

Quality of Life Matters®

End-of-life care news & clinical findings for physicians

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Provision of Culturally Competent Care Can Increase Patient/Family Satisfaction

End-of-life preferences vary among cultural groups, yet many issues are important to all

Awareness of cultural differences surrounding the care of patients at the end of life can aid health care professionals in providing culturally competent care. However, while some end-of-life preferences are held in common, others can vary within groups, both by sex and by individual, a recent study has found.

“Health care providers should remember that racial/ethnic differences in end-of-life preferences can be used to guide practice and improve cultural sensitivity but do not supersede the need to recognize varying individual preferences,” note the authors. Their findings were published in the January 2006 issue of the *Journal of the American Geriatrics Society*.

The research team analyzed the responses of 73 focus group participants (mean age,

End-of-life issues important to all groups included:

- Physician communication
- Hope and optimism
- Being comfortable
- Knowing that responsibilities are taken care of

—Sonia A. Duffy, et al
Journal of the American Geriatrics Society

67 years; range, 50 to 83 years) identifying themselves as members of one of five racial/ethnic groups: Hispanic, black, white, Arab Muslim, or Arab Christian.

Researchers identified a number of end-of-life issues important to all groups [see

sidebar, left], with the following concerns found common to most groups:

- Love and compassion; being cared for
- Expressing feelings
- Fixing relationships
- Having choices and making plans
- Being ready to go and saying goodbye

Dying with dignity and good care were of major concern to **Hispanics**. This group opposed nursing home care but was receptive to hospital and hospice care. Hispanic participants were more likely than others to want control over their place of death and to oppose feeding tube placement.

African-American participants were the least opposed to nursing homes and the most likely to prefer to die away from home.

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Care of the Dying: A Nation’s Responsibility

As the United States, along with the rest of the industrialized world, continues its unprecedented demographic shift to a “mass geriatric society,” a genuine crisis in caregiving — both professional and unpaid — is imminent. **It is imperative that society address two crucial issues: how we die and who will care.**

That is according to The President’s Council on Bioethics, which explored questions raised by the graying of the population in a report released September 2005, entitled “Taking Care: Ethical Caregiving in Our Aging Society.”

“Many of the questions center around caregiving,” writes the council. “Who will need it? Who will do it? Who will pay for it? And perhaps most importantly, what kind of care is owed to those at the end of life?”

In the year 2000, the number of Americans aged 65 years and older was 35 million,

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Provision of Culturally Competent Care

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However, black men and women differed in their preferences regarding two major issues.

While **African-American women** were in favor of extensive medical intervention at the end of life and opposed to physician-assisted suicide, **African-American men** indicated that they did not oppose assisted suicide and wanted little intervention to maintain life. The preferences of **Hispanic men and women** were split along similar lines on these same two issues.

“The sex differences within groups could be a problem, because spouses often make decisions regarding end-of-life treatments,” comment the authors. “Health care professionals should encourage couples to discuss end-of-life preferences while they are still able to do so.”

White participants were the most likely

to want to know what to expect physically as they approached the end of life and want to be offered choices. They did not feel it was the family’s responsibility to care for them and were open to hospice and nursing home care, although many preferred to die at home.

All **Arab Americans** felt that the family should take care of a dying person at home, often with the help of the entire neighborhood. Entering a nursing home was to be avoided at all costs. Although opposed to both extending life artificially and assisted suicide, Arab participants were largely unaware of hospice care.

Culturally uncomfortable with telling the patient “bad news” or mentioning the words “cancer” or “death,” nearly all Arabs nonetheless indicated that they themselves would want to be told if they had a terminal illness, so they could prepare for entering heaven.

Women across cultures were more likely than men to feel connected to their cultural group. Women were also more likely than men to have a durable power of attorney, want to resolve unfinished business, prefer to remain alert, want to be touched, and to feel it was important to pray.

“The provision of culturally competent care can increase patient/family satisfaction,” the authors conclude. “Moreover, providing culturally competent care can increase cost effectiveness by eliminating services that are not acceptable to selected groups and individuals and enhancing those that are effective.”

Source: “Racial/Ethnic Preferences, Sex Preferences, and Perceived Discrimination Related to End-of-Life Care,” Journal of the American Geriatrics Society; January 2006; 54(1):150-157. Duffy SA, et al; Center for Practice Management and Outcomes Research, Ann Arbor Veterans Affairs Hospital, Ann Arbor, Michigan.

Care of the Dying: A Nation’s Responsibility

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or 12.4% of the population, the report notes. By 2030, that number is expected to reach 71.5 million, or nearly 20% of the population. Further, the fastest-growing segment of the population — those aged 85 years and older — is projected to more than quadruple from 4 million to 18 million persons by 2050.

The council considers advance directives on their own to be inadequate, and strongly encourages early advance care planning discussions among patients, family, and physicians, as well as the use of advance proxy directives, which identify for health care professionals the person trusted to make caring medical decisions for the patient under changing situations.

“We should always seek to benefit the life incapacitated persons still have, and never treat even the most diminished in-

dividuals as unworthy of our company and care,” affirms the report. **“Dying, like living, is a human matter, not merely a medical or technological one.”**

Because of the many dilemmas facing an aging society, the report strongly recommends the establishment of a presidential commission on aging, dementia, and long-term care to develop policy reforms for improving the capacity of families to care for their loved ones.

“A mature and caring nation, concerned about staying human in a technological age, will not shy away from its responsibilities,” the report concludes. “If asked, ‘Who cares?’ the answer must be, ‘We do.’”

The full report, which recommends many hospice-related sources of information

and support, is available online:

www.bioethics.gov

Guidelines for Ethical Caregiving Include:

- The goal of ethical caregiving in the clinical setting is not to extend the length or postpone the end of the patient’s life as long as is medically possible, but always to benefit the life the patient still has.
- The clearest ethical grounds for forgoing life-sustaining treatments are an obligation to avoid inflicting treatments that are unduly burdensome to the patient being treated and an obligation to avoid treatments that are not at all (or not any longer) efficacious in attaining their desired result.

—The President’s Council on Bioethics
Taking Care: Ethical Caregiving in Our Aging Society

Improving Quality of Life in Nursing Home Residents

Two studies published recently in the *Journal of the American Geriatrics Society* report on ways that care might be improved, especially for residents who are terminally ill

Poorly Controlled Pain: Screening Tool May Help

Many nursing home residents have poorly controlled pain due to inappropriate prescribing practices, a multidisciplinary research team has found. The team tested a recently developed tool for screening overall suitability of pain medication treatment in a nursing home setting.

Using the Nursing Home Pain Medication Appropriateness Scale (PMAS), the researchers compared direct resident pain assessments to the pain medications prescribed for a repeated 20% random sample of 2,031 Colorado nursing home residents.

The mean total PMAS score was 64% of optimal compliance, suggesting that “pain prescribing practices in nursing homes are

KEY PRINCIPLES OF PAIN MEDICATION APPROPRIATENESS SCALE INCLUDE:

- The criterion standard against which pain medication management is measured is the resident's own description of their pain.
- The resident's assessment of the quality of their pain relief should be included in the assessment.
- Items on the scale should be derived from evidence-based guidelines of national professional organizations.
- There are pain medications and adjuvants whose use must be avoided in frail older people.

generally poor,” investigators report. Only 25% of all subjects reported complete pain relief.

“Because of the subjective nature of pain, developing an evidence base for what works to ameliorate it is challenging, but critical to improving the quality of life of nursing home residents,” conclude the authors. They urge further updating and testing of the PMAS as a possible quality-improvement tool.

Source: “Assessing the Appropriateness of Pain Medication Prescribing Practices

in Nursing Homes,” *Journal of the American Geriatrics Society*; February 2006; 54(6):231-239. Hutt E, Pepper GA, Vojir C, Fink R, Jones KR; Denver Veterans Affairs Medical Center and Department of Medicine, School of Nursing, and Health Sciences Center, University of Colorado, Denver; College of Nursing, University of Utah, Salt Lake City; and School of Nursing, Yale University, New Haven, Connecticut.

Overhospitalization: Medical Directors Cite Need for End-of-Life Care Information, Support

Medical directors and directors of nursing within nursing homes cite the lack of end-of-life care information and support for residents as a chief reason for excess hospitalization, a new study has found. Lack of familiarity with patients by covering physicians was ranked second in importance by medical directors.

“For medical directors, the need for better information and support to residents and families around end-of-life care ranks first among the causes of overhospitalization,” write the authors.

Researchers analyzed the results of a survey of medical directors and directors of nursing of 448 nursing homes serving elderly residents in 25 states. Almost half

of residents had dementia, and 1.1% of patients were enrolled in hospice.

Factors that most influenced the decision to hospitalize included resident and family preferences, quality of life, amount of discomfort from acute illness, and likelihood of increased disability or death.

Both medical directors and directors of nursing agreed strongly that hospitalization can be traumatic for residents, with neither group expressing strong beliefs in aggressive treatment for these patients. Tube feeding, for example, was not supported as an intervention for most residents who cannot eat, and the decision to tube feed was agreed to be primarily a reflection of patient and family wishes.

“Most causes of overhospitalization are modifiable,” conclude the authors. “With improved education and support around end-of-life care, improved communication between covering doctors and nurses, and improved access to selected resources in the nursing home, it may be possible to minimize unnecessary hospitalizations for nursing home residents in the future.”

Source: “Nursing Home Capabilities and Decisions to Hospitalize: A Survey of Medical Directors and Directors of Nursing,” *Journal of the American Geriatrics Society*; March 2006; 54(3):458-465. Buchanan JL, Murkofsky RL, et al; Department of Health Care Policy, Harvard Medical School, Boston; and Department of Geriatric Medicine, John A. Burns School of Medicine, University of Hawaii, Honolulu.

Post-Acute Care Settings: Helping Patients to ‘Live Until They Die’

When acute care no longer benefits terminally ill patients — and care at home is not feasible — hospital physicians recommending transfer can take steps to maximize quality and continuity of care. As outlined in a recent article, these steps include not only communicating treatment goals and orders, but also making wise recommendations from among the available setting options for post-acute palliative care.

“To ensure high-quality palliative care for patients after discharge, hospital-based physicians should learn to identify the most promising post-acute care settings in their community,” write the authors in their article published in the *Journal of the American Medical Association*.

After determining that the potential benefits to the patient outweigh the risks of transfer, physicians can collaborate with a discharge planning nurse or social worker to help the patient and family choose among setting options, suggest the authors.

Important considerations in choosing a setting include:

- Patient and family preferences
- Professional nursing needs
- Insurance coverage and ability to pay
- Type and quality of local services

Post-acute care settings vary in their provision of such services as: professional nursing care, support for activities of daily living (ADLs), and access to hospice and palliative care. **“Hospital-based physicians need to understand the basic parameters of inpatient hospice, nursing home care, and assisted living or residential care,”** state the authors, who offer criteria and questions physicians can ask for evaluating palliative care in these settings.

DEDICATED HOSPICE UNITS

Inpatient hospice provides the most comprehensive palliative care; beds can be available in free-standing hospices, nursing homes, or hospitals. Physicians can ask: *“Is this service available*

in the patient’s community? Are beds available for short-term intensive symptom management? For long-stay supportive care?”

NURSING HOMES WITH HOSPICE

Most nursing homes contract with local hospices for provision of palliative care services, such as specialized nursing care for symptoms, spiritual care, and bereavement support. **“Several studies have demonstrated that the addition of hospice to usual nursing home care improves the quality of end-of-life care,”** comment the authors. “Family caregivers perceive improved quality of care for symptoms, and half believe hospice reduces the need for hospitalization.”

However, physicians may find that discharging a patient whose only insurance is Medicare directly from hospital to nursing home hospice care can raise financial difficulties, warn the authors. The patient may be required to elect either hospice or skilled nursing care for rehabilitative services, and the skilled nursing benefit is economically more advantageous to both the patient and the nursing home, unless the patient is also covered by Medicaid.

Physicians can ask: *“Does this nursing home have a hospice contract? Is the facility willing to forgo the skilled nursing benefit and*

accept a Medicare patient directly into hospice care? Will the accepting physician endorse the palliative care plan?”

NURSING HOMES WITHOUT HOSPICE

Physicians can ask: *“Does this nursing home have access to a pain team or a palliative care consult service? Do its leaders endorse palliative care as essential to their mission? Is the staff trained to provide end-of-life care? How do they respond to symptom crisis? Is there a chaplain? Will the accepting physician endorse the palliative care plan?”*

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Continuity of Care

To ensure continuity of care following patient discharge, the authors recommend that physicians clearly communicate treatment goals, life-sustaining treatment orders, and “anticipatory orders” for symptom management. Because nursing homes have 30 days after transfer to provide the required physician admission assessment, gaps in medical care can sometimes occur. In addition, the transfer itself can escalate symptoms. Physicians can:

- Write “on call” orders for medication during transfer and sliding scale orders for dosages covering symptoms assessed as mild, moderate, or severe
- Include individualized protocols to anticipate and guide management of acute complications, so as to avoid hospital readmission
- Ensure that transfer records include documentation of goals of care and treatment decisions

—Hanson and Ersek
Journal of the American Medical Association

‘Dignity Therapy’ Addresses Suffering at the End of Life

Research suggests that psychosocial and existential issues are of major concern to terminally ill patients, causing perhaps even greater distress than pain and physical symptoms. A novel psychotherapeutic intervention, dignity therapy, may reduce suffering and distress by engendering hopefulness — a sense of meaning and purpose — in patients living life at the end of life.

That is according to Harvey Max Chochinov, MD, PhD, and colleagues, who conducted a feasibility study of the novel therapy. Their findings were reported in the *Journal of Clinical Oncology*.

“The beneficial effects of dignity therapy reside in being able to bolster a sense of meaning and purpose while reinforcing a continued sense of worth within a framework that is supportive, nurturing, and accessible, even for those proximate to death,” write the authors.

Participants in the trial were 100 terminally ill cancer patients (life expectancy, < 6 months; mean age, 63.9 years) receiving palliative care services in Winnipeg, Canada, and Perth, Australia, from 2001 to 2003. Patients were asked to complete pre- and post-intervention measures of a broad range of outcomes,

FEASIBILITY STUDY FINDINGS INCLUDE:

- 91% of participants reported feeling satisfied or highly satisfied with dignity therapy
- 86% reported that the intervention was helpful, and 81% said that it had been or would be of help to their family
- 76% indicated that the therapy had heightened their sense of dignity
- 68% reported an increased sense of purpose; 67%, a heightened sense of meaning
- 47% said the intervention had increased their will to live

—Chochinov, Hack, et al
Journal of Clinical Oncology

and to commit to two 30- to 60-minute therapeutic sessions.

In the first session, patients were invited by a trained therapist to discuss aspects of their lives that mattered most to them or that they would most want remembered. Their responses were taped, transcribed, and read back to them in the second session. The resultant edited tran-

script, or “generativity document,” was then presented to the patient to bequeath to a family member or friend.

Post-intervention measures of suffering showed significant improvement, as did self-reports of depressed mood. [See sidebar, left, for other findings.]

There are very few nonpharmacological interventions designed to lessen suffering at the end of life, the authors note. Strategies are often invoked that “offer the equivalent of emotional analgesia without necessarily addressing the source or cause of the underlying psychic pain.”

The authors conclude, **“... evidence from this trial speaks to the importance of using every clinical encounter as an opportunity to acknowledge, reinforce, and, where possible, reaffirm the personhood of patients charged to [a clinician’s] care.”**

Source: “Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life,” *Journal of Clinical Oncology*; August 20, 2005; 23(24):5520-5525. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M; Department of Psychiatry, Family Medicine, Community Health Sciences, and Faculty of Nursing, University of Manitoba; St. Boniface General Hospital, Winnipeg, Manitoba; and Edith Cowan University, Perth, Australia.

Post-Acute Care Settings: Helping Patients to ‘Live Until They Die’ (from Page 4)

ASSISTED LIVING FACILITIES WITH HOSPICE

Residential care or assisted living settings offer variable nursing services and a limited ability to support ADL needs or complex therapies. Hospice services are covered the same as they would be in a home setting. “The only systematic study of end-of-life care in this setting found that hospice is used more often in assisted living than in nursing homes, and families are equally satisfied with the quality of end-of-life care,” write the authors.

Physicians can ask: “Does this facility have a hospice contract? Are terminally ill patients permitted by state regulations to remain in the facility? Will the accepting physician endorse the palliative care plan?”

Source: “Meeting Palliative Care Needs in Post-Acute Care Settings: ‘To Help Them Live Until They Die,’” *Journal of the American Medical Association*; February 8, 2006; 295(6):681-686. Hanson LC, Ersek M; Division of Geriatric Medicine, Pain and Symptom Care Program, University of North Carolina, Chapel Hill; Pain and Palliative Care Research Department, Swedish Medical Center, and Biobehavioral Nursing and Health Systems, University of Washington School of Nursing, Seattle.

CLINICIAN RESOURCES

Ways to Improve Nutrition and Hydration Decision Making

“All patients who forgo ANH should be offered comprehensive palliative care, including hospice... A comprehensive palliative care or hospice plan should address physical and psychological symptoms and should include emotional and spiritual support as well as bereavement support for the family after the patient’s death.”

The appropriate use of artificial nutrition and hydration (ANH) has been guided by an agreement that is not universal, but “well established among ethicists, clinicians, and the courts,” according to a Philadelphia team of experts on bioethics and geriatric medicine. The team has examined the principles underlying decisions about ANH, and offers recommendations for promoting clinical practices more consistent with these principles.

“In general, ANH has been seen as a medical treatment that patients or their surrogates may accept or refuse on the basis of the same considerations that guide all other treatment decisions: the potential benefits, risks, and discomfort of the treatment and the religious and cultural beliefs of the patients or surrogates,” write the authors in a paper published in the *New England Journal of Medicine*.

Disagreement can stem from the belief that ANH is a basic intervention, providing something that must always be offered, like shelter or pain relief, note the authors. Although persons are entitled to hold this belief, physicians can aid in the informed-consent process by presenting the patient and family with information about ANH. [See sidebar, above.]

The authors offer recommendations for ensuring that patients and families retain the right to make independent decisions about ANH, and that their decisions are supported “at the bedside” by health care professionals, the health care system, and the law. Recommendations include:

- **“All clinicians need to be better able to engage patients and families in meaningful discussions” about ANH.** This will require that medical educators address the

PHYSICIANS CAN EXPLAIN THAT:

- ANH is a medical treatment for a medical indication. Unlike simple feeding, the procedure requires technical expertise to initiate and professional training to administer and monitor.
- ANH is associated with uncertain benefits and considerable risks and discomfort.
- The goal of ANH is not to increase comfort.

—Casarett, et al
New England Journal of Medicine

subject, that physicians are properly reimbursed for their time, and that they and other clinicians have access to nutritional assessments and decision aids.

- **“Decision making about ANH in nursing homes should be shielded from financial and regulatory pressures.”** Nursing homes should not be highly reimbursed for patients receiving ANH, which costs less to administer than hand feeding. Further, surveyors should not cite nursing homes for weight loss among patients deciding to forgo ANH. Although ANH has not been found to improve survival in patients with dementia, one in three cognitively impaired residents has a feeding tube.
- **“State laws should allow the same standard of evidence of a patient’s preferences for decisions about ANH as they do for other decisions.”** Some states require written evidence specifically stating that the patient has chosen to forgo ANH, preventing family and surrogates

from making caring, reasoned decisions on the patient’s behalf to withhold or withdraw the treatment.

- **“Attorneys, physicians, and other health care providers should encourage and help patients to complete advance directives and to include preferences about ANH.”** Advance directives must also name a decision maker. To avoid confusion and dissension, state laws could establish a hierarchy of decision makers.
- **“Health care facilities should ensure that preferences are respected in all health care settings.”** The patient’s preferences need to be clearly documented and readily accessible upon transfer between settings.

The authors urge professional medical organizations, legal associations, and other health care organizations to work together to ensure that patients and families are allowed to make decisions about ANH and other medical treatment in an informed-consent process guided by established ethical principles.

“More generally,” they conclude, “efforts to facilitate decisions about ANH that are compassionate, ethically sound, and clinically reasonable need to be part of a larger agenda to improve care for all patients with serious illness.”

Source: “Appropriate Use of Artificial Nutrition and Hydration – Fundamental Principles and Recommendations,” New England Journal of Medicine; December 15, 2005; 353(24):2607-2612. Casarett D, Kapo J, Caplan A; Center for Health Equity Research and Promotion, Veterans Affairs Medical Center, Philadelphia; Center for Bioethics and Institute on Aging, Division of Geriatric Medicine and Department of Medicine, and the Leonard Davis Institute of Health Economics, University of Pennsylvania, Philadelphia.

CLINICIAN RESOURCES

Epidemiology Internet Search Tool Offers Access to Data on Death and Dying

— www.edeledata.org —

EDELE (Epidemiology of Dying and End-of-Life Experience) is an online, centralized resource for linking quickly to publicly available data on end-of-life care. The tool is designed for use by health care professionals, researchers, community service agencies, policy makers, and others needing access to information on the experience of dying in this country.

Users of the tool can search for information by topic, keyword, U.S. state, or frequently asked questions. An advanced search option allows for the combination of multiple search elements. Results are returned as an annotated list of active links to relevant data displays — such as narrative reports, tables, graphs, and maps.

Types of data linked in the EDELE database include: user-ready tables or charts; searchable datasets allowing custom reporting; and raw datasets, downloadable for offline analysis.

Search topics include:

- **Decedent Characteristics** (Demographics/Social Factors, Health Status/Cause of Death, Health Beliefs/Cultural Factors)
- **Utilization/Use of Health Care and Community Services** (End-of-Life Care, Grief and Bereavement Care)
- **Experience/Quality/Outcomes of Care** (Evaluated Outcomes and Quality of Care, Costs of Care)
- **Health Care Environment and Community Characteristics** (Health Care Services Available, Health Care Policy and Laws)
- **Community Support for End-of-Life Care** (Community Resources for EOL Care, Health Care Financing)

While use of the site is free, a one-time registration (also free) enables users to save search results, obtain updates to targeted preferences, and receive email alerts as updates become available.

EDELE is a project of The Carolinas Center for Hospice and End-of-Life Care and the National Hospice and Palliative Care Organization and is funded by the Administration on Aging of the federal Department of Health and Human Services.

The first phase of the EDELE project was launched in 2005, offering access to comprehensive data on North and South Carolina, with more limited data available for other states and the nation as a whole. This database is currently being expanded, and further phases of the project will add information on databases and literature not available on the Internet.

The EDELE search tool is available at www.edeledata.org

End-of-Life Care Websites

www.aahpm.org

American Academy of Hospice and Palliative Medicine

www.eperc.mcw.edu

End of Life/Palliative Education Resource Center (EPEC)

www.epec.net

The EPEC Project (Education in Palliative and End-of-Life Care)

www.nhpco.org

National Hospice & Palliative Care Organization

www.caringinfo.org

National consumer engagement initiative to improve end-of-life care

www.promotingexcellence.org

Promoting Excellence in End-of-Life Care

www.hospicefoundation.org

Hospice Foundation of America

www.americanhospice.org

American Hospice Foundation

www.hpna.org

Hospice and Palliative Nurses Association

www.medicaring.org

Palliative Care Policy Center

www.abcd-caring.org

Americans for Better Care of the Dying

www.mcw.edu/pallmed/

Medical College of Wisconsin Palliative Care Center

www.medsch.wisc.edu/painpolicy/

University of Wisconsin Pain and Policy Studies Group

www.capcmssm.org

Center to Advance Palliative Care

www.stoppain.org

Pain Medicine & Palliative Care, Beth Israel Medical Center

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