

Navigating Palliative and Hospice Care: Challenges and Opportunities for Primary Care Physicians in Providing End-of-Life Support

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Abstract

In the mid-1900s, Hospice and Palliative care emerged as end-of-life medical services, offering comfort and support to dying patients and their families. These two services share common goals while also exhibiting distinct characteristics. However, many healthcare providers, including physicians, physician assistants, and nurses, lack comprehensive training and knowledge in these areas. In this paper, we aim to provide an extensive review of Hospice and Palliative care for internist and primary care physicians, covering various aspects such as indications and eligibility criteria, similarities, and differences between the two types of care, factors that might disqualify a patient from enrolling, and the role or application of these services during the COVID-19 pandemic.

Keywords: Palliative care; Hospice care; Primary care physicians; Clinical judgment; End-of-life support; Accessible care; Underrepresented populations

Introduction

Hospice and Palliative care form an integral part of end-of-life medical services, providing crucial support and comfort to patients nearing death and their families. The modern Hospice care originated in 1967 in the UK, thanks to the pioneering work of Cicely Saunders, a visionary physician who introduced both inpatient and home-based Hospice care. Simultaneously, in 1969, Elisabeth Kübler-Ross's best-selling book, "On Death and Dying," advocated for a more compassionate approach to caring for dying patients, challenging institutionalized death practices that lacked support for individuals and their families [1,2]. Following the lead of Dr. Saunders, Florence Wald, the dean of Yale School of Nursing, spearheaded the hospice movement in the US after studying the care approach with Dr. Saunders in London. In 1975, she established the first Hospice in the US, modeled after Dr. Saunders' St. Christopher inpatient Hospice in London. Palliative care, born out of the Hospice movement, was recognized as a separate medical specialty by Dr. Balfour Mount, a surgical oncologist from McGill University, in 1974. The distinction between Hospice and Palliative care gained further recognition when the World Health Organization (WHO) acknowledged Palliative care as a separate medical specialty in 1990. Subsequently, in 2006, the American Board of Medical Specialties (ABMS) and the Accreditation Council for Graduate Medical Education (ACGME) approved both Hospice and Palliative care as distinct, separate specialties. This recognition reflects the growing importance of these fields in providing compassionate and comprehensive care to patients and families facing the challenges of end-of-life care. According to Saunders [3], Hospice care is defined as focusing on quality rather than length of life, providing humane and compassionate support to individuals in the final stages of incurable diseases. Hospice care is typically initiated when a patient is expected to live six months or less, and there is no possibility of a cure for the illness. This type of care is reimbursed by Medicare and other insurance companies if certain requirements are met, such as having a terminal illness with a life expectancy of six months or less and eligibility for Medicare Part A Insurance [4]. On the other hand, Palliative care, as recommended by the World Health Organization (WHO), should be initiated as early as possible during the course of any chronic, ultimately fatal illness [5]. For instance, patients with lung cancer may require palliation for common symptoms like cough and

dyspnea, pain management, and addressing metastatic lesions [6]. The WHO's definition of Palliative care also encompasses the needs and well-being of the patient's caregivers and family members, emphasizing a comprehensive approach to care. This paper aims to address the lack of knowledge and training among many physicians on the utilization and appropriate referrals for Hospice and Palliative care services. Misuse of these services by referring unqualified patients can lead to significant financial losses for insurance companies. Therefore, we provide a comprehensive review for primary care physicians (PCPs), family medicine physicians (FM), and internists to better understand and distinguish between Hospice and Palliative care, as well as their respective indications. Palliative care encompasses an interdisciplinary approach to managing serious illnesses, addressing physical, emotional, spiritual, and psychosocial needs of patients and their caregivers [7-9]. While Hospice and Palliative care are often used interchangeably, it is essential to recognize that Palliative care is a broader term that includes both Hospice and Non-hospice care [9]. Non-hospice Palliative care is provided before Hospice care and has distinct eligibility criteria. Any individual with a major illness or chronic complex diseases affecting their quality of life, significant disease symptoms, and the need for supportive treatment for curative diseases may be eligible for Palliative care [8,9]. Conditions like deterioration of disease status, decreased mobility, oxygen dependency, progressive weight loss, and specific illnesses such as heart failure, AIDS, COPD, and cancer warrant consideration for Non-hospice Palliative care referral [7]. On the other hand, patients become eligible for Hospice care when their life expectancy is less than six months [9]. Hospice referrals commonly involve conditions like cancer, cardiac and circulatory problems, dementia, respiratory disease, and stroke.

This comprehensive review will aid PCPs, FM physicians, and

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internists in understanding the distinct indications for Hospice and Palliative care, allowing for appropriate referrals and improved patient care. Moreover, we will also explore the application of these care programs and principles in the context of COVID-19 patients. Physician judgment, in conjunction with the Palliative Performance Index (PPS), serves as an excellent tool for determining eligibility for hospice care. PPS evaluates factors such as ambulation, conscious level, food/fluid intake, self-care and activity level, and the extent of the disease. Studies have shown that a PPS score of 10 is associated with 1-3 days of survival, while a score of 30 is linked to 5-36 days of survival, though an exact cutoff point has not been determined. Furthermore, patients with a PPS score of less than 70 typically have a survival rate of less than six months, and a score of 40 indicates a significant disease burden and poor functional status [10,11].

Despite both palliative care and hospice care aiming to improve the quality of life for patients, they are often misinterpreted and confused by patients and their caregivers [12]. However, there are several key differences between the two, as outlined in Table 1. Notably, clinical studies have demonstrated the benefits of early palliative care in hastening patient recovery and enhancing their overall quality of life [13-15]. Moreover, the timely transition from palliative care to hospice care has been shown to reduce the financial burden on both patients and insurance companies. Therefore, it is crucial for primary care physicians and internists to grasp the distinction between palliative care and hospice care to provide better support, improved quality of life, and increased awareness for patients and their families.

Similarities

With the increasing burden of chronic illnesses affecting patients' quality of life and lifespan, healthcare providers must choose between two available forms of medical care: Palliative Care and Hospice Care. Palliative care is commonly used for patients suffering from terminal or chronic illnesses that could eventually lead to death, as well as for elderly individuals experiencing discomfort or disability [16,17]. On the other hand, Hospice care aims to provide comprehensive care to patients within the last six months of their life. Despite their different focus, both care modalities share several key similarities, including:

- Customized treatment and care tailored to meet the specific needs of each patient.
- Acknowledgment of life and death as natural processes, with no intention to prolong life artificially or hasten death.
- Focus on alleviating patient symptoms to enhance the quality of the remaining life.
- Implementation of an interdisciplinary team approach to cater to the diverse needs of the patient.
- Provision of physical, psychological, and emotional support to both patients and their families, helping them navigate difficult health situations, spiritual challenges, and bereavement.

By recognizing and understanding these shared characteristics, healthcare providers can better navigate the nuances between Palliative Care and Hospice Care and provide optimal support and care to patients and their families throughout their healthcare journey.

Differences

Palliative care:

- Palliative care commences upon the diagnosis of a chronic

illness, such as congestive heart failure (CHF), chronic kidney disease (CKD), dementia, tumors, or bone fractures. Unlike Hospice care, patients need not be terminally ill to qualify for Palliative care.

- In Palliative care, patients receive treatment primarily for their actual illness, along with additional emotional, mental, spiritual, social, and symptomatic support. For example, patients with early-stage lung cancer may undergo chemotherapy while also receiving social support, pain medication, sedatives, and anti-emetics to address physical symptoms.

- In Palliative care, the use of life-prolonging medications is encouraged. This type of care is typically provided in hospitals, outpatient clinics, special Palliative care clinics, and patients' homes.

- It can be administered for both short-term and long-term illnesses, with the care being discontinued once the illness is cured.

- Examples of Palliative care interventions include prescribing sedatives for insomnia in geriatric patients, pain medications for hip bone fractures, and anti-anxiety medication for patients with cancer or dementia.

- Palliative care is typically covered by personal insurance, including outpatient visits and medications billed by the primary care physician, subject to standard co-pays, deductions, and other limitations. Medicaid and Medicare partially cover Palliative care charges.

- Throughout the patient's healthcare journey, Palliative care addresses their mental, physical, social, and spiritual well-being, encompassing support from diagnosis to cure. This comprehensive approach involves a multidisciplinary team consisting of primary care doctors, specialists, nurses, counselors, and social workers, working collaboratively to ensure the best possible care for the patient's holistic needs.

Hospice care:

- Hospice care is initiated when a patient is determined to have only six months or less to live, regardless of their diagnosis. The patient's eligibility for hospice care requires evaluation and certification by two doctors or specialists.

- In hospice care, the treatment is focused on medications that alleviate physical symptoms and provide emotional, spiritual, social, and mental support. This type of care is introduced when the patient has exhausted all possible treatments for their illness and is no longer responsive to them.

- For example, patients in the terminal stage of lung cancer, who are no longer responding to chemotherapy, may receive sedatives, pain medications, and social support in hospice care. Unlike palliative care, hospice care does not involve the use of life-prolonging medications.

- Hospice care is usually provided at the place preferred by the patient, such as their home, nursing homes, retirement homes, special Hospice care clinics, and occasionally at hospitals. It is specifically designed as end-of-life care, continuing until the patient's passing.

- Hospice care is fully covered by either Medicaid or Medicare. This comprehensive coverage includes medication, medical equipment, 24/7 nursing care, social services, chaplain visits, grief support, and any other services requested by the hospice patient, all of which are covered by Medicare. Additionally, some personal insurances also provide coverage for hospice charges.

- In addition to prioritizing the patient's well-being and comfort, Hospice care places significant emphasis on preparing both the patient and their family for the end of life. Furthermore, the Hospice care team offers continued bereavement support to the patient's family for a duration of 13 months following the patient's passing.

- Hospice care primarily engages various individuals, including family members, family caregivers, visiting Hospice nurses, chaplains, social workers, and occasionally a doctor.

Both Hospice and Palliative care can be delivered across a range of clinical settings, including homes, assisted living facilities, long-term care facilities, and hospitals, depending on the specific clinical needs and conditions of the patients. Enhanced knowledge of disease processes, treatment options, and care choices can assist healthcare professionals in making informed decisions regarding the appropriate care for patients [18-20]. Patient education, consultations, and fostering effective doctor-patient relationships can encourage greater involvement in self-care, the development of individualized care plans, and ultimately aid in making the right choice between Palliative and Hospice care.

Conclusion

As the elderly population grows, the demand for Palliative and Hospice care increases for patients with chronic or acute conditions. Primary care physicians play a crucial role as they are often the first point of contact for these patients and are responsible for making referrals. In our study, we examined the indications for Hospice and Palliative care to assist physicians in making appropriate referrals. However, we found a lack of sufficient guidelines or clear indications for PCPs, NPs, and internists to follow. Relying solely on clinical judgment can sometimes lead to delays and complications in the care process. The challenges have been further exacerbated during the COVID-19 pandemic, where providing hospice or palliative care has become even more daunting and burdensome for the healthcare industry. Clear and comprehensive guidelines are essential to facilitate the process and integrate Palliative and Hospice care into national pandemic planning. Hospice and Palliative care is a fundamental human right, and it is imperative to address barriers that prevent its accessibility to all individuals, including underrepresented populations. Efforts should be made to eliminate obstacles such as lack of means to access, lack of awareness, or biases from healthcare providers that may hinder certain populations from receiving these vital services. Ensuring equitable access to Hospice and Palliative care is vital to providing compassionate and dignified end-of-life care for everyone.

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Conflict of Interest

Author declares no conflict of interest.

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