Review Article

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Mapping the Landscape of Palliative Care in Indonesia: A Scoping Review of Availability, Accessibility, and Quality

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Abstract:

Indonesia has made notable strides in palliative care services over recent decades, yet substantial challenges persist, particularly in rural and under-resourced regions. This scoping review assesses the current landscape of palliative care in Indonesia, focusing on service availability, accessibility, and quality, including the effects of the coronavirus disease 2019 (COVID-19) pandemic. Following the Joanna Briggs Institute's methodology and the PCC (Population, Concept, Context) framework, relevant studies published between 2016 and 2024 were sourced from databases such as ScienceDirect and PubMed. Findings indicate that although some progress has been achieved, palliative care services remain limited and unevenly distributed, with stark urban–rural disparities and a heavy reliance on out-of-pocket payments or charitable support. Integration into the national healthcare system remains minimal, hindered by inadequate infrastructure, insufficient policy implementation, and a shortage of trained providers. In the absence of formal support, the burden of care largely falls on family members, who face significant financial and emotional strain. These findings underscore an urgent need for strengthened policy frameworks, dedicated funding mechanisms, and culturally appropriate care models to improve access and equity. Future efforts should prioritize embedding palliative care into Indonesia's core health services while addressing the diverse needs of patients and families across the country.

Keywords: Indonesia, palliative care, prevention, scoping review, terminal care

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Introduction

In the last decade, Indonesia has begun to recognize the broader scope of palliative care, moving beyond just end-of-life support[1-4]. This review examines the integration of palliative care with curative treatments[2,5-7], its applicability to various patient groups[8,9], and the cultural factors influencing its development[4].

It also addresses significant challenges, such as regulatory issues, limited access to opioids, and uneven healthcare resource distribution[1,10,11]. Opioid availability is likely to remain heavily restricted due to strict regulatory controls and prescriber hesitancy, often stemming from concerns about misuse, addiction, and legal repercussions[1,12,13]. These constraints severely limit pain management options, especially for patients in advanced stages of illness[1,14,15]. Additionally, bureaucratic complexities and limited prescribing rights further hinder consistent access across healthcare settings[1,12,13]. Despite these barriers, there are positive developments, including dedicated healthcare workers and grassroots initiatives working to improve access[1,6,9].

This review seeks to illuminate the evolution of palliative care in Indonesia, providing insights for policymakers and healthcare advocates. It emphasizes the need for integration into the universal healthcare system, aiming for a future where all Indonesians receive compassionate support during serious illness.

Material and Methods

To conduct the proposed scoping review, we will use the methodological framework recommended by the Joanna Briggs Institute (JBI) Manual[14], which outlines 5 stages for scoping reviews. Additionally, for the final study report, we will adhere to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses checklist for scoping reviews (Appendix)[15].

Framework

The "Population, Concept, and Context" (PCC) framework was selected as the guiding framework for this scoping review. The research question in this article is, "What is the current state of palliative care services in Indonesia in terms of their availability, accessibility, and quality?" The application of the PCC framework in formulating the research question is illustrated in Table 1 below.

Table 1 Population, Concept, and Context (PCC) framework[15]

Population (P)	Concept (C)	Context (C)
Indonesia	Availability: Presence and extent of palliative care services across Indonesia. Accessibility: Ease of access to palliative care services for patients and their families. Taking into consideration factors like geographical location, cost, cultural barriers, etc. Quality: Current standards and effectiveness of the palliative care services provided in Indonesia. Considering factors such as patient and caregiver satisfaction, adherence to international palliative care guidelines, and quality-of-life outcomes.	The situation of palliative care in Indonesia, with potential sub-contexts including various healthcare settings (hospitals, community care, home care), policy frameworks, cultural aspects, and healthcare system characteristics that influence palliative care services.

Inclusion and exclusion criteria

This scoping review provides an in-depth overview of palliative care services in Indonesia, focusing on their availability, accessibility, and quality. Using a comprehensive and systematic approach, relevant literature was searched, including peer-reviewed research articles, reviews, and gray literature. Inclusion criteria ensured relevance, focusing on studies within the Indonesian healthcare context and written in English. Exclusion criteria maintained focus by omitting studies from other countries, articles not addressing core concepts, non-English articles, opinion pieces, and those lacking empirical data or sufficient relevance (Table 2).

Search strategy

Relevant literature was reviewed following searches of databases including ScienceDirect, PubMed, CINAHL, AMED, and AgeLine, using the following keywords: "Palliative care", "Palliative services", "Indonesia", and terms related to "availability", "accessibility", "quality", "policy", "implementation", "barriers", and "challenges". The search spanned from 1993 to 2024, with the most recent search conducted on April 19, 2024, and included filters such as full-text access and free full-text availability where applicable. Grey literature was also reviewed from relevant sources to ensure a comprehensive overview of palliative care services in Indonesia. This included official reports, national policy documents, Ministry of Health publications, academic theses, non-governmental organization (NGO) reports, and conference proceedings sourced from institutional websites such as the Indonesian Ministry of Health, World Health Organization (WHO), the Asia Pacific Hospice Palliative Care Network (APHN), and relevant university repositories.

s-PRISMA flowchart

The PRISMA flowchart illustrates the rigorous study selection process for the scoping review on palliative care services in Indonesia (Figure 1). Starting with 358 records from various databases, the team screened 341 after removing duplicates. They excluded 311 records that didn’t meet the criteria, focusing solely on English-language articles from Indonesia. After a thorough analysis, 15 studies were selected, offering valuable insights into the availability, accessibility, and quality of palliative care in the country. This careful curation ensures a comprehensive understanding of the current landscape of palliative care services in Indonesia.

Table 2 Inclusion and exclusion criteria

Criteria	Inclusion	Exclusion
Population	Indonesia only	Any other countries
Concept	Studies discussing the availability, accessibility, and/or quality of palliative care services in Indonesia.	Articles do not address the core concepts of availability, accessibility, or quality of palliative care.
Context	Research conducted in the Indonesian healthcare setting, including various care settings and policy frameworks.	Studies focused on palliative care outside of Indonesia without specific relevance to the Indonesian context.
Language	English only	Any other languages
Type of literature	Peer-reviewed research articles, reviews, and gray literature.	Opinion pieces, editorials, and commentaries without empirical data, or substantial literature review.
Data specificity	Studies providing specific data or insights into palliative care services in Indonesia.	Studies with insufficient data for extraction or not specifically related to the research question.

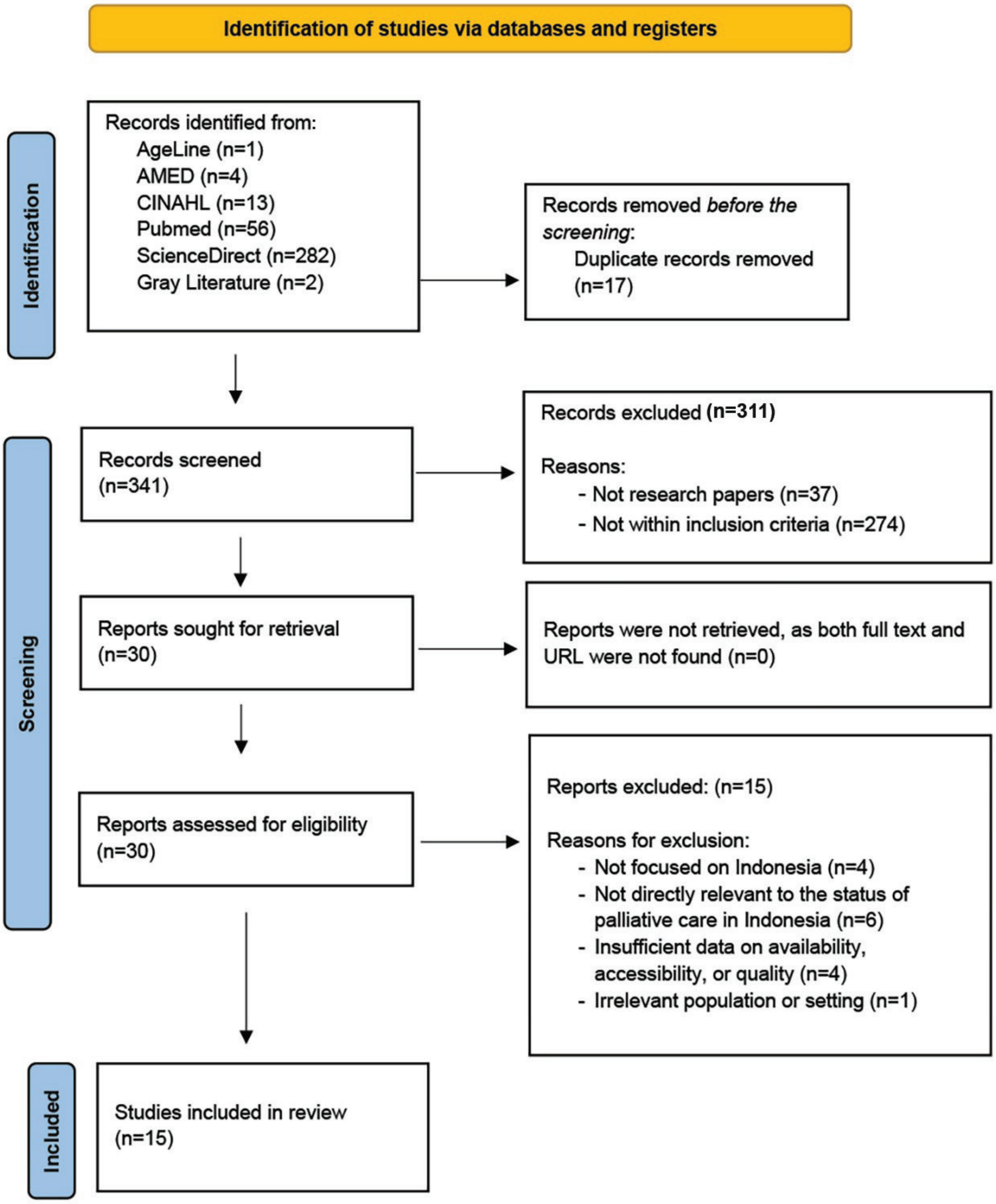

Figure 1 Search results s-PRISMA flowchart[15]

Results

This review selected 15 papers, which were categorized by the types of diseases/patients they handle and their study types. The studies focusing on specific patient groups include Effendy and Kristanti[5], which examines palliative care for coronavirus disease 2019 (COVID-19) patients, and Effendy et al.[8], which addresses both cancer and HIV/AIDS patients. Several studies specifically focus on cancer patients, such as Andriastuti et al.[7], Soebadi and Tejawinata[12], Nuraini et al.[2], and Widjaja et al.[6] (Table 3). The remaining studies address general palliative care issues, with some highlighting specific challenges in pain management[3] and the integration of local cultural values into care practices[4] (Table 3).

Regarding study types, as shown in Table 3, the papers include a mix of qualitative studies[4,10,13,16], scoping review[1], narrative reviews[8,9,17,18], cross-sectional studies[2,3], a randomized controlled trial[7], a mixed-methods study[12], a perspective article[5], and a systematic review[6]. This diverse range of study designs and focus areas provides a comprehensive overview of the current status and challenges of palliative care services in Indonesia.

Palliative care in Indonesia (2024)–key findings

This review reveals that palliative care services in Indonesia are largely concentrated in urban areas like Surabaya, Jakarta, and Denpasar, leaving rural regions with significant shortages. In these urban centers, services are more likely to include hospital-based palliative care units such as those at the Dharmais Cancer Hospital in Jakarta and the Dr. Soetomo Hospital in Surabaya, which offer outpatient clinics and respite care services[8]. Jakarta and Surabaya have also implemented community-based palliative care through primary health centers (puskesmas), with over 300 trained in Jakarta alone and 63 integrated in Surabaya in order to provide care across inpatient, outpatient, and home settings[9]. Key barriers to equitable distribution include geographic, economic, and cultural challenges, compounded by financial constraints and misconceptions about palliative care. The quality of care varies widely, highlighting the need for standardized training for healthcare providers. Importantly, integrating spiritual care has been shown to enhance patient comfort and emotional well-being. The findings emphasize the urgent need for improved palliative care protocols, especially during the COVID-19 pandemic, and advocate for increased training and resources to elevate care quality across the country.

Current progress–availability, accessibility, and quality

The development of palliative care services in Indonesia has been gradual since the 1990s, with availability largely concentrated in urban areas like Jakarta, Yogyakarta, Denpasar, and Surabaya, while rural regions face significant shortages[1,6,8]. These urban areas often host hospital-linked palliative care units and oncology outpatient clinics[8], along with home visit services and community outreach programs coordinated by hospitals and non governmental organizations[8,9]. Recent studies indicate emerging practices in places like Aceh, but comprehensive infrastructure remains lacking[10]. Notably, while specialized palliative care for children with cancer exists, it is underutilized[7].

Ongoing efforts to improve accessibility are hampered by geographic, economic, and cultural barriers[3]. Financial constraints and misconceptions about palliative care further restrict access, particularly in remote areas[1,6,8]. For example, Shatri et al.[3] highlight the economic challenges in Jakarta, while Indarwati et al.[16] point to the lack of trained personnel for older adults in nursing homes. The integration of palliative care into the national healthcare system is still limited, reflecting urban-rural disparities.

Table 3 Data extraction summary of palliative care included studies in Indonesia

Study ID	Author(s)	Year	Title	Study design	Objective(s)	Setting & population	Key finding	Availability	Accessibility	Quality	Challenges	Recommendations & research gaps
1	Lickiss	1993	Indonesia: status of cancer pain and palliative care	Narrative review	To evaluate the status and development of cancer pain relief and palliative care in Indonesia	Indonesia; General population, healthcare professionals	Indonesia's early palliative care efforts focused on pilot hospital programs, improved morphine access, and strong government backing to integrate services into the national health system.	Limited availability of palliative care services, focused on pilot projects in major hospitals	Limited by geographic distribution, lack of awareness, and policy barriers	Quality varies, with early implementation stages showing variability	Infrastructure limitations, insufficient opioid availability, lack of training	Implement palliative care teams in hospitals, develop guidelines, adjust policies for opioid availability, increase training and education, conduct research
2	Soebadi & Tejawinata	1996	Indonesia: status of cancer pain and palliative care	Mixed-methods study	To evaluate the implementation of cancer pain relief and palliative care at Dr. Soetomo Hospital	Indonesia; Cancer patients at Dr. Soetomo Hospital	This study describes the development of a community-based, family-oriented palliative care program in Indonesia, identifying major implementation barriers such as limited morphine availability, insufficient training, and geographic challenges.	Palliative care services established as a pilot project, limited availability of oral morphine	Geographic and economic barriers, limited access to strong opioids	Quality improved with implementation of WHO pain relief guidelines, training required for consistency	Geographic challenges, lack of resources, limited funding, training needs	Conduct epidemiological research, provide training for healthcare workers, improve accessibility of opioids, develop community-supported care, increase cooperation with NGOs and WHO

Table 3 continued

Study ID	Author(s)	Year	Title	Study design	Objective(s)	Setting & population	Key finding	Availability	Accessibility	Quality	Challenges	Recommendations & research gaps
3	Effendy et al.	2015	The nascent palliative care landscape of Indonesia	Narrative review	Provide an overview of palliative care provision in Indonesia and identify areas for improvement	Indonesia; Cancer and HIV/AIDS patients in major cities	Palliative care in Indonesia remains limited to select urban centers, with significant challenges including poor referral systems, low public and professional awareness, and lack of national standard procedures, highlighting the urgent need for culturally adapted models, education, and policy integration.	Palliative care services mostly available in urban areas like Surabaya, Jakarta, Yogyakarta, Denpasar, Makassar	Limited access in rural areas, financial constraints, cultural barriers, limited public awareness	Quality varies, significant gaps in service standardization and healthcare provider training	Geographic and cultural diversity, limited funding, insufficient training, lack of policy support	Develop more services, enhance palliative care education, introduce quality indicators, increase public awareness, seek culturally appropriate models of care, improve coordination between hospitals and primary care centers, conduct further research on effective delivery models
4	Rochmawati et al.	2016	Current status of palliative care services in Indonesia: a literature review	Scoping review (1. No critical appraisal, 2. No specific clinical problems to address)	To review healthcare literature in relation to the provision of palliative care in Indonesia and identify factors impacting palliative care development	Indonesia; Various healthcare settings	This review found that palliative care in Indonesia is still in its infancy, with limited services, inadequate provider training, and significant geographic and opioid access barriers, but also highlighted strong familial and community support as key facilitators for future development.	Limited services, mostly in urban areas, some progress with national guidelines	Limited access due to geographic challenges, financial barriers, and cultural barriers	Quality varies, lack of standardization, limited trained personnel	Limited knowledge among healthcare professionals, challenging geography, limited access to opioids	Training for nurses and doctors, integration of palliative care in medical and nursing curriculum, educating family and community about basic care; further research on rural areas, more data on service outcomes

Table 3 continued

Study ID	Author(s)	Year	Title	Study design	Objective(s)	Setting & population	Key finding	Availability	Accessibility	Quality	Challenges	Recommendations & research gaps
5	Putranto et al.	2017	Development and challenges of palliative care in Indonesia: role of psychosomatic medicine	Narrative review	Discuss the development and challenges of palliative care	Indonesia; Patients in major cities, healthcare professionals	Palliative care in Indonesia remains uneven and underdeveloped, with limited services confined to major cities, and psychosomatic medicine is identified as a valuable interdisciplinary approach to address unmet psychosocial and spiritual needs.	Services available in major cities, slow progress overall	Accessibility limited to urban areas, financial constraints, cultural barriers	Quality impacted by lack of training and awareness, variability in service delivery	Government policy issues, lack of education, professional attitudes, social conditions, wide geographic area, opioid regulations	Increase training for healthcare providers, advocate for better policies, develop community care models, increase palliative care workforce; further research on integration of psychosomatic care and its outcomes
6	Nuraini et al.	2018	Spirituality-focused palliative care to improve Indonesian breast cancer patient comfort	Cross-sectional study	Develop a path model of the relationships between nursing care, patient coping, family support, patient spirituality, and patient comfort in breast cancer patients	Jakarta, Indonesia; 308 breast cancer patients at three referral hospitals	Spirituality-focused palliative care significantly improved comfort in Indonesian breast cancer patients by reducing anxiety and depression, highlighting the vital role of nurses in addressing emotional and spiritual needs.	Palliative care services available but not fully integrated into oncology practice; spiritual care integrated into palliative care	Geographic and financial barriers limit access to services; cultural misconceptions about palliative care	Quality improved with spiritual care, reduced anxiety and depression, enhanced emotional well-being	Lack of training for healthcare providers on spiritual care, cultural resistance to palliative care, inadequate integration of palliative care in oncology practice	Increase training for healthcare providers in spiritual care, promote integration of palliative care into standard oncology practice, further research on long-term impact of spirituality-focused palliative care

Table 3 continued

Study ID	Author(s)	Year	Title	Study design	Objective(s)	Setting & population	Key finding	Availability	Accessibility	Quality	Challenges	Recommendations & research gaps
7	Shatri et al.	2019	Factors associated with pain in palliative patients and the role of spiritual services in pain management	Cross-sectional study	Determine factors associated with pain and assess the role of spiritual services in pain management	Jakarta, Indonesia; 285 palliative patients at Dr. Cipto Mangunkusumo Hospital	Pain in palliative patients, especially those with cancer, is significantly influenced by psychological factors like depression, and combining spiritual care with opioids shows greater effectiveness in pain relief than either approach alone.	Pain management services available, incorporating spiritual care	Accessibility limited by economic and geographical factors	Quality varies; spiritual services enhance pain management	Limited training in spiritual care, insufficient infrastructure	Increase training for integrating spiritual care into palliative services; further studies on long-term effects of spiritual care integration
8	Arisanti et al.	2019	Implementation of palliative care for patients with terminal diseases from the viewpoint of healthcare personnel	Qualitative study	Explore the current conditions and expectations regarding palliative care from the perspective of healthcare personnel	Bandung District, Indonesia; 12 physicians and 5 nurses from primary, secondary, and tertiary healthcare facilities	Healthcare personnel noted that limited training, low public awareness, geographic barriers, and weak system coordination hinder effective palliative care delivery, underscoring the need for early integration and systemic support.	Limited implementation at all healthcare levels, mainly in urban hospitals	Geographical barriers, lack of information, poor socialization of palliative care	Quality varies, need for better training and standardized care	Cultural and socioeconomic factors, lack of education and training, limited coordination, insufficient funds	Develop policies and guidelines for comprehensive care, improve training for healthcare personnel, increase public awareness and education on palliative care; further research on broader settings and perspectives

Table 3 continued

Study ID	Author(s)	Year	Title	Study design	Objective(s)	Setting & population	Key finding	Availability	Accessibility	Quality	Challenges	Recommendations & research gaps
9	Indarwati et al.	2020	Palliative and end-of-life care's barriers for older adults	Qualitative Study	Explore barriers to effective palliative and end-of-life care (EOLC) for older adults in nursing homes from the perspective of nurses	Surabaya, Indonesia; 15 nurses in a nursing home	Nurses in Indonesian nursing homes face barriers to palliative care including limited knowledge, communication challenges, and lack of medical resources, highlighting the need for better training and support.	Limited palliative/EOLC services in nursing homes, inadequate resources and facilities	Barriers due to geographic distribution, lack of trained personnel, and insufficient policy support	Variable quality of care, significant gaps in training and resources	Lack of knowledge, ineffective communication, insufficient resources (medical devices, drugs, and physicians)	Develop better policies, provide continuous training, integrate palliative care into nursing education, promote interdisciplinary collaboration, and increase resource allocation
10	Effendy & Kristanti	2021	The importance of providing palliative care for patients with severe COVID-19 in Indonesia	Perspective Article	Describe the importance and implementation of palliative care for patients with severe COVID-19 in Indonesia	Indonesia; Patients with severe COVID-19, healthcare providers	This study emphasizes the urgent need to integrate palliative care into COVID-19 management in Indonesia, highlighting the role of nurses, the importance of communication technology, and addressing physical, psychosocial, and spiritual distress despite limited resources and training.	Limited dedicated palliative care services for COVID-19 patients, need for better integration	Geographic and financial barriers, limited policy support, cultural barriers to palliative care understanding	Quality varies, dependent on healthcare provider training and resources available	Lack of formal palliative care training, cultural resistance, limited resources, high workload for healthcare providers	Increase training for healthcare providers, improve use of communication technology to connect patients with families, integrate palliative care into COVID-19 protocols, further research on effective palliative care practices during pandemics

Table 3 continued

Study ID	Author(s)	Year	Title	Study design	Objective(s)	Setting & population	Key finding	Availability	Accessibility	Quality	Challenges	Recommendations & research gaps
11	Andriastuti et al.	2022	Home-based palliative intervention to improve quality of life in children with cancer: a randomized controlled trial	Randomized controlled trial (RCT)	Determine the benefits of integrated home-based palliative care for the quality of life and symptoms intensity in Indonesian children with malignancies	Jakarta, Indonesia; 60 pediatric cancer patients aged 2–18 years	Home-based palliative care significantly improved quality of life and symptom management in children with cancer, showing effectiveness in reducing pain, nausea, sleep disturbance, and anxiety compared to standard care.	Home-based palliative care services available, not widely used	Logistical and financial barriers for patients and families, limited reach beyond urban areas	Significant improvement in quality of life (QoL) and symptom management in the intervention group compared to control group	Lack of medical insurance coverage, limited human resources, need for specialized training	Increase awareness and implementation of home-based palliative care, advocate for better insurance coverage and training for healthcare providers; further research on long-term impacts and scalability of home-based palliative care
12	Widjaja et al.	2022	What contributes to palliative care practice in cancer patients in Indonesia	Systematic review	Identify factors affecting palliative care practice in cancer patients in Indonesia	Indonesia; Cancer patients, healthcare providers, caregivers	This literature review identified patient, provider, and system-level factors influencing palliative care in Indonesia, emphasizing the need for improved caregiver support, provider communication, and healthcare infrastructure to achieve optimal cancer care.	Palliative care services primarily available in major cities; lack of integration in rural areas	Geographic and economic barriers, limited public awareness, inadequate policy support	Quality varies significantly; gaps in standardization and training for healthcare providers	Geographic and cultural diversity, limited funding, insufficient training, lack of policy support	Develop more services, enhance palliative care education, introduce quality indicators, increase public awareness, seek culturally appropriate models of care, improve coordination between hospitals and primary care centers, conduct further research on effective delivery models

Table 3 continued

Study ID	Author(s)	Year	Title	Study design	Objective(s)	Setting & population	Key finding	Availability	Accessibility	Quality	Challenges	Recommendations & research gaps
13	Eng et al.	2023	Indonesia's unique social system as key to successful implementation of community- and home-based palliative care	Narrative review	Provide insights into Indonesia's practice and strategies in developing community- and home-based palliative care	Indonesia; General population, healthcare professionals, volunteers	Indonesia's community participation, tiered population system, and integration of volunteers and NGOs support effective delivery of community- and home-based palliative care, especially in urban areas.	Community and home-based palliative care services supported by the Indonesian Cancer Foundation (ICF) and volunteer network; limited but expanding hospice services	Accessibility improved through community participation, volunteer engagement, and integration with the national health care system; still limited in rural and remote areas	Quality enhanced by integrating spiritual and psychosocial support; variable depending on region and resources	Large population and geographic diversity present challenges; lack of formal training for volunteers; limited funding and resources in rural areas; need for standardized procedures	Expand volunteer training programs; improve integration of community resources with national health care system; enhance funding and resources for rural areas; conduct further research on effective community-based palliative care models
14	Wilson et al.	2024	Barriers and mechanisms to the development of palliative care in Aceh, Indonesia	Qualitative study	Identify barriers and mechanisms in the development of palliative care in Aceh	Aceh province; healthcare professionals, academics, spiritual leaders	This study identifies cultural, structural, and policy barriers to palliative care in Aceh and emphasizes the need for a culturally appropriate, community-integrated care model supported by local leadership and sustainable funding.	Limited services, some emerging palliative care practices	Accessibility limited by geography, lack of policy and funding, cultural barriers	Quality impacted by limited understanding and training; early shoots of palliative care practices emerging	Poor infrastructure, lack of funding and policy support, limited opioid access, cultural resistance	Develop culturally and socioeconomically relevant palliative care models, focus on family and community support, increase research on effective interventions, advocate for policy integration

Table 3 continued

Study ID	Author(s)	Year	Title	Study design	Objective(s)	Setting & population	Key finding	Availability	Accessibility	Quality	Challenges	Recommendations & research gaps
15	Wicaksono et al.	2024	Tie your camel first, then rely on God: reconceptualizing Javanese Islamic values to support palliative care at home	Ethnographic study	Analyze Javanese Islamic values and how they can support palliative care practices at home in rural Java	Banyumas, Central Java; 49 patients, families, and health professionals	This ethnographic study in Central Java identified three Javanese-Islamic values: ikhtiar (effort), ikhlas (sincerity), and pasrah (surrender), as essential for culturally aligning palliative care with local beliefs, thereby enhancing acceptance and delivery of home-based services.	Limited dedicated palliative care services in rural Java, emerging awareness and integration of local values	Accessibility limited by geographic barriers, economic constraints, and cultural misunderstandings	Quality of care improved by integrating values of ikhtiar (effort), ikhlas (sincerity), and pasrah (surrender), leading to better patient and family acceptance and comfort	Geographic and economic challenges, cultural resistance, limited training and awareness of healthcare providers, insufficient integration of palliative care concepts	Incorporate local values into palliative care practices, increase training and awareness among healthcare providers, develop policies that support the integration of cultural values into care practices, further research on culturally sensitive palliative care models

WHO=World Health Organization, NGOs=non-governmental organization, COVID-19=coronavirus disease 2019

Quality of care varies significantly, influenced by the training and resources available to healthcare providers[1,13]. Studies reveal gaps in standardization and training, with urban areas generally offering higher quality services, but variability persists[1,13,18]. Effendy and Kristanti[5] stress the need for improved integration of palliative care protocols, particularly during the COVID-19 pandemic. Additionally, ongoing research by Soebadi and Tejawinata[12] and Putranto et al.[18] advocates for continuous policy development and training to enhance the consistency and quality of palliative care across the country.

Facilitating factors

This review identified several facilitating factors that support the development and provision of palliative care services in Indonesia. One of the key facilitating factors is the involvement of the community and support from volunteer networks, such as the Indonesian Cancer Foundation (ICF) and, volunteer networks in supporting community and home-based palliative care services[9]. Community participation and volunteer engagement have been instrumental in improving accessibility to palliative care, particularly in areas where formal healthcare services are limited[9]. Volunteers are often provided with basic training to support palliative patients and their families, enhancing the overall quality of care[9].

Family support also plays a significant role in the provision of palliative care in Indonesia. Effendy et al.[8] emphasize the strong family ties in Indonesian culture, where family members are often the primary caregivers for patients with life-limiting illnesses. This cultural aspect can be leveraged to enhance palliative care delivery by training family members to assist with patient care, thereby addressing some of the resource constraints faced by healthcare providers[9]. Additionally, Putranto et al.[18] discuss how the integration of family support into palliative care practices can improve patient outcomes and satisfaction.

Subsequently, the integration of spiritual care into palliative care practices is another facilitating factor that has been shown to improve patient comfort and emotional well-being[2]. Incorporating spiritual care into the palliative care framework significantly reduces anxiety and depression among patients, enhancing their overall quality of life[2]. This integration aligns with the cultural and spiritual values of Indonesian patients, making palliative care more holistic and acceptable[2]. Similarly, Wicaksono et al.[4] identified that incorporating Javanese Islamic values, such as "ikhtiar" (making an effort), "ikhlas" (being sincere), and "pasrah" (being in a state of surrender), significantly enhances the quality of life for palliative care patients. These values help in reducing anxiety and depression, fostering a sense of contentment, and improving overall well-being, thereby making palliative care more culturally sensitive and contextually appropriate[4].

Newer insights regarding the challenges

This review builds upon the foundational work by Rochmawati, Wiechula[1]; however, new barriers since 2016 have surfaced. Recent studies, shown in Table 3, have highlighted poor infrastructure and inadequate policy support as critical barriers to the development of palliative care in Indonesia[8,10,16]. Wilson et al.[10] underscore that limited funding and insufficient healthcare facilities particularly hinder the establishment and sustainability of palliative care services in less developed regions. This lack of robust infrastructure creates significant obstacles to providing consistent, high-quality palliative care, especially in rural and remote areas[10]. Additionally, the lack of coordination between different levels of healthcare providers and the insufficient integration of palliative care into the national healthcare system exacerbate the problem[5,6,13]. Arisanti, Sasongko[13] and Effendy and Kristanti[5] point out that this fragmentation leads to inconsistent service delivery and gaps in care continuity. The absence of a cohesive approach makes it challenging to implement standardized palliative care practices across various regions, further complicating efforts to improve care accessibility and quality[9,13,18].

Cultural resistance and economic constraints also present significant hurdles. Moreover, Andriastuti et al.[7] highlight the lack of medical insurance coverage for palliative care services as a major financial barrier, preventing many patients from accessing necessary care. This financial limitation is particularly acute for lower socio-economic groups, underscoring the need for policies that provide better economic support for palliative care[3,7,8].

Ongoing Barriers

Several enduring challenges discussed by Rochmawati et al.[1] continue to impede the progress of palliative care in Indonesia. This review identifies limited access to opioids, inadequate education and training for healthcare professionals, and significant geographical constraints as persistent issues[1,10]. The restrictive regulations on opioid use, combined with cultural fears around their safety, limit effective pain management[10,12]. The absence of structured palliative care education in medical and nursing schools results in a shortage of trained specialists, particularly in rural areas[16,18]. Furthermore, Indonesia's vast archipelagic geography complicates the delivery of palliative care services, making consistent access challenging for many patients living outside major urban centers[9,13]. These ongoing barriers suggest that the situation has not improved much since 2016, also highlighting the multifaceted nature of the challenges that must be addressed in order to improve palliative care across the country.

Discussion

Historical perspective and persistent challenges

In comparison to studies with similar research questions conducted by Rochmawati et al.[1], Soebadi and Tejawinata[12], Lickiss[17], this review provides a timeline of the development and persistent challenges of palliative care in Indonesia. Despite early efforts in the 1990s to integrate palliative care into the mainstream healthcare system, progress has remained slow and inconsistent[12,17]. In the early 1990s, initiatives focused on cancer pain relief and establishing pilot projects for oral morphine use to expand these programs nationwide[17]. By the mid-1990s, Soebadi and Tejawinata[12] highlighted the establishment of multidisciplinary teams and the adoption of the WHO's three-step ladder for pain relief. However, recent studies have shown that these challenges, such as the limited availability of medications and inadequate training, persisted[3,5,10].

Fast forward to 2016, Rochmawati et al.[1] noted that palliative care services were still in their infancy, with significant gaps in service provision, particularly in rural areas. Rochmawati et al.[1], along with more recent studies, emphasized the need for increased educational efforts, policy support, and the integration of palliative care into medical curricula[5,13,16], indicating that these barriers persist. Despite some progress noted by Rochmawati, Wiechula[1], the availability and accessibility of palliative care services remain limited, with urban areas benefiting more than rural regions[7,9,18].

Quality indicators

The concept of quality, though inherently broad and multifaceted, was operationalized in several of the included studies through observable clinical and experiential outcomes. The most frequently reported indicators were related to pain and symptom management, with improvements noted in pain relief, nausea, anxiety, and sleep disturbance following palliative interventions[2,3,7,12]. Spiritual and emotional well-being also featured prominently, particularly in studies where culturally grounded or spirituality-focused care enhanced patient comfort among cancer and COVID-19 populations[2–5]. In some cases, caregiver and provider perspectives were used to assess service quality, drawing attention to gaps in training, coordination, and system support[6,8,10,12,13,16,18]. Although formal tools such as quality-of-life scales and satisfaction surveys were not consistently applied, several studies referenced alignment with WHO-recommended palliative care components, which emphasize holistic care and the integration of psychosocial and spiritual support[3,11]. Taken together, these findings suggest that in the Indonesian context, quality is often interpreted through culturally meaningful care practices and practical outcomes, rather than standardized metrics alone.

Newer insights

Recent studies from 2017 to 2024 reveal ongoing and emerging barriers to palliative care development in Indonesia. Poor infrastructure and inadequate policy support remain significant challenges[5,10,16]. Wilson et al.[10] and Effendy et al.[8] highlight that cultural resistance and restricted opioid access further hinder effective pain management. A lack of a cohesive national strategy and insufficient funding exacerbate these issues, making it difficult to deliver consistent, high-quality services[8,10,16].

Coordination gaps among healthcare providers and insufficient integration of palliative care into the national healthcare system lead to fragmented services, particularly in rural areas[5,6,13]. Economic constraints pose additional hurdles, with financial burdens restricting access for lower socio-economic groups[3,5,7]. Andriastuti et al.[7] and Shatri et al.[3] emphasize that the absence of medical insurance coverage worsens these financial barriers. The 2015 Road to National Health Insurance (JKN) document highlights the need for improved insurance coverage to ensure equitable access[3,7].

Despite these challenges, several facilitators can enhance palliative care access. Community involvement and volunteer support play vital roles, with trained volunteers significantly improving care quality[9]. Strong family ties and the integration of spiritual care further enhance patient comfort and align services with Indonesian values[2,4,8]. These insights underscore the importance of culturally sensitive, community-based approaches to improving palliative care in Indonesia[2,4].

Limitations

This scoping review, with its broad and exploratory research question, provides a comprehensive overview of palliative care services in Indonesia. However, it is subject to several limitations that may affect the interpretation of its findings. First, the review may underrepresent services in rural and remote areas due to limited documentation and publicly accessible data, potentially skewing the overall picture toward urban-centric developments. Additionally, this review was limited to studies available in English, which may have resulted in the exclusion of relevant research published in other languages, particularly Indonesian. Future research should consider including non-English studies to capture a more comprehensive and inclusive understanding of palliative care developments within the local context. Moreover, the rapid changes in healthcare policies and the impact of the COVID-19 pandemic on healthcare delivery systems suggest that some findings may already be outdated. The dynamic nature of healthcare provision, especially in response to crises, underscores the need for ongoing research and regular updates to maintain an accurate understanding of palliative care services in Indonesia. These limitations also suggest that the results should be interpreted with caution, as they may not fully reflect the current breadth, accessibility, or quality of palliative care services across all regions in Indonesia.

Implications for public health advocacy and policy

Martina et al.[11] estimate that around 1,451,000 individuals in Indonesia require palliative care each year. Most services are self-funded or supported by charitable donations and are primarily located in hospitals, with some aid from non-profit organizations[11]. However, palliative care lacks formal recognition in the national health system, addressed only in a few Ministry of Health policies related to AIDS and cancer[11].

Advocating for the formal inclusion of palliative care in Indonesia's national health system is crucial. This involves developing comprehensive policies that recognize it as an essential service and integrating it into primary healthcare. Increased funding and resource allocation are necessary to expand services into rural areas. Education and training for healthcare professionals must also improve in order to standardize care practices nationwide.

Strengthening community-based initiatives and volunteer networks is essential. Providing extensive training for volunteers and incorporating them into healthcare teams can enhance service delivery[9]. Policymakers should also consider Indonesia's socio-cultural context, leveraging family ties and integrating spiritual care into practices to improve patient acceptance[2,4,8]. Addressing these areas can significantly enhance the availability, accessibility, and quality of palliative care services in Indonesia.

Implications for future research

Although palliative care research in Indonesia is limited, future studies can address the identified gaps and challenges. Research should focus on culturally appropriate strategies to improve quality and reach, exploring cultural influences, comparing nursing interventions, and understanding patient and family preferences. Additionally, developing tools to measure health status changes and patient satisfaction, integrating palliative care into the national health system, and assessing policy impacts are crucial. Evaluating training programs, conducting longitudinal studies, and examining the financial burden on patients and families is essential to inform policy and practice, ultimately enhancing palliative care services in Indonesia.

Conclusion

This scoping review reveals that palliative care in Indonesia, while showing some progress, remains limited in availability and quality, with stark urban-rural disparities. Most services rely on self-funding or donations and are poorly integrated into the national health system. Key barriers include inadequate infrastructure, policy support, and healthcare provider training, particularly affecting lower socio-economic groups. Although community-driven initiatives offer some assistance, they are insufficient to meet rising demand. Future research should focus on culturally appropriate strategies to enhance palliative care delivery. Hence, ensuring equitable access and a sustainable impact, enhanced government funding, robust policy support, and the full integration of palliative care into Indonesia's core health services are urgently needed.

Conflict of interest

No competing interests

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Appendix

Scoping reviews (PRISMA-ScR) checklist[15]

Section	Item	PRISMA-ScR checklist item	Reported on page[#]
Title			
Title	1	Identify the report as a scoping review.	1
Abstract			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	2
Introduction			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	2, 3, 4, 5 & 6
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	2, 3, 4, 5 & 6
Methods			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	N/A
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	7
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	7 & 8
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	7, 8 & 27
Selection of sources of evidence	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	7, 8 & 9
Data charting process[‡]	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	8 & 9
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	8 & 9
Critical appraisal of individual sources of evidence	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N/A
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	8, 9 & 10
Results			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	9
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	15, 16, 17 & 18
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A

Section	Item	PRISMA-ScR checklist item	Reported on page[#]
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	15, 16, 17 & 18
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	10, 11, 12, 13 & 14
Discussion			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	10, 11, 12, 13 & 14
Limitations	20	Discuss the limitations of the scoping review process.	21
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	19, 20, 21 & 22
Funding			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	N/A

JBI=Joanna Briggs Institute, PRISMA-ScR=Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

*Where sources of evidence (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

[†] A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with information sources (see first footnote).

[‡] The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

[§] The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).