Pulmonary Diseases and Critical Illnesses: New Clinical Guidelines Endorse Palliative and Hospice Care

The American Thoracic Society (ATS) has issued an official clinical policy statement on palliative and end-of-life care, thus joining the growing number of health care professional organizations providing guidelines or position papers on the integration of palliative care into standard clinical management.

“This is the first statement from the society on this topic,” says ATS task force co-chair Paul N. Lanken, MD, professor of medicine, Hospital of the University of Pennsylvania, Philadelphia. “It recognizes palliative care as an important part of what doctors, nurses, and other health care professionals should be doing.”

The new guidelines for care of adult and pediatric patients with advanced respiratory diseases and critical illnesses were published in the April 15, 2008, issue of the American Journal of Respiratory and Critical Care Medicine.

Based on core values and principles, the statement provides a set of basic knowledge on the application of palliative care to common clinical practice situations, supplemented by an extensive set of references and citations found on websites.

**AMERICAN THORACIC SOCIETY STATEMENT ENDORSEMENTS INCLUDE:**
- Individualized, integrated palliative care for patients and their families at all stages of illness
- Comprehensive physical and psychological symptom management
- Training or ability in recommended core competencies of palliative care for pulmonary and critical care clinicians
- Consultation with palliative care specialists as appropriate

Researchers analyzed survey responses of 116,974 family members whose loved ones died while under the care of one of 819 hospices located in the U.S. The data was obtained from the national repository of the Family Evaluation of Hospice Care (FEHC), which is maintained online by the National Hospice and Palliative Care Organization (NHPCO).

For purposes of the study, only the overall rating of hospice care as “excellent” was used to determine the association of individual processes of hospice care with high overall satisfaction. All other ratings (very
Pulmonary and Critical Illnesses: New Guidelines Endorse Palliative and Hospice Care

Continuation of support for bereaved family members

A patient seeking eligibility for hospice must be certified by both a treating physician and the hospice medical director to have a prognosis that is terminal — “that is, more likely than not having less than six months of life,” the statement explains. “It is important to realize that the physician who certified that a hospice patient is terminal does not ‘guarantee’ death within six months.”

Further, although a patient must agree to forgo curative treatment to be eligible for Medicare hospice care, a do-not-resuscitate order is not a requirement. The participating hospice can call for emergency medical treatment if the patient requests resuscitation.

The statement strongly encourages education, training, program development, and research in palliative care. “We hope that the statement will spur more and better palliative care curricula in schools and hospitals,” comments task force co-chair Peter B. Terry, MD, professor of medicine, Johns Hopkins University, Baltimore.

The guidelines have been formatted into an internet activity for CME credit, available at www.medscape.com/viewarticle/573150. The entire policy statement can be accessed online at www.thoracic.org.


Top Marks: Families Value the Communication, Support, and Care Coordination Services of Hospice

WHAT FAMILIES LIKE BEST ABOUT HOSPICE

Communication of information: Families were almost four times as likely to rate hospice services as excellent if they were kept regularly informed about their loved one’s condition. They were twice as likely to give high evaluations if they were told what to expect as death approached.

Emotional support: Family members were more than twice as likely to rate hospice services highly if they felt they received the right amount of emotional support from the hospice team prior to the patient’s death.

Coordination of care: Respondents were two times as likely to give high ratings of satisfaction if they: felt the team gave consistently accurate information about the patient’s medications and treatments; were given access to one nurse identified as being in charge of the patient’s care; and felt the team was knowledgeable enough about the patient’s medical history to provide the best possible care.

Symptom control and patient support: Families were about twice as likely to evaluate hospice highly if they felt the patient received the right amount of pain control, emotional support, and relief of dyspnea.

“Our study reiterates that providing bereaved family members with information about their loved one’s condition may influence their overall satisfaction with hospice services,” the authors comment. As a result, complications of the grieving process (depression, anxiety) may be reduced.

Expanding on previous findings about bereaved family members’ concerns, the current study used “a validated, widely disseminated instrument to not only identify ‘problem areas,’ but to also identify specific processes of care that appear to positively influence overall satisfaction with services.”

The FEHC survey was implemented in 2005 by NHPCO as part of a quality improvement process to evaluate hospice services.

Addressing patients’ simultaneous needs for physicians to both support their hope and to deliver explicit prognostic information about their life-threatening illness is challenging. Lack of physician understanding of patient needs in this type of communication can pose a serious barrier to end-of-life care discussions.

That is according to researchers at the University of Washington, Seattle, who have developed an approach that may help physicians understand how individual patients and their families incorporate the dual needs for hope and information, and thus how best to tailor delivery of prognostic information.

“[P]atients and families differ in their needs and desires for hope and explicit prognostic information,” write the authors of a report in the Journal of Palliative Medicine. “[W]e found that simply asking patients how much information they want, without exploring their emotions and concerns, did not adequately elicit informational needs.”

The investigators analyzed responses gathered in multiple in-depth interviews with 147 participants in the Seattle-Tacoma area: physicians practicing in pulmonaryology, oncology, or internal medicine (n = 31); their patients with either advanced cancer or severe chronic obstructive pulmonary disease (COPD), about whom the physicians “would not be surprised if the patient died from any cause in the next year” (n = 55); family members (n = 36); and nurses identified by patients or physicians as involved in discussions of patient illness (n = 25).

Initially, when asked how much information they wanted about the patient’s illness, all patients and family members declared that they would want “all” the information; but upon deeper questioning, a substantial minority expressed reservations about knowing certain types of explicit information.

For the deeper exploration, patients and family members were invited to discuss each diagram in a four-diagram conceptual model depicting different methods of integrating hope and the need for information (e.g., alternating between hope and information; balancing both; integrating hope and information; redirecting hope).

**Key Findings Include:**

- Patients and families varied greatly in their desires for hope and explicit prognostic information.
- Simply asking, “How much information do you want?” was an unrevealing approach to understanding individual needs.
- The four-diagram approach enabled patients and families to explain their concerns and preferences for delivery of prognostic information.
- Based on the diagram chosen, respondents described their preferred prognosis communication approach, which resolved into one of two methods: direct and indirect.

**Indirect Approach**

The indirect approach to conveying prognostic information, as recommended by participating patients and families, included certain physician strategies as:

- Taking into account the fragility of the patient’s and family’s emotional states
- Avoiding blunt or precipitous statements
- Verbalizing a commitment to non-abandonment
- Suggesting a clear and comprehensive care plan
- Presenting outcomes for groups rather than for the individual patient

**Direct Approach**

For the direct approach, respondents invited physicians to communicate fully and explicitly what could happen in the future. “These participants were able to manage the emotional impact of prognostic information, and were less dependent on the clinician to facilitate their emotional adjustment to the news,” the authors comment.

“[P]hysicians’ inability to balance concerns about providing prognostic information with supporting patients’ hope may be an important barrier to communication with patients and families about end-of-life care,” the authors write.

They note that their four-diagram model may be a useful clinical tool for understanding individual patient and family needs and thus improving physician-patient/family communication, but recommend further research.

**Source:** “An Approach to Understanding the Interaction of Hope and Desire for Explicit Prognostic Information among Individuals with Severe Chronic Obstructive Pulmonary Disease or Advanced Cancer,” Journal of Palliative Medicine; May 2008; 11(4):610-620. Curtis JR, Engelberg R, Young JP, Vig LK, Reinke LF, Wenrich MD, McGrath B, McCown E, Back AL; Department of Pulmonary and Critical Care Medicine, Department of Gerontology and Geriatric Medicine, Department of Biobehavioral Nursing and Health Systems, Department of Medicine, Department of Oncology, University of Washington, Seattle.
Extensive Use of Antibiotics at the End of Life in Patients with Advanced Dementia Raises Concerns

Use of Antimicrobials in Nursing Home Residents Found to Increase as Death Approaches

The rate of administration of antimicrobial agents — often via the parenteral route — among nursing home residents with advanced dementia is high, and increases steadily toward the end of life, a team of Boston researchers has found.

“The proportion of residents taking antimicrobials was seven times greater in the last two weeks of life compared with six to eight weeks before death,” write the authors of a study published in a recent issue of the Archives of Internal Medicine.

“This extensive use of antimicrobials and pattern of microbial management in advanced dementia raises concerns not only with respect to individual treatment burden near the end of life, but also with respect to the development and spread of antimicrobial resistance in the nursing home setting.”

The team analyzed antimicrobial use among 214 patients with advanced dementia (mean age, 85.2 years; female, 86.0%; white, 88.3%) residing in 21 nursing homes in the Boston area. During the mean follow-up period of 322 days, 99 of the subjects died.

Overall Findings Include:

- 66.4% of advanced dementia patients received at least one course of antimicrobial therapy during the study period.
- Mean number of courses per subject was 4.0.
- Quinolones (38.3%) and third-generation cephalosporins (15.2%) were the most commonly prescribed antimicrobials.
- Mean days of therapy per 1000 resident-days for all patients was 53.0.

Among the 99 decedents:

- 51.5% received at least one dose of antimicrobials in the last two weeks of life.
- Days of therapy per 1000 resident-days jumped from 24.1 at eight weeks to 171.9 at two weeks or less before death.
- Therapy courses delivered parenterally rose from 28% at two to four weeks before death to 41.7% within the last two weeks of life.
- Respiratory tract (63.5%) and urogenital (17.5%) infections were the most common indications for treatment prior to death.

Treatment decisions for patients with advanced dementia can be difficult for families and physicians alike, state the authors. Life prolongation and symptom control are the purported reasons for treating infections, but the benefit vs burden evidence for antimicrobial therapy in this population is inconclusive.

“Our findings further support that antimicrobials may not meaningfully extend the life of patients with advanced dementia, for whom infections are frequently a terminal event.” Palliation is often the main goal of care for these patients, they note, yet it remains unclear whether antimicrobial therapy promotes symptom relief more effectively than do more conservative approaches to palliation, such as oxygen and acetaminophen.

Infections caused by antimicrobial-resistant bacteria have a rate of mortality five times higher than those caused by bacteria susceptible to the therapy, the authors point out. Further, 40% of older persons in nursing homes — where approximately 70% of Americans with dementia will reside during the final stage of the disease — have been found to harbor at least one species of antimicrobial-resistant bacteria.

A MESSAGE TO THE MEDICAL COMMUNITY

“The findings in this study require the medical community to ask whether the extensive use of antibiotics in this particular patient population is appropriate, taking two factors into consideration: the benefit to the patient treated and the risk imposed on other patients,” comment the authors of an accompanying editorial.

“The principle increasingly espoused in medical education of treating the patient rather than the disease should prompt physicians to consider — for each decision regarding antibiotic use — whether treatment in fact offers benefit to the patient, rather than merely representing a response on the part of the physician to a disease state,” continue the authors, who are specialists in infectious disease medicine at the Tel Aviv Medical Center, Israel.

“Moreover, we argue that the principle *primum non nocere* should apply, in the case of antibiotics, not only to the specific patient treated, but also to others potentially harmed by inappropriate use.”

—Schwaber and Carmeli, Archives of Internal Medicine

Continued on Page 5
Increasingly Late Referral to Palliative Care Found Among Cancer Patients

The length of time between referral of patients with advanced cancer to palliative care services and their deaths is not only short, it is getting shorter, a team of researchers at the University of Texas M.D. Anderson Cancer Center in Houston has found. “Most referrals to palliative care and hospice occur late in the trajectory of the disease, although an earlier intervention could decrease patients’ symptom distress,” the researchers write in their report published in a recent issue of the Journal of Palliative Medicine.

The team reviewed the charts of 2868 consecutive patients (female, 49%; white, 70%; median age, 60 years) who were diagnosed at the center with advanced cancer, and who had their first palliative care consult between April 2003 and September 2005.

Because the cancer center’s palliative care department is involved in the care of patients, whether or not they are receiving chemotherapy or other cancer treatments, the investigators anticipated that the interval between access to acute palliative care and death would increase over the 30-month study period.

Findings Include:
- Median length of time from first palliative care consult to death was 42 days.
- Over five half-year periods, this interval decreased from a median of 46 to 34 days.
- However, the number of patients accessing acute palliative care during the same period increased by 20%.

“Access to palliative care at our comprehensive cancer center is still occurring late in the trajectory of the disease, with a trend towards decrease rather than increase — which may provide neither enough beneficial time for our patients and their families nor a seamless transition to other community care programs such as hospice,” the authors write.

Earlier Access to Palliative Care Was Found Among:
- Patients with solid tumor
- Younger patients (< 65 years old)
- Females

The median consult-to-death interval was more than three times longer in patients with solid cancers than in those with liquid tumors (48 vs 14 days). The authors suggest this could be because patients with hematologic malignancies (leukemia, lymphoma, myeloma) experience lower frequency of sentinel symptoms such as major pain syndromes and cachexia, and are thus often referred to palliative care services closer to death.

Further, there are viable treatment options available for patients with liquid tumors, even in advanced disease, but a lack of reliable indicators of refractory disease, the authors add. In a previous study at their cancer center, the investigators found hematologic malignancy to be the highest predictor of death in a hospital.

The authors recommend the development of palliative care programs targeted to the specific needs of patients with hematologic malignancies, and further studies to determine the trend of access to acute palliative care. “Prospective studies are needed to establish the appropriate timing of the first palliative care consultation.”

Source: “Interval between First Palliative Care Consult and Death in Patients Diagnosed with Advanced Cancer at a Comprehensive Cancer Center,” Journal of Palliative Medicine; January 2008; 11(1):51-57. El Osta B, Palmer JL, Paraskevopoulos T, Pei B, Roberts LE, Poulter VA, Chacko R, Bruera E; Department of Palliative Care and Rehabilitation Medicine, University of Texas M.D. Anderson Cancer Center, Houston.

Extensive Use of Antibiotics in Dementia Patients Raises Concerns (from Page 4)

hallmark of end-stage dementia,” they conclude. “The extensive antimicrobial use demonstrated in this study is concerning, given the lack of demonstrable benefits and the potential burdens of treatment in this terminally ill population for whom the goal of care is often palliation. Moreover, we believe that the widespread use of antibiotics in advanced dementia may pose a potential public health risk through the emergence of antibiotic resistance.”

Source: “Patterns of Antimicrobial Use among Nursing Home Residents with Advanced Dementia,” Archives of Internal Medicine; February 25, 2008; 168(4):357-362. D’Agata E, Mitchell SL; Divisions of Infectious Diseases and Geriatrics, Department of Medicine, Beth Israel Deaconess Medical Center; Harvard Medical School; and Hebrew Senior Life Institute for Aging Research, Boston. “Antibiotic Therapy in the Demented Elderly Population: Redefining the Ethical Dilemma,” ibid., pp. 349-350; Schwaber MJ, Carmeli Y; Division of Epidemiology, Tel Aviv Medical Center, Tel Aviv, Israel.
Heart Failure Patients Overestimate Survival Time

‘End-of-Life Issues Should Be at the Forefront of Heart Failure’

Patients with chronic heart failure — particularly those who are younger or have more advanced disease — tend to substantially overestimate their life expectancy as compared with predictions of a well-validated tool. This has implications for decision making regarding appropriate therapies and end-of-life planning, according to the authors of a report published in a recent issue of the Journal of the American Medical Association.

“Given the progressive nature of heart failure, its high mortality rate, and its predilection for affecting elderly persons, end-of-life issues should be at the forefront of heart failure management,” state the authors, adding, “Understanding patient perceptions of prognosis is vital for making appropriate care decisions.”

Researchers analyzed survey responses of 122 ambulatory heart failure patients (mean age, 61 years; New York Heart Association [NYHA] functional class I/II, 58%; NYHA III/IV, 42%). Patient predictions were compared with those from the Seattle Heart Failure Model (SHFM), actuarial tables of life expectancy without disease, and observed survival over a median follow-up period of 3.1 years.

“Patient predictions of life expectancy were more similar to those predicted by empirically derived actuarial life tables based on age and sex alone, without regard for the presence of heart failure,” the authors report. “The implication is that even when patients have a good understanding of prognosis, they may choose not to apply that information to themselves.”

Factors independently associated with patient overestimation of survival include:
- Younger age
- Higher NYHA class
- Lower ejection fraction
- Measures of less depression

“These data suggest that many patients with heart failure have survival expectations that differ markedly from the anticipated natural history of their disease,” write the authors. “Efforts to better integrate palliative care into the treatment of selected patients with heart failure will require a more sophisticated appreciation of patient perceptions of prognosis.”

Source: “Discordance between Patient-Predicted and Model-Predicted Life Expectancy among Ambulatory Patients with Heart Failure,” Journal of the American Medical Association; 299(21) 2533-2542. Allen LA, Yager JE, Funk MJ, Levy WC, Tulsy JA, Bowers MT, Dodson GC, O’Connor CM, Felker GM; Duke Clinical Research Institute and Division of Cardiology and Center for Palliative Care and Division of General Internal Medicine, Duke University Medical Center, Durham, North Carolina; Cardiac Care Associates, Fairfax, Virginia; Department of Epidemiology, University of North Carolina, Chapel Hill; and Division of Cardiology, University of Washington, Seattle.

NEW RESOURCE:

Improving Care for the End of Life:
A Sourcebook for Health Care Managers and Clinicians

By physicians Joanne Lynn, Janice Lynch Schuster, Anne M. Wilkinson, and Lin Noyes Simon, this second edition sourcebook offers practical guidance on how health care professionals in a variety of settings — from the hospital unit to the physician’s office — can implement strategies to improve the care of patients with terminal illness “almost immediately.”

The authors present a proven quality improvement methodology that organizations can use right now to improve patients’ quality of life, with numerous insights, approaches, and tips from experienced improvement teams nationwide. The book’s appendix includes resources for care of the whole person, with instruments for measuring improvements in specific domains as well as assessment tools for pain, spirituality, and grief.

Sections of the book include a focus on: Changes patients and families need and want, environments that encourage better practice, and opportunities for improving care for patients with specific terminal diseases.

Material new to this second edition includes: discussion of issues such as continuity of care and the special needs of dementia patients and their families; details on trajectories of specific illnesses and their effect on decision making; and updated and expanded information on such topics as advance care planning, pain management, and advanced heart and lung disease.

Published by Oxford University Press, 2nd edition, 2007; (hardcover); 464 pp.
Fast Facts and Concepts, the collection of clinically relevant summaries of key information on palliative care topics, passed the #200 mark this year. Started by Eric Warm, MD, at the University of Cincinnati eight years ago, the educational tool has since been maintained and freely offered on the EPERC (End-of-Life/Palliative Education Resource Center) website.

The peer-reviewed, evidence-based monographs average one to two pages long and can be printed from the website or downloaded onto a PC or PDA.

“I have heard stories of Fast Facts being plastered on staff bathroom walls in hospitals, as well as family members of dying patients handing them to doctors, asking why aren’t they doing it like the Fast Fact says,” comments the resource’s editor-in-chief Drew A. Rosielle, MD, of the Medical College of Wisconsin.

Recently added titles include:
- Advance Care Planning in Chronic Illness (see summary below)
- Professional-Patient Boundaries in Palliative Care
- Managing One’s Emotions as a Clinician

In addition, many earlier titles (#80 to #99) have been edited to update information and to include the latest references. Updated titles include: Oxycontin; Opioid Withdrawal; Medicare Hospice Benefit: Parts I, II, and III; and Patient Controlled Analgesia in Palliative Care.


Approach to Advance Care Planning in Chronic Illness
(ADAPTED FROM EPERC FAST FACT #162)

Advance care planning (ACP) is a process, which should be initiated — at the very minimum — when the physician would not be surprised if a patient with chronic illness died within the next 12 months. Physicians are encouraged to:

- **Take the lead in opening the discussion.** “How do you feel things are going?” “Have you given any thought to how you would like to be cared for as your illness worsens?”
- **Explain how ACP can benefit the patient.** “I’d like to spend some time talking to you about the future course of your illness so I can have a clear understanding of your wishes.”
- **Use positive, everyday language.** “I want to be sure you’ll receive the kind of treatment that you want.”
- **Provide realistic information** on prognosis and treatment options, addressing the effect the illness progression will likely have on the patient’s daily activities.
- **Identify a surrogate decision maker,** and encourage communication between the patient and surrogate.
- **Determine how future decisions will be made,** with explicit discussion of how information is to be shared with family members.
- **Determine the goals of care** if such decisions need to be made at that time.

Newsletter Member Benefit Helps Hospices Get Earlier Referrals!

The Hospice and Palliative Nurses Association is pleased to provide you with this issue of Quality of Life Matters, the physician outreach newsletter used by hospices nationwide to educate area physicians about end-of-life care.

PREFERRED READERSHIP

Each quarter, you will receive the latest issue of Quality of Life Matters via email before the newsletter is even off the printing press. This way, you and your colleagues will have immediate access to the timely clinical summaries and news articles published each issue.

MEMBER DISCOUNT

Should your work setting choose to use Quality of Life Matters as a customized educational tool for your area physicians, a special discount applies. If anyone on your clinical team is a member of the HPNA, you will receive an additional 5% HPNA discount* for newsletter costs. (This is in addition to the 10% in existing newsletter discounts already available to hospices).

For more information, call Addison at Quality of Life Matters:

1-877-513-0099
www.QoLpublishing.com

* Please note: This 5% discount is available to each organization that has on its clinical team either a member of the HPNA or a member of the American Academy of Hospice and Palliative Medicine.

Quality of Life Matters®

Now in its tenth year of publication, Quality of Life Matters is recommended as an educational resource by the American Academy of Hospice and Palliative Medicine. The periodical is dedicated solely to end-of-life care news and clinical findings and is researched and written by professional medical journalists who specialize in covering palliative care issues. It is an independent publication; it is not affiliated with any health care organization or company. The quarterly newsletter is published by Quality of Life Publishing Co., a firm dedicated to easing the way for patients with life-limiting illnesses and their families.

We customize copies of the newsletter for hospices and other organizations to provide as an educational service for their local clinicians. For information and rates:

TOLL FREE in U.S. and CANADA: 1-877-513-0099

GRIEF SUPPORT BOOKS. Call us or visit our website to order our award-winning gentle grief support books and booklets. Discounts offered to hospices and other professionals.

www.QoLpublishing.com

© 2008 by Quality of Life Publishing Co. All rights reserved. No part of this newsletter may be reproduced without prior permission of the publisher. For reprint requests or information:

Mail: P.O. Box 112050
Naples, FL 34108-1929
Tel: 239-513-9907
Toll Free: 1-877-513-0099 (U.S. and Canada)
Fax: 239-513-0088
Email: info@QoLpublishing.com

Karla Wheeler
Editor & Founder
Jan Carlton Doetsch
Clinical Editor
L. Addison Smelko, Jr.
Vice President of Sales
Dashia Larimer
Vice President of Customer Relations
Gretchen Landolt
Director of Marketing
Dianne Gray
Marketing Specialist
Kelly Cabrera
Publishing Assistant

Quality of Life Matters® is a registered trademark of Quality of Life Publishing Co.

HPNA
Hospice and Palliative Nurses Association

COMPENDIUM OF TREATMENT OF END STAGE NON-CANCER DIAGNOSES

The Compendium is a series of seven books designed to serve as a resource in constructing an appropriate plan of care for individuals and their families experiencing these diseases. The Heart Failure and Pulmonary compendiums are available for purchase through the HPNA website:

http://www.hpna.org/publications_CompendiumOverview.aspx

Also, available for free, are an HPNA Patient/Family Teaching Sheet on Dementia and an HPNA Nursing Assistant TIPS Sheet: TIPS for Dementia posted on the HPNA website under the ‘Education’ menu.

Your copy of Quality of Life Matters is provided as an educational service by Hospice and Palliative Nurses Association