



Palliative Care Education in the Acute-care Setting

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PART 1

Editor's note: End-of-life cases are being covered more and more frequently by the media. One extremely controversial case last year led to conflicts between legislators and the justice system after the US Supreme Court refused to hear a case struck down by the US Circuit Court of Appeals. This is the first of two articles on the issue of palliative care. The first half provides an overview of the issues. Part two will examine the study performed at the acute care hospital, its findings, recommendations for the hospital, and a palliative-care plan checklist.

The Office of Population Census and Surveys (OPCS) reported in 1992 that even though most patients would rather die at home, they are most likely to die in a hospital setting.³ Given this statistic and the growing health care needs of the baby-boomer generation, the call for better care of the dying and education for those who will care for them, becomes urgent.¹⁷

“Persons with serious, complex, and chronic illnesses are among the most underserved and vulnerable patients in our country.”⁷ The incorporation of palliative care for patients with progressive illnesses at acute-care hospitals would be an avenue to address patients’ symptoms and meet their psychosocial needs. The mission of the acute-care hospital studied in this article is to provide all patients with the highest quality health care, efficiently, effectively and compassionately. The patient population that would benefit from palliative care is identified as intergenerational and covers many diagnostic categories.

Palliative care is a fairly new and developing subspecialty that concentrates on relief of pain and suffering.⁷ Client-centered goal planning through palliative care is one solution that will meet patient and family needs. Physicians can facilitate care that is patient specific and addresses each patient’s needs. Individual care plans can be written for each patient based on diagnosis and patient values.

The goal of palliative care would be to aid patients in achieving the best possible quality of life and to help families cope by offering care from an interdisciplinary team of the hospital that consists primarily of a physician, nurse and social worker and pastoral care.⁷ “To meet the needs of a growing population of Americans who will require palliative care, a program must be developed to train experts who can in turn educate all physicians-in-training.”⁷ Acute-care hospitals can no longer offer only curative treatment, they must address a patient’s needs or goals for long-term care.

Statement of the problem

The Palliative Care Task Force at the study hospital identified several areas of patient care that are not being met. As a teaching hospital with level I

trauma designation, the hospital currently does not have a palliative care service. They do, however, have a physician-led palliative-care consultation service. This is a resource that physicians may use for patients who desire an improved quality of life through pain and symptom control. Although this is available to all physicians at this hospital, the service is not used appropriately.

There are several reasons that can be attributed to this observation. One significant reason is the lack of knowledge about palliative care and the discomfort that many physicians experience when discussing end-of-life issues with their patients. Many physicians feel they are giving up or have failed their patients if they no longer pursue aggressive treatment options. According to the medical director of the palliative care consultation service, there are several areas of care that they are meeting minimally and areas of palliation that they are not meeting at all. This reinforces the reasons why palliative care should be a core competency for all physicians, as well as an integral component of any quality health care across the disciplines.⁷

In order for palliative care to be achieved as a part of the acute-care setting, education must precede any palliative-care efforts. Communication with patients, their families and other health care providers is not an area that is currently addressed through formal education. Residents and staff members may have only minimal access to formal education in areas of communication with regard to end-of-life or palliative care. It can be surmised that the continuity of care increases as communication increases. Well established protocols will ensure respect for the patient’s goals of care and acknowledgement of those goals.

A review of services was conducted by the medical director of the palliative care consult service at the study hospital, and several areas of care were identified as deficits in palliative care (Table 1).

Table 1 Summary of the problem

Areas of palliative care that the study hospital meets minimally
Appropriate physical environment for palliative care patients
Good relationship with hospice within the hospital
Active quality improvement when offering patient care
Spiritual/religious support
Active “phase of dying” management (currently there is lack of identification of these patients)
Understanding of ethical/legal aspects of end-of-life (EOL) care
Areas of palliative care that the study hospital fails to meet
Identification of patients who would benefit from or desire palliative care
Core elements of palliative care <ul style="list-style-type: none"> ● Interdisciplinary team with care plan development ● Volunteers for patient support ● Emotional support for staff caring for patients ● Continuity of care ● Pain and symptom management
Bereavement services and grief support
Cultural needs addressed
Psychological and psychiatric aspects of care
Social aspects of care

Need for the study

The notion that suffering before death is inevitable is no longer acceptable to the patient or their families.⁸ “Multiple studies show that palliative care programs reduce symptom distress, improve patient and family satisfaction, and ensure cost-effective care by delivering the right care to the right patient at the right time and the right place.”⁸

According to studies done by Education for Physicians on End of Life Care (EPEC), there is a large gap between the way Americans currently live with life-threatening illness and death, and the way they would like to experience the end of life in their home. “Ninety percent of the respondents to a Gallup survey in 1996 desire to die at home, yet nearly 80% currently die in institutions.”¹¹ Curative treatment and the mindset to “fight death” at all costs, impel many physicians to initiate aggressive treatment, leaving patients with symptoms that are not controlled or who have lost their independence. In 1997, an American Medical Association (AMA) survey identified that patients expect their physicians to be confident and competent to provide them with care when they do develop a life-threatening or progressive illness.

The aim of this study was to determine the knowledge level of staff members within the acute-care study hospital. It may be of interest to the palliative task force at this hospital to know whether formal education should include curriculum concerning palliative care. Orientation for new staff members could include palliative-care education. This would aid staff by knowing what resources are available for patients who benefit from palliative care.

Literature review

Foundation of palliative care

Chronic illnesses, not accidents, are the most common causes of death among older adults. “End of life has changed from overwhelming illness, typically lasting minutes or days, to a period of slow deterioration that may last months or years.”⁶ According to the Federal Interagency Forum on Aging-Related Statistics, the six leading causes of death among Americans age 65 or

older are heart disease, cancer, stroke, chronic obstructive pulmonary disease, influenza and pneumonia.²¹ These disease processes lead to disabilities that may be financially burdensome to the patient and/or family, as well as draining to the health care system.⁶

Death and dying should be viewed as a process, just as pregnancy and birth are considered a process.²¹ A report by the Institute of Medicine, *Approaching Death: Improving Care at the End of Life*, identified three trajectories of illness and death.⁶ The first trajectory is that of a sudden and unexpected death, such as a car accident. The second trajectory applies to those patients who are terminally ill and experience a steady decline in their physical health and a relatively short terminal phase.⁶ The third trajectory is most often experienced by older adults as a result of longevity, a prolonged decline in health with periodic crises that can last several years ending in death.⁶ This article will focus on the third trajectory of illness.

Palliative care initially focused on cancer patients and their families; however, it has been extended to encompass the care of other individuals who suffer from a progressive or chronic illness. For example, a patient with a neurodegenerative disease, such as Parkinson’s disease, will face a long-term, physical wearing of the body in years or decades that also includes long periods of dependency.¹³ The inability of health care providers to alter the disease progression is sometimes interpreted to mean that nothing more can be done; however, this is specifically the time to address pain management and symptom control through palliative-care efforts.¹³

Incorporating palliative care into the acute-care setting highlights the shift of goals for the patient and family. Traditionally, the goal in acute-care is curing disease and restoring health through the use of extensive technology. As goals change for the patient due to the underlying disease process, there should be a shift from aggressive treatment to palliative care. This way, health care providers are assured they are meeting the patient’s desired goals of care, as well as their psychosocial needs. The major distinction

between conventional care and palliative care is that conventional care focuses on prognostic indicators with emphasis on quantity of life, while palliative care shifts the focus to quality of life.¹⁴ It reflects a holistic philosophy of care, implemented across diverse settings.

Barriers to end-of-life care

The role of the physician is to recommend care, whether it is hospice or traditional curative care. The inability to determine the prognosis of a terminal illness, or the course the disease will take and, ultimately when death will occur, is a significant barrier to the provision of good end-of-life care⁶ (Table 2). Prognostication, with the help of a risk index or scale, will enable health care providers who work with older adults to plan clinical strategies in collaboration with the patient and family members and in considering their needs. These plans may include home care, long-term

she failed to recognize her family, stopped walking and eating, and became incontinent in her bowel and bladder. She was unable to sit without pain, which was attributed to a chronic back condition.⁶ Ms G was diagnosed with gastrointestinal bleeding. Her physician suggested major surgery, and her family saw no reason to disagree with the suggestion. Although she was diagnosed with Alzheimer's disease, she was not perceived to have a terminal illness, and there was no thought to suggest a palliative model of care.⁶

Identifying transitions in the patient's condition will aid the patient, family and health care providers in preparing the patient for his or her end of life.⁶ For example, a patient with chronic obstructive pulmonary disease may have no change in her condition until she falls ill with influenza and never fully recovers. In this case, contracting influenza is a transition point in this patient's condition. As in Ms G's case, a nurse should have discussed with the family, the possible effect that major surgery could have on her already compromised mental status and rehabilitative potential.⁶

It is understandable that a family may be surprised at a patient's sudden death, when the patient had survived exacerbations of the illness. Nurses are often caught off guard as well when patients are hospitalized for simple problems yet never return home.⁶ It is very difficult for nurses to provide proper end-of-life care if they are unaware that the patient is dying. Prognostication tools will allow nurses to determine whether a patient's chronic illness has reached a terminal phase, and both families and patients can make decisions regarding care at the end of life.

Formal education in end-of-life care has just recently been added to nursing programs, medical schools and residency training. Many physicians feel ill equipped to care for the dying. When surveyed by the American Medical Association in 1997-1998, only four of 126 US medical schools required a separate course in end-of-life care. Even though 121 schools indicate they encompass end of life care as a topic, currently there is no standardization for education in end-of-life care in medical schools at any level.

Table 2 Barriers to end-of-life care

Health care providers have not acknowledged the importance of end-of-life care. It is usually too late upon diagnosis to be effective, and funding is inadequate to deliver quality palliative care.
Fears of drug addiction, exaggerated risk of adverse drug effects and restrictive legislation have resulted in inadequate control of pain and symptoms.
Uneasiness and lack of confidence cause many physicians to avoid dealing with patients who are actively dying.

care, hospice, or other supportive services.⁶ Prognostication is as important to the patient as it is to health care providers, since it identifies when a patient is entering the predeath period. Prognostication can assist the staff in identifying the severity of disease, especially with regard to chronic illnesses that are not considered terminal.

For example, when Ms G, a patient who received care at an acute-care hospital, returned to her nursing home after abdominal surgery, the nursing staff noted a considerable change in her behavior and cognition. She was combative and would throw her meal tray onto the floor. She failed to recall any of the nurses' names, and became increasingly confused. As time went on,

Medicine's shift

According to the EPEC Project, with the integration of science, technology and communication, we have become a “death-denying” society.¹¹ Currently, medical care focuses on productivity, youth and independence, while devaluing age, family and caring for one another.¹¹ While this mindset may work for some, it is inevitable that we all will die. As we care for patients with life-threatening illnesses, it is important for health care providers to recognize the symptoms of dying, while at the same time understanding the importance of their patient's goals. When discussion moves from curative treatment to pain and symptom control, ethical concerns can arise regarding assisted suicide and the withdrawal or withholding of treatment at the end of life.¹² Assisted suicide and euthanasia are both illegal in the United States, although Oregon has legalized assisted suicide.

The American Nursing Association's (ANA) position on end-of-life care states that nurses should act as leaders and advocates for the delivery of dignified and humane end-of-life care.¹² Nurses should demonstrate respect, support and lasting commitment to patients and their families at the end of life.

The ANA supports the rule of “double effect” when the decision is made to allow natural death (due to the underlying disease process) with comfort versus hastening death.¹² When caring for patients at the end of life, it is important to understand the rule of double effect and the likelihood of dying. For example, a physician may not treat a patient or may withdraw a treatment, thereby allowing for the natural progression of the disease that leads to death. This can be perceived as having respect for the patient.

The rule of double effect has four conditions. The first affirms that the act is, in itself, good or at least morally indifferent. For example, “when a nurse is trying to distinguish between aggressively treating pain with opioids from causing death, the rule of double effect would say that the act of administering opioids to relieve pain is good or at least morally indifferent.”¹²



The second condition states that with respect to the intention of the action, the good effect is directly intended and the bad effect can be predicted, but unintended. Using the example above, the administering of opioids will relieve pain and the possible suppression of respiration is foreseeable, but unintended.

The third condition is that “the good effect is not achieved by the means of the bad effect.”¹² This condition means that the person is not pain free because they are dead; they are pain free because of the opioids.

The fourth condition says that the good effect is proportionate to the bad effect. Ethically, it is not justifiable to use a higher dose of opioids than necessary to manage pain, knowing the foreseen bad effect.¹²

It is important that nurses and other health care providers realize that both their profession and the rule of double effect ethically allow for aggressive pain management, even if death may be hastened with the treatment; although most studies support there is no hastening of death with the use of opioids for pain management. The ANA feels that the promotion of comfort care and aggressive efforts to relieve pain and other symptoms in dying patients are obligations of the nurse. Nurses should not hesitate to use full and effective doses of pain medication for the proper management of pain in the dying patient. “The increasing titration of medication to achieve adequate symptom control, even at the expense of life, thus hastening death secondarily, is ethically justified.”¹²

Benevolence

The ability to identify the transition of the patient's condition aids the patient, family and health care providers as the patient moves closer to the final stage of life. There may be instances, however, when family members and/or physicians feel that being completely honest with a patient regarding the diagnosis or treatment options may do harm to the patient. As a result, the plan of care may include a benevolent deception (eg deceiving the patient for a good reason).¹² If there is ever a question about full disclosure to the patient, a conference should be held to discuss the anticipated benefits as well as the possible harms of full disclosure.

Health care providers should have high regard concerning the patient's autonomy to ensure benevolent deception is the proper course of action for that patient. If there is opportunity, the patient should be asked if they want to defer any decisions to a surrogate while they still have full capacity to make decisions. This allows for patient autonomy in decision making; thus, clinicians are not violating any principles in regards to patient care.¹² When health care providers treat patients and family members as partners as they develop goals of care, they show respect for the patient, beneficence and the avoidance of malfesance.

The decision to withdraw or withhold care

When the decision is made that an intervention would do more harm than good to a patient, then it can be ethically justified to withhold or withdraw that intervention.²⁷ There is a difference, however, in the action of withdrawing care or withholding care. Intubation and ventilation may be initiated as interventions, expecting a favorable response from the patient. The advantage of initiating an intervention is that much can be learned about actual versus potential harms and benefits.¹² If the response does not produce any improvement from the patient, then it can be assumed that the intervention does not provide any benefit, and the patient should be removed from ventilation.²⁷ This is seen as active intervention. Withholding a treatment because of potential harm is often seen as a passive intervention. According to Carolyn Hayes, there are important considerations in both:¹²

- What are the harms
- What are the benefits
- What are the patient's wishes given what is now known

The decision to withhold or withdraw intervention may be justifiable as long as there is consideration of autonomy, beneficence, nonmalfesance and the deliberation of intentionality.¹²

There is symptom burden related to chronic illnesses. This can be measured in terms of the number of symptoms, the length of time the symptom is experienced, the degree to which normal activity is restricted and the amount of time lost from work.⁶ As a disease progresses, symptoms increase and palliative care should increase appropriately. The most common symptoms seen in older adults include mental confusion, incontinence, and difficulty in hearing and seeing, dizziness, pain, dyspnea and emotional need. As people are dying at an older age, it means the symptom burden is carried for a much longer period of time and the quality of life diminishes as patients experience weakness, falls, delirium, dementia, urinary incontinence, sleep disturbances and serious depression.⁶



In the January 2004 issue of *the Journal of the American Medical Association*, a survey showed that staff inadequately addressed several areas of care: pain (24%), dyspnea (22%), and emotional needs (50%).⁹ Changes are needed to rectify this situation. Providers, policy makers and the public must talk about the need for a change from a pro-long-life-at-any-cost approach to one where the goal looks at the patient's priorities, the quality of life, and the relief of suffering. The current mindset does not address these concerns until the provider realizes that a cure is no longer possible.⁹

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) identified many inequities and barriers that prevent the dying patient from receiving appropriate care.¹⁵ Palliative care addresses three main barriers to appropriate care: lack of professional knowledge and skill in end-of-life care; lack of understanding and communication concerning the goals of medicine; and the barriers to providing appropriate care in the acute-care setting.

Principles of autonomy and informed consent

For every patient, the goals of care should be decided on the promise of beneficence and non-maleficence. Decisions about care are based on probabilities, because there are so few absolutes in medicine.¹¹ Health care providers often experience ethical dilemmas when their personal beliefs and societal mandates are in discord. Common ethical concerns include knowing the difference between futile care and palliative care.¹² Palliative-care measures can include but are not limited to, the use of sedation, narcotics, antibiotics, artificial nutrition and/or hydration, antipyretics, cardiopulmonary resuscitation, oxygen, ventilator support, tracheotomies, dialysis and surgery.¹⁰ Every intervention available could be seen ethically as justifiable by some clinicians or family members and unjustifiable by others.

It is the patient's right and decision to determine what treatment will address their needs. The Patient Self-Determination Act (PSDA) was passed in 1990 to allow all patients to make choices and decisions about the type and extent

of the medical care they receive. The PSDA also ensures that hospitals, long-term care facilities and home-health agencies that receive Medicare and Medicaid reimbursement recognize living wills and power of attorney for health care as advance directives. Goals of care should be established before deliberation of the benefits or burdens of suggested treatments.¹² Health care providers must offer options of care based on established standards of care, research and evidence-based practice.¹² The optimal time to establish goals of care is when the patient first enters the hospital.

Establishing the appropriate level of treatment in the acute hospital setting is important, as it addresses the needs of the older patient population who will have one or more chronic illnesses during their lives. Under-treating the patient's symptoms may cause conflicts during the decision-making process about a patient's care. As well, a physician's belief of curative treatment beyond its usefulness can make this an even more difficult time. These years are typified by physical and psychological distress, functional dependence and the increased need for family support.

Hospice

Hospice care is an invaluable asset to people with a terminal illness. Whether administered at home, freestanding hospice facility, long-term care facility or a hospital, hospice care focuses on comfort care, rather than curative treatment.⁵ Hospice care is a program of multidisciplinary health care for patients with terminal illnesses.¹ Admission to hospice care requires that the patient's prognosis for survival is six months or less, assuming the disease follows its normally expected pathway. Under Medicare and other insurers, eligibility for hospice is limited to those who are within six months of death and are willing to give up coverage for curative or life-prolonging treatment.⁸

The goal of hospice care is to neither hasten death nor prolong life. The care is aimed at improving the quality of life and promoting comfort. The hospice team aids families for up to 13 months after the death of a family member.

Palliative care

The goal of palliative care is to help patients with an incurable illness achieve the best possible quality of life by using an interdisciplinary team consisting of at least a physician, nurse, and social worker.⁸ Studies show that palliative care can effectively relieve pain and other symptoms and improve patient and family satisfaction with their medical care.⁸ Palliative care should be offered simultaneously with all other appropriate medical treatments. Medical costs can actually be reduced with the improvement of the health care system by ensuring the patient receives the right care at the right time.

Palliative care is considered a field of medicine that grew out of the hospice movement. It applies the goals of hospice, specifically the physical and emotional support for family members, facilitated from a team of professionals to a broader group of patients, independent of their prognosis and whether or not the patient is continuing to pursue life-prolonging treatments.⁸ Palliative care is facing a new development phase as patient needs have changed.¹¹ In the past, the focus centered on patients with cancer and on short periods of terminal care. With the development of technology and new drugs, patients may survive longer. This requires a more comprehensive plan of care. Models of palliative care include:

- Hospital palliative-care support methods, which may train others to give service.
- (Specialist palliative-care wards in hospitals; separate units for terminal care in a general hospital.
- Encouraging a palliative-care approach among nonspecialist staff.
- Developing palliative care as an outpatient service or day care.
- Inpatient hospice care.
- Developing the palliative care role of the primary health-care team.
- Hospice home-care nurses.
- Multidisciplinary home-care support teams.

Different models of care should not exclude any of the others; each may be useful at different stages of the disease process.¹¹

Conclusion

Traditionally, medicine focuses on two goals; to cure disease and prolong life, or to provide comfort care. With this dichotomy, the decision to concentrate on reducing suffering is made only after life-prolonging treatment has been ineffective and death is forthcoming.¹⁷ With the number of patients who have complex, serious illnesses, the health care system needs to find a way to treat them effectively and efficiently. Hospital-based palliative-care programs offer high-quality care, improve the continuity of patient care across the board, ease burdens on staff, lower costs and are able to meet quality and pain accreditation standards.⁴

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Additional resources

- American Medical Association (AMA), www.ama-assn.org/
- American Nurses Association (ANA), <http://nursingworld.org/>
- Education for Physicians on End of Life Care (EPEC), www.epec.net/
- Hospice Association of America (HAA), www.hospice-america.org/
- Human Investigation Committee (HIC) Yale University School of Medicine, <http://info.med.yale.edu/hic/>
- National Hospice and Palliative Care Organization (NHPCO), www.nhpco.org/
- Patient Self Determination Act (PSDA), www.dgcenter.org/acp/pdf/psda.pdf#search='Patient%20Self%20Determination%20Act
- The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), <http://jama.ama-assn.org/cgi/content/abstract/274/20/1591?>