Barriers to Palliative Care

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Background: Palliative care is received by a small number of patients with terminal illness, most of them with cancer.

Methods: Data are reviewed and evaluated that relate to the barriers and problems that limit access of patients to appropriate palliative and/or hospice care.

Results: Palliative care generally is not well integrated into the health care system. Access is limited, and many health care professionals and laypeople are unaware of its possible benefits. Cultural and religious barriers often apply, and problems exist in obtaining narcotics. Palliative care for patients other than those with cancer may be especially difficult to achieve.

Conclusions: Recognizing and overcoming the barriers to the provision of palliative care can bring about changes in education, health care practices, and administration to achieve the desired goals.

Introduction

In the United States, as in most developed countries, death is rarely unexpected. It usually occurs in older persons with chronic progressive illnesses that often are complicated by infections or exacerbations. In most hospitalized patients, death is preceded by a "Do not resuscitate" order.[1] However, the predictability of death has not led to effective efforts to improve the quality of death or to palliate symptoms before death. The objectives of palliative care are not to cure the underlying disease but to relieve symptoms and to improve the quality of life and death to patients with chronic as well as terminal illnesses. Hospice care refers to care provided to terminally ill patients who usually have a life expectancy of six months or less.

The tenets of modern palliative care have been practiced in the hospice movement for over 30 years. Although hospice care in the United States began in its modern form in the 1970s and has been reimbursed by Medicare since 1983, only approximately one third of cancer patients receive formal hospice care, often in the last few weeks of their illnesses.[2] Patients with other terminal illnesses (eg, progressive neurological illnesses, end-stage cardiac or pulmonary disease, and acquired immunodeficiency syndrome [AIDS]) are even less likely to be admitted into hospices, and palliative care may be unavailable or inadequate for those outside of hospices.

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) examined the care given to 9,105 patients with one or more of nine life-threatening diagnoses (eg, nontraumatic coma, multiple organ system failure with sepsis) who were admitted to five teaching hospitals in the United States. Phase I of the SUPPORT study, which was observational, found that dying patients often are treated aggressively, that their pain frequently is untreated or undertreated, that advance directives may not be heeded, and that communication regarding "Do not resuscitate" and other orders often is lacking.[3] Phase II of the SUPPORT study, which was an intervention to correct these deficiencies, demonstrated the difficulties in correcting these shortcomings in routine medical care. Physicians in the intervention group received regularly updated probability estimates of six-month survival, outcomes of functional disability at two months, and outcomes of cardiopulmonary resuscitation. A specially trained nurse contacted the patient, family, physician, and hospital staff to elicit patient and family preferences, to clarify understanding of outcomes, and to improve advance care planning and communication. No improvement in care was seen with this intervention.

The lack of effective palliative care has many causes, including the lack of integration of palliative care into most health care systems, the inaccessibility of hospice care, ignorance of methods of palliative care, difficulties in obtaining narcotics, cultural and religious beliefs of the patient and family, and the problems of providing effective palliative care for terminal illnesses other than cancer (Table).

Lack of Integration

In today's health care system, palliative care is most widely available in the form of hospice care. Thus, aside from the limited number of hospitals with palliative care services, formal palliative care is available only in a package that many patients and families may be unable or unwilling to accept.

A harsh view of the lack of integration of hospice care into the rest of the health care system follows: To enter a hospice, patients and families must forfeit other forms of care, including only palliative care, and make no attempt to prolong life. The hospice determines what forms of palliative care are appropriate, including whether and when to admit the patient for inpatient care. Chemotherapy, radiation therapy, transfusions, and tube feedings generally are not considered appropriate palliative care. The health care providers in the hospice may differ from those who cared for the patient before hospice admission. When the patient is admitted for hospice care, it may be to a different hospital. When the patient is dying, the family is told to call the hospice number rather than the familiar "911" number.

This synopsis is exaggerated, and there are good reasons for many of these requirements, including the requirements of Medicare funding and the history of hospice care in America as a protest against aggressive acute care. The overall effect, however, is to segregate hospice care from other, more familiar forms of health care and thus add the trauma of separation at a time when both patient and family are already traumatized.

Even palliative care that is provided in an acute care hospital often is in the form of "comfort care," implying that other forms of treatment are no longer being considered. It is a fallacy to assume a dichotomy between dying patients who should receive palliative care and all other patients who are not assumed to need...
comprehensive symptom relief.[4] In some hospitals, palliative care services are available even to those who are receiving other forms of treatment. However, palliative care as the comprehensive treatment of suffering generally is reserved for those patients who do not wish to receive other treatments.

Palliative care in the United States currently is provided by discrete organizations called hospices, by physicians caring for their patients in conjunction with palliative care services or, in most cases, by physicians in the community who care for patients without other assistance. Integration of palliative care education into medical school and residency training programs is needed to improve physician care and to generate appropriate hospice referrals of terminally ill patients. Such education will promote continuity of care of terminally ill patients for the benefit of both the patients and the students. These changes in medical education will require the flexible participation of hospices and palliative care services. In order to continue the development of palliative care services and to allow more flexibility for hospices, changes in reimbursement mechanisms for terminal care will be necessary. Given the present aggressive nature of terminal care in many acute care hospitals, these changes may be cost effective.

Inaccessibility of Palliative Care

Many causes contribute to the lack of access to palliative care, such as the shortage of available hospices and the inability to fulfill requirements for hospice admission. In 1990, there were more than 1,800 hospices in the United States, of which over two thirds were certified by Medicare, indicating they provided a full range of services. No similar comprehensive survey of palliative care consultation services has been conducted, but anecdotally, some services are available in relatively large teaching hospitals. Hospices tend to be concentrated in urban and suburban areas, with a paucity in rural and inner-city areas. Nursing homes are the site of death for an increasing number of terminally ill older patients, and many nursing homes do not have contracts with nearby hospices.

Another barrier to access of palliative care is the stringent hospice admission requirements. Many hospices require that the patient have a primary caregiver who is available on a full-time basis. Those without nearby family members or whose family members work but lack funds to hire a caregiver may be denied admission. Most hospices accept at least some patients with no insurance coverage but may be limited in the amount or kind of care they can provide to indigent patients. These patients also are likely to lack a primary caregiver.

Another reason for lack of access to palliative care is the paucity of physician referrals. Since many patients and family members are unaware that hospice care exists, their primary care physicians are gatekeepers to hospice care. In addition, physicians must certify that their patients are terminally ill, and patients with progressive terminal illnesses often are not referred or referred late to hospice. The average length of stay in a hospice is 59 days, and many patients are referred only days or hours before death. Under these circumstances, hospices and palliative care services can do little to help the patient and the family.

There are many reasons for the lack of or lateness of referrals.[5] Medicare regulations require physician certification that the patient has only six months to live, but accurate prognoses are difficult to make, even for patients with cancer.[6] Even if the prognosis is evident, the physician may be reluctant to “admit defeat” or to discuss the prognosis with the patient and family. The physician also may be reluctant to relinquish control of the patient's care to a multidisciplinary team or may erroneously believe that he or she will not be part of this team. Finally, since hospice care does not involve interventions that would contribute to the physician's income, the patient may not be referred due to this financial disincentive.

Several approaches may improve the accessibility of hospice and palliative care to patients. Integration of these services into routine medical practice is needed. Also, providing information to laypeople and health care professionals by means of inservice sessions, grand rounds, and community education meetings is an important part of the hospice mission, and many hospices attempt to communicate with referring physicians on the status of the patient. Another approach to enhance access requires modifications to the hospice prerequisites for admission, such as eliminating the need for a caregiver who is available full-time by working with patients and families to arrange shared caregiving. Another barrier to care involves Medicare's requirements of a six-month life expectancy as well as the stipulation that 80% of a hospice's patient care days must be used for home care. Hospice organizations have advocated for the elimination of these requirements, arguing that abuse resulting from these changes is unlikely given present hospice usage patterns. They also suggest that many patients who presently receive more expensive inpatient acute care for their terminal illnesses could be cared for in the hospice setting.

Lack of Knowledge

As a result of the lack of integration into routine medical care, health care professionals and laypeople often are unaware of the principles of palliative care - especially of adequate pain control - and the services available in hospices. Palliative care and hospice care are not routinely available at most medical centers and thus are not included in most residency programs. Some fellowship programs, especially in geriatric care and oncology, include training in palliative care.

Health care professionals may be concerned about addiction, sedation, and respiratory depression when using narcotics.[7-9] They may lack information on appropriate drugs, adjuvant therapy, prevention and treatment of side effects, and alternate routes of administration. Patients and family members often have similar concerns, especially about drug abuse. To some degree, these concerns may be the result of substance abuse programs that classify abusive drugs with drugs used for medical purposes.

Many health care professionals are unaware of hospice operations, reimbursement mechanisms, and insurance coverage. A common misconception is that hospices are only inpatient units where patients go to die. To combat the negative effects of this lack of information, improvements in palliative care education for medical students and residents are needed. Palliative care training is especially important in areas such as geriatric care and oncology. In addition, a cadre of specialists in palliative care is needed to train others. At present, few fellowship programs exist. A credential such as the Certificate of Added Qualifications that is used for those trained in geriatric care may encourage such training.

Access to Narcotics

Adequate doses of opiates and appropriate adjuvant medications can control pain in 75% to 90% of cancer patients without undue side effects (some patients require unusual routes of administration or complete or partial sedation to be pain-free).[10,11] A median dose of 30 mg of morphine every four hours is the norm to maintain unusual routes of administration or complete or partial sedation to be pain-free. Weak narcotics can be given in doses high enough for analgesia in patients with severe pain, but the number of pills required and the expense would be prohibitive, as would the toxicity from aspirin or acetaminophen. Some states not only require patients using opiates for chronic pain to register as “habitual users,” but also limit the doses of medication that can be prescribed, the number of pills that can be given, or the length of time for which the prescription is intended. Many states also limit or prohibit refills on narcotic prescriptions. The language used in state regulations may be vague or intended for illicit drug use.
use, and the parameters used by drug regulatory agencies to determine whether narcotics are being used appropriately often are ambiguous. These regulations discourage the prescription of narcotics in adequate doses for the appropriate treatment of pain.

Practical difficulties can arise once the appropriate prescription is written. Many pharmacies, concerned about crime, paperwork, and regulatory oversight, either do not carry narcotics or stock only a limited number of drugs in only a few dosage forms. Pharmacies located near or associated with cancer centers and hospices often are better stocked. Many health maintenance organizations and government-funded hospitals restrict their patients to drugs from formularies that may be limited in the drugs or dosage forms available.

The Wisconsin Pain Initiative is the first of several state and regional initiatives designed to educate professionals and laypeople about the appropriate use of narcotics in pain control, to incorporate pain control into the curriculum of medical schools and residency training, and to eliminate laws and regulations that limit good pain management.[16]

The Intractable Pain Treatment Act of Texas is an example of an attempt to change regulatory barriers by stating that controlled drugs can be used by Texas physicians to treat their patients with intractable pain.[14] Because cultural confusion between illicit and licit use of drugs is common, similar initiatives that incorporate professionals, professional organizations, and laypeople will almost certainly be necessary for change elsewhere.

Cultural and Religious Beliefs

Over the last 30 years, most American doctors have adopted the practice of informing their terminally ill patients about their prognoses and allow them to make their own decisions about treatment options.[17,18] Most patients already believe they should be told.[19] This belief is based on American cultural beliefs about the importance of autonomy, on the work of Elizabeth Kubler-Ross on death and dying,[20] and on the tenets of the first hospices. This mainstream view is shared by most hospice workers who believe that patients should be encouraged to talk openly about their feelings regarding death and dying. These discussions can be carried to the point of rigidity or discomfort for their patients. To quote a hospice patient, “They keep wanting to talk about death; I’d rather talk about how the Cubs are doing.”

Another mainstream view is that modern medicine often is overaggressive in treating possibly terminal illness. These views are not shared by all cultures or traditions; even within mainstream American culture, differences regarding open discussion of death and dying and the family decision-making dynamic can be found in individuals, families, and age groups. Minorities (especially African-Americans and Hispanics) often are not well represented in hospices, as staff members, patients, or volunteers. Persons from minority backgrounds may not have time or energy to serve as volunteers.[21] Many hospice workers do not speak Spanish, even in Hispanic communities, and minority professionals may be difficult to recruit to facilities where no other minority staff are present. Perhaps most important, medical over-treatment is not traditionally a problem of minority groups, so hospice care may be seen as nonessential at best, both by minority health care professionals and by patients. In Asian and Hispanic cultures, discussions of death and dying often involve family members rather than the patient. Decisions may be reached by the family’s elders or by consensus and not always with the patient’s involvement. Thus, the hospice environment of open discussion of the disease and of death with hospice workers is alien to this family dynamic.[22]

Hospice care is consistent with Catholicism and most mainstream Protestant traditions, as well as with Reform and Conservative Judaism. However, in some Orthodox interpretations of Jewish law, death cannot be hastened (eg, through withdrawing or withholding artificial nutrition and hydration or other treatments that may prolong life); however the dying process need not be prolonged. Therefore, if a therapy is not effective in prolonging life, it need not be offered, and palliative care, including hospice care, is acceptable.[23] Some patients and family members may have religious concerns based on a misunderstanding of the requirements of their religion.

Hospice workers must be flexible regarding the need for open discussion with the appropriate family decision-makers. Not all Caucasian American patients want to discuss their illnesses and possible deaths or make their own decisions; in fact, most want to discuss the issues with their families. Not all Asian American patients want to be stoic and have their families make decisions.

Recruitment of minority staff members and volunteers is important. At least some of the staff members and volunteers in heavily Hispanic areas should speak Spanish. Patient and family preferences regarding gender of staff and volunteers should be respected where possible. Pastoral counselors and chaplains may help in dispelling mistaken beliefs about religious requirements.

Terminal Illnesses Other Than Cancer

Most hospice patients (90% to 95%) are cancer patients, and hospice staff are adept at treating cancer pain and other symptoms, due in to the prominence of pain as a symptom of cancer as well as to the training of palliative and hospice care workers to treat cancer pain. Also, a prognosis for cancer is easier to determine than that of other diseases. However, most deaths in the United States are the result of noncancer causes, and the role of traditional palliative care in these deaths is unclear. For example, cardiovascular disease is the most common cause of death for most adult age groups, and many patients with this disease may have a better quality of life when treated aggressively with catheterization, angioplasty, valve replacement, and surgery where appropriate. Even patients with end-stage congestive heart failure may have less dyspnea when treated with aggressive medical management, including intravenous diuretics.

Dementias and their associated sequelae, infections and malnutrition, are common causes of death in the very old, but patients with these illnesses are uncommon in hospices. The life expectancy of patients with severe dementia is dependent in part on the aggressiveness with which intervening infections are treated, which may be difficult to estimate. Hospice care may not fulfill the wishes of patients with dementia, since their wishes often are unclear. While many patients with end-stage dementias are in nursing homes, where hospice care is relatively rare, these patients might be more comfortable with less aggressive care, and many do receive palliative care. Some palliative care programs have been developed specifically for dementia patients.[24]

The life expectancy of persons with AIDS depends to a large degree on the aggressiveness with which infections are diagnosed and treated, with medical treatments for the disease itself becoming more effective. The treatments or procedures that are palliative and those that are life prolonging often are nebulous. A complicating factor is the relative youth of many patients with AIDS, with corresponding changes in psychosocial and family dynamics and in the extent of insurance coverage. However, many persons with AIDS are cared for in hospices, and several inpatient and outpatient hospices have been developed specifically for those with AIDS.

The Health Care Financing Administration (HCFA) recently requested focused medical reviews and investigations by Medicare intermediaries into Medicare hospice admissions of patients with noncancer diagnoses. These diagnoses can be difficult to determine and, from the point of view of the payer, the patients may remain in the hospice for a long time while requiring little care from the hospice. The National Hospice Organization, the Academy of Hospice Physicians, and the HCFA are attempting to establish guidelines for admission to hospice care for patients with noncancer diagnoses. The results of the investigations and the ensuing guidelines may further limit access to hospice care for patients with noncancer diagnoses.

With their expertise in psychosocial dynamics, multidisciplinary care, family-patient care, and the treatment of symptoms (eg, anorexia, malaise, dyspnea) that are common in many illnesses, hospice workers can provide valuable help not only to patients with cancer, but also to those with other illnesses. Flexibility of hospice
Conclusions

At present, most dying patients do not receive formal hospice or palliative care, and most physicians are not trained in palliative care. The separation and segregation of palliative care from routine medical care present barriers in communication, referrals, and cross-fertilization. Integrating palliative care into routine medical settings, improving education in palliative care for students and residents, revising admission requirements, recruiting minority staff, improving availability to appropriate medical narcotics, and continuing research to determine which patients with illnesses other than cancer will be best served by palliative care will result in more widespread use of palliative care services. Palliative care is necessary for the humane care of dying patients, and the barriers to patients receiving that care should be demolished.

References


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