

Quality of Life Matters®

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

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Hospice Care Still Underutilized and Misunderstood?

Expert Says Patients Need Not Have Cancer or Be Imminently Dying to Enroll

Hospice care delivers high-quality end-of-life care, with consistently high rates of family satisfaction, research has found. Use of the Medicare hospice benefit has been steadily increasing, with more than 1.2 million Americans enrolled in hospice programs in 2005.

Yet many patients who could benefit from hospice care are never enrolled; and of those who are, 30% enter hospice within one week of death — far too short a time in which to benefit from the full range of services hospice provides, according to a commentary published in a recent issue of *The New England Journal of Medicine*.

“[D]espite its increased use, many aspects

of hospice care are still misunderstood by both physicians and patients,” writes author Gail Gazelle, MD, of Brigham and Women’s Hospital, Boston.

Facts about hospice care that some physicians and patients may not know include:

- **More than half of patients are enrolled in hospice with a diagnosis other than cancer.**
- **Hospice care at home is free:** all medical services, medication, and equipment related to the terminal diagnosis are paid in full by Medicare in 80% of cases.

Hospice and palliative medicine was accredited in 2006 as a fully independent medical subspecialty, in recognition of the

‘Hallmark’ Hospice Services Covered Under the Medicare Hospice Benefit Include:

- Emotional and spiritual support for both patient and family
- 24-hour crisis management
- Bereavement support for at least one year following the death of a loved one

high level of expertise required to address the unique and multiple domains of care needs in terminally ill patients.

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Alzheimer’s Association Releases Recommendations Specific to End-of-Life Care

Hospice and Palliative Care Considered ‘Particularly Helpful’

The losses associated with dementia often require the transfer of a patient to the care of a nursing home or assisted living facility. The Alzheimer’s Association reports that about 57% of dementia-related deaths occur in nursing homes, and more than 50% of residents of these facilities have Alzheimer’s disease or some form of dementia or cognitive impairment.

The association has released its recommendations for addressing the unique care needs of persons with dementia at the end

of life in its document entitled “Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes, Phase 3: End-of-Life Care.”

Key aspects of the report include:

- The need for advance care planning discussion as soon as possible following diagnosis or facility admission
- Emphasis on person-centered palliative care tailored to the individual’s

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Hospice Care Still Underutilized and Misunderstood?

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Yet some clinicians may continue to apply curative models to end-stage incurable illnesses, in the belief that ceasing their efforts to increase the quantity — rather than the quality — of life will destroy a patient's hope, notes Gazelle.

Other physician factors that may contribute to delayed hospice referral include fear of professional failure, difficulty determining a 6-month prognosis (the Medicare hospice eligibility guidelines “do not represent hard-and-fast requirements,”

notes Gazelle), and lack of training in the discussion of bad news.

“But perhaps the most critical factor is that physicians view hospice care as something reserved for the imminently dying, instead of as a service designed to help people live as well as possible in the face of advanced incurable disease,” writes Gazelle.

With the aging of the population, hospice care use is likely to continue to increase, and a generation of elderly baby boomers can be expected to demand more control

over all aspects of their health care, including their quality of life at the end of life.

“It is especially important, therefore, that physicians become more familiar with what hospice care offers and work to overcome barriers in talking frankly with patients about what lies ahead,” Gazelle concludes.

Source: “Understanding Hospice—An Underutilized Option for Life’s Final Chapter,” The New England Journal of Medicine; July 26, 2007; 357(4):321-324. Gazelle G; Division of General Medicine and Primary Care, Brigham and Women’s Hospital, Boston.

Alzheimer’s Association Releases Recommendations Specific to End-of-Life Care

From Page 1

preferences, abilities, and changing needs

- The importance of training residence staff in dementia-specific end-of-life care issues, often available upon request from the hospice staff

The evidence-based recommendations include practical approaches to care, with suggestions and examples, and have received the support of more than 30 national professional and advocacy organizations, including the American Academy of Hospice and Palliative Medicine and the American Medical Directors Association.

Recommended care practices for dementia cover the following areas:

- Communication with residents and families, including educational and contact information regarding hospice care
- Assessment and care of physical and behavioral symptoms
- Psychosocial and spiritual support for

“Access to hospice and palliative care can be particularly helpful in providing expertise regarding the complicated psychosocial and spiritual needs that residents and families may have.”

— *Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes*

residents and families

- Family participation in care
- Care coordination and communication with hospice staff
- Acknowledgment of death and provision of bereavement services

“The involvement of hospice services can provide additional, experienced staff members who are skilled at meeting the grief and bereavement needs of family members,” the report states. The patient/family-centered approach of hospice can be coordinated with that of the residence staff. “Hospice staff can provide training

to residential care staff that covers the types of care that hospices provide and the role of the hospice team.”

Person-centered care emphasizes the importance of:

- Consistency in individualized care approaches
- Development of relationships between staff and patients
- Increasing familiarity of staff with individual residents’ needs, abilities, and preferences

The full document can be accessed by clicking on the “News & Events” link at www.alz.org.

ALS and Other Fatal, Progressive Neurologic Diseases: Addressing Hospice and Palliative Care Issues

Caring for patients with chronic neurodegenerative disorders such as amyotrophic lateral sclerosis (ALS) can present great challenges. The devastating, multiple symptoms associated with ALS and its always fatal prognosis demand that physicians approach patient discussions with sensitivity and compassion, along with a positive message of hope and the assurance of continued care.

That is according to two experts from Columbia University, New York, in an article published in the *Journal of the American Medical Association*.

“Clinicians face a delicate balance in effectively managing the multiplicity of symptoms, while preserving the dignity and autonomy of the patient and minimizing the fears of the patient and family,” the authors write. “Sooner rather than later, the clinician must discuss the nature of the disease and the importance of advance directives, always striving to maintain realistic hopes.”

Based on their clinical experience, the authors offer “words to say” as approaches to: presenting a diagnosis of ALS; discussing the risks and benefits of interventions for symptom management; and recommending hospice care. [See sidebar.] A listing of Medicare hospice entry criteria is also included in the article.

Patients with ALS should be offered palliative care immediately upon diagnosis and the skills of a multidisciplinary team as the disease progresses, urge the authors. There are 76 multidisciplinary ALS clinics in North America. Studies have shown that care in such clinics is associated with enhanced quality of life and may possibly extend survival.

“In the absence of curative treatments, the focus is on enabling the patient to achieve maximal function and independence at each stage of illness by providing relief of the

Triggers Indicating the Need for ALS End-of-Life Discussions

- The patient or family asks — or opens the door — for end-of-life information and interventions (elicited or spontaneous, verbal or nonverbal)
- Severe psychological, social, or spiritual distress or suffering
- Pain requiring high dosages of analgesic medications
- Dysphagia requiring feeding tube
- Dyspnea or symptoms of hypoventilation or a forced vital capacity of 50% predictable or less
- Loss of function in two body regions (regions include bulbar, arms, and legs)

‘Words to Say’ Regarding Hospice Care

“I wish I could use hospice service as early as possible, preferably as soon as the diagnosis of ALS is made, although the hospice rules do not provide for that. Hospice, which is covered by Medicare, provides the best palliative care and comfort. At-home services include visits by a nurse, social worker, or chaplain; some home health aide coverage; and 24-hour on-call nursing. We work with the hospice team because we are responsible not only for maintaining your function, quality of life, and dignity, but also for making you comfortable.”

— Mitsumoto and Rabkin,
Journal of the American Medical Association

multiple symptoms that develop over time.”

Supportive interventions for ALS patients to consider include percutaneous enteral gastrostomy feeding, noninvasive ventilation (NIV), and tracheostomy and long-term mechanical ventilation (LTMV). With LTMV, patients may reach a “locked-in state,” making communication impossible. Nearly all patients agree to try NIV, note the authors, but in this country only 2% agree to LTMV. This is in contrast to Japan, where LTMV use is 27%.

“When desperately ill patients and their families opt for desperate treatments, they should also be asked under what circumstances death would be preferable to life with severe impairment and whether treatments should be discontinued if those circumstances occur,” states an editorial quoted in the article.

Deterioration in ALS patients is often faster than patients and families anticipate, comment the authors. The multidisciplinary

professionals at ALS clinics can help with identifying and adjusting to these changes and with initiating hospice care when appropriate.

“Home hospice is particularly helpful for ALS patients in late-stage illness because most are essentially housebound due to loss of mobility, and the multiple services hospice provides at home would not otherwise be available,” the authors point out.

“Even as death approaches, a multidisciplinary strategy should be used, assisting family caregivers who play a central role in patient management,” they conclude.

Source: “Palliative Care for Patients with Amyotrophic Lateral Sclerosis: ‘Prepare for the Worst and Hope for the Best,’” Journal of the American Medical Association; July 11, 2007; 298(2):207-216. Mitsumoto H, Rabkin JG; Eleanor and Lou Gehrig ALS/MDA Center, College of Physicians and Surgeons, Columbia University, Neurological Institute; and Department of Psychiatry, College of Physicians and Surgeons, Columbia University, New York City.

Needs-Based Palliative Care Urged for Patients with COPD

'We need to accept the uncertain prognosis and focus... on high-quality palliative care'

Because the final years for patients with chronic obstructive pulmonary disease (COPD) are characterized by poor quality of life, with heavy symptom burden, progressive functional decline, and increasing dependency, approaches to palliative care for these patients should be based not on prognosis but on patient needs.

That is according to a Canadian team of COPD experts whose article appears in the *Journal of Palliative Medicine*.

"Patients with advanced COPD have special palliative care needs. Patients themselves recognize these needs, but until recently, palliative care has focused predominantly on patients with cancer," write the authors.

Physicians and their patients with COPD do not yet have the benefit of such broad and rigorous research studies as those conducted among cancer patients, note the authors. "While we accumulate this research knowledge base, we need to break down the barriers to effective palliative care for patients with advanced COPD."

Impediments to quality end-of-life care for COPD patients include:

- A highly unpredictable disease trajectory
- Failure of patients and caregivers to recognize that COPD is a life-threatening disease
- Patients' limited understanding of treatment options
- Lack of effective communication due to attitudes of patients, physicians, and caregivers
- The often limited ability of physicians to judge when palliative care services would be helpful

In order to break down these barriers, state the authors, "**perhaps we need to accept the uncertain prognosis and focus instead on how to tailor high-quality palliative care to individual patient needs as COPD progresses.**"

The article offers a discussion of the management of patients

'Notoriously Inaccurate' Prognoses

"Prognoses for individual patients with COPD are notoriously inaccurate; only dementia has a less certain six-month prognosis among the other 19 reasons for hospice referral in the United States."

Begin Palliative Care Earlier

"The provision of quality palliative care as COPD progresses to its final phases needs to begin, not when dyspnea becomes intractable in the terminal stages, but earlier, when physicians would not be surprised if their patient died in the next 12 months."

— Rocker, et al,
Journal of Palliative Medicine

with advanced COPD — beyond the traditional treatments of airflow obstruction — from the perspective of clinicians and researchers working in end-of-life care. Topics include: determining who needs palliative care; recognizing patient needs; improving communication and decision making; and symptom relief.

Dyspnea is the symptom least well palliated by traditional approaches, the authors note. Additional measures, such as opioid therapy, "should be implemented when there is good empirical evidence to support their use, and not just in terminal stages of lung disease," they state.

Recommendations for initiating opioid therapy are included, as well as a graphic depiction of a "Dyspnea Ladder," similar in concept to the well-known Pain Ladder for symptom control. "We need to

have confidence in the evidence that low-dose opioids do not appear to cause significant respiratory depression."

Anxiety and depression affect up to 40% to 50% of COPD patients, note the authors, and their impact on the patient-family unit can often be overlooked. "Recognition of the psychosocial needs of patients and care providers of patients with COPD has come relatively late, but will increasingly need to be recognized as a key facet of the provision of quality care in advanced stages of COPD." Treatment of depression can also have a positive effect on dyspnea, they add.

"Palliative care is extending its traditional boundaries to encompass more patients with advanced COPD. We should ensure that they, and all other patients with complex and troubling symptoms that diminish the quality of living through the final years, will benefit from the highest quality evidence-based integrated and interdisciplinary model of care that we can provide."

Source: "Advanced Chronic Obstructive Pulmonary Disease: Innovative Approaches to Palliation," *Journal of Palliative Medicine*; June 2007; 10(3):783-797; Rocker GM, Sinuff T, Horton R, Hernandez P; Division of Respiratory and Division of Palliative Medicine, QEII Health Sciences Centre, and Dalhousie University, Halifax, Nova Scotia; Department of Critical Care and Division of Respiratory, University of Toronto, and Sunnybrook Health Science Centre, Toronto, Ontario, Canada.

Hospice Care for Dementia Patients Receives Same High Family Rating as for Cancer and Other Chronic Diseases

In a national survey of more than 77,000 families, 76% of respondents rated overall hospice care as excellent, regardless of the patient's primary diagnosis

Alzheimer's disease, with its own unique clinical challenges, was the fifth leading cause of death among older Americans in 2004. Although patients with Alzheimer's and other types of advanced dementia account for only about 10% of hospice admissions, the quality of their care is high, and comparable to that experienced by patients with other diseases, a national study has found.

"Our findings are encouraging, as they suggest that hospice providers are able to meet the unique challenges of end-of-life care in dementia, at least as well as they do for the more common diagnoses among hospice recipients," write the authors of a report published in a recent issue of the *Journal of Pain and Symptom Management*.

Investigators analyzed the results of 77,123 family evaluation surveys collected by 796 hospices nationwide during 2005 and submitted to the National Hospice and Palliative Care Organization. Respondents were bereaved family members of patients over 65 years of age with a primary diagnosis of dementia, cancer, or end-stage chronic disease (e.g., cardiovascular, pulmonary, or kidney disease).

Key findings include:

- 76.4% of all respondents rated the overall hospice care their loved ones received as excellent (dementia group, 73.3%).
- An additional 18% (dementia group, 20.6%) rated care as very good.
- Only 0.6% or fewer of respondents

in each group rated care as poor.

- Dementia was the primary diagnosis in 11.3% of the decedents.

"Hospice services have been shown to be beneficial for persons dying with dementia, and our findings further demonstrate that satisfaction with these services is comparable to other terminal conditions," the authors note. "Nonetheless, a relatively small proportion of persons dying with advanced dementia receive hospice care."

Although hospice stays exceeding 180 days were significantly more common among patients with dementia (13.7%, dementia group vs 7.6%, overall), note the authors, only 1.6% of family members in the dementia group felt that the timing of hospice referral was too early.

"Prognostication is particularly challenging in end-stage dementia," write the authors, "such that this requirement has hindered access and appropriate timing of hospice referrals for dementia patients.

The final stage of dementia also tends to be longer compared to terminal cancer."

Barriers to hospice enrollment for dementia patients include:

- Lack of recognition of dementia as a terminal condition
- Challenges in estimating a six-month prognosis
- Variable accessibility of hospice services in nursing homes

Investigators found that clinical challenges encountered in the management of advanced dementia include:

- Symptom control in the cognitively impaired
- Behavior problems
- Reliance on substitute decision making

"[O]ur results suggest that current hospice care appears to manage the specific problems in end-stage dementia with reasonable success as perceived by family members, and support efforts toward improving the delivery and quality of hospice services to the growing number of Americans dying with dementia," the authors conclude.

Source: "Hospice Care for Patients with Dementia," Journal of Pain and Symptom Management; July 2007; 34(1):7-16. Mitchell SL, Kiely DK, Miller SC, Connor SR, Spence C, Teno JM; Institute for Aging Research, Hebrew SeniorLife, and Beth Israel Deaconess Medical Institute for Aging Research, Boston; Center for Gerontology and Health Care Research, Department of Community Health, Brown Medical School, Providence, Rhode Island; and National Hospice and Palliative Care Organization, Alexandria, Virginia.

"These data suggest that the evaluation of hospice care for older patients is generally high, and does not vary with respect to terminal diagnoses."

— Mitchell, et al,
Journal of Pain and Symptom Management

CLINICIAN RESOURCES

Clinicians Offered Strategies to Reduce Stress of Surrogate Decision Making

Medical decisions for terminally ill patients are often made by designated surrogates — estimates run from 44-69% of decisions for nursing home residents to 75% of decisions made for patients hospitalized with life-threatening illness. Having a family member who is critically ill or dying is stressful in itself, notes a team of researchers from Seattle, WA. The added stress of making medical decisions for that loved one can have a negative impact on surrogate health.

“If clinicians are aware of the challenges that surrogates may be facing, they may be able to implement interventions to address those challenges, facilitate decision making, and possibly preserve surrogate health,” write the authors of a report published in the *Journal of General Internal Medicine*.

Although clinicians will probably interact with many surrogates, few have received the training needed to understand surrogates’ interpretation of patient preferences and their own need for support, the authors note. “A first step toward addressing these challenges may be to understand what makes decision making more or less difficult from the surrogate’s perspective.”

The team analyzed the interview responses

of 50 designated surrogates with a wide range of decision-making experiences on behalf of older, chronically ill veteran patients. Factors with a positive or negative influence on decision making fell into four domains: surrogate characteristics and life circumstances; surrogate social networks; surrogate-patient relationship/communication; and surrogate-clinician relationship/communication.

Clinician-related factors that helped decision making include:

- **Clinician availability** to answer questions and offer support
- **Frank information** in lay terms about the patient’s condition and prognosis, including: chances of recovery, illness progression, and what dying would be like upon withdrawal of life support
- **Treatment recommendations** based on clinician knowledge of the patient
- **Reassurance** that the decision made was a good one
- **Respect** from the care team; having one’s input listened to and valued

Factors that hampered decision making include:

- Encounters with too many clinicians

- Not being able to follow the patient’s preferences
- Difficulty in weighing patient preferences against the patient’s quality of life
- Surrogates’ own health issues

Psychosocial factors affecting surrogate decision making included: personal coping strategies and spiritual beliefs; support from family, community, and friends; and feeling committed to the patient’s wishes and educated sufficiently on the patient’s medical condition to make a “good” decision — all issues addressed during end-of-life care by the multidisciplinary support of hospice.

“[C]are that addresses and supports both patient and family concerns (i.e., hospice care) may produce better health outcomes for surrogates,” the authors write. **“Recent studies of hospice use have identified lower mortality rates and lower rates of depression in family members of patients who had hospice care prior to death.”**

Source: “Surviving Surrogate Decision Making: What Helps and Hampers the Experience of Making Medical Decisions for Others,” Journal of General Internal Medicine; September 2007; 22(9):1274-1279. Vig EK, et al; Division of Gerontology and Geriatric Medicine, University of Washington, Seattle; Geriatrics and Extended Care, Veterans Affairs Puget Sound Health Care System, Seattle.

Interventions Clinicians Can Use to Support Surrogate Decision Makers

Before decision making:

Include future surrogates in advance care planning discussions while the patient is relatively stable. This may lessen later decision-making burden by addressing some of the social network and surrogate-patient relationship factors. For instance, familiarizing future surrogates and other family members with a patient’s preferences can help prevent future family conflict.

During decision making:

Define the surrogate role as that of helping the clinician to make treatment recommendations for outcomes that best align with the patient’s goals and wishes.

Designate one person to communicate information concerning the patient’s condition, prognosis, and treatment options.

Identify and address surrogate stressors. For example, surrogates can be asked to identify the most difficult aspect of a current decision, whether there are additional causes of stress, and if a support system exists to help them.

Refer surrogates to social workers, chaplains, palliative care teams, or ethics consult services when appropriate.

Give surrogates enough time to make the decision they would be most comfortable living with.

After decision making:

Offer reassurance that the surrogate made a good decision for the loved one. This may help bring the decision-making process to closure and reduce the potential stress of continued questioning and regret.

— Adapted from Vig, et al, *Journal of General Internal Medicine*

CLINICIAN RESOURCES

Online Resources for Physicians

POLST: 'Physician Orders for Life-Sustaining Treatment'

Portable form translates patient wishes into physician orders

————— www.polst.org —————

State-specific information on obtaining a “portable” form that documents physician orders honoring patients’ treatment wishes at the end of life is available online from the Oregon Health & Science University (OHSU), Portland.

The standardized document, Physician Orders for Life-Sustaining Treatment (POLST), was developed by the OHSU Center for Ethics in Health Care for use in Oregon, where more than one million of the forms have been distributed. To date, nearly 20 other states have either the POLST program or its paradigm in effect or under development.

The POLST paradigm form, which must be signed by the attending physician, summarizes patient wishes and clarifies treatment intentions regarding the following: cardiopulmonary resuscitation, specific medical interventions, antibiotics, and artificially administered nutrition.

Because the form is intended to streamline the transfer of patient records from one health care setting to another, it has a one-page, two-sided format, and is generally brightly colored for easy recognition. Sample forms from participating programs are offered on the website, as is state-by-state contact information for obtaining forms appropriate to specific legal and regulatory requirements.

Also available on the OHSU website is a printable informational brochure for patients and families, with explanations and definitions of terms, in either English or Spanish.

Palliative Care 'Case of the Month'

————— www.dgim.pitt.edu/iepc —————

The University of Pittsburgh Institute to Enhance Palliative Care maintains a website offering palliative care resources and information for physicians and other health care professionals. Among the resources is the Case of the Month, a series of brief case studies in printable one- or two-page PDF format.

Intended for individual use or as a stimulus for group discussion, the more than 50 studies are prepared by members of the University of Pittsburgh Medical Center’s (UPMC) multidisciplinary palliative care team. Case of the Month titles include:

- Opiate Dosing for Respiratory Distress
- Giving Prognostic Information
- I Didn’t Know Dementia was a Fatal Disease. Why Didn’t Anybody Tell Me Before?
- Request for a Hastened Death
- When a Lot of Small Things Make a Big Difference
- The Family Says Not to Tell

Other resources include the UPMC 2007 Pain and Symptom Cards, more than a dozen printable cards with brief palliative care guidelines for the diagnosis and management of pain and other symptoms, such as delirium, depression, nausea and vomiting. There is also a list of links to outside end-of-life care/palliative medicine educational materials.

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 (EPERC)

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.painpolicy.wisc.edu/

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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