BARRIERS TO PALLIATIVE CARE IMPLEMENTATION IN INDONESIA:A LITERATURE REVIEW

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Abstract. Palliative care services are an important component of the healthcare system to improve the quality of life of patients with chronic or terminal illnesses. In Indonesia, this service is still less popular than curative and rehabilitative care, although the need is increasing with the aging population and the prevalence of degenerative diseases. The WHO has emphasised the importance of palliative care as part of comprehensive care for non-communicable diseases. This study aims to evaluate the implementation of palliative care in Indonesia through analyses of policy, clinical practice, resource availability, and challenges and opportunities in its provision. The literature review was conducted using the PRISMA flowchart, using the keywords 'Implementation, palliative care services, Indonesia, barriers' on PubMed, Google Scholar, and Science Direct. A total of 35 articles met the criteria, 15 articles were selected based on relevance, publication between 2019-2024, and in Indonesian or English, focusing on barriers and implementation of palliative care in Indonesia. Barriers found include financial problems, lack of information and education, lack of training and education for health workers, lack of psychological and operational support, disparities in access and quality of care, and suboptimal development of community-based care and existing guidelines. With the implementation of appropriate policies, practices and education as well as further research, it is expected that the quality of palliative care in Indonesia can be significantly improved. This improvement will bring great benefits to patients and their families, as well as improve the welfare of health workers involved in palliative care.

Key words: Implementation, Palliative Care Services, Indonesia, Barriers

INTRODUCTION

In Indonesia, palliative care is still less common than curative and rehabilitative care (Wilson et al., 2024). This is true even though the number of adults and children with terminal illnesses, such as cancer, obstructive pulmonary disease, HIV, degenerative diseases, heart failure, and other illnesses, is still rising (Gysels & Higginson, 2011). At the global level, WHO and UN agencies can work together to design policies and strategies to reduce the risk of NCDs and have explicitly stated the importance of palliative care as part of comprehensive care in non-communicable diseases (NCDs) (Budreviciute et al., 2020).

Since 2007, the Republic of Indonesia's Ministry of Health has published a Palliative Care Policy, however not much has changed in terms of the number of medical facilities adopting palliative care. Furthermore, there are still relatively few studies in Indonesia that address palliative care (Sinaga et al., 2024).

Providing patients and their families with grieving support or preparation is intimately associated with palliative care. But the availability of grieving support continues to be a roadblock to the systemic adoption of palliative care (José Luis Castro, 2020). There are no set rules for offering bereavement support; instead, health workers—especially nurses—rely on their capacity to build a personal relationship or touch with patients who will soon pass away (El-Jawahri et al., 2020).

To enable palliative care to be used in a variety of healthcare settings, a thorough examination of the obstacles to its implementation in Indonesia must be carried out. This literature review aims to identify the obstacles to palliative care implementation in Indonesia.

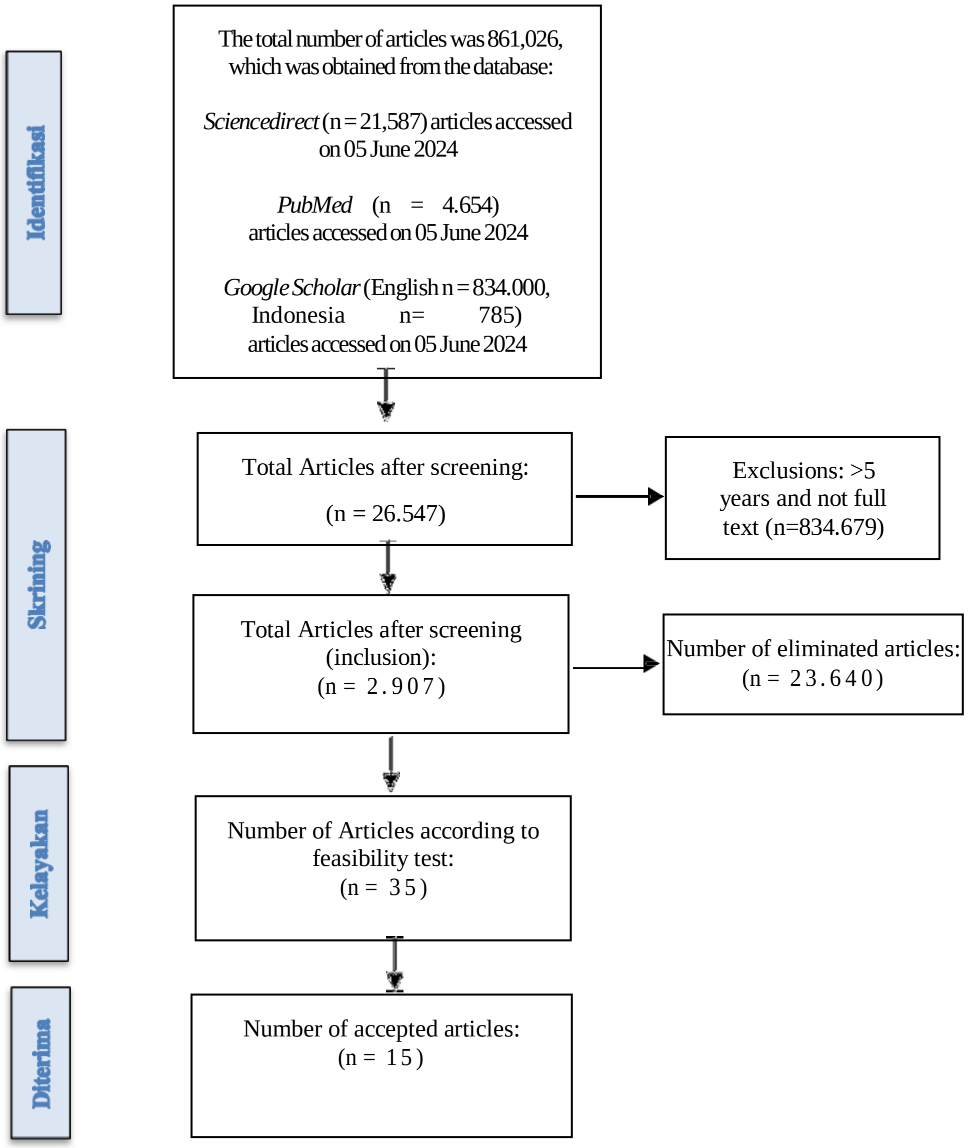
METHODS

This study used the literature review method. Searches were conducted through electronic databases and websites using Pubmed, Google Scholar, and Science Direct. The search strategy used the keywords 'Implementation, Palliative Care Services, Indonesia, Barriers'. This literature study was conducted with the PRISMA flow guide (Matthew James Page, Joanne McKenzie, Patrick Bossuyt, Isabelle Boutron, Tammy Hoffmann, cindy mulrow, Larissa Shamseer, Jennifer Tetzlaff, Elie Akl, 2020).

The literature search was conducted by identifying studies published between 2019 and 2024, in

English on “Barriers to Palliative Care” and in Indonesian on “Hambatan dalam Pelayanan Paliatif”. A total of 861,026 articles were identified from 3 electronic databases. Exclusion outside 2019 to 2024 and not full text resulted in 834,679 articles. Then screened according to the inclusion criteria of 2,907 articles, then sorted according to the eligibility test of 35 articles. Furthermore, articles not in accordance with the research question were excluded, and the results were 15 articles. Finally, 15 articles met the criteria (figure, 1). Data extraction was performed by the researchers and in this review data was extracted using the researcher's name, title, study design, year, purpose and outcome (table, 1). In the 15 articles, 3 were quantitative studies, 7 were qualitative studies and 5 were mixed methods. Each article was identified then summarised and extracted.

Figure 1. Diagram Flow Literature Review (PRISMA)



RESULTS AND DISCUSSION

In accordance with the inclusion criteria, 15 articles were found using keywords from literature search results including 7 articles from Sciencedirect, 2 articles from Pub Med, and 6 articles from Google Schoolar. The Literature Review Flow Diagram using PRISMA in Figure 1 shows the results of the literature search. Table 1 shows the synopsis and analysis of the reviewed articles.

Table 1. The synopsis and analysis of the reviewed articles

Authors and Title	Research Methods	Research Outcome
Chandra Isabella Hostanida Purba, Bridget Johnstona, Grigorios Kotronoulasa. An Exploration of Family Caregivers' Health Care Needs When Caring for Patients with Cancer in the Resource-Challenged Context of West Java, Indonesia. (2023).	• **Research Design:** Quantitative, with cross-sectoral surveys. • **Population:** Caregivers caring for a family member with cancer in a resource-limited context in West Java, Indonesia. • **Sample:** Caregivers caring for a family member with cancer 220 respondents.	Caregivers experienced difficulties in managing their living budget and cancer treatment costs. They also need information to care for their family.
Yati Afiyanti, Dewi Gayatri, Besral Besral, Haryani Haryani, Dyah Juliastuti. Unmet Supportive Care Needs Survey among Male Partners of Gynecological Cancer Survivors in Indonesia. (2021).	• **Research Design:** Quantitative, using descriptive statistics and multiple linear regression. • **Population:** Husbands of gynaecological cancer survivors in 2 public hospitals in Indonesia. • **Sample:** Husbands of gynaecological cancer survivors, 152 respondents**.**	Husbands of gynaecological cancer survivors in Indonesia need information and assistance with legal, financial and healthcare support**.**
Lukas Radbruch, et. al. Redefining Palliative Care-A New Consensus-Based Definition. (2020).	• **Research Design:** Qualitative with consensus method. The process consists of three phases. • **Population:** Health workers from 88 countries with varying income levels. • **Sample:** 450 health workers from different countries.	The article provides insight into the importance of clear definitions and global consensus in palliative care.
Constantina Cloconi, Mary Economou, Andreas Charalambous. Burnout, coping and resilience of the cancer care workforce during the SARS-CoV-2: A multinational cross-sectional study. (2023).	• **Research Design:** Quantitative, with the Connor-Davidson Resilience Scale, Brief-COPE (Coping Orientation to Problems Experienced) Scale, and The Maslach's Burnout Inventory. Data analysis was conducted using descriptive statistics and multilinear regression analysis. • **Population:** This cross-country study was conducted online between March-May 2021 on healthcare professionals specialising and/or working in the oncology sector from around the world. • **Sample:** Health professionals specialising and/or working in the oncology sector from around the world, 271 respondents.	Findings emphasise the need for timely and appropriate health system preparations to support cancer care professionals in the face of the health emergency.
Marieke Torensma, Jeanine L. Suurmond, Agnes van der Heide, Bregje D. Onwuteaka-Philipsen. Care and Decision-Making at the End of Life for Patients with a Non-Western Migration Background Living in The Netherlands: A Nationwide Mortality Follow-Back Study. (2020).	• **Research Design:** Using the mortality follow-back research method. • **Population:** Attending physicians involved in end-of-life decision-making for patients with a non-Western migration background in the Netherlands, 9351 respondents. • **Sample:** Attending physicians involved in end-of-life decision-making for patients, 5327 respondents.	Treatment differences exist. Patients with a non-Western migration background received less morphine or morphine-like drugs and sustained deep sedation. End-of-life decisions were made less frequently for patients with a non-Western migration background, decisions for euthanasia and assisted suicide were less frequent. End-of-life care for patients with non-Western migration backgrounds focused more or longer on maximal and curative treatment, and end-of-life decisions were made less frequently.
Christantie Efendy, Deby Kristiani Uligraf, Selvia Harum	• **Research Design:** Qualitative with phenomenological design.	Home-based PPC provides significant benefits with positive impacts for children diagnosed with cancer as well as their families. Nurses

Sari, Fany Angraini, Lynna Chandra. Experiences of family caregivers of children with cancer while receiving home-based pediatric palliative care in Indonesia: a qualitative study. (2022).	• **Population:** Family caregivers of children with cancer receiving home-based Paediatric Palliative Care (PPC) in Indonesia. • **Sample:** Family carers of children with cancer as many as 12 respondents.	involved in home-based PPC services provide holistic care with a family-centred approach.
Tommy Cederholm, et. al. Guidance for assessment of the inflammation etiologic criterion for the GLIM diagnosis of malnutrition: A modified Delphi approach. (2024).	• **Research Design:** Using a modified Delphi approach. The process included an electronic survey and a Delphi score to assess the level of agreement. • **Population:** Involved a multi-round review and revision process by the GLIM working group. • **Sample:** GLIM working group of 36 respondents.	The article emphasises the importance of inflammatory assessment in relation to malnutrition and provides detailed guidance for the use of CRP and clinical assessment in practice.
Cornelia U. Loechl, et. al. Approaches to Address the Anemia Challenge. (2023).	• **Research Design:** Using an ecological approach to understand and address anaemia. • **Population:** Various approaches to address anaemia challenges. • **Sample:** There are 2 scientific approaches taken viz: Nutritional approaches and approaches that address the non-nutritional causes of anaemia.	Multifactorial approach: Factors causing anaemia represent an ecology consisting of internal and external environments. Need to be considered when selecting interventions including inflammation, genetic mutations, nutrient delivery, biological availability, and safety. Research and Policy: key research areas and recommendations for future directions in addressing anaemia.
S.M. Hernández-Zambrano, et. al. Perspective of health personnel on end-of-life care in Intensive Care Units. (2020).	• **Research Design:** Qualitative with Action-Research Design (AI). • **Population:** Health workers about end-of-life care in the Intensive Care Unit (ICU). • **Sample:** ICU Multidisciplinary Team of 20 respondents.	Palliative Care: Emphasises comprehensive care to meet the physical, emotional and spiritual needs of the patient and family, and supports the patient's right to autonomy in decision-making.
Kristianto Dwi Nugroho, Sri Hartini Mardi Asih, Swanny Trijanti Widyaatmadja. Studi Fenomenologi: Gambaran Penatalaksanaan Pasien Paliatif di Area Pre-Hospital Kota Semarang. (2022). Phenomenological Study: An Overview of Palliative Patient Management in the Pre-Hospital Area of Semarang City. (2022).	• **Research Design:** Qualitative with phenomenological method. • **Population:** Palliative patients in the pre-hospital area of Semarang city. • **Sample:** 7 palliative patients.	Emotional support to the patient and family. The existence of staff concern for the patient's condition. Stakeholder collaboration. Limited facilities and infrastructure. Improving pre-hospital services, with education and training for officers.
Syarifah Lubbna. Mengembangkan Perawatan Paliatif Berbasis Masyarakat Di Indonesia: Belajar dari Implementasi Sukses di India dan Uganda. (2020). Developing Community-Based Palliative Care in Indonesia: Learning from Successful Implementations in India and Uganda. (2020).	• **Research Design:** Qualitative with phenomenological method. • **Population:** Community-based palliative care in India and Uganda and how it can be applied in Indonesia. • **Sample:** CBPC Development, Effective Strategies.	The article provides recommendations to promote the development of CBPC in Indonesia, including the importance of effective financial management and the role of volunteers.

Wijanarko Heru Pramono, Emilia Puspitasari Sugiyanto, Candra Hadi Prasetyo. Pelatihan Program Layanan Kesehatan Masyarakat Tentang Paliatif Dan Screning Paliatif Untuk Pengurus Panti. (2023). Community Health Service Programme Training on Palliative Care and Palliative Screening for Nursing Home Administrators. (2023).	• **Research Design:** Using descriptive method. • **Population:** Management of “Harapan Ibu Nursing Home” Ngaliyan Semarang. • **Sample:** Management of “Harapan Ibu Nursing Home” Ngaliyan Semarang as many as 10 respondents.	The article highlights the importance of training home carers in providing effective and comprehensive care to palliative older adults.
Anissa, Ifa Hafifah, Tina Handayani Nasution. Gambaran Pengetahuan Perawatan Paliatif Pada Perawat ICU di RSUD Ulin Banjarmasin. (2022). Overview of Palliative Care Knowledge in ICU Nurses at Ulin Banjarmasin Hospital. (2022).	• **Research Design:** Descriptive quantitative. • **Population:** ICU nurses at Ulin Hospital Banjarmasin. • **Sample:** ICU executive nurses at RSUD Ulin Banjarmasin as many as 32 respondents.	The article emphasises the importance of increasing palliative knowledge and training for ICU nurses to improve the quality of palliative care services.
Dahniar, Juliani Ibrahim, Rahmawati. Pelatihan Kader Community-Based Palliative Care. (2023). Community-based Palliative Care Cadre Training. (2023).	• **Research Design:** Interpersonal interaction, visual simulation, and psychospiritual communication techniques. • **Population:** Community-Based Palliative Care *Cadre* at Siti Khadijah Aisyiyah Hospital. • **Sample:** Community-Based Palliative Care *Cadre* as many as 20 respondents.	There were 20 cadres for community-based palliative care, home visits, an increase in respondents' knowledge by 62.34% from the initial knowledge of the trainees, and sustainable services.
Mariam Dasat, Uswatul Khasanah, Sigit Mulyono, Dian Anggraini. Hambatan Yang Dialami Keluarga Dalam Menjalankan Program Pelayananan Paliatif Pasien Kanker Stadium Lanjut. (2023) Barriers Experienced by Families in Implementing Palliative Care Programmes for Advanced Cancer Patients. (2023).	• **Research Design:** Qualitative with a phenomenological approach. • **Population:** Families of advanced cancer patients in the West Jakarta area in May 2021. • **Sample:** Families of advanced cancer patients as many as 9 respondents.	The article emphasises the importance of support for families in caring for patients at home, including cooperation with health professionals and financial support from the neighbourhood.

In the body of literature analysed, several interrelated themes emerged relating to the needs and challenges in palliative care including the development of community-based models of care, health worker wellbeing, disparities in care, and the importance of guidelines and consensus in palliative care practice. The following is a comprehensive discussion that integrates the findings from these studies:

1. Needs and Challenges in Palliative Care

Studies by Hostanida Purba et al. (2023) and Afiyanti et al. (2021) highlighted the urgent need for family carers and partners of cancer patients to obtain adequate financial support and information. Difficulties in managing living budgets and cancer treatment costs, as well as the need for legal and health information, suggest that palliative care in Indonesia still faces major challenges in providing comprehensive support for patients' families. These findings are in line with the study by Dasat et al. (2023), which emphasised the importance of financial support and collaboration with health professionals for families of patients with advanced cancer (Purba et al., 2023; Afiyanti et al., 2021;Dasat et al., 2023).

2. Community-based Palliative Care Development

The development of community-based palliative care (CBPC) models has been the focus of several studies. Lubbna (2020) proposed the adaptation of successful CBPC models in India and Uganda to the Indonesian context, highlighting the importance of effective financial management and the role of volunteers. While Dahniar et al. (2023) showed that training CBPC cadres can improve knowledge and provide sustainable services such as home visits. This is also in line with the findings of Effendy et al. (2022) who showed significant benefits of home-based paediatric palliative care in improving the quality of life of children with cancer and their families (Lubbna & Lane, 2020; Dahniar et al., 2023; Effendy et al., 2022).

3. Burnout and Wellbeing of Healthcare Workers

Burnout and wellbeing of healthcare workers are important issues identified in the literature. Cloconi et al. (2023) emphasised the need for adequate health system preparation to support health workers in dealing with emergency situations such as the COVID-19 pandemic. This study suggests that psychological and operational support is necessary to reduce burnout among health workers. Nugroho et al. (2022) also highlighted the importance of continuous training for ICU nurses to improve the quality of palliative care. While Hernández-Zambrano et al. (2020) further emphasised that end-of-life care should include physical, emotional and spiritual aspects for both patients and healthcare workers (Cloconi et al., 2023; Dwi Nugroho et al., 2022; Hernández-Zambrano et al., 2020).

4. Disparities in Palliative Care

Torensma et al. (2020) revealed disparities in access and quality of palliative care based on migration background in the Netherlands. Patients with non-Western migration backgrounds received less optimal palliative care and end-of-life decisions such as euthanasia. This suggests that cultural factors and socio-economic background may influence the quality of care received by patients. These disparities are noteworthy in the Indonesian context as well, as demonstrated by studies highlighting the challenges faced by caregivers and families of cancer patients (Torensma et al., 2020).

5. Guidelines and Consensus in Palliative Care

The studies of Radbruch et al. (2020) and Cederholm et al. (2024) emphasised the importance of guidelines and consensus in palliative care. This was also conveyed by Radbruch et al. that clear definitions and global consensus are important to improve understanding and consistent implementation of palliative care in various countries. Whereas Cederholm et al. provide detailed guidelines for the assessment of inflammation in the diagnosis of malnutrition, which is important to ensure appropriate nutritional interventions in palliative care (Radbruch et al., 2020; Cederholm et al., 2024).

Findings from the analysed literature suggest that palliative care requires a holistic and integrated approach, involving financial support, education and training for caregivers, families and health workers. The development of community-based care and ongoing training for health workers are essential to improve the quality of palliative care. Global guidelines and consensus also help to provide more consistent and evidence-based care across different contexts.

The issue of disparities in care must be addressed to ensure that all patients, regardless of their socio-economic or cultural background, receive appropriate and equitable care. By addressing these challenges, the quality of life of cancer patients and their families can be improved, and the well-being of the health workers who care for them can be assured. A combination of financial support, continuous training, community development and global consensus will be important steps in achieving effective and sustainable palliative care.

CONCLUSION

Families and partners of cancer patients face a range of challenges, including financial barriers, lack of information and education, and inadequate training for health workers in palliative care. In addition, fatigue and wellbeing of health workers are also significant barriers. Access and quality of care varies based on socio-economic and cultural backgrounds, potentially hindering equal access for all patients. Community-based palliative care can be a potential solution, but requires effective financial management and training for volunteers and cadres. The lack of guidelines and consensus in palliative care, as is the case in Indonesia, may hinder the implementation of consistent and evidence-based care. To address these challenges, a holistic approach is needed that includes strengthening financial support for patients' families, improving access to information and education on palliative care, and intensive training for health workers. In addition, it is important to develop policies that ensure the well-being of health workers to prevent burnout. Community-based palliative care programmes should be supported by transparent and sustainable financial management strategies, as well as comprehensive training for volunteers and cadres to enable them to provide effective support. The establishment of clear and evidence-based national guidelines is also crucial to ensure equitable and quality palliative care across the country.

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