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Mapping an evidence-based end-of-life care framework for older adults in Chinese nursing homes: protocol for a scoping review

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ABSTRACT

Introduction End-of-life care is essential for older adults aged ≥60, particularly those residing in long-term care facilities, such as nursing homes, which are known for their home-like environments compared with hospitals. Due to potential limitations in medical resources, collaboration with external healthcare providers is crucial to ensure comprehensive services within these settings. Previous studies have primarily focused on team-based models for end-of-life care in hospitals and home-based settings. However, there is a lack of sufficient evidence on practices in such facilities, particularly for Chinese older adults. The aim of this scoping review is to map the existing literature and inform the development of an appropriate care framework for end-of-life care in nursing homes. The focus of this article will be on the scope of services, guidelines for decision making, roles within interdisciplinary teams, and the practical feasibility of care provision.

Methods and analysis A systematic search will be conducted across nine electronic databases: PubMed, Scopus, EMBASE, Cochrane, PsycINFO, ERIC, CINAHL, China National Knowledge Infrastructure (CNKI), and Wanfang Data. The search will identify literature published in English and Chinese from January 2012 onwards. Articles will be selected based on their relevance to older adults aged ≥60 with disabilities or life-threatening chronic conditions receiving end-of-life care in nursing homes or similar settings. The data extraction process will be guided by the Canadian Hospice Palliative Care Association model (CHPCA) and the Respectful Death model. Qualitative data analysis will be performed using a framework method and thematic analysis, employing both inductive and deductive approaches, with three reviewers participating in the review process.

Ethics and dissemination Ethical approval is not required because the data for this review is obtained from selected publicly available articles. The results will be disseminated through publications in peer-reviewed journals and presented at relevant conferences. Furthermore, the findings will be shared with policymakers and healthcare professionals engaged in end-of-life care to inform practice and decision making.

Study registration The review protocol has been registered on osf.io (https://osf.io/3u4mp).

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ A scoping review approach will be used to effectively map the diverse and fragmented literature.
⇒ The extensive search strategy across nine databases ensures comprehensive coverage.
⇒ The involvement of multiple reviewers in data extraction and coding enhances reliability.
⇒ There may be a lack of studies with detailed and consistent descriptions of essential roles and training specific to nursing homes.
⇒ Another limitation is the lack of formal evaluation of the quality of included studies, including their potential for bias that may affect the validity of the conclusions.

INTRODUCTION

Many countries, including China, are facing complex challenges in the healthcare system due to rapid ageing.[1] In 2020, there were more than 36 million older adults in China that required moderate assistance with mobility and medication, while another 45 million older adults had severe cognitive or physical impairments necessitating constant supervision.[2] Consequentially, there is a growing trend among the ageing population in China to choose nursing homes as an alternative living arrangement. The shift towards nursing homes has also been driven by broader societal changes including the one-child policy and increasing rate of globalisation, which have resulted in inadequate family care, specifically due to adult children often living far from their ailing parents.[3] Data from the Ministry of Civil Affairs indicates that as of March 2020, over 2 million older adults resided in approximately 40 000 nursing homes throughout China. The highest proportion of older residents in these institutions were located in Shanghai, where they comprised 1.96% of the ageing population.[4] Older residents in nursing homes typically have significant health challenges, with

some individuals experiencing disabilities or cognitive impairments.[5] Nursing homes provide a more homelike and comfortable environment than hospitals, making them a more attractive option for older adults, particularly those needing end-of-life care.[6 7]

The concept of hospice care was introduced in China during the 1980s and was classified as a service within the field of social work, primarily aimed at critically ill patients and the ageing population.[8 9] End-of-life care and palliative care are collectively referred to as hospice care (An Ning Liao Hu) in China, where these services provide medical, psychological, and spiritual support to patients and their families.[9 10] The services are carried out by interdisciplinary teams in hospitals, including physicians, nurses, and psychotherapists.[11] In recent decades, the Chinese government has made significant progress in promoting hospice care, for instance, the municipal government of Shanghai released 56 documents between 2012 and 2021 to facilitate the regulation, supervision, and education of human resources within the field.[11 12]

However, end-of-life care in China focuses primarily on cancer patients and pain management,[13] with the majority delivered by oncology units in secondary and tertiary hospitals. Recently, the Chinese authorities are introducing and promoting a collaborative approach involving homes, communities, and hospitals to aid end-of-life care due to the shortages of skilled nurses, knowledgeable caregivers, and bed capacity in the hospitals.[11 14] Nevertheless, only 1% of patients can access such care[15] which presents a major gap for older adults aged ≥60 with terminal conditions, particularly in nursing homes.[12 16 17] Chronic illnesses among older adults, leading to gradual deterioration and disability, have further increased demand for end-of-life services.[18] Given the high cost of in-home care and the logistical challenges faced by family caregivers, nursing homes emerge as a crucial alternative for this demographic.[19 20] Despite this, end-of-life services in nursing homes remain underdeveloped. For example, only 30.8% of nursing homes in Hebei province offer hospice care and the services provided often fail to meet established standards.[21 22]

Existing nursing homes in China are characterised by limited medical resources and depend on external healthcare providers to deliver end-of-life care.[23] While previous studies have highlighted the benefits of team-based models of end-of-life care for home-based patients,[24] there is limited research focused on nursing home settings, particularly in China.[16 16] The evidence from these studies lacks impact on clinical practice.[25] This is because the role of interdisciplinary teams in delivering care to older adults in nursing homes is not well understood, particularly in terms of decision making processes for older adults with severe cognitive or physical impairments.[26 27] Additionally, further understanding of how formal and informal care teams interact and the essential training that is needed to meet the demands of older adults and their families are warranted.[28 29]

This research aims to fill these gaps and provide valuable insights for improving end-of-life care in nursing homes in China. It will explore the current state of end-of-life care in these facilities and propose an evidence-based practice framework tailored to meet the needs of older adults in this context. The results of this scoping review will enhance our understanding of the challenges facing nursing homes in China and offer insights into improving the quality of care provided to older adults during the terminal stages of life.

Objectives of the review

Given the fragmented and heterogeneous nature of the existing literature on end-of-life care in nursing homes, a scoping review is the most suitable approach for mapping the most current evidence. Hence, the objectives of this review will be to:

1. Analyse the service scope for each essential care step, along with the challenges associated with implementing end-of-life care for older adults in nursing home settings.
2. Identify indicators or guidelines for evaluating complexity and making informed decisions regarding end-of-life care for older adults.
3. Categorise the departments involved in the interdisciplinary team to improve work efficiency and the quality of care, particularly within the collaborative team in nursing homes with limited medical resources.
4. Define the responsibilities and the essential training required for the end-of-life care team, including nurses and care coordinators, who manage scheduling, communication, and resource organisation, while addressing the patient's holistic needs.
5. Map an end-of-life care framework for nursing home settings that considers practical feasibility and is targeted towards Chinese authorities.

METHODS AND ANALYSIS

A systematic search will be conducted on nine electronic databases according to the research objectives. Initially, a scoping search of the PROSPERO database and Cochrane Library revealed no preexisting literature reviews or review protocols on this topic. In the subsequent scoping review, studies to be included must be published in either English or Chinese. The search for publications will be restricted to those from January 2012 to the date of the final search, aiming to capture the current perspective on this practice. The reason for choosing this particular year is that Izumi *et al*., (2012) made a distinction between end-of-life care and palliative care from a nursing ethics perspective. They defined the end-of-life as a later stage when a person is aware of the end-of-life regardless of a medically determined period before death.[30] In 2013, the Canadian Hospice Palliative Care Association model (CHPCA Model)[31] underwent revisions to support the implementation of high-quality comprehensive palliative care. This will be used as guidance to identify the time

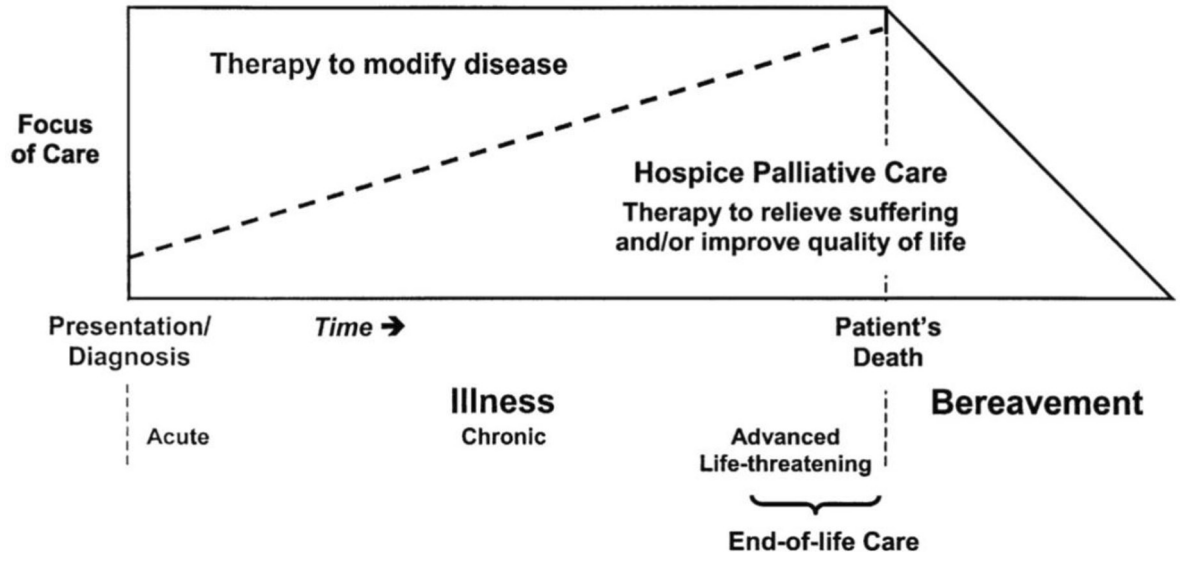

Figure 1 Canadian Hospice Palliative Care Association model.

period of end-of-life care distinct from palliative care and to establish inclusion criteria for literature selection. The practical Respectful Death Model (RDM)[32] will guide the coding of cooperation and interaction among all departments and the roles of personnel involved in the end-of-life care team, such as nurses, caregivers, and care coordinators. The Framework Method and thematic analysis, utilising both inductive and deductive approaches, will guide the data analysis. This process will involve transcription, familiarisation, coding, developing an analytical framework, applying the framework, and charting the qualitative data for thematic analysis.[33] Meanwhile, the square of care metric table in the CHPCA model can be utilised to ensure that relevant data are extracted in the essential care steps, from needs assessment to care delivery.[31 34] The review will be reported according to the checklist of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR).[35] The review protocol has been registered on osf.io (URL: https://osf.io/3u4mp). As this is a scoping review, no quality or risk of bias assessment will be conducted, given the focus will be on mapping key concepts and identifying gaps rather than evaluating study quality.

Theoretical frameworks

The CHPCA Model (figure 1) serves as a global guide for patient care.[31] Initially, it focuses on end-of-life care, addressing the hospice and palliative care movements. End-of-life care refers to the stage when a person's condition deteriorates to the extent that death is expected within the next 12 months, typically occurring in the final 6 months or even within a matter of days or hours.[36–38] This model aids in assessing and making decisions for end-of-life care by distinguishing the periods and scopes of service following palliative care. By providing clear criteria, the CHPCA Model enables nursing home staff to identify critical transition points in a resident's condition, prompting timely interventions and facilitating access to specialised palliative or hospice care teams. This approach ensures that the care provided aligns with the resident's evolving needs, emphasising comfort, symptom management, and emotional support in the final stages of life.

The RDM model (figure 2) is a holistic and research-based end-of-life care model that outlines the establishment of a therapeutic relationship between the practical end-of-life care team and patients, as well as their family members.[32] Unlike other theories that heavily rely on medication to alleviate suffering, the RDM places emphasis on practical end-of-life care, including actively listening to patients, engaging in deeper conversations about life and death, integrating patients' and their family members' hopes and concerns into the care plan, and assisting in fulfilling these tasks. Its application in nursing homes is particularly valuable as it helps care teams to develop deeper emotional connections with patients and their families, enabling a more personalised and compassionate approach to care. By focusing on these non-medical aspects, the RDM model complements traditional care methods and enhances the quality of support provided in the final stages of life. With necessary changes in healthcare systems and policies, healthcare professionals can help patients achieve respectful deaths in the future. In practice, members of the end-of-life care team, including nurses, caregivers, and care coordinators, may benefit from mentoring by experienced nurses or healthcare professionals to effectively fulfil these roles. It is important to note that while this model's perspective on culture and beliefs about death primarily focuses on the United States. This model is still suitable for identifying the roles of end-of-life care personnel and can serve as a reference for coding.

Eligibility criteria

The inclusion and exclusion criteria of the identified literature will be determined based on the time periods

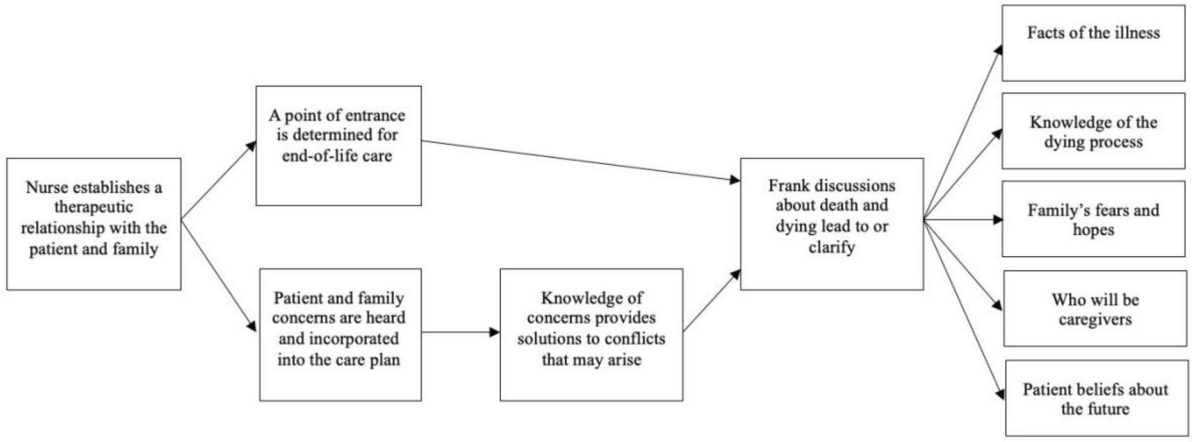

Figure 2 The Respectful Death Model

defined by the CHPCA model[31] and by Izumi *et al*.[30] In this context, nursing home settings refer to long-term care facilities where nursing and medical care may be provided on-site or by healthcare professionals from external resources, 24 hours a day, for older adults with complex health requirements and heightened vulnerability. This encompasses care homes and assisted living facilities.[39] Table 1 outlines the inclusion and exclusion criteria for screening reviewed literature.

Information sources and search strategy

A preliminary search was conducted on PubMed to optimise search strategies and refine keywords. Nine electronic bibliographic databases (PubMed, Scopus, EMBASE, Cochrane, PsycINFO, ERIC, CINAHL, China National Knowledge Infrastructure (CNKI), and Wanfang Data) were used for literature searches. The keywords 'end-of-life care', 'hospice care', and 'terminal care' were selected to identify relevant literature.[25 30 40] Terms such as 'nursing home', 'care home', 'long-term care facility', and 'assisted living facility' were used to narrow down the settings for end-of-life care. 'Elderly people' and 'older adults' were used to specify the target population. The keywords were searched within the titles and abstracts of the literature to ensure relevance. Additionally, eligible literature identified through other sources, such as citations in eligible literature, will be included. The preliminary search, along with examples of the search strategy used on PubMed, is documented in online supplemental file 1).

Selection of reviews

The selection of eligible literature will occur in three phases: (1) screening of the title and abstract; (2) retrieval and screening of the full text according to the inclusion and exclusion criteria; (3) data extraction and interpretation. Three reviewers will be involved in the selection process. The first reviewer (YYZ) will conduct a comprehensive search on the electronic databases and import all eligible literature into the Endnote X9 library for further screening. Duplicates will be removed and the library will be shared with the other reviewers (EMG and YHT). All reviewers will screen titles and abstracts in parallel. Two out of these three reviewers will be involved in the full text screening process. Inclusion and exclusion criteria will be applied to both abstracts and full-text

Table 1 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
The literature focuses on end-of-life care for older adults aged≥60 with disabilities and life-threatening chronic conditions.	Aged <60.
The included studies encompass qualitative, quantitative, mixed methods research, as well as other literature reviews, such as systematic reviews or scoping reviews, addressing end-of-life care in clinical practices, interventions, clinical trials, and experiences of operations.	Editorials, letters, comments, conference abstracts without full texts, policy documents, and non-clinical practices, such as theories, theoretical models, and conceptual frameworks.
The study settings include nursing homes, care homes, and other long-term care facilities.	Additional settings, such as, home-based care and hospital settings.
The literature is published in English or Chinese.	Literature in languages other than English and Chinese.
Comprehensive care primarily emphasises maintaining the quality of life, hospice care, psychological support, and spiritual support for older adults as they approach the end-of-life.	The focus is on medical interventions and therapies aimed at modifying diseases to optimise patients' quality of life.

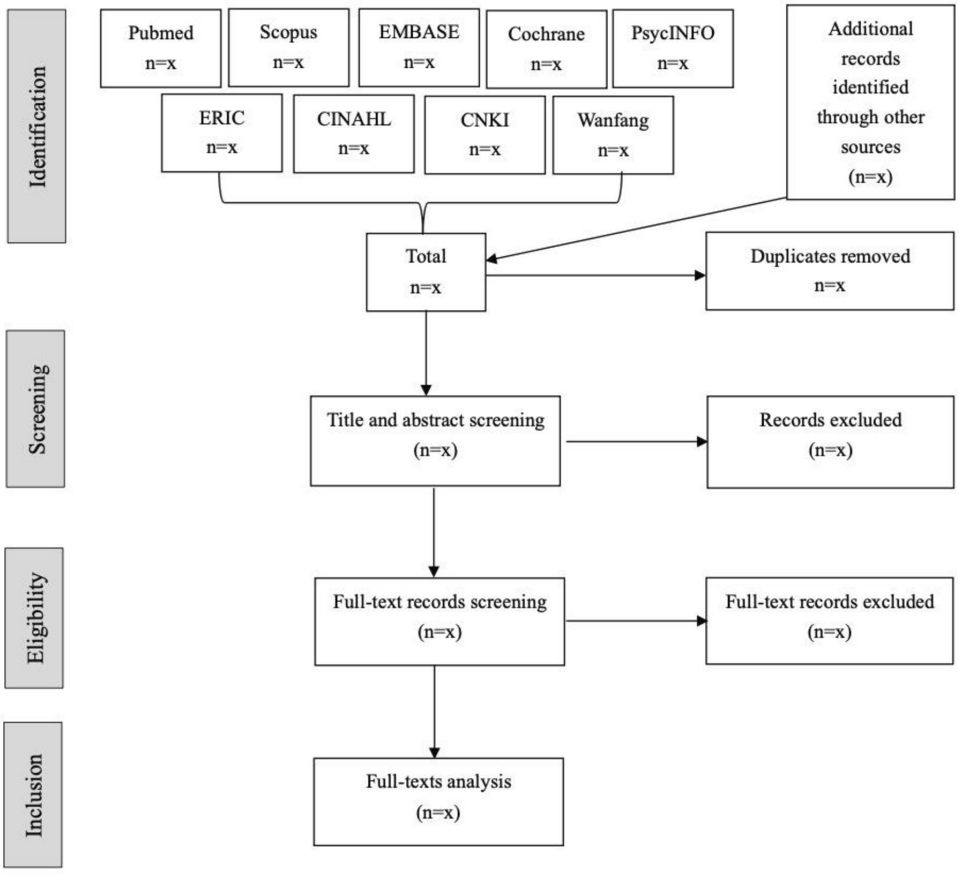

Figure 3 Scoping review flow diagram.

screening. Consensus must be reached among at least two of the three reviewers. The PRISMA-ScR chart (figure 3) illustrates the phases of identification and selection for eligible literature.

Data extraction and charting

Data extraction will be based on the review objectives and the framework method. One reviewer (YYZ) will conduct data extraction. Another two reviewers (EMG and YHT) will check a random 50% of the data extraction sheet in parallel. Data extraction and item design will be guided by the CHPCA model, the square of care conceptual framework, and RDM. Both inductive and deductive approaches will be applied for coding and categorising into themes. Agreement for codes and themes must be reached among at least two of the three reviewers. Table 2 presents the domains and data extraction items. The service scope with practical challenges of end-of-life care in nursing homes will be extracted in a separate table since it will be input into the square of care metric table. The data extraction form is provided in online supplemental file 2).

Patient and public involvement

There will be no patient or public involvement since this will be a literature search and analysis.

ETHICS AND DISSEMINATION

Ethical approval is not required because the information for this review is obtained from selected publicly available articles. The results will be disseminated through publications in peer-reviewed journals and presented at relevant conferences. Furthermore, the findings will be shared with policymakers and healthcare professionals engaged in end-of-life care to inform practice and decision making.

DISCUSSION

This scoping review is the first comprehensive effort to address the knowledge gap in delivering end-of-life care in nursing home settings, focusing on its practical feasibility for China's rapidly ageing population. By mapping the fragmented literature, the review provides a broad overview of current practices and challenges across key phases of care. The findings aim to improve decision making and enhance the quality of care for older adults nearing the end of life. The comprehensive search strategy employed across nine databases ensures wide-ranging coverage, effectively capturing a variety of studies relevant to the Chinese context or comparable settings. The review will offer valuable insights to guide future senior care for older adults aged ≥60 and nursing education, particularly

Table 2 Data extraction items

Domains	Items for data extraction	Description
Basic information of reviewed literature	Authors, year, country, study design, site, population, sample size	Basic information is provided to categorise the reviewed literature for future comparison, analysis, and interpretation.
Service scope in each essential care step and challenges	Practice assessment, care planning, information sharing, decision making, care delivery, confirmation (CHPCA metric) and the practical challenges of implementing end-of-life care in nursing homes	The process of providing care is outlined in six essential and multiple basic steps that guide clinical interactions. The square of care conceptual framework will be used to guide all activities related to older adults and family care, measuring end-of-life care in symptom management, physical, psychological, social, spiritual, practical, death management, and dealing with loss or grief.
Interdisciplinary teams and their interaction	Collaborating departments within interdisciplinary teams, their roles, and functions	End-of-life care is generally operated by interdisciplinary teams, particularly in nursing homes, consisting of different departments from hospitals, communities, and other non-governmental organisations.
Personnel involved in the end-of-life care team	Roles, backgrounds, skills, and training provided to end-of-life care team members, including nurses, caregivers, and care coordinators	Nurses play key roles in end-of-life care, while other members of the healthcare team are involved in delivering services under the supervision of healthcare professionals.
Indicators or guidelines for end-of-life care implementation	Indicators, medical codes, or guidelines for physical and medical assessment to progress to end-of-life care, or even personal requests for older adults	The distinction between end-of-life care and palliative care lies in the time period and service scope, which is intended to simply relieve suffering or maintain quality of life rather than modify diseases through therapies. Assessments are repeated to ensure adequate information is available for guiding care planning, strategy changes, and decision making. For example, the assessments and decisions about withholding or withdrawing therapies, evaluating the potential benefits for older adults and families, and considering other factors related to the patient's requests.
Outcomes	The satisfaction of older adults or their family members, medical or practice outcomes, improvements in work efficiency, experiences, and the results of education for end-of-life care personnel	This approach will be used to measure the outcomes of future end-of-life care models/ frameworks.

for Chinese authorities and stakeholders involved in implementing end-of-life care in nursing homes.

The practical feasibility of implementing end-of-life care for Chinese nursing home residents has been demonstrated when care plans are established in advance.[41] A team-based care model adopted within hospitals or community clinics has the potential to enhance the end-of-life care in nursing home settings.[23 24] However, Chinese researchers often use various terms such as hospice, palliative care, and end-of-life care to translate and describe the hospice concept. All of these foundational concepts fall within the broader scope of palliative care.[11 13 16 42–44] This scoping review will evaluate end-of-life care services in nursing homes across multiple care steps, along with the practical challenges associated with each step.[31] The results will identify service gaps and provide robust evidence to help establish a comprehensive framework for end-of-life care practice in Chinese nursing homes.[45]

Healthcare professionals can serve as substitute decision makers for patients regarding medication, particularly for older adults who lack decision making capacity or do not have family members available to act as surrogates.[26 46] Decision making in end-of-life care is a complex process that involves establishing care goals, assessing treatment options along with the potential benefits and risks, considering the necessity of withholding or withdrawing therapy, and respecting any advance directives.[31] Continuing with medically non-beneficial interventions can sometimes lead to further complications or harm.

For example, the use of feeding tubes in older adults with advanced dementia has been associated with pain and infection at the insertion site.[47] Making decisions in these circumstances requires a solid understanding of legal and regulatory frameworks, ethical considerations, and the individual patient's values, goals, and autonomy, as these elements significantly impact the quality of life for individuals receiving end-of-life care.[47 48] Addressing these factors is essential to ensure that end-of-life care services follow high-quality standards and are equitable for those who need or qualify for them, including older adults who may already have diminished decision making capacity in nursing home settings.[27]

Interdisciplinary teams are essential for addressing the complex physical, psychological, and spiritual needs of patients in end-of-life care, as well as for the patients' families in order to deliver satisfactory services to everyone concerned.[24 28] Previous studies have demonstrated that these teams improve the quality of life for both patients and their family members through comprehensive clinical practices, effective symptom management, and attentive daily care routines.[49 50] As a result, patients with severe illnesses have significant needs that can be best met by interdisciplinary teams.[51] Typically, these teams include a mix of full-time and part-time clinical staff, along with non-clinical staff or volunteers who provide direct or indirect care during both day and night shifts.[49] However, prior research has found various team configurations and professions without clear definitions of roles and composition of interdisciplinary teams, particularly in nursing home settings.[28] Hence, one of the aims of this scoping review is to evaluate the dynamics of team functioning and the related benefits, including core team components, service scopes, and modes of patient interaction. The ultimate goal is to enhance work efficiency and improve the quality of care for patients and their families.[24 52]

Personnel involved in end-of-life care whether directly, such as nurses, physician assistants, caregivers, and social workers or indirectly, including nursing home administrators, therapeutic harpists, and massage therapists, play a crucial role in addressing the expectations, needs, hopes, and fears of patients and their families as they confront the challenges associated with underlying diseases or conditions.[31 49] Nurses and care coordinators typically spend the most time with patients and their families.[32] However, limited knowledge about end-of-life care, insufficient educational background, and a lack of specialised training among these professionals create significant barriers to delivering comprehensive care.[53] In China, the Oncology Nursing Committee of the Chinese Nurses Association has developed a brief training programme for end-of-life care. However, there is currently no certification programme tailored to this field.[11] Team members involved in end-of-life care should possess the skills necessary to anticipate and address the needs of patients and their families,[54] including the ability to engage in effective conversations and communication with those navigating end-of-life issues.[55] To establish a clear care pathway, it is imperative to clarify the roles of personnel and address the practical obstacles to implementing end-of-life care, as well as providing education and training for both direct and indirect caregivers.[45]

Prominent challenges to effective end-of-life care in nursing home settings include the lack of patient-centred environments, an insufficient number of healthcare professionals, inadequate supervision, limited knowledge about care delivery, low awareness among residents and their families, and personal attitudes or beliefs about death.[54 56] The high cost of medical care and hiring caregivers at home complicates the sustainability of both hospital-based and home-based end-of-life care models for the ageing Chinese population.[19 45] Additionally, traditional Chinese culture and Confucianism foster a prevailing belief that healthcare and treatment should fight against disease until the very end. This mindset can hinder acceptance of end-of-life care in China.[57]As the government actively promotes end-of-life care and public awareness rapidly increases, there is an urgent need to establish a viable practice pathway for end-of-life care in various settings, including nursing homes.[8]

Conducting a scoping review to address the outlined objectives presents several potential limitations. First, the published literature may have limited data specific to end-of-life care in nursing homes. Many studies may be from academic medical centres and hospitals rather than home-based care and the community setting. Additionally, there may be substantial variability in the definitions and standards for essential end-of-life care services across different nursing homes and contexts of care, making it challenging to generalise findings or standardise care step analysis. However, this variability, including that which may arise from indicators and guidelines assessing end-of-life care will be identified in this review and harmonised to consistent benchmarks using standardised frameworks that facilitate evidence synthesis to inform future studies. Another related limitation is the exclusion of materials published in languages other than English and Chinese, which may result in the omission of relevant studies and could restrict the global applicability of the findings. Also, publication bias toward studies with significant findings may underrepresent the practical challenges in real-world end-of-life care implementation, limiting a balanced perspective on both successes and obstacles. However, we perceive this to be a lesser problem owing to the broad scope of the review objectives and not the effectiveness of certain treatments in clinical trials.

Additionally, the review does not include a formal assessment or evaluation of the quality and potential biases of the included studies, potentially impacting the robustness and validity of the conclusions drawn from the literature. This omission is consistent with the typical methodology of scoping reviews, which focus on mapping the breadth of available evidence rather than evaluating the quality of individual studies. Despite these limitations, the future findings and the proposed end-of-life care

framework can still offer valuable qualitative evidence to inform the development of national practice standards and guide funding allocations for nursing home settings, with consideration of practical feasibility and relevance to Chinese authorities.

Thus, from a methodological perspective, future research may build on the framework developed in this scoping review by conducting qualitative studies with stakeholders in Chinese nursing homes. This approach may help to identify optimal strategies for sustaining end-of-life care in various settings, including nursing homes and community-based long-term care centres throughout China.

CONCLUSION

While this review focuses on the Chinese context, particularly nursing home practices, the unique sociocultural, legislative, regulatory, and healthcare systems in China may restrict the applicability of the findings to other countries. Nonetheless, the proposed framework offers practical insights that could be adapted to similar environments where healthcare resources are limited and team-based care models are advantageous. Furthermore, this scoping review can serve not only as the basis for subsequent qualitative studies but also for confirmatory validation studies that are quantitative in nature.

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Contributors All authors have made substantial intellectual contributions to the development of this protocol, study design, and have approved the final manuscript for submission to the journal. In particular, YYZ and YHT proposed the study topic, drafted the manuscript, and will conduct the qualitative scoping review. GEM will contribute to study selection and review the literature published in English. YHT will be involved in selecting and reviewing the literature in Chinese. As an expert in methodology, BHC will monitor the review and analysis process. All authors will be involved in the thematic analysis. YYZ is responsible for the overall content as guarantor.

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Patient consent for publication Not applicable.

Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data sharing not applicable as no datasets generated and/or analysed for this study.

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