e-ISSN: 2774-2962

Community Medicine and Education Journal

CMEJ

https://hmpublisher.com/index.php/cmej

The Impact of Health Policy on Community-Based Palliative Care Services: A Mixed-Methods Evaluation in Bandung, Indonesia

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ARTICLE INFO

Keywords:
Bandung
Community-based care
Health policy
Mixed-methods
Palliative care

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All authors have reviewed and approved the final version of the manuscript.

https://doi.org/10.37275/cmej.v6i1.697

ABSTRACT

Palliative care is a crucial component of comprehensive healthcare, yet access to community-based palliative care services remains limited in many low- and middle-income countries, including Indonesia. This study aimed to evaluate the impact of existing health policies on community-based palliative care in Bandung, Indonesia. A mixed-methods approach was employed, combining quantitative and qualitative data collection and analysis. Quantitative data included a retrospective analysis of patient records (n=350) from three community-based palliative care providers in Bandung from 2018-2023, assessing referral patterns, service utilization, and patient demographics. Qualitative data were gathered through semi-structured interviews with policymakers (n=10), healthcare providers (n=15), and patients/caregivers (n=20) to explore their perspectives on policy implementation and its impact. Data were analyzed using descriptive statistics, thematic analysis, and a framework approach guided by the WHO Health Systems Framework. The study found that while national health policies acknowledge the importance of palliative care, significant gaps exist in implementation at the local level. The number of patients accessing community-based palliative care increased modestly from 45 in 2018 to 78 in 2023, but this represents a small fraction of the estimated need. Key policy-related barriers identified included: limited funding allocated specifically for community-based palliative care , inadequate training and workforce capacity in palliative care, lack of standardized referral pathways from hospitals to community-based services and limited public awareness of palliative care. In conclusion, health policies in Indonesia have not yet translated into widespread access to quality community-based palliative care in Bandung. Strengthened policy implementation, increased funding, workforce development, improved referral systems, and enhanced public awareness are crucial to address this gap and improve the quality of life for patients with life-limiting illnesses and their families.

1. Introduction

In an era marked by demographic shifts and evolving disease burdens, the demand for palliative care is escalating globally. Palliative care, as defined by the World Health Organization (WHO), is a comprehensive approach that focuses on enhancing the quality of life for patients and their families facing life-threatening illnesses. This approach emphasizes the early identification and meticulous assessment of pain and other physical, psychosocial, and spiritual issues, aiming to prevent and alleviate suffering. The global need for palliative care is substantial, with an estimated 40 million people requiring such care annually. Notably, the majority of those in need, approximately 78%, reside in low- and middle-income countries (LMICs). The increasing prevalence of non-communicable diseases (NCDs), such as cancer, cardiovascular diseases, and chronic respiratory illnesses, is a significant driver of this growing demand for palliative care. These conditions often lead to prolonged illness trajectories and complex symptom burdens, requiring specialized care to manage pain, address psychosocial distress, and provide support for patients and their families. Furthermore, the global trend of aging populations further intensifies the need for palliative care, as older adults are more likely to experience multiple chronic conditions and require comprehensive support to maintain their quality of life.[1-2]

Indonesia, as the world's fourth most populous nation, faces a particularly acute challenge in meeting the burgeoning need for palliative care. The country is experiencing a demographic transition characterized by an aging population and a rising burden of NCDs. These factors contribute to an increased demand for palliative care services, which the existing healthcare system is currently ill-equipped to handle. While Indonesia has made commendable strides in expanding healthcare access through the Jaminan Kesehatan Nasional (JKN), its national health insurance scheme, the integration of palliative care within this system remains incomplete. This leaves a significant gap in the provision of essential services for patients with life-limiting illnesses and their families.[3-4]

Community-based palliative care, which delivers care in patients' homes or familiar community settings, is of paramount importance in addressing the palliative care gap in Indonesia. This model of care aligns with cultural preferences for home-based care and addresses the limited availability of specialized palliative care units in hospitals. It also proves particularly valuable given Indonesia's geographically dispersed population, ensuring that care reaches those in remote or underserved areas. Community-based palliative care offers numerous benefits for patients and their families. It allows patients to receive care in the comfort of their own homes, surrounded by loved ones, which can significantly improve their quality of life. It also reduces the financial burden associated with hospitalizations and allows for more personalized and holistic care.[5-6]

The Indonesian government has recognized the importance of palliative care by issuing national policies and guidelines, including the National Palliative Care Policy in 2007. These policies underscore the need for integrated palliative care services across all levels of care. However, translating these national policies into effective implementation at the local level, particularly in community-based settings, has proven challenging. Several policy-related barriers hinder the development and accessibility of community-based palliative care in Indonesia. These include limited funding allocated specifically for community-based palliative care, inadequate training and workforce capacity in palliative care, lack of standardized referral pathways from hospitals to community-based services, and limited public awareness of palliative care.[7-8]

Bandung, a major urban center in Indonesia, serves as a relevant case study for examining the impact of health policy on community-based palliative care. The city boasts a diverse population, a mix of public and private healthcare providers, and several organizations offering community-based palliative care services. However, access to these services remains uneven, and various policy-related barriers impede their effectiveness. Previous research on palliative care in Indonesia has predominantly focused on hospital-based settings or specific aspects of palliative care, such as pain management. There is a dearth of research investigating the broader impact of health policies on the delivery and accessibility of community-based palliative care services, particularly using a mixed-methods approach that combines quantitative data on service utilization with qualitative insights from key stakeholders.[9-10] This study aims to address this gap by conducting a comprehensive mixed-methods evaluation of the impact of health policies on community-based palliative care services in Bandung, Indonesia.

2. Methods

This study employs a mixed-methods approach to comprehensively evaluate the impact of health policies on community-based palliative care services in Bandung, Indonesia. This approach integrates quantitative and qualitative data collection and analysis methods, providing a more nuanced and holistic understanding of the complex interplay between policy and practice in palliative care provision. The study adopts an explanatory sequential mixed-methods design, a two-phase approach where quantitative data collection and analysis precede the qualitative phase. This design allows for the quantitative findings to guide the subsequent qualitative inquiry, providing a deeper understanding of the statistical results and exploring the underlying reasons and contextual factors that shape them. In the initial quantitative phase, we will gather data on patient demographics, referral patterns, service utilization, and other relevant metrics. The subsequent qualitative phase will involve semi-structured interviews with key stakeholders, including policymakers, healthcare providers, and patients and their caregivers. This qualitative data will help explain the quantitative trends, explore the perspectives and experiences of those involved in palliative care, and identify challenges and opportunities related to policy implementation.

The study is conducted in Bandung, the capital city of West Java province and one of Indonesia's largest urban centers. Bandung is selected as the study site due to its diverse population, a mix of public and private healthcare providers, and the presence of several organizations offering community-based palliative care services. This setting provides a relevant context for examining the impact of health policies on community-based palliative care, as it reflects the challenges and opportunities present in many urban areas of Indonesia. The findings from Bandung can potentially be generalized to other similar settings, contributing to a broader understanding of palliative care provision in the country.

The quantitative phase involves a retrospective analysis of patient records from three community-based palliative care providers in Bandung. These providers are purposively selected to represent a range of organizational models, including a non-governmental organization (NGO), a hospital-affiliated program, and a private foundation. This purposive sampling strategy ensures the inclusion of diverse perspectives and experiences in palliative care provision. All patient records from January 1, 2018, to December 31, 2023, meeting the inclusion criteria are included in the analysis. A total of 350 patient records are reviewed, providing a substantial sample size for quantitative analysis. The qualitative phase involves semi-structured interviews with three key stakeholder groups; Policymakers: Ten policymakers involved in health policy development and implementation at the national and local levels are purposively selected. This includes representatives from the Ministry of Health, the West Java Provincial Health Office, and the Bandung City Health Office. This sampling strategy ensures the inclusion of policymakers with diverse perspectives and responsibilities related to palliative care; Healthcare Providers: Fifteen healthcare providers working in community-based palliative care are purposively selected. This includes physicians, nurses, social workers, and spiritual care providers, representing the three participating organizations. This sampling strategy ensures the inclusion of healthcare providers with diverse roles and experiences in palliative care provision; Patients and Caregivers: Twenty patients receiving community-based palliative care or their primary caregivers are purposively selected. This sample represents a range of ages, diagnoses, and socioeconomic backgrounds, ensuring the inclusion of diverse patient and caregiver perspectives and experiences.

Quantitative data is collected through a retrospective review of patient records using a standardized data extraction form. The form is designed to gather information on the following; Patient Demographics: Age, gender, diagnosis, socioeconomic status (estimated based on occupation and address), and insurance status (JKN coverage); Referral Source: Hospital, primary care physician, self-referral, or other sources; Services Received: Medical consultations, nursing care, psychosocial support, spiritual care, bereavement support, and medical equipment loan; Service Utilization: Number of home visits and duration of care; Palliative Performance Scale (PPS): PPS scores at intake and discharge, where available, to assess the patient's functional status. Trained research assistants familiar with medical records and palliative care terminology collect the data, ensuring consistency and accuracy in data extraction. Qualitative data is collected through semi-structured interviews with the selected stakeholders. Separate interview guides are developed for each stakeholder group, focusing on the following topics; Policymakers: Awareness of palliative care policies, implementation challenges, perceived impact of policies, and suggestions for improvement; Healthcare Providers: Experiences providing community-based palliative care, challenges faced, perceptions of policy impact, and suggestions for improvement; Patients and Caregivers: Experiences receiving community-based palliative care, perceived benefits and challenges, satisfaction with services, and suggestions for improvement. Trained interviewers fluent in both Bahasa Indonesia and English conduct the interviews in Bahasa Indonesia, the local language. The interviews are audio-recorded with the participants' consent and transcribed verbatim for analysis.

Quantitative data is entered into SPSS version 28 for statistical analysis. Descriptive statistics, including frequencies, percentages, means, and standard deviations, are used to summarize the data and describe the study population and service utilization patterns. Chi-square tests and t-tests are employed to examine associations between variables, such as referral source and service utilization, exploring potential relationships between patient characteristics and the care they receive. Qualitative data is analyzed using a framework approach guided by the WHO Health Systems Framework. This framework provides a comprehensive lens for examining the various components of the health system that influence palliative care provision, including service delivery, health workforce, health information systems, access to essential medicines, financing, and leadership/governance. The transcripts are coded using NVivo 12 software, facilitating the organization and analysis of qualitative data. The coding process involves both deductive coding, based on the WHO framework, and inductive coding to identify emergent themes and patterns within the data. The analysis focuses on identifying key themes and patterns related to the impact of health policies on community-based palliative care, drawing on the perspectives and experiences of the various stakeholders.

Ethical approval for this study is obtained from the Research Ethics Committee of CMHC Indonesia, ensuring the study adheres to ethical guidelines and protects the rights and well-being of participants. Informed consent is obtained from all participants in the qualitative phase, ensuring their voluntary participation and understanding of the study's purpose and procedures. For the quantitative phase, a waiver of consent is granted by the ethics committee, as the data is collected retrospectively from existing records and anonymized, protecting patient privacy. Confidentiality and anonymity are maintained throughout the study by assigning unique identifiers to participants and removing any identifying information from the data. This ensures that participants' identities are protected and that they can share their experiences and perspectives without fear of reprisal.

3. Results

Table 1 provides a breakdown of the demographic characteristics of the 350 patients included in the study. The majority of patients were 50 or older. The largest group (34.3%) fell within the 50-64 age range, followed closely by those aged 65-79 (31.4%). This aligns with the fact that many life-limiting illnesses, especially chronic diseases, become more prevalent with age. There was a fairly even distribution between males (45.7%) and females (54.3%). This suggests that access to community-based palliative care in this sample wasn't heavily skewed towards one gender. Cancer was the most common diagnosis (60%), followed by cardiovascular diseases (20%) and respiratory diseases (11.4%). This reflects the global trend of non-communicable diseases being major contributors to the need for palliative care. A significant portion of patients came from low socioeconomic backgrounds (40%), with middle (45.7%) and high (14.3%) following. This indicates that community-based palliative care is reaching those with lower incomes, which is important for equitable access to care. 60% of patients had JKN coverage, while 40% did not. This suggests that while JKN plays a role in facilitating access to palliative care, a substantial portion of patients still lack this insurance. This raises questions about the affordability and financial burden of palliative care for those without JKN. The average PPS score at intake was 45, dropping to 32 at discharge. The PPS is a measure of functional ability, with lower scores indicating more severe disability. This decrease suggests that patients' functional status declined during their time receiving community-based palliative care. This could be due to the natural progression of their illnesses. However, it also highlights the need for further investigation into the effectiveness of the care provided in preventing functional decline or improving quality of life.

Table 1. Patient demographics (n=350).

Characteristic	Category	Frequency (n)	Percentage (%)
Age (Years)	< 50	55	15.7
	50-64	120	34.3
	65-79	110	31.4
	≥ 80	65	18.6
Gender	Male	160	45.7
	Female	190	54.3
Diagnosis	Cancer	210	60.0
	Cardiovascular Disease	70	20.0
	Respiratory Disease	40	11.4
	Other	30	8.6
Socioeconomic Status	Low	140	40.0
	Middle	160	45.7
	High	50	14.3
JKN Coverage	Yes	210	60.0
	No	140	40.0
PPS at Intake (mean)		45	
PPS at Discharge (mean)		32	

Table 2 illustrates the diverse pathways through which patients accessed community-based palliative care services; Self-Referral (40%): A significant portion of patients referred themselves to palliative care services. This suggests a degree of awareness among patients and families about the availability of such care. However, it also raises questions about whether these individuals might have benefited from earlier referrals through healthcare professionals, potentially leading to earlier access to symptom management and support; Primary Care Physician (20%): Referrals from primary care physicians constituted a notable portion. This highlights the important role of primary care in identifying patients who could benefit from palliative care and initiating the referral process; Other (28%): This category encompasses a variety of sources, potentially including community health workers, social workers, or other healthcare providers. It underscores that referrals can come from various avenues beyond hospitals and primary care; Hospital (12%): Surprisingly, hospital referrals accounted for the smallest percentage. This low rate is concerning as it indicates a potential disconnect between hospital-based care and community-based palliative care services. It suggests that opportunities for transitioning patients from hospital settings to community-based care may be missed, potentially leading to delayed or fragmented care.

Table 2. Referral source (n=350).

Referral source	Frequency (n)	Percentage (%)
Hospital	42	12.0
Primary care physician	70	20.0
Self-referral	140	40.0
Other	98	28.0

Table 3 provides valuable insights into the types of services received by the 350 patients in the study; Medical Consultations (85.7%): The vast majority of patients received medical consultations, highlighting the core role of physicians in providing palliative care. This likely includes assessment, diagnosis, symptom management, and medication prescribing; Nursing Care (91.4%): Nursing care was the most frequently received service. This encompasses a wide range of support, including vital sign monitoring, medication administration, wound care, and assistance with daily activities. The high percentage underscores the crucial role of nurses in delivering hands-on care and support to patients in the community; Psychosocial Support (71.4%): A substantial proportion of patients received psychosocial support. This is essential in palliative care to address the emotional, social, and psychological impact of life-limiting illnesses on patients and their families. It may include counseling, support groups, and assistance with coping strategies; Spiritual Care (51.4%): Over half of the patients received spiritual care, reflecting the importance of addressing spiritual needs and concerns in palliative care. This could involve providing access to religious leaders, facilitating spiritual practices, and offering support for existential distress; Bereavement Support (42.9%): This service provides support and counseling to families after the death of a loved one. The inclusion of bereavement support highlights the commitment of community-based palliative care to providing comprehensive care that extends beyond the patient's life; Medical Equipment Loan (28.6%): A significant number of patients benefited from the loan of medical equipment, such as hospital beds, wheelchairs, and oxygen concentrators. This service helps ensure that patients have access to the necessary equipment to manage their symptoms and maintain their comfort at home; Average Home Visits/Month (3.2): On average, patients received 3.2 home visits per month. This indicates regular contact between healthcare providers and patients, allowing for ongoing monitoring, symptom management, and support.

Table 3. Services received (n=350).

Service	Frequency (n)	Percentage (%)
Medical Consultations	300	85.7
Nursing Care	320	91.4
Psychosocial Support	250	71.4
Spiritual Care	180	51.4
Bereavement Support	150	42.9
Medical Equipment Loan	100	28.6
Average Home Visit/month	3.2	

Figure 1 visually represents the trends in the number of patients receiving community-based palliative care in Bandung from 2018 to 2023. The pie chart format allows us to see the proportion of patients served each year relative to the total number of patients over the six-year period. While the exact numbers aren't provided, it's clear that the proportion of patients receiving care has generally increased over time. This suggests a positive trend in the reach of community-based palliative care services in Bandung. The pie slices show some variation in size from year to year. For example, 2023 represents the largest slice (20.5%), indicating that this year saw the highest proportion of patients. On the other hand, 2018 has the smallest slice (11.8%), suggesting that the service was reaching fewer people then. These fluctuations could be due to various factors, including changes in awareness, funding, or availability of services. There don't appear to be any dramatic spikes or dips in patient numbers. This suggests a relatively steady, albeit gradual, increase in service utilization over the six years.

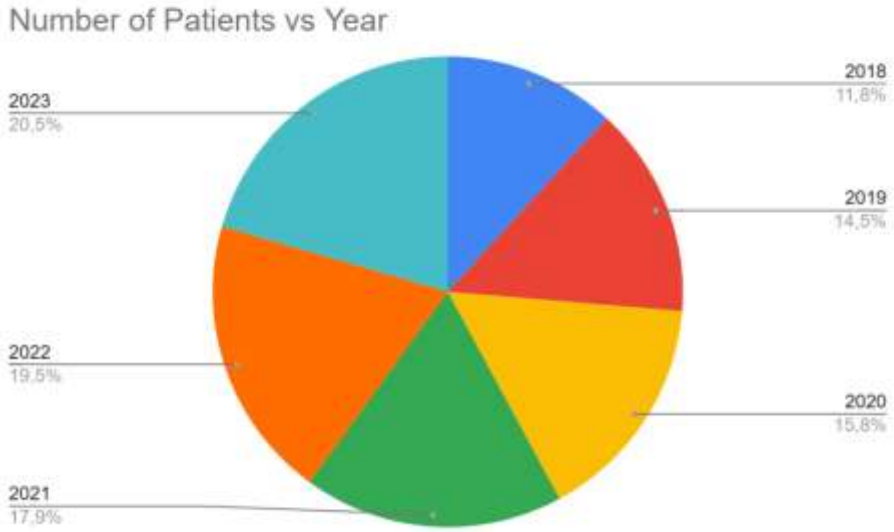

Figure 1. Trends in community-based palliative care patient numbers in Bandung (2018-2023).

Table 4 presents a rich tapestry of qualitative findings from the study, organized by the WHO Health Systems Framework. This framework provides a helpful lens for understanding the various factors influencing the delivery of community-based palliative care; Leadership & Governance: While there's awareness of national palliative care policies, particularly at the national level, a gap exists in translating these policies into practical guidance for local implementation. This disconnect is evident in the quotes from both national policymakers and local healthcare providers, highlighting a need for more concrete steps and operationalization of policies at the community level. The study reveals poor coordination and collaboration between different government departments and between the public and private sectors. This fragmentation hinders the seamless delivery of palliative care, as different agencies operate in silos with varying budgets and priorities. There's a clear need for more specific guidelines, protocols, and operational manuals for community-based palliative care. This includes standardized training curricula, service provision guidelines, and quality monitoring indicators. The absence of such standards makes it challenging to ensure consistency and quality of care across different providers; Financing: A severe lack of funding emerges as a critical barrier. Palliative care is often allocated a minuscule portion of the overall health budget, leading to reliance on donations, volunteers, and underpaid staff. This financial constraint limits the capacity to expand services, provide adequate resources, and ensure the sustainability of community-based palliative care programs. While the JKN aims to provide universal health coverage, inconsistencies in its coverage for palliative care services create confusion and barriers for patients and providers. Unclear policies and limited coverage for essential services like psychosocial and spiritual care hinder comprehensive palliative care provision. The reliance on project-based funding creates instability and hinders long-term planning for community-based palliative care programs. This uncertainty makes it challenging to build sustainable programs and invest in staff, infrastructure, and service expansion; Health Workforce: There's a significant shortage of healthcare professionals with specialized training in palliative care, particularly doctors and nurses. This scarcity is compounded by geographic maldistribution, with trained professionals concentrated in urban centers. Limited access to affordable and relevant training programs further exacerbates the workforce shortage. Existing training programs may be expensive, inaccessible, or fail to adequately address the specific needs of community-based palliative care. Low salaries, poor working conditions, and the emotionally demanding nature of palliative care contribute to high staff turnover. This constant churn undermines the continuity and quality of care and makes it challenging to build a stable and experienced palliative care workforce; Health Information Systems: Inconsistent data collection methods and a lack of standardized tools hinder the ability to track and compare palliative care provision across different providers. This makes it difficult to monitor performance, identify areas for improvement, and advocate for increased resources based on evidence. Even when data is collected, it's often not effectively utilized for planning and resource allocation. This missed opportunity limits the ability to make data-driven decisions and improve the efficiency and effectiveness of palliative care services. The lack of a national registry makes it challenging to track palliative care provision nationwide, understand the scope of services, and identify gaps in coverage. This hinders the development of a comprehensive national strategy for palliative care; Access to Essential Medicines: Strict regulations and fear of misuse create barriers to accessing essential opioid analgesics for pain management in palliative care. This can lead to unnecessary suffering for patients and limit their ability to maintain their quality of life. Stockouts and delays in the supply chain for essential palliative care medicines, including opioids, disrupt care and cause distress for patients and families. This unreliable supply chain underscores the need for a more robust system to ensure access to essential medications. The high cost of medications, particularly for uninsured patients, poses a significant financial barrier to accessing essential palliative care. This can force families to make difficult choices between purchasing medications and other essential needs; Service Delivery: Palliative care services tend to be concentrated in urban areas, leaving rural communities underserved. This uneven distribution of services creates inequities in access to care and requires patients to travel long distances to receive support. Poor referral pathways and a lack of integration with primary care lead to missed opportunities for early identification and referral of patients who could benefit from palliative care. This late referral can limit the effectiveness of palliative care and result in patients receiving care only in the later stages of their illness. A shortage of trained staff, including social workers and spiritual counselors, limits the provision of psychosocial and spiritual support, which are essential components of comprehensive palliative care. This gap leaves many patients and families struggling with emotional, social, and spiritual distress.

Table 4. Qualitative findings: key themes and illustrative quotes by WHO health systems framework building block.

WHO building block	Theme	Sub-theme (if applicable)	Illustrative quotes
1. Leadership & Governance	**Policy Awareness and Commitment (Mixed)**	**National Level Awareness: High awareness of national policies, but limited practical guidance.**	*"We have the national policy on palliative care, and it's a priority in the Ministry's strategic plan. But we need more concrete steps on how to actually do it at the community level." (National Policymaker); "The national policy is good on paper, but it doesn't tell us how to set up a community program, how to get funding, or how to train our staff." (Local Healthcare Provider)*
		Local Level Implementation Gaps: Disconnect between national policy and local action.	*"There's a lot of talk about palliative care, but when you look at the city health budget, there's barely anything allocated specifically for it." (Local Policymaker); "We feel like we're working in isolation. There's no clear leadership or support from the district health office." (Community-Based Palliative Care Nurse)*
	Coordination and Collaboration (Poor)	**Inter-agency Fragmentation: Lack of coordination between government departments.**	*"The Ministry of Health has its policy, the Ministry of Social Affairs has its programs for the elderly, but they don't really talk to each other." (National Policymaker); "We try to collaborate with the social services, but it's difficult. Different budgets, different priorities." (Healthcare Provider)*
		Public-Private Sector Disconnect: Challenges in integrating public and private providers.	*"The private sector has some excellent palliative care services, but they are mostly for the wealthy. How do we make sure the poor have access too?" (Policymaker); "We'd like to partner with the government hospitals, but it's hard to navigate the bureaucracy." (Private Palliative Care Provider)*
	Lack of Clear Guidelines and Standards	**Absence of Practical Guidance: Need for detailed protocols and operational manuals.**	*"We need clear guidelines on what community-based palliative care should look like in Indonesia. What services should be offered? What are the minimum staffing requirements?" (Healthcare Provider); "There's no standardized training curriculum for community palliative care nurses." (Nurse Educator)*
		Quality Monitoring Challenges: Difficulty in assessing and ensuring service quality.	*"How do we measure the quality of community-based palliative care? We don't have any standard indicators." (Policymaker); "It's hard to know if we're doing a good job because there's no benchmark to compare ourselves to." (Healthcare Provider)*
2. Financing	**Insufficient Funding (Severe)**	**Limited Budget Allocation: Inadequate resources for operational costs and expansion.**	*"The budget for palliative care is a tiny fraction of the overall health budget. It's simply not enough to meet the need." (Local Health Official); "We rely heavily on donations and volunteers. We can't afford to pay our staff decent salaries." (NGO Palliative Care Provider)*
		Competition for Resources: Palliative care often loses out to other health priorities.	*"There are so many competing demands – infectious diseases, maternal health, child health. Palliative care often gets pushed to the bottom of the list." (Policymaker)*
	JKN Coverage Inconsistencies	**Unclear Coverage Policies: Ambiguity about which services are covered.**	*"The JKN rules are confusing. Some patients get their home visits covered, others don't. It seems to depend on the individual case manager." (Healthcare*

			Provider); "We had to fight to get my mother's pain medication covered by JKN. It was a long and stressful process." (Caregiver)
		Limited Coverage for Essential Services: Many crucial aspects of palliative care not covered.	*"JKN covers basic medical consultations, but not psychosocial support or spiritual care, which are essential parts of palliative care." (Social Worker); "We often can't afford to provide the full range of services that patients need because JKN doesn't cover everything." (Palliative Care Physician)*
	Lack of Dedicated Funding Streams	**Project-Based Funding: Instability and lack of long-term planning.**	*"We get funding from year to year, based on proposals. It's hard to build a sustainable program when you don't know if you'll have funding next year." (NGO Director); "There's no line item in the local government budget specifically for community-based palliative care." (Local Policymaker)*
3. Health Workforce	**Shortage of Trained Professionals**	**Overall Scarcity: Lack of doctors, nurses, and other specialists with palliative care expertise.**	*"There are very few doctors in Bandung who have specialized training in palliative care. Most of us are learning on the job." (Physician); "We desperately need more nurses with palliative care skills, but there aren't enough to go around." (Nurse Manager)*
		Geographic Maldistribution: Trained professionals concentrated in urban centers.	*"Most of the palliative care specialists are in Jakarta. It's hard to attract them to work in smaller cities like Bandung." (Policymaker); "We have a hard time recruiting trained staff to work in the more rural areas outside the city center." (Healthcare Provider)*
	Lack of Training Opportunities	**Limited Access to Training: Few affordable and accessible training programs.**	*"The training programs are expensive and often require travel to other cities, which is difficult for many healthcare workers." (Nurse); "We need more local training opportunities, specifically designed for community-based palliative care." (Healthcare Provider)*
		Curriculum Gaps: Existing training may not adequately address community-based needs.	*"The training we received focused mostly on hospital-based palliative care. We need more training on how to manage patients at home, how to work with families, and how to navigate the local healthcare system." (Community Nurse)*
	High Staff Turnover	**Low Salaries and Poor Working Conditions: Leading to burnout and staff leaving the field.**	*"The pay is very low, and the work is emotionally demanding. Many nurses burn out and leave for better-paying jobs." (Nurse Manager); "We lose a lot of good people because we can't offer competitive salaries or benefits." (NGO Director)*
4. Health Information Systems	**Lack of Standardized Data Collection**	**Inconsistent Data Collection Methods: Each provider uses different systems.**	*"We all collect data, but we use different forms and different definitions. It's impossible to compare our performance." (Healthcare Provider); "There's no standardized way to track the number of patients receiving community-based palliative care in Bandung." (Local Health Official)*
		Data Quality Issues: Concerns about the accuracy and completeness of data.	*"The data in the patient records is often incomplete. It's hard to get a clear picture of what services patients are receiving." (Research Assistant)*
	Limited Use of Data for Decision-Making	**Data Not Used for Planning: Collected data not effectively utilized for resource allocation.**	*"We collect a lot of data, but I'm not sure how much it's actually used to inform policy decisions." (Policymaker); "We need to use the data we have to show the need for palliative care and to advocate for more resources."*

			(Healthcare Provider)
	Absence of a National Palliative Care Registry	**Lack of National Overview: Difficulty in tracking palliative care provision nationwide.**	*"A national registry would be incredibly helpful. It would allow us to track the number of patients receiving palliative care, their needs, and the quality of services provided." (National Policymaker); "Without a national registry, it's hard to get a comprehensive picture of palliative care in Indonesia." (Researcher)*
5. Access to Essential Medicines	**Limited Availability of Opioid Analgesics**	**Strict Regulations: Difficulties in prescribing and dispensing opioids.**	*"The regulations are so tight that doctors are afraid to prescribe opioids, even when they are medically necessary." (Physician); "The paperwork required to prescribe opioids is incredibly burdensome. It takes up so much time." (Nurse)*
		Fear of Misuse: Concerns about opioid addiction and diversion.	*"There's a lot of fear and stigma around opioids. People are afraid that patients will become addicted." (Pharmacist); "We need to educate healthcare providers and the public about the safe and effective use of opioids for pain management." (Palliative Care Specialist)*
	Supply Chain Issues	**Stockouts and Delays: Interruptions in the supply of essential medicines.**	*"We sometimes run out of morphine, and it can take weeks to get more. This is devastating for patients in pain." (Nurse); "The supply chain for palliative care medicines is unreliable. We need a better system to ensure that patients have access to the medications they need." (Pharmacist)*
	Affordability of Medications	**High Cost for Uninsured Patients: Financial barriers to accessing essential medications.**	*"The cost of pain medication is a huge burden for many families. They have to choose between buying medicine and buying food." (Caregiver); "Even with JKN, there are still co-payments and out-of-pocket expenses that can be difficult for low-income families." (Social Worker)*
6. Service Delivery	**Limited Geographic Coverage**	**Uneven Distribution of Services: Concentration of services in urban areas.**	*"There are very few palliative care services available in the rural areas surrounding Bandung. Patients have to travel long distances to get care." (Healthcare Provider)*
		Lack of Outreach Programs: Limited efforts to reach underserved populations.	*"We need to do more to reach out to patients in remote areas and to make sure they know about the services that are available." (Community Health Worker)*
	Lack of Integration with Primary Care	**Poor Referral Pathways: Lack of clear mechanisms for referring patients from primary care.**	*"Primary care doctors often don't know about palliative care or how to refer patients. We need to educate them." (Palliative Care Physician); "There's no formal system for referring patients from primary care clinics to community-based palliative care." (Nurse)*
		Missed Opportunities for Early Identification: Patients not identified and referred early enough.	*"Many patients are referred to us very late in their illness, when they are already very sick. We could do so much more if we could see them earlier." (Palliative Care Physician)*
	Inadequate Psychosocial and Spiritual Support	**Shortage of Trained Staff: Limited availability of social workers and spiritual counselors.**	*"We don't have enough social workers or counselors to meet the psychosocial and spiritual needs of our patients and families." (Healthcare Provider); "Many patients and families are struggling with grief, anxiety, and spiritual distress. We need more resources to support them." (Caregiver)*

4. Discussion

The quantitative findings demonstrate a modest increase in the number of patients accessing community-based palliative care over the study period, suggesting some progress in expanding service reach. However, this increase falls far short of meeting the estimated need for palliative care in Bandung, given the growing burden of non-communicable diseases (NCDs) and the aging population. This persistent gap underscores the urgent need for strengthened policy implementation and increased investment in community-based palliative care services. The low referral rates from hospitals highlight a critical disconnect between hospital-based care and community-based services. This finding aligns with research in other low- and middle-income countries, which also identifies weak referral systems as a major barrier to accessing palliative care. The high proportion of self-referrals suggests that patients and families are actively seeking palliative care services but may not be aware of formal referral pathways or may face barriers in accessing them through the healthcare system. This underscores the need for increased public awareness campaigns about palliative care and its benefits, as well as efforts to simplify the referral process.[11-15]

The qualitative findings, guided by the WHO Health Systems Framework, provide a deeper understanding of the policy-related barriers hindering the development of community-based palliative care in Bandung. These barriers span across various aspects of the healthcare system, creating a complex web of challenges that require a multifaceted approach to address. Insufficient funding emerges as the most significant challenge, echoing findings from other studies in resource-constrained settings. The lack of dedicated funding streams for community-based palliative care and the inconsistencies in Jaminan Kesehatan Nasional (JKN) coverage create financial instability and hinder the expansion and sustainability of services. Many providers rely heavily on donations and volunteers, struggling to cover operational costs and provide competitive salaries to attract and retain qualified staff. This financial constraint limits the capacity to provide comprehensive palliative care services, including essential components like psychosocial and spiritual support. It also creates challenges in accessing essential medicines, particularly opioid analgesics, which are often expensive and subject to strict regulations. The high cost of medications can be a significant burden for patients and families, particularly those without JKN coverage or with limited financial resources. The shortage of trained healthcare professionals in palliative care, particularly physicians and nurses, is another critical barrier. This shortage is exacerbated by limited training opportunities, high staff turnover, and the concentration of trained professionals in urban centers. Many healthcare providers in community-based settings are learning on the job, lacking access to formal training programs that equip them with the specialized knowledge and skills needed to provide quality palliative care. The high turnover rate among palliative care staff, driven by low salaries, poor working conditions, and the emotionally demanding nature of the work, further undermines the workforce capacity. This constant churn disrupts the continuity of care and hinders the development of a stable and experienced palliative care workforce. Investing in palliative care education and training, improving working conditions, and providing adequate remuneration are crucial to building a sustainable palliative care workforce. The lack of standardized data collection and the limited use of data for decision-making hinder efforts to monitor the performance of community-based palliative care services and advocate for increased resources. Each provider often uses different data collection systems and definitions, making it challenging to compare performance, identify trends, and assess the overall impact of palliative care services. The absence of a national palliative care registry further compounds this challenge, limiting the ability to track palliative care provision nationwide and identify gaps in coverage. A national registry would provide valuable insights into the number of patients receiving palliative care, their needs, and the quality of services provided, informing policy decisions and resource allocation. The limited availability and accessibility of essential medicines, particularly opioid analgesics, remain a major concern. Indonesia's strict regulations on opioid prescribing, while intended to prevent misuse, may inadvertently create barriers to accessing appropriate pain management for patients in need of palliative care. This reflects the global challenge of balancing the need for pain control with concerns about opioid misuse and addiction. Supply chain issues, including stockouts and delays, further complicate access to essential medicines, disrupting care and causing distress for patients and families. The high cost of medications, even with JKN coverage, can also pose a significant financial barrier for many patients. The findings also highlight the need for greater integration of community-based palliative care with primary healthcare services. This would facilitate early identification and referral of patients, improve continuity of care, and potentially reduce the burden on hospitals. Models of integrated palliative care have been successfully implemented in other countries and could be adapted to the Indonesian context. Expanding the geographic reach of palliative care services is also crucial, as services tend to be concentrated in urban areas, leaving rural communities underserved. This uneven distribution creates inequities in access to care and requires patients to travel long distances to receive support.[16-20]

5. Conclusion

This mixed-methods study evaluated the impact of health policies on community-based palliative care in Bandung, Indonesia, revealing a complex interplay of factors influencing service provision. While national policies support palliative care, local implementation gaps persist. A modest increase in patient numbers was observed, but substantial unmet needs remain. Key barriers include limited funding, workforce shortages, referral system gaps, and low public awareness. The study underscores the urgent need for strengthened policy implementation, increased funding, workforce development, and improved referral systems. Enhanced public awareness is also crucial. Addressing these challenges will improve access to quality community-based palliative care, ultimately enhancing the quality of life for patients with life-limiting illnesses and their families in Bandung. This research contributes valuable insights to the field of palliative care in Indonesia, highlighting the importance of a mixed-methods approach to comprehensively evaluate policy impact. The findings can inform policy recommendations and interventions to strengthen community-based palliative care services in Bandung and other similar settings. Further research is needed to explore the long-term effects of policy changes and to evaluate the effectiveness of interventions aimed at improving access to and quality of palliative care services.

6. References

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