

The Differences Between Hospice and Palliative Care

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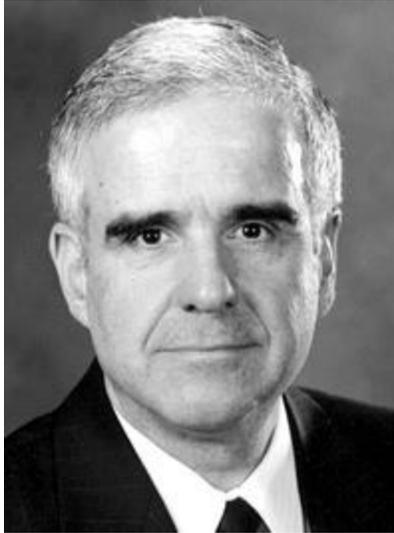
Hospice and palliative care are both medical practices designed to care for and assist patients living with serious illnesses. While they both are considered similar in certain aspects, the two have different indications and goals and are often provided in different settings [1]. By definition, hospice care is considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury. It involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Hospice focuses on caring, not curing and in most cases care is provided in the patient's home setting [2]. On the other hand, by definition, palliative care is specialized medical care for people living with a serious illness. This type of care is focused on relief from the symptoms and stress of a serious illness. The goal of palliative care is to improve quality of life for both the patient and the family. It is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support [3]. Palliative care is most often received in the home, apartment, or during a short-term hospital admission [4]. The term "hospice" can be traced back to medieval times when it referred to a place of shelter and rest for weary or ill travelers on a long journey. The name was first applied to specialized care for dying patients by physician Dame Cicely Saunders, who began her work with the terminally ill in 1948 and went on to create St. Christopher's Hospice, the first modern hospice in a residential

suburb of London. Saunders introduced the idea of specialized care for the dying to the United States during a 1963 visit with Yale University. She gave a lecture that launched a chain of events, which resulted in the development of hospice care as we know it today [2].



Dame Cicely Saunders

On the other hand, palliative care was prompted by Dr. Balfour Mount when he opened the first acute inpatient palliative care unit in Royal Victoria Hospital in Montreal, Quebec in 1976 because of the neglect of dying patients in the acute care setting. His purpose was to provide a crisis-intervention service for patients who were actively dying, and this continues to be the main reason for consulting palliative care services in the hospital. Since the 1970s, palliative care has evolved and is now used in a variety of situations: a life-limiting illness in a patient who is not terminally ill or who has symptoms but with the potential to recover, and a chronic illness such as heart failure or chronic obstructive pulmonary disease in a patient who is on disease-modifying therapy but has symptoms and will eventually succumb to illness, but is expected to live longer than someone with advanced cancer [1].



Dr. Balfour Mount

In terms of payment methods, hospice care is paid for in full by the Medicare Hospice Benefit and by Medicaid Hospice Benefit. Most insurances and the Veteran's Administration also cover hospice services in full or with minimal co-pays. The Center for Hospice Care is committed to providing hospice and palliative care to anyone in the community who needs it and meets the qualifications, even if they are uninsured, underinsured or unable to pay. On the other hand, palliative care is paid for by Medicare, Medicaid and most private insurances if the patient meets criteria [4].

Inpatient palliative care units are often mistaken for hospices [1]. Hospice and palliative care often appear together in titles of reports in literature, but they are not the same thing. As mentioned previously, palliative is specialized care for patients living with a serious illness. Hospice care is service funded and capitated under Medicare part A and is largely provided as an outpatient home care for those deemed terminally ill [1].

There are no major cultural differences between the two practices, since they share many similarities. Existing research shows patients who are involved in hospice and palliative care are often more active in maintaining their personal

relationships and are more in touch with their emotional and spiritual growth [5]. Both practices emphasize their workers being aware of the religious and cultural influences in their patients' lives and be aware of cultural diversity in end-of-life care practices in order to best support their client and provide culturally sensitive care [5]. As mentioned previously, this does fall more on hospice care, since it is more centered around caring for people at the end of their life.

However, there is room for both hospice and palliative to grow in terms of cultural competency. It has been widely reported that ethnic minorities underutilize not only health care services in general but hospice and palliative care services specifically. This is due to a number of reasons including a lack of awareness of hospices services, language barriers, ethnocentrism, prejudice, racism and discrimination, lack of insurance coverage, mistrusting or suspicious of health care providers, and lack of cultural and linguistic competence among health care providers. While hospices and long-term care facilities are known to manage pain relief, alleviate caregiver burdens, and improve the quality of life during the last stages of life, ethnic minorities continue to be underserved by hospices. This underutilization of hospice services by ethnic minorities can lead to under treatment, inadequate treatment or even worse outcomes [6]. The best way to solve this issue is for volunteers to receive more cultural competency training. This can be done in a variety of ways, such as first-hand experience, receiving various pamphlets and handouts with usual information and reminders, and hearing from community minority leaders [6].

In the United States, there are still discrepancies between what constitutes hospice and palliative care, which is reflected in the U.S. healthcare system. Hospice care is more established because of the clear definition of care: it can

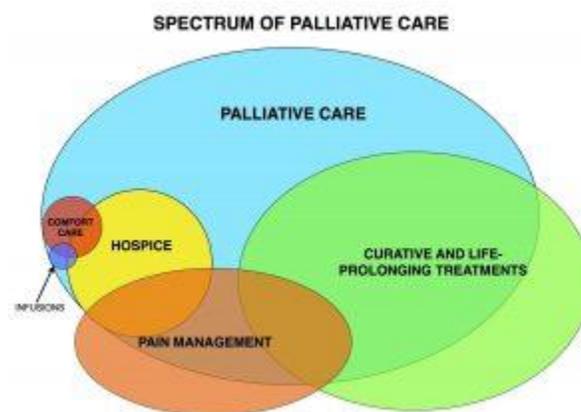
only be prescribed if the patient is expected to live no longer than 6 months [7]. While most types of hospice care are provided by Medicare and most private insurance companies, palliative care is not as widely covered. For example, most insurance companies only provide pain management coverage but might not provide social work, religious and mental health services. This provides a dilemma for both patients seeking palliative care and health care professionals prescribing different types of care. Palliative care is usually prescribed by a team of professionals from various fields that can help decide which aspects of treatment need to be focused on [8]. This can become a problem if the insurance provider does not cover certain aspects of the prescribed treatments, which can lead to changes in prescribing treatment plans. The differences between the multitude of insurance plans that one can have led to problems with prescribing palliative care for all patients with debilitating illnesses [7].

The transition between palliative and hospice care also leads to some ethical questions. In order for one to enroll in hospice care, there has to be a cease of all curative treatments. This differs from palliative care, which can begin as early as when the diagnosis is received. This provides a difficult decision for the patient, their family, and health care providers to determine whether or not the illness has become too advanced for any curative treatments to potentially work. This brings in the ethical principles of beneficence and nonmaleficence, which state that the proposed solution must have the most benefits for the patients and least risk of harm [9]. It is up to the patient and their loved ones to decide what is best for the patient, and this raises a dilemma of whether or not there is reason to cease all curative care. Stopping curative treatments can be considered by health care providers as being the best option for the patient as there is no point to continue treatment and managing symptoms would result in the best patient

outcome. However, the patient and family members could still want to continue care in the hopes that there will be a turnaround in health. This leads to a dissonance between professionals and loved ones that might need to be resolved with legal help [9]. Palliative care is much broader, so care can be administered in the hospital or at home depending on what the patient needs [7]. There is also a question of costs and time commitments as well as finding resources to either move to a hospice facility or begin hospice care at home. Patients and families also have to come to terms with the shift in focus from treating the illness to managing the symptoms. To many who have not considered palliative or hospice care, this seems to be a contradiction with the principle of medicine, which is to treat and cure [9].

One of the biggest challenges that healthcare professionals face when providing palliative or hospice care is balancing the amount of personal investment that they give into the patient and maintaining some neutrality with regards to the patient. In an article that discusses the role of the primary care provider in pediatric palliative care, the authors mention a case of a 10-year-old girl who was diagnosed with terminal cancer. The patient's family became very close with the hospital staff to the point where they considered the staff a second family. When the patient passed, several staff members came to speak at the funeral and provided condolences. However, that communication ended abruptly and the family of the deceased patient expressed their sadness and disappointment that the hospital staff did not continue to reach out [10]. This brings into question the capacity that healthcare professionals have to provide support for a family. It is unfair to ask every health care professional to extend the same courtesy of attending a patient's funeral or checking up with a patient's family because it would hinder those professionals from providing

quality care to other patients. This ties in with the ethical principle of utilitarianism, which states that the best solution is one that yields the best results for the greatest amount of people [9]. If health care providers were to give all their patients the same amount of compassion and attention throughout their time, then that would not result with most people benefitting. However, this does not mean that health care providers should solely focus on the patient's diagnosis. Involving the patient and family on a deeper level allows for the relationship between the patient and the care to grow, which can lead to better patient outcomes. It is up to the health care provider to find a balance between apathy and overinvestment so that the patient and their family can feel comfortable through a difficult transition in their lives [11]. One of the ways that health care providers can accomplish this delicate balance is by enlisting a team of professionals that can collectively work to benefit patients. These teams usually have individuals who are doctors, nurses, social workers, psychologists and other professions; they work together to decide what types of treatments are necessary and recommended for the patient [10].



Palliative Care Spectrum

Given the challenge presented to medical professionals and volunteers in hospice and palliative care, high levels of stress and burnout are associated with

these positions because of the patient-centered nature of this kind of healthcare. Various studies have examined the resiliency of people working in hospice and palliative facilities. In one particular study, ten palliative care nurses were thoroughly interviewed, as they were asked several different questions about the nature of their work and why they chose this particular career path for themselves [12]. The researchers expected to obtain results pointing to mounting psychological stress due to the incredible amount of death and suffering the nurses bear witness to [13]. However, after analyzing the data for common themes in the rhetoric of the nurses during their interviews, the researchers found ten distinct commonalities between the subjects as to why they continue to work as a palliative care nurse. Overall, the nurses exhibited such resiliency to psychological stress due to their work because of two distinct personality traits: “hardiness and a sense of coherence” [13]. According to the researchers, “Hardiness comprises three closely related dispositional tendencies; commitment, control and challenge...Sense of coherence is an integrated perception of one’s life as being comprehensible, manageable and meaningful” [13].

Though all of the nurses interviewed shared the common theme that their past experiences influence their caregiving, there were some differences among the group [12]. The most distinguishing difference between the nurses and how they remained resilient to the tragedies they face in the workplace was how they viewed change. In the study, change was defined as:

“Something occurring within a work context characterized by change, whether that be individual patient care, where there may be uncertainty around life and

death, or national policy, where new agendas for supportive and palliative care are being introduced and implemented”

For example, the nurses who embraced the changes they faced as an opportunity for improvement in the loss of their patients exhibited more hardiness and zealousness in their caretaking style. The nurses who did not particularly enjoy changes in their workplace had a higher sense of coherence, and therefore needed stability to remain resilient [13].

Given the patient-centered nature of hospice and palliative care, the patients receiving care face many challenges when entering end of life care. Hospice and palliative care can act as a major stressor for dying patients and their families, given the various stigmas surrounding the two forms of end of life care [14].

Patients and their families who choose to enter hospice and palliative care are faced with a multitude of options as to what path they should take regarding end of life care. One study examines the way 191 hospice and palliative care patients perceive the different settings in which they can receive end-of-life healthcare. The vast majority of the patients who completed the questionnaire were white, with ages ranging from 41-94 years of age, with roughly half of the respondents being male and the other half being female. Given the demographics of the study, this reflects the lack of minority present in hospice and palliative care facilities. The four different settings examined were inpatient palliative care, hospice day-care, palliative units in nursing homes, and hospice home care. The study found that patients perceived inpatient palliative care units as providing the best possible end of life care. Patients ranked this form of end of life care best in providing a safe and cooperative for both the patient and their

families, as well as having the most respectful and empathetic interactions with palliative care staff in the inpatient center [15].

The major differences among the four types of palliative care examined in this study were based upon how quickly the patient's needs were met, how comfortable the patient felt with the staff in the facility, and the overall atmosphere of the care they received. Inpatient palliative care scored the highest across the board, with p-values of 0.026, 0.004, and <0.001, respectively [16].

This shows that when quantified, the statistical significance of each category based on the setting in which palliative and hospice care takes place can greatly influence how the patient perceives the care they are receiving. The data also suggests that patients who receive palliative care versus hospice care scored each category so high because palliative care offers a much wider range of care options, while also keeping the patient at the center of their care plan.

Both patient perception of care and the resilience of hospice and palliative care nurses can greatly impact the overall experience patients have when receiving end of life care. The study examining patient perceptions of the care they received in various hospice and palliative care settings very briefly showed the differences between hospice and palliative care. The results of the study showed that inpatient palliative care was preferred by most patients, and this can most likely be attributed to the fact that palliative care covers a much broader spectrum of care than hospice does. The second study examining the resiliency of hospice and palliative care nurses did not differentiate between the two types of end of life care.

Examining the differences between hospice and palliative care through a cultural, ethical and scientific perspective can provide insight into how medicine is ultimately focused on improving patients' quality of life. Although the

differences between the two types of care are not as clear with regards to treatment for the patient and the resiliency of medical staff, there are major discrepancies in the way that hospice and palliative care are covered by insurance as well as how these two types of care impact patient outcomes and satisfaction. Recently, hospice and palliative care have become more widespread, which brings awareness to the importance of a holistic treatment plan. However, minorities remain largely underrepresented in receiving hospice and palliative care, raising many questions about the shortcomings of the healthcare system and end-of-life care. Hospice and palliative care have greatly contributed to the medicalization of death around the world and new methods of end-of-life care continue to arise, putting the patient first and maintaining quality of life at the end of life.

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