

Quality of Life Matters®

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

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As Hospice Use Continues to Grow, Late Referral Resulting in 'Short Hospice Experience' Raises Concerns

Nearly 40% of all 2008 deaths in the United States occurred under the care of a hospice program, with a record 1.45 million patients receiving hospice services during that year, according to an annual report released by the National Hospice and Palliative Care Organization (NHPCO) in November.

Yet, more than 35% of those patients served by hospice died within just seven days of enrollment, a 4.6% increase in what NHPCO considers a "short hospice experience" over the year before.

"More awareness of the care options

available when facing a serious or life-limiting illness — among both the public and health care professionals — is still needed," stated J. Donald Schumacher, PsyD, NHPCO president and CEO.

When hospice referral occurs "way too late," both patients and their families can be prevented from receiving the maximum benefit of the full range of interdisciplinary medical care and support services characteristic of hospice. [See sidebar, page 3.]

Entitled "NHPCO Facts and Figures: Hospice Care in America," the state-of-the-industry report gathers yearly information from its membership, which represents approximately 80% of the 4850 hospice programs nationwide.

NON-CANCER DIAGNOSES INCREASINGLY OUTNUMBER MALIGNANCIES

Non-cancer diagnoses increasingly outnumber cancer as the admitting diagnosis, a trend that has continued since 2003. In 2008, 61.7% of patients were enrolled in hospice with a diagnosis other than cancer. Non-cancer primary diagnoses include:

- Heart disease (11.7%)
- Dementia (11.1%)
- Lung disease (7.9%)
- Stroke or coma (4.0%)
- Kidney disease (2.8%)
- Debility unspecified (15.3%)

FAMILY EVALUATIONS REMAIN POSITIVE

Family evaluations of hospice care and services, based on data compiled through several NHPCO performance measures, remained consistently high in 2008.

- 96.5% of families reported the patient's plan of care was clearly explained by the hospice team.
- 75.4% rated patient care as "excellent."
- 76.7% of families felt that hospice met their bereavement needs "very well."

Hospice care has been linked to longer survival in some terminally ill patients. The report cites the findings of a large cohort study by Conor, et al, published

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KEY FINDINGS INCLUDE:

- 35.4% of patients died or were discharged within 7 days, an increase from 30.8% in 2007.
- The average length of service increased to 69.5 days, up from 67.4 days in 2007.
- Median (50th percentile) length of stay was 21.3 days, up from 20.0 days.
- 68.8% of hospice patients died at home or in a residential facility; 21.0% died in a hospice inpatient facility.
- Service provided to those of Latino origin (5.6%) or of mixed race (9.5%) increased in 2008, while service to African-Americans dropped to 7.2% from 9.0% in 2007.

Consensus Guidelines Developed for Incorporating Spirituality into End-of-Life Care

A life-threatening illness affects a patient biologically, psychologically, socially, and spiritually. Among these effects, spiritual concerns have traditionally been the least well addressed, even though studies and surveys have shown that spirituality significantly influences quality of life for seriously ill patients.

That is according to the authors of an article published in the *Journal of Palliative Medicine*, which offers consensus guidelines to ensure that consistent, effective spiritual care is available to all palliative care patients and families.

The article, "Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference," outlines guidelines formulated by a group of 40 national experts who attended a consensus conference sponsored by the Archstone Foundation of Long Beach, California.

"For the first time we have a practical model for the implementation of interprofessional spiritual care, which will result in improved health care outcomes for patients," says lead author Christina Puchalski, MD, of The George Washington Institute for Spirituality and Health and The George Washington University School of Medicine.

SEVEN KEY AREAS FOR IMPROVEMENT

The consensus guidelines address the following main ways of improving spiritual care:

- **Spiritual Care Models:** Ways of connecting with patients, to understand their concerns and to work as partners to treat the whole patient.
- **Spiritual Assessment:** Standard ways to assess spiritual needs.
- **Spiritual Treatment/Care Plans:** Ways to address concerns from the assessment, as part of the overall treatment plan.
- **Roles of Members of the Interprofessional Team:** Ways in which individual members of the interdisciplinary team can work collaboratively to meet patients' spiritual needs.
- **Training and Certification:** Formal training in spiritual care as well as in other aspects of palliative care.
- **Personal and Professional Development:** The understanding of the inherently spiritual nature of health care, as well as the personal impact of relationships with patients.
- **Quality Improvement:** The continual refinement of the quality of care, based on continuing assessment of the current quality of care, planning of ways to improve care, and implementation of the improvements.

Key Consensus Guidelines

- Spiritual care should be an integral part of patient-centered health care and should honor the dignity of the patient.
- Health care providers should treat spiritual distress or religious struggle with the same urgency as treatment for any other medical or social problem.
- Spiritual issues should be a part of routine care. Institutional policies for spiritual history and screening must be integrated into intake policies and ongoing assessment of care.
- Spiritual care models should be interdisciplinary, and a clinical pastoral, education-trained, board-certified chaplain should be part of the interprofessional team.
- All patients should receive a simple and time-efficient spiritual screening when entering the health care system. Health care providers should make appropriate referrals when needed.
- Each patient's spiritual symptoms, values, and beliefs should be assessed and become part of the plan of care.
- Patients should be encouraged and supported in the expression of their spiritual needs and beliefs. Written material regarding spiritual care, including a description of a chaplain's role, should be made available to patients and families.
- Family and patient requests specifically related to desired rituals at any point in their care, and particularly at the time of death, should be honored.
- Clinical sites should develop policies to facilitate networking, communication, and coordination among spiritual care providers.
- All members of the palliative care team should be trained in spiritual care. This training should be required as part of continuing education for all clinicians.

— Puchalski, et al, *Journal of Palliative Medicine*

According to a growing body of recent literature, the authors note, seriously ill patients consistently report a strong desire "...to have spirituality included in their care." When health care providers recognize and address the importance of spiritual care, they can improve quality of life for patients and their families.

Source: "Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference," *Journal of Palliative Medicine*; October 2009; 12(10):885-904. Puchalski C, Ferrell B, Virani R, et al; The George Washington Institute for Spirituality and Health, The George Washington University School of Medicine, Washington, DC; City of Hope National Medical Center, Duarte, California.

National Survey Finds 'Dire Need' for Palliative Care Training of Neurology Resident Physicians

Current literature shows that only 52% of neurology residency programs offer a didactic experience in palliative and/or end-of-life care and fewer than 8% of programs provide residents with clinical rotations.

That is according to the authors of a study designed to assess the basic palliative care knowledge of neurology residents. Their preliminary findings are published in the *Archives of Neurology*.

The authors write, "Palliative care and symptom management play a central role in the care of patients with neurologic disease...It is, therefore, surprising that such a pervasive theme is inadequately addressed during neurology residency training."

One-third of neurology residency programs (n=34) agreed to participate in the

survey, with one-fifth of residents nationwide (n=338) completing questionnaires.

Residents were asked questions about several main components of palliative care. Key findings include:

- **Commonly used medications:** 14.6% of residents were able to correctly answer a question about the half-life of the commonly used intravenous medication lorazepam in patients who are not in organ failure.
- **Hospice and Medicare:** 24.1% of respondents correctly answered a question regarding Medicare reimbursement for patients enrolled in hospice.
- **Medical decision-making capacity:** 55% of residents correctly identified requirements for determining whether

a patient is capable of making his or her own medical decisions.

- **Advance directives:** 77.7% of respondents correctly answered a question regarding validity and changes to advance directives.

"The results of this preliminary study support earlier studies and confirm the dire need to enhance palliative care education of neurology resident physicians, who play a vital role in the care of patients faced with a life-threatening, life-limiting, and/or life-changing disease," the authors conclude.

Source: "Are Neurology Residents Prepared to Deal with Dying Patients?" Archives of Neurology; November 2009; 166(11):1427-1428. Creutzfeldt CJ, et al; Department of Neurology, University of Washington, Seattle.

As Hospice Use Continues to Grow, Late Referral Resulting in 'Short Hospice Experience' Raises Concerns

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in the *Journal of Pain and Symptom Management* in 2007.

Researchers found that overall mean survival was 29 days longer for hospice patients than for those not in hospice, with the largest differences in survival found among patients with congestive heart failure and some cancers. No significant association of hospice care with shorter survival times was found.

The study authors suggested that the increased longevity found among hospice patients might be due to: hospice programs' improved monitoring and coordinated interdisciplinary care; avoidance of overtreatment of already weakened patients; and a greater sense of well being encouraged by hospice psychosocial support.

The NHPKO stresses its concern over the increase in short lengths of service, and strongly recommends that physicians, patients, and families learn about and discuss end-of-life care options *before* a health crisis occurs.

For more information, visit www.nhpko.org.

Standard Hospice Interdisciplinary Services Include:

- Managing patient pain and controlling symptoms
- Assisting the patient with emotional, psychosocial, and spiritual aspects of dying
- Instructing the family on patient care
- Providing needed medications and medical equipment and supplies
- Delivering special services when needed, such as physical and speech therapy
- Offering short-term inpatient care for family respite time, or when pain or other symptoms become too difficult to treat at home
- Providing family and friends with bereavement care and counseling

Palliative Sedation: National and International Experts Address ‘Last Resort’ Issues

*U.S. medical ethicists define three distinct forms of sedation;
European group offers framework for procedural guidelines*

Palliative sedation, the use of medications to reduce consciousness in a small percentage of patients with severe, intractable suffering at the very end of life, can vary considerably in availability and practice.

This is partly because of unclear or non-existent formal institutional policies regarding sedation, and partly because of confusion about different kinds of sedation, according to a team of ethicists writing in the *Annals of Internal Medicine*.

“We provide a comprehensive approach to palliative sedation in patients who experience severe suffering at the end of life to prevent the potential for abandonment in a symptom crisis,” write the authors, led by Timothy E. Quill, MD, of the Center for Ethics, Humanities, and Palliative Care at the University of Rochester Medical Center, New York.

Their article describes the real case of a patient dying of lung cancer who had been promised the last-resort choice of “total sedation” if the severe suffering he feared became unacceptable. This option was denied him by his new care team, whose organization had no policy regarding any type of sedation. Although arrangements for sedating medication were made with the original palliative care consultant after the patient was transferred back home, the new care team felt demoralized and guilty, and the patient and family felt they had been abandoned.

TYPES OF SEDATION

The team identifies the following three types of sedation:

- **Ordinary sedation:** The use of sedative medications with the goal of relieving symptoms without reducing the

“We believe that patients and their families deserve to know the full range of palliative options available to them, especially those who have particular fears and expectations about future treatment options.”

— Quill, et al, *Annals of Internal Medicine*

patient’s level of consciousness. Such sedation is used in everyday medical practice for the treatment of anxiety, agitated depression, insomnia, or related disorders.

- **Proportionate palliative sedation (PPS):** Use of progressively increased sedating medications for otherwise intractable physical suffering in imminently dying patients. The goal is relief of suffering that is acceptable to the patient through the use of the minimum amount of sedation needed. Although PPS occasionally requires sedation to unconsciousness, alertness is maintained as much as possible.
- **Palliative sedation to unconsciousness (PSU):** Administration of sedatives with the intended goal of unconsciousness. This is initiated when a patient at the very end of life finds severe physical symptoms intolerable and continued consciousness unacceptable, despite receiving state-of-the-art palliative care.

While PPS is widely accepted, there is considerable controversy regarding the use of PSU, particularly for the treatment of existential suffering, note the authors, who examine key ethical and legal issues regarding both practices.

Further, there is frequent confusion between PPS and PSU. The authors strongly

recommend that all palliative care and hospice programs develop explicit policies and guidelines on the use of both practices. If an organization permits refusal of both, it must have a plan for so informing patients upon enrollment. If only PSU can be refused to the patient, plans should include guidelines on how physicians might respond if PSU is requested.

BENEFITS OF POLICIES

Benefits of establishing institutional policies about palliative sedation include:

- Increased transparency and patient/family awareness of these “last-resort options”
- Reduction in variation due to underutilization and overutilization
- Improvement in the quality of symptom management, through mandatory education and mandatory consultation concerning refractory cases

“The obligation of clinicians who care for seriously ill patients at the end of life to address intractable suffering requires that they become informed about available options and that they be as responsive as possible without violating fundamental ethical principles.”

INTERNATIONAL FRAMEWORK

The European Association for Palliative Care (EAPC) has issued a recommended framework for the development of institutional guidelines on the use of palliative sedation for intractable suffering at the end of life. The position paper was published in *Palliative Medicine*, official journal of the United Kingdom Association for Palliative Medicine and the research journal of the EAPC.

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Routine Bereavement Practices of Physicians Vary Widely, Researchers Report

Recent literature shows that few oncologists provide bereavement follow-up routinely, even though studies have found that a majority of caregivers of patients with cancer desire and benefit from such support.

That is according to a team of Toronto researchers who conducted a survey of physicians' bereavement practices to learn whether or not they contact the family following a patient's death. Their findings are published in the *Archives of Internal Medicine*.

Investigators sent surveys to all Canadian medical oncologists, radiation oncologists, and palliative care physicians (n=756) who were active members of their respective societies. Seventy-one percent (n= 535) of physicians completed the survey.

KEY FINDINGS

- 33.3% of physicians said they usually or always make a telephone call, send a condolence card, or attend a funeral.

- 30.5% said they perform at least one of these practices sometimes.
- 36.2% reported performing at least one of these practices rarely or never.

HELPFUL RESOURCES

Among perceived barriers to bereavement support, lack of time and lack of resources were cited most often. Respondents said the following resources would help them provide bereavement follow-up more routinely:

- A list of bereavement support services (83.6%)
- Identification of an appropriate family member to contact (57.5%)
- Condolence letter instructions (27.4%)
- A standardized letter (27.7%)

The investigators note, "The great variation in the frequency and type of bereavement follow-up in our study suggests that there is no consensus on what bereavement practice should be...despite recent literature that encourages all physicians to pro-

vide bereavement follow-up."

In response to the study, a letter by Daniel J. Morris, MD, appeared in a subsequent issue of the *Archives of Internal Medicine*. Morris says he conducted his own informal study of bereavement practices of oncologists in Florida with similar findings.

Morris finds that sending a personalized condolence card in which staff members participate "is a good experience for us from a caring and team-building perspective." Morris also takes time to attend funerals. "Speaking to the families in this setting has improved my interpersonal skills and helps me avoid professional burn-out," he concludes.

Source: "Bereavement Practices of Physicians in Oncology and Palliative Care," *Archives of Internal Medicine*; 169(10):963-971. Chau NG, Zimmerman C, et al; Departments of Medical Oncology & Hematology and Public Health Sciences, University of Toronto, Canada. "Medical Oncologists' Experience in Attending a Funeral and Communicating Condolences," *ibid*; 169(19):1811-1812. Morris DJ; *Medical Oncology, Naples Medical Center, Naples, Florida*.

'Last Resort' Issues of Palliative Sedation (from page 4)

"Palliative care provides effective symptom relief and psychosocial care for the vast majority of patients," states EAPC president Lukas Radbruch, MD. "However, once in a while, adequate relief will not be possible. For those patients still suffering severely, palliative sedation provides a last resort when other options have failed."

The consensus-based framework is intended to spur the development of procedural guidelines that can be customized to the cultural and legal climate in various settings and at different levels.

Topics among its ten points range from identifying and describing the indications for sedation to providing supportive care to members of the medical team. Guidance is given on how to organize, initiate, titrate, monitor, and evaluate the sedation procedure.

Appendices include: pharmaceuticals used for sedation with their recommended doses; tools for assessing and monitoring distress in sedated patients; and a list of special considerations for the controversial use of sedation for psychosocial or existential distress.

Source: "Last-Resort Options for Palliative Sedation," *Annals of Internal Medicine*; Sept. 15, 2009; 151(6):421-424. Quill TE, Lo B, Brock DW, Meisel A; Center for Ethics, Humanities and Palliative Care, University of Rochester Medical Center, Rochester, New York; Program in Medical Ethics, University of California, San Francisco; Harvard Medical School, Boston; Center for Bioethics and Health Law, University of Pittsburgh, Pittsburgh. "European Association for Palliative Care (EAPC) Recommended Framework for the Use of Sedation in Palliative Care," *Palliative Medicine*; October 2009; 23(7):581-593. Cherny NI, Radbruch L; Board of the European Association for Palliative Care; Cancer Pain and Palliative Medicine Unit, Department of Oncology, Shaare Zedek Medical Center, Jerusalem, Israel; *Palliative Medicine, Aachen University, Aachen, Germany*.

CLINICIAN RESOURCES

Dialysis Patients: Nephrologists Encouraged to Use Palliative Approach and Refer to Hospice

The American Society of Nephrology has released a free podcast about palliative care. The program offers information about treating pain in dialysis patients and about when and how to address end-of-life issues with patients and families. The program includes information about useful palliative care resources for physicians.

“Good palliative medicine and geriatric principles provide a systematic way to deliver excellent renal care and simultaneously address quality of life and humanistic concerns no matter what treatment plan the patient is undergoing,” says Mark A. Swidler, MD, assistant professor of medicine at Mount Sinai School of Medicine.

Alvin H. Moss, MD, of West Virginia University School of Medicine, who also participated in the podcast, notes, **“We want nephrologists to better understand that a palliative care approach to dialysis patients can relieve patient pain and suffering and assist in identifying and respecting their goals for care. We also want to let our colleagues know about new research that is available to nephrologists to more accurately predict dialysis patients’ prognosis and to allow timely referral to hospice.”**

Both Moss and Swidler state that palliative care should be integrated into patient care whenever patients need relief from pain and other symptoms of chronic kidney disease (CKD), regardless of whether the patient is on dialysis. They cite the need for nephrologists in general to better integrate palliative care into practice, as well as to receive better training for palliative care.

Nephrologists, like palliative care specialists, they note, have always provided a multidisciplinary approach to medical care. Adding palliative care elements such as advance care planning, health care prox-

Pain Management for Dialysis Patients

The Mid-Atlantic Renal Coalition and the Kidney End-of-Life Coalition have developed a free online booklet, “Clinical Algorithm & Preferred Medications to Treat Pain in Dialysis Patients.” The publication offers tips for assessing pain to determine its intensity and character, methods for treating all types of pain, insights into complications such as constipation, and recommended preferred medications for patients with chronic kidney disease.

Download the booklet at <http://kidneyeol.org/painbrochure9.09.pdf>.

ies, and symptom assessment to this approach is relatively simple and can provide a great benefit to patients.

INTEGRATING PALLIATIVE CARE

To improve the integration of palliative care into nephrology practice, Moss and Swidler suggest:

- **Forming relationships with local hospices.** Hospice personnel can help with advance care planning and completion of advance directives. Also, if a patient is dying of a disease that is not kidney related, he or she can continue to receive dialysis while also benefiting from hospice’s multidisciplinary services for pain and other symptom management related to the terminal illness.
- **Formal palliative care training.** Moss notes that although every patient eventually dies, medical schools and residency/fellowship training programs spend less time on end-of-life care than on some rare kidney disorders that physicians may never see in their practices. The physicians suggest a method for assessing how well a patient may respond to dialysis and whether palliative care is appropriate:
 - Ask the physician or nurse practitioner who is treating the patient, **“Would you be surprised if this patient died within**

the next year?” If the answer is no, the patient is 3.5 times more likely to die within the next year.

- Assess the following factors that help in predicting prognosis: older age, decreased functional state, decreased nutritional state, and comorbidity. If the combination of these factors is significant, the patient is less likely to do well in dialysis.

Moss says research shows that 95% of dialysis patients want to discuss end-of-life issues with their physicians, but are waiting for the nephrologist to raise the subject. As well, when nephrologists address advance care planning, they routinely discuss removal of feeding tubes and decisions regarding CPR, but they frequently neglect to discuss discontinuing dialysis.

Moss concludes, “I’m hoping that as we train the new physicians of the future, that they’ll be better at palliative care — all of them: nephrologists, geriatricians, general internists — everybody will be better at pain and symptom management and at identifying and respecting patients’ wishes. ...Quality is the right thing for the right patient at the right time.”

View the podcast by visiting <http://asn-online.org/publications/kidneynews/podcast.aspx> and searching for the podcast titled “Palliative Care.”

CLINICIAN RESOURCES

BOOK FOR CLINICIANS

Mastering Communication with Seriously Ill Patients: Balancing Honesty with Empathy and Hope

This new book by Anthony Back, MD, Robert Arnold, MD, and James Tulsy, MD, provides step-by-step “roadmaps” to help physicians communicate with patients who are seriously ill.

According to a review published in the *Journal of Palliative Medicine*, the authors promote a mutual exchange between patient and physician, rather than focusing on ways that physicians can simply deliver information to patients.

As the authors state, “Communication is not about delivering an information pill and seeing how much the patient can swallow; it is about sending messages to the patient and receiving messages in return.”

The book helps physicians learn skills to communicate effectively in a variety of situations, such as:

- Building patient-physician rapport
- Communicating with patients about goals for advanced care planning
- Talking about prognosis and communicating serious news
- Communicating about transitions to end-of-life care
- Discussing spiritual issues
- Holding family conferences
- Managing end-of-life conflicts

The authors list basic principles recommended for many interactions between physicians and patients, including:

- Start with the patient’s agenda.
- Track the emotional and cognitive data you get from the patient.
- Move the conversation forward one step at a time.
- Articulate empathy explicitly.
- Discuss what you can do before discussing what you cannot do.

- Discuss big picture goals before discussing specific medical interventions.
- Spend at least a moment giving the patient your complete attention.

Each chapter addresses a specific type of communication and describes suggested techniques. For example, in the chapter on transitions to end-of-life care, the authors first define a transition, and then outline an eight-step roadmap for a transitions conversation. Readers are offered information about how to prepare for each step, pitfalls to avoid, and language to use.

At the end of each chapter, the authors include a script of a sample conversation that illustrates the use of the roadmap for that chapter.

Readers are encouraged to use a variety of strategies for learning to communicate more effectively, including “deliberate practice” of specific types of conversations. The authors use examples from their own experiences and from current research, giving clinicians detailed instructions on how to practice communication skills described in each chapter as they interact with patients and families.

The book emphasizes the importance of developing emotional intelligence. The authors explain that they have worked to cultivate communication skills in their own practices, noting, “We’ve spent a lot of time figuring out how we’re feeling after a tough conversation, how our own emotions influence what we say (and don’t say), and how we can use our own emotions in a positive, healing way.”

The book is published by Cambridge University Press, 2009; 158 pp.

End-of-Life Care Websites

www.aahpm.org

American Academy of Hospice and Palliative Medicine

www.eperc.mcw.edu

End of Life/Palliative Education Resource Center (EPERC)

www.epec.net

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

www.nhpc.org

National Hospice & Palliative Care Organization

www.caringinfo.org

Caring Connections: 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.capc.org

Center to Advance Palliative Care

www.stoppain.org

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