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Palliative Care and Human Choice in Dignity

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ABSTRACT

Palliative care has become one of the leading branches of medicine, providing comprehensive medical, emotional, and social support to patients with terminal illnesses. Its primary function is to enhance the quality of life for patients with life-threatening illnesses and their families. Throughout history, physicians have worked to alleviate the suffering of patients with incurable diseases while maintaining emotional balance. The bio-psycho-social model of palliative care is based on a person-centered approach and the protection of human rights. Solutions within this model are individualized, sensitive, and tailored to each person, with a focus on respecting human dignity. Palliative care encompasses multiple aspects of patient care; its goals extend beyond merely relieving suffering to ensure individuals can spend their final days with dignity.

Keywords: Dignity; emotional support; human rights; palliative care; philosophy; social support; suffering.

BACKGROUND

This article analyzes the essence of palliative care for patients and their family members. This essence lies in protecting human rights, prolonging life, alleviating pain, and ensuring a dignified end of life. However, awareness of palliative care can cause physiological distress. Individuals may experience a sense of disconnection and a lack of meaning and purpose when their spiritual or religious belief system is disrupted. In the modern world, people face a significant choice: to accept an incurable disease and its accompanying processes or to choose to live without acknowledging the phenomenon of death.

REVIEW

The importance of palliative care and its role in modern medicine

Global aging is associated with declining birth rates and increasing life expectancy. By 2050, the number of people aged 60 and above is expected to reach 2 billion. This will lead to an increase in chronic diseases requiring long-term treatment and disease management. This, in turn, will place an additional burden on healthcare systems, forcing them to meet the needs of the elderly, which will impact the economy and social structures.[1]

The World Health Organization has developed a strategy for 2020-2030 aimed at promoting the healthy aging of the population. Several priorities have been set within this strategy, including ensuring access to continuous healthcare.[2] Integrating palliative care services into the global health strategy is crucial to ensuring an optimal quality of life for patients with chronic, incurable diseases.[1]

The term "palliative care" originates from the Latin word "Pallium," which means a mantle or a mask in Greek. The field itself originated due to the growing number of patients suffering from chronic, incurable diseases, including cancer, and the trend of the global population aging. Unfortunately, despite significant advances in treatment methods and the extension of disease duration, some diseases cannot be cured entirely. As a result, the need for palliative care is increasing dramatically, affecting not only patients but also their families, who face challenges associated with life-threatening illnesses.[1] Since the 1980s, the need for palliative care has primarily been considered for patients with oncology. In 2002, the WHO expanded the definition of palliative care to include all patients and their family members diagnosed with a chronic incurable disease, alongside other incurable diseases added to the list of oncological diseases.

According to the amendment, any patient with a chronic, incurable, terminal illness is considered part of the palliative care group. Such diseases include HIV/AIDS, congestive heart failure, cerebrovascular disease, neurodegenerative disorders, COPD (chronic obstructive pulmonary disease), chronic respiratory diseases, drug-resistant tuberculosis, and diseases in the geriatric population at an incurable stage.

The primary objectives of palliative care are to alleviate pain, suffering, and discomfort associated with an illness, mitigate stress for patients and their family members, enhance the patient's quality of life, and support the family. Palliative care encompasses pain management, symptom control, and treatments tailored to the individual's unique medical needs and preferences, taking into account their wishes for physical, psychological, and spiritual care.

The WHO defines palliative care as "an approach to improving the quality of life for people living with serious or potentially life-limiting illnesses. It improves the quality of life for patients with life-threatening illnesses and their families through early identification, assessment, and treatment of pain and other physical, psychosocial, and mental problems, as well as the prevention and relief of suffering".[3] It provides the necessary medical, emotional, and social support to help cope with the burdens of a serious illness.

Improving the quality of life globally and providing continuous healthcare support are among the priorities of the UN's Sustainable Development Goals. This includes prevention, treatment, rehabilitation, and palliative care within a unified system aimed at preventing and relieving suffering through early identification, proper assessment, and treatment of pain and other physical, psychosocial, or spiritual issues.

Historical foundations of palliative care

Palliative care originated in ancient civilizations, where the importance of alleviating suffering was already recognized. In ancient times, when culture was at its peak, medicine played a crucial role in shaping society, as it was the healing practice that helped prolong human life. Ancient philosophers believed that the human soul, or mind, is directly connected to the universal spirit. Consequently, it was natural for such a culture to associate illness with a lost connection between the human soul and the cosmos. Hippocrates emphasized the importance of alleviating pain and suffering and favored a treatment model that addressed physical symptoms, improved quality of life, and reduced suffering. Hippocrates, widely known for his quote "First, do no harm" (primum non nocere), emphasized the importance of holistic care and considered it impossible to separate the body and soul during the healing process. This concept formed the foundation for the holistic nature of palliative care, which involves treating the person as a whole rather than just managing the symptoms of a specific disease.

In ancient Rome, influential physicians adhered to the principles of Hippocrates, aiming to alleviate the suffering of patients with incurable diseases. For this reason, opium was frequently used as a painkiller in Roman medicine and became the primary tool for pain management. The use of opium for pain relief was documented by the renowned Roman physician Galen, who believed that relieving pain and maintaining the quality of life were essential for patients with serious illnesses. Historian Susan Mattern, in her autobiographical work The Prince of Medicine, highlights Galen's regular use of opium for patients with severe incurable diseases and his patient-centered care until the end of life.[4]

American philosopher Martha Nussbaum's work, The Therapy of Desire: Theory and Practice in Hellenistic Ethics, emphasizes that ancient Hellenistic philosophers, particularly the Stoics and Epicureans, developed ethical systems that functioned as therapeutic practices, offering practical methods for individuals to overcome suffering and maintain emotional balance. The study examines the works of Greek philosophers Epicurus, Zeno, Cleanthes, and Chrysippus, as well as those of Roman philosophers Seneca, Epictetus, and Marcus Aurelius. In her paper, Nussbaum discusses Stoic ethics as a form of therapy that aims to reduce suffering by cultivating self-mastery and emotional control.[5]

In Stoic philosophy, Epictetus, Marcus Aurelius, and Seneca explored the nature of suffering. According to Stoicism, pain and illness are often inevitable, and perception plays a crucial role. Suffering can be alleviated by developing temperance, courage, and wisdom. Epictetus emphasized that humans cannot control the external world, but they can control their attitude toward external factors. He believed that by accepting pain as a fact, patients could avoid spiritual and emotional suffering.[6] Marcus Aurelius presents a similar view in his writings, emphasizing the acceptance of pain with peace and the need to manage suffering through emotional and spiritual support.[7] According to Seneca, self-control, courage, and wisdom are vital for maintaining dignity in times of suffering. One should use pain as a means of demonstrating strength. "We are not troubled by the events of our environment but by our attitude toward them.[8] Although Stoicism is not directly related to modern palliative care, there are apparent correlative factors between them, including accepting pain as a fact, maintaining inner peace during suffering, and aligning with the goals of palliative care to preserve the patient's quality of life and dignity at the end of life. Stoicism is analogous to palliative care in that it encourages people to set aside passions and strong emotions to preserve their quality of life in favor of dignity. Stoicism involves overcoming suffering by maintaining inner stability and rationality without losing oneself or one's dignity.

In the Middle Ages, the Church played a crucial role in caring for those suffering from severe, incurable illnesses. Hospices were established to provide care and spiritual support to patients with incurable illnesses. These hospices were established in churches and monasteries, involving monks, nuns, and volunteers.[9] The Church's belief in the sacredness of life heavily influenced hospice care. Care for the terminally ill, including prayer and preparation for immortality, reflected the essence of Christianity—that death is not the end but a transformation to eternal life. During this period, there was a close connection between care for the terminally ill and the theological and moral teachings of the Church, particularly the Christian doctrine of the imago dei, the belief that every person is created in the image of God.[10] By caring for the sick, the Church fulfilled its moral and religious obligations, reflecting Christ's compassion for suffering.[11,12]

In the New Testament, we often see Jesus healing the sick and comforting the oppressed, a model of Christian behavior that has become a hallmark of the faith. Since the Middle Ages, specific changes occurred during the Renaissance (14th–17th centuries). Scientists Andreas Vesalius and Paracelsus revolutionized medicine through empirical studies and anatomical dissection. A broader scientific understanding of the human body and diseases began during this period. In the Middle Ages, illness was often viewed as a spiritual ordeal. Still, during the Renaissance, medical knowledge began to expand, and doctors shifted their focus to the biological causes of diseases, with empirical research gradually replacing religious approaches.[13]

During the Age of Enlightenment in the 17th and 18th centuries, physicians developed evidence-based theories based on observational methods. This included experiments with drugs, medical techniques, and medical instruments. During this period, the focus was also on managing pain and other symptoms in patients with chronic diseases. Despite the growing influence of science, spiritual care remains essential for patient care. Many people believed that prayer, rituals, and contact with priests were necessary to alleviate suffering, especially for terminally ill patients. In this era, medical care, together with spiritual support, was vitally important for patients with chronic terminal illnesses.[14]

At the beginning of the 19th century, the development of medicine led to the establishment of hospitals that focused mainly on curing diseases, often neglecting patients' emotional and spiritual needs. In 1842, Jean Garnay founded the first hospice in Lyon, which remains operational to this day. Additionally, in 1879, the "Hospice of the Virgin Mother" in Dublin was established, specifically designed to care for patients nearing the end of their lives. Hospice care is specialized palliative care for patients with incurable illnesses or multiple illnesses with a limited life expectancy. Palliative care focuses on maintaining the highest quality of life while managing treatment and pain relief rather than solely treating the disease.[15] In 1905, three hospices were operating in London, one of which was the famous St. Luke's Hospice, which published annual reports on the emotional and spiritual needs of seriously ill patients and their values before death and established a morphine regimen to alleviate pain and suffering.[16]

After World War II, there was a sharp reassessment of global values, and the World Health Organization (WHO) adopted a definition of "well-being" as "a dynamic state of physical, mental, social, and spiritual well-being, and not merely the absence of disease."[17] The development of modern palliative care began in the mid-20th century with Dame Cicely Saunders, the founder of the first hospice in London, in the 1960s. This model became the foundation for modern hospices. Saunders decided to establish a hospice after visiting St. Luke's Hospice in 1947, where she met a young patient, a Polish pilot named Tasma. During their conversation, they discussed the needs of terminally ill patients and how to spend the last days of life with dignity. These conversations became the foundation of the hospice movement.

Saunders aimed to manage not only the physical symptoms and pain of terminally ill patients but also the psychoemotional problems, providing support and compassion for their families. Saunders and her colleagues observed that the value systems of palliative care patients shift in their final moments. Spiritual values become a priority, including the essence of life and its meaning, understanding the causes of suffering, and the fear of death. Before death, it becomes important for patients to resolve relationships with their environment and loved ones and address critical issues. To help resolve these issues, Saunders introduced the concept of "total suffering," encompassing physical, emotional, social, and spiritual aspects of suffering. He considered comprehensive care essential to alleviate total suffering.

In 1970, under the auspices of the WHO, a group of palliative care experts began working in more than 40 countries, including the United Kingdom, the United States, Canada, Central European countries, and Australia. At the initiative of this group, the term "palliative care" was included in the Index Medicus in 1996, alongside other terms such as "terminal care" and "hospice." In 1977, American psychiatrist George Engel developed the biopsychosocial theory of illness, which states that "illness and disease throw a person out of the usual course of life and often radically change him."[18] Engel argued that biopsychosocial factors determine vulnerability to disease, and the biomedical model, widely used in medicine, is focused only on treating the disease and fails to meet the spiritual needs of a person. The person should be considered in the context of multifaceted social and spiritual needs.[18]

In 1978, the National Hospice and Palliative Care Organization (NHPCO) was founded in the United States, serving as a platform for advocacy, education, and research on palliative care. In 1990, the WHO developed a definition and objectives for palliative care, stating: "Palliative care is multidisciplinary care for patients with chronic, incurable diseases, and its goal is to relieve and control pain and other symptoms, as well as to support patients psychologically, spiritually, and socially." The main goal of palliative care is to improve the quality of life for patients and their family members."[19] In addition to symptoms, patients suffering from chronic and incurable diseases also face existential problems, such as the meaning and purpose of life, which are directly related to fear, anxiety, and depression. A person is gradually isolated from society, which not only affects the patient's quality of life but also intensifies the symptoms of the disease. According to Engel, biopsychosocial factors determine increased vulnerability to disease, and the current treatment-oriented biomedical model of disease does not meet the spiritual needs of the person. Instead, the individual should be considered within a context of multifaceted needs.[18]

Implementing the biopsychosocial model in practice is challenging as it requires both material and human resources. This model is particularly challenging to implement in a conservative medical environment. However, the biopsychosocial model offers a more comprehensive understanding of the origins of disease, health, and overall well-being.[20] The development of this philosophy has significantly contributed to medicine by shifting the patient's perception from an "object" to a "subject" - a person with a disease who has rights.[21]

In the biomedical healthcare model, doctors focus on a specific disease, attempting to diagnose it based on its etiology and pathogenic components, and then prescribe appropriate treatment. While this approach is essential, it is not sufficient. Each patient and their family perceive the disease differently, and the manifestations of the disease and complaints in the patient's body also vary. The biomedical model overlooks the patient's spiritual, social, and personal aspects, as well as the patient's attitude toward a particular treatment and the family's social resources. This gap often leads to problems in the doctor-patient relationship, an increase in the number of dissatisfied patients, higher medical service costs, and, most importantly, the violation of the patient's rights.[21]

The holistic biopsychosocial model aims to provide a comprehensive understanding of the disease, encompassing the patient's physical, psychological, social, and spiritual needs. It views the patient as a person with rights rather than focusing solely on the disease. This model is more humane and cost-effective.[21] Ten years before George Engel's theory, Cecily Saunders set the goal of not only managing physical symptoms and pain in patients with serious illnesses but also addressing their psychoemotional problems and providing support and compassion to their family members. Spiritual needs acquire particular significance in the last days and moments of life. Specifically, spiritual well-being, hope, personal dignity, and the ability to maintain a dignified life have a direct impact on patients' quality of life, the course of the disease, and the outcomes of treatment.

Palliative care, by its very nature, is holistic. Respecting the patient as a person reduces the degree of suffering in the final days of life.[22] The entire biopsychosocial model of palliative care is a clear example of the humanization of medical care, a person-centered approach, the protection of human rights, respect for individual values, and the preservation of human dignity.[21] It should be equally accessible to everyone who suffers, as the right to a dignified life is a fundamental human right.[23]

Philosophical aspects of palliative care

Ethical decisions in palliative care hold significant importance. Despite the bio-psycho-social model of palliative care, which emphasizes a patient-oriented approach and the protection of human rights, several challenges arise. The solutions to these challenges are highly individualized and sensitive, differing from general guidelines. A key consideration in palliative care is the phenomenon of death. In this context, the patient has the right to be fully informed about their condition, and the medical staff must ensure this. The European Authority on Patients' Rights states: "A hospital patient has the right to be informed about his condition. The patient's interests must be the key factor in determining the information to be provided to him. The information provided must enable the patient to be fully informed about all aspects of his condition, whether medical or otherwise. Patients should be involved in decisions that affect their well-being and make informed choices.

Article L. 1111-2 of the Public Health Code reinforces this by asserting, "Every person has the right to be informed about his or her health status. This information includes details about proposed examinations, treatments, their benefits, potential complications, risks, and alternative options." This is in alignment with Article 35 of the Code of Medical Deontology, which stipulates that "a physician is obliged to provide honest, clear information to the person he examines, treats, or advises about his condition and the examinations he proposes."

Doctors often perceive the need for palliative care as the obligation to "inform only about the 'bad.'" This is not a narrative of recovery or triumph over death but, instead, a message indicating that at this moment, medical control may fail, and the patient's life may be approaching its end. The patient's awareness of palliative care is linked with the recognition of the failure to cure and the inevitability of death, leaving no room for future hope.

This raises an important ethical question: Is such behavior by the doctor an act of kindness? How beneficial is information for the patient if it only conveys the harsh reality of their condition? The issue is not about the doctor's morality but whether we provide patients with information they wish to hear. A person has the right to be fully informed about their illness and its possible complications, but they also has the right to maintain confidentiality. Additionally, patients have the right to remain unaware of their diagnosis and continue living without the burden of this knowledge. Our fundamental obligation is to respect human dignity in all circumstances.

What is the emotional impact when a doctor discusses the impending death of a patient or the complications of an incurable disease? Is this merely information the patient needs to know about their condition, or is something deeper at play? Awareness of the need for palliative care extends beyond just knowing the illness. The doctor's refusal to engage in further discussions or provide clarifying answers is more telling than a diagnosis on paper. This silence can be perceived as a death sentence to a patient who is still alive.

Humans experience life and death simultaneously—life clings to existence, while death does not wait. In the patient's consciousness, a profound thirst for life and the awareness of impending death become intricately intertwined. This represents a profound existential struggle in which the patient seeks to navigate life while confronting their mortality. Palliative care is inherently paradoxical. Its aim is not merely to alleviate suffering but to help individuals live out their remaining days in a way that preserves their dignity. This underscores the undeniable truth that a person has the right to live their final moments with dignity.

CONCLUSIONS

The demand for palliative care has been steadily increasing due to its comprehensive approach that addresses patients' physical, psychological, and spiritual needs. This holistic care model supports patients and their families, emphasizing individualized care that prioritizes patient dignity and rights. By offering compassionate and patient-centered care, palliative care plays a crucial role in alleviating suffering on a global scale.

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