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Research Article

Improving Palliative Care in Indonesia: Bridging Coverage Gaps and Integrating Spirituality for Comprehensive Healthcare

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Abstract

Universal Health Coverage (UHC) was implemented in Indonesia in 2014 to ensure healthcare access for all citizens. However, the provision of palliative care remains insufficient, despite its essential role in the holistic treatment of terminally ill patients, who often face significant financial obstacles. The impracticality of charging for spiritual care during palliative treatment, alongside the financial burden of home care on patients, is noteworthy. Addressing this gap, Panti Rapih Hospital Yogyakarta has proactively incorporated palliative care into its long-standing 94-year faith-based nonprofit institution embedded within longstanding religious traditions . This study utilizes an observational analytic methodology to explore the most effective model of palliative care within the context of Indonesia's primary healthcare system, a nation characterized by its six major religions. The main objective is to identify optimal strategies for screening palliative patients, delivering effective nursing care, and offering religious support tailored to family needs. The findings underscore the critical importance of non-out-of-pocket support in Indonesia's UHC framework for enhancing palliative care. Furthermore, integrating spirituality notably enhances the effectiveness and delivery of palliative services . In sum, Indonesia urgently requires comprehensive support for palliative care within the UHC framework, which involves removing financial barriers and recognizing spirituality's vital contribution to effective, holistic care. Implementing these initiatives will facilitate Indonesia's progress toward universal access to high-quality palliative care for all patients in need.

Background

Universal Health Coverage (UHC) in Indonesia has been operational through the National Health Insurance Program, since its initiation in 2014, in alignment with global public health frameworks to ensure equitable health access. The Healthcare Social Security Agency (BPJS Kesehatan) governs this UHC program, crafted primarily to guarantee the availability of essential quality healthcare services for all. This reflects a national effort to harmonize with international health standards to make health care more accessible and efficient, mirroring global trends in public health policy [1,2].

Within Indonesia's healthcare framework, social insurance schemes are regulated by the government to cater to the diverse needs of its population [3,4]. The first one is a contributory health insurance program that is tiered based on individuals' financial capability, with monthly premiums set at USD 9.3 for Class I, USD 6.2 for Class II, and USD 2.2 for Class III. This stratification ensures that a wider range of citizens can afford and access the necessary healthcare services, adhering to the principles of equity and inclusivity in health coverage [5].

The second scheme is a non-contributory health insurance plan specifically designed for the impoverished, fully funded by the government to alleviate the financial burden on the most vulnerable populations. Patients under this scheme do not incur any costs, making critical healthcare services accessible to those in dire need. Both contributory and non-contributory insurances adopt a Diagnosis-Related Groups (DRG)-based hospital payment system, which standardizes payments for hospital services, fostering an efficient and equitable health service delivery system across the country. This inclusivity underscores Indonesia's commitment to achieving UHC,

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ensuring that all citizens, regardless of their economic status, have access to necessary healthcare services [6,7].

Reflecting on Government Decree No. 51/2023 [8] and the stark differences in regional minimum wages (RMW) across Indonesia as seen on Figure 1, the challenge becomes evident: the uniform health insurance contributions and benefits do not take into account regional economic disparities, nor do they adequately cover the costs associated with palliative care, particularly in Type B hospitals, which commonly deliver such services. This static financing model places undue financial strain on individuals in regions with lower wages, and it also restricts the ability of the healthcare system to provide comprehensive palliative care services, which are crucial for maintaining the quality of life for patients with life-threatening illnesses.

Palliative care is a holistic approach to enhance the quality of life for individuals of all ages, including children, who are facing life-threatening illnesses. It focuses on those nearing the end of life by preventing and alleviating serious health-related suffering. This involves early identification, careful assessment, and comprehensive treatment of pain and other physical symptoms. Additionally, palliative care addresses psychosocial and spiritual concerns, providing support to both patients and their families. Striving to relieve suffering, palliative care ensures a dignified and comfortable experience through its service-oriented approach [10-12].

In light of these issues, the role of social insurance in palliative care should be reexamined and recalibrated. Social insurance schemes could introduce variable contribution rates based on an individual's income or geographic area, which would make the system more equitable. Additionally, these schemes could offer specialized palliative care packages, including home care services, which are currently not covered. This would not only provide more comprehensive care for patients in need but also alleviate the financial burden on families and caregivers, ensuring that palliative care is accessible to all, regardless of their economic status or where they live in Indonesia [10,13,14].

Religiously-affiliated nonprofit hospitals also have a critical role to play within this framework. By leveraging their community ties and moral authority, these hospitals can advocate for and implement sliding scale payment options for palliative care services, thus making them more accessible to the underserved populations. Furthermore, they can act as pioneers in developing community-based palliative care programs, mobilizing local resources, volunteers, and donations to support home care services. This approach not only extends the reach of palliative care services but also creates a community of care that supports patients and families during difficult times, embodying the principles of compassion and service at the heart of many religious organizations [15-17].

By addressing the financial barriers to palliative care head-on and leveraging the unique strengths of social insurance systems and religiously-affiliated nonprofit hospitals, Indonesia can create a more inclusive, compassionate, and effective healthcare system. This would represent a significant step toward achieving UHC and ensuring that all Indonesians have access to the care they need at the end of life. In accordance with government regulations on UHC aimed at addressing coverage gaps and embracing spirituality for holistic healthcare, this study was conducted to determine the optimal screening methods for palliative patients.

Study site

The current study took place at Panti Rapih Hospital, a religiously-affiliated nonprofit hospital with a remarkable history of 94 years of service, situated in the Special Region of Yogyakarta, Indonesia. This hospital, which boasts a capacity of 340 beds, is classified as a type B facility within the Indonesian healthcare system. In this category of hospitals, the cost of inpatient palliative care is estimated to range from USD 126 to 168 per case, calculated based on a DRG payment system [18-20].

Study design

An observational analytic method was employed to investigate the implementation and efficacy of a newly developed palliative care system in our hospital, spanning from February to August 2023. The establishment of this system was marked by three key activities: (1) the creation of a dedicated palliative care team, (2) the execution of systematic

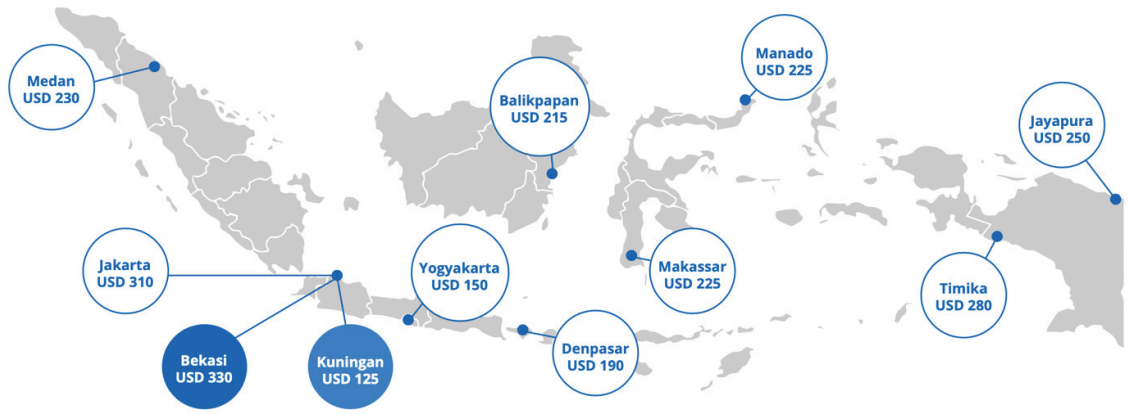

Figure 1: Regional Minimum Wages (RMW) in Indonesia [9].

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training sessions aimed at enhancing the team's knowledge and skills, and (3) the regular convening of team meetings to ensure continuous improvement and integration of care practices. Additionally, the study involved the selection and application of palliative screening tools, a critical component of the intervention model. Validated screening tools were adopted based on current empirical research and literature, ensuring that the methodology was both rigorous and aligned with established best practices in palliative care .

To further comprehend the broader context of palliative care within Indonesia, the study also incorporated a thorough data collection method aimed at exploring the policy landscape, particularly how palliative care is situated within the DRG-based hospital payment system. This aspect was crucial in understanding the financial and regulatory framework impacting the delivery of palliative care services, allowing for a comprehensive analysis of how systemic factors influence the accessibility and quality of palliative care.

This study distinguishes itself by focusing on the provision of palliative care services within missionary health services in Indonesia. Unlike other studies, it emphasizes the challenges posed by the country's Diagnosis-Related Group (DRG) payment system, which limits the cost of inpatient palliative care. In this context, missionary hospitals are compelled to uphold high standards of professional care despite financial constraints, offering a unique perspective not extensively explored in existing literature.

Discussion

The enduring commitment of Panti Rapih Hospital to delivering healthcare services in the UHC era is admirable, particularly its dedication to serving patients regardless of financial constraints. The integration of government financial schemes for inpatients, while intended to facilitate access to healthcare, has highlighted significant disparities in financial coverage, as evidenced by the negative balance between inpatient hospital costs and DRG payments over the years. Notably, in 2021, a financial shortfall, where hospital costs ($5.6 million) significantly exceeded DRG reimbursements ($3.3 million) highlights a concerning trend that also manifested in preceding years as shown in Figure 2.

These financial challenges underscore a crucial question regarding the sustainability of palliative care within the current reimbursement framework. Palliative care, inherently resource-intensive but essential for maintaining quality of life of seriously ill patients, faces a precarious future if existing financial mechanisms do not evolve to recognize and cover its comprehensive needs.

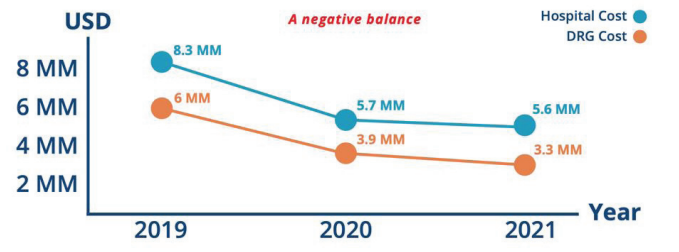

Figure 2: Inpatient Hospital Cost vs. DRG Cost in Panti Rapih Hospital.

In response to these challenges, Panti Rapih Hospital has proactively adopted a multifaceted approach to enhance palliative care delivery. Central to this strategy is the implementation of systematic training sessions designed to augment the healthcare team's capabilities in delivering palliative care. These initiatives ensure that staff are not only equipped with the requisite knowledge and skills but are also consistently aligned with current best practices in palliative care provision [10].

Moreover, the hospital's commitment to regular team meetings is pivotal for the continual reassessment and refinement of care practices. These gatherings serve as a platform for interdisciplinary dialogue, enabling the seamless integration of insights across various specialties, which is critical for holistic patient care [21,22].

The introduction of palliative care screening tools, including the Problems and Needs Questionnaire and the Prognostic Index, as seen in Figures 3,4 and Tables 1,2, represents a strategic move towards personalized care. By identifying patients' specific needs and estimating survival, these tools facilitate a tailored approach to palliative care, ensuring efficient and compassionate resource allocation .

Patients have been identified for palliative care through SPICT™ if they meet two or more general indicators, or at least one clinical indicator, with or without general indicators [23-26].

Panti Rapih Hospital offers a trio of no-cost health services designed to support patients and their families in a holistic manner, addressing the emotional, spiritual, and social aspects of care that extend beyond the clinical. The emphasis is on pastoral, medical, and social support, ensuring a comprehensive approach to patient care. By integrating these services, the hospital aims to look after the patient as a whole, recognizing that healing and comfort come from addressing every aspect of a patient's needs with care and compassion. This holistic approach is more than medical treatment; it's about providing emotional and spiritual support that respects the individual's dignity and their journey [34].

Another innovative service provided by the hospital is through its public relations team, which focuses on facilitating memory-making initiatives for patients and families for patients and their families. This unique service includes the crafting of heartfelt photographs that capture moments of love, support, and compassion. By offering this memory-making service free of charge to families, the hospital acknowledges the importance of memory-making in the healing process, providing families with tangible keepsakes that honor their loved ones and the time shared with them [35-38].

Moreover, the hospital has taken a significant step in enhancing palliative care by including a certified physician specifically trained as a pastoral thanatologist. This role is

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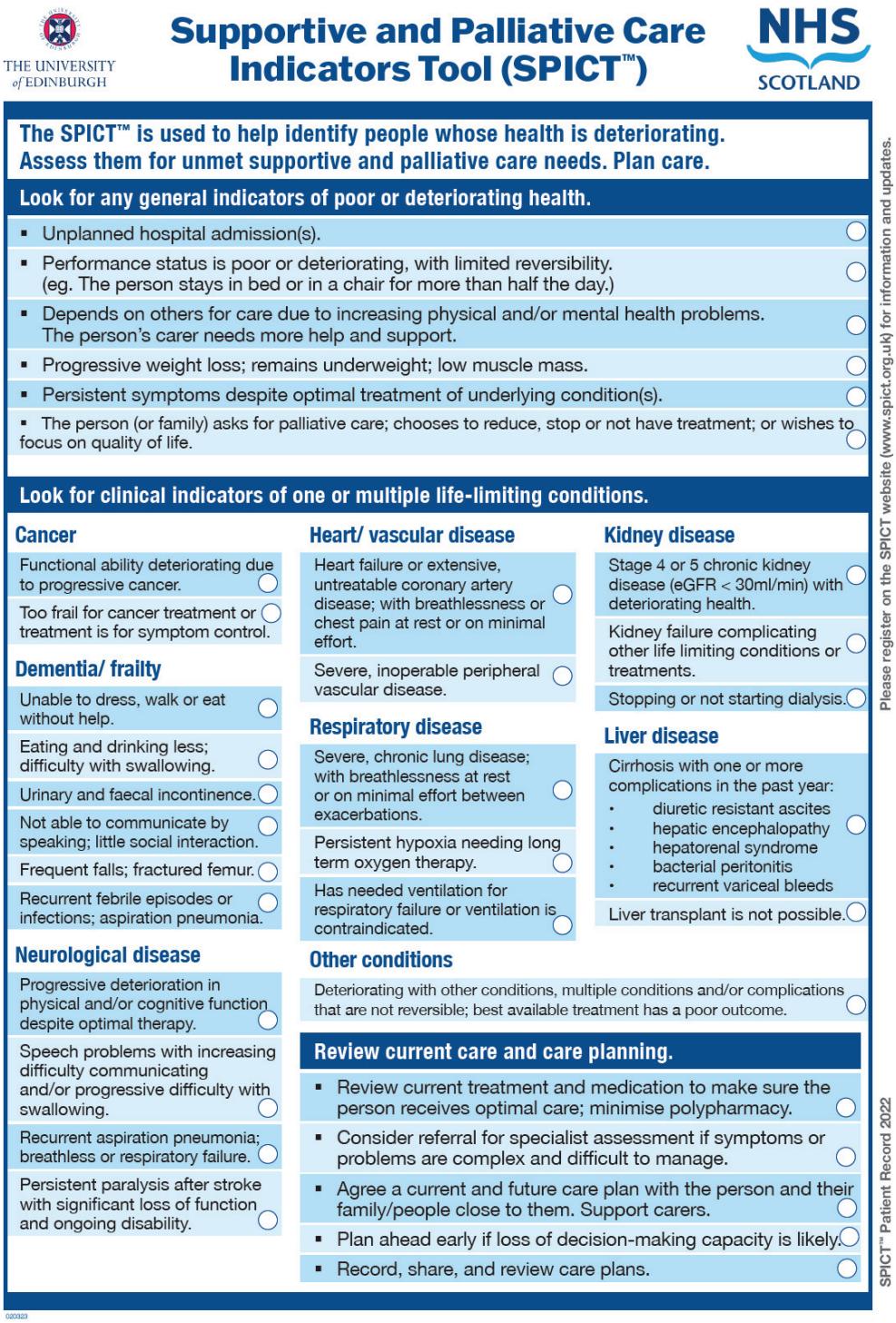

Figure 3: Supportive and Palliative Care Indicators Tool (SPICTTM) Available at https://www.spict.org.uk/the-spict/

crucial in recognizing the signs of approaching death, enabling the provision of profound support not only to the patient but also to their families throughout the challenging journey [39,40]. From pre-loss counseling to assisting in navigating the complex waters of grief and bereavement, this service is instrumental in providing holistic end-of-life care. This approach to bereavement support aims to ensure families receive compassionate guidance during their most challenging times [41,42].

Looking towards the future, Panti Rapih Hospital aspires to secure professional funding for these invaluable services, possibly through philanthropy. The hospital's experience underscores the significant role spirituality plays in enhancing the effectiveness of palliative care services. Recognizing services like spirituality, memory making, and bereavement support as essential components of holistic care, the hospital aspires to become a center of excellence for compassionate end-of-life care that offers support and healing, while

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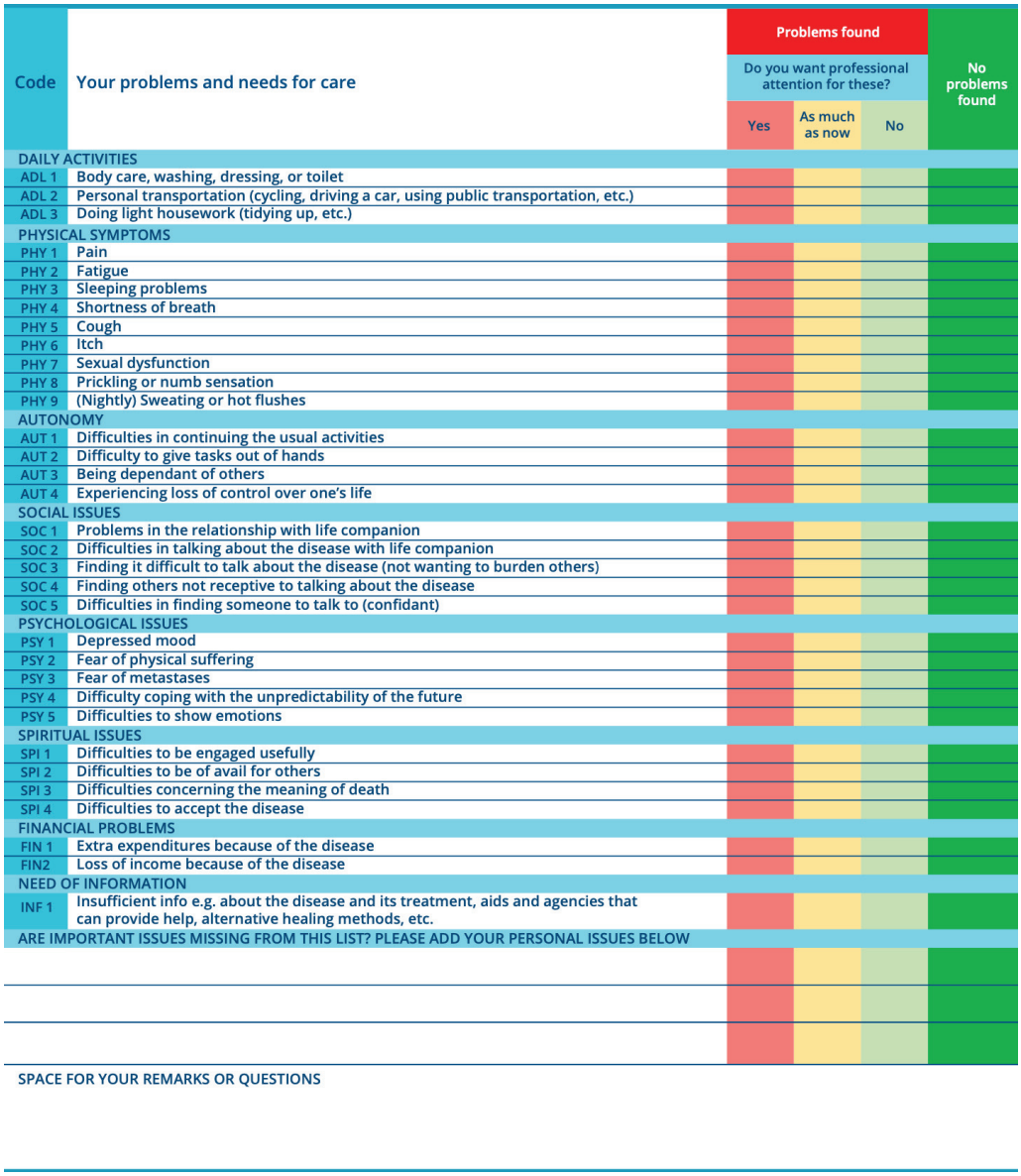

Code	Your problems and needs for care	Problems found: Do you want professional attention for these? Yes	As much as now	No	No problems found
DAILY ACTIVITIES					
ADL 1	Body care, washing, dressing, or toilet				
ADL 2	Personal transportation (cycling, driving a car, using public transportation, etc.)				
ADL 3	Doing light housework (tidying up, etc.)				
PHYSICAL SYMPTOMS					
PHY 1	Pain				
PHY 2	Fatigue				
PHY 3	Sleeping problems				
PHY 4	Shortness of breath				
PHY 5	Cough				
PHY 6	Itch				
PHY 7	Sexual dysfunction				
PHY 8	Prickling or numb sensation				
PHY 9	(Nightly) Sweating or hot flushes				
AUTONOMY					
AUT 1	Difficulties in continuing the usual activities				
AUT 2	Difficulty to give tasks out of hands				
AUT 3	Being dependant of others				
AUT 4	Experiencing loss of control over one's life				
SOCIAL ISSUES					
SOC 1	Problems in the relationship with life companion				
SOC 2	Difficulties in talking about the disease with life companion				
SOC 3	Finding it difficult to talk about the disease (not wanting to burden others)				
SOC 4	Finding others not receptive to talking about the disease				
SOC 5	Difficulties in finding someone to talk to (confidant)				
PSYCHOLOGICAL ISSUES					
PSY 1	Depressed mood				
PSY 2	Fear of physical suffering				
PSY 3	Fear of metastases				
PSY 4	Difficulty coping with the unpredictability of the future				
PSY 5	Difficulties to show emotions				
SPIRITUAL ISSUES					
SPI 1	Difficulties to be engaged usefully				
SPI 2	Difficulties to be of avail for others				
SPI 3	Difficulties concerning the meaning of death				
SPI 4	Difficulties to accept the disease				
FINANCIAL PROBLEMS					
FIN 1	Extra expenditures because of the disease				
FIN2	Loss of income because of the disease				
NEED OF INFORMATION					
INF 1	Insufficient info e.g. about the disease and its treatment, aids and agencies that can provide help, alternative healing methods, etc.				
ARE IMPORTANT ISSUES MISSING FROM THIS LIST? PLEASE ADD YOUR PERSONAL ISSUES BELOW					

SPACE FOR YOUR REMARKS OR QUESTIONS

Figure 3: Problems and Needs in Palliative Care Questionnaire by PNPC-sv-engl 200527 and PNPC-sv Indonesian by Effendy, et al. 2015 [28].

Table 1: Karnofsky and Eastern Cooperative Oncology Group (ECOG) Performance Status [29-31].

Karnofsky Performance Status			ECOG Performance Status	
A: Able to carry on normal activity and to work. No special care is needed.	Normal, no complaints.	100%	0	- Fully active. - Able to carry on all pre-disease performance without restriction.
	Able to carry on normal activities. Minor signs or symptoms of disease.	90%		
B: Unable to work. Able to live at home, care for most personal needs. A varying degree of assistance is needed.	Normal activity with effort.	80%	1	- Restricted in physically strenuous activity but ambulatory. - Able to carry out work of a light or sedentary nature, e.g., light house work, office work.
	Care for self. Unable to carry on normal activity or to do active work.	70%		
	Requires occasional assistance, but able to care for most of his needs.	60%	2	- Ambulatory. - Capable of all selfcare but unable to carry out any work activities. - Up and about more than 50% of waking hours.
	Requires considerable assistance and frequent medical care.	50%		
C: Unable to care for self. Requires equivalent of institutional or hospital care. Disease may be progressing rapidly.	Disabled. Requires special care and assistance.	40%	3	- Capable of only limited selfcare. - Confined to bed or chair more than 50% of waking hours.
	Severly disabled. Hospitalisation indicated though death nonimminent.	30%		
	Very sick. Hospitalisation necessary. Active supportive treatment necessary.	20%	4	- Completely disabled. - Cannot carry on any selfcare. - Totally confined to bed or chair.
	Moribund.	10%		
	Dead.	0%	5	Dead.

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Table 2: Palliative Prognostic Index [32,33].

Criterion	Assessment	Partial Score
Karnofsky Performance Status	≥ 60% (ambulating, able to care for self, awake and alert)	0
	30% - 50% (mainly in bed, considerable assistance, may be confused)	2,5
	10% - 20% (bedbound, total care, drowsy)	4
Oral intake	Normal	0
	Moderately reduced (> mouthfuls/day)	1
	Severely reduced (< mouthfuls/day)	2,5
Edema	Absent	0
	Present	1
Dyspnea on exertion	Absent	0
	Present	3,5
Delirium	Absent	0
	Present	1

Total score < 4 indicates > 6 weeks survival; score 4–6: 3–6 weeks; > 6: < 3 weeks.

upholding dignity and respect for patients and their families. The goal is to continue providing these services at no cost, to ensure equitable access to comprehensive, compassionate care without the burden of financial strain [43-45].

Panti Rapih Hospital upholds its mission as a faith-based nonprofit healthcare service. Its religiosity has been rooted since it was established 94 years ago. Some literature suggests that religiosity is a key motivation for giving to others [46-50]. Despite the limited budget of the social insurance scheme in palliative care, this service can still be provided to patients by optimizing the spirituality of team members, including healthcare workers, social workers, and the pastoral care team. A year after the palliative care system was established at Panti Rapih Hospital, the hospital continuously delivers palliative care approaches for patients under the social insurance scheme. This is one of the private sector's contributions to aiding the government in improving the community's quality of life [51].

Conclusion

This study identifies an urgent need to strengthen palliative care within Indonesia, demanding unwavering support under the overarching umbrella of UHC. This approach is not only essential but also urgent, as it ensures that palliative care services are accessible, comprehensive, and integrated into the broader health care system, allowing for a more holistic and dignified approach to end-of-life care. By addressing these needs, Indonesia can move closer to its goal of universal access, ensuring that all patients in need of palliative care receive the quality support and services they deserve, regardless of their economic status.

Moreover, the integral role of spirituality in palliative care cannot be underestimated, as it significantly enhances the quality and effectiveness of care provided. This spiritual component acts as a vital pillar, supporting patients and their families through the complexities of end-of-life challenges, offering solace and strength. Ensuring long-term sustainability of such care will depend on the acquisition of philanthropic support. Such support not only offers a stable financial foundation but also embodies the collective will of society to care for its most vulnerable members. With a concerted effort from all stakeholders, including the government, private sector, and civil society, Indonesia aims to achieve universal access to quality palliative care, thus advancing national goals of health equity and dignified care delivery.

Disclosures

This study was presented as poster presentation during European Congress for Palliative Care 2024 in Barcelona. The author did not receive specific grants from funding agencies in the public sector, commercial, or non-profit section.

Researcher characteristics and reflexivity

The author's professional background encompasses roles as a medical doctor and a public health consultant, currently pursuing doctoral studies in health philanthropy. With specialized training in palliative care, he dedicated two years to serving as a missionary doctor at a non-governmental religious health center in Indonesia's easternmost province, prior to the implementation of UHC in Indonesia. His deep connections with religious communities, alongside domestic and international donors, underscore his commitment, and has actively contributed to missionary healthcare initiatives in multiple countries.

Ethical considerations

This study at Panti Rapih Hospital aims to develop a Hospital Palliative Care System in 2023. The screening tools and approaches have been approved by the hospital director under directive number 415/RSPR/SK/A/VI/2023. Ethical considerations were integral to their development, demonstrating the hospital's compliance with ethical research standards and patient rights .

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