,44,48} Figure 2B (summary bar chart) quantifies these findings, showing that 33.3% of studies had some concerns in D2, while the remaining domains, including randomization (D1), missing outcome data (D3), measurement of outcomes (D4), and selective reporting (D5), were consistently rated as low risk in all studies. These findings reflect a generally strong methodological quality among the RCTs included in the review.

Risk of Bias Assessment in Cluster Randomized Controlled Trials

Based on the cluster randomized controlled trials assessed (Figure 3), all studies demonstrated low risk of bias in five key domains: bias arising from the randomization process (D1), deviations from intended interventions (D2), missing outcome data (D3), measurement of outcomes (D4), and selection of the reported result (D5). However, domain D1b, concerning the timing of identification and recruitment of individual participants, revealed some concerns in three studies,^{36,39,42} due to issues such as delayed or staggered recruitment relative to cluster allocation. As a result, while most studies^{30,32,39,40,46} were judged to have an overall low risk of bias, those with concerns in D1b were rated as having some concerns overall. These findings highlight the methodological challenge of synchronizing participant recruitment with cluster assignment in such designs.

Risk of Bias in Non-Randomized Studies

Figure 4A and B present the risk of bias assessment for non-randomized controlled trials using the ROBINS-I tool. As illustrated in Figure 4A (traffic light plot), all included studies exhibited low risk in domains related to participant selection (D2), classification of interventions (D3), and missing data (D5). However, moderate risk was frequently

		Risk of bias domains						
		D1	D1b	D2	D3	D4	D5	Overall
Study	³⁸ Husebø et al. (2016)	+	+	+	+	+	+	+
	⁴³ Agar et al. (2017)	+	+	+	+	+	+	+
	⁶⁹ Hanson et al., 2017	+	+	-	+	+	+	-
	⁴⁶ Ballard et al., 2017	+	-	+	+	+	+	-
	³⁷ Pieper et al., 2018	+	+	+	+	+	+	+
	²⁸ Hanson et al., 2019	+	+	+	+	+	+	+
	³⁰ Van den Block et al., 2019	+	-	-	+	+	+	-
	⁴¹ Myrenget et al., 2024	+	+	+	+	+	+	+

Domains:

D1 : Bias arising from the randomization process.

D1b: Bias arising from the timing of identification and recruitment of Individual participants in relation to timing of randomization.

D2 : Bias due to deviations from intended intervention.

D3 : Bias due to missing outcome data.

D4 : Bias in measurement of the outcome.

D5 : Bias in selection of the reported result.

Judgement

- Some concerns

+ Low

Figure 3 Risk of Bias Traffic Light Plot for Cluster Randomized Controlled Trials (ROB2 Tool – Cluster Extension). Each row represents a study, and columns represent domains of bias: randomization (D1), timing of identification and recruitment (D1b), deviations from intended intervention (D2), missing outcome data (D3), measurement of outcome (D4), and selection of reported result (D5). Judgments are shown using color codes: Low risk (green) and Some concerns (yellow).

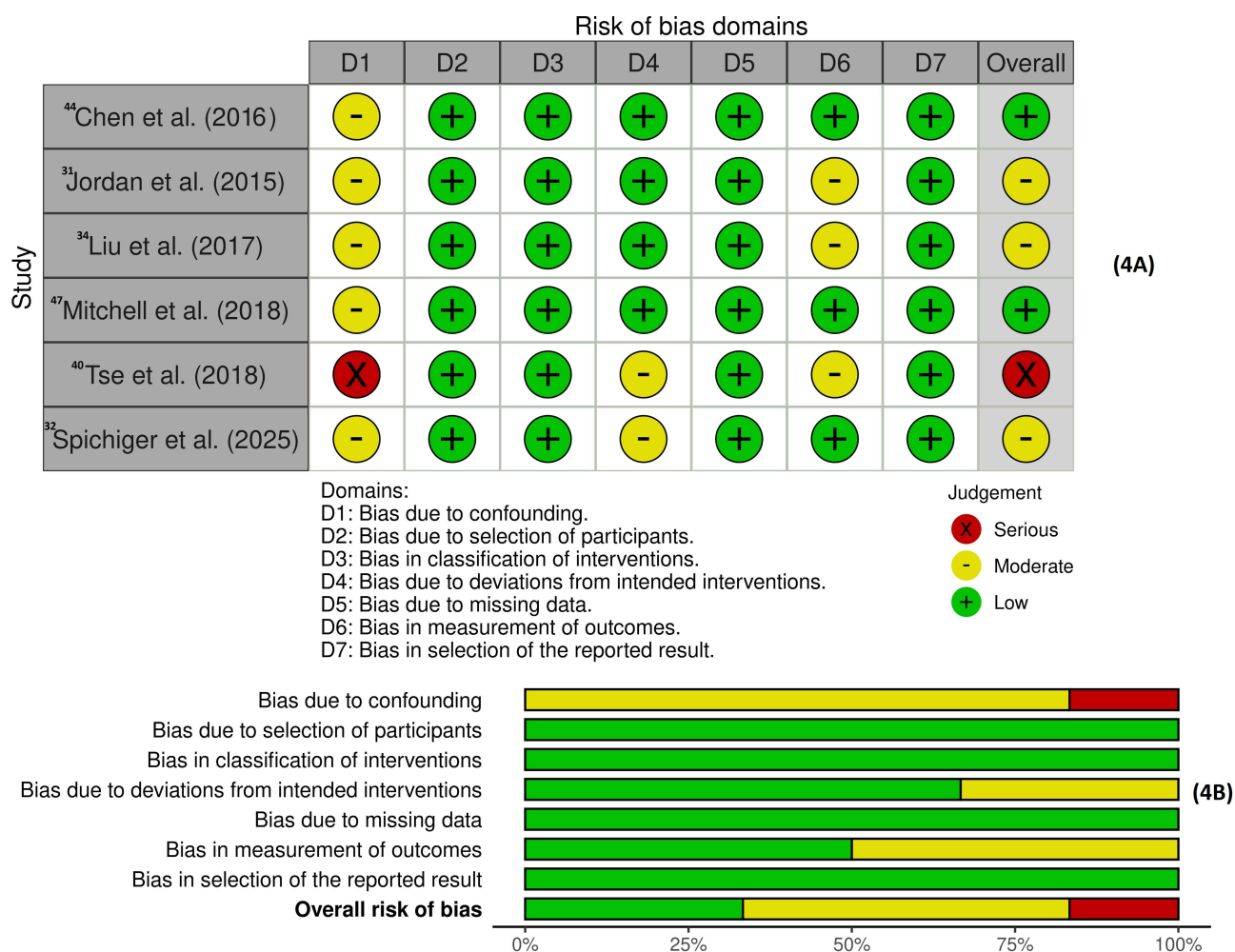


Figure 4 Risk of Bias Summary for Non-Randomized Studies (ROBINS-I). (A) Shows a traffic light plot of domain-level judgments across seven non-randomized studies, covering seven ROBINS-I domains: confounding, selection, classification, deviations, missing data, outcome measurement, and reporting. Green = low risk, yellow = moderate risk, red = serious risk. (B) Presents a bar chart summarizing the proportion of studies rated at each risk level across all domains and overall bias.

observed in domains such as confounding (D1), deviations from intended interventions (D4), measurement of outcomes (D6), and selection of reported results (D7). Notably, Tse et al (2018) demonstrated a serious risk in both D1 and the overall assessment,³⁵ while the rest of the studies^{26–28,33,47} were judged as having moderate overall risk. Figure 4B (summary bar chart) confirms these findings, showing 100% low risk in three domains, approximately 71.4% moderate risk in D1, and 14.3% serious risk overall. These findings underscore the need for careful adjustment for confounding variables and enhanced blinding of outcome assessors in future non-randomized trials to strengthen methodological rigor.

Certainty of Evidence (GRADE Assessment)

While nurse-led interventions demonstrated meaningful benefits across key domains, the certainty of evidence, assessed using the GRADE framework, varied by outcome (Table 4). High certainty was observed for advance care planning completion, supported by consistent findings from well-designed RCTs. Moderate certainty was assigned to outcomes such as caregiver satisfaction and communication quality, due to some heterogeneity and reliance on subjective assessments. Pain and agitation control were supported by moderate-to-low certainty, primarily due to inconsistencies in measurement tools and limited follow-up durations. Future trials should aim for standardized outcome reporting and longer-term assessments to enhance certainty and generalizability.

Table 4 GRADE Summary of Evidence for Key Outcomes

Outcome	No. of Studies	Study Design	Effect Direction	Certainty (GRADE)	Key Limitations
Pain reduction	7	Mostly RCTs	Consistent positive effect	Moderate	Heterogeneity in intervention duration and outcome tools
Agitation control	5	Mixed (RCTs, non-RCTs)	Moderate to strong effect	Low	Subjective ratings, lack of blinding
ACP documentation	6	RCTs and cluster-RCTs	Strong and consistent effect	High	Minimal limitations across studies
Caregiver satisfaction	4	Cluster-RCTs	Moderate improvement	Moderate	Inconsistent measurement tools
Communication quality	3	Mixed	Positive trend	Moderate	Small samples, cultural variability
ER visit reduction	3	RCTs and protocols	Positive effect	Low	Protocol bias, few trials
Quality of life improvement	5	RCTs and non-RCTs	Positive effect	Moderate	Diverse QOL scales, short follow-up

Discussion

Individuals with advanced dementia face profound physical, emotional, and existential distress driven by progressive cognitive and functional decline.^{49,50} Addressing these needs requires proactive, nursing-led palliative care approaches tailored to communication barriers and complex symptom profiles. This systematic review highlights the critical role of nurses in delivering such care, leveraging their sustained bedside presence, clinical judgment, and familiarity with patient needs. Through person-centered interventions, nurses can facilitate meaningful goals-of-care conversations, reduce distress, and preserve dignity in the final stages of life.^{31,47}

Evidence across reviewed studies suggests that nursing-led interventions play a pivotal role in alleviating pain, breathlessness, agitation, and psychological discomfort in advanced dementia. By embedding palliative care principles into daily routines, nurses can respond more promptly and individually to unmet needs.^{40,50} Importantly, these interventions align with emerging neurobiological insights into the disease: atypical pain behaviors may arise from disrupted pain-processing pathways, while agitation and affective dysregulation reflect frontotemporal and limbic dysfunction.^{9,51,52} Integrating such pathophysiological perspectives underscores why nursing strategies must be tailored, vigilant, and symptom-specific. Although symptom burden in dementia often mirrors that of advanced cancer, patients with dementia are less likely to receive timely symptom relief.⁵³ The use of validated tools such as PAINAD,²⁸ Doloplus-2,³⁷ and STA OP!³² has enhanced the recognition of pain in non-verbal individuals and facilitated appropriate intervention. These outcomes reinforce the importance of proactive symptom surveillance by frontline nurses to reduce distress and prevent unnecessary hospitalizations.⁵⁴

Although psychotropic medications and acetylcholinesterase inhibitors are frequently used to address neuropsychiatric symptoms,⁵⁵ non-pharmacological strategies have gained traction. Person-centered modalities, such as reminiscence therapy, sensory stimulation, and Namaste Care, reduce agitation, improve mood, and foster engagement.^{56–58} In our review, music therapy, doll therapy, and multisensory programs, delivered by trained nursing staff, produced measurable behavioral gains.^{44,46,50} Embedding these approaches into daily routines enhances both feasibility and sustainability. Nevertheless, standardization of outcome metrics, evaluation of staff workload, and assessment of long-term benefits remain important gaps.⁵⁹

Engaging families in care planning is essential to high-quality palliative dementia care. Nursing-led case conferences promote structured dialogue around prognosis, treatment⁵⁷ preferences, and care goals, improving alignment between families and care teams.^{47,60} Such involvement enhances satisfaction, emotional preparedness, and decisional confidence.^{61,62} These forums also support personalized goal setting, consistent with person-centered care principles.⁶³ However, challenges such as infrequent scheduling, poor documentation, and caregiver literacy gaps persist, particularly in resource-limited environments.^{31,64} Proactive use of structured communication protocols may help overcome these barriers and support consistent family involvement.

Structured caregiver support is a critical component of palliative dementia care due to the emotional and psychological burden of caregiving. Nurse-led psychoeducational programs, such as those described by Gonella et al (2022), equip caregivers with coping tools, practical skills, and emotional support.⁶⁵ These interventions reduce caregiver stress and enhance engagement in care planning. Peer support groups, often facilitated by nurses, further mitigate isolation and promote resilience.^{19,66} Active caregiver involvement in advance care planning has also been linked to greater confidence

in end-of-life decisions and reduced uncertainty.^{67,68} However, long-term outcomes, such as grief adjustment, financial strain, and post-bereavement support, remain underexplored and warrant further research.

While the overall findings were encouraging, the lack of standardization in intervention design and nurse training emerged as a key limitation. Programs varied widely in duration, delivery mode, and content, making it difficult to compare outcomes or replicate effective models. In many cases, the absence of fidelity monitoring and inconsistent documentation of implementation processes further weakened the strength of evidence. To enhance generalizability and scalability, future studies should adopt unified frameworks that define core intervention components, training protocols, and reporting standards.⁶⁹ Moreover, digital innovations such as MoSART+, which support real-time symptom tracking and clinical decision-making, were rarely utilized, representing a missed opportunity to improve intervention efficiency and responsiveness.⁴⁵

The evidence base is geographically skewed, with most trials conducted in high-income, well-resourced settings. This limits generalizability to low- and middle-income countries (LMICs), where care delivery is shaped by staff shortages, limited infrastructure, and distinct cultural contexts. Methodological issues, such as small sample sizes, short follow-up periods, and lack of blinding, further weaken the strength of evidence in some studies.^{35,63} Future research should focus on rigorously designed, multicenter trials in diverse contexts and apply implementation science frameworks to assess scalability, cost-effectiveness, and long-term sustainability. Long-term caregiver outcomes, including bereavement adjustment and post-care trajectories, were rarely assessed, indicating an important gap for future research.

This review highlights the need to formally embed nursing-led palliative care into standard dementia care pathways. Nurses should be equipped to initiate advanced care planning, use validated tools like PAINAD and QUALIDEM, and deliver person-centered, non-pharmacological interventions. Routine integration of case conferencing and family education can strengthen shared decision-making and caregiver preparedness. Achieving these goals requires institutional investment in nurse training, adequate staffing, and policy frameworks that support sustainable implementation (National Consensus Project, 2021). Incorporating palliative competencies into training curricula and fostering interdisciplinary collaboration are also critical for delivering comprehensive, high-quality care.

Limitations

Despite the methodological rigor and comprehensive scope of this review, several limitations must be acknowledged. A major challenge was the substantial heterogeneity in intervention components, delivery formats, training protocols, and outcome measures, which limited cross-study comparability and precluded meta-analytic synthesis. Additionally, many randomized controlled trials lacked detailed reporting on allocation concealment, blinding of outcome assessors, and fidelity monitoring, especially in cluster designs, where contamination and inconsistent timing of recruitment added further complexity. While the inclusion of non-randomized studies enhanced real-world applicability, it also introduced a higher risk of confounding and potential bias. Another key limitation lies in the geographical concentration of evidence: the majority of studies were conducted in high-income countries, limiting generalizability to low- and middle-income settings where healthcare systems, cultural practices, and nursing capacities differ significantly. The feasibility, scalability, and sustainability of nursing-led interventions in LMICs remain insufficiently explored. Moreover, important implementation science dimensions, such as cost-effectiveness, intervention acceptability, and system-level integration, were rarely assessed, limiting insights into real-world translation. Lastly, caregiver-centered outcomes such as long-term psychological health, bereavement adjustment, and economic burden were underreported, highlighting the need for more comprehensive outcome evaluation in future studies.

Future Scope

Building on these conclusions, future research should focus on developing standardized, scalable models of nursing-led palliative care that are adaptable across diverse clinical and cultural contexts. Multicenter trials with rigorous designs, longer follow-up periods, and mixed-method evaluations are needed to assess the long-term effectiveness and generalizability of these interventions. Culturally sensitive frameworks should be embedded to ensure relevance in low- and middle-income countries, where healthcare resources and caregiving structures may differ substantially. There is also a pressing need for economic evaluations to determine cost-effectiveness, resource use, and return on investment, key considerations for health system adoption. Digital technologies, including real-time symptom tracking, decision-support systems, and mobile applications, represent underutilized tools that could enhance nursing efficiency and care

personalization. In addition, future studies should prioritize caregiver-reported outcomes and include follow-up into the post-bereavement period to fully capture the psychosocial impact of interventions. Finally, integrating implementation science frameworks, such as hybrid effectiveness-implementation models, can support the translation of evidence into practice. By evaluating real-world feasibility, acceptability, and fidelity, these approaches will be essential for informing policy, workforce planning, and sustainable care delivery models.

Conclusion

This systematic review demonstrates that nurse-led palliative care interventions play a central role in alleviating pain, agitation, communication difficulties, and psychological distress, while also supporting advance care planning and caregiver engagement in advanced dementia. Evidence across studies shows consistent improvements in these domains, though evidence on long-term caregiver outcomes, such as bereavement adjustment, remains limited. Structured tools such as PAINAD, Doloplus-2, and STA OP! were instrumental in enabling timely, accurate assessment and management of distressing symptoms, particularly in non-verbal patients. Notably, interventions integrated into routine nursing workflows proved more feasible and sustainable than isolated or externally driven programs. However, wide variability in intervention design, training models, and outcome reporting limits the comparability of findings and challenges replication. These results reinforce the central role of nurses as frontline providers of person-centered, evidence-based palliative care and underscore the importance of institutional investment in standardized, scalable models. Embedding nursing-led palliative approaches into dementia care pathways and national policies will be essential for ensuring dignity, comfort, and improved outcomes for this vulnerable population. Beyond immediate clinical benefits, these findings advance the theoretical understanding of nursing leadership in dementia care and highlight practical directions for policy, education, and research integration.

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References

1. WHO. *Global Status Report on the Public Health Response to Dementia*. Geneva: Switzerland: WHO; 2021.
2. Culbertson JW, Kopel J, Sehar U, Reddy PH. Urgent needs of caregiving in ageing populations with Alzheimer's disease and other chronic conditions: support our loved ones. *Ageing Res Rev*. 2023;90:102001. doi:10.1016/j.arr.2023.102001
3. Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*. 2020;396(10248):413–446. doi:10.1016/S0140-6736(20)30367-6
4. Catala-Lopez F, Collaborators GDF, Vollset SE. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *Lancet Public Health*. 2022;7(2):e105–e125. doi:10.1016/S2468-2667(21)00249-8
5. Gaugler J, James B, Johnson T, et al. Alzheimer's disease facts and figures. *Alzheimers Dement*. 2022;18(4):700–789.
6. Kenigsberg P-A, Aquino J-P, Berard A, et al. Dementia beyond 2025: knowledge and uncertainties. *Dementia*. 2016;15(1):6–21. doi:10.1177/1471301215574785
7. Eisenmann Y, Golla H, Voltz R, Perrar KM. Palliative care in advanced dementia. *Front Psychiatry*. 2020;11:699. doi:10.3389/fpsy.2020.00699
8. Browne B, Kupeli N, Moore KJ, Sampson EL, Davies N. Defining end of life in dementia: a systematic review. *Palliat Med*. 2021;35(10):1733–1746. doi:10.1177/02692163211025457
9. Yao K, Wang S, Xu Z, et al. Mechanisms of comorbidity between Alzheimer's disease and pain. *Alzheimers Dement*. 2025;21(2):e14605. doi:10.1002/alz.14605
10. Palermo S, Benedetti F, Costa T, Amanzio M. Pain anticipation: an activation likelihood estimation meta-analysis of brain imaging studies. *Human Brain Mapp*. 2015;36(5):1648–1661. doi:10.1002/hbm.22727
11. Di Gregorio F, Battaglia S. The intricate brain-body interaction in psychiatric and neurological diseases. *Adv Clin Exp Med*. 2024;33(4):321–326. doi:10.17219/acem/185689
12. World Health Organization. *Palliative Care*. Geneva: WHO; 2020.
13. Lopez RP, Kris AE, Rossmassler SC. Nursing leadership and palliative care in long-term care for residents with advanced dementia. *Nurs Clin North Am*. 2022;57(2):259–271. doi:10.1016/j.cnur.2022.02.006
14. Walsh SC, Murphy E, Devane D, et al. Palliative care interventions in advanced dementia. *Cochrane Database Syst Rev*. 2021;9(9). doi:10.1002/14651858.CD011513.pub3.

15. Pocknell CE, Hartigan I, Brady N, et al. Education and training for the delivery of person-centred palliative care in advanced dementia in nursing homes: a scoping review protocol. *OSF Registries*. 2024. doi:10.17605/OSF.IO/X9W5T
16. David L, Popa SL, Barsan M, et al. Nursing procedures for advanced dementia: traditional techniques versus autonomous robotic applications. *Exp Ther Med*. 2022;23(2):124. doi:10.3892/etm.2021.11047
17. Cabrera E, Sutcliffe C, Verbeek H, et al. Non-pharmacological interventions as a best practice strategy in people with dementia living in nursing homes. A systematic review. *Eur Geriatric Med*. 2015;6(2):134–150. doi:10.1016/j.eurger.2014.06.003
18. Endsley S, Main R. Palliative care in advanced dementia. *Am Family Phys*. 2019;99(7):456–458.
19. Navia RO, Constantine LA. Palliative care for patients with advanced dementia. *Nurs2024*. 2022;52(3):19–26.
20. Wang T, Tan J-YB, Liu X-L, Zhao I. Barriers and enablers to implementing clinical practice guidelines in primary care: an overview of systematic reviews. *BMJ Open*. 2023;13(1):e062158. doi:10.1136/bmjopen-2022-062158
21. Evans CJ, Harding R, Higginson IJ. MORECare ‘Best practice’ in developing and evaluating palliative and end-of-life care services: a meta-synthesis of research methods for the MORECare project. *Palliative Med*. 2013;27(10):885–898. doi:10.1177/0269216312467489
22. Huang KH, Saragih ID, Suarilah I, Son NT, Lee B-O. Systematic review and meta-analysis of effects of nurse-led intervention for people with dementia. *Nurs Res*. 2023;72(6):430–438. doi:10.1097/NNR.0000000000000685
23. Hendriks SA, Smalbrugge M, Galindo-Garre F, Hertogh CM, van der Steen JT. From admission to death: prevalence and course of pain, agitation, and shortness of breath, and treatment of these symptoms in nursing home residents with dementia. *J Am Med Directors Assoc*. 2015;16(6):475–481. doi:10.1016/j.jamda.2014.12.016
24. Knapp M, Iemmi V, Romeo R. Dementia care costs and outcomes: a systematic review. *Int J Geriatric Psychiatry*. 2013;28(6):551–561. doi:10.1002/gps.3864
25. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*. 2021;372(372):n71. doi:10.1136/bmj.n71
26. Jordan S, Gabe-Walters ME, Watkins A, et al. Nurse-led medicines’ monitoring for patients with dementia in care homes: a pragmatic cohort stepped wedge cluster randomised trial. *PLoS One*. 2015;10(10):e0140203. doi:10.1371/journal.pone.0140203
27. Chen Y-H, Lin L-C. Ability of the pain recognition and treatment (PRT) protocol to reduce expressions of pain among institutionalized residents with dementia: a cluster randomized controlled trial. *Pain Manage Nurs*. 2016;17(1):14–24. doi:10.1016/j.pmn.2015.08.003
28. Liu JY, Lai CK. Implementation of observational pain management protocol for residents with dementia: a cluster-RCT. *J Am Geriatr Soc*. 2017;65(3):e56–e63. doi:10.1111/jgs.14763
29. Hanson LC, Zimmerman S, Song M-K, et al. Effect of the goals of care intervention for advanced dementia: a randomized clinical trial. *JAMA Intern Med*. 2017;177(1):24–31. doi:10.1001/jamainternmed.2016.7031
30. Agar M, Luckett T, Luscombe G, et al. Effects of facilitated family case conferencing for advanced dementia: a cluster randomised clinical trial. *PLoS One*. 2017;12(8):e0181020. doi:10.1371/journal.pone.0181020
31. Brazil K, Carter G, Cardwell C, et al. Effectiveness of advance care planning with family carers in dementia nursing homes: a paired cluster randomized controlled trial. *Palliative Med*. 2018;32(3):603–612. doi:10.1177/0269216317722413
32. Pieper MJ, van der Steen JT, Francke AL, Scherder EJ, Twisk JW, Achterberg WP. Effects on pain of a stepwise multidisciplinary intervention (STA OP!) that targets pain and behavior in advanced dementia: a cluster randomized controlled trial. *Palliative Med*. 2018;32(3):682–692. doi:10.1177/0269216316689237
33. Mitchell SL, Shaffer ML, Cohen S, Hanson LC, Habtemariam D, Volandes AE. An advance care planning video decision support tool for nursing home residents with advanced dementia: a cluster randomized clinical trial. *JAMA Intern Med*. 2018;178(7):961–969. doi:10.1001/jamainternmed.2018.1506
34. Aasmul I, Husebo BS, Sampson EL, Flo E. Advance care planning in nursing homes—improving the communication among patient, family, and staff: results from a cluster randomized controlled trial (COSMOS). *Front Psychol*. 2018;9:2284. doi:10.3389/fpsyg.2018.02284
35. Tse MM, Lau JL, Kwan R, et al. Effects of play activities program for nursing home residents with dementia on pain and psychological well-being: cluster randomized controlled trial. *Geriatrics Gerontol Int*. 2018;18(10):1485–1490. doi:10.1111/ggi.13509
36. Ballard C, Corbett A, Orrell M, et al. Impact of person-centred care training and person-centred activities on quality of life, agitation, and antipsychotic use in people with dementia living in nursing homes: a cluster-randomised controlled trial. *PLoS Med*. 2018;15(2):e1002500. doi:10.1371/journal.pmed.1002500
37. Rostad HM, Utne I, Grov EK, Småstuen MC, Puts M, Halvorsrud L. The impact of a pain assessment intervention on pain score and analgesic use in older nursing home residents with severe dementia: a cluster randomised controlled trial. *Int J Nursing Stud*. 2018;84:52–60. doi:10.1016/j.ijnurstu.2018.04.017
38. Arendts G, Chenoweth L, Hayes B, et al. CELPI: trial protocol for a randomised controlled trial of a Carer End of Life Planning Intervention in people dying with dementia. *BMC Geriatr*. 2022;22(1):869. doi:10.1186/s12877-022-03534-1
39. Hanson LC, Kistler CE, Lavin K, et al. Triggered palliative care for late-stage dementia: a pilot randomized trial. *J Pain Sympt Manage*. 2019;57(1):10–19. doi:10.1016/j.jpainsymman.2018.10.494
40. Husebø BS, Ballard C, Aarsland D, et al. The effect of a multicomponent intervention on quality of life in residents of nursing homes: a randomized controlled trial (COSMOS). *J Am Med Directors Assoc*. 2019;20(3):330–339. doi:10.1016/j.jamda.2018.11.006
41. Froggatt K, Best A, Bunn F, et al. A group intervention to improve quality of life for people with advanced dementia living in care homes: the Namaste feasibility cluster RCT. *Health Technol Assess*. 2020;24(6):1. doi:10.3310/hta24060
42. Van den Block L, Honinx E, Pivodic L, et al. Evaluation of a palliative care program for nursing homes in 7 countries: the PACE cluster-randomized clinical trial. *JAMA Intern Med*. 2020;180(2):233–242. doi:10.1001/jamainternmed.2019.5349
43. Smaling HJ, Joling KJ, van de Ven PM, et al. Effects of the Namaste care family programme on quality of life of nursing home residents with advanced dementia and on family caregiving experiences: study protocol of a cluster-randomised controlled trial. *BMJ open*. 2018;8(10):e025411. doi:10.1136/bmjopen-2018-025411
44. Vaccaro R, Molteni V, Molteni V, et al. Doll therapy intervention for women with dementia living in nursing homes: a randomized single-blind controlled trial protocol. *Trials*. 2020;21:1–12. doi:10.1186/s13063-020-4050-8
45. Kusters J, Janus SI, van den Bosch KA, et al. Soundscape awareness intervention reduced neuropsychiatric symptoms in nursing home residents with dementia: a cluster-randomized Trial with MoSART+. *J Am Med Directors Assoc*. 2023;24(2):192–198.e5. doi:10.1016/j.jamda.2022.11.010

46. Myrenget ME, Rustøen T, Myskja A, et al. The effect of a music-based caregiving intervention on pain intensity in nursing home patients with dementia: a cluster-randomized controlled study. *Pain*. 2024;165(7):1550–1558. doi:10.1097/j.pain.00000000000003156
47. Spichiger F, Koppitz AL, Riese F, et al. Person profile dementia intervention in long-term care: a stepped-wedge cluster-randomized trial. *J Am Med Directors Assoc*. 2025;26(1):105351. doi:10.1016/j.jamda.2024.105351
48. Sachs GA, Johnson NM, Gao S, et al. Palliative care program for community-dwelling individuals with dementia and caregivers: the IN-PEACE randomized clinical trial. *JAMA*. 2025;333:962–971.
49. Denning KH, Scates C, Lloyd-Williams M. Palliative care in dementia: a fragmented pathway? *Int J Palliative Nurs*. 2018;24(12):585–596. doi:10.12968/ijpn.2018.24.12.585
50. Van der Steen JT, Radbruch L, Hertogh CM, et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliative Med*. 2014;28(3):197–209. doi:10.1177/0269216313493685
51. Di Fazio C, Scaliti E, Stanziano M, et al. rTMS for enhancing cognitive reserve: a case report. *Brain Disorders*. 2025;18:100221. doi:10.1016/j.dscb.2025.100221
52. Palermo S, Di Fazio C, Scaliti E, Stanziano M, Nigri A, Tamietto M. Cortical excitability and the aging brain: toward a biomarker of cognitive resilience. *Front Psychol*. 2025;16:1542880. doi:10.3389/fpsyg.2025.1542880
53. Volicer L. Review of programs for persons facing death with dementia. *Healthcare*. 2019;7(2):62. doi:10.3390/healthcare7020062
54. Mitchell SL, Palmer JA, Volandes AE, Hanson LC, Habtemariam D, Shaffer ML. Level of care preferences among nursing home residents with advanced dementia. *J Pain Sympt Manage*. 2017;54(3):340–345. doi:10.1016/j.jpainsymman.2017.04.020
55. Knight R, Khondoker M, Magill N, Stewart A, Landau S. A systematic review and meta-analysis of the effectiveness of acetylcholinesterase inhibitors and memantine in treating the cognitive symptoms of dementia. *Dementia Geriatric Cognit Disord*. 2018;45(3–4):131–151. doi:10.1159/000486546
56. Yanagida N, Yamaguchi T, Matsunari Y. Evaluating the Impact of Reminiscence Therapy on Cognitive and Emotional Outcomes in Dementia Patients. *J Personal Med*. 2024;14(6):629. doi:10.3390/jpm14060629
57. Yous ML, Ploeg J, Kaasalainen S, McAiney C. Namaste care delivered by caregivers of community-dwelling older adults with moderate to advanced dementia: a mixed methods study protocol. *J Adv Nurs*. 2021;77(2):1027–1036. doi:10.1111/jan.14623
58. Lee KH, Lee JY, Kim B. Person-centered care in persons living with dementia: a systematic review and meta-analysis. *Gerontologist*. 2022;62(4):e253–e264. doi:10.1093/geront/gnaa207
59. Sieradzki B Addressing the strengths and gaps in education and training for long-term care staff who provide direct care to individuals living with dementia [Master's thesis]. Winnipeg (MB): University of Manitoba; 2017. Available from: <https://mspace.lib.umanitoba.ca/server/api/core/bitstreams/673e9041-5013-482b-9101-909d6abe28ca/content>
60. Balconi M, Angioletti CA-KR-L, Allegratta K-R-RA, Angioletti L, Crivelli D, Balconi CA-LA-M. Why a dynamic multicomponent model of decision making: some milestones and a preliminary tool. *Neuropsychol Trends*. 2023;33(33):9–16. doi:10.7358/neur-2023-033-balm
61. Mbakile-Mahlanza L, Van Der Ploeg ES, Busija L, Camp C, Walker H, O'Connor DW. A cluster-randomized crossover trial of Montessori activities delivered by family carers to nursing home residents with behavioral and psychological symptoms of dementia. *Int Psychogeriatrics*. 2020;32(3):347–358. doi:10.1017/S1041610219001819
62. Tasserion-Dries PE, Smaling HJ, Nakanishi M, Achterberg WP, van der Steen JT. What are best practices for involving family caregivers in interventions aimed at responsive behaviour stemming from unmet needs of people with dementia in nursing homes: a scoping review. *BMJ open*. 2023;13(12):e071804. doi:10.1136/bmjopen-2023-071804
63. Luckett T, Chenoweth L, Phillips J, et al. A facilitated approach to family case conferencing for people with advanced dementia living in nursing homes: perceptions of palliative care planning coordinators and other health professionals in the IDEAL study. *Int Psychogeriatrics*. 2017;29(10):1713–1722. doi:10.1017/S1041610217000977
64. Tieman J, Gravier S, Emy-Albrecht K. Palliative care guidance in aged care: role of palliAGED. In: Poster session presented at Oceanic Palliative Care Conference 2019; Perth, Western Australia, Australia; 2017.
65. Gonella S, Mitchell G, Bavelaar L, et al. Interventions to support family caregivers of people with advanced dementia at the end of life in nursing homes: a mixed-methods systematic review. *Palliative Med*. 2022;36(2):268–291. doi:10.1177/02692163211066733
66. Hines S, McCrow J, Abbey J, et al. The effectiveness and appropriateness of a palliative approach to care for people with advanced dementia: a systematic review. *JBI Evidence Synth*. 2011;9(26):960–1131.
67. Dixon J, Karagiannidou M, Knapp M. The effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their carers: a systematic review and critical discussion. *J Pain Sympt Manage*. 2018;55(1):132–150.e1. doi:10.1016/j.jpainsymman.2017.04.009
68. Huang H-L, Lu W-R, Liu C-L, Chang H-J. Advance care planning information intervention for persons with mild dementia and their family caregivers: impact on end-of-life care decision conflicts. *PLoS One*. 2020;15(10):e0240684. doi:10.1371/journal.pone.0240684
69. Webster L, Groskreutz D, Grinbergs-Saull A, et al. Core outcome measures for interventions to prevent or slow the progress of dementia for people living with mild to moderate dementia: systematic review and consensus recommendations. *PLoS One*. 2017;12(6):e0179521. doi:10.1371/journal.pone.0179521