

Quality of Life Matters™

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

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JCAHO Introduces New, Explicit Standards for Pain Management

"Effective management of pain is a crucial component of good care," says JCAHO President

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has announced the development of standards with new expectations for the assessment and management of pain in accredited health care organizations.

Focusing on pain as a major, yet largely avoidable, public health problem, JCAHO developed the standards in a two-year collaborative effort with the University of Wisconsin-Madison Medical School.

The new standards, which have been endorsed by the American Pain Society, Glenview, Illinois, recognize that pain is a frequently co-existing

condition with a number of diseases and injuries, and requires explicit attention. "Unrelieved pain has enormous physiological and psychological effects on patients," says JCAHO President Dennis S. O'Leary, MD. "The Joint Commission believes the effective management of pain is a crucial component of good care."

Under the new standards, hospitals, nursing homes, outpatient clinics, health plans, and others will be called upon to:

■ Recognize the right of patients to appropriate assessment and management of pain;

■ Assess the existence, nature, and intensity of pain in all patients;

■ Record results to facilitate regular reassessment and follow-up;

■ Determine and assure staff competency in pain assessment and management;

■ Establish policies and procedures to support the prescription or

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Physicians Can Learn to Diagnose Suffering, Says Cornell Researcher

Physicians who are excellent at diagnosing disease may not be aware of the need to recognize and diagnose suffering, yet the alleviation of suffering is crucial in all of medicine, particularly in the care of the dying.

So states ethicist Eric J. Cassell, MD, Weill Medical College, Cornell University, New York, whose article "Diagnosing Suffering: A Perspective," was published in the Oct. 5, 1999, issue of *Annals of Internal Medicine*.

Suffering is personal, says Cassell, and has been defined as "a specific state of distress that occurs when the intactness or integrity of the person is threatened or disrupted." But, warns Cassell, "Suffering cannot be treated unless it is recognized and diagnosed."

To make a diagnosis of suffering, Cassell suggests that physicians:

■ **MAINTAIN A "HIGH INDEX OF SUSPICION"** in the presence of serious disease or distressing symptoms.

■ **ASK THE PATIENT DIRECTLY:** "Are you suffering? I know that you have pain, but are there things that are even worse for you?" "What is the worst thing about all this?" "Are you frightened? What are you afraid is going to happen to you?"

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International Survey Reveals Wide Variations in Diagnosis of Breakthrough Pain

Standardized Checklist of Cancer Pain Syndromes Suggested

A 24-nation survey of cancer pain specialists and their patients has found that clinicians across different countries diagnose transitory or “breakthrough” pain very differently, and that cancer pain characteristics, syndromes, and pathophysiologies are widely heterogeneous. The survey report recommends the development of a common nomenclature to be used worldwide for clinical phenomena, and suggests a written checklist approach to syndrome identification of pain.

The prospective, cross-sectional, multicenter survey was conducted by the Task Force on Cancer Pain of the International Association for the Study of Pain. Researchers analyzed data collected by mailed questionnaires from 58 cancer pain practitioners (mean number of years in practice, 15.4) and 1095 of their patients (mean age, 58.2 years). All patients experienced cancer pain severe enough to require opioid medication, and more than 76% had a Karnofsky performance status score ≤ 70 . All infor-

mation was supplied by the clinical investigators at each center with the exception of pain intensity, which was acquired directly from the patients.

Nearly 25% of the patients experienced two or more pains, and 64.8% experienced breakthrough pain in addition to their continuous background pain. A large majority (92.5%) had one or more pains caused directly by the cancer, while 20.8% had one or more pains caused by cancer therapies. More than two thirds (66.7%) of the patients rated the intensity of their worst pain experienced on the day before the survey at ≥ 7 on a 10-point scale.

Factors univariately associated with higher pain intensity included the presence of breakthrough pain, somatic or neuropathic pain, age younger than 60 years, and lower performance status score. In multivariate analysis, the most important predictors of intense pain were the presence of breakthrough pain, somatic pain, and lower performance status. The odds of ex-

periencing a worst pain level of 7-10 were found to be 1.5 times higher for patients with breakthrough pain than for those without such pain.

According to the study authors, the identification of a high incidence of breakthrough pain — despite the absence of data on this item from many countries — is consistent with the findings of previous surveys. “Breakthrough pain is an important phenomenon, which may increase patient distress and reduce the responsiveness to opioid therapy,” they note. “Additional studies of breakthrough pain phenomenology and impact are needed.”

Source: “An International Survey of Cancer Pain Characteristics and Syndromes,” Pain; Sept. 1, 1999; 82(3):263-274. Caraceni A, Portenoy RK, a working group of the IASP Task Force on Cancer Pain; Pain Therapy and Palliative Care Division, National Cancer Institute of Milan, Italy; Department of Pain Medicine and Palliative Care, Beth Israel Medical Center, New York; International Association for the Study of Pain, Seattle.

More Faculty Scholars to Receive End-of-Life Care Funding

The Project on Death in America (PDIA) of the Open Society Institute based in New York has announced one million dollars in funding for eight new participants in its ongoing Faculty Scholars Program.

The program identifies clinical faculty committed to improving end-of-life care, supports the development and dissemination of models of good care, and promotes new approaches to educating health professionals in the care of dying

patients and their families.

During the past five years, PDIA has funded 58 faculty scholars at 42 medical institutions in the U.S. and Canada.

Among the recent projects are:

■ “Integrating Palliative Care in the Intensive Care Unit,” Mount Sinai School of Medicine, New York;

■ “Improving Care at the End of Life for Children with Cancer,” Dana-Farber Cancer Institute, Boston; and

■ “Creating a Palliative Care Clinical,

Educational, and Research Initiative in a Community-Based, Rural, Oncology Setting,” Oncology Symptom Control Research, Community Cancer Care, Inc., Indianapolis.

The PDIA Faculty Scholars Program grants fellowships of up to \$150,000 for two years for projects aiming to improve end-of-life care. **The next deadline for application is Jan. 6, 2000.** For more information, call 617-632-6182, or visit the PDIA web site at www.soros.org/death.

Balance Called for in State Drug, Pain Policies

The Pain & Policy Studies Group (PPSG) at the University of Wisconsin, Madison, has released the results of its analysis of policies governing controlled substances in 17 states and found that many interfere with pain management.

The PPSG report, "Achieving Balance in State Pain Policy," provides a model for evaluating pain-related policy for use by professional and patient groups, governments, and other interested parties. Policies governing controlled substances, medical practice, and pharmacy in each of the 17 states are identified and reviewed as either enhancing or impeding pain management.

Criteria for provisions that may enhance pain management include:

- Controlled substances are recognized as necessary for the public health;
- Pain management is recognized as part of general medical practice;
- Medical use of opioids is recognized as legitimate professional practice;
- Practitioners' concerns about regulatory scrutiny are addressed.

Criteria for provisions that may impede pain management include:

- Opioids are implied to be a last resort;
- The belief that opioids hasten death is perpetuated;
- Physical dependence or analgesic tolerance are confused with "addiction;"
- Medical decisions are restricted.

The study is the first phase of a research project funded by the Robert Wood Johnson Foundation, Princeton, New Jersey. The second phase, a comprehensive evaluation of all 50 states plus federal policy, will be completed in 2000.

To obtain a copy of the report, contact the Pain & Policy Studies Group at **608-263-7662**.

JCAHO's Pain Management Standards

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ordering of effective pain medications;

- Educate patients and their families about effective pain management;

- Address patient needs for symptom management in the discharge planning process.

The 2000-2001 standards manu-

als will include the new pain management standards, which will first be scored for compliance in 2001. For more information, call the Department of Standards at **630-792-5900**, or access the Pain Assessment and Management Standards section on the JCAHO web site at **www.jcaho.org**.

Guidelines for Diagnosing Suffering

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- **GIVE THE PATIENT TIME TO ANSWER.** Keeping the questions vague tells the patient it is safe to talk and there are no expectations about the answers.
- **LISTEN ATTENTIVELY.** Physicians who may feel somewhat uncomfortable at first listening to stories of distress may be surprised at how gratifying the process can be and how beneficial it is to the patient.
- **LEARN TO BE OPEN** in the presence of the patient. This, according to Cassell, is the hard part. Physicians can learn to gather information about the patient by dropping all preconceptions and interpretations and simply allowing the intuitive mind to process the experience.

Cassell says he believes that physicians have been trained to treat bodies, not persons, to think objectively rather than subjectively; the language of the patient's narrative is different from the language of the case history, and may thus seem less valuable. If gathering information subjectively seems threatening, says Cassell, "Remember that you are working. It is you, the doctor, doing and being this way, not the personal you." The benefit of this approach is that physicians will learn how to assess what their patients are feeling by using a form of nondiscursive thought, which is common to experts in many fields.

In conclusion, Cassell urges physicians to take the crucial step of "starting on the path to knowledge about patients as persons. The relief of suffering depends on it."

RESEARCH MONITOR

Families and Friends Are Primary Caregivers

Non-Cancer Patients Report More Unmet Needs

Family members and friends are the primary caregivers for 96% of terminally ill patients in the United States, with 42.4% of patients who need nursing care relying exclusively on their family and friends, according to a landmark study published in the Sept. 23, 1999, issue of the *New England Journal of Medicine*.

In addition, researchers found that cancer patients report less substantial need for care, fewer unmet needs, and less reliance on paid assistance than do patients dying of other terminal illnesses.

Ezekiel J. Emanuel, MD, PhD, chair of the department of bioethics at the National Institutes of Health, Washington, DC, led the investigation to determine the patterns and disparities in meeting the caregiving needs of the terminally ill — the first study of its kind in more than 10 years. Participants were patients from six areas (four metropolitan areas with high managed-care penetration; one metropolitan area with low managed-care penetration; and one rural county) whose physicians identified them as having less than six months to live.

In detailed interviews, 988 patients (mean age 66.5 years; patients aged 65 or older, 59.4%) with clinically significant illness (excluding human immunodeficiency virus infection

or acquired immunodeficiency syndrome) and 893 caregivers were asked to rate the patient's need for assistance on a four-point scale (none at all, some, substantial, and total). The four areas of need were: transportation, nursing care, homemaking services, and personal care.

Only 4% of the patients were in an institutional setting; all others were living in a private residence.

The most common types of terminal illness were:

- Cancer (51.8%)
- Heart disease (18%)
- Chronic obstructive pulmonary disease (10.9%)

Reporting a substantial need for care were:

- 28.9% of cancer patients
- 40.9% of patients with other diseases

Reporting unmet needs were:

- 14.6% of cancer patients
- 22.9% of patients with other diseases

Patients who had substantial needs, unmet needs, or who relied mostly on paid assistance were about twice as likely as those who did not have substantial needs to want additional hospice or home care.

Entitled, "Assistance from Family Members, Friends, Paid Care Givers, and Volunteers in the Care of Terminally Ill Patients," the study is one of eight research components funded by the Commonwealth Fund and the Nathan Cummings Foundation.

Based in New York, the organizations fund efforts to expand the nation's understanding of the dying experience and to find ways to improve it. Other research projects will explore issues such as: euthanasia and suicide; the impact of managed care on the terminally ill; pain management at the end of life; and suffering and the unique care needs of the dying.

For more information on the Commonwealth-Cummings Project on the End of Life, call the Commonwealth Fund at **212-535-0400**, or the Nathan Cummings Foundation at **212-787-7300**.

Implications for Physicians

"There are two points to be made to referring physicians," Ezekiel J. Emanuel, MD, PhD, told *Quality of Life Matters* regarding the study implications.

"First, know that families have a great burden in caring for the patient who is dying." Ask how things are going for the patient at home, he suggests, and see if the patient's needs are being met. "You can't just assume that you know what is going on in the house," he warns.

Secondly, Emanuel calls on non-oncologists to be aware of the disparity in care between that received by cancer patients and those with other terminal illnesses. "Non-oncologists don't often take into account that their patients are dying," he notes, "and clearly we are not doing well in this area."

RESEARCH MONITOR

Elderly Need Variety of Choices in Terminal Care Sites

Because little is known about the reasons for patients' preferences for the site of terminal care, the current tendency to compare the merits of home care and hospital care may be too restrictive, particularly when considering the unique concerns of older patients, says a recent study.

Investigators conducted both quantitative and qualitative interviews with patients 65 years of age or older who had been recently hospitalized with congestive heart failure, chronic obstructive pulmonary disease, or pneumonia. In the quantitative interviews, patients (n=246) identified their preference for hospital care (48%) or home care (43%) in the event of a terminal illness.

"In contrast to the 17% of adults 65 years of age or older who died in their homes in 1990, 43% of participants in our study expressed a preference for receiving terminal care at home."

Terri R. Fried, MD, et al

When the scenario was changed to a nonterminal illness, one third of the patients switched their preferences.

In the qualitative interviews, patients (n=29) were asked open-ended questions to elicit the reasons for their preferences, but were no longer restricted to the choice of home or hospital. Responses now included a nursing home as the site of preference, as well as a high rate of refusal to consider any preference (n=9). Once again, many patients changed their preferences when asked to consider a nonterminal illness.

Reasons for preferences in terminal care sites included: the availability of necessary care for acute episodes (hospital), the desire to be with family and loved ones (home), and concerns about burdening family with long-term care of chronic disability (nursing home).

The authors conclude that "the variability in preference for the site of end-of-life care supports a system of care equipped to treat older patients across a spectrum of treatment sites."

Source: "Older Persons' Preferences for Site of Terminal Care," Annals of Internal Medicine; July 20, 1999; 131:109-112. Fried TR, van Doorn C, O'Leary JR; Veterans Affairs Connecticut Healthcare System, New Haven, Connecticut; Yale University School of Medicine, New Haven, Connecticut.

Italian Study Finds Same Late Referral to Palliative Care as in U.S.

A large multicenter study designed to obtain a representative sample of cancer patients admitted to palliative care centers in Italy found that, as in the United States and other Western countries with different health systems, referral of terminally ill cancer patients to palliative care tends to occur late in the course of the disease.

Researchers followed a random sample of 589 cancer patients prospectively selected from 2667 eligible patients admitted to 58 palliative care units (PCUs) from January to June 1995. Median survival was 37.9 days, with 14.3% of patients dying within 7 days, and 15.3% living longer than 180 days. These figures are substantially the same as those observed in studies of patients enrolled in hospice programs in the U.S., note the study authors.

Since access to PCUs in Italy is free of charge, and there is no time limit on access to care, referral delay cannot be due to regulatory restrictions, the authors comment. They suggest that the value system of Western-trained physicians imposes poor acceptance of palliative care, pointing out that 26.3% of the terminally ill cancer patients in this study were referred by nonmedical persons, while only 13% of total referrals were from oncologists.

Source: "Terminal Cancer Patients and Timing of Referral to Palliative Care: A Multicenter Prospective Cohort Study," Journal of Pain and Symptom Management; Sept. 30, 1999; 18:243-252. Costantini M, Toscani F, Galluci M, et al, and the Italian Cooperative Research Group on Palliative Medicine; Clinical Epidemiology and Trials Unit, National Cancer Institute, Genoa; Palliative Care Unit, Cremona Hospital, Cremona; Palliative Care Unit, Desio Hospital, Milan.

Abdominal Drain Helps Patient with Intractable Malignant Ascites

Surgical implantation of a Tenckhoff catheter as a permanent abdominal drain can be useful in the management of intractable malignant ascites, according to a recent report from Australia, where insertion of the catheter has successfully provided palliation for one patient for at least 17 months.

A 67-year-old woman diagnosed in 1994 with locally advanced infiltrating lobular left breast carcinoma had

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been undergoing increasingly frequent procedures of paracentesis for rapid reaccumulation of ascitic fluid by July 1997, when the Tenckhoff catheter was inserted. She has since been managing her ascites effectively at home, performing self-drainage twice weekly under supervision of her palliative care team.

The researchers report minor postoperative infection, but no subsequent complications as of December 1998. Advantages of the drain include: effective palliation of symptoms with improved quality of life; less risk of the hemodynamic disturbances associated with intermittent paracenteses; no risk of disseminated intravascular coagulation as in peritoneovenous shunting; and the opportunity for the patient to contribute in a positive way to her own care.

Source: "Effective Community Palliation of Intractable Malignant Ascites with a Permanently Implanted Abdominal Drain," *Journal of Palliative Medicine*; Fall 1999; Vol. 2, No. 3. Bui CDH, Martin CJ, Currow DC; Nepean Hospital, Penrith, Sydney, Australia; Wentworth Area Health Services, Penrith, Sydney, Australia.

Institutions Advised to Adopt Fair Process Policy on Medical Futility

According to the Council on Ethical and Judicial Affairs of the American Medical Association, the point at which medical intervention becomes futile is difficult to define. Controversy arises in clinical practice when patients or their proxies disagree with health professionals concerning values or goals of care. The council recommends the use of a case-by-case process-based approach to resolve any conflicts in order to reach agreement and provide the proper level of care.

The mediation process recommended by the council for all health care institutions, regardless of size, includes four steps for deliberation and resolution including all involved parties. If agreement is reached at any point below, there is no need to continue to the next of the four steps. The four steps are:

- Prior deliberation of values
- Joint decision-making using outcomes data and value judgments
- Involvement of consultant(s)
- Involvement of ethics committee

If agreement has not been reached, there are two steps aimed at securing alternatives:

- Attempt to transfer care within the institution
- Transfer to another institution

If neither of the above options is possible, the futile intervention is ceased. "This fair process approach insists on full and fair deference to the patient's wishes, placing limits on this patient-centered approach only when the harm to the patient is so unseemly that, even after reasonable attempts to find another institution, a willing provider of the service was not found," the authors note.

Source: "Medical Futility in End-of-Life Care. Report of the Council on Ethical and Judicial Affairs," *Journal of the American Medical Association*; March 10, 1999; 281:937-941. Council on Ethical and Judicial Affairs, American Medical Association.

Hospice Nurses Rated Excellent in Pain Management Skills

In a study designed to evaluate cancer pain assessment and management skills, hospice nurses scored highly in identifying pain intensity (85%) and location (70%), recommending analgesics (96%), and handling fear of opioid addiction (100%). In addition, most of the hospice nurses recommended increasing opioid dosage for persistent severe pain in a follow-up (93%), and more than half included analgesic recommendations for breakthrough pain (56%).

The standardized patient examination test was administered to 27 nurses (range of experience, 1 month to 10 years) from several hospice agencies. The test evaluation was developed by consensus from an interdisciplinary panel of pain experts from an area university.

Neither experience nor hospice certification was related to scores on any of the test items. The researchers note: "One explanation is that the preparation of hospice nurses before initiation of their practice was excellent; thus, even inexperienced hospice nurses have a good understanding of cancer pain assessment and management."

The study authors add: "The performance of nurses practicing in the field of hospice fares very well when compared with findings of several studies among nonhospice nurses from the United States."

Source: "Cancer Pain Assessment and Management Recommendations by Hospice Nurses," *Journal of Pain and Symptom Management*; August 1999; Vol. 18, No. 2. Sloan PA, Vanderveer BL, Snapp JS, Johnson M, Sloan DA; Departments of Anesthesiology, Behavioral Science, and Surgery, University of Kentucky, Lexington.

PHYSICIAN RESOURCES

Medical Textbook Publishers Honored for End-of-Life Care Content

At a unique gathering of editors, publishers, medical researchers, and end-of-life care experts, the publishers of seven medical and nursing textbooks were presented with awards for their publications' inclusion of educational material on end-of-life care by Last Acts, the national coalition to improve care and caring at the end of life. Participants were invited to discuss strategies for enhancing textbook content at the day-long conference, which was hosted in New York last spring by the Project on Death in America.

Leaders of three research teams that had recently assessed current medical textbooks for coverage of end-of-life care — and found it to be minimal — presented their findings and offered suggestions. Joanne Lynn, MD, director of the Center to Improve Care of the Dying at George Washington University, Washington, DC, had evaluated four widely used general medical textbooks and reported her findings in the Jan. 5, 1999, issue of *Annals of Internal Medicine*.

"End-of-life care might improve if medical students had reliable textbooks..."

Joanne Lynn, MD

The other two studies were funded by the Robert Wood Johnson Foundation, Princeton, New Jersey, and presented at the meeting. Stephen McPhee, MD, professor of medicine at the University of California, San Francisco, directed a review of the top 50 medical specialty textbooks; Betty Ferrell,

PhD, research scientist at the City of Hope National Medical Center in Duarte, California, led an investigation of the top 50 textbooks in nursing.

All three studies found the end-of-life care content of the medical textbooks to be generally inadequate and often absent. "End-of-life care might improve," noted Lynn in her study, "if medical students had reliable textbooks and if practitioners could rely on those textbooks for guidance with unfamiliar clinical situations in advanced disease."

The awards for superior textbook coverage of end-of-life care included:

- **Family Medicine, 4th Ed.**, Springer-Verlag, for best general textbook with end-of-life care content;
- **Textbook of Family Practice, 5th Ed.**, W.B. Saunders, for best chapter with end-of-life care content in a medicine textbook;
- **Principles and Practice of Pediatric Oncology**, Lippencott-Raven, for best specialty textbook with end-of-life care content;
- **Cancer: Principles and Practice of Oncology**, 5th Ed., Lippencott-Raven, for best chapter with end-of-life care content in a specialty textbook; and
- **Merck Manual of Diagnosis and Therapy, 17th Ed.**, Merck Research Laboratories, for most committed to excellence in changing end-of-life care content in medical textbooks.

End-of-Life Care Websites

www.aahpm.org

American Academy of Hospice & Palliative Medicine.

www.nho.org

National Hospice Organization.

www.hospicefoundation.org

Hospice Foundation of America.

www.americanhospice.org

American Hospice Foundation.

www.gwu.edu/~cicd

Center to Improve Care of the Dying, George Washington University.

www.abcd-caring.com

Americans for Better Care of the Dying.

www.lastacts.org

Last Acts, care and caring at the end of life.

www.mcw.edu/pallmed/

Palliative Medicine Program at the Medical College of Wisconsin. Includes, "Improving End-of-Life Care: a Resource for Physician Education."

www.chcr.brown.edu

Center for Gerontology and Health Care Research.

www.halcyon.com/iasp/

International Association for the Study of Pain.

www.medsch.wisc.edu/painpolicy

University of Wisconsin Pain and Policy Studies Group.

www.soros.org/death

Project on Death in America of the Open Society Institute.

www.stoppain.org

Pain Medicine & Palliative Care, Beth Israel Medical Center.

Upcoming Meetings for Physicians Interested in End-of-Life Care Education

Palliative Medicine 2000. February 3-5, 2000, Key West, Florida. Contact: The Cleveland Clinic Foundation. Phone: 216-444-5695; Fax: 216-445-9406.

Palliative Care 2000. March 19-23, 2000, Jerusalem, Israel. Sponsors: the European Association for Palliative Care and Israel Association of Palliative Care, P.O. Box 50006, Tel Aviv 61500, Israel. Fax: 972 (3) 514-0077; e-mail: palliative@kenes.com

12th MASCC (Multinational Association of Supportive Care in Cancer) International Symposium. March 22-25, 2000, Washington, DC. Contact: Imedex, 70 Technology Drive, Alpharetta, Georgia, 30005-3969. Phone: 770-751-7332; Fax: 770-751-7334; e-mail: meetings@imedex.com

Palliative Care Into the 21st Century. June 7-9, 2000, Dublin Castle, Ireland. Contact: Ms. Olwyn Ryan, 5 Northumberland Road, Dublin 4, Ireland. Phone: 353 (1) 668-1855; Fax: 353 (1) 668-7599; e-mail: oryan@irishcancer.ie

Worldwide Pain Conference. July 15-21, 2000, San Francisco Marriott Hotel, San Francisco, California. Contact: Meetings Plus, 242 Lafayette Circle, Lafayette, California, 94549. Phone: 925-284-4040; e-mail: painconference2000@meetingsplus.com

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- The quality of each life MATTERS, particularly at the end of life; and
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