



PALLIATIVE CARE IN NEUROLOGY

The American Academy of Neurology Ethics and Humanities Subcommittee

Palliative care is defined by the World Health Organization (WHO) as

The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.¹

Providing optimal palliative care requires the coordinated efforts of a health care team, usually including physicians, nurses, therapists, social workers, and clergy, among others.

Palliative Medicine, a recognized medical specialty in several countries and an evolving discipline in the United States, is defined in the Oxford Textbook of Palliative Medicine as

The study and management of patients with active, progressive, far-advanced disease, for whom the prognosis is limited and the focus of care is the quality of life.¹

Although palliative care evolved from hospice care and has traditionally been associated with the treatment of patients with terminal cancer, it should be recognized as an important concept in the management of any patient with a progressive, incurable illness. Because many neurologic illnesses are progressive and incurable, the optimal care of such patients requires that neurologists understand and apply the principles of palliative medicine. Indeed, the principles of palliative care are relevant to the management of almost all patients because minimizing distress and controlling pain and other symptoms are important even for patients with curable diseases.

Palliative medicine emphasizes symptom management to relieve suffering and improve the quality of life for those patients in whom the underlying disease cannot be cured or alleviated. Distressing physical symptoms, such as pain, dyspnea, cough, agitation, anxiety, nausea, vomiting, anorexia, and constipation, as well as feelings such as fear, anger, indignation, hopelessness, powerlessness, loneliness, and isolation, usually can be alleviated with appropriate pharmacologic and nonpharmacologic interventions. Successful management of such symptoms and feelings can greatly diminish suffering and enhance quality of life. A team approach to palliative care permits the optimal management of psychological and social problems and attention to the spiritual needs of the patient.

Palliative care and the goals of medicine. The goals of medicine are many and include cure of disease, prevention of death, improvement or maintenance of functional status, relief of symptoms and suffering, promotion of health and prevention of disease, and minimizing harm resulting from treatment.² Providing optimal care for each patient depends on the careful determination of the most appropriate and realistic goals of medical treatment and implementing appropriate treatment measures designed to achieve those goals.

When one can eliminate the cause of the patient's symptoms, medical treatments are generally directed toward that patient's underlying disease rather than the symptoms themselves. Although symptom control is always an important element of treatment, it is generally inappropriate to focus on merely eliminating the symptoms if one can instead eliminate their cause. However, when the patient's underlying disease is incurable and progressive, symptom control appropriately becomes the primary goal of medical treatment.

Standard cure-oriented medical treatment, intended to cure illness and prevent death, may itself cause unintended, but foreseeable, suffering. When there is a reasonable chance of achieving the goals of curing illness and preventing death, the suffering caused by such cure-oriented medical treatment is usually accepted as unfortunate but justified and acceptable. However, when the goals of curing illness and preventing death no longer are realistic, the suffering caused by such medical treatment may be perceived as an intolerable burden. Moreover, the pain and other symptoms caused by the disease itself can usually be alleviated with appropriate therapy, as long

as the goals of relief of suffering and enhancing quality of life are recognized as paramount. Unfortunately, because these goals are not adequately emphasized, most physicians still fail to provide adequate pain medication for dying patients.^{3,4}

Providing optimal medical treatment requires that all medical decisions be based on a thoughtful and realistic assessment of the potential benefits and burdens of treatment. When a person has a progressive and incurable illness, the goals of treatment must be carefully considered. Confronting such difficult realities demands both honesty and compassion on the part of the physician.

Palliative care, euthanasia, and physician-assisted suicide. Palliative care is neither voluntary active euthanasia nor physician-assisted suicide because the goal of palliative care is to relieve suffering rather than to cause or assist death.

Voluntary active euthanasia is the intentional killing of a patient, at the patient's request, to end his or her suffering. Physician-assisted suicide consists of providing the medical means for a patient to intentionally end his or her life, usually to avoid suffering from the effects of an incurable progressive illness.

Palliative care relieves pain and suffering. It aims neither to hasten death nor to postpone death. Providing optimal palliative care will often prolong a patient's life as a consequence of decreasing pain and suffering. However, palliative care may at times cause unintended, but foreseeable, shortening of the patient's life. Although unintended, this foreseeable consequence is accepted and justified because minimizing suffering has become the primary goal of medical treatment.

Patients have the legal and ethical right to refuse life-sustaining treatments. They may refuse such treatments because they believe the burdens outweigh the benefits. Although accepting the risk, or even the certainty, of an earlier death, such patients are not committing suicide, because their goal is to minimize their suffering rather than to cause their own death. For such patients, the promise of optimal palliative care to minimize their suffering is of critical importance. Indeed, enhanced awareness and increased availability of optimal palliative care may prevent many patients from committing suicide, whether with or without a physician's assistance.⁵

Palliative care in neurologic diseases. Examples of neurologic disorders for which only palliative care may be appropriate include severe strokes, high cervical spinal cord lesions, locked-in syndrome, advanced dementia, advanced MS, and progressive and incurable neuromuscular diseases such as some motor neuron diseases and some muscular dystrophies.

Patients with severe strokes or advanced dementia may retain the capacity to suffer pain and anxiety. They may develop agitation or dyspnea. Each of these symptoms, and most others, generally can be managed with specific pharmacologic or nonpharmacologic therapy, as long as appropriate efforts are made. For example, pain can be controlled with adequate doses of morphine. Agitation and anxiety will respond to adequate doses of benzodiazepines. Mechanical restraints are likely to increase anxiety and agitation, may cause pain or even injury, and should be avoided whenever possible. Underlying causes of dyspnea should be treated, if possible; providing oxygen by nasal cannula may be beneficial. When other measures fail, morphine may be administered to relieve dyspnea.

Conscious alert patients with progressive and incurable neuromuscular diseases or advanced MS who refuse life-sustaining therapies, such as mechanical ventilators or tube feeding, may suffer many of the symptoms described above. Conscious patients who refuse mechanical ventilation for treatment of respiratory failure are particularly prone to suffering with anxiety and dyspnea. In such patients, these symptoms should be treated aggressively with benzodiazepines and morphine.⁶ To relieve these symptoms, it is appropriate to sedate such patients, even to the point of unconsciousness if necessary and requested. Because the goal of such treatment is to relieve suffering, it is entirely justified and appropriate, even if it unintentionally hastens the patient's death. Similarly, conscious patients who are unable to swallow and refuse tube feedings may desire sedation to suppress anxiety and feelings of hunger.

Conclusion. Providing optimal medical care depends on determining the most appropriate goals of treatment and the most appropriate means of achieving those goals for each patient. This is especially important in the care of patients with progressive and incurable diseases. Many patients with such diseases will refuse potentially life-sustaining treatment. The relief of suffering and easing the burden of death are among the most important benefits that physicians can provide to patients.

Many patients with neurologic diseases die after long illnesses during which a neurologist acts as the principal or consulting physician. Therefore, it is imperative that neurologists understand, and learn to apply, the principles of palliative medicine.

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