



# A Phased Plan for the Expansion of Hospice and Palliative Care

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Palliative care is a comprehensive approach aimed at improving the quality of life for patients and their families. The symptom burden and care needs of patients with end-stage, non-malignant diseases are similar to those experienced by patients with advanced cancer. Therefore, the World Health Organization (WHO) has recommended the expansion of palliative care to encompass a broad spectrum of diseases. However, in Korea, the adoption of palliative care for non-malignant conditions remains markedly low, presenting numerous challenges that differ from those associated with cancer. Key barriers to implementing hospice care for non-malignant diseases include the difficulty in predicting end-of-life and a general lack of awareness about hospice palliative care among healthcare providers, patients, and their families. Additionally, there is a risk that suggesting palliative care to patients with non-malignant diseases might be misinterpreted as an endorsement by healthcare providers to cease treatment or abandon the patient. This article explores strategies to broaden the scope of hospice and palliative care for patients with non-malignant diseases.

**Key Words:** Neoplasm, Hospice care, Palliative care, World Health Organization, Chronic disease

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## INTRODUCTION

Palliative care is a comprehensive approach designed to improve the quality of life for both adult and pediatric patients, as well as their families, who are facing life-threatening illnesses [1]. This type of care seeks to prevent and relieve suffering by ensuring early detection, precise assessment, and effective treatment of pain and other problems, whether physical, psychological, or spiritual [2].

Since the implementation of the Act on Decisions on Life-Sustaining Treatment for Patients in Hospice Palliative Care in August 2017, South Korea has aimed to enhance access to hospice services, ensure self-determination in end-of-life care, and improve the quality of life for the families of terminally ill patients. Initially, hospice care was exclusively for cancer

patients, but it has since expanded to include AIDS, chronic obstructive pulmonary disease (COPD), chronic liver cirrhosis (as of 2018), and more recently, chronic respiratory failure (as of 2022) [3,4]. Despite the promising aspects of this legislation in broadening the scope of hospice care to include non-cancerous conditions, numerous obstacles have hindered its effective implementation. Consequently, the utilization of hospice services for these conditions remains exceedingly low. A report from the Ministry of Health and Welfare indicates that in 2018, out of 7,638 deaths from AIDS, COPD, and chronic liver cirrhosis, only 29 individuals received hospice palliative care, resulting in a utilization rate of just 0.38%. This figure is starkly lower than the 22.9% utilization rate observed among cancer patients [5].

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## MAIN TEXT

### 1. Importance of hospice and palliative care for patients with non-malignant diseases

The symptom burden and care needs of patients with end-stage, non-malignant diseases are comparable to those of patients with advanced cancer. Common and severe symptoms among those requiring palliative care include pain and difficulty breathing. For instance, patients with end-stage chronic obstructive pulmonary disease (COPD) typically face an average of 7~11 physical, emotional, social, and functional challenges. Their quality of life is significantly diminished, as they endure severe breathlessness and need help with basic activities such as eating and dressing [6]. Addressing suffering extends beyond managing physical symptoms [7-9]. It also has the potential to reduce the financial strain on patients and families, as well as on the insurance system. Patients who receive hospice and palliative care often undergo less invasive treatment and are less likely to die in an intensive care unit (ICU) compared to those receiving standard care [10]. This leads to reduced healthcare costs through the end of life, underscoring its importance within the healthcare system [11,12].

### 2. The barriers to expanding palliative care for patients with non-malignant diseases

Several barriers hinder the introduction of hospice and palliative care for non-malignant diseases. The first barrier is the challenge of estimating life expectancy, which complicates the timely initiation of palliative care services. The Lunney model illustrates various trajectories of functional decline in the dying process, emphasizing the variability in patient experiences across different diseases—sudden death, terminal illness, organ failure, and frailty [13]. Non-malignant diseases often follow unpredictable courses, marked by periods of stability interspersed with sudden exacerbations, making it difficult to determine the appropriate time to introduce palliative care. The second barrier is the limited awareness and understanding of palliative care among physicians, caregivers, and patients. Often, palliative care is misunderstood as solely end-of-life care rather than a comprehensive approach to symptom management and support. This misconception exists among patients,

families, and healthcare providers alike. Additionally, there is a notable lack of specialized training in palliative care for non-malignant diseases among healthcare professionals [14,15]. The third barrier involves the complexity of symptoms associated with non-malignant diseases. Patients frequently exhibit a diverse array of symptoms that are challenging to manage and require a multidisciplinary approach. Unlike cancer, where palliative care may be more episodic, non-malignant diseases typically necessitate ongoing and long-term palliative interventions [6]. The chronic nature of these diseases also often results in prolonged emotional and social strain on both patients and their families, highlighting the need for extensive psychosocial support. The final barrier is the difficulty in accessing palliative care. Resources for palliative care are often prioritized for cancer patients, resulting in limited availability for those with non-malignant conditions.

### 3. Strategies to facilitate the implementation of palliative care for patients with non-malignant diseases

Palliative care is a crucial component of integrated, people-centered health services. It aims to alleviate serious health-related suffering, whether physical, psychological, social, or spiritual, which is considered a global ethical responsibility [1]. The WHO has indicated that palliative care may be necessary for a range of conditions including cardiovascular disease, cancer, major organ failure, drug-resistant tuberculosis, severe burns, end-stage chronic illness, acute trauma, extreme birth prematurity, or the extreme frailty associated with old age. It emphasizes that such care should be accessible at all levels of the healthcare system [2]. The IAHPHC advocates for the provision of comprehensive services at home, addressing not only the medical but also the emotional needs of patients and their families [15]. Despite previous discussions, it remains challenging to provide adequate palliative care for patients with non-malignant conditions in Korea. Consequently, there is a pressing need for strategies to enhance the implementation of palliative care for patients with non-malignant diseases [16,17].

First, it is necessary to ensure adequate training for healthcare providers in managing specific conditions and their associated symptoms, as recommended by the WHO. Second, we

should implement comprehensive patient assessment tools to customize care plans according to individual needs. Symptoms among patients with non-malignant diseases vary widely, and continuous specialized treatment and maintenance not only prolong life but also significantly aid in symptom relief, such as managing breathlessness and controlling exacerbations. Third, an effective system must be established to enable patients with non-malignant diseases to access hospice care, which includes consultation-based specialist teams, home hospice, and community-based services. Implementing hospice care through advance care planning requires considerable time and effort; therefore, reimbursement rates should be adjusted accordingly for hospital-based palliative care involving consultation-based specialist teams. Fourth, it is crucial to monitor and evaluate the implementation process to continuously improve the quality of care and outcomes. A key component is the education program about death. By establishing and expanding age-specific educational curricula—covering childhood, adulthood, and middle age—we provide opportunities for individuals to consider end-of-life self-determination in advance. In the UK, end-of-life education encompasses various initiatives aimed at preparing and educating people about death and related issues. These educational approaches support patients in making their own treatment decisions and encourage advance care planning, respecting and considering the wishes of the patients.

## CONCLUSION

Palliative care is explicitly recognized under the human right to health. It should be delivered through person-centered and integrated health services that are attentive to the specific needs and preferences of individuals. Considering that the concept of hospice includes all services designed to assist terminal or end-of-life patients and their families in spending their final days with dignity, a paradigm shift is necessary. This shift should expand the range of diseases included in hospice care, enabling more patients to spend their last moments meaningfully.

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## CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

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