

The Role of Palliative Care Interventions in Improving End-of-Life Quality: Insights from a Systematic Review

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ABSTRACT: **Introduction:** Palliative care (PALC) interventions are pivotal in enhancing the quality of life and quality of care (QOC) for patients with terminal illnesses. Assessing their impact across diverse settings is essential for improving patient outcomes and family satisfaction with care (SWC). This systematic review examined the impact of PALC interventions on end-of-life care outcomes. **Methods:** Articles from PubMed, Web of Science, and Scopus published between 2013-2023 were reviewed. Participants included staff and/or family members of adult individuals who have recently died. Interventions encompassed any PALC intervention in end-of-life care compared to usual care. Outcomes assessed included symptom management/burden, comfort around dying, QOC, and SWC. The risk of bias was evaluated using Cochrane tools. **Results:** Five studies (n=1905 patients) were included reporting deaths occurring either in nursing homes (n=3) or hospital wards (n=2). Some studies showed improved symptom management, particularly for discomfort and anxiety, while others found no significant differences between groups. Variability was noted in comfort around dying, with improvements reported by healthcare professionals but inconsistent support from family assessments. QOC outcomes varied, with some studies indicating improvements while others did not. SWC outcomes were heterogeneous, influenced by acute comorbidities. **Conclusions:** PALC interventions demonstrate potential in enhancing aspects of end-of-life care, though findings are varied. Further research is essential to address methodological limitations and standardize intervention protocols to optimize PALC's impact on patient and family outcomes.

KEY WORDS: Hospital Units; Nursing Home; Palliative Care; Patient Comfort; Patient Satisfaction; Quality of Health Care; Symptom burden; Systematic Review.

KEY SUMMARY POINTS: **Aim:** This systematic review investigated the impact of palliative care interventions on symptom management, comfort around dying, quality of care, and satisfaction with care in patients receiving end-of-life care. **Findings:** The review found that palliative care interventions improved symptom management for discomfort and anxiety in some studies, while others showed no significant differences. Additionally, comfort around dying was reported to improve by healthcare professionals, but family support remained inconsistent. Quality of care outcomes varied, with satisfaction influenced by acute comorbidities. **Message:** These findings highlight the need for consistent support from family members and healthcare providers to optimize the effectiveness of palliative care interventions at the end of life.

INTRODUCTION

Rationale – Death is an inevitable part of human life. While medicine aims to maintain and improve quality of life, ensuring a dignified and comfortable dying process is equally crucial. Delivering optimal end-of-life care (EOLC) presents significant challenges due to the complex needs of dying individuals, requiring a comprehensive approach.^[1,2]

In developed countries, many cancer patients and individuals with life-threatening illnesses die in hospitals,^{3,4} with studies indicating that 25% to 85% of those who could benefit from palliative care (PALC) pass away in these settings, often without adequate relief from their suffering.^[5] This trend is also seen in nursing homes, where over a quarter of residents die, frequently experiencing unrecognized and untreated symptoms,^[6,7] which impacts the quality of care (QOC). Many endure burdensome treatments that compromise the quality of the dying process.^[1,8-13] Despite the importance of quality healthcare in the final stages of life, services often fail to meet patients' needs, highlighting the necessity for new strategies to improve the quality of dying.

Evidence shows that specialized PALC enhances both quality of life and quality of death,^[14] reduces hospital admissions,^[15,16] and promotes advance care planning.^[17] Tailored advanced care preferences are associated with better quality of death by minimizing futile interventions and improving medical teams' skills in discussing EOLC.^[18,19] This comprehensive approach should consider patients' social, cultural, and spiritual contexts.^[20,21]

Studies suggest that specialist PALC services are linked to higher satisfaction with care (SWC) among patients' family members,^[15,17] emphasizing the importance of involving surrogates in symptom management and decision-making.^[22-24]

This study aimed to examine the evidence on PALC and its impact on end-of-life quality.

Objectives – This study addressed the primary question: "What is the impact of PALC strategies compared to usual care on the quality of the end-of-life process?"

We aimed to systematically review the literature assessing the impact of PALC on the quality of the end-of-life, focusing on four key outcomes: symptom management/burden; comfort around dying; QOC; and SWC.

METHODS

This systematic review adhered to the recommendations outlined in the "Cochrane Handbook for Systematic Reviews of Interventions",^[25] and was reported in accordance with the guidelines provided by the "Preferred Reporting Items for Systematic Reviews and Meta-Analyses".^[26]

Eligibility Criteria – Participants: Staff members and/or Family members of adult individuals who have recently died; **Interventions:** Any form of PALC intervention implemented in the end-of-life; **Comparators:** Usual care; **Outcomes:** Symptom management/burden, comfort around dying, QOC, and SWC; **Study Design:** Clinical studies/trials and randomized controlled trials (RCT). Studies were required to provide a detailed description of the PALC intervention employed.

Information Sources – The PubMed, Web of Science and Scopus databases were searched for articles published between January 1, 2013, and December 31, 2023. Each source was last searched on January 07, 2024.

Search Strategy – The search encompassed free-text terms in the title, abstract, and keyword fields, and utilized specific database headings: ("palliative care" or "hospice care" or "terminal care" or "end-of-life care") AND (death or dying) AND (comfort* or symptom* or "quality of care" or "satisfaction with care"). Filters for age (adults), language (English), and article type (RCT, clinical studies and trials) were applied during the search process.

Selection Process – During the initial screening phase, articles were chosen based on the examination and analysis of their titles and abstracts, with both authors independently participating in this process. Subsequently, a list of potentially relevant articles was compiled, leading to a full-text analysis conducted independently by two reviewers. Any discrepancies regarding study selection and data extraction were resolved through discussion between the authors. No automation tools were employed in this selection process.

Data Charting Process – Two independent reviewers extracted data from each report using a data extraction form created with Excel 16.0® spreadsheet software (Microsoft Corporation, 2023). The original authors

were not contacted to obtain or verify the data, and no automation tools were utilized throughout the process.

Data Items – Data were sought for four outcomes: comfort, symptom management/burden, QOC, and SWC. These outcomes were examined individually or in combination. All results relevant to each outcome domain in each study were extracted.

Additionally, data were gathered for other variables, including: article characteristics (e.g., authors, country of origin, year of publication); study design; objectives; population; setting; outcomes; intervention; comparator or control; relevant results; and observations (any additional pertinent information identified by the reviewers).

Study Risk of Bias Assessment – The risk of bias assessment was conducted using the RoB 2 Cochrane tool for RCT,^[27] and the ROBINS-I Cochrane tool for non-RCT.^[28] Each study underwent an independent assessment by two reviewers, followed by subsequent discussion and consensus between them. No automation tools were employed in the assessment process.

Effect Measures – For each outcome, we accepted the effect measures as declared by the authors of each study. These measures were utilized both in the synthesis and in the presentation of the results.

Synthesis Methods – A meta-analysis was not conducted due to the limited number of studies and the lack of homogeneity in the subjects, interventions, and outcomes. Therefore, the evidence was presented in a narrative format.

Tables 1, 2, and 3 summarize the study characteristics, PALC interventions, and key results, respectively.

RESULTS

Study Selection – A total of 529 articles were identified through searches in the PubMed, Web of Science, and Scopus databases. Additionally, seven more articles were found through the references of the initially retrieved articles, bringing the total to 536 references. After removing duplicates, 477 unique publications remained for eligibility assessment. During the title screening, 435 articles were excluded, and an additional 22 were excluded during abstract screening. The

full texts of the remaining 20 articles were thoroughly reviewed, leading to the exclusion of 15 additional articles. Specifically, four were excluded due to the absence of any relevant outcomes, five for not focusing on a relevant or specific population, two due to limited access to the study protocol, two for not being relevant interventions for the review, and two for having a different study design.

Five articles were deemed eligible for review and qualitative synthesis. The flow diagram of the search process can be found in Figure 1.

Study Characteristics – Four randomized studies,^[29-32] and one uncontrolled before-after trial³³ were considered eligible for inclusion in this review. Two studies were conducted in Australia,^[29,31] and the remaining in European countries: one in Italy,^[33] one in Belgium,^[30] and one across seven countries: Belgium, England, Finland, Italy, the Netherlands, Poland, and Switzerland.^[32] The total number of patients across the

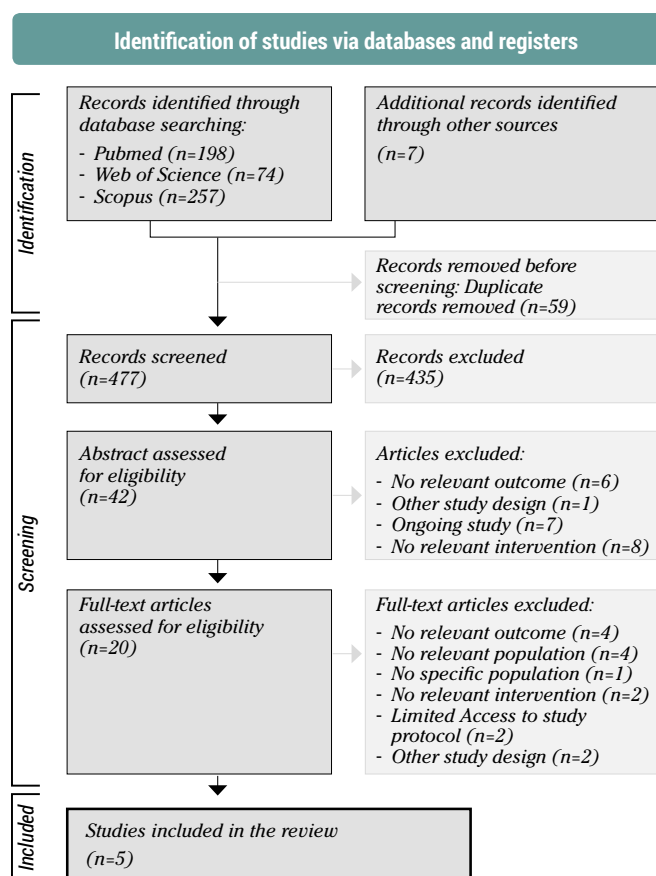


Fig 1. Flow diagram of the study selection process.

TABLE 1. Characteristics of individual studies (n=5)

Study; Country; Year	Type of Study	Participants (Staff and/or Family members) & Setting	Characteristics of the patients	Intervention & Control groups	Main Outcomes	Comments
AGAR et al.; Australia; 2017 ^[29]	Parallel cluster randomized controlled trial	Participants: Nurses and family members of deceased patients with advanced dementia from 20 nursing homes in two major cities in Australia.	Intervention group (n=67): Mean age 84.7±7.9 years; 61.0% female. Length of stay in nursing home – 29.0 months. FAST: level 7 (72.0%), level 6 (28.0%). Control group (n=64): Mean age 85.8±8.2 years; 58.0% female. Length of stay in nursing home – 20.5 months. FAST: level 7 (80.0%), level 6 (20.0%).	Intervention: Facilitated Family Case Conferencing. Control: Usual care.	Primary outcomes: CAD-EOLD in the last 7 days of life, family-rated; SM-EOLD in the last 90 days of life, family-rated; SWC-EOLD during the last 90 days of life, family/caregiver-rated. Secondary outcomes: Nurse-rated CAD-EOLD; nurse-rated SM-EOLD; nurse-rated QUALID monthly; Symptoms and care in the last month of life pharmacological/non-pharmacological strategies, symptom assessment frequency, acute care episodes, and potentially inappropriate non-palliative interventions.	- The study lasted for 18 months. - It was reported a lower than estimated mortality rate, causing the study's primary endpoint on EOLC quality to be underpowered. - Higher reporting by nurses of pain and other symptoms in the intervention arm suggests that case conferences foster greater proactivity and awareness in symptom identification.
BEERNAERT et al.; Belgium; 2017 ^[30]	Multicentre cluster randomized control trial	Participants: nurses and family carers of deceased elderly patients in acute geriatric wards of ten hospitals in the Flemish region, Belgium. Intervention group (n=164): 80% nurses; 29% family carers: 76.6% son/daughter, 8.5% partner, 2.1% brother/sister. Control group (n=118): 92% nurses; 19% family carers: 65.2% son/daughter, 21.7% partner, 4.3% brother/sister.	Intervention group: Mean age 85.8±6.8 years; 53.0% male. Length of hospital stay 28.0 days; Cause of death: 27.0% pneumonia, 19.0% other infections, 13.0% cancer. Control group: Mean age 84.0±7.5 years; 56.0% male. Length of hospital stay 23.3 days. Cause of death: 20.0% pneumonia, 13.0% other infections, 21.0% cancer	Intervention: The Care Programme of the Last Days of Life – CAREFUL. Control: Usual care.	Primary outcomes: CAD-EOLC in the last 48h of life and SM-EOLD, nurse- and family-rated. Secondary outcomes: Symptoms and Care Needs in the last three days of life (PCOS); SWC-EOLD in the last 48 hours of life, family-rated; nurses-reported symptomatic burden in the last 48 hours of life (self-developed items) Additional secondary outcomes: medical and nursing interventions in the last 48 hours of life, medication use, communication between clinical staff and patients/relatives and among clinical staff, and level of grief of the relatives.	- This study included elderly patients who were hospitalized for more than 48 hours and died in the ward. - Due to the low participation of family caregivers, the negative effect of the intervention on satisfaction with care is difficult to interpret. - The standardization of care, resulting from the implementation of the care guide, may have occurred, with some nurses believing that distributing leaflets to patients' families would be sufficient, neglecting communication in response to their questions and needs.
LIU et al.; Australia; 2020 ^[31]	Prospective stepped wedge randomized control trial	Participants: staff members of 12 care homes for elderly individuals in Canberra, Australia. Staff self-reported capability assessment: 161 responses post-intervention; 84 responses pre-intervention.	Intervention group (n=263): Mean age 86.0±8.6 years; 33% male. Primary diagnosis: 31% dementia, 17% cardiovascular disease, 7% frail aged, 22% other (hypertension, anxiety, depression, schizophrenia, macular degeneration and blindness). Control group (n=208): Mean age 88.0±8.2 years; 42% male. Primary diagnosis: 34% dementia, 13% cardiovascular disease, 10% frail aged, 26% other (hypertension, anxiety, depression, schizophrenia, macular degeneration and blindness).	Intervention: Palliative Care Needs of Rounds. Control: Usual care.	"Quality of Death and Dying", based on the domains of symptom control, preparation, connectedness, and transcendence; staff self-reported capability and confidence in caring for people at the end of life (CAPA); completion of advance care plans and appointment of medical power of attorney.	- All facilities crossed over bi-monthly from the control group to the intervention group in clusters of 2 or 3, with monthly follow-up on all sites. - The investigation concluded six months following the implementation of the intervention at the last sites.

TABLE 1. (continue)

Study; Country; Year	Type of Study	Participants (Staff and/or Family members) & Setting	Characteristics of the patients	Intervention & Control groups	Main Outcomes	Comments
VAN DEN BLOCK et al.; Belgium, England, Finland, Italy, the Netherlands, Poland, and Switzerland; 2020 [32]	Multi facility cluster - randomized clinical trial	Participants: nursing staff and family members of deceased elderly patients in 78 nursing homes from seven European countries. Intervention group (staff) (n=1159): mean age 44.1±11.7 years; 85.5% female. Staff: nurses 51.9%, care assistants 48.1%. Experience working in direct resident care 14.9±10.7 years. Control group (staff) (n=1278): mean age 42.3±12.1 years; 89.0% female. Staff: nurses 49.8%, care assistants 50.2%. Experience working in direct resident care 14.9±11.0 years. Relatives responses: 221 in intervention group; 273 in control group. Staff responses: 425 in intervention group; 558 in control group.	Intervention group (n=425): Mean age 85.9±8.6 years; 64.0% female. Functional status 1-month before death: 18.75±5.14 Control group (n=558): Mean age 85.6±8.8 years; 64.7% female. Functional status 1-month before death: 18.9±4.9	Intervention: The Pace Steps to Success Program. Control: Usual care.	Primary outcomes: CAD-EOLD during the last week of life, staff-rated; staff knowledge of Palliative Care (Knowledge Construct of the Palliative Care Survey). Secondary outcomes: Staff-reported quality of EOLC during the last month of life (QOD-LTC); Staff's self-efficacy in end-of-life communication with residents and their families (Self-Efficacy in EOLC Survey); Staff's self-perceived educational requirements concerning communication, cultural, and ethical values (End-of-Life Professional Caregiver Survey); Staff's opinions on palliative care (Rotterdam Move2PC). Other secondary outcomes: CAD-EOLD in the last week of life, family-rated; SWC-EOLD, family-rated; Physician-family communication (FPPFC), family-rated.	Randomization was performed by a median number of beds independently for each country in a ratio of 1:1.
COSTANTINI et al.; Italy; 2014 [33]	Uncontrolled before-after intervention cluster trial	Participants: Family members of patients who died of cancer in three general medicine wards and one respiratory diseases ward at the Villa Scassi Hospital in Genoa, Italy. Intervention group (n=33): face to face interviews 63.6%; telephone interviews 36.4%; mean interval death-interview 130.0±33.0 days. Control group (n=46): face to face interviews 93.5%; telephone interviews 6.5%; mean interval death-interview 145.7±22.0 days.	Intervention group (n=33): Mean age 73.0±9.8 years; 54.5% male. Length of hospital stay (median) 14.0 days. Primary tumor (system): respiratory 48.6%, digestive 12.1%, genitourinary 12.1%. Control group (n=46): Mean age 75.3±9.1 years; 65.2% male. Length of hospital stay (median) 10.0 days. Primary tumor (system): respiratory 45.7%, digestive 26.1%, genitourinary 13.0%.	Intervention: The Liverpool Care Pathway (Italian version). Control: Usual care.	Quality of EOLC in the last week of life (Toolkit After-Death Family Interview) which involves: Shared decision-making among patients, family, and medical team; Respect, dignity, and kindness; Symptom control (pain, dyspnea, and nausea-vomiting); Emotional support for the family and self-efficacy of the family; Spiritual/religious support; Care coordination.	- Experimental phase- 6 months. Subsequently, patients who died of cancer 4 months before/after the intervention were assigned to the control/intervention group, respectively. - Quality of EOLC was measured using the 'Toolkit After-Death Family Interview', conducted with the closest family member two months after the patient's death, preferably in person or by telephone if necessary.

LEGEND – CAD-EOLD: Comfort Assessment in Dying – End-of-Life in Dementia scale; CAPA: Capacity to Adopt a Palliative Approach tool; EOLC: End-Of-Life Care; FAST: Functional Assessment Staging Tool; FPPFC: Family Perception of Physician-Family Communication; PCOS: Palliative Care Outcome Scale; QOD-LTC: Quality of Dying in Long Term Care; QUALID: Quality of life in Late-Stage Dementia scale; SM-EOLD: Symptom management- End-of-Life in Dementia scale; SWC-EOLD: Satisfaction with Care-End-of-Life in Dementia scale.

TABLE 2. Palliative Care Interventions Used in the Included Studies (n=5)

Study; Country; Year of publication	Palliative care interventions
AGAR et al.; Australia; 2017 [29]	"Facilitated Family Case Conferencing" – involved meetings with family members, nursing home staff, and external health professionals to discuss current and future care plans and treatment strategies, and to share information about each patient's preferences and needs.
BEERNAERT et al.; Belgium; 2017 [30]	"Care Programme for the Last Days of Life" (CAREFuL) – provided care guidelines and tools for the last days of life, as well as support documents such as leaflets for the patient's family about the dying phase and grieving.
LIU et al.; Australia; 2020 [31]	"Palliative Care Needs Rounds" – involved monthly meetings between a PALC specialist and healthcare professionals at care homes to discuss care strategies and management for residents with higher symptom burdens and risk of dying.
VAN DEN BLOCK et al.; Belgium, England, Finland, Italy, the Netherlands, Poland, and Switzerland; 2020 [32]	"Palliative Care for Older People Steps to Success Program" – included six steps: advance care planning discussions with residents and families, regular assessments, multidisciplinary palliative review meetings, pain and depression management, and family support after death.
COSTANTINI et al.; Italy; 2014 [33]	"Liverpool Care Pathway" – a structured 10-step program designed to enhance the QOC across all relevant dimensions at the end of life, including symptom control, comfort, psychological-insight measures, religious-spiritual support, and communication with the patient, family, and care team.

TABLE 3. Results of individual studies (n=5)

Study; Year	Statistically significant differences favoring the Intervention group	No statistically significant differences between Intervention and Control groups
AGAR et al.; 2017 [29]	• MORE DOCUMENTATION in the intervention arm of pain/discomfort (p=0.04), restlessness (p=0.02), constipation (p=0.002), skin tears (p=0.005), and other symptoms (p<0.001). • MORE CHANGES in the intervention arm of both pharmacological (p<0.01) and non-pharmacological (p<0.05) strategies during the last month of life. • MEDICATION INITIATIONS in the intervention arm were more frequently symptom-oriented than diagnosis-oriented (83%vs 9%).	• Comfort during the last 7 days of life; family-rated & nurse-rated (CAD-EOLD; p>0.05). • Symptom management in the last 90 days of life; family-rated & nurse-rated (SM-EOLD; p>0.05). • Satisfaction with care during the last 90 days of life; family-rated (SWC-EOLD; p>0.05). • DOCUMENTATION of breathlessness, coughing, difficulty swallowing/eating/drinking, choking/gurgling, vomiting, fear or anxiety, diarrhea and depression (all p>0.05).
BEERNAERT et al.; 2017 [30]	• Comfort in the last 48h of life; nurse-rated (CAD-EOL; BAMD=4.30, 95%CI 2.07–6.53, p<0.0001, ICC=0.025, ES=0.78). • SYMPTOMS RELATED TO COMFORT; nurse-rated (CAD-EOL): discomfort (BAMD=0.57, 95%CI 0.32–0.82, p<0.001, ICC=0.023, ES=0.85); pain (BAMD=0.29, 95%CI 0.04–0.54, p=0.02, ICC<0.001, ES=0.42); restlessness (BAMD=0.45, 95%CI 0.19–0.72, p=0.001, ICC=0.017, ES=0.64); shortness of breath (BAMD=0.31, 95%CI 0.02–0.60, p=0.04, ICC=0.05, ES=0.40); choking (BAMD=0.28, 95%CI 0.03–0.53, p=0.03, ICC=0.010, ES=0.43); difficulty swallowing (BAMD=0.39, 95%CI 0.09–0.68, p=0.01, ICC=0.011, ES=0.50); fear (BAMD=0.34, 95%CI 0.07–0.60, p=0.01, ICC=0.040, ES=0.47); serenity (reversed) (BAMD=0.3, 95%CI 0.05–0.56, p=0.02, ICC=0.037, ES=0.46); peace (reversed) (BAMD=0.29, 95%CI 0.04–0.54, p=0.02, ICC=0.037, ES=0.45); calm (reversed) (BAMD=0.28, 95%CI 0.05–0.52, p=0.02, ICC=0.036, ES=0.46). • Symptoms and care needs in the last 3 days of life, nurse-rated (PCOS, BAMD=2.62, 95%CI 4.96–0.71, p=0.009, ICC<0.0001, ES=0.51). • Symptom burden during the last 48h of life (self-developed items assessed by nurses): bothersome mucus (BAMD=0.27, 95%CI 0.00–0.54, p=0.047, ICC<0.0001, ES=0.38), vomiting (BAMD=0.23, 95%CI 0.05–0.41, p=0.014, ICC=0.016, ES=0.47).	• Comfort in the last 48h of life, family-rated (CAD-EOL; BAMD=0.62, 95%CI -6.07–4.82, p=0.82, ICC<0.0001, ES=0.10). • Symptom management in the last 48h of life, both nurse-rated (SM-EOLD, BAMD=0.41, 95%CI -1.86–1.05, p=0.58, ICC=0.037, ES=0.12) and family-rated (SM-EOLD, BAMD=0.59, 95%CI -3.75–2.57, p=0.71, ICC=0.078, ES=0.17). • SYMPTOMS RELATED TO COMFORT; nurse-rated (CAD-EOL): gurgling (BAMD=0.17, 95%CI -0.11–0.44, p=0.24, ICC=0.002, ES=0.22); anxiety (BAMD=0.22, 95%CI -0.04–0.49, p=0.10, ICC=0.015, ES=0.32); crying (BAMD=0.09, 95%CI -0.05–0.23, p=0.19, ICC<0.001, ES=0.24); moaning (BAMD=0.11, 95%CI -0.13–0.35, p=0.37, ICC=0.003, ES=0.17). • Satisfaction with care in the last 48h of life, family-rated (SWC-EOLD; BAMD=4.00, 95%CI -7.87–0.12, p=0.04, ICC<0.0001, ES=0.74). • Symptom burden in the last 48h of life (self-developed items assessed by nurses): nausea (BAMD=0.15, 95%CI -0.03–0.35, p=0.11, ICC=0.026, ES=0.31), reduced appetite (BAMD=0.04, 95%CI -0.27–0.35, p=0.81, ICC=0.080, ES=0.05), fatigue (BAMD=0.19, 95%CI -0.09–0.48, p=0.19, ICC=0.003, ES=0.25).
LIU et al.; 2020 [31]	• Quality of Death and Dying (treatment effect=8.07, 95%CI 3.8–12.4, p<0.01). • Staff capability in looking after people at end of life (CAPA; difference of average scores between groups= 4.7, 95%CI 2.7–6.7, p<0.01).	N/A
VAN DEN BLOCK et al.; 2020 [32]	• Quality of care in the last month of life, staff-rated (QOD-LTC; BAMD=3.40, 95%CI 2.01–4.80, p<0.001, ICC=0.05). • Staff knowledge of palliative care (Palliative Care Survey; BAMD=0.02, 95%CI 0.001–0.03, p=0.03, ICC=0.02).	• Comfort in the last week of life, both staff-rated (CAD-EOLD; BAMD=0.55, 95%CI -1.71–0.61, p=0.35, ICC=0.08) and family-rated (CAD-EOLD; BAMD=0.91, 95%CI -1.03–2.85, p=0.36). • Perception of the quality of end-of-life care, family-rated (SWC-EOLD; BAMD=1.72, 95%CI -0.15–3.59, p=0.07). • Family perception of physician-family communication (BAMD=0.02, 95%CI -0.29–0.25, p=0.90).
COSTANTINI et al.; 2014 [33]	• Respect, dignity and kindness in the last week of life (TADS; MDBG=16.8, 95%CI 3.6–30.0, p=0.015, ES=0.53). • Family emotional support in the last week of life (TADS; MDBG=20.9, 95%CI 9.6–32.3, p<0.001, ES=0.77).	• Overall control of pain in the last week of life (VOICES; OR=1.4, 95%CI 0.5–4.0, p=0.514). • Overall control of breathlessness in the last week of life (VOICES; OR=1.5, 95%CI 0.6–4.2, p=0.408). • Overall control of nausea/vomiting in the last week of life (VOICES; OR=2.3, 95%CI 0.6–9.5, p=0.261).

LEGEND – BAMD: baseline-adjusted mean difference; CAD-EOLD: Comfort Assessment in Dying – End-of-Life in Dementia scale; CAPA: Capacity to Adopt a Palliative Approach tool; CI: Confidence Interval; ES: Effect size; ICC: unconditional Intraclass Correlation coefficient; MDBG: mean difference between groups; N/A: not available/not found; OR: odds ratio; PCOS: Palliative Care Outcome Scale; PCS: Palliative Care Survey; QOD-LTC: Quality of Dying in Long Term Care; SM-EOLD: Symptom management- End-of-Life in Dementia scale; SWC-EOLD: Satisfaction with Care-End-of-Life in Dementia scale; TADS: Toolkit After-Death scales; VOICES: Views Of Informal Carers - Evaluation of Services.

included studies was 1905, comprising 146 with cancer, 294 with advanced dementia, and the remainder were elderly patients in hospital acute wards or nursing homes. Three studies reported that patients died in nursing homes,^[29,31,32] while two studies indicated that deaths occurred in hospital wards.^[30,33]

The key characteristics of the studies and the PALC interventions in each study are summarized in Table 1 and Table 2, respectively.

Risk of Bias in Studies – Concerning the randomized reviewed articles, the overall risk of bias in all of them is assessed as having some concerns. As shown in Figure 2, there is a low risk of bias in the randomization process domain in all studies since appropriate methods, such as computerized random sequence generators, were used to generate random allocation sequences. Additionally, measures were taken to ensure that researchers involved in the investigations were unaware of the allocations of the various randomization units. Furthermore, all studies demonstrate a low risk of bias in the selection of the reported results and deviations from the intended intervention domains.

However, all studies present some concerns in the measurement of outcomes domain. Despite patients and their families being blinded to the outcomes and aims of the research, it was not possible to ensure the blinding of the staff and healthcare professionals who provided care to the patients and subsequently assessed the outcomes through surveys. Their training and expertise in implementing intervention strategies were necessary for the study.

Regarding Agar et al., in addition to concerns about the measurement of outcomes, this study also presents issues related to missing outcome data.^[29] Due to a lower-than-expected participant mortality rate, the study was underpowered, which introduced some risk of bias. Furthermore, the study does not elaborate on the techniques used to manage missing data, raising concerns about its impact on the results. Additionally, Beernaert et al. revealed a lower response rate in the intervention group compared to the control group, and an appropriate statistical method for handling missing outcome data was not used, resulting in a risk of bias in the missing outcome data domain.^[30]

Recall bias of unknown direction should also be considered in all studies, as the outcomes were assessed after the events occurred, potentially influencing respondents' responses and, consequently, the results.

Despite this, due to the nature of the intervention and the necessity of data collection after patients died in each arm, mitigating this risk was not feasible.

Finally, in a nonrandomized study by Constantini et al., the overall risk was deemed serious (Figure 3) due to serious risks of bias in the Selection of Participants and Measurement of Outcomes domains.^[33] In this before-after study, differences in the characteristics of participants in both groups and the modality of data acquisition were observed. Some risk was also identified regarding the distinct distribution of researchers who assessed the data in both groups,^[34] as well as a Hawthorne Effect given that patients' families were aware of the aims of the study.

Due to the scarcity of studies on this topic, and despite the high risk of bias identified in the appraisal, we decided to include the study by Constantini et al. in our systematic review.^[33]

The rationale for the risk of bias assessment is detailed for all articles in the "Supplementary File 1".

		Risk of bias domains					
		D1	D2	D3	D4	D5	Overall
Study	Agar et al., 2017	+	+	-	-	+	-
	Beernaert et al., 2017	+	+	-	-	+	-
	Van den Block et al., 2020	+	+	+	-	+	-
	Liu et al., 2020	+	+	+	-	+	-

Domains:
D1: Bias arising from the randomization process.
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

Fig 2. Risk of bias summary for randomized studies (n=4).

		Risk of bias domains							
		D1	D2	D3	D4	D5	D6	D7	Overall
Study	Constantini et al., 2014	+	×	+	?	+	×	+	×

Domains:
D1: Bias due to confounding.
D2: Bias due to selection of participants.
D3: Bias in classification of interventions.
D4: Bias due to deviations from intended interventions.
D5: Bias due to missing data.
D6: Bias in measurement of outcomes.
D7: Bias in selection of the reported result.

Judgement:
× Serious
+ Low
? No information

Fig 3. Risk of bias in non-randomized studies (n=1).

SUPPLEMENTARY FILE 1 Rationale for Risk of Bias AssessmentAssessment of Risk of Bias in AGAR et al., 2017^[29]

Domain	Support for Judgment	Review authors' judgment
Randomization process	In this study, randomization was performed in blocks using a computer-generated allocation sequence. Although blocked randomization can pose a risk of bias regarding allocation concealment, there is no evidence that it was possible to predict future assignments based on previous assignments. Thus, the allocation was adequately concealed and was implemented at the nursing home level after the collection of baseline data, without baseline imbalances that are incompatible with chance.	Low risk
Deviations from intended intervention	Although the staff, residents, and their families in each of the nursing homes were blinded to the study's objective, researchers, project managers, and nursing home managers could not be blinded. Additionally, healthcare professionals in the institutions allocated to the intervention arm were aware of differences in care delivery implementation. There were deviations from the intended interventions, but since researchers implemented analyses that excluded nursing homes that did not implement the intervention to any planned degree, these deviations were not likely to have affected the outcome.	Low risk
Missing outcome data	In this domain, it is important to consider that, due to the observed mortality rate among study participants being lower than expected, "(...) the study's primary endpoint of quality of end-of-life (EOL) care was underpowered and did not show evidence of effect." Furthermore, the study does not elaborate on the techniques used to manage missing data, which raises concerns about the impact of this missing data on the results. However, it is unlikely that the missing outcome data depended on its true value.	Some concerns
Measurement of the outcomes	The outcome assessments in the study were conducted by both staff of the nursing home, who provided nurse-rated assessments, and research staff who collected both nurse-rated and family-rated outcome measures through face-to-face or telephone interviews. The authors of the study emphasize that the research staff were blinded regarding the aim of the study and collected data from only one of the study arms in an attempt to minimize the risk of bias. However, as mentioned in the article, "(...) those in the nursing homes in the intervention arm were aware of the introduction of the PCP role and changes in case conferencing and staff education and so may have been more inclined to report favorably on the quality of palliative care offered as a result". However, it is not likely that knowledge of the intervention status influenced the outcome assessment.	Some concerns
Selection of the reported results	The study protocol is made available, and all predefined outcomes are analyzed and reported in the results section, along with the respective scales and analytical methodologies used, in accordance with the predefined plan. The results are unlikely to have been selected based on the outcomes.	Low risk
Overall risk of bias	The study raises some concerns in several domains, including deviations from intended interventions, missing outcome data, and measurement of the outcome. Although the intention-to-treat analysis was conducted, it did not adequately manage the missing outcome data as no detailed imputation methods were used. Additionally, the potential for performance and detection bias due to lack of blinding and variability in outcome measurement timing introduces further concerns. However, the study does not exhibit a high risk of bias in any single domain.	Some concerns

Assessment of Risk of Bias in BEERNAERT et al., 2017^[30]

Domain	Support for Judgment	Review authors' judgment
Randomization process	"A statistician outside the research group allocated the hospitals to the CAREFUL or control group using a random number generator", and the researchers considered the number of beds and the proportion of patients who had given consent during the baseline period in the stratification of each hospital. Thus, the allocation sequence was random and adequately concealed, and there is no evidence that baseline differences between groups suggest a problem with the randomization process.	Low risk
Deviations from intended intervention	Although patients and their families were unaware of the arm to which they had been allocated, due to the nature of the intervention, hospital staff could not be masked regarding the allocation. However, there is no evidence that deviations from the intended intervention arose because of the trial context. In fact, as the authors of the study point out, "The fidelity measures done during the study showed that CAREFUL was implemented according to the protocol in most of the wards." On the other hand, intention-to-treat analysis was used to estimate the effect of assignment to intervention, which is considered appropriate.	Low risk
Missing outcome data	A lower response rate was observed among nurses in the intervention group compared to the control group, while among family members, the intervention group had a higher response rate compared to the control group and an appropriate statistical method for handling missing outcome data was not used ("All results in the main text were analyzed without a technique for missing data"). However, it is unlikely that the missing outcome data depended on its true value.	Some concerns
Measurement of the outcomes	Primary outcomes were assessed by nurses and family members using validated scales and as previously mentioned, nurses were not blinded to the intervention, which could have influenced the assessment of the outcomes. However, it is not likely that knowledge of the intervention status influenced the outcome assessment, which is a condition for evaluating the risk of bias as high risk. Therefore, this domain presents some concerns regarding the risk of bias.	Some concerns
Selection of the reported results	The study protocol is made available, and all predefined outcomes are analyzed and reported in the results section, along with the respective scales and analytical methodologies used, in accordance with the predefined plan. The results are unlikely to have been selected based on the outcomes.	Low risk
Overall risk of bias	The trial is judged to raise some concerns in at least one domain for this result, but not to be at high risk of bias for any domain.	Some concerns

Assessment of Risk of Bias in LIU et al., 2020^[31]

Domain	Support for Judgment	Review authors' judgment
Randomization process	Randomization was conducted by an independent researcher at the institutional level, not at the individual level, to avoid contamination of staff exposure to the intervention. Simple randomization was performed using an internet program that randomly selected sites for each step. After this stage was completed, the various institutions were informed of the date of their transition from the control group to the intervention group under study. For those reasons, the allocation sequence was random and concealed. Furthermore, any baseline differences observed between intervention groups appear to be compatible with chance.	Low risk
Deviations from intended intervention	Considering the intervention under study, blinding participants and care home staff at the sites involved in the study was not possible. The variability in intervention fidelity across care homes could be a potential bias. However, the authors monitored the level of adherence and fidelity of the institutions to the intervention and the previously mentioned protocol, and they analyzed the different outcomes taking this factor into account. Additionally, intention-to-treat analysis was used to estimate the effect of assignment to intervention, which is considered appropriate.	Low risk
Missing outcome data	There is insufficient information in the study regarding how missing data were addressed, as well as the reasons that led one of the institutions to withdraw from the study shortly after its initiation. However, it is not likely that the missing outcome data depended on its true value.	Low risk
Measurement of the outcomes	The method of measuring the outcomes was appropriate and did not differ between both phases. However, the assessment of the outcome could have been influenced by the fact that the staff was not blinded to the intervention, but there is no reason to believe that it did, which would be a condition for classifying this domain as having a high risk of bias.	Some concerns
Selection of the reported results	The study protocol is made available, and all predefined outcomes are analyzed and reported in the results section, along with the respective scales and analytical methodologies used, in accordance with the predefined plan. The results are unlikely to have been selected based on the outcomes.	Low risk
Overall risk of bias	The trial raises some concerns in the domain "measurement of the outcome". However, it is not judged to be at high risk of bias in any single domain.	Some concerns

Assessment of Risk of Bias in VAN DEN BLOCK et al., 2020^[32]

Domain	Support for Judgment	Review authors' judgment
Randomization process	The randomization process was conducted by independent individuals, stratified by country and number of beds, in a 1:1 ratio using a computer-generated random sequence. Furthermore, there is no information about baseline imbalances.	Low risk
Deviations from intended intervention	Owing to the nature of the study, blind treatment was not possible for participants or researchers. However, despite the authors admitting that the implementation of the intervention might have been suboptimal in some nursing homes, there is no evidence that deviations from the intended intervention arose because of the trial context. Intention-to-treat analysis was used to estimate the effect of assignment to intervention, which is considered appropriate.	Low risk
Missing outcome data	The article mentions nonresponse rates for some outcome measures, with discrepancies in response rates between the intervention and control groups, as well as varying timing of data collection, indicating incomplete outcome data. However, it is unlikely that the missing outcome data depended on its true value. All data were analyzed using intention-to-treat and complete-case analysis methods, reducing the risk of bias.	Low risk
Measurement of the outcomes	Staff members who were asked to complete questionnaires about resident outcomes were not blinded to the group allocation of their nursing home, and their awareness of the intervention status could potentially bias their responses. However, it is unlikely that knowledge of the intervention status influenced the outcome assessment, which is a condition for evaluating the risk of bias as high risk. Furthermore, the outcomes were measured using validated tools (like EOLD-CAD). Therefore, this domain presents some concerns regarding the risk of bias.	Some concerns
Selection of the reported results	The study protocol is made available, and all pre-defined outcomes are analyzed and reported in the results section, along with the respective scales and the analytical methodologies used. The results are unlikely to have been selected based on the outcomes.	Low risk
Overall risk of bias	The trial raises some concerns in the domain "measurement of the outcome". However, it is not judged to be at high risk of bias in any single domain.	Some concerns

SUPPLEMENTARY FILE 1 (continue)Assessment of Risk of Bias in **CONSTANTINI et al., 2014**^[33]**Target randomized trial specific to the study****Design:** Cluster Randomized Trial

Participants: Clusters would include hospital wards participating in the pilot implementation of the Italian version of the Liverpool Care Pathway (LCP) program. Patients admitted to these wards who are identified as being in the last weeks of life will be included.

Experimental intervention: In the experimental arm, hospital wards will implement the Italian version of the Liverpool Care Pathway (LCP) program for end-of-life care. This intervention includes structured pathways, staff training, documentation procedures, and support from a specialized palliative care team.

Comparator: In the control arm, hospital wards will continue providing usual end-of-life care without implementing the LCP program.

Preliminary considerations of confounders and co-interventions: The review's authors did not identify confounders and co-interventions in this study.

This study's effect of interest is the assessment of the effectiveness of starting and adhering to the interventions as specified in the protocol, as it seeks to understand how these interventions impact the quality of end-of-life care for cancer patients.

Domain	Support for Judgment	Review authors' judgment
Pre-intervention		
Confounding	Outcomes are unlikely to be influenced by factors affecting treatment decisions, so the study can be considered at low risk of bias due to confounding, similar to a fully randomized trial.	Low risk
Selection of participants	The study notes differences in characteristics between the before and after groups, such as gender, time spent in hospital and ward, and the interview modality of families. On the other hand, ward staff and caregivers who witnessed improvements in the study outcomes in the after group may have shown greater availability and motivation to participate in the study, demonstrating the association between participant selection in the study and the intervention and outcomes. The study does not provide information on whether adjustments for this selection bias were made in the analyses.	Serious risk
At intervention		
Classifications of interventions	The intervention status is well defined, as are the intervention groups. The timing of the intervention implementation provides a clear delineation between the before and after groups, indicating that the intervention status is based on the information collected at the time of the intervention implementation. For these reasons, the risk of bias in this domain is low.	Low risk
Post-intervention		
Deviations from intended interventions	In this study, it would be important to consider the fidelity of implementation and adherence to the protocol by healthcare professionals from different wards. However, information on whether there is deviation from the intended intervention and its influence on the outcomes is not provided.	No information
Missing data	In this study, 73% of the families from the "before intervention" group and 68.8% from the "after intervention" group were interviewed, with similar reasons for the inability to collect data in these cases. Moreover, it is significant to note that an intention-to-treat approach was used, helping to mitigate the impact of missing data and thereby reducing the risk of bias in this domain.	Low risk
Measurement of outcomes	In this domain, it is important to consider that the interviewed families were aware of the study's aims, which may have led to some degree of the "Hawthorne effect". Additionally, the fact that all of the interviewers conducted data collection in both groups means they were not blinded to the allocation of the groups in the intervention. On the other hand, "the distribution of the interviewers is substantially different before and after for at least two interviewers" (Costantini et al., 2011), and it is important to note that some interviewers tend to measure systematically higher or lower values than the other interviewers, thereby increasing the risk of bias. Finally, there were differences in obtaining data through interviews with patients' family members regarding modality (face-to-face versus telephone), timing and duration, and the proportion of these differences varied between both groups.	Serious risk
Selection of the reported results	The measurements and analyses of outcomes are consistent to a pre-established plan. There is no evidence suggesting the selection of specific analyses among multiple options, and there is no indication of selecting cohorts or subgroups for analysis based on the results.	Low risk
Overall RoB judgement		Serious risk

Results of Individual Studies – Table 3 presents the key results of each study included in this review.

Results of Synthesis

1) SYMPTOM MANAGEMENT/BURDEN

Symptom management and burden were analyzed in three articles.

Agar et al.^[29] in a moderate risk-of-bias study, found no statistically significant differences between groups in symptom management during the last 90 days of life, as assessed by both nurses and families. However, they noted that medication initiations in the intervention arm were symptom-oriented rather than diagnosis-oriented ($p < 0.05$), with more frequent pharmacological ($p < 0.01$) and non-pharmacological ($p < 0.05$) changes during the last month of life. Moreover, formal assessments of various symptoms were conducted more frequently in the intervention group. There were no statistically significant differences between groups in the assessment of several symptoms, including difficulty swallowing/eating/drinking, breathlessness, coughing, choking/gurgling, vomiting, fear or anxiety, diarrhea, and depression.^[29]

In the study by Beernaert et al.^[30] which was assessed as having a moderate risk of bias, when analyzing separate items from the “Comfort Assessment in Dying – End-of-Life in Dementia” (CAD-EOLD), statistically significant improvements in favor of the intervention group were observed in several symptoms assessed by nurses, including discomfort, pain, restlessness, shortness of breath, choking, difficulty swallowing, and fear. However, no differences were found between groups in other symptoms of the CAD-EOLD, namely gurgling, anxiety, crying, or moaning. Regarding “Symptom Management”, both nurse-assessed and family-assessed, there were no statistically significant differences between groups. There were statistically significant improvements in “Symptoms and Care Needs” in the intervention. Likewise, in the “Symptom Burden”, in the intervention group, there were statistically significant improvements in troublesome mucus and vomiting, but no differences were found for nausea, reduced appetite, and fatigue between groups.^[30]

Costantini et al.^[33] in a high-risk-of-bias study, demonstrated statistically significant improvements favoring the intervention group during the last week of life in family spiritual support and self-efficacy. No significant differences were found between groups in overall pain, dyspnea, nausea, and vomiting control.^[33]

2) COMFORT AROUND DYING

Comfort around dying was evaluated in three studies.

Beernaert et al.^[30] reported a statistically significant improvement in comfort during the last 48 hours of life in favor of the intervention group, as assessed by nurses. Analysis of individual items from the CAD-EOLD revealed statistically significant improvements favoring the intervention group, namely in peace, serenity, and calmness. However, no statistically significant differences were found in comfort as rated by family members.^[30]

Agar et al.^[29] found no statistically significant differences in comfort ratings by both nurses and family members during the last seven days of life. They also observed that higher levels of acute intercurrent comorbidities were associated with lower comfort assessments by staff during the dying process.^[29] Similarly, in the study by Van den Block et al.^[32] which had a moderate risk of bias, no statistically significant differences in comfort were found between groups in the last week of life, as rated by both staff and family members.

3) QUALITY OF CARE

QOC was assessed in three studies.

Van den Block et al.^[32] showed statistically significant differences favoring the intervention group in the QOC in the last month of life, as assessed by staff members and from families' perceptions. Similarly, Liu et al.^[31] in a moderate risk-of-bias study, found a statistically significant improvement in quality of EOLC, demonstrating that professionals in the care homes felt more capable and confident during the implementation phase of the PALC intervention. Conversely, Costantini et al. found no statistically significant differences between groups in the QOC in the last week of life.^[33]

4) SATISFACTION WITH CARE

SWC was assessed in three studies.

Beernaert et al.^[30] and Van den Block et al.^[32] found a statistically significant difference in family SWC, favoring the control group in the former and the intervention group in the latter study. Conversely, Agar et al.^[29] found no significant differences between groups in family-assessed SWC during the last days of life. Additionally, Agar et al. observed that the more patients faced acute intercurrent comorbidities, the lower the family-rated SWC.^[29]

DISCUSSION

Summary of Evidence – This systematic review encompasses five articles (n=1905 patients) investigating PALC interventions targeting improvements in EOLC within hospital wards and nursing homes. The review included four randomized studies and one uncontrolled before-after trial, with three studies conducted in Europe and two in Australia. While some studies showed improved symptom management, particularly for discomfort and anxiety, others found no significant differences between groups. Variability was noted in comfort around dying, with improvements reported by healthcare professionals but inconsistent support from family assessments. QOC outcomes varied, with some studies indicating improvements while others did not. SWC outcomes were heterogeneous, influenced by acute comorbidities.

SYMPTOM MANAGEMENT AND BURDEN – Evidence gathered from our review suggests mixed findings regarding the impact of PALC interventions on symptom management and burden across various settings, including cancer patients in hospital wards,^[33] elderly patients with dementia in nursing homes,^[29] and older patients with multiple conditions in acute care facilities.^[30]

Some physical symptoms improved with PALC interventions, consistent with findings from Quinn et al.'s systematic review and meta-analysis of 28 randomized clinical trials involving 13664 patients (mean age 74 years) with chronic non-cancer illnesses.^[35] This study showed that PALC interventions were statistically significantly associated with a modestly lower symptom burden compared to usual care.^[35] Similarly, in a population-based study of 11242 patients who died from gastrointestinal cancers, Merchant et al.^[36] found that while 50% experienced moderate-severe scores in tiredness, lack of well-being, and lack of appetite earlier (weeks 18 to 12 before death), and 50% experienced moderate-severe scores in drowsiness, pain, and shortness of breath later (weeks 5 to 2 before death), the initiation of outpatient PALC was associated with a 1- to 3-point decrease in subsequent scores, with the greatest reductions in pain [odds ratio (OR) -1.91, 95% confidence interval (CI) -2.11 to -1.70] and nausea (OR -3.01, 95% CI -3.31 to -2.71).^[35] Conversely, a systematic review incorporating data from four studies involving 525 participants on pain management in hospital-based specialist PALC found no evidence of a difference compared to usual care.^[37] Our

systematic review findings did not consistently show improvements in the management of pain, dyspnea, and vomiting with PALC interventions compared to usual care.^[30,33]

Kavalieratos et al.'s meta-analysis of 43 RCT revealed that PALC interventions were associated with statistically and clinically significant improvements in symptom burden at the 1- to 3-month follow-up,^[38] although this association was not statistically significant in trials at low risk of bias (n=5).

Health-related suffering is serious when it cannot be relieved without professional intervention and when it compromises physical, social, spiritual, and/or emotional functioning.^[39]

In a cross-sectional study involving 1549 terminally ill patients (mean age 77.4 years),^[40] the top five distressing symptoms identified through Relative Importance Index analysis were poor mobility (64.4%), family anxiety (63.5%), difficulty sharing feelings with family/friends (61.4%), weakness/lack of energy (58.1%), and hardly feeling at peace (50.7%). Among patients with dementia, the most distressing symptom was poor mobility (67.8%), while cancer patients rated perceived family anxiety (66.1%) as the most distressing symptom.^[40]

In a study with bereaved respondents (n=2796), the largest gaps in symptom management were found in settings such as home without hospice and acute care.^[41] The adjusted marginal difference for unmet need for pain was 25.6 percentage points higher (95% CI 16.7 to 34.6) at home without hospice, while in acute care settings, the unmet need for dyspnea was 20.7 percentage points higher (95% CI 10.1 to 31.3), and the unmet need for emotional support was 20.5 percentage points higher (95% CI 11.5 to 29.5), compared to dying at home with hospice.^[41]

Makaroun et al.^[42] showed that bereaved respondents (n=1653) reported that decedents experiencing late transitions at the end-of-life were more likely to be treated without respect [21.3% vs. 15.6%; adjusted odds ratio (AOR) 1.59, 95% CI 1.09 to 2.33] and had more unmet needs for spiritual support (67.4% vs. 55.2%; AOR 1.48, 95% CI 1.03 to 2.13).^[42]

Miyashita et al.,^[43] in a study involving 885 bereaved relatives, found that during the last three months before death, symptom severity was moderate to overwhelming in over 30% of cases for all causes of death. The absence of a reliable key health professional was consistently associated with higher symptom burden (p=0.002) and more practical problems (p=0.001).⁴³

Agar et al.^[29] did not find the PALC intervention effective in improving symptom outcomes, but they did observe that nurses performed formal assessments of patients' pain more frequently during the implementation of the PALC strategy. These results are noteworthy, considering that all included studies suggest that healthcare professionals expressed greater confidence in pain control and felt more capable of providing EOLC after the PALC intervention. When interpreting these results, it is important to consider that the emphasis on symptom assessment and the necessity to fill out questionnaires may make staff more attentive and efficient at recognizing symptoms, potentially resulting in enhanced reporting and masking the potential effects of the PALC intervention. Additionally, life-threatening diseases in their terminal phase tend to present a greater symptomatic burden, which is inherently more difficult to control.

COMFORT AROUND DYING – Evidence from our systematic review suggests mixed findings regarding the impact of PALC interventions on comfort around dying. Only one study indicated improvements with the intervention, as assessed by nurses, in elderly patients admitted to acute hospital settings.^[30] Similarly, a study that introduced a bundle of care to enhance palliative and EOLC in an acute tertiary hospital demonstrated increased use of comfort care, improved recognition of dying patients, higher referral rates to PALC nurses and physicians, and a reduction in the number of medical emergency team calls.^[44] Conversely, Miranda et al.^[45] analyzed results from two retrospective epidemiological studies in Flanders and found that, between 2010 and 2015, there was a 15% increase in dementia prevalence ($p<0.01$) and an 11% decrease in cognitive impairment ($p=0.04$) among 381 nursing home residents with dementia. However, when controlling for residents' characteristics, there was no significant change in overall comfort, although a 20% increase in the use of pain assessment was verified in the last week of life ($p<0.03$).^[45]

Although the study by Costantini et al.^[33] did not focus specifically on comfort, there was a statistically significant difference in favor of the intervention group in terms of respect, dignity, and kindness. These factors could contribute to a "sense" of comfort around dying.

Tappen et al.^[46] in a qualitative study involving 16 nursing home residents, 10 family members, and 20 staff members, identified three main themes from the content analysis: promoting comfort; the centrality of comfort;

and what matters most at the end of life. All participant groups overwhelmingly endorsed comfort as a priority. Some participants would accept aggressive treatment to alleviate suffering and promote comfort. Residents were concerned about the well-being of their families, whereas family members emphasized the importance of their presence and ensuring their dying relatives were not suffering. Staff sometimes filled this role on their behalf. Ancillary staff emphasized bathing, dressing, and grooming the residents to preserve their dignity.^[46]

Given that comfort is a priority for EOLC, there is a need for more discussion to enhance and promote comfort for patients and families. In our systematic review, three studies found no statistically significant differences between PALC intervention and usual care in comfort, as rated by family members.^[29,30,32] These data demonstrate that there is room for improvement, not only in optimizing patient comfort but also in addressing the concerns and doubts of family members to better serve them. The World Health Organization emphasizes the value of PALC as a holistic approach to care, recognizing both the patient and family members as the unit of care, and advocating for its early application in the course of the illness.^[47]

The non-inclusion of the family in EOLC decision-making processes, limited communication from healthcare professionals regarding the inherent symptoms of the dying process, and the emotional and psychological stress and grief can often lead to anxiety among bereaved family members. This can exacerbate their perception that their loved one experienced discomfort and that their needs were unmet in the last moments of life.^[48]

QUALITY OF CARE – Findings from our systematic review suggest that PALC interventions enhance the QOC compared to usual care. Two studies with low to moderate bias demonstrated improvements in QOC as assessed by staff members,^[31,32] and families' perceptions.^[32]

The positive relation between PALC interventions and QOC was observed in several settings of care. In a study with 2796 bereaved family members or close friends examining the episode of care in the last month of life, hospice at home was associated with a higher rating of the QOC, with 60.2% (95% CI 40.2 to 69.0) stating the care was excellent.⁴¹ In contrast, inpatient PALC services in hospital, hospice residence, or hospice inpatient unit settings received lower ratings.^[41]

A national Danish survey assessing the quality of EOLC for cancer patients who received specialized PALC received responses from 787 bereaved spouses.^[49] The study revealed that in the last three months of life, 83% of respondents rated the overall quality of all services as good, excellent, or outstanding, with a significant association with the place of death ($p=0.0051$), indicating that fewer respondents rated the care as “fair” or “poor” if the patient died at home. Additionally, 93% of respondents reported that the patient died at the right place, although only 74% of patients died at their preferred place.^[49]

A qualitative study involving 24 caregivers (12 from PALC units and 12 from non-PALC units) identified two main themes related to QOC: perception of person-centered care and perception of the scientific and technical appropriateness of care.^[50] The latter was further subdivided into diagnostic tests and treatment, and symptom control. Caregivers of patients in PALC units described their EOLC experiences positively, while those in non-PALC units reported negative experiences.^[50]

Vandenbogaerde et al.^[51] analyzed 208 questionnaires from bereaved relatives of nursing home residents with dementia regarding the quality of EOLC. The study found that the quality of EOLC was positively associated with relatives receiving information on PALC and medical care from care providers.^[51]

In an observational study involving 329 bereaved caregivers of decedents with advanced cancer who received hospice care it was found that, controlling for covariates, better symptom control was independently associated with an improved overall quality of dying.^[52] Likewise, in an international prospective cohort study involving PALC units across Japan, South Korea, and Taiwan, among 998 patients, improved symptom control, particularly for dyspnea and delirium was significantly associated with better QOC.^[53]

In a study on perceptions of EOLC quality, bereaved respondents ($n=1653$) were less likely to rate the QOC as excellent when there was a late transition at the end-of-life (43.6% vs. 48.2%; AOR 0.79, 95% CI 0.58 to 1.06).^[42] Subgroup analyses showed that transitions between a nursing home and hospital (13% of all late transitions) were associated with even worse QOC.^[42]

In a Canadian study, 100 caregivers of patients who passed away in a residential hospice were interviewed four to six months after the patient's death to assess the quality of dying and death.^[54] The study revealed an overall intermediate quality rating (“neither

good nor bad”), with significantly higher ratings observed for patients who had a hospice length of stay exceeding one week compared to those with a shorter stay ($p<0.001$).^[54] This could be explained by the importance of a strong professional-patient relationship in effective healthcare. As this relationship develops, patients feel more engaged, understood, and supported. Trust forms the foundation, enabling open communication, shared decision-making, and better health outcomes. The perception of person-centered care encompasses effective communication, emotional support, and facilitating the farewell process.^[50]

SATISFACTION WITH CARE – Evidence from our systematic review indicates mixed findings regarding the impact of PALC interventions on SWC. One study favored the PALC intervention,^[32] another favored the control group,^[30] and a third found no differences between groups.^[29]

In a pooled analysis of mortality follow-back surveys ($n=885$), across all causes of death, 28%-38% of bereaved relatives reported some level of dissatisfaction with care during the last three months before death.^[43] Patients with cardiovascular disease and dementia experienced lower symptom burden and dissatisfaction compared to those with cancer. Higher dissatisfaction with care was associated with the absence of a reliable key health professional ($p=0.001$).^[43]

A longitudinal, descriptive correlational design study involving 101 caregivers of deceased patients with advanced cancer revealed, through multiple linear regression analyses, that caregiver SWC was negatively impacted by patient admissions to the intensive care unit and by having more than one hospitalization before death.^[55] Similarly, our review indicated that Agar et al. observed a decrease in family-rated SWC as patients faced more acute intercurrent comorbidities.^[29]

In a study involving 202 bereaved caregivers of cancer decedents who received hospice care in Uganda, it was found that family SWC was independently associated with better preparation for death.^[52]

In a prospective pre- and post-intervention study utilizing a PALC pathway in a hospital setting, questionnaires were distributed to relatives of deceased cancer patients to assess perceptions of communication and satisfaction with EOLC.^[56] The study found no significant overall effect of the PALC pathway on the communication process or SWC reported by bereaved relatives.^[56] Findings from very low- to low-quality evidence sug-

gested that hospital-based specialist PALC, compared to usual care, may provide modest benefits for person-centered outcomes such as patient QOL, symptom burden, and patient SWC.^[37]

In a prospective pre- and post-loss study involving 114 family caregivers of terminal cancer patients, SWC provided at the end of life was found to be associated with the quality of life of bereaved family caregivers six months post-loss.^[57]

Findings from very low- to low-quality evidence suggested that hospital-based specialist PALC, compared to usual care, may provide modest benefits for person-centered outcomes such as patient QOL, symptom burden, and patient SWC.^[37]

Limitations

This systematic review has several limitations. Firstly, the review was not registered with any specific registration platform. Additionally, we only consulted three databases for our review. Another limitation of this study is that the governance structures and care standards in nursing homes and hospital wards are not equivalent, which likely contributed to the heterogeneity of our findings.

The studies included in the review exhibit considerable heterogeneity in participant characteristics, methodologies, employed measures including assessment tools, follow-up and evaluation periods, types of analyses, and reported statistics. This variability impeded direct comparisons and affected the results. The components, format, and duration of the programs provided by the PALC intervention teams varied across studies. Additionally, the control or comparator groups, mostly designated as usual care, differed between studies according to local practices.

It is also important to emphasize the quality of the included publications, with all of them revealing a moderate to high overall risk of bias. This included recall bias and the Hawthorne effect due to the methodological characteristics of the studies. Considering the research question, other strategies were not feasible. The diversity of the studies restricted our capacity to conduct meaningful comparisons and meta-analyses.

These limitations may have influenced the results presented in this review.

CONCLUSIONS

This systematic review synthesizes findings from five studies involving 1905 patients to assess the impact of PALC interventions on EOLC within hospital wards and nursing homes.

Symptom management outcomes were mixed, with some studies showing no significant differences between PALC interventions and usual care, while others noted improvements in specific symptoms like discomfort and anxiety.

Similarly, comfort around dying showed variability, with improvements reported by nurses in one study but no consistent differences found by family members in others.

Regarding QOC, PALC interventions showed improvements in two studies, though one study found no significant differences.

SWC also varied, with some studies showing benefits from PALC interventions while others did not, especially in cases involving acute comorbidities.

In conclusion, while PALC interventions hold promise in enhancing aspects of EOLC, the evidence is mixed and highlights the need for further research. Addressing methodological limitations, standardizing intervention components, and ensuring comprehensive evaluation methods are crucial to better understand and optimize the impact of PALC on patient and family outcomes at the end of life.

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LIST OF ACRONYMS AND ABBREVIATIONS

CAD-EOLD – *Comfort Assessment in Dying - End-of-Life in Dementia*CI – *Confidence Interval*EOLC – *End-of-Life Care*OR – *Odds Ratio*PALC – *Palliative Care*QOC – *Quality of Care*RCT – *Randomized Controlled Trial(s)*SWC – *Satisfaction With Care*

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