Review Paper

Palliative Care Models for Dementia in Nursing Homes: A Systematic Review

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ABSTRACT

Background and Purpose: Palliative care is essential for improving the quality of life (QoL) for individuals with dementia, especially in nursing homes. This systematic review aims to recognize, weigh, and appraise different palliative care models specifically designed for people with dementia in nursing homes.

Materials and Methods: A systematic search was carried out on PubMed, Scopus, Web of Science, ScienceDirect, and Google Scholar to find palliative care models or interventions specifically designed for individuals with dementia cared for in nursing homes and studies reporting outcomes related to their characteristics or efficacy. The strengthening the reporting of observational studies in epidemiology (STROBE) checklist and consolidated standards of reporting trials (CONSORT) were used to evaluate the quality of the included articles. The search period spanned from inception until July 2023.

Results: Of 1880 articles retrieved, 5 were deemed eligible in the study. Also, 5 models were identified: The palliative care for older people in Europe (PACE) steps to success program, comfort first, palliative care consultations, Improving palliative care education and training using simulation in dementia (IMPETUS-D), and the compassion model.

Conclusion: By thoroughly examining these different models, we shed light on the achievements and obstacles in improving the quality of care for individuals with dementia in nursing homes. However, more research is needed to ensure the effectiveness of these models, specifically those tailored to dementia patients in nursing homes. Identifying these five models represents a crucial step forward, but further investigation is essential to validate their efficacy and suitability within this population.

Keywords: Aged, Palliative care, Dementia, Nursing homes

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Introduction

Dementia stands as a formidable challenge in the background of healthcare, particularly within the aging population [1]. With the aging of societies worldwide, the incidence and prevalence of dementia have witnessed a concerning upsurge [2]. According to a 2023 World Health Organization (WHO) report, 55 million people globally live with dementia, a number projected to increase substantially in the coming decades [3]. Understanding and addressing dementia is crucial for promoting successful aging and ensuring the well-being of older adults worldwide [4].

Nursing homes are pivotal in providing care and support to individuals with advanced dementia [5]. These facilities offer an environment tailored to individuals' unique needs, requiring specialized attention, constant supervision, and comprehensive care [6]. Nursing homes serve as living spaces and therapeutic settings where trained professionals can deliver person-centered care, promote social engagement, and address the complex physical and emotional challenges that accompany dementia [5].

Palliative care represents a paradigm shift in healthcare, prioritizing quality of life (QoL) and holistic well-being for individuals facing severe illnesses, including dementia [7]. Rooted in a multidisciplinary approach, palliative care encompasses symptom management, psychosocial support, communication enhancement, and comprehensive care coordination [8]. The overarching goal is to alleviate suffering, enhance comfort, and empower individuals and their families to make informed decisions about care options [9].

For individuals with dementia, palliative care assumes a particularly vital role, as the disease's progressive nature brings about unique challenges that extend beyond physical symptoms [10]. Cognitive decline, emotional distress, and communication difficulties can exacerbate the experience of both the individual and their caregivers. Palliative care in dementia focuses on addressing these complexities, tailoring interventions to preserve dignity, manage symptoms, foster emotional connection, and enhance the overall QoL [11].

Palliative care's significance within nursing homes lies in its capacity to provide a comprehensive and compassionate framework for addressing the intricate needs of residents with advanced dementia [12, 13]. With their structured and supportive environment, nursing homes offer an ideal setting for implementing palliative care principles [14]. By integrating palliative care, these institutions can ensure that residents receive care that aligns with their preferences, values, and goals, fostering a sense of comfort and security [15].

The provision of palliative care within nursing homes for individuals with dementia presents a constellation of complex challenges that demand careful consideration. As dementia progresses, cognitive decline and communication impairments often hinder the effective assessment and management of pain and other distressing symptoms, leading to under-recognition and undertreatment of discomfort [16, 17]. Furthermore, the dynamic and fluctuating nature of dementia symptoms complicates care planning and necessitates an adaptable approach to symptom management [18]. Difficulties in accurately gauging residents' preferences and goals of care, coupled with ethical dilemmas surrounding end-of-life decision-making, further accentuate the intricacies of delivering person-centered palliative care [12, 19].

This study aims to fill a critical need by conducting a systematic review of palliative care models in nursing homes specifically tailored for individuals with dementia. Recognizing the significant importance of this endeavor, our review seeks to identify and evaluate various applied models, assess their successes and challenges, and provide a comprehensive synthesis of the findings. By synthesizing existing research, we aim to offer crucial guidance to clinicians, policymakers, and researchers, thereby facilitating informed decisions that optimize palliative care provision in nursing homes. Ultimately, the main objective is to enhance the QoL for people with dementia by identifying effective palliative care models.

Materials and Methods

Our search for this systematic review was conducted without a specified time limit. We utilized four databases (PubMed, ScienceDirect, Web of Science, and Scopus) and the scientific search engine Google Scholar. We employed keywords such as "palliative care", "palliative", "dementia", and "nursing home" to retrieve relevant articles. To expand the search results, we set no restrictions on the publication year of the articles. Subsequently, we imported the results into Endnote (an information management program). Finally, the reference lists of the identified articles were reviewed to identify pertinent literature.

Inclusion and exclusion criteria

Inclusion criteria

The inclusion criteria were studies focusing on individuals with dementia residing in nursing homes, using palliative care models or interventions specifically designed for individuals with dementia in nursing homes, studies with full access to the entire text, with experimental (e.g. randomized controlled trials) and non-experimental study designs (e.g. observational studies, qualitative research), studies reporting outcomes related to the characteristics or efficacy of palliative care models for dementia in nursing homes, such as QoL, symptom management, caregiver burden, or healthcare resource utilization, and finally studies in English.

Exclusion criteria

We rejected review studies, studies on the implementation of a palliative care approach rather than those that specifically describe or evaluate a comprehensive palliative care model, duplicate studies, and non-English studies.

Study selection

The study's selection process followed the preferred reporting items for systematic reviews and meta-analyses (PRISMA) guidelines. At first, duplicate studies were excluded. Then, the remaining articles were screened based on their Titles and Abstracts to meet the inclusion criteria. Afterward, the main texts of selected articles underwent a thorough review. To ensure consistent results, two researchers independently performed all selection process and extraction stages. When there was disagreement between researchers, a third reviewer was consulted as an arbitrator.

The strengthening the reporting of observational studies in epidemiology (STROBE) checklist was employed to evaluate and determine the quality of articles based on observational studies. This checklist monitors 6 parts of "title", "abstract", "introduction", "methods", "results", and "discussion" with 32 items and assesses various aspects of the study methodology. These elements cover the problem statement, objectives, study type, statistical population under investigation, sampling method and size determination, the definition of variables and procedures used for data collection, and analysis methods to derive statistical findings. Articles with a score of 16 or higher on the STROBE checklist earn medium to high methodological quality. On the other hand, articles with scores below 16 are regarded as having low methodological quality and thus excluded from further consideration.

Concurrently, the consolidated standards of reporting trials (CONSORT) tool was used for trial studies. The tool has a structured framework to evaluate the reporting quality of randomized controlled trials. We systematically evaluated the rigor and transparency of the trial studies by examining various components of the CONSORT checklist. These components include trial design, participant recruitment, interventions, outcome assessments, statistical analyses, and results presentation.

Data extraction

Two authors conducted the data extraction process using a pre-determined checklist, which included criteria such as the primary author's identity, publication year, study site, sample size, palliative model, outcome measures, and summary of notable findings. Due to substantial heterogeneity observed in the palliative models, outcome measures employed, and analytical methodologies applied across studies reviewed, conducting a meta-analysis was deemed inappropriate for drawing significant conclusions. This decision aligns with the guidelines outlined in section 9 of the Cochrane handbook [20].

Results

A total of 1880 articles were initially identified and managed using Endnote software. Then, 842 duplicates were excluded during the selection stage. Next, the "titles" and "abstracts" of the remaining articles were checked against the inclusion and exclusion criteria, excluding 992 articles. During the full review stage, 46 studies were evaluated, with 40 additional articles eliminated based on inclusion/exclusion criteria. One study was not written in English and thus excluded. Ultimately, 5 eligible articles remained for final evaluation (Figure 1), and their detailed information is presented in Table 1.

The PACE steps to success program

In a recent study by Miranda et al. (2021) [21], the effectiveness of implementing the palliative care for older people in Europe (PACE) steps to success program in nursing homes for individuals with dementia was examined concerning its impact on the quality of care and end-of-life experiences during the final month of life. The findings revealed that this multi-component
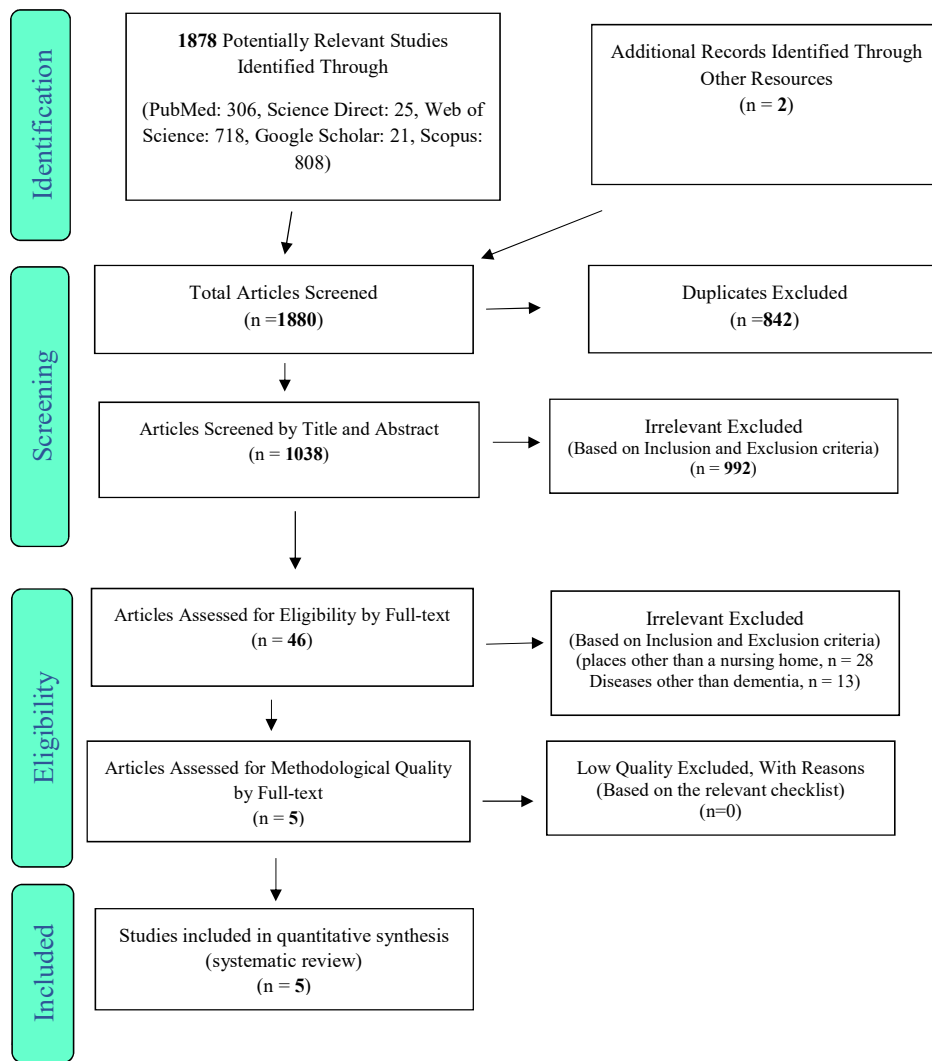
Sharifi S, et al. Dementia Palliative Care in Nursing Homes. Iran J Health Sci. 2024; 12(2):79-88.

81

Figure 1. The PRISMA flowchart

program, which utilizes a train-the-trainer approach encompassing six steps, enhanced the overall quality of care provided (mean difference=2.7, 95% CI=−0.4, 5.9). However, it is essential to note that no statistically significant evidence was found indicating an improvement in comfort among residents at end-of-life stages, regardless of whether or not they had dementia. The PACE steps to success program integrates general and non-disease-specific palliative care into nursing home settings. It trains staff members to render high-quality palliative care throughout all stages, from advanced care planning and comprehensive support to pre-death phases.

The PACE steps to success program was developed to enhance the quality of care and end-of-life experience for residents in nursing homes. The program encompassed six sequential steps:

Advance care planning involving active engagement with both residents and their families,

Thorough assessment, comprehensive care planning, and periodic resident needs and challenges evaluation,

Facilitation of coordinated care through regular interdisciplinary palliative care review meetings on a monthly basis,

Provision of high-quality palliative care services that prioritize effective management of pain and depression symptoms,

Implementation of specialized care during the final days leading up to an individual's passing and, delivery of post-death support and bereavement services.

Table 1. Summary of characteristics of included studies

Author and Place of Study	Year of Study	Participants	Design	Palliative Care Model	Outcome Measures	Results
Miranda et al. [21], Seven European countries	2021	Seventy-eight nursing homes with 177 residents with profound dementia, 126 with moderate dementia, and 156 without dementia	Randomized clinical trial study	The PACE steps to success program is a multicomponent intervention for integrating basic non-specialist palliative care in nursing homes.	Staff-reported comfort in the last week and last month of life (comfort assessment in dying–end-of-life in dementia [CAD-EOLD] scale, quality of dying in long-term care [QOD-LTC] scale, respectively)	The program did not significantly improve end-of-life comfort for residents with or without dementia (mean sub-group difference 2.1; P=0.177). However, it did enhance the quality of care and end-of-life experiences.
Hanson et al. [22], USA	2023	Three nursing facilities in North Carolina, nursing home staff	Clinical trial study	Comfort first; the model combines evidence-based practices in palliative care and geriatrics.	Post-test knowledge scores	Post-test knowledge scores were high, from 90% (addressing pain) to 99%.
Miller et al. [23], USA	2017	In thirty-one nursing homes, 203 participants received palliative care consultations.	Retrospective cohort study	Palliative care consultations included reviewing diagnoses and prognoses, addressing symptom control needs, reviewing advance directives, and discussing goals of care.	Hospitalization in the last seven days of life, total Medicare Part A expenditures	Residents who received palliative care consultations had lower hospitalization rates in the last seven days of life compared to controls (95% CI, −21.8%, −4.7%).
Tropea et al. [24],Australia	2022	Staff members working in residential aged care facilities	Cluster randomized controlled trial (RCT)	IMPETUS-D	The proportion of hospital transfers or deaths in hospital over 6 months	The study results indicated no significant difference in the proportion of hospital transfers or deaths in hospital among residents with dementia between the intervention and control groups over a 6-month (OR: 1.14; 95% CI, 0.82,1.59) and 12-month period.
Saini et al. [25], UK	2016	Two nursing homes: Family members, general practitioners, nursing home staff, and external healthcare professionals	Ethnographic study	Compassion model: A model of end-of-life care engaging an interdisciplinary care leader to promote integrated care, educate staff, support holistic assessments, and discuss end-of-life with families	Strategies for improving practice in end-of-life care discussions between families of people with advanced dementia and nursing home staff	The role of the interdisciplinary care leader demonstrated potential in facilitating and augmenting end-of-life discussions.

Sharifi S, et al. Dementia Palliative Care in Nursing Homes. Iran J Health Sci. 2024; 12(2):79-88.

83

Within this framework, the program specifically incorporated three elements tailored towards individuals affected by dementia, including training in communication strategies for advanced stages of dementia. It targeted approaches for symptom control in both dementia-afflicted and non-dementia-afflicted residents alike [26].

Comfort first

Hanson et al. (2023) executed a comfort-focused model in nursing homes and significantly improved post-test knowledge scores across multiple domains. Their findings showed notably high average scores, ranging from 90% in the domain of "addressing pain" to 99% in both "promoting QoL and comfort" and "making comfort first a reality" [22].

The comfort first training program promotes integrating palliative care and geriatric care principles employed in comfort matters dementia care. Its primary objective is to optimize comfort and boost the quality of care provided to individuals diagnosed with Alzheimer disease and related dementias (ADRD) within nursing home settings.

The program consists of a web-based training toolkit with six video modules that cover various topics related to dementia care, such as understanding the person with dementia, promoting QoL and comfort, working as a team in comfort-focused care, responding to distress in people with dementia, addressing pain in individuals with dementia, and making comfort first a reality in person-directed care plans. These modules feature professional narration, onscreen text graphics, and video demonstrations of best practices. The program provides an implementation manual with detailed instructions on implementing and sustaining the comfort first program. It includes guidance on engaging administrative and clinical leaders, delivering training as in-service programs, and recommending procedures for performance improvement.

Palliative care consultations

In a study by Miller et al. in 2017, individuals who received counseling services related to palliative care exhibited a lower frequency of hospitalizations within the final seven days before their death [23]. These consultations, led by nurse practitioner palliative care specialists under the supervision of certified palliative care physicians, comprised a comprehensive assessment and support framework. They involved a thorough review of diagnoses and prognoses, assessment of symptom control, examination of advance directives, and facilitated discussions regarding goals of care. In addition, these consultations often included family meetings to ensure alignment and understanding of the care plan. The study's main findings indicated a significant reduction in hospitalizations during the final days of life among individuals who received these specialized palliative care consultations, underscoring the importance of proactive and multidisciplinary approaches in end-of-life care.

Improving palliative care education and training using simulation in dementia (IMPETUS-D)

According to the Tropea et al. study (2022), the findings indicate that the IMPETUS-D training program does not demonstrate any significant impact on hospital transfer rates or mortality outcomes among residents diagnosed with dementia over the 6- and 12-month periods [24].

The primary objective of the IMPETUS-D program is to enhance the quality of palliative care delivery and improve outcomes for individuals with dementia residing in nursing homes. This comprehensive program comprises 11 modules that encompass essential elements of optimal palliative and end-of-life care for this population. These modules incorporate case studies and concise video scenarios filmed within genuine care home environments, facilitating practical application and contextual understanding.

Compassion model

Saini et al. study (2016) findings demonstrate the influential role of the compassion model in promoting and facilitating discussions pertaining to end-of-life care [25].

The compassion intervention, developed as part of a research program on end-of-life care in advanced dementia, consists of two core components. Firstly, it focuses on facilitating integrated care for individuals with advanced dementia. This issue involves promoting engagement with healthcare professionals from various disciplines to address the diverse needs of residents. The intervention identifies barriers nursing home residents face in accessing healthcare services. It employs an integrated care leader (ICL) who conducts holistic assessments, collaborates with nursing home nurses and general practitioners, attends multidisciplinary team meetings, and discusses with family members to ensure comprehensive care planning.

Secondly, the intervention provides training and support for families and caregivers caring for individuals

with advanced dementia. The ICL conducts formal training sessions for staff members covering topics such as behavioral symptoms management, pain management, and end-of-life care. Family sessions focus on enhancing their understanding of dementia progression, common end-of-life symptoms experienced by individuals with dementia, and sharing personal experiences related to caregiving. In addition to formal training sessions, ICL provides informal on-the-job advice and support [27].

Discussion

This systematic review examined different palliative care models for individuals with dementia in nursing homes. Another objective was to probe the characteristics and efficacy of models. The review identified five distinct models: The compassion model, IMPETUS-D, palliative care consultations, comfort first, and the PACE steps to success program. These models have been specifically designed to address the unique needs of people with dementia residing in nursing homes.

The efficacy of these palliative care models varies based on their objectives and approaches. For example, the PACE steps to success program enhances the overall quality of care for individuals with dementia in nursing homes [21]. Similarly, the comfort first model significantly improves post-test knowledge scores across multiple domains [22]. However, the IMPETUS-D training program has no significant impact on hospital transfer rates or mortality outcomes among residents with dementia [24]. Also, the compassion intervention model highlighted the significance of an integrated care approach for individuals with advanced dementia [25].

Dementia care principles are vital in providing optimal care for individuals with dementia residing in nursing homes. Person-centered care is a fundamental approach, focusing on tailoring the environment and interventions to meet individuals' unique needs and preferences [28]. This issue includes promoting autonomy, maintaining dignity, and fostering meaningful social engagement [29]. In addition, staff training programs that emphasize a person-centered approach and equip caregivers with the necessary knowledge and skills are essential for delivering quality dementia care within nursing home settings [30]. Notably, the principles of person-centered care are seen across all models under discussion. Each model uniquely strives to align with these principles by enhancing personalized care, minimizing distress, and maintaining a dignified and engaging care environment.

The nursing home environment presents a multifaceted context characterized by intricate contextual barriers outlined in prior research, including prominent factors like high staff turnover and heavy workloads [31]. These barriers encompass diverse aspects, ranging from staff-oriented concerns such as turnover and workload to organizational dynamics like time limitations and communication gaps [32]. Moreover, the intricate and voluntary nature of the training intervention contributes to further challenges. These complex hurdles are notably evident within palliative care models that rely on training nursing home staff, exemplified by initiatives like IMPETUS-D and comfort first.

In this context, the insufficiency of specialized palliative care services becomes a notable challenge in nursing homes. The limited availability of palliative care experts within healthcare systems hampers consistent consultation access, partly due to staffing constraints and geographical limitations [33]. This challenge is particularly relevant in models centered around consultation-based palliative care interventions.

Similarly, within the scope of the comfort first model, engaging family members and caregivers in the process proves to be challenging due to various factors such as logistical constraints, differing expectations, or emotional distress [34]. Moreover, fostering robust social support networks for family caregivers of Alzheimer patients is essential [35], as it can mitigate the multifaceted challenges encountered in implementing palliative care initiatives within nursing home settings, where diverse obstacles, both internal and external, influence the effectiveness of models designed to enhance care provision for individuals with dementia.

One notable limitation of this systematic review is its restriction to English-language articles. By exclusively focusing on literature written in English, the review may have overlooked valuable contributions and perspectives from non-English sources, potentially limiting the inclusivity and diversity of the findings. However, despite this limitation, the systematic review offers a significant foundation for comprehending the landscape of palliative care models tailored to individuals with dementia residing in nursing homes.

In summation, this systematic review has provided valuable insights into palliative care models in dementia care in nursing homes. It emphasizes the significance of person-centered principles, explores the nuances of integration, and underscores the multifaceted challenges inherent in delivering comprehensive care to this vul-

Sharifi S, et al. Dementia Palliative Care in Nursing Homes. Iran J Health Sci. 2024; 12(2):79-88.

85

nerable population. Looking ahead, our study calls for future research to explore innovative approaches, evaluate long-term outcomes, and embark on cross-cultural comparisons. These findings offer practical implications for healthcare practitioners seeking to implement effective palliative care models, fostering a holistic and dignified care journey for individuals with dementia in nursing homes.

Conclusion

In conclusion, this systematic review has shed light on the landscape of palliative care models for individuals with dementia residing in nursing homes. Through the comprehensive examination of 5 distinct models (compassion, IMPETUS-D, palliative care consultations, comfort first, and the PACE steps to success program), this study explored the successes and challenges inherent in enhancing care quality for this vulnerable population. The review underscores the significance of person-centered care principles as a guiding force within these models, emphasizing the tailored, dignified, and holistic approach they collectively advocate. However, it is noteworthy that the compassion model and palliative care consultations demonstrate comparatively better outcomes in terms of effectiveness. Nonetheless, these models' varying degrees of effectiveness reflect the complex interplay between their objectives, strategies, and the intricate nursing home environment.

Ethical Considerations

Compliance with ethical guidelines

This article is a meta-analysis with no human or animal sample.

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Authors contributions

Conceptualization and supervision: Sina Sharifi and Mahmoud Rahmati; Methodology: Sina Sharifi and Fatemeh Rostami; Data collection: Kimia Babaei Khorzoughi; Data analysis: Sina Sharifi and Fatemeh Rostami; Funding acquisition and resources: Mahmoud Rahmati; Investigation and writing: All authors.

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87

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