

# Hospice vs Palliative care: A comprehensive review for primary care physician

Mona Sheikh<sup>1,2</sup>, Sruthi Sekaran<sup>1</sup>, Hansini Kochhar<sup>1</sup>, Asma Tasnim Khan<sup>1</sup>,  
Ishita Gupta<sup>3</sup>, Arpit Mago<sup>1,4</sup>, Upasana Maskey<sup>1</sup>, Sima Marzban<sup>5</sup>

<sup>1</sup>Division of Clinical and Translational Research, Larkin Community Hospital, South Miami, Florida, <sup>2</sup>University of North Texas Health Science Center School of Public Health, Fort Worth, Texas, USA, <sup>3</sup>Dubai Health Authority, Dubai, UAE, <sup>4</sup>Jawaharlal Nehru Medical College Belgaum, Karnataka, India, <sup>5</sup>Department of Research and Academic Affairs, Larkin Health System, South Miami, Florida

## ABSTRACT

End-of-life medical services in the form of Hospice or Palliative care were initiated in the middle of 1900 in order to comfort the dying patients and support their families. There are a lot of similarities and differences between the two services. Many healthcare providers, including physicians, physician assistants, and nurses, are not fully trained or have comprehensive knowledge of these two types of end-of-life medical care. Through this paper, we aim to provide a thorough review of Hospice and Palliative care for internist and primary care physicians both in terms of indications or eligibility criteria; the similarities and differences between the two types of care; factors that disqualify an enrolled patient; and lastly, the role or use of Hospice and palliative care during COVID-19 pandemic.

**Keywords:** COVID-19, disqualifications, geriatric, history, hospice care, indication, origin, palliative care, review

## Introduction

Hospice and Palliative care are part of end-of-life medical care that provide support and comfort to patients who are near death and to their families. Modern Hospice care was initiated in 1967 in the UK by a pioneering physician named Cicely Saunders, who created both inpatient and home Hospice care. In 1969 Elisabeth Kübler-Ross published her book *On Death and Dying*, which became a bestseller, and she pleaded in her book for a better way to care for dying patients. She argued against institutionalized death that dehumanized individuals and did not provide support for their families. In 1975, Florence Wlad, the dean of Yale School of Nursing, started the hospice movement in the US after

she had studied the hospice care approach with Dr. Saunder in London. Florence Wald established the first Hospice in the US in Connecticut, modeling the first Hospice created by Dr. Saunders, St. Christopher inpatient Hospice in London.<sup>[1]</sup> Palliative care was born from the Hospice movement. Dr. Balfour Mount, a surgical oncologist from McGill University, is the pioneering physician who coined and established Palliative care as a separate care from Hospice in 1974.<sup>[2]</sup> Palliative care was recognized as a separated medical speciality by the World Health Organization (WHO) in 1990, while in 2006, both the American Board of Medical Specialties (ABMS) and the Accreditation Council for Graduate Medical Education (ACGME) approved Hospice and Palliative care as distinct separate specialities.<sup>[2]</sup>

Saunders<sup>[3]</sup> defined Hospice care as, “Hospice care focuses on quality rather than length of life. It provides humane and compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as

**Address for correspondence:** Dr. Mona Sheikh,

Division of Research and Academic Affairs, Larkin Community Hospital, 700 SW 62<sup>nd</sup> Ave, South Miami, FL 33143, USA.

E-mail: monasheikh@my.unthsc.edu

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possible.<sup>22</sup> When one is expected to live six months or less and a cure for the illness is not possible, that is when Hospice care is begun. Hospice care is reimbursed by Medicare and other insurance companies as long as the requirements are met, i.e., a patient has a terminal illness with a life expectancy of six months or less and is entitled to Medicare part A Insurance.<sup>4</sup>

For providing Palliative care, the World Health Organization (WHO) recommends that it should be started as early as possible in the course of any chronic, ultimately fatal illness.<sup>5</sup> For example, patients with lung cancer would require palliation for some common symptoms like cough and dyspnea, for pain, and also for managing metastatic lesions.<sup>6</sup> The needs and well-being of the patient's caregivers and family members are also included in the widened definition of Palliative care by WHO.<sup>5</sup>

Many physicians lack the knowledge and training on how to use these two services and when to refer patients. Insurance companies spend a lot of money on these services and can incur heavy losses when the services are misused by referring unqualified patients. This paper will provide a comprehensive review for PCPs, FM physicians, and internists. This review focuses on defining both Hospice and Palliative care and also highlights the indications for each. We also discuss the various similarities and differences between Hospice and Palliative care and identify what care programs and principles are being used in COVID patients.

### Indications for Hospice and Palliative Care

Palliative care is a broader term that comprises an interdisciplinary collaboration of caring for patients and their caregivers to manage serious illness and provide physical, emotional, spiritual, and psychosocial requirements.<sup>7-9</sup> Hospice and Palliative are often used interchangeably, though they are different. Palliative care is a broader term, and Hospice is part of it. It is worth mentioning for a better understanding of Palliative care that it comprises two things—Hospice and Non-hospice.<sup>9</sup>

Non-hospice is the palliative care that is given prior to hospice care. As they are different, their eligibility criteria also differ from each other. Any person can be eligible for Palliative care who meets the following criteria: Has a major illness; chronic complex diseases that negatively affect the quality of life; has significant disease symptoms; the disease or symptoms are stressful for the patient and the caregiver; and the patient needs supportive treatment for the curative disease.<sup>8,9</sup> The conditions that make an individual eligible for non-hospice Palliative care referral are deterioration of disease status, decreased mobility, oxygen dependency, progressive weight loss, etc. There are also some diseases, such as heart failure, AIDS, COPD, cancer, which should prompt their caregiving physician for considering Palliative care referral.<sup>7</sup> On the other hand, patients become eligible for Hospice referral when their life expectancy is less than six months.<sup>9</sup> Cancer, cardiac and circulatory problems, dementia, respiratory disease, stroke are the most prevalent conditions seen in Hospice referrals. With physician judgment, Palliative

Performance Index (PPS) is an excellent tool to determine hospice eligibility which comprises Ambulation, conscious level, food/fluid intake, self-care and activity level, and the extent of the disease.<sup>10,11</sup> One study shows that a PPS score of 10 is associated with 1–3 days survival, and 30 is associated with 5–36 days survival, though no accurate cut-off point is determined.<sup>10</sup> It is also found that patients with a PPS score of less than 70 have less than six months survival rate, and a score of 40 stipulates major disease and poor functional status.<sup>10,11</sup>

### Differences between Hospice and Palliative Care

Palliative care and Hospice care are often interchanged and misunderstood by the patients and their caregivers.<sup>12</sup> Although, as per the definition, both Palliative and Hospice care focus on improving the quality of life of the patients, there exists a few major differences between the two, which are listed in the table below [Table 1].

Quite a number of clinical studies have shown that the early onset of Palliative care has proven to fasten the recovery of the patient and improve their quality of life.<sup>15,16</sup> Studies have also proven that the adoption of Palliative care and its timely transition to Hospice care had reduced the financial burden on the patients as well as insurance companies.<sup>18,19</sup> Hence, it is of prime importance that the primary care physician/internist understand the difference between Palliative care and Hospice care to provide better assistance, quality of life, and awareness to the patients and their families.

### Similarities between Hospice and Palliative Care

With an increasing burden of diseases that alter the quality of life and reduce the lifespan of patients suffering from chronic illness, healthcare providers have to decide and adapt between the two available forms of medical care—Palliative Care and Hospice Care.<sup>22</sup>

Palliative care is often employed for patients who suffer from terminal or chronic illness that could eventually lead to death and for the aged population suffering from discomfort or disability. While Hospice care aims at providing comprehensive care to patients within six months to the end of their life, both the care modalities share many similarities, including<sup>22</sup>–

- Customized treatment and care according to patient needs.
- Recognition of life and death as natural processes with no intention to prolong life or hasten death.
- Alleviation of patient symptoms to aim for a better quality of the remaining life.
- Based on an interdisciplinary team approach to cater to the patient needs
- Provide physical, psychological, and emotional support to both the patients as well as the families to tide over difficult health situations, spiritual challenges, and bereavement.

**Table 1: The major difference between Palliative care and Hospice care**

	PALLIATIVE CARE	HOSPICE CARE
Time of Onset of Care	Palliative care begins with a diagnosis of a chronic illness, e.g., CHF, CKD, Dementia, Tumor, Bone Fracture. Patients need not be terminally ill to qualify. <sup>[8,11,13-15]</sup>	Hospice care begins at the time when the patient has only six months or less to live, irrespective of the diagnosis. Two doctors/specialists need to evaluate and certify that the patient is expected to live only for six months or less in order to begin hospice care. <sup>[8,11,13-15]</sup>
Treatment	Patients here get treatment primarily for their actual illness, apart from which they get additional emotional, mental, spiritual, social, and symptomatic support. E.g.: Initial stage lung cancer patients get chemotherapy along with social support and pain medication and sedatives, and anti-emetics for their physical symptoms. The use of life-prolonging medications is encouraged in Palliative care. <sup>[7,10,13-16]</sup>	Patients' treatment here is restricted to medications that alleviate their physical symptoms along with emotional, spiritual, social, and mental support. Hospice care begins only when the patient has stopped responding to all possible treatments for their illness. E.g.: Terminal stage lung cancer patients who have stopped responding to chemotherapy are treated with sedatives, pain medications, and social support; no life-prolonging medications are used in Hospice care. <sup>[7,10,13-16]</sup>
Place	Where the patient first sought treatment. Mostly at hospitals, out-patient clinics, special Palliative care clinics, and homes. <sup>[8,11,13-15]</sup>	At places which the patient prefers. Mostly, their home, nursing homes, retirement home, special Hospice care clinics, and rarely at hospitals. <sup>[8,11,13-15]</sup>
Prognosis	Palliative care can be given for both short-term and long-term illnesses. This is stopped once the illness is cured. <sup>[16,17]</sup> E.g.: Sedative for insomnia in geriatric patients, pain medications for hip bone fracture, anti-anxiety medication for cancer/dementia patients.	Hospice care is an end of life care and ends only on the death of the patient. <sup>[16,17]</sup>
Insurance	Palliative care is paid by personal insurance, including out-patient visits and medications billed by the primary care physician. The standard co-pay, deductions, and other limitations will apply. Medicaid and Medicare only partially cover Palliative care charges. <sup>[18-20]</sup>	Hospice care is paid in full by either Medicaid or Medicare. Medication, medical equipment, 24/7 nursing care, social service, chaplain visits, grief support, and any other service requested by the Hospice patient is covered by Medicare. Certain personal insurances also covers Hospice charges. <sup>[18-20]</sup>
Type of care	Palliative care addresses a patient's mental, physical, social, and spiritual well-being from diagnosis to cure. <sup>[8,11,13,14,21]</sup>	Apart from the patient's well-being and comfort, Hospice care mainly focuses on preparing the patient and his/her family for the patient's end of life. Continued bereavement support for the patient's family for 13 months post the death of the patient is provided. <sup>[8,11,13,14,21]</sup>
Provider	Palliative care involves a multidisciplinary team including primary care doctors, specialists, nurses, counselors, and social workers. <sup>[8,11,13,14,21]</sup>	Hospice care primarily involves family members, family caregivers, visiting Hospice nurses, chaplains, social workers, and occasionally a doctor. <sup>[8,11,13,14]</sup>

Abbreviation: CHF: congestive heart failure, CKD: chronic kidney disease

Both Hospice and Palliative care can be provided in different clinical settings from home, assisted living facilities, long-term care facilities to hospitals based on the clinical conditions of the patients<sup>[22]</sup>

Increased understanding of disease processes, care choices, advancements in treatment could aid healthcare professionals in making the right choice for care. Patient education, consultation, and the effective doctor-patient relationship could promote increased participation in self-care, individualized care plans, and help in making the right choice between Palliative and Hospice care.

### Factors Disqualifying an Enrolled Patient from Continuing to Receive Hospice or Palliative Care

Palliative care is considered when a patient is thought to be marginally responsive to treatment, such as when more active therapies would be ineffective. It is a time at which the doctor and the patient mutually agree that the treatment goal has switched from “trying to treat the disease” to “looking to maximize the patient’s quality of life given this incurable sickness.”

However, in certain cases, the enrolled patients can become disqualified; these could be for the following reasons<sup>[23-25]</sup>:

- Patients revoke Hospice/Palliative care: This is when a patient themselves withdraw from receiving Hospice or Palliative care without consulting a doctor. It is quite common following the beginning of the treatment for the patient to feel better, their symptoms are well-controlled, and they have considerable alleviation in pain or other symptoms, so they may be able to return to work.<sup>[23,25]</sup>
- Patient “graduates” hospice: There may be some patients who outlive their six-month mark, which then calls for a reassessment by a physician. If found to be improved and/or no longer terminally ill, Hospice services may be withdrawn following reassessment.<sup>[24]</sup>
- Transfer: Patient/their Nominated Representative decides to transfer to another institution.<sup>[23,25]</sup>
- Curative treatments: Many times, patients or their families may decide to resume curative treatments thereby, foregoing Palliative/Hospice care.<sup>[23-25]</sup>
- Patient Discharged: In rare cases, if a patient is found to be disruptive or found to interfere with the Hospice care facility’s activities, the facility may opt to discharge the patient.
- Due to uncooperative family members: In some situations,

home Hospice may also end if the family members are found to be unpleasant or abusive.

- Death of the patient.

### Role of Hospice and Palliative Care during COVID-19 Pandemic

The COVID-19 disease caused by the SARS-CoV-2 virus was first seen in December of 2019, which then escalated to a pandemic that affected all the countries worldwide.<sup>[26]</sup> As of August 30, 2021, there have been 217,080,846 confirmed cases of the disease, and the death toll stands at 4,509,821.<sup>[27]</sup> The patients that are more vulnerable to the disease are, unfortunately, the same patients that are in the geriatrics wards and nursing homes, Palliative care centers, and Hospice centers.<sup>[28]</sup> People who are frail and with multiple comorbidities are disproportionately affected more by the COVID-19 disease.<sup>[29]</sup> The health care professionals need to have end of life discussions in these unforeseen circumstances where there is a limited healthcare infrastructure to deal with a pandemic of this scale. Not all patients can be accommodated in intensive care units due to a finite number of beds, staff, and other vital resources.<sup>[30]</sup> Physicians should always maintain high ethical standards of beneficence and nonmaleficence and act in the best interest of patients in these situations.<sup>[31]</sup> A Palliative pandemic plan that provides Palliative care outside the critical care has proven to be beneficial with prior experiences dealing with H1N1 outbreaks.<sup>[32]</sup> The goals of Palliative and end-of-life care should be met via honest conversations and should be individualized to each patient. Treatment escalation plans and essential Palliative or end-of-life care plans should be well documented beforehand and may need to be revised as the situation changes. The Palliative care guidelines adopted for symptoms control of other diseases should be continued for these patients as well, such as antibiotic treatment for infections, management of other comorbid diseases such as COPD, heart failure, O<sub>2</sub> for breathlessness, anxiolytics, paracetamol for fever, opioids for pain, etc.<sup>[33]</sup>

During these unprecedented times, in terms of Hospice care, those seeking home Hospice experienced significant delays due to the restrictions, while the community-based services saw a surge in cases.<sup>[34]</sup> One of the challenges in the Palliative and Hospice centers was providing family-centered care,<sup>[35]</sup> which is an important aspect that aids and prepares the family members for making some important decisions.<sup>[36]</sup> This approach has also proven to reduce mental stress along with anxiety and depression, both for the patients and the family members.<sup>[35]</sup> Although the use of technology like smartphones and computers was heavily relied upon, this brought about racial and health care disparity issues with people in rural areas and elderly people not having access to these services or being tech-savvy.<sup>[35]</sup> The breach of confidentiality is a risk with this avenue, and full disclosure is needed.<sup>[37]</sup> A lack of specialists and human resources was also identified. Thus, it is important to have Palliative and Hospice care as part of pandemic planning at national levels.<sup>[38]</sup>

### Discrimination and Under-Serving in End of Life Care

According to WHO, approximately 40 million people globally qualify for Palliative care, of which 78% are residents of low and middle-income nations.<sup>[39]</sup> Out of this enormous figure, however, only 14% receive it. At first, Palliative care services were exclusively for Hospice patients. Now, however, Palliative care is widely available in hospitals. The duration of Palliative care received, though, has considerably shortened, with the typical length of stay in a Hospice being less than three weeks. Advanced treatment modalities now available for terminal illnesses like cancer could be a factor in play. To gain the optimum benefits of Hospice care, three weeks are too short a duration.<sup>[39]</sup>

Patients from under-represented groups are even less likely to enroll in Hospice care. Some patient-reported barriers are misdiagnosis/late diagnosis, lack of healthcare coverage, racial diversity, the behavior of doctors, language barrier between doctor-patient, and patients' limiting beliefs.<sup>[40-42]</sup> Other well-established factors are lack of resources, lack of knowledge, restrictive eligibility criteria for programs, family reluctance, reluctance of providers to refer.<sup>[43,44]</sup>

### Conclusion

As the pool of geriatric patients increases, more and more patients with chronic or acute conditions require Palliative and Hospice care. Primary care physicians are most of the time the first people to care for them and are responsible for making referrals. In our study, we reviewed the indications for Hospice and Palliative care, which can guide physicians to refer patients. We also noted that there are not enough guidelines or clear indications which can be used by PCPs, NPs, or internists. Although the decision for Hospice and/or Palliative care depends on clinical judgment, sometimes this can lead to delays and complicate the process. Providing hospice or palliative care during the time of COVID makes it even more difficult and can feel like a burden on the healthcare industry. More meticulous and clear guidelines are needed for the same, and it is also important to have Palliative and Hospice care as part of pandemic planning at national levels. Hospice and Palliative care is a human right, and efforts should be made to actively address barriers to Hospice and Palliative care, making it accessible to everyone including, under-represented populations, who either lack the means to access or the awareness towards it or suffer from bias from the providers.

### Abbreviation

COVID-19: Coronavirus Disease of 2019, WHO: World Health Organization, ACGME: Accreditation Council for Graduate Medical Education, ABMS: American Board of Medical Specialties, PPS: Palliative Performance Index, AIDS: Acquired Immune Deficiency Syndrome, COPD: Chronic Obstructive Pulmonary Disease, CHF: Congestive Heart Failure, CKD: Chronic Kidney Disease.

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There are no conflicts of interest.

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