

Quality of Life Matters[®]

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

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End-of-Life Discussions Offer Patients Benefits, Not Distress

No difference in psychological distress was found among patients with advanced cancer who reported having discussed end-of-life care with their physicians, when compared with patients who had not had such discussions, new research has found. On the contrary, such discussions were associated with positive effects on patient care.

That is according to early findings from Coping with Cancer, an ongoing, prospective, longitudinal, multi-institutional study of 603 advanced cancer patients. The study is funded by the National Cancer Institute and

the National Institute of Mental Health.

“End-of-life care discussions between physicians and patients with advanced cancer are not associated with psychological distress,” reported investigators presenting at the American Society of Clinical Oncology annual meeting in June.

“Furthermore, these discussions may result in increased patient understanding of illness severity, fewer invasive procedures, and lower rates of ICU admission at the end of life.”

Key findings include:

- Only 31.2% of patients reported discussing end-of-life care with their physicians.
- Patients who reported having end-of-life discussions were not more likely to meet criteria for depression or to report feeling “nervous or worried” than those who did not have such discussions.

Patients who reported having end-of-life discussions were:

- More likely to acknowledge being terminally ill (adjusted odds ratio [AOR] = 2.24)
- More likely to value comfort care over life extension (AOR = 3.23)
- More likely to complete a do-not-resuscitate order (AOR = 3.62)

Among the 323 patients who died,

those who reported discussions about end-of-life care were more than twice as likely to enter a hospice program (AOR = 2.3). Further, these patients were less likely than those who did not discuss end-of-life care to be admitted to an ICU or to undergo ventilation.

Significant cost savings

In related findings from the Coping with Cancer study, having end-of-life discussions with physicians was associated with a **30% reduction in health care costs in the last week of life** (cost difference = \$874).

“If extrapolated to the national level, based on the number of U.S. cancer deaths per year, these data suggest a difference in end-of-life care expenditures of \$304,539,932 between individuals who had end-of-life discussions and those who did not,” note the researchers.

[See Page 2 for related article.]

Source: “Medical Care and Emotional Distress Associated with Advanced Cancer Patients’ End-of-Life Discussions with Their Physicians,” *Journal of Clinical Oncology*; May 20, 2008 Supplement; 26(15); 2008 ASCO Annual Meeting; Abstract 6505. Wright AA, Ray A, Zhang B, et al; Dana-Farber Cancer Institute, Boston. “Associations between Advanced Cancer Patients’ End-of-Life Conversations and Cost Experiences in the Final Week of Life,” *ibid.*, Abstract 9530. Zhang B, Wright AA, Nilsson ME, et al; Dana-Farber Cancer Institute, Boston.

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Oncologists Urged to Help Patients ‘Think Clearly’ about Chemotherapy for Late-Stage Disease

Helping patients with advanced cancer make informed decisions regarding the appropriate use of chemotherapy near the end of life can be challenging. Yet, oncologists need not hesitate to discuss the value of palliative and hospice care out of fear that these patients will become upset or lose hope, say experts in an article published in the *Journal of the American Medical Association*.

“No data are available that show hope can be taken from patients, as was once thought, or that patients are harmed by carefully provided information,” write the authors. [See Page 1 for recent findings on this topic.]

Patients who do not understand their prognosis and the options available to them can be missing the chance to have the time needed to make plans for life review, relax with their families, and prepare for a peaceful death. The authors provide a summary of results from multinational studies examining how patients perceive their advanced cancer and its prognosis. **“It is critical to understand that people looking death in the eye have a different perspective,”** they note.

Studies have found that most patients want their physicians to be realistic, truthful, and compassionate, and to continue caring for them. **“[B]ecause patients are vulnerable to fastening on slim hopes, oncologists must improve their skills in helping patients think clearly about the appropriateness of chemotherapy,”** state the authors.

Before treatment:

- Don’t assume. Ask patients how much they would like to know about their diagnosis.
- Differentiate “response” from “cure.” Define each, using simple terms (e.g.,

OFFERING THE HOSPICE OPTION

- Incorporate the option of hospice care as part of usual medical care for cancer patients.
- Introduce hospice before all oncology options have been exhausted: “Don’t ask hospice to just manage the acute deaths at home,” write the authors.
- Discover your patients’ average length of hospice stay, as well as the number of your patients who died within seven days of enrollment, and strive to meet or exceed the national average length of stay (26 days in 2005, the most recent year for which figures are available).
- Assure patients you will not abandon them if they choose hospice. Making bimonthly appointments for your hospice patients, for example, can reassure them and remind you to call or visit those who can no longer keep the appointment.

— Harrington and Smith, *Journal of the American Medical Association*

“10 in 100,” rather than “10%”).

- Write down the benefits and risks of the chemotherapy.
- Determine patients’ goals of care. Two months can be highly important to some patients and irrelevant to others.
- Begin a discussion of what to do if the cancer resists treatment, including the option of hospice. *“We hope to control the disease, but at some point it may grow so that it will end your life. We need to prepare for that, too.”*

During treatment:

- Tell the patient, *“The cancer is shrinking, but is still there.”* Do not say, “The cancer is responding,” unless you give an estimate of the duration of response.
- Emphasize what is likely to happen, so that patients can make plans.
- Be hopeful. Most people can find something to hope for, even if the cancer is growing.
- Begin a discussion of do-not-resuscitate orders. *“The cancer is growing, and may end your life. There are some important*

issues to discuss. Tell me how much you want to know.”

- Reintroduce the hospice option.

The authors suggest the use of decision aids, such as a prompt list of questions patients may want to ask, an example of which is provided in the article. This list can be kept available in the waiting room. Suggested patient questions address topics such as treatment, prognosis, family issues, and spiritual and psychological issues.

“However, without a clear goals-of-care discussion, patients...and their families may be unprepared for what the final few months, weeks, or even days may bring,” comment the authors. **“Through honest and respectful communication about the last stages of cancer, physicians can give patients a genuine choice about how to spend their last phase of life.”**

Source: “The Role of Chemotherapy at the End of Life: When Is Enough, Enough?” Journal of the American Medical Association; June 11, 2008; 299(22):2667-2678. Harrington SE, Smith TJ; Department of Internal Medicine; Thomas Palliative Care Program of the Massey Cancer Center; and Division of Hematology/Oncology and Palliative Care, Virginia Commonwealth University, Richmond.

End-of-Life Care Choices Linked to Health Literacy, Not Race

Video depiction of patient with advanced disease found helpful in decision making

Health literacy skills and level of education — rather than race or cultural background — were each found to be independent predictors of preferences concerning type of care desired at the end of life, according to two studies reported in the *Journal of Palliative Medicine*.

“This suggests that race should not be the primary focus of research and patient care regarding end-of-life preferences,” writes the studies’ lead author Angelo E. Volandes, MD, of Massachusetts General Hospital, Boston. **“Rather, health literacy and a heightened commitment to patient education and communication should be the top priority.”**

Health literacy, not race

In the first study, researchers analyzed interview responses of African American (n = 80) and white (n = 64) patients over the age of 40 years who visited six primary care clinics in the Boston area between December 2005 and January 2007.

Subjects were given a health literacy assessment (rated as low, marginal, or adequate), then asked their end-of-life care preferences following a verbal description of advanced dementia. Preferences were dichotomized as “comfort care” and “aggressive care” (life-prolonging, limited, or do not know).

Initial findings include:

- African American patients were nearly five times more likely than white patients to prefer aggressive care (odds ratio [OR], 4.8; 95% confidence interval [CI], 2.1-10.9).
- 67% of subjects with low health literacy and 57% of those with marginal health literacy preferred aggressive care, while only 10% of those with adequate health literacy did so.

AT A GLANCE

Most African Americans, whites, and Latinos who initially stated they would prefer life-prolonging care if facing advanced dementia changed their preference to comfort care after viewing a two-minute video depicting a patient living with the disease.

In multivariate analysis, however:

- The effect of race on care preferences was no longer significant (OR, 1.1; 95% CI, 0.3-3.2).
- Health literacy remained a significant predictor. When compared to patients with adequate health literacy, those with low and marginal literacy were seven and five times more likely to select aggressive care, respectively.
- After controlling for both race and health literacy, the only patient characteristic to remain as a significant and independent predictor of preferences was educational level (OR, 4.5; 95% CI, 1.1-18.6).

Patients were then given the identical verbal description of advanced dementia — accompanied this time by a two-minute video depicting a patient with the condition — and asked once again for their preferences. “The vast majority of subjects across both races and all health literacy groups chose comfort care after viewing the video,” the authors report. No whites, 13% of African Americans, and 11% and 10% of those with low and marginal health literacy, respectively, chose aggressive care post-video.

“[O]ur data show that accepting a patient’s preferences based on a verbal conversation about a future disease state

may not reflect a patient’s fully informed preferences for end-of-life treatments: the diversity of preferences that have often been attributed to racial and cultural differences are a result of differences in health literacy, not race.”

Educational level, not cultural background

In the second study, the researchers examined the responses of 104 Latino patients regarding end-of-life care preferences both before and after being shown a two-minute video depicting a patient with advanced dementia.

Before viewing the video, 41% of patients chose life-prolonging care, 11% chose limited care, and 40% chose comfort care. Following the video, however, only 8% desired life-prolonging care, 13% desired limited care, and 75% chose comfort care. Statistically significant differences found to correlate to educational level pre-video had disappeared in the post-video analysis.

“While attention to patients’ culture is important, it is also important to avoid ascribing choices to culture that may actually reflect inadequate comprehension,” note the authors. **“Prematurely accepting aggressive preferences for end-of-life treatments may inadvertently condemn patients to an unwanted and misunderstood course of medical treatments at the end of life.”**

*Source: “Health Literacy Not Race Predicts End-of-Life Care Preferences,” Journal of Palliative Medicine; June 2008; 11(5):754-762. Volandes AE, Paasche-Orlow M, et al; Massachusetts General Hospital; Boston Medical Center; Harvard Medical School; and Brigham and Women’s Hospital, all of Boston; Department of Medicine, University of Chicago. “Overcoming Educational Barriers for Advance Care Planning in Latinos with Video Images,” *ibid.*, pp. 700-706. Volandes AE, Ariza M, et al.*

Medical Students' Ratings of End-of-Life Care Instruction Have Risen Nationally, Yet 'Much More Work Needs to Be Done'

Significant progress in the improvement of U.S. medical schools' attention to end-of-life care curriculum is indicated by the increasingly higher ratings of graduating medical students concerning the quality of their training in this area.

That is according to a report written by a team of New York researchers, which was published in the *Journal of Palliative Medicine*.

"The vast majority of U.S. medical schools are now reporting teaching of end-of-life care, especially now that the Liaison Committee on Medical Education requires it," write the authors. Earlier, localized studies at medical schools have shown encouraging improvements in student knowledge and attitude, they note. **"Curricula that include clinical experiences, such as time with hospice patients, seem particularly effective."**

The researchers analyzed data from the Association of American Medical Colleges' Graduation Questionnaire, a survey completed annually by approximately 11,000 medical students graduating from 125 accredited U.S. medical schools. Student

responses from the years 1998 to 2006 (2005, for pain management) to questions on the adequacy of their instruction time on palliative and end-of-life care were dichotomized as "adequate" (appropriate or excessive) or "inadequate."

During the 1998-to-2006 response period:

- The proportion of graduating medical students who rated their training in pain management as adequate rose from 34.3% to 55.3%.
- Those indicating their instruction time in palliative care was adequate rose from 59.9% to 74.8%.
- Students rating their curricular time in death and dying as adequate rose from 70.8% to 79.5%.

Female students and Asian students gave significantly lower ratings for the adequacy of their instruction in all three categories; older students gave lower ratings for palliative care and death and dying, but not for pain management. The reasons for perceived training inadequacies among these

groups may be cultural or due to more personal experiences with death and dying, and deserve further investigation, the authors suggest.

"The national results are certainly gratifying for those who have worked diligently to improve teaching about care at the end of life in U.S. medical schools," comment the authors, led by Daniel P. Sulmasy, MD, of St. Vincent's Hospital, New York City.

"Nonetheless, it is sobering to note that even after a decade of effort, 21% of students report their schools' curricular attention to death and dying inadequate, 45% report their curricular attention to pain management inadequate, and 25% report their curricular attention to palliative care inadequate. Clearly, much more work needs to be done in these areas."

Source: "U.S. Medical Students' Perceptions of the Adequacy of Their Schools' Curricular Attention to Care at the End of Life: 1998-2006," Journal of Palliative Medicine; June 2008; 11(5):707-716. Sulmasy DP, Cimino JE, Frishman WH; John J. Conley Department of Ethics, St. Vincent's Hospital, New York City; Palliative Care Institute, Calvary Hospital, Bronx; Department of Medicine, New York Medical College, Valhalla, New York.

AMA Approves Palliative Sedation for Intractable Symptoms at the End of Life

Sedation to unconsciousness for some patients at the end stage of a terminal illness is both medically and ethically acceptable, according to a new policy adopted by the American Medical Association (AMA) at its annual meeting in June 2008.

Although such practice is rare, "physi-

cians are obligated to offer palliative sedation as a last resort when symptoms cannot be diminished by all other means of palliation," reports an article in the *American Medical News*, an AMA publication. The new policy recommendations were presented by the AMA Council on Ethical and Judicial Affairs.

Palliative sedation is appropriate when severe or distressing symptoms such as pain, delirium, dyspnea, and nausea and vomiting have not responded to other aggressive interventions, including symptom-specific treatments.

"These are unusual circumstances

Continued on Page 6

RESEARCH MONITOR

Physicians Offered Two Brief Spiritual Assessment Tools

Patient attitudes toward spirituality may 'make or break' a medical regimen, says expert

Regardless of physicians' own privately held beliefs — but especially, regardless of whether they consider it to be part of their professional role to address the topic at all — physicians should be willing to evaluate the spiritual needs of their seriously ill patients, according to a pediatrician/pastoral theologian writing in the *Journal of the American Medical Association*.

“Spirituality is an important part of medical care, especially when patients are very ill or dying, because spirituality is part of what it means to be human,” writes Patricia Fosarelli, MD, DMin, acting dean at the Ecumenical Institute of Theology, Baltimore, and assistant professor of pediatrics at The Johns Hopkins University School of Medicine, Baltimore.

“[A]lthough physicians do not necessarily need to deliver spiritual care, asking questions to discern the spiritual needs of their patients might be both in their own

and in the patients' best interest,” notes Fosarelli.

Fosarelli acknowledges the wide range of opinions held by physicians on the place of spirituality in medicine, but suggests that the “healing art” of medicine includes treating the whole person. At the very least, physicians should be willing to listen carefully for signs of spiritual distress and refer a patient to pastoral care. “To franchise this responsibility to a nurse or social worker is to practice something short of the art of medicine, no matter how expert the practice of the science.”

Fosarelli offers two examples of brief tools that can be used for guiding a spiritual assessment in the clinical setting. [See sidebar, below.] Both address the possible effect of patient belief on medical decision making, and the resulting spiritual history can then be easily incorporated into the regular patient history. These tools were developed by Christina Puchalski, MD, and Harold G. Koenig, MD, respectively.

[For more information on Koenig's handbook, see article, Page 6.]

“If asked in a compassionate, nonproselytizing, nonjudgmental way, the questions on these instruments are designed to reveal information about a patient's available resources (spiritual and otherwise) during illness,” writes Fosarelli. **“As such, they can reveal attitudes that might 'make or break' a medical regimen.”**

In closing, Fosarelli strongly urges that caution be used when examining the plethora of poorly conceived studies of spirituality and patient health in the literature. “Because spirituality is nonlogical and the science of medicine is highly logical, scientific ways of measuring ‘spirituality’ (if it can be measured at all) can yield results that are confusing at best or erroneous at worst,” she warns.

Source: “*Medicine, Spirituality, and Patient Care*,” *Journal of the American Medical Association*; August 20, 2008; 300(7):836-838. Fosarelli P; Ecumenical Institute of Theology, Baltimore.

Spiritual Assessment Tools for Physicians

CSI-MEMO

- Do your religious/spiritual beliefs provide **C**omfort, or are they a source of **S**tress?
- Do you have spiritual beliefs that might **I**nfluence your medical decisions?
- Are you a **M**EMber of a religious or spiritual community, and is it supportive to you?
- Do you have any **O**ther spiritual needs that you would like someone to address?

— Fosarelli, *Journal of the American Medical Association*

Koenig H, *Journal of the American Medical Association*, July 24/31, 2002; 288(4):487-493. Koenig H, *Spirituality in Patient Care*, Second Edition; Templeton Foundation Press, 2007.

FICA

- **F**aith and **B**elief: What is your faith or belief? “Do you consider yourself to be a religious or spiritual person? What do you believe in that gives meaning to your life?”
- **I**mportance and **I**nfluence: Is your belief important in your life? “What influence does it have on how you take care of yourself? How have your beliefs influenced your behavior during this illness? What

role do your beliefs play in regaining your health?”

- **C**ommunity: Are you part of a spiritual or religious community? “Is this of support to you and how? Is there a person or group of people you really love or who are really important to you?”
- **A**ddress or **A**pplication: How would you like me to address these issues in your health care?

— Fosarelli, *Journal of the American Medical Association*

Puchalski C, Romer AL, *Journal of Palliative Medicine*, March 2000; 3(1):129-137.

RESEARCH MONITOR

AMA Approves Palliative Sedation for Intractable Symptoms at the End of Life

From Page 4

that require us to urgently relieve these symptoms by sedating patients to unconsciousness,” said council member and oncologist H. Rex Greene, MD, of Lima, OH, in the article. “This is not intended to end life.”

When implementing palliative sedation, physicians should:

- Consult with a multidisciplinary team, including a palliative care expert, to ensure the appropriateness of the treatment.

- Discuss the care plan with the patient and/or surrogate regarding the expectations of future withholding or withdrawal of life-sustaining treatments and whether the sedation will be intermittent or constant.
- Procure the informed consent of the patient and/or surrogate.
- Document the rationale for the sedation in the medical record.
- Closely monitor the patient to ensure appropriate care.

Although palliative sedation may be

appropriate for severe psychological distress not attributable to treatable mental health conditions, it is not appropriate for addressing emotional symptoms, such as the “existential suffering” some patients experience at the end of life. Providing needed social or spiritual support is recommended for these patients.

The council reported finding no evidence that palliative sedation hastens death. However, the report states unequivocally that the technique must never be used to intentionally end a patient’s life.

HANDBOOK FOR CLINICIANS

Spirituality in Patient Care: Why, How, When, and What, Second Edition

By Harold G. Koenig, MD, MHSc, this clinician handbook offers an explanatory framework and specific guidance on identifying and addressing the spiritual needs of patients faced with serious illness or loss. [See related article, Page 5.]

The performance and documentation of a spiritual assessment is required by the Joint Commission for the Accreditation of Healthcare Organizations for each patient admitted to a hospital, long-term care facility, or home-care program.

In light of recent findings and literature on the relationship between spirituality and health, this expanded and updated version of the 2002 edition includes practical suggestions for physicians wishing to integrate the spiritual assessment into their clinical practice.

Contents include:

- Three screening instruments of several questions each, as well as an example of a single-question spiritual assessment
- A discussion of the impact of physician involvement in

this area on patient health, compliance, and coping ability, as well as how taking a spiritual history may affect the patient-physician relationship

- Detailing of sacred traditions relating to health for each of four major religious groups
- When and how to refer a patient to a chaplain or clergy member
- Overviews of the roles of mental health professionals, nurses, social workers, and others in integrating spirituality into patient health
- A ten-session model course curriculum on spirituality and health care for medical students and residents, with suggestions for adapting it for other health care professionals

Koenig is associate professor of psychiatry and medicine and director of the Center for the Study of Religion/Spirituality and Health at Duke University Medical Center, Durham, NC.

Published by Templeton Foundation Press, 2007; ISBN: 139781599471167 (paperback); 272 pp.

CLINICIAN RESOURCES

Virtual Mentor: **Online Ethics Journal from the AMA**

virtualmentor.ama-assn.org

An open-access journal exploring ethical issues likely to be encountered by practicing physicians, residents, and medical students is maintained online by the American Medical Association (AMA). Founded in 1999, *Virtual Mentor* is published each month on a specific theme.

Each issue presents original articles in the form of clinical case studies with commentary and a clearly identified learning objective, discussions of recent theme-related literature, and suggestions for improvement in medical training. There is also a section on health law, policy, and medicine in society.

Two of the most recent issues and their article titles include:

June 2008 Issue: Quality of Life and Geriatric Patients

Articles include:

- “Physician Responsibility for Patients’ Quality of Life”

The learning objective for this article states, “Understand the argument that physicians have an obligation to consider patients’ quality of life when making treatment decisions and should consider offering patients the options of withholding or withdrawing aggressive treatment if that treatment will not restore the kind of life the patient finds meaningful.”

- “Family-Centered Decision Making”
- “When Home Care Is Not Enough”
- “Differentiating among Depression, Delirium, and Dementia in Elderly Patients”

August 2008 Issue: Establishing the Boundaries of Informed Consent

Articles include:

- “Framing Permission for Halting or Continuing Life-Extending Therapies”
The stated learning objective for this article reads, “Understand the special importance (given our society’s preference for continuing life-extending therapy) of choosing how to frame the conversation with parents about halting or continuing such therapy for their children who will not recover.”
- “How Reliable Is the Competency Assessment Process?”
- “The Legal Boundaries of Informed Consent”

Other themes from past issues include: Humanist Approaches to Care at the End of Life (September 2006); Difficult Conversations in Medicine (August 2005); and The Role of Faith in the Patient-Physician Relationship (May 2005).

All current and past issues of the journal are available for printing or downloading at <http://virtualmentor.ama-assn.org>.

End-of-Life Care Websites

www.aahpm.org

American Academy of Hospice and Palliative Medicine

www.eperc.mcw.edu

End of Life/Palliative Education Resource Center (EPERC)

www.epec.net

The EPEC Project (Education in Palliative and End-of-Life Care)

www.nhpco.org

National Hospice & Palliative Care Organization

www.caringinfo.org

National Consumer Engagement Initiative to Improve End-of-Life Care

www.promotingexcellence.org

Promoting Excellence in End-of-Life Care

www.hospicefoundation.org

Hospice Foundation of America

www.americanhospice.org

American Hospice Foundation

www.hpna.org

Hospice and Palliative Nurses Association

www.medicaring.org

Palliative Care Policy Center

www.abcd-caring.org

Americans for Better Care of the Dying

www.mcw.edu/palliativecare.htm

Medical College of Wisconsin Palliative Care Center

www.painpolicy.wisc.edu/

University of Wisconsin Pain and Policy Studies Group

www.capcmssm.org

Center to Advance Palliative Care

www.stoppain.org

Pain Medicine & Palliative Care, Beth Israel Medical Center

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To view HPNA's Position Statements on **Palliative Sedation** (revised in April 2008) and **Spiritual Care**, visit www.hpna.org. Select Educational Services on the left and then select Position Statements.

Also available for free on the HPNA website are **HPNA Patient/Family Teaching Sheets on Managing Spiritual Distress and Managing Psychological Distress** posted under the 'Education' menu.

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