

Quality of Life Matters®

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

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Physicians Urged to Guide Patients to More Effective Use of Hospice Care

'If we always see death as failure, 100% of patients and 100% of physicians will ultimately fail'

Physicians play a major role in helping patients with life-limiting illness receive the comprehensive care they and their families need. By addressing common barriers to and misconceptions about hospice care, physicians can ensure that patients receive multidimensional end-of-life care much sooner.

This is according to an article published in the March 7, 2005, issue of *American Medical News*, a publication of the American Medical Association.

Although physician acceptance of hospice care is becoming more widespread, the median length of stay for hospice patients remains at just over 20 days. This pattern of late and thus less-than-effective

use of hospice can be improved by physician consideration of some of the barriers to hospice care encountered by patients, families, and physicians, says Joshua Hauser, MD. Hauser is instructor of medicine and palliative care and director of education at the Buehler Center on Aging, Northwestern University Feinberg School of Medicine, Chicago.

BARRIERS TO EFFECTIVE USE

OF HOSPICE CARE INCLUDE:

- **Not discussing goals of care.** With disease progression, patient desires can change, and the goals of care must be discussed and adjusted accordingly. "Considering the patient's and family's goals of care is always crucial in medicine, but is especially so near the end of life," writes Hauser. **"Goals are not defined so much by cure rates as by what is important to a patient and the family."**
- **Emphasizing "winning" while not attending to prognosis.** "If we always see death as failure, 100% of patients and 100% of physicians will ultimately fail, and this will be neither satisfactory for patients nor fulfilling for physicians," Hauser points out. The wish to defeat illness is not always realistic. **For terminally ill patients, "failure must be redefined to mean 'not succeeding in helping patients and their families reframe goals and hopes,'" he states.**

- **Perceiving hospice as "giving up" on medical care.** Many patients believe that enrolling in hospice care means forgoing all other treatment for comfort care only. This is not so, says Hauser; **excellent care at the end of life includes both palliative and curative elements.** For example, he notes, a patient with metastatic lung cancer might reasonably want and receive treatment to cure a bladder infection.
- **Fearing negative repercussions if patients survive longer than six months in hospice.** Physicians may hesitate to refer patients earlier to hospice care, believing that under Medicare's six-month prognosis requirement, patients who live longer will be discharged or the hospice will be decertified. However, just as there are clear guidelines for admission prognosis, notes Hauser, **there are guidelines for an unlimited number of hospice recertifications, provided the prognosis continues to meet the eligibility requirement.**
- **Believing hospice applies only to patients with cancer.** "Doctors should not hesitate to consult with a palliative care team whenever a shortened prognosis, psychosocial concerns, pain management, and end-of-life planning needs exist, even with the absence of a cancer diagnosis," writes Hauser. According to the National Hospice and

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National Institutes of Health Panel Calls for Nationwide Improvements in End-of-Life Care

Many patients and families do not receive full range of needed care

A panel convened by the federal National Institutes of Health (NIH) has found that, for many terminally ill patients and their families, regulatory restrictions and a health care system that delivers fragmented care can make the end-of-life experience extremely difficult.

The panel's report, entitled the "NIH State-of-the-Science Statement on Improving End-of-Life Care," addresses factors associated with improved or worsened outcomes for patients and their families. The report also suggests directions for future research to improve the quality of care delivered to the growing number of seriously ill and dying people in the nation.

The precise definition of the interval called "end of life" has not been established, notes the statement, although the medical literature supports a formulation of its components. [See sidebar.] In any case, end of life is usually not defined by the scientific data, but by the regulatory environment.

"A regulatory definition is a barrier to improving care and research relating to end of life," states the report. **"End of life should not be defined by a specific time frame unless evidence can support reliable prognostication."**

With its requirement of a six-month prognosis for eligibility, the current design of the hospice benefit under Medicare limits the provision of the full range of services and interventions needed by many people at the end of life, the panel reports.

COMPONENTS OF END OF LIFE

1. The presence of chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate
2. The symptoms or impairments resulting from the underlying irreversible disease require formal or informal care and can lead to death

—NIH State-of-the-Science Conference Statement on Improving End-of-Life Care

Delivery of care to those approaching the end-of-life phase is often fragmented, notes the statement, due to lack of continuity of care, unshared clinical information across providers and settings, and financial incentives that discourage high-quality care and perpetuate discontinuity.

The rapid development of an infrastructure to extend and improve end-of-life research is vitally important to public health, both in terms of resource considerations and to dying patients and their surviving loved ones, says the report. **"All people will die. Most deaths are not sudden. Most persons will experience death also as caregivers or family."**

The final statement, which was posted on the NIH website in February 2005, can be accessed at <http://consensus.nih.gov>.

Physicians Urged to Guide Patients to Hospice

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Palliative Care Organization, more than half (51%) of all patients served by hospice in 2003 had a noncancer diagnosis upon admittance.

"Each [of these barriers] can be overcome with straightforward and open discussion that focuses not on diseases but on goals, not on winning but on hopes, and not on being correct in our predictions but on being compassionate in offering them," Hauser concludes.

Growing Support for Palliative Care

The number of certifications in hospice and palliative medicine continues to grow along with membership in The American Academy of Hospice and Palliative Medicine (AAHPM), the main professional society for physicians.

The AAHPM defines palliative care as comprehensive care provided by an interdisciplinary team to patients and families living with a life-threatening or severe ad-

vanced illness expected to progress toward dying, where care is particularly focused on alleviating suffering and maintaining quality of life.

The main concerns of palliative care are pain and symptom management, information sharing, advance care planning, psychosocial and spiritual support, and coordination of care.

—Hauser, American Medical News

American Pain Society Issues New Clinical Guideline for Treatment of Cancer Pain

'People dying from cancer should not live the remainder of their lives with unrelieved pain because of fear of side effects'

Responding to reports of continuing undertreatment of cancer pain in all settings, despite great strides made recently in the field of pain management, the American Pain Society (APS) has issued a new, evidence-based practice guideline to help clinicians manage one of the problems that cancer patients fear the most.

"Because pain is pervasive in cancer, all health care professionals who care for patients at any stage of their illness should know how to assess pain, how to treat it, and when to refer to others with more expertise those patients whose pain they are unable to manage," the guideline states.

"Guideline for the Management of Cancer Pain in Adults and Children," developed for the APS by leading cancer pain experts, updates and revises the first national cancer pain guideline, which was published in 1994 by the U.S. Agency for Health Care Policy and Research (now the Agency for Healthcare Research and Quality).

The guideline includes pain assessment tools and opioid dosage charts. It addresses professional, patient, and system barriers to effective cancer pain management and stresses the importance of patient and family education and participation for successful management of pain.

Many patients with cancer experience daily or persistent pain. Thus, advises the guideline, **it is important that patients be educated on the reasons for taking opioid-based analgesics — such as morphine, oxycodone, and fentanyl — on a regular basis, rather than just "as needed."**

Since many cancer patients at the end

of life have been receiving opioid analgesics for a significant period of time, **"the fear that a higher dose will shorten life is usually unfounded,"** notes the report. In any case, when a patient's death is imminent due to primary disease progression, the report continues, the possible increased risk of earlier death is of negligible concern, compared with the clear benefit of pain relief and a comfortable death.

"People dying from cancer should not live the remainder of their lives with unrelieved pain because of fear of side effects; rather they should be given appropriately aggressive palliative support," the

report states.

Although assessment of pain in a patient who is dying may be difficult, notes the report, **"opioids should not be stopped abruptly, and clinicians should be cognizant that patients may feel pain even when comatose."**

The APS, based in Glenview, Illinois, is a multidisciplinary organization of scientists, practicing clinicians, and policy experts committed to advancing pain-related research, education, treatment, and professional practice. The guideline can be purchased on the APS website at www.ampainsoc.org or by calling 847-375-4715.

Updated Recommendations for Cancer Pain Management Include:

- **ASSESSMENT.** Perform a comprehensive pain assessment at each outpatient visit or hospital admission. The patient's self-report should be used as the foundation for the assessment.
- **PREVENTION.** Recognize that the most effective pain relief is accomplished by anticipating and preventing pain.
- **REASSURANCE.** Clarify myths and misconceptions about pain and pain management; reassure patients and their family caregivers that most cancer pain can be relieved safely, quickly, and effectively.
- **PAIN MANAGEMENT PLAN.** Provide patients and family with an understandable written pain management plan that includes such information as: the causes(s) of their pain; the rationale for their analgesic medications; how to manage side effects; and whom to call if pain is not relieved or increases in intensity.
- **PAIN MANAGEMENT DIARY.** Encourage patient and family participation in pain management. To maintain continuity of effective pain management across settings, teach patients and caregivers how to keep a pain management diary.

—Guideline for the Management of Cancer Pain in Adults and Children

Awareness of Typical Illness Trajectories May Help Clinicians Plan Appropriate End-of-Life Care

Patients diagnosed with a life-limiting illness who ask “How long have I got?” frequently also mean “What will happen?” Being aware of distinct illness trajectories can help physicians not only to answer both of these questions, but also to plan and implement care that addresses the varying patterns of needs and experiences found among people facing the end of life.

That is according to an article published in the April 30, 2005, issue of the *British Medical Journal*. “**The key to caring well for people who will die in the (relatively) near future is to understand how they may die, and then plan appropriately,**” write the authors.

Investigators conducted a review of current literature and data on three distinct illness trajectories described for different diseases at the end of life. [See sidebar.] Although there are some diseases that can be cured today and others that can be effectively managed, an understanding of trajectories allows clinicians to appreciate that “doing everything” to attempt a cure can often be a misdirected approach, the authors point out.

“**Optimizing quality of life before a timely, dignified, and peaceful death are the primary aims of palliative care,**” the authors write. “Understanding and considering trajectories may help professionals take on board, at an earlier stage than would otherwise be the case, that progressive deterioration and death are inevitable.

“A realistic dialogue about the illness trajectory between patient, family, and professionals can allow the option of supportive care — focusing on quality of life and symptom control — to be grasped earlier and more frequently.”

Not all terminal illnesses will follow one of these three trajectories, the authors caution. Other typical trajectories may yet be described, and some patients with more than one disease may have two trajectories running concurrently. Thus, the authors urge that physicians regularly review the care plans for seriously ill patients, as priorities and needs change.

“In Hippocrates’ day, the physician who could foretell the course of the illness was most highly esteemed, even if he could not alter it,” conclude the authors. “Where we cannot alter the course of events we must at least . . . predict sensitively and together plan care, for better or for worse.”

Source: “*Illness Trajectories and Palliative Care*,” *British Medical Journal*; April 30, 2005; 330(7498):1007-1011. Murray SA, Kendall M, Boyd K, Sheikh A; Division of Community Health Sciences, General Practice Section, University of Edinburgh, Edinburgh.

Trajectory 1: Reasonably predictable decline, usually with a clear terminal phase

Example: **CANCER**

With the current trend towards earlier diagnosis and discussion of prognosis, there is generally time to prepare for needs and implement end-of-life care plans for patients with cancer, note the authors. It is important that patients understand that they are likely to experience steady disease progression, with a short period of evident decline in the last months of life, so that they can avail themselves of desired palliative care and hospice services in a timely fashion.

Trajectory 2: Gradual decline punctuated by unpredictable exacerbations; death often seems ‘sudden’

Examples: **HEART FAILURE, COPD**

Many patients with organ system failure, such as end stage heart failure and chronic obstructive pulmonary disease (COPD), experience long-term limitations punctuated by serious episodes, any one of which may result in death. However, patients often survive many such episodes, usually with a decline in health and functional status following each. Because the decline in these patients is more gradual than that in cancer patients and death is more likely to appear sudden, advance care planning for preferred place of death is extremely important. “**People with non-malignant disease may have more prolonged needs, but these are as pressing as those of people with cancer.**”

Trajectory 3: Prolonged gradual decline

Examples: **DEMENTIA AND FRAILTY IN ELDERS**

Older individuals without malignant disease or organ system failure are likely to die of brain failure, such as Alzheimer’s disease or other dementia, or of generalized frailty of multiple body systems. Since these patients experience progressive disability from an already low functional baseline, and their lives can end suddenly following either a minor or acute physical event, the authors stress again the importance of advance planning for choice of terminal care.

—Murray, et al, *British Medical Journal*

Bereaved Family Members of Cancer Patients Believe Referral to Palliative Care Came Too Late

Findings in Japan offer significance to other countries, including the United States

A survey of families of patients who died of cancer while receiving end-of-life care in Japan has found that nearly half of bereaved family members think that referrals to palliative care were given too late to improve the quality of life for their loved ones.

“Earlier referrals to palliative care are essential to alleviate suffering and improve treatment outcomes and quality of life for people with cancer,” comments lead author Tatsuya Morita, MD, Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatabara Hospital, located in Shizuoka, Japan. His report was published in the April 20, 2005, issue of the *Journal of Clinical Oncology*.

The study provides a perspective on the timing of palliative care referral that is of significance to other countries — including the United States — notes Betty Ferrell, PhD, research scientist at the City of Hope National Medical Center in Duarte, California, in her accompanying editorial.

Morita’s team found that the median admission period for cancer patients in palliative care units in Japan in 2003 was 22 days; the median length of stay for all dying patients served by hospices in the United States in the same year was also 22 days, according to the National Hospice and Palliative Care Organization.

“There is international recognition about the need to ease what is an incredibly difficult decision for patients and families about palliative care and increase earlier referrals to such programs,” comments Ferrell.

“This study supports closer collaboration between oncologists and pallia-

EARLIER REFERRALS:

RECOMMENDATIONS FROM FAMILY MEMBERS

Suggestions from bereaved families included:

- ✓ Having oncologists with better knowledge of palliative care (97%)
- ✓ Allowing patients and families to see palliative care physicians early (90%)
- ✓ Distributing pamphlets about palliative care early in the course of the disease (89%)
- ✓ Having oncologists introduce the topic of end-of-life care in advance, whether or not patients or families mention the subject (82%)

—Morita et al,
Journal of Clinical Oncology

...tive care specialists, rather than simply a swift transfer from one provider to the other as the patient’s condition declines.”

The Japanese investigative team analyzed the responses of 318 family members of patients with cancer who died in nine palliative care units in 2003. Unlike the United States, where home-based hospice care is widely available, in Japan the most common form of specialized palliative care service is currently the palliative care unit, the authors note.

While 49% of respondents believed that the timing of referrals of their loved ones

to palliative care was late or very late, only 3.8% felt that the referrals were early or very early. Among those family members who indicated what patients had said about referral timing (n = 138), 59% and 5.1% reported that the patients had deemed the referrals as coming too late and too early, respectively.

Independent determinants of family perception of referrals as late included:

- Family belief before admission that palliative care shortens the patient’s life
- Families’ insufficient preparation for changes in the patient’s condition
- Treatment in hospital prior to palliative care unit admission
- Insufficient advance discussion about end-of-life care with physicians

“Patients and their families should feel comfortable discussing end-of-life care with their physicians and each other so that palliative care services can be given at the most appropriate moment for the patient,” says Morita.

The respondents who reported that earlier cooperation of oncologists with palliative care physicians would be of help in achieving appropriately timed referral to palliative end-of-life services (n = 182) were asked for their advice in this regard. [See sidebar.]

Source: “Late Referrals to Specialized Palliative Care Service in Japan,” *Journal of Clinical Oncology*; April 20, 2005; 23(12):2637-2644. Morita T, Akechi T, Ikenaga M, et al; Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatabara Hospital, Shizuoka, Japan. “Late Referrals to Palliative Care,” *Journal of Clinical Oncology*; April 20, 2005; 23(12):2588-2589. Ferrell B; City of Hope National Medical Center, Duarte, California.

PHYSICIAN RESOURCES

Addressing Conflict in Caring for the Seriously Ill: A Practical Approach for Clinicians

Because of the complexity of medical, emotional, and logistical issues often associated with the care of a patient with a life-limiting illness, differing perspectives can easily lead to conflict in the medical setting — between the physician and family and between the physician and other members of the medical team.

Rather than avoiding conflict as undesirable and destructive, however, physicians can use it as an opportunity for negotiating agreement to improve care, according to palliative care experts Anthony L. Back, MD, Department of Medicine, University of Washington, Seattle, and Robert M. Arnold, MD, Department of Medicine, University of Pittsburgh.

“Dealing with conflict is a critical skill for physicians... Conflict handled well can be productive, and the clarity that results can lead to clearer decision making and greater family, patient, and clinician satisfaction,” write the authors in an article published in the March 16, 2005, issue of the *Journal of the American Medical Association*.

The authors describe types of conflict encountered in caring for patients who are seriously ill, identify common pitfalls in handling conflict, offer communication tools, and provide a step-wise approach — both reflective and active — for negotiating a solution that satisfies the needs of both parties.

An approach they suggest for addressing conflict includes:

- **Prepare for negotiation.** Assess your state of mind. (Am I too angry to listen fully? Am I feeling punitive?)
- **Find a nonjudgmental starting point.** Ask yourself what an impartial third person would say this conflict is about. Start by exploring perspectives.
- **Reframe emotionally charged issues.** *“For a lot of people, providing food is a way of showing love. . . let’s talk about ways other than by having a feeding tube placed that you can do that.”*
- **Search for options** that satisfy both parties’ needs.
- **Get help** from an outside consultant if needed.

“Recognizing and dealing with conflict can improve relationships, shed light on complicated clinical situations, and help guide family members, patients, and other clinicians through difficult decisions,” conclude the authors. **“The rewards for physicians who acquire and use these skills are also evident: a grateful family and a personal sense of satisfaction.”**

Source: “Dealing with Conflict in Caring for the Seriously Ill: ‘It Was Just Out of the Question,’” *Journal of the American Medical Association*; March 16, 2005; 293(11):1374-1381. Back AL, Arnold RM; Department of Medicine, University of Washington, Seattle; Department of Medicine, University of Pittsburgh, Pittsburgh.

Dealing with Conflict: Useful Communication Tools

- **Active listening.** *“What I’m hearing you say is that you want us to do everything possible to prolong your mother’s life.”*
- **Self-disclosure.** *“I am worried that even the best medical care will not be able to achieve your hopes.”*
- **Explanation.** *“My view of this situation is that providing intravenous fluid would give her, at best, a 50-50 chance of improving.”*
- **Empathy.** *“I think anyone would feel as worried as you, given the circumstances.”*
- **Reframing.** *“Now, I think we should look at the issue of intravenous fluid as not just ‘Do we do it?’ but as part of the bigger picture of her care.”*
- **Brainstorming.** *“Let’s try to come up with a few ideas about how to prepare for her death.”*

Defusing Physician-Physician Conflict

- **Reframe a personally critical affront** (e.g., “I can’t believe Mrs. Z got a feeding tube!”) as an attack on the problem. *“Well, I can tell you that dealing with Mrs. Z’s family has not been a simple process, and it has been frustrating for me as well.”*
- **Reframe the affront with a request for advice.** *“It hasn’t been easy, and if you have constructive suggestions, I would love to hear them.”*
- **Offer to explain the situation.** *“The family and I have spent a great deal of time considering the right course of action. Perhaps when you have time, I can fill you in on what happened.”*

—Back and Arnold
Journal of the American Medical Association

PHYSICIAN RESOURCES

New Website Offers Advance Care Planning Education, Resources

The American Hospital Association (AHA) has launched an outreach initiative to help patients and families — and hospitals and other providers — to raise awareness of the importance of advance care planning. Educational material and resources related to preparing an advance directive are available online as part of the AHA's "Put It in Writing" campaign.

A free, downloadable brochure explains basic facts about advance directives in a question-and-answer format. The brochure includes a glossary of terms related to types of advance directives, life-prolonging medical procedures, and care options, such as hospice and palliative care.

Also available on the site is a downloadable wallet card, which states that the patient has discussed advance directives with family and physician(s). The card provides space for listing contact names and numbers. Online links to other resources are provided. These include:

- State-specific advance directives and instructions are offered free on the Caring Connections website (www.caringinfo.org), which is maintained by the National Hospice and Palliative Care Organization (NHPCO).
- A ten-item consumer toolkit for advance health care planning is also available free of charge, courtesy of the American Bar Association Commission on Law and Aging (www.abanet.org/aging).

Information on the "Put It in Writing" website is available in both English and Spanish, including a public service announcement video entitled "Your Life, Your Terms." Professional organizations cooperating with the AHA in this initiative include the American Academy of Family Physicians, the American College of Emergency Physicians, the American Nurses Association, and the NHPCO.

Copies of the "Put It in Writing" brochure can also be purchased from the AHA at bulk rates.

For more information, visit www.putitinwriting.org.

NEW TEXT: *Oxford Handbook of Palliative Care*

By Max Watson, MD, Caroline Lucas, MD, Andrew Hoy, MD, and Ian Back, MD, this practical guide is designed to offer clear and concise information for physicians and other clinicians involved in the daily care of adults, children, and families with palliative care needs.

The handbook is formatted for quick access to key clinical information on disease-specific symptom management and contains suggestions for addressing psychological and spiritual issues in adults and special populations (e.g., children and the elderly). A brief history of palliative care and the growth of palliative medicine as a specialty is also included. Topics include:

- Ethical issues • Breaking bad news
- Oncology and palliative care • The terminal phase
- Palliative care in the home • Palliative care in non-malignant disease
- The contribution to palliative care by associated health professionals

Published by Oxford University Press, 2005; ISBN: 0198508972 (hardcover); 784 pp.

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 on Palliative and End-of-Life Care)

www.nhpc.org

National Hospice & Palliative Care Organization

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

Center for Palliative Care Studies

www.abcd-caring.org

Americans for Better Care of the Dying

www.mcw.edu/pallmed/

Palliative Medicine Program at the Medical College of Wisconsin

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

www.growthhouse.org

An online community for end-of-life care

End-of-Life Care Meetings for Clinicians

Children's Hospice International's 17th World Congress. September 29-October 2, 2005, Salt Lake City, UT. Phone: 800-242-4453; Email: info@chionline.org; Website: www.chionline.org

The Science & Art of Pain and Symptom Management, 12th Annual Conference. November 18-19, 2005, Toronto, ON. Sponsored by Continuing Education, Faculty of Medicine, University of Toronto. Phone: 416-978-2719; Fax: 416-946-7028; Email: ce.med@utoronto.ca

7th International Conference on Pain & Chemical Dependency. January 11-14, 2006, Brooklyn, NY. Presented by Beth Israel Medical Center, Department of Pain Medicine and Palliative Care. Phone: 404-233-6446; Fax: 404-233-2827; Website: www.painandchemicaldependency.org

Annual Assembly of the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association. February 8-11, 2006, Nashville, TN. Phone: 847-375-4712; Fax: 877-734-8671; Email: info@aahpm.org; Website: www.aahpm.org

Today's Education, Tomorrow's Quality Care. April 26-28, 2006, San Diego, CA. National Hospice and Palliative Care Organization's 7th Clinical Team Conference. Phone: 703-837-1500; Website: www.nhpco.org/ctc2006

25th Annual Scientific Meeting of the American Pain Society. May 3-6, 2006, San Antonio, TX. Phone: 847-375-4715; Fax: 877-734-8758 (United States) or 732-460-7318 (international); Email: info@ampainsoc.org; Website: www.ampainsoc.org

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