

Exploring the benefits and barriers of community palliative care in low- and middle-income countries: A Scoping Review

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Abstract

Implementation of community-based palliative care tends to vary across low- and middle-income countries (LMICs). The increasing trend of diseases requiring palliative care, if not properly managed, can reduce patients' quality of life and increase healthcare costs burden. This scoping review aims to identify community-based palliative care programs, benefits, and barriers in LMICs. The article search was conducted using four databases namely PubMed, Web of Science, Sage Journals, and ScienceDirect. We used Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Scoping Review (PRISMA-ScR). The research question based on Population: palliative patient and providers in community setting; Concept: program, benefits, and barriers; Context: implementation of community palliative care in LMICs. The Joanna Briggs Institute (JBI) Critical Appraisal Checklist was used to assess the quality of the articles. Eleven articles were identified in this study, reporting that most palliative care programs implemented in communities in LMICs do not involve local health workers, and thus still play a dominant role. Benefits identified include ease access to services, improving patients' and family quality of life, also enabling family and community support. Barriers include inadequate training for health workers: lack of knowledge, funding, infrastructure, and medication; and low public awareness. Palliative care improves quality of life and supports patients and families. Cross-sector support is needed to strengthen and expand services sustainably.

Keywords: Community health; End-of-life care; Home-based care; Low- and middle-income countries; Palliative care

1. Introduction

Palliative care is holistic care that aims to improve patients' quality of life by addressing physical, spiritual, and psychosocial barriers, especially for those who are currently experiencing life-threatening conditions [1–3]. Currently, most palliative care services are still delivered clinic-based, although community-based models have developed as an approach that integrates with local care systems [4]. The community palliative model is done by integrating care into primary care or home care, with the hope that it can be accessed more easily by the community [5,6]. Research has shown that providing community and home level care can improve health outcomes, reduce disparities, and support local economic activity [7].

While there has been much research on palliative care in high-income countries, progress in low-income countries has been slower [8]. High rates of heart and vascular disease, chronic respiratory disease, and cancer are major factors in the growing need for palliative care worldwide [9]. According to data released by the World Health Organization, 56.8 million people per year require palliative care, most of whom live in low- and middle-income countries (LMICs) [10]. Bridging the resource gap in the palliative care system in LMICs is a goal in the community-based care model. This care

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involves the community to provide ease of access, cultural sensitivity, and affordability for patients and families [11,12]. A supportive environment for the implementation of palliative care can increase experience, support, and open opportunities for cross-sector collaboration [13]. However, community-based palliative care still faces a number of barriers that need to be addressed and become challenges in its implementation.

To address these barrier, various initiatives have been undertaken to create community-based palliative services initiated by non-governmental organizations, local health workers, and in collaboration with international organizations [14–16]. Strengthening palliative care that is equitable, comprehensive, and supported by clear policies should be a top priority in LMICs to reduce the burden of chronic disease [17]. Palliative care planning by empowering patients and families will improve quality of life [18]. Therefore, this article aims to provide evidence on the implementation of palliative care programs in LMICs, focusing on the programs, their benefits, and the barrier they face. In the future, this review can serve as a basis for developing community-based palliative care models that are both appropriate to the characteristics of LMICs and sustainable.

2. Methods

2.1. Research Design

The design of this study is a scoping review where a literature search was conducted based on the research question “What are the benefits and barriers to the implementation of community-based palliative care services in low- and middle-income countries?”

2.2. Search Strategies

This study used secondary data sources from various scientific databases, including PubMed, Web of Science, Sage Journals, and ScienceDirect. A literature search was conducted using keywords such as Barrier, Implementation, Palliative Care, End-of-Life Care, Services, Programs, Community, and mentioning specific countries on the LMICs classification list based on data from the World Bank in fiscal year 2025 (e.g. India, Bangladesh, Tanzania, Zimbabwe). The development of these keywords was guided by relevant Medical Subject Headings to ensure accuracy and consistency in the search strategy. Inclusion criteria were set as follows: original articles, articles published in the last five years (2020—2024), written in English, open access, available in full text, and articles that address palliative care services in the community. Exclusion criteria included review articles, articles that addressed hospital-based palliative care services, articles that did not cover the implementation of palliative programs, and studies conducted in high-income countries. In addition to exclusion criteria, instrument development articles, review articles, protocol studies, and abstracts only were also excluded.

2.3. Article Selection

Selected articles have been screened based on predefined criteria and the PCC framework (Population: palliative patients and providers in community setting; Concept: programs, benefits, and barriers; Context: implementation of community palliative care in LMICs following the PRISMA-ScR (2020) guidelines [19]. To ensure a systematic and efficient selection of studies relevant to the research question, the researchers employed Rayyan as a tool for screening and managing the article selection process. Furthermore, the researchers held discussions to further analyze to avoid conflicts, ambiguities, and ensure the accuracy of the article search results.

2.4. Data Synthesis

The selected articles were extracted using the Guide for Conducting Systematic Scoping Reviews [20]. Data extracted included author name, year, study aim, country of study, population, program, and resources of the palliative program. This synthesis approach was undertaken to ensure consistency of data generated and analyzed subsequently.

3. Results

3.1. Search Results

A total of 7,546 articles were found, with PubMed (n = 1,999), Web of Science (n = 1,812), Sage Journals (n = 1,183), ScienceDirect (n = 2,552). Screening began by removing duplicate articles (n = 1,461), inappropriate articles (n = 98) and excluding articles for other reasons (n = 101), leaving 5,886 articles. Screening continued by removing articles that did not discuss palliative care (n = 2,327) and research was not conducted in countries in the LMICs setting (n = 2,964), which then left 595 articles. The articles were then screened again based on eligibility criteria such as research

conducted in the hospital setting ($n = 328$), limited access to full articles ($n = 105$), articles that discuss instrument development ($n = 11$), review articles ($n = 83$), protocol study articles ($n = 13$), and abstracts only ($n = 44$), which then left 11 articles that were suitable for review in this scoping review. The article search process is described systematically in the following scheme (Figure 1).

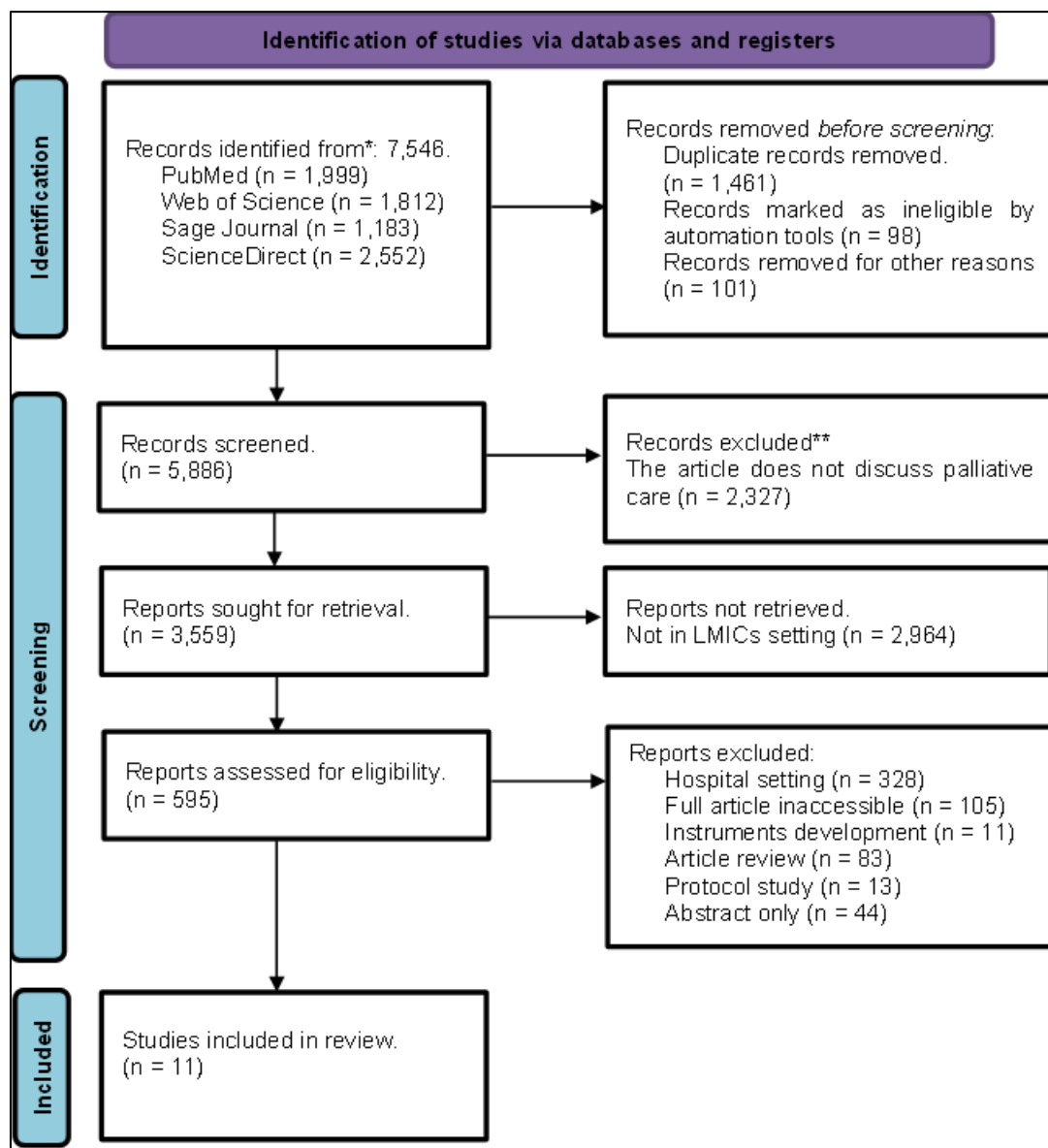


Figure 1 PRISMA-ScR (2020) diagram in the literature search process and article screening process

3.2. Study Characteristic

This study used 11 articles, consisting of three quantitative and eight qualitative articles. All articles were from LMICs, namely Nigeria, Bangladesh, Ethiopia, India, Liberia, Zimbabwe, and Tanzania. The majority of participants were palliative patients, health workers, and community resources. The synthesis results showed programs, benefits, and barriers in community-based palliative care in LMICs. The main highlight found was that community palliative care has not been prioritized in health policy, so its implementation is still limited (Table 1).

Table 1 Summary of articles (n = 11)

Author and Year	Aim	Country	Population	Programs	Resources
Afolabi et al., 2022	Identify expectations of palliative patients, families, and palliative care providers' readiness to deliver primary care.	Nigeria	n total = 48. People living with serious illness (n = 21) with 6 male and 15 female Family caregivers (n = 15) with 7 male and 8 female Healthcare providers (n = 12) with 3 male and 9 female	Integrated Primary Palliative Care	Medical doctors Nurse Community health officers
Akter et al., 2022	Explore the experiences of palliative patients and their carers enrolled in a palliative care project.	Bangladesh	n total = 19 Ten patients Nine caregivers	Community-based palliative care program	Community Palliative Care Assistants (PCAs)
Aregay et al., 2023	Explore the implementation and challenges of palliative care in rural and regional settings of Ethiopia.	Ethiopia	n total = 58 Policy makers (n = 2) Pharmacist (n = 7) Doctors (n = 5) Health officers (n = 4) Nurses (n = 17) Academic leaders at university (n = 3) Regional college (n = 1) Health Extension Workers (HEWs) (n = 3) Farmers (women and men), community and religious leaders (n = 16).	Palliative care in Ethiopia's rural and regional health care settings	HEWs Non-Government Organization (NGO)
Chowdury et al., 2023	Observe the impact of palliative care on health-related quality of life and symptom management in cancer patients.	Bangladesh	Compassionate Narayanganj community palliative care group: n = 39 cancer patients (male n = 10 (25,6%); female n = 29 (74,4%)) Oncology group n = 31 (male n = 22 (71%); female n = 9 (29%))	Compassionate Narayanganj community palliative care group	PCAs Nurse Physicians Physiotherapist
Chowdury et al., 2021	Increase understanding of the benefits of palliative care interventions for children and families in improving quality of life.	Bangladesh	n total = 25 respondents	Compassionate Korail Children's Palliative Care Project	PCAs Palliative care nurse and pediatric physician A physiotherapist

					and speech pathologist
Ghosal et al., 2022	Describe the quality of palliative care services in India based on national standardized measurement tools.	India	n total = 223 palliative care providers	N/A	Palliative care specialist Nurse Social worker
Lusaka et al., 2023	Inform future palliative needs and programs required locally, regionally and nationally.	Liberia	n total = 8 cancer patients Male n = 2 (25%) Female n = 6 (75%)	Process evaluation of community-based palliative care programs	Nurse Physician Assistant
Musonda et al., 2021	Explore the challenges faced by Home-Based Palliative Caregivers.	Zambia	n total = 25 participants	Home-Based Palliative Care	Community volunteers
Prajitha et al., 2023	Understanding the social mechanisms that underpin the implementation of Community-Based Palliative Care (CBPC) in rural India and the challenges to its sustainability.	India	n total = 45 participants Male n = 19 (42%) Female n = 26 (58%)	CBPC through the Sanjevan program	Palliative care specialist Nurse Other trained health workers Social workers and psychologists
Sirili et al., 2024	Document the unique and religious opportunities and challenges of strengthening palliative care services in primary healthcare settings.	Tanzania	n total = 15 participants Male n = 5 (33.3%) Female n = 10 (66.7%)	Home-based and health promotion program	N/A
Tapera et al., 2021	Investigate strategies to overcome barriers to accessing treatment and care for women with cervical cancer.	Zimbabwe	n total = 84 participants Male n = 21 (25%) Female n = 63 (75%)	Free palliative care	Caregiver Health workers

Table 2 Findings on the benefits and barriers to the implementation of palliative care at the community level in LMICs.

Author and Year	Benefits	Barriers
Afolabi et al., 2022	Improved access to palliative care Increased trust in primary care Psychosocial support for families and patients	Lack of knowledge Lack of resources Less of autonomy Lack of infrastructure
Akter et al., 2022	Feeling satisfied with the service provided Physical, mental, and spiritual support	Gaps Service availability Patients' financial problem
Aregay et al., 2023	Maintenance assistance Ease of consultation	Lack of public awareness and policy-related education to the community Lack of funding

		Less holistic service
Chowdury et al., 2023	Improves the patient's overall quality of life. Reduces symptoms of pain and discomfort. Reduce financial burden	Difficult access to service Lack of systematic monitoring system
Chowdury et al., 2021	Palliative care needs identified.	Culture and language
Ghosal et al., 2022	Improving the quality of palliative care Mental health conditions in children Socio-economic improvement Psychosocial support to caregivers	N/A
Lusaka et al., 2023	Reduced waiting time Coordination Providing social and spiritual support	Distance Lack of medications Access to communication Trust in traditional medicine
Musonda et al., 2021	Patients and family support Access to palliative care services Reduction in the cost of care	Lack of resources Poor coordination Lack of training Working conditions Transport
Prajitha et al., 2023	Improve the quality of life of palliative patients. Easier access to care Increase the role of the family in the care process	N/A
Sirili et al., 2024	Government support Good referral system	Lack of knowledge Limited medicines
Tapera et al., 2021	Improved access to cancer care Transport support Community education Health facility expansion	N/A

Some of the articles we reviewed mentioned the involvement of resources in community palliative programs such as doctors, nurses, families, community volunteers, social workers, and psychotherapy (Table 1). In addition, the implementation of palliative programs in the community provides benefits such as improved access to care [21–24], ease of coordination [24,25], reduced financial burden on patients and health services [24,26], social support [21,25,27,28], and increased patient satisfaction [26,28]. Barriers include a lack of trained resources [21,24], communication and language barriers [29], low community awareness and knowledge [30,31], and a lack of policies governing the implementation of palliative care in the community [30,31]. These findings indicate that palliative care programs in LMICs are needed as a fundamental service, but its implementation is still not optimal so that the benefits cannot be felt thoroughly, especially in the communities (Table 2).

4. Discussion

The National Consensus Project for Quality Palliative Care defines palliative care as a multidisciplinary care delivery that aims to anticipate, prevent, and manage severe disease in order to improve the quality of life of patients, their families, and caregivers [32]. Therefore, palliative care requires a comprehensive multidisciplinary approach to the physical, psychological, social, spiritual, and cultural needs of patients and their families, and provide effective responses to improve healthcare quality and encourage better resource utilization [33]. An interprofessional palliative

care team includes health professionals including doctors, nurses, caregivers, social workers, clergy, therapists, and volunteers. All team members work together to provide care to patients and their families based on needs identified through initial and ongoing assessments [34].

The implementation of community-based palliative care in LMICs showed variations in program structure and approach facilitated by health care assistants and community volunteers. Home-based palliative care supported by health care assistants has been shown to have several benefits such as providing direct care, providing monitoring and communication with the healthcare team; providing social and emotional support; improving cost-effectiveness, supporting symptom management of palliative patients and providing end-of-life support [35,36]. In addition to relying on assistants, the contribution of community volunteers is also important in providing psychosocial support, assisting patients' practical needs, and bridging patients with health workers [37]. Furthermore, health workers and community health volunteers can increase awareness and identification of patients who need palliative care, manage pain, and provide home-based practice including psychological and spiritual support [15].

To maximize the delivery of community-based palliative care services in LMICs, integrating palliative care programs with primary care facilities is important. This is useful to address inequalities that are often a major problem in palliative care [38]. However, low knowledge of palliative care delivery among health professionals makes it difficult to implement in the community, so specialized training and education is needed for the implementation of community palliative care in LMICs [39]. Adequate palliative care education is important as it is an indicator of improved access to palliative care in primary health care [40]. The need for palliative care education is important in order to improve the availability and quality of palliative care services. A common knowledge approach helps to implement palliative care in the community and can increase knowledge of palliative care for all health professionals and the public [41].

With the variety of services offered, community-based palliative care requires a variety of resources that support the improvement of quality of life and patient satisfaction through a variety of comprehensive programs, training of personnel involved, and careful planning of interventions [42]. Currently developed innovations such as telehealth are an option in reaching a wider community by creating interpersonal relationships with health care professionals by involving palliative patients [43]. However, in the implementation of palliative care in the community, health workers involved such as nurses complain of limited access to training and feel that the incentives provided are not in accordance with the workload performed [44]. Therefore, policies, guidelines, financial support, identification of local change management, and community strengthening are needed so that palliative care can be targeted and quality [45].

4.1. Strength and Limitation

The strength of this scoping review lies in its focus on palliative care services in LMICs, a topic that remains under-explored and has not been a major focus of health programs. Additionally, the review highlights the wide range of community-based palliative care programs implemented, which have contributed to improving the quality of care at the community level. It offers valuable insights from both the patient perspective and the perspective of service providers. However, a key limitation is that many of the included articles did not focus exclusively on patient experiences, limiting the depth of analysis on patient-centered outcomes.

Recommendations

The implementation of community-based palliative care services varies across LMICs. Based on this review, we recommend the development of culturally appropriate guidelines specific to the local context. This will not only optimize the use of local resources but also encourage the expansion of sustainable services and strengthen community involvement. These guidelines should be developed based on long-term outcome evaluations and effective implementation strategies tailored to local needs.

5. Conclusion

Community-based palliative care in LMICs offers significant benefits, including improved access to healthcare services, improved quality of life, symptom relief, psychosocial and spiritual support, reduced financial burden, and increased trust in local healthcare services. However, its implementation faces barriers such as resource constraints, lack of trained healthcare personnel, inadequate infrastructure, and cultural barriers. Future research should explore effective strategies to expand services, assess long-term outcomes, and develop culturally appropriate interventions to enhance community engagement.

Compliance with ethical standards

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Disclosure of conflict of interest

No conflict of interest to be disclosed.

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