The Care of Dying Patients: A Position Statement from the American Geriatrics Society

AGS Ethics Committee*

BACKGROUND

Dying is the final portion of the life cycle for all of us. Providing excellent, humane care to patients near the end of life, when curative means are either no longer possible or no longer desired by the patient, is an essential part of medicine. The American Geriatrics Society (AGS) recognizes that most people near the end of life desire and should be able to obtain attentive and effective care directed at relieving symptoms, maximizing comfort, and maintaining dignity and control. Providing excellent care to dying patients and their families is time consuming and requires expertise as well as compassion. Care of patients who are dying is more than just withholding burdensome treatments; it is the provision of a special form of medical care, one in which physicians can take pride and find fulfillment. Making such care regularly available will require improvements in systems for service delivery and in professional education.

DEFINITIONS

Patients Who are Dying

Within this document, people are considered to be dying when they have a progressive illness that is expected to end in death and for which there is no treatment that can substantially alter the outcome. Thus, people are dying when they have illnesses such as advanced dementia or severe congestive heart failure, in addition to illnesses more routinely recognized as terminal, such as advanced cancer. Care of dying patients also encompasses patients who have elected to forgo available treatments that might forestall death, such as dialysis for end stage renal disease.

Palliative Care

Within this document, palliative care, also referred to as comfort care, refers to care directed toward the quality of life of patients who are dying, including the relief of pain and other symptoms, attention to the psychological and spiritual needs of the patient, and providing support for the dying patient and the patient's family.

PATIENT CARE ISSUES

Position 1

The care of the dying patient, like all medical care, should be guided by the values and preferences of the individual patient.

Rationale

Optimal medical care of all patients, not just those who are dying, rests on frank and sensitive communication between patients and physicians. For dying patients, this ordinarily entails recognition and discussion of the facts surrounding prognosis and the likely course with a palliative plan of care. The conversations throughout must continue to elicit and respond to the patient's needs. When the patient loses decision-making capacity, care should be guided by these previous conversations as well as by written advance directives, if available.

Position 2

Palliative care of dying patients is an interdisciplinary undertaking that attends to the needs of both patient and family.

Rationale

In caring for dying patients, physicians must themselves develop a broad array of knowledge and skills and an attentiveness to comprehensive care. In addition, whether or not the patient is enrolled in a formal hospice program, physicians most often should function as members of a team. The team may include nurses, social workers, homemakers, home health aides, physical therapists, chaplains, volunteers, and the patient's family. Each team member contributes the special knowledge and skills of his or her discipline to help meet the needs of dying patients. Together, team members provide care for the patient and assist the family in coping with the patient's dying and death. Family members (with "family" defined by the individual patient) usually play a critical role in both providing care for dying patients and in making decisions for dying patients who have lost decision-making capacity. Providing support for the patient's family, including a period after the patient dies, is an important aspect of the palliative care of dying patients.

Position 3

Care for dying patients should focus on the relief of symptoms, not limited to pain, and should be addressed by both pharmacologic and nonpharmacologic means.

Rationale

Pain, anxiety, depression, dyspnea, constipation, and other symptoms can all be significantly ameliorated, if not eliminated, in the vast majority of dying patients, provided we employ fully our pharmacologic armamentarium and appropriate nonpharmacologic interventions. Symptoms should be treated vigorously, even if the unintended effect of
these efforts is the hastening of death. Though not medical symptoms, dignity and control are central issues for many dying patients.

HEALTH CARE DELIVERY ISSUES
Position 4
Dying patients should be guaranteed access to comprehensive, interdisciplinary palliative care across the spectrum of care settings as part of any federal or state health care reform plan, without care being conditioned on the financial status of the patient.

Rationale
Palliative care is often provided most appropriately in the patient's own home, a setting where reimbursement is inadequate under many existing insurance plans. Dying patients should be able to receive palliative care in the home, the hospital, and the nursing home, depending on the needs and preferences of the patient, without a disruption in the continuity of the patient's care.

Position 5
Reimbursement policies should be modified to enhance the availability of palliative care.

Rationale
Patients and families are presently faced with major financial obstacles to choosing palliative care, while payment for continued highly technological, acute care (e.g., dialysis, ventilator care, etc.) is readily available. Physician reimbursement should also be modified to promote palliative care. Like other forms of primary care, palliative care is time consuming, does not involve highly reimbursed procedures, and requires substantial counseling of patients and families.

Position 6
Administrative and regulatory burdens that may serve as barriers to palliative care should be reduced.

Rationale
Currently, hospices providing care for dying patients face special administrative burdens in addition to the usual paperwork facing all health care institutions. Requirements regarding availability of family and a home for caregiving regularly prevent some patients from receiving palliative care through hospices. Uncertain or unavailable estimates of prognosis also may serve inappropriately to exclude patients in need of palliative care services. Regulations intended to promote adequate nutrition for nursing home residents and laws intended to prevent assisted suicide and euthanasia should be written or revised so that these issues are not confused with proper palliative care decisions and treatment.

EDUCATION ISSUES
Position 7
Physicians, as well as other health care professionals, at all levels of training should receive concrete, insightful, and culturally sensitive instruction in the optimal care of dying patients.

Rationale
Medical students and physicians in training in the United States today rarely receive specific and in-depth instruction on the care of dying patients. This instruction should address attitudes toward and reactions to death and care of the dying, symptom management (especially pain control and adequate use of narcotic analgesics), and communication skills. The importance of knowledge about the care of dying patients should be reinforced by evaluating it on board exams and other specialty certification exams.

Position 8
The public, including our patients and our colleagues, needs to be educated regarding the availability of palliative care as an important and desirable option for dying patients.

Rationale
It is the position of AGS that this kind of educational effort would benefit many by dispelling the notion that the only options available to dying patients are continued futile therapy in a medical setting or turning to assisted suicide or euthanasia (see related AGS position statement).

RESEARCH ISSUES
Position 9
Adequate funding for research on the optimal care of dying patients should be provided.

Rationale
Much of the information base needed to inform patients and physicians regarding optimal care of dying patients does not yet exist. Studies documenting the outcomes of various types of care plans, medications, and treatment settings, especially ones focused on the experience of the dying patient, should take place. Although traditional biomedical research on symptom relief is needed, much of what is already known about symptom relief is not implemented effectively because of professional ethical concerns about aggressive symptom management and institutional barriers to the provision of palliative care. Research on these matters, including educational approaches and interventions to promote palliative care, is needed.