Review Article

Mapping Existing Informal Home Caregiver Support Guidelines for Palliative Care: A Scoping Review

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Abstract

Background
Although health systems increasingly recognize the benefits of home-based palliative care, informal caregivers often lack adequate training and guidance to support terminally ill patients effectively. This underscores the need for comprehensive guidelines addressing pain and symptom management as well as patients' social, psychological, economic, and spiritual needs. This scoping review aimed to identify reliable guidelines to support informal home-based caregivers for patients cared for in home-based palliative care services.

Methods
A literature scoping review using Arksey and O'Malley's five-step process identified 1055 studies, excluding non-English publications, opinion pieces, and grey literature without full-texts. Of these, 58 articles were assessed for inclusion, focusing on informal caregivers supporting adults with advanced chronic conditions or in palliative care.

Results
The review identified key themes in existing guidelines for home-based palliative caregivers, including recognition of palliative care as a fundamental human right. However, substantial inconsistencies were found in scope, depth, and content, with no standardized approach to guide essential care practices.

Conclusion
This review examined global literature on informal home-based caregiver support in palliative care, with relevance to Rwanda. Findings showed that available documents were largely policy-oriented and lacked detailed guidance on comprehensive care and clearly defined caregiver roles. Key priorities include integrating palliative care into health systems, recognizing it as a legal right, ensuring culturally appropriate home-based care, and strengthening caregiver support. Effective service delivery requires holistic approaches, defined team roles, harmonized care models, and ongoing monitoring to ensure sustainable, high-quality care.

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Introduction

Home-based palliative care is an increasingly important model for addressing the complex needs of ageing populations and individuals with life-limiting illnesses.[1] By providing holistic, patient-centred care in the home environment, it improves quality of life, reduces healthcare utilization, and aligns care with the preferences of patients and their families.[1,2] Many patients prefer to spend their final days at home, close to loved ones.[3]To support them, family members, friends, volunteers, and other unpaid individuals often serve as informal caregivers, despite limited training.[4] They provide essential emotional, physical, and practical support during end-of-life care.[5] Caring at home can be demanding and costly, particularly due to repeated consultations. [6] Beyond medical care, patients' social, cultural, spiritual, psychological, and financial needs must also be addressed to provide comprehensive support.[2,7–9]

Despite advances in healthcare, palliative care systems remain under pressure from ageing populations, changing health structures, and evolving social expectations.[10] Collaboration among health professionals, palliative care teams, patients, families, and informal caregivers is crucial to align care with patient preferences.[11,12] Informal caregivers face significant challenges, balancing multiple responsibilities while managing patients' diverse needs. Effective guidance from trained palliative care teams is often lacking.[13,14] Some countries have developed guidelines to support informal caregivers, aiming to improve care quality, reduce suffering, and promote informed decision-making.[15,16]

However, existing guidelines vary in scope, quality, and applicability. Many are designed for high-income settings and may not suit low-resource contexts.[17,18] The World Health Organization also lacks specific standards for informal caregivers, and despite NGO efforts, major gaps remain. Without clear guidelines, caregivers often struggle to provide consistent and safe care. [19,20]

This scoping review therefore aims to identify and synthesize evidence-based guidelines for supporting informal home caregivers in palliative care, informing future guideline development and strengthening caregiver support systems in Rwanda.

Methods

This scoping review aimed to map the existing literature on informal home caregiver support within palliative care services, with the purpose of understanding the types of support available, how caregivers are engaged, and the gaps in current guideline development. A scoping review was selected because it allows for iterative "mapping" of a broad and complex body of literature to identify key concepts, the extent of existing evidence, and areas requiring further research. Our approach was informed by Arksey and O'Malley's scoping review framework and guided by the PRISMA-ScR Checklist to ensure transparency, consistency, and methodological rigour. [19] Following these guidelines, we applied a five-stage process: i) Identifying the research question, ii) Identifying relevant studies, iii) Selecting studies, iv) Charting the data, collating, summarizing the data, v) Reporting the results (Figure 1) .

i.Identifying the research question

The research question addressed the need for evidence on existing support guidelines for informal home caregivers in palliative care. Specifically, the review asked:
"What support guidelines are available to assist informal home caregivers in the daily care of palliative patients?" This question guided the review in identifying current guidelines and understanding how they support caregivers in providing quality care and maintaining their own well-being.

ii. Identifying relevant studies

To identify studies addressing the research question, all study designs published in peer-reviewed journals and English-language grey literature were considered.

A comprehensive, systematic search was conducted using Google Scholar, PubMed, Hinari, the Cochrane Library, MEDLINE, and BMJ Supportive & Palliative Care. The primary search terms included: (palliative care OR terminal care OR hospice care OR end of life) AND (patient OR family) AND (clinical guideline OR policies) AND (caregivers' home OR caregiver OR informal home caregivers) AND (chronic disease OR chronic illness in adults).

A broad search strategy was employed to capture all relevant literature related to guideline development in diverse contexts, with a particular focus on caregiving and palliative care. The search encompassed clinical trials, practice guidelines, meeting abstracts, dissertations, and grey literature, including sources related to digital health in palliative care and home-based care. All identified studies were imported into Mendeley, where duplicates were removed. The search was restricted to literature published in English between 2004 and 2025, a 21years timeframe chosen to capture major global health reforms and ensure a comprehensive and contemporary evidence base.

iii. Selecting studies

Studies were included if they met the following criteria: 1) the target population comprised adults (aged 18 or older) with advanced chronic conditions at the end stage of their illness; 2) the studies focused on advanced chronic diseases and/or palliative care guidelines, as well as the experiences of informal home caregivers; 3) empirical research (of any design) that examined the needs and experiences of palliative caregivers supporting individuals with advanced disease; 4) articles that explored caregivers' perspectives and lived experiences regarding the provision of palliative care services at home; 5) findings that are generalizable and/or transferable to inform home-based care settings; 6) protocols; and 7) publications and guidelines released by governmental entities and various organizations that highlight the firsthand perspectives of patients supported by informal home-based caregivers while receiving palliative care services. The exclusion criteria included studies not published in English, book chapters, opinion pieces, editorials, conference articles, and grey literature lacking full-text published articles.

iv.Charting, collating, and summarizing of data

Charting

Data were extracted using a standardized tool developed for this scoping review, adapted from established frameworks (Arksey & O'Malley, JBI) to ensure consistent capture of publication characteristics, target populations, guideline focus, caregiver support components, and methodological features.[17] Two teams of four members each conducted the extraction. Team 1 applied the tool to all included studies, entering information while preserving original terminology, and Team 2 independently verified the data for completeness and accuracy. Discrepancies were resolved through discussion, and the final dataset was compiled into a master extraction sheet.

A total of 1,055 articles were identified through database searches. After removing 272 duplicates, 783 titles were screened, resulting in 521 exclusions for not meeting inclusion criteria. Of the 262 full-text articles assessed, 204 were excluded for insufficient relevance, leaving 58 studies for inclusion. Among the excluded articles, 26 did not focus on home-based palliative care, 81 were not aligned with the context or timeframe, 24 were book chapters, 6 were opinion articles, 8 did not clearly address palliative care objectives, 42 were textbooks from unknown organizations, 7 were guideline reviews without references, and 14 were guidelines with unknown publishers. The included studies were conducted across sub-Saharan Africa (n = 6), South Asia (n = 7), South America (n = 6), Europe (n = 12), the USA (n = 8), Canada (n = 7), and non-governmental organizations (n = 12), with publication years ranging from 2004 to 2024.

Collating and summarizing

Each included article was analyzed using inductive thematic analysis to comprehensively identify and explore relevant findings. Studies were read thoroughly and coded according to emerging themes. The codes were then organized into key categories within each theme. Extracted data were reviewed multiple times to identify recurring patterns, similarities, and differences related to informal home caregiver support guidelines in palliative care. Charting techniques were used to group similar themes and categories, facilitating a structured synthesis of the findings.

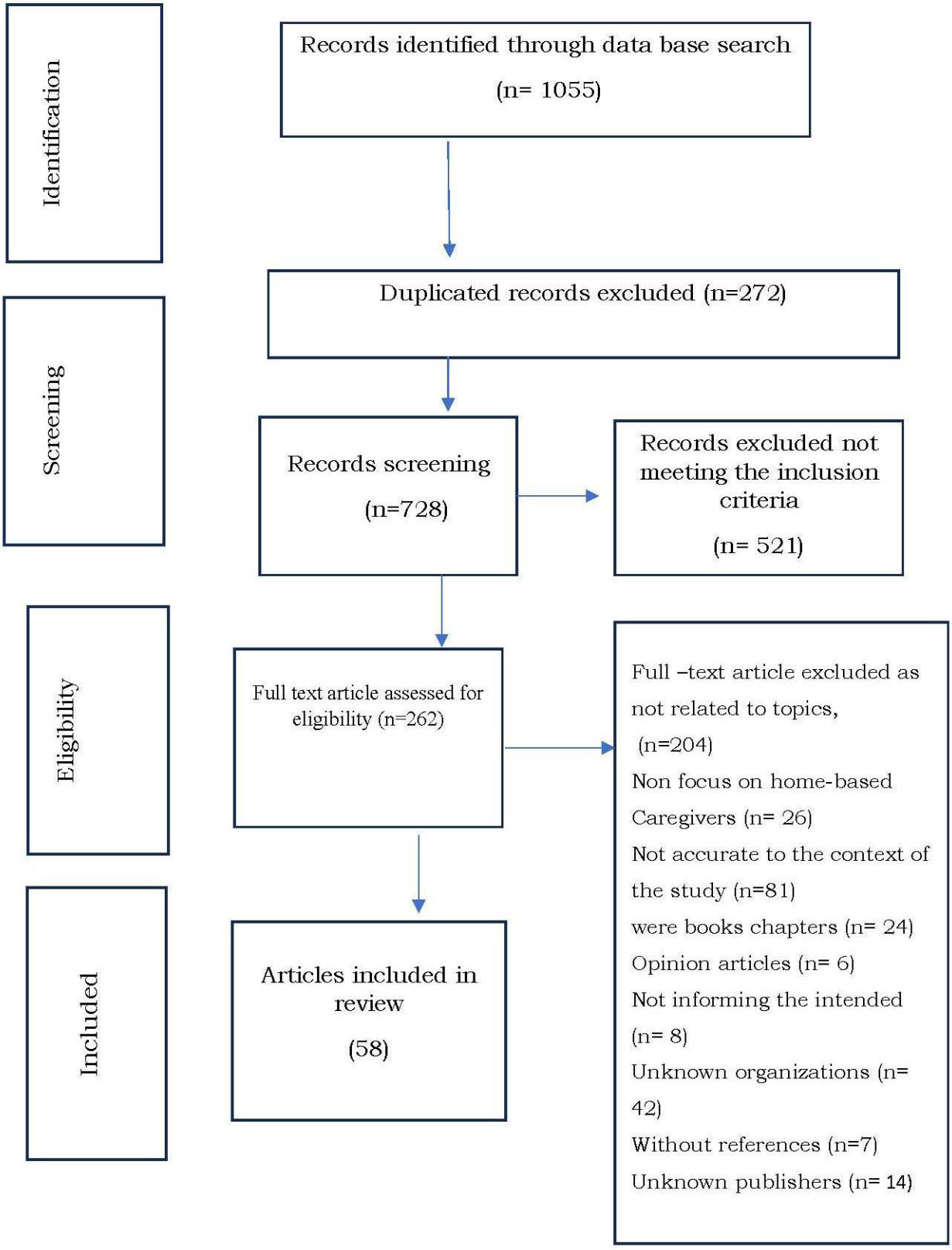

Figure1. Chart on study selection process according to the PRISMA guideline

v) Reporting results

The final themes were presented in a clear and descriptive manner to reflect the scope and nature of the available guidance. Prior to conducting the search, the research team reached consensus on anticipated key themes through discussion, drawing on their expertise and considering the complexities of patients' experiences in palliative care.

Results

Analysis of the 58 studies identified seven key themes related to guidelines supporting informal home-based palliative caregivers (Table 1). These included an integrated philosophy of palliative care within healthcare systems; models and principles guiding palliative care delivery; clearly defined roles and responsibilities of palliative care teams; recognition of care for the dying as a national policy right and its integration into health systems; programs supporting family and informal caregivers; home care services aligned with culturally accepted practices; and reporting, monitoring, and evaluation systems to ensure sustainable palliative care services..

Integrated Philosophy of Palliative Care Services in the Healthcare System

All 58 studies included in this scoping review endorsed an integrated palliative care approach within healthcare systems (Table 1). Forty-four of these studies provided definitions and descriptions of the requirements for such integrated services. One source described palliative care as a strategy aimed at preventing and alleviating suffering through early diagnosis, accurate assessment, and management of physical, psychological, and spiritual concerns, thereby enhancing the quality of life for patients and their families facing end-of-life conditions.[9]

The philosophical goal of palliative care guidelines, as stated in another two articles, is to give advice to those who are providing care for individuals with life-limiting illnesses and their families so that they can receive the best possible treatment.[10] A national palliative care system or program should be in place with the goal of establishing and enhance the objectives of palliative care. In this review, three articles addressed national approaches. Proposed the establishing a national palliative care plan, involving a budget, a responsible individual, resource education and tools, a reporting system, and indicators to track and oversee advancement in palliative care. The palliative care strategy may consider national social norms and principles and health care systems philosophy and available resources.[11]

Palliative care should took a holistic view, highlighting physical symptoms and functional status, psychological issues, cultural and social concerns, spiritual issues, practical issues, informal home caregiver and family issues, and health professional issues, by putting emphasizes on the wellbeing of both the patient as well as all those engaged in the care.[12] In the palliative care context, key principles, often referred to as the Golden Rules, guide symptom management by assessing underlying causes, developing a plan, addressing reversible factors, considering non-drug approaches, and considering patient prognosis, choices, and therapeutic goals. The care model should consider the respect of human rights.[13,14]

Palliative care models and principles in health care systems

This scoping review identified eight integrated palliative care models including telemedicine, hospice, home-based, outpatient, nursing home, primary care, and day care that address the needs of patients, families, and informal caregivers. These flexible models operate across different stages of illness rather than as alternatives (Table 1). Effective communication is essential in both resource-rich and resource-limited settings. Overall, the models provide comprehensive, patient-centered care based on assessment and prognosis, delivered by qualified healthcare professionals.[13]

Palliative care within various healthcare systems can be categorized as primary, moderate, intermediate, or maximal, based on the standards outlined in the basic palliative care model. This model defines the care parameters for both the patient and their family, who together form the care unit, and reflects the overall philosophy of palliative care. Senior political and health system leaders seek involvement from relevant steering committees, expert panels, and international partner organizations for national-level initiatives, with specific duties and responsibilities that may differ across countries.[14-15]

The range of care approaches that offer support to the patient as well as to their caregivers were addressed in three articles considered in this review based on model. It has been obviously accepted that a major disease may affect the entire family. Patient conditions are predicted to worsen over time and ultimately prove terminal ,Palliative care may be essential for individuals with a wide range of health issues(Table 1).[16–18] Two resources outlining indications for palliative care emphasized that everyone with a life-threatening illness should have access to care tailored to their needs, regardless of setting or diagnosis. Implementation should follow eight foundational principles: (1) regular treatment and standardized assessment of palliative care needs for patients and informal home caregivers; (2) co-developed individualized care plans aimed at optimizing quality of life; (3) provision of practical, emotional, psychosocial, and spiritual support for patients and informal caregivers, including during bereavement; (4) creation of an enabling environment within homes, communities, and hospitals; (5) support for primary healthcare providers to integrate palliative care into routine services, including clear organizational structures, defined roles, and adequate workforce training; (6) strong political support and policy implementation; (7) comprehensive education of healthcare workers in all aspects of palliative care; and (8) education of patients and informal caregivers regarding illness, symptoms, prognosis, and necessary precautions.[19,20]

The models also in this review underscored that, patients with complex needs must be guaranteed, access to specialized palliative care, with increased service capacity to provide this effective care and deliver an integrated care model.[21] Three sources stressed the significance of prompt and efficient information exchange among medical professionals and specialized palliative care practitioners, patient and caregivers , along with culturally sensitive communication. Furthermore, palliative care delivery should incorporate quality enhancement.[22–24]

The value of consent was emphasized by the scoping review. Underlining the importance of gaining the patient's consent for all decisions. If incapable of making decisions for themselves, a close relative should act on their behalf, acting in good faith and with the best wishes for the patient and their family at heart.[25] National policies on the funding of palliative care are needed.[26]

Palliative care guiding principles' primary goals are to reduce health disparities across various population groups, ensure timely and equitable access to health care services for everyone, regardless of financial situation, and deliver high-quality, long-lasting services. These guiding principles emphasize the application of evidence, a person-centered approach, active community and patient contact, acknowledging cultural diversity, and integration within a systematic and well-considered framework.[27]

Care provided in case of life-threatening illnesses should consider the sensitive to their values, interests, and requirements. Palliative care is a method that recognizes the intrinsic worth of every life and helps people live as freely as possible for as long as they can. The vital to this process, are Caregivers.[28] To uphold these values and principles, the characteristics of palliative

care services must be clearly defined, including continuity, integration, and comprehensiveness. Prioritizing palliative care is necessary to guarantee equitable treatment everywhere. The services should be enduring, effective, sensitive to community requirements, and pertinent to the local area.[29]

Care for patients nearing the end of life must include understanding ethical and legal aspects, as well as knowledge of medications, their usefulness, and side effects. This ensures clinicians and informal caregivers are equipped to address the diverse needs of patients and provide compassionate, holistic care.[30–33] Multidisciplinary care process and planning need to be accounted for and anticipate the requirement for equipment and procedures related to occupational health and safety for staff members making visits of patient at Home. These standards and procedures need to be included into a thorough palliative care framework that is applied across healthcare providers and settings.[34]

Supportive care standards are necessary to address the current disparities in the quality of services offered both within and between countries, as the scoping assessment showed.[35] In order to support those who have palliative needs and their families, as well as to raise community understanding of death, dying, and mourning, it is imperative to promote palliative care. A crucial component of this approach is the ongoing dialogue about advance care planning among patients, their families, and health care providers.[36]

Informal home-based caregivers have demonstrated how important it is to maintain a sense of community while an individual is passing.[37] This suggests that such care typically occurs later in the course of the sickness, after all possible treatments have been attempted.[38] Three fundamental principles for good home care are: clearly defined desired outcomes, specified care for carers (both paid and unpaid) to stick to, in addition to inputs of resources to help these processes.[39]

Programs need to be customized to meet the needs of specific patient groups with serious illnesses require a variety of services. These efforts need to be flexible enough to follow local laws, services, and resources and closely work with community resources such community paramedicine services, hospice and palliative care organizations, and home healthcare professionals it has reviewed in seven resources.[40]

Clear definition of position, roles and responsibilities for the palliative care team

In this review, nine publications emphasized distinct roles and duties related to patient care in home based palliative care services (Table 1). Palliative care requires supporting informal home caregivers. These caregivers are essential in providing their loved ones with hands-on care, emotional support, and maybe even financial assistance. Responsibilities that were formerly handled by qualified healthcare professionals are frequently taken over by them. Determination of patient home based care mostly dependent on the availability of informal caregivers, which reflects the social norms and values in different countries.[41] At the same time, Patients deserve right to make decisions about their own care, including how their physical requirements are satisfied and what they want done when they pass away. It is equally crucial to care to the emotional, spiritual, and cultural requirements of patients and their families. Unless otherwise noted, patients often want close relatives to be informed about their overall health and prognosis.[42,43]One article in this review further emphasized the importance of companionship, the need for individuals to adapt to evolving roles and relationships, and the challenge of preparing for end-of-life arrangements while simultaneously coping with the future.[44]

Building on these considerations, this scoping review also identified three studies that emphasized the importance of effective information sharing in delivering high-quality end-of-life care.

Patients' preferences regarding the sharing of confidential information must be respected, while recognizing that informal caregivers and family members may need to be involved to ensure appropriate care, particularly in response to changes in the patient's condition.

In such cases, caregivers often require access to relevant information about the patient's diagnosis and disease trajectory. This may include genetic information, family and medical history, current symptoms, diagnostic test results, treatments, and follow-up care. Ensuring that this information is shared appropriately can support timely decision-making and improve the overall quality of care. Recognizing when a patient is nearing the end of their life is crucial for providing prompt, acceptable, and empathetic end-of-life care.[45] End-of-life care should be patient- and family-centered, addressing the needs and preferences of both the patient and their loved ones. A holistic approach involving teamwork at all levels ensures comprehensive care of end of life.[46] In fifty-one resources consulted emphasized that in all decisions and activities related to their care Patients should be always included where possible. [47] Beneficial partnerships for successful palliative care are also mutually promoted for the enhanced connections.[48]

Informal home caregivers may experience stress, which can have a detrimental effect on the care recipient as well as the caregiver. Stress related to providing care has been linked to patient harm in recent research, particularly when overseeing home interventions are charged by untrained informal caregivers. This emphasizes how critical it is to address caregiver distress as well as the possibility of unfavorable patient outcomes. The interventions of giving caregivers the knowledge and psychological support they need to improve their abilities and lessen their discomfort in the purposes to minimize the risk of harm to the patient. [49]

Incorporation of palliative care into national policies as legal right

Palliative care should be included into national policy as a legal right, according to ten of the articles. Four of them emphasized that whether or not someone receives palliative care depends on the jurisdiction of the context in which she or he lives based on the nation in which they reside People with terminal diseases may be eligible for certain legal rights concerning hospice care and pain management (Table 1). Given the significant unmet requirements of these patients, healthcare institutions must encourage the distribution and acknowledgement of palliative care as a fundamental human right.[50–53]

Two of the ten articles addressing patient rights referenced WHO recommendations for integrating palliative care into national healthcare systems (Table 1). These guidelines advise governments on setting priorities and implementing national initiatives for palliative care and cancer control. Key policy measures include ensuring medication availability, educating policymakers, supporting and motivating healthcare professionals, improving public service delivery, and developing palliative care programs at all societal levels.[54]

In this review, three resources highlighted the role of existing societies and groups dedicated to advocating for the rights of patients in need of palliative care, their caregivers, and disease survivors(Table 1). The presence of a national terminal illness plan and an effective execution framework are crucial and should be Established and advanced.[55,56] Two additional articles highlighted the advantages of this approach, including providing individuals with up-to-date information on palliative care and available resources, integrating palliative care into healthcare systems, and ensuring its future availability(Table 1). The approach also promotes expanding support networks for those with terminal illnesses and emphasizes the need for government systems and policies to recognize the crucial role of palliative care in supporting every community member.[57,58]

A comprehensive approach grounded in human rights and gender equality is essential. Laws, policies, and initiatives must address gender inequality to protect dignity and well-being, focusing on restricted access to resources, harmful gender norms, and power imbalances. In palliative care, addressing these inequities is crucial as they affect access to healthcare, hinder the exercise of health-related rights, and increase vulnerability.[46] In order to better understand children's needs, much work must be done to determine the scope of palliative care, when it should be provided, the precise stages of the care continuum, and the pertinent healthcare system sectors. to address the particular requirements of youth while keeping in mind the national context Models of palliative care need to be adjusted for that.[59]

Care principles should prioritize respect for each individual's dignity and integrity, honoring their right to make choices while safeguarding their privacy and confidentiality. The skills and competence of the healthcare team are essential in providing care that meets these standards, ensuring professionalism and respect for both patients and informal home caregivers.

Integrated of palliative care within the wider health care services

Thirteen articles that detailed changes to palliative care policies stressed how crucial it is to encourage avenues for palliative care services (Table 1). The changes frequently centered on strategies intended to surmount barriers to improving the quality of life for patients and their families facing life-limiting.[22] Whenever feasible In order to provide great palliative care, telemedicine concepts and technical solutions should be employed in an evidence-based strategy that adopts a person-centered approach, actively involves patients and communities, and recognizes and respects cultural diversity. The framework of a planned, coordinated, and integrated approach to enhance the delivery of high-quality palliative care should include all of these.[27]

National health budget should consider and fund these activities.[60,61] All patients with terminal illnesses, regardless of age, diagnosis, prognosis, or setting, should receive high-quality palliative care. A supportive environment should include monitoring and reporting systems to ensure efficient follow-up and evaluation, improving the overall care process and outcomes. [29,62,63]

Patients and families feel supported through ongoing care, including planned follow-up visits and a shared care plan. Home visits can be scheduled to anticipate care transitions and potential emergencies. Timely completion of paperwork helps track progress and preparedness, while follow-up communication plans should also be established.[55]Both the customer and supplier must uphold confidentiality, with patient data shared only with explicit consent. Privacy must be maintained throughout the entire care process, using secure archiving and storage solutions for client records. All parties involved, including unpaid home caregivers with access to medical information, must adhere to confidentiality regulations.[64]

The care plan should address complex grieving to support family caregivers. Ideally, discussions about bereavement should occur before death, providing information on grieving, expectations, and resource referrals. Palliative care should continue offering bereavement support to the family and informal caregivers, with timely additional support provided after the patient's death if needed.[65-67] Adequate resourcing is essential for palliative care services to meet the needs of patients and family caregivers. Personnel, financing, and available resources directly impact service delivery. Increasing these inputs should result in expanded access to care and improved services. A key responsibility of any health system is to ensure services are accessible, available, and meet basic quality standards.[68]

Families often face a significant financial burden when caring for loved ones, potentially losing income and covering medical expenses. Policies and initiatives should prioritize social justice, ethics, and equity. Given limited resources, services must consider the diverse needs of individuals in various circumstances.[7,30]

Home care services and the accepted cultural concept of caregivers

Nine articles highlighted the importance of home-based care in national policies and guidelines (Table 1). Patients receiving home-based palliative care stay in their homes, cared for by their families. The palliative care team visits to provide medical attention, nursing guidance, and psychological support. This care is most effective when delivered by a multidisciplinary team with palliative care training.[69]

Advanced illness impacts many aspects of life, including relationships with family and caregivers. Informal home caregivers often bear the heaviest burden, frequently unprepared for the challenges they face. Whether living with the patient or far away, caregivers struggle with work-life balance, income loss, reduced benefits, and additional expenses like travel and medications. Three articles noted that the physical demands of caregiving can lead to strain and injury. Cultural perceptions of caregiving vary, but globally, palliative care aims to offer timely, coordinated, and culturally sensitive access to a wide range of services.[70]

In home-based settings, quality palliative care must be maintained and improved by using data to guide improvement initiatives and implementing evidence-based treatments at the point of care. Health information and services should be readily available, accessible when needed, and meet the highest standards of acceptability and quality.[71]

Approaching the brink of their lives At-home patients ought to have the same standard of care as everyone else. Especially when faced with difficult choices and circumstances involving their care, they ought to receive considerate and respectful treatment. respect of their privilege is necessary of secrecy and their privacy preferences.[43] A caring and compassionate society is reflected in the provision of home-based care for terminally ill individuals. Many caregivers, though, are unprepared to face death and loss, despite their inevitability. To improve care standards, healthcare systems should prioritize stronger connections between patient progress and their situation, ideally when communities are ready to embrace these services, ensuring continuity of care. [30,72–74]

This helps to strengthen the field by promoting the adoption of a shared language among all members of the interdisciplinary team, which in turn enables the creation of personalized care plans tailored to each individual's needs.[75] Caring for a loved one can be a deeply fulfilling experience for caregivers. Knowing they are providing high-quality care brings them joy. Being involved in decision-making and discussions reinforces their values, while learning new skills boosts their sense of competence. Ultimately, caregivers find satisfaction in genuinely supporting the person under their care.[76]

Reporting, monitoring and evaluation systems for palliative care services for sustainability

The effectiveness of palliative care is influenced by implementation strategies, monitoring, and assessment.[66,67] The significance of reporting, monitoring, and evaluating the palliative care system was discussed in 23 papers(Table 1). The undervaluation of informal home caregivers by medical professionals in home-based palliative care services highlights a serious healthcare need. Because of the rigorous nature of their jobs, informal caregivers are sometimes viewed as "hidden patients," dealing with significant mental and physical health issues that can be emotionally and physically draining.[49]

Case reports are important tools for evaluating and understanding differences in healthcare practices, In the reviewed articles offered case reports which enable the comparison and evaluation of healthcare education ,delivery and reporting across diverse cultures.[77] The sustained enthusiasm, dedication, and contributions of time, energy, and resources from patterners have been crucial in advancing the development of palliative care. The success of reporting and evaluation has been greatly emphasized on during this review by more done ten resources among the reviewed.[78]

In addition to the implementation of a transparent reporting mechanism Technology, supplies, patient care devices, and essential equipment should all be taken into account when evaluating the success of a program.[72] Identifying possible treatments, reporting the cases of pain and anxiety medication, and providing advice on when to seek more medical aid are all part of managing physical signs and symptoms. These components are necessary for high quality palliative care.[79]

Table 1. Existing guidelines regarding palliative care (N=58)

Author and Year	Country	Nature	Scope	Description
WHO,2017	Switzerland	Guideline	Palliative care	Palliative care improves quality of life of patients and families facing life-threatening illness, through prevention and relief of suffering via early identification and assessment of pain and other problems, and treatment of physical, psychosocial, and spiritual issues.
Nucci et al., 2014	United States	Original research	Core precepts and structures of clinical palliative care programs	Definition of Palliative Care, Core Elements of Palliative Care, Models of Palliative Care Delivery, Clinical Practice Guidelines for Quality Palliative Care, Endorsing Organizations.
Rhee et al., 2017	Africa	Global report	Development of palliative care in African countries	Home-based Palliative Care Services in Hospices, Patients Cared for by Palliative Care Services, Hospitals with Inpatient Palliative Care Units, Palliative Care Plans or Programs, Policy Indicators, Palliative Care Education, Medicines, Professional Activity, Palliative Care Research.
Wessex Palliative Physicians, 2019	United Kingdom	Clinical guideline	Clinical management in palliative care	Golden Rules for palliative treatment, End-of-life care.
Osman et al., 2018	United States	Clinical guideline	Implementing palliative care for cancer patients and caregivers	Palliative Care Models, Timing, Workforce Knowledge and Skills, Nurse Role in Pain Management, Spiritual Care, Social Work/ Counselling.
Chang et al., 2023	India	Clinical guideline	End-of-life care and decision-making	Individualized Approach to Dignified End-Of-Life Care, Symptom-Free End-Of-Life Care, Palliative Sedation Decision-Making Algorithm, End-of-Life Nursing Care Approach.

Table 1. Continued

Author and Year	Country	Nature	Scope	Description
WA Cancer and Palliative Care Network, 2010	Australia	Government guideline	Experiences in providing palliative care	Evidence-based clinical guideline for adults in the terminal phase.
Ministry of Health & Family Welfare, 2012	India	Government policy	Improve palliative care service delivery	Implementation of Palliative Care, Availability and accessibility of pain relief and palliative care, Education and community behavior change, Develop national standards.
Murray, 2008	United Kingdom	Review article	Palliative Care for All	Access to Specialist Palliative Care, Role of Non-Specialist Palliative Care, Eligibility, Referral and Discharge Criteria.
Australian governments, 2018	Australia	National strategy	Holistic care	Accessing effective palliative care, Helping people nearing end of life live as well as possible.
Ministry of Health Rwanda, 2011	Rwanda	National policy	Access to quality palliative care by 2020	Situation Analysis, Policy rationale, Mission, Vision, Objectives, Values, Strategic Orientation, Care Characteristics, Priority Interventions, Access to Controlled Narcotics, Implementation, Financial Issues, Monitoring & Evaluation.
Kirk & Mahon, 2010	United States	Review article	Palliative Sedation	Pain symptom management for imminently dying terminally ill patients.
Dans et al., 2017	United States	Clinical guideline	Integration of palliative care into oncology care	Symptom management.
Richmond, 2018	United States	Policy report	Quality Palliative Care	Interdisciplinary Team, Comprehensive Assessment, Care Plan, Continuity, Care Settings, Team Education, Coordination, Emotional Support, Continuous Quality Improvement, Physical, Psychological, Social, Spiritual, Cultural, Ethical, Legal aspects.
Javanparast et al., 2022	Australia	Mixed-methods research	Patient and family care model	Nationally accepted principles and norms of practice.
Abramowicz et al., 2013	Australia	Guideline	Multidisciplinary care planning process	Community palliative care services, Client support, Best practice care planning.
Western et al., 2016	United Kingdom	Clinical audit	Advance Care Planning	End-of-life care planning.
Fischer et al., 2006	United States	Observational study	Who may benefit from palliative care	Timelier symptom management, advance care planning, spiritual support, prognostic criteria for end-of-life.
Friedberg et al., 2009	United States	Review article	Revitalize primary care practices	Medical home improvements: healthcare quality, patient experience, provider satisfaction, costs, recruitment of medical students.

Table 1. Continued

Author and Year	Country	Nature	Scope	Description
Health Care for the Homeless Clinicians' Network, 2018	United States	Practice guideline	End-of-life care for people experiencing homelessness	Recommendations for palliative care provision.
Institute for Health Information & canadien dinformation sur la santé, 2023	Canada	National report	Patient- and family-centered palliative care	Honor beliefs and preferences, comprehensive information on options, Access to Palliative Care.
Hennings & Froggatt, 2019	United Kingdom	Qualitative study	Family caregivers in nursing homes	Changing relationships, need for companionship, adjusting to new roles, anticipating death.
Gagnier et al., 2013	Germany	CARE guideline	Resources for preferred death setting	Implementation of CARE guideline, family support.
Connor & Sepulveda Bermedo, 2014	United Kingdom	Global report	Hospice and palliative care development worldwide	Global Atlas of Palliative Care at the End of Life.
Dans et al., 2017	Ireland	guideline	Cancer patient needs	Evidence-based, safe, high-quality, patient-centered care, supported by national standards.
John Sellors, M.D. et al., 2004	Kenya	Program evaluation	Caring for women with terminal cervical cancer	Palliative care, Managing Physical, Social, Emotional, and Spiritual issues.
Reinhard et al., 2008	United States	Policy report	Supporting family caregivers	Improve caregiver outcomes, nurse support in health care process.
Kelley & Meier, 2010	United States	Review article	Comprehensive palliative care services	Focus on patient-centered care.
Connor et al., 2017	United States	Global report	Hospice and palliative care development	Medicare Hospice Benefit, growth, regulatory challenges, workforce, access, quality improvement.
Beasley et al., 2019	United States	Policy report	Non-hospice palliative care models	Supportive care, multidisciplinary team, patient and caregiver focus, holistic approach.
Callaway et al., 2018	United Kingdom	Global report	Palliative care toolkits development	Human rights, main diseases, need, barriers, availability, global models, resources.
United et al., 2020	Tanzania	Government report	Cancer Treatment Guidelines	National cancer treatment protocols.
Ministry of Health Malaysia,2019	Malaysia	National guideline	Nationwide palliative care program	Background, need, challenges, integration with healthcare, national policies, Hospital/ Community/Paediatric care, Education, Essential medications, Research, Sustainable funding.
Queensland, 2022	Australian	State guideline	Patient-centered measures	Selecting meaningful measures, inform policy/funding, evidence for improved end-of-life outcomes.

Table 1. Continued

Author and Year	Country	Nature	Scope	Description
Brown et al., 2024	Canada	Clinical guideline	Care of dying individuals	Assessment and management at the end of life, education, organization, policy.
Rosa et al., 2018	Rwanda	Observational study	Palliative care advancement	Experiences in practice, education, research, culturally relevant palliative care literacy.
Commission & Care, 2021	Australian	Policy report	Safe and high-quality end-of-life care	Clinical governance, consumer partnership, infection control, medication safety, comprehensive care, communication, blood management, acute deterioration response.
Family Practice Oncology Network, 2017	Canada	Clinical guideline	End-of-life symptom and family support	Relief of pain and distressing symptoms, psychological and spiritual integration, team approach, bereavement counselling.
Mental Health Commission of Canada, 2013	Canada	National strategy	Palliative care workforce foundation	Guidelines to support family caregivers of adults with mental health problems.
Jane Bates et al., 2021	Malawi	Observational study	Access to quality health care	Palliative care after advanced cancer diagnosis reduces household poverty.
Rhee et al., 2017	Africa	Global report	Palliative care advocacy	Growth in national palliative care associations, dedicated personnel.
Wenk & Bertolino, 2007	Not Specific	Review article	Resource-poor regions	Collaborative networks for development and sustainability of hospice and palliative care.
Casarett et al., 2001	United States	Observational study	Grief management	Clinician skills for supporting grief before, during, and after a loved one's death.
EU, 2021	European Union	Policy framework	Chronic and disabling conditions	End-of-life care, human rights, cognitive capacity, decision-making, uncertainty of treatment, emotional support, resource constraints, resolving disagreements.
A.Carers, 2014	Australia	National report	Role of unpaid carers	Prevent and relieve suffering, early identification and treatment of pain and other problems.
Gruber et al., 2002	Brazil	Observational study	Definitions in oncology literature	Clarifying palliative care, end-of-life, terminally ill terminology.
Hudson et al., 2004	Australia	Review article	Family-directed palliative care interventions	Identify barriers for health professionals in supportive family care.
Davaasuren et al., 2007	Mongolia	Observational study	Improve policy, education, drug legislation	Palliative care system strengthening.
Radbruch et al., 2018	Germany	International guideline	European palliative care collaboration	Bring together stakeholders from Europe and beyond.
Bloomer et al., 2019	Australia	Qualitative study	End-of-life care mapping	Essential Elements operationalized in mainstream care systems to ensure safe, high-quality care.

Discussion

Effective end-of-life care requires an integrated approach that combines strong policies, quality clinical and psychosocial support, and assistance for caregivers. However, gaps in access and quality remain, making support for informal caregivers and bereavement care essential for truly patient-centered palliative care.[80–84]

Palliative care focuses on dignity, comfort, and holistic support during the end-of-life period, which may extend up to long time before death. Both formal and informal caregivers are central to care delivery, with informal caregivers providing most day-to-day support despite significant physical, emotional, and financial burdens. [4,13,15,16,85,86,87] Effective palliative care requires integrated systems, supportive policies, access to essential medications, culturally appropriate services, bereavement support, and strengthened caregiver support systems.[5,7,8,11,14,18,88-90] Informal caregivers are essential in supporting people with life-limiting illnesses, yet they remain under-recognized and insufficiently included in care planning. Their responsibilities can significantly affect their physical, emotional, and social well-being, especially where formal support is limited. Cultural diversity further complicates care delivery, highlighting the need for culturally sensitive approaches. Overall, strengthening recognition, inclusion, and support for caregivers is crucial to improving both patient outcomes and caregiver well-being. [91-95]

Palliative care also offers broader health system and economic benefits, including reduced healthcare costs through fewer intensive interventions.[96,97,99,100] These studies show that improving healthcare access in rural and low-resource settings depends on addressing cultural and socioeconomic barriers, strengthening primary care, and supporting informal caregivers.

Effective care transitions from hospital to community require coordinated, interprofessional teams to ensure continuity, equity, and high-quality care for patients. [41,58,60,79,88-101] Home-based palliative care, increasingly emphasized in super-aged societies and low-resource settings, offers benefits such as patient-centered care, better alignment with patient and family preferences, and opportunities for earlier integration of supportive interventions, although challenges remain including caregiver burden, limited training, and gaps in policy support.[1,3,6,12,19,102,103]

Strengths and limitations

Limitations

This review has several limitations. Restricting the search to studies published between 2004 and 2025 may have excluded earlier foundational work, and limiting the review to English-language publications may have omitted valuable non-English evidence. Excluding grey literature may introduce bias, while the underreporting of negative or inconclusive findings could contribute to selection bias. Variations in the definition of palliative care across studies complicate comparison, and evidence from high-resource settings may not fully apply to low-resource contexts. Finally, limited access to government guidelines and subscription-based databases in some countries may have restricted the inclusion of relevant research.

Strengths

Despite these limitations, the review has several strengths. Its broad search strategy across multiple databases ensured comprehensive coverage of available evidence. Identifying eight palliative care models provides a clear and diverse overview of approaches across different illness stages. Inclusion of studies from both high- and low-resource settings increases global relevance. The focus on integrated care and the needs of patients, families, and caregivers supports a holistic, people-centered perspective. In addition, the structured scoping review methodology enhances transparency and facilitates systematic synthesis.

Conclusion

This scoping review examined evidence on informal home-based caregiver support in palliative care in Rwanda. Only policies were found, which lacked guidance on comprehensive care and the role of informal caregivers. Key issues identified include palliative care philosophy, care models, and clearly defined team roles and responsibilities. The review highlights the need to integrate palliative care into broader healthcare systems, recognize it as a legal right, and ensure culturally appropriate home care services. An integrated approach should address practical caregiving tasks, caregiver support, and bereavement, while ensuring early detection and attention to patients' and caregivers' physical, psychological, and spiritual needs. Harmonized care models and clear communication during transitions from hospital to home are essential for effective, multidisciplinary care. WHO emphasizes access to medications, socioeconomic support, and culturally sensitive care, particularly in rural areas. Monitoring, reporting, and evaluation systems are necessary to sustain high-quality services. Overall, the review underscores the critical role of informal caregivers and the need for policies and programs that formally support and integrate them into home-based palliative care

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TJC: Proposed the study title; identified the research question; contributed to identifying and selecting relevant studies; participated in data charting and in collating, summarizing, and reporting the results; drafted the initial manuscript; and took part in critical revisions.MM: Reviewed the proposed title and research question; contributed to identifying and selecting relevant studies; assisted with data charting and synthesis; and reviewed the initial manuscript.
MF: Reviewed the proposed title and research question; contributed to identifying and selecting relevant studies; assisted with data charting and synthesis; and reviewed the initial manuscript.KG: Provided critical review of the manuscript for intellectual content, guided the interpretation of findings, and approved the final version for submission.

Competing interests
The authors declare no competing interests.

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