

Quality of Life Matters®

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

Vol. 6, Issue 4 Feb/Mar/Apr 2005

Noncancer Diagnoses Continue to Rise Along with Number of Patients Served by Hospice

Of the 950,000 Hospice Patients Cared for in 2003, More Than Half Had Noncancer Diagnoses

As the number of terminally ill Americans using hospice care continues to rise, so, too, does the percentage of those hospice patients with diseases other than cancer, according to a November 2004 report from the National Hospice and Palliative Care Organization (NHPCO).

More than 950,000 dying patients received hospice care from the nation's 3,300 providers in 2003, an increase of 22% over the estimated 775,000 patients served in 2001, the NHPCO reports. In addition, the median length of service rose to 22 days in 2003, up from 20.5 days in 2001.

"Patients and families are becoming better advocates for their own

TOP FIVE NONCANCER DIAGNOSES

- End-stage **heart** disease: 11%
- **Dementia**: 9.6%
- **Lung** disease: 6.8%
- End-stage **kidney** disease: 2.8%
- End-stage **liver** disease: 1.6%

— 2003 Fact Sheet from National Hospice and Palliative Care Organization

health care, and the medical community increasingly is recognizing the value of hospice when dealing with a life-limiting illness," says J. Donald

Schumacher, PsyD, NHPCO president and CEO. "It is gratifying to see more and more people understand what hospice providers have known for many years — that compassionate, high quality care for the dying and their families is available."

According to the NHPCO Hospice Fact Sheet, of all patients served by hospice in 2003, more than half (51%) had noncancer diagnoses at admission [see box for breakdown]. This compares with 47% of all patients served by hospice in 2001.

Hospice works to honor the wishes of those Americans with terminal illness who prefer to die in their own

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83% of Americans Want to Die at Home

88% Would Consider Hospice Care for Themselves or Others

Eighty-three percent of Americans would like to live the end of life at home, cared for by loved ones and supported by in-home health care professionals, according to findings of a national survey presented to the National Hospice and Palliative Care Organization in November 2004.

In a demographically representative sample, 400 adults across the nation were asked in telephone interviews about their wishes concerning hospice and end-of-life care. Key findings include:

- 88% of respondents said they would consider using hospice if they or some-

one they knew were terminally ill.

- **98% of respondents whose family had previously been served by hospice said it was a positive experience.**
- 90% of people who have discussed death and dying have done so with a family member.

Respondents said the most important aspects of a "good death" were dying with family members around, dying with dignity, dying pain free, and dying with the benefit of spiritual counseling.

For more information, visit www.nhpc.org.

Palliative Medicine Physician Training Programs Receive Accreditation

Nine fellowship training programs have successfully completed the new accreditation process conducted by the Palliative Medicine Review Committee (PMRC), becoming the first physician training programs in the nation to receive accreditation specifically in hospice and palliative medicine.

“Graduates of these newly accredited training programs will go out into the community and help their colleagues with challenging palliative care situations,” says PMRC chairman Steven Radwany, MD. “They will have careers in academic medicine and train the next generation of physicians to attend to symptoms and alleviate suffering.”

The PMRC conducts the accreditation process for the American Board of Hospice and Palliative Medicine (ABHPM) and the American Academy of Hospice and Palliative Medicine, which jointly developed the accreditation program as a prelude to formal accreditation by the Accreditation Council for Graduate Medical Education (ACGME).

PALLIATIVE MEDICINE KNOWLEDGE AND COMPETENCIES INCLUDE:

- ✓ A high level of clinical expertise in addressing the physical, emotional, and spiritual dimensions of life-threatening illness, including a practical skill set in symptom control interventions
- ✓ A high level of expertise in both clinical and non-clinical issues related to death and dying
- ✓ A commitment to the interdisciplinary team approach
- ✓ A strong focus on the family as the unit of care

According to the ABHPM, the specialty practice of palliative medicine involves a distinct body of knowledge and competencies [see box].

Hospice and palliative medicine trainees must have already completed an ACGME approved residency program in a discipline such as internal medicine, family medicine, neurology, or physical medicine. Residents in the programs learn to help families and health care teams with ethically difficult choices, to focus

on the relief of suffering, and to communicate effectively and compassionately with patients from many cultural backgrounds.

“These are skills that too often have been given short shrift during earlier phases of a physician’s education,” comments Radwany. **“Most physicians are strongly motivated to provide this care, but have often not been exposed to this training in their residency programs.”**

For more information, visit www.abhpm.org.

Noncancer Diagnoses Rise Along with Number of Patients

Continued from Page 1

homes and on their own terms by providing care from an interdisciplinary team trained in pain control and symptom management, psychosocial support, and spiritual care, according to the NHPCO.

Of those patients who died in 2003 **while under hospice care:**

- 50% died at home
- 23% died in a nursing facility
- 9% died in the hospital
- 7% died in a hospice unit, 7% in a free-standing hospice inpatient facility, and 4% in a residential care setting

In contrast, among **all Americans** who died in 2003:

- 25% died at home
- 25% died in a nursing facility
- 50% died in the hospital (15% in the emergency department and 35% in acute care)

Although many people still believe that hospice care “is what you do when there is nothing more to do,” notes Schumacher, “that couldn’t be further from the truth. **Hospice provides a wide range of services to the family and patient that maximize quality of life and help people live as fully as possible, on their terms.**”

For more information, visit www.nhpco.org.

End-of-Life Care Decision Making: A Structured Approach for Physicians

Physicians play a central role in helping patients and families make the clinically and emotionally challenging decision of when to shift from life-prolonging treatment to an approach focused on end-of-life-care goals.

That is according to David E. Weissman, MD, of the Palliative Care Center, Division of Neoplastic Disease and Related Disorders, Medical College of Wisconsin, Milwaukee, whose structured approach for physicians appears in the October 13, 2004, issue of *Journal of the American Medical Association*.

Weissman's suggestions include:

ALLOW TIME TO EXPLORE OPTIONS

For a patient with a terminal diagnosis, the topic of goals of care should be introduced early in the disease course so that care goals can be defined before an acute medical crisis. As the disease progresses or exacerbations occur, the care plan will most likely need modification. The physician must allow time for further discussion of end-of-life goals and treatment options, including treatments used to alleviate distress. **"Patients need reassurance that no matter what treatment option is chosen, the goal of comfort will always be paramount."**

PROVIDE TIMELY, HONEST PROGNOSTIC INFORMATION

"Prognostic information is often the single most important piece of information that patients need to make informed choices," states Weissman. Some physicians may be reluctant to relay accurate prognostic information for fear of destroying hope. But "hope should not be static," he points out. **"Dying patients can still have hope for symptom control, of resolving personal relationships, and for a dignified death."**

MAKE CLEAR RECOMMENDATIONS

Once the goals of care are defined, it is important to discuss the preferred place of end-of-life care and support for the patient and family. **Physicians can introduce the topic of hospice care and help the patient and family to accept the hospice concept** by saying, *"We have discussed your goals for the time you have left. To best meet these goals, I am recommending that you enroll in a hospice program."*

FACILITATE PATIENT-FAMILY DISCUSSIONS

It is often harder for family and loved ones to accept the fact of impending death than it is for the patient, Weissman notes. He suggests that physicians include individuals who are close to the patient as active participants in discussions concerning the patient's goals and concerns.

AFFIRM PATIENT CHOICES AND STAY FOCUSED ON THE GOAL

Once the decision to forgo life-sustaining treatment and pursue comfort care has been made, it is important for physicians to demonstrate their support and to explore any further patient goals. (*"I want you to know that I fully support your decision and will do my best to honor your wishes."* *"What do you need or want to do in the time you have left?"*)

Physicians can help patients meet their goals by reviewing current medications, tests, and interventions, and asking themselves, "Is this contributing to comfort? Is this helping the patient achieve their goals?" Asserts Weissman, "Any elements not contributing to the patient's goals should be discontinued."

"No laboratory test, clinical pathway, or computer algorithm will replace the

A Structured Approach to End-of-Life Care

- Assess the patient's current physical symptoms and psychological and spiritual needs
- Assess family and social support systems
- Estimate and communicate prognosis
- Ask the patient to define his or her end-of-life goals

Factors for Physicians to Consider in Helping Patients Make Informed Decisions

- Nature of the terminal disease (often divided into cancer vs. noncancer)
- Mutual understanding of the prognosis
- Patient end-of-life goals
- Treatment risk vs. benefit
- Symptom burden
- Comorbidities
- Patient age and life stage
- Past response to interventions
- Temporal pattern of the illness
- Treatment burden to family
- Financial burden of treatment
- Psychological variables
- Cultural variables

— Weissman
Journal of the American Medical Association

central role of the physician in helping patients and families navigate an increasingly complex medical care system," Weissman concludes. "Working as partners with patients and families to make difficult decisions requires in-depth medical knowledge, leadership, the ability to self-reflect, and outstanding communication skills. The challenge for today and the future is to ensure that all physicians acquire and demonstrate these attributes."

Nursing Home Physicians Cite Need for Building Consensus as Central to Good End-of-Life Care

A survey of nursing home physicians has identified consensus — the shared understanding of the patient's medical status developed into shared goals — as crucial to providing quality end-of-life care among this population.

Common obstacles to consensus building were also identified, according to a report published in the August 2004 issue of the *Journal of Palliative Medicine*. Study findings include:

- ✓ **Consensus about the resident's prognosis and care plan is integral to good end-of-life care.** "End-of-life care is gratifying when everyone is on the same page about it," commented a respondent. "Once that consensus is reached, everyone is working together to provide intensive comfort care," added another.
- ✓ **Identified barriers to consensus included:** the challenge of communicating the need for transition to palliative care to the patient, family, and staff; unwillingness of families and staff to forgo aggressive

treatment interventions; staff shortages and the high turnover rate of staff frequently encountered in the nursing home setting; and hospitalizations.

- ✓ **Advance directives can set the stage for conversations about end-of-life care.** The respondents considered advance directives of more value for initiating discussions

with patients and families about care plans than for directing care in themselves. "You really have to clarify with the patient what they mean by it, because those forms can be misleading," noted one physician. "Physicians need to make sure that they themselves participate in those discussions, as opposed to seeing some boxes checked on a piece of paper."

Source: "Getting Everyone on the Same Page: Nursing Home Physicians' Perspectives on End-of-Life Care," Journal of Palliative Medicine; August 2004; 7(4):533-544. Bern-Klug M, Gessert CE, Crenner CW, Buenaver M, Skirchak D; University of Iowa, Iowa City; St. Mary's/Duluth Clinic Health System, Duluth, Minnesota; University of Kansas Medical Center, Kansas City.

PHYSICIANS PLAY PIVOTAL ROLE INITIATING HOSPICE

'Physicians can play a pivotal role in guiding decisions about the care provided to nursing home residents as death approaches... In addition to participating in advance care planning, physicians can initiate hospice and affect pain management...'

— Bern-Klug, Gessert, et al
Journal of Palliative Medicine

Patients with Serious Illness May Welcome Physician Inquiry about Spirituality

Although physicians may often be reluctant to broach the topic of spirituality with their patients, most adult respondents (83%) in a recent survey indicated that they wanted their physicians to ask about their spiritual or religious beliefs in at least some clinical circumstances, a team of Ohio researchers has found. Their report was published in the July/August 2004 issue of *Annals of Family Medicine*.

The team analyzed responses of 921 adults (798 consenting patients; 123 accompanying adults) to a questionnaire administered at four urban family practice residency sites and one suburban private practice in northeastern Ohio. Median participant age was 39 years (range, 18 to 90 years); physical and mental health status scores indicated similar health status of

respondents to that of the average general American population.

Respondents indicated that they would welcome a discussion of spirituality with their physicians in the following situations:

- Life-threatening illness (77%)
- Serious medical condition (74%)
- Loss of a loved one (70%)

Among those persons who desired spiritual discussion, the most important reasons cited included:

- Promotion of physician-patient understanding (87%)
- Enhancement of physician ability to provide compas-

Continued on Page 5

Physicians Offered Framework for Managing Comorbidities in Patients with Life-Limiting Illness

Patients with advancing, life-limiting illness often have chronic comorbidities for which they take long-term medications. As the terminal illness progresses, systemic changes reduce the need for many of these drugs or alter their metabolism, while additional drugs are introduced for symptom control. Addressing the dilemma of continuing, changing, or discontinuing medication in these patients requires ongoing assessment, argues a team of palliative care experts from Australia and the United States.

“Every clinician is responsible for the quality use of medications. In the face of life-limiting illness, the combination of drugs for symptom control and long-term comorbidities creates specific challenges for which little guidance exists,” writes the team in a review published in the *British Medical Journal*.

The team offers a framework to aid physicians in clinical decision making for the management of chronic conditions at

the end of life. The framework’s knowledge base requires an understanding of the metabolism of drugs, the pathophysiology of death, prognostication, measure of benefit for clinical interventions, and the aims of intervention for comorbidity.

Highlights of the authors’ report include:

- “The risk of a serious adverse drug interaction is greater than 80% when more than seven drugs are taken,” they state. However, long-term drugs for comorbidities should not be withdrawn without consideration of the natural course of the condition.
- **As death approaches, the progressive and irreversible process of involution affects the intake, absorption, and bioavailability of drugs.** Since the cachexia characteristic of end-stage disease is progressive, frequent assessment of the patient’s drugs for therapeutic benefit is needed.
- Psychological concerns experienced

by patients when long-term treatments are stopped have not been well researched but may be inferred from the difficulty often encountered during patient-physician discussion of discontinuing medication. The authors offer several possible patient reactions (mistrust, fear of imminent death, fear of medical complications, abandonment, and futility) and suggest potential physician responses.

In conclusion, the authors note, **“Decisions to adjust drugs should be taken actively as whole body changes occur in life-limiting illness, rather than in response to adverse effects.”** To read the full article, visit www.bmj.com.

Source: “Managing Comorbidities in Patients at the End of Life,” British Medical Journal; October 16, 2004; 329:909-912. Stevenson J, Abernethy AP, Miller C, Currow DC; Repatriation General Hospital, Daw Park, South Australia, Australia; USA Division of Medical Oncology, Department of Medicine, Duke University Medical Center, Durham, North Carolina; Department of Palliative and Supportive Services, Flinders University, Adelaide, Australia.

Patients May Welcome Inquiry about Spirituality

Continued from Page 4

sion and encourage realistic hope (67%)

- Improvement of physician ability to give appropriate medical advice (66%) and to change medical treatment (62%)

“Providing understanding, compassion, and hope are hallmarks of a good physician and are not necessarily faith dependent,” write the authors. More than half of respondents desiring discussions of spirituality agreed that physician referral to a spiritual advisor would be an acceptable course of action.

In conclusion, the researchers note, “To bridge the gap between medicine and spirituality, the physician must identify, coordinate, and utilize referral sources for patient-generated requests.”

Source: “Discussing Spirituality with Patients: A Rational and Ethical Approach,” Annals of Family Medicine; July/August 2004; 2(4):356-361. McCord G, Gilchrist VJ, Grossman SD, et al; Department of Family Medicine, Northeastern Ohio Universities College of Medicine, Rootstown, Ohio.

Update: DEA Withdraws Support of Joint Pain Document

Last issue, *Quality of Life Matters* published an article entitled “DEA and Pain Experts Release Joint Document on Medical Treatment of Pain.” Unfortunately, the DEA later retracted its support of the document, removing it from its website. *Quality of Life Matters* will be following the progress of the revised joint document on pain and will provide updated information as it becomes available.

PHYSICIAN RESOURCES

Physicians' Empathy Key to Patient Satisfaction

Conducting a Patient-Centered Interview: A First Step in Facilitating Empathy

Physicians' ability to empathize with their patients is believed to be an important component of patient care and a major determinant of patient satisfaction. Although empathy is a multistep process influenced by physician/patient personality variables, the first step — gaining insight into patient concerns by conducting a “patient-centered” interview — is a teachable skill, according to the authors of an article published in *Academic Medicine*, the journal of the Association of American Medical Colleges.

The authors offer a number of suggestions for conducting a patient-centered interview, including:

- **Demonstrate a willingness to listen.** Begin with an open question such as: “*Could you tell me why you have come to see me?*” Listen carefully to the patient’s account, and do not interrupt for at least two minutes.
- **Inquire further.** “*Could you tell me more about (your chest pain,... family,... past health)?*” Respond with an explicit and accurate acknowledgment of the patient’s concerns.
- **Ask closed questions only toward the end of the interview,** to further define the patient’s symptoms and chief complaint. “*Did the pain radiate to your arm?*” Focusing too early on the chief complaint can turn the interview into a “disease-centered” interrogation in which patients are unlikely to express their concerns.
- **Write the history** at the end of the interview, using the standard sequence. Recording the history while the patient is talking prevents eye contact; nonverbal clues may be missed,

and the patient may feel that the physician is disinterested or lacks respect.

“The acquisition of an insight into patients’ concerns is a legitimate field of inquiry and essential for a therapeutic doctor-patient relationship,” write the authors. “Given the same time constraints, listening to and encouraging the patient’s narrative may be more informative and therapeutic than a closed-question interrogation.” The authors add, “**Making a diagnosis and understanding the patient should not be seen as separate and mutually exclusive endeavors.**”

Source: “What Is Empathy, and How Can It Be Promoted during Clinical Clerkships?” Academic Medicine; September 2004; 79(9):832-839. Benbassat J, Bauml R; JDC-Brookdale Institute, The Smolder Center for Health Policy Research, Jerusalem, Israel; Department of Laboratory Medicine and Pathobiology, Toronto Hospital for Sick Children, University of Toronto, Toronto, Ontario.

Clear Definitions Related to Medical Use of Opioids Posted Online

Recommended Definitions Include:

ADDICTION is a primary, chronic, neurobiologic disease, with genetic, psychosocial, and environmental factors influencing its development and manifestations. It is characterized by behaviors that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm, and craving.

PHYSICAL DEPENDENCE is a state of adaptation that is manifested by a drug class specific withdrawal syndrome that can be produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug, and/or administration of an antagonist.

TOLERANCE is a state of adaptation in which exposure to a drug induces changes that result in a diminution of one or more of the drug’s effects over time.

—The American Academy of Pain Medicine, the American Pain Society, and the American Society of Addiction Medicine

In an effort to promote a clear understanding of the nature and risk of addiction, three leading professional pain organizations have made available online their consensus statement defining frequently confused terms related to the use of opioids for the medical treatment of pain.

“Clear terminology is necessary for effective communication regarding medical issues,” states the document. “**Confusion regarding the treatment of pain results in unnecessary suffering, economic burdens to society, and inappropriate adverse actions against patients and professionals.**”

Entitled “Definitions Related to the Use of Opioids for the Treatment of Pain,” the statement has been approved by the boards of directors of the American Academy of Pain Medicine, the American Pain Society, and the American Society of Addiction Medicine.

As an accompaniment to the recommended definitions, the document includes a discussion of the characteristic features, associated behaviors, and adverse consequences of the addictive use of medications. Pseudoaddiction, physical dependence, and tolerance are also described and discussed.

The document is available online at www.painmed.org. Select “Publications and Products,” then “Position Statements.”

PHYSICIAN RESOURCES

Online Resource Offers Free CME Credits in Hospice Referral and Care

Medscape, a multidisciplinary resource for clinicians and other healthcare professionals, has recently added “Hospice Referral and Care: Practical Guidance for Clinicians” to its online list of accredited continuing medical education (CME) activities for physicians, as well as approved continuing education hours for registered nurses. All other healthcare professionals who complete the program can receive a certificate of participation.

The self-study activity, formatted to include text and graphics, can be viewed online or printed in its entirety for offline reference. Access to the program and to all other educational tools and medical information on the Medscape site is free, following a one-time registration. The program will be valid for credit through September 3, 2005.

According to Medscape, clinicians completing the activity will learn:

- Indications for hospice referral
- Provisions of the Medicare Hospice Benefit available to beneficiaries and their families
- Patient assessment variables needed to determine the optimum time for hospice referral
- How and when to initiate end-of-life care planning discussions

Topics among the 19 program sections include:

- What Is Hospice?
- Recent Developments in Hospice Care
- Criteria and Eligibility for Hospice Services
- The Prognosis: How Can I Be Sure It’s Time to Refer to Hospice Services?
- Clinical Judgment and Nontraditional Patients
- Measuring Clinical Decline
- What to Say and When to Say It
- Working with Hospice Clinicians/Organizations

References — some with links to the original documents — are included, and the sections on resources for physicians and resources for patients, families, and caregivers provide links to professional, organizational, governmental, and consumer advocate sites.

“For dying patients and their families, hospice is an invaluable service that for most still comes very ‘late in the game,’” writes program author Perry Fine, MD, Department of Anesthesiology, University of Utah, Salt Lake City. “The most common statement made by families of hospice patients is, ‘Why didn’t we know about hospice earlier?’ For the clinician, hospice can be an excellent tool for relieving the suffering that comes at the end of life.”

Visit www.medscape.com and search for “Hospice Referral and Care” under “CME.”

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.epeconline.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

Palliative Medicine 2005. March 15-17, 2005, Fort Lauderdale, FL. Sponsor: Cleveland Clinic Foundation. Phone: 216-444-5696 or 800-762-8173; Website: www.clevelandclinic.org/palliative

Quality Leadership in Long-Term Care: Affirming the Physician Role. March 17-20, 2005, New Orleans. Sponsor: American Medical Directors Association. Annual symposium with topics including palliative care and hospice. Phone: 410-740-9743; Website: www.amda.co

24th Annual Scientific Meeting of the American Pain Society and 5th Annual Pediatric Pain Forum. March 29-April 2, 2005, Boston. Phone: 847-375-4715; Fax: 877-734-8758; Email: info@ampainsoc.org; Website: www.ampainsoc.org

9th Congress of the European Association for Palliative Care. April 6-10, 2005, Aachen, Germany. Phone: +49 241 80 85 715; Email: congress2005@ukaachen.de; Website: www.eapcnet.org/Aachen2005/index.html

Science, Skills, and Soul: Advancing the Continuum of Care. May 19-20, 2005, Atlanta. Sponsor: National Hospice and Palliative Care Organization's 6th Clinical Team Conference. Phone: 703-837-1500; Website: www.nhpco.org/ctc2005

Opening Doors, Building Bridges. August 1-3, 2005, St. Louis, MO. Sponsor: National Hospice and Palliative Care Organization and Missouri Hospice and Palliative Care Association. First National Conference on Access to Hospice and Palliative Care. Phone: 703-837-1500; Email: conferences@nhpco; Website: www.nhpco.org/access2005

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