In a first-of-its-kind comparison of the end-of-life practices of seven developed nations, the U.S. had the lowest percentage of hospital deaths among patients with cancer and the fewest per capita hospital days during the last six months of life, an international team of researchers has found. However, the U.S. also had the highest number of chemotherapy episodes and the highest rate of intensive care unit (ICU) admissions near the end of life — more than double that of all other nations studied.

“Death in U.S. acute care hospitals has declined considerably, and in 2010, death in the hospital was half of most other countries studied,” write the authors of a report published in the Journal of the American Medical Association. “Yet excessive utilization of high-intensity care near the end of life, particularly in the U.S. relative to other developed countries, underscores the need for continued progress to improve end-of-life care practices.”

Investigators conducted a retrospective cohort study of patients aged > 65 years (mean age, 78.5 to 79.5 years) who died in 2010 with a diagnosis of cancer in one of seven countries: Belgium, Canada, England, Germany, the Netherlands, Norway, and the U.S. The registry and administrative claims data sets were examined from the seven nations, which were selected for their high-quality data sources and diverse modes of health care financing and delivery.

The study, designated by the authors as the “first international comparative study... of site of death, health care utilization, and hospital expenditures at the end of life,” focused on patients with a diagnosis of cancer because it is the second leading cause of death (accounting for more than 20% of deaths in developed nations), is easily identifiable in administrative data, and is among the most resource-intensive of illnesses, the authors explain.

**KEY FINDINGS:**

**HOSPITAL DEATHS**

- The U.S. had the lowest proportion of cancer patients who died in acute care hospitals (22.2%), followed by the Netherlands (29.4%).
- When deaths in skilled nursing facilities were factored in, the U.S. proportion of inpatient deaths was 29.5%.
- Canada (52.1%) and Belgium (51.2%) had the highest proportion of hospital deaths among cancer patients, while percentages among the remaining three nations ranged from 44% to 38%.

**KEY FINDINGS:**

**TREATMENT AND CARE**

- 40.3% of U.S. decedents had at least one ICU admission in the last 180 days of life, compared with < 18% in all other countries.
- In the last 30 days of life, 27.2% of U.S. decedents were admitted to an ICU, compared with ≤ 11% in other reporting countries.
- 38.7% of U.S. patients had at least one chemotherapy episode in the last six months — more than any of the other nations, whose rates ranged from 29.1% to 18.1%.

**KEY FINDINGS:**

**HOSPITAL EXPENSES**

- Spending for hospital care in the last 180 days of life (with all currencies converted to 2010 U.S. dollars) was highest in Canada ($21,840), followed...
Between families of patients who received palliative sedation at the end of life and families of patients who did not receive sedation, no significant difference was observed in their satisfaction with their own lives, their general health, or in their mental well-being after the loved one’s death, Dutch researchers have found.

In addition, no differences were found between the two groups in the family members’ assessments of the quality of end-of-life care received, the quality of the patient’s life in the last week of life, or the quality of the patient’s death.

“Based on these findings, the use of sedation does not appear to have a negative influence on bereaved persons’ experience of the dying phase of their deceased relative or on their own well-being after the patient’s death,” write the authors of a report published in *PLoS One.*

“Nevertheless,” they add, “palliative sedation is a far-reaching and ethically complex intervention that requires caregivers to focus on providing comfort, support, and continuous information to both the patient and the patient’s family.”

Few studies have examined how family members experience palliative sedation during the dying phase or whether it later affects their health and well-being, the authors note. Insights from their findings may contribute to the development of evidence-based care strategies that support both patients and their relatives during the death experience.

The investigators conducted an observational questionnaire study among bereaved relatives and close friends of a consecutive sample of patients who had died in the Netherlands between 2010 and 2013 as inpatients at either a cancer institute (an academic hospital with a specialized inpatient unit for palliative cancer care) or the nation’s largest hospice/palliative care center. Participants provided scale ratings of the patients’ quality of life in the last week of life, their quality of dying, and the quality of end-of-life care.

Overall, 151 patients had been sedated (median age, 71 years) and 90 had not (median age, 77 years). Sedated patients were more likely to die of cancer (92%) than were non-sedated patients (72%).

The median overall score for severity of symptoms was slightly higher among sedated patients (42; range, 34–52) than among non-sedated patients (38; range, 30–46) on a scale of 15 (not severe) to 75 (very severe).

**KEY FINDINGS**

- **Median score for family members’ satisfaction with their own lives three months after the patient’s death was 6 in both groups (on a scale of 0–10).**
- **Median score for relatives’ general health was 3 in both groups (scale, 1 to 5); for mental health, the median was 12 when palliative sedation was used and 11 for no sedation (scale, 0–25).**
- **For the overall quality of end-of-life care, the median score in both groups was 9 (scale, 0–10).**

Most respondents also indicated that the information they received about the dying phase and palliative sedation was sufficient (palliative sedation, 88%; no sedation, 82%), a higher proportion than found in other studies of family satisfaction with communication, the authors note.

“One explanation for this could be that our study mainly concerned relatives of patients who were cared for in a hospice (91%), which is a place of care where bereaved family members have relatively few unmet needs regarding information,” they continue.

“Providing information to family members and involving them in discussions about medical care and interventions is known to reduce symptoms of post-traumatic stress, anxiety, and depression,” comment the authors. They suggest that further research is needed to gain a deeper understanding of the factors that contribute to the well-being of relatives prior to and after the patient’s death.

In its 2009 position paper on palliative sedation, the European Association for Palliative Care (EAPC) emphasizes the importance of providing supportive care and regular information updates during the patient’s care, as well as post-death assessment meetings for family members and loved ones of patients who have received palliative sedation.

“Families often need repeated reassure. They recommend that other methods have been sufficiently trialed and/or carefully considered but were ineffective, that sedation is unlikely to shorten the patient’s life, and that sedation can be discontinued or reduced if needed,” the paper states.

**U.S. PROFESSIONAL ORGANIZATIONS’ POSITIONS**

**NHPCO.** The National Hospice and Palliative Care Organization (NHPCO), in a 2010 position statement, defines palliative sedation as “the lowering of patient consciousness using medications for the express purpose of limiting patient awareness of suffering that is intractable and intolerable.”

According to the NHPCO, palliative sedation is an important option to be considered only for patients:

- With pain and suffering that is unresponsive to other palliative interventions
- Whose symptoms are intolerable to them

**Continued on Page 3**
by Norway ($19,783) and the U.S. ($18,500). Hospital expenses were lowest in the Netherlands ($10,936) and England ($9352).

- However, the mean hospital expenditures per day were highest in the U.S. ($1729), followed by Canada ($1149). Lowest per diem hospital expenditures were found in Belgium ($567) and England ($510).

- Because only the U.S. reimburses physician expenses separately from hospital costs, the authors estimated that physician costs would add 11.5% to overall U.S. hospitalization expenditures.

“There’s been a widespread perception that the U.S. spends a tremendous amount on end-of-life care, but until now there’s never been a comparative study to put U.S. spending and resource utilization in context,” says senior author Ezekiel J. Emanuel, MD, PhD, of the University of Pennsylvania. “End-of-life care is intensive and expensive, and what we know now is that the U.S. does not have the worst end-of-life care and that no country is optimal. All countries have deficits.”

HOSPICE CARE PLAYS KEY ROLE

With their lower hospital costs, other nations may experience less economic pressure than does the U.S. to avoid hospital deaths, note the authors. A further reason for its lower percentage of cancer deaths in acute care is that the U.S. currently has more than 5300 hospices. Two-thirds of these hospices provide care at home, which is where most patients say they would prefer to die, the authors add.

Over the last 30 years in the U.S., the recognition of people’s desire for home-based end-of-life care and of patients’ rights to refuse medical interventions, plus growing economic pressures to expand hospice use and lower end-of-life costs, have all played an important role in advancing end-of-life care, note the authors.

“But we can and should do better,” write Emanuel and lead author Justin E. Bekelman, MD, in an editorial published in The New York Times. “We should start by providing universal access to the highest quality palliative care as the default for all Americans near the end of life.”


Palliative Sedation (from Page 2)

- Who are terminally ill and whose death is “imminent,” or expected in less than two weeks, as defined by the NHPCO?

The NHPCO’s statement clearly and carefully distinguishes palliative sedation — which “is legal and is an appropriate clinical option throughout the United States” — from forms of hastened death.

“Properly administered, palliative sedation of patients who are imminently dying is not the proximate cause of patient death, nor is death a means to achieve symptom relief,” states the NHPCO. Thus, palliative sedation is considered “clinically and ethically distinct” from euthanasia and physician-assisted death.

AAHPM. “Practitioners who use palliative sedation should be clear in their intent to palliate symptoms and to not shorten survival,” declares the American Academy of Hospice and Palliative Medicine (AAHPM) in its 2014 position statement.

According to the AAHPM, palliative sedation is ethically defensible:

- After careful interdisciplinary evaluation and treatment
- When other palliative treatments have failed, or are considered by the clinician as likely to fail
- When its use is not expected to shorten the life of the patient
- Only for the duration of the symptoms, actual or expected; it may be appropriate to reverse sedation in some cases

The full AAHPM position statement is available online at http://aahpm.org/positions/palliative-sedation.

The disparity in the quality of care received at the end of life between African Americans and whites has been well documented. And although advance care planning (ACP) is widely promoted as a desirable and effective process for guiding goal-concordant care, far fewer African Americans than whites participate in formal planning for future medical care.

A special issue of the *Journal of Palliative Medicine*, entitled “Palliative and End-of-Life Care for African Americans,” has gathered original research and opinion pieces offering insight into understanding the factors that influence this population’s choices and preferences for care and suggested approaches to delivering the care that is wanted, rather than the care patients are expected to want.

**DISCUSSION PREFERRED TO DOCUMENTATION**

“African Americans are more likely to pursue informal planning than to formally document their care preferences,” write the authors of a report presenting a model for understanding factors that affect African Americans’ decision making. Future research should focus not on advance directive (AD) completion by African Americans, but on improving ACP discussions and the quality of patient communication with family and clinicians, they suggest.

Investigators conducted a systematic review of quantitative and qualitative studies published from 1985 to present day that examined the perceptions, opinions, and practices of African Americans concerning ACP and ADs. From this information, researchers developed a model illustrating the interaction between factors that affect medical decision making. The authors hope that their model will serve to guide the development of interventions to improve ACP and the quality of life at the end of life in this population.

**Approach to Improving EOL Care for African Americans**

1. Recognize, acknowledge, and respect the exploitation, maltreatment, and racism that African Americans suffered in the past and that many patients continue to suffer.
2. Develop awareness of one’s own internal (often unconscious) biases. Preventing “microaggressions” — communications that subtly nullify the thoughts, feelings, or experiences of another person — requires close examination of one’s behaviors, thoughts, and beliefs.
3. Recognize the importance of religion and spirituality in the African-American community, including the vital importance of hope. Medical teams should include discussion of religious beliefs during ACP conversations in a way that does not strip patients of their hope.
4. Strive for continuous improvement in communication. Partner with community-based clergy. Develop a common understanding not only of the medical issues faced by terminally ill patients, but also of the effect their faith-based beliefs have on their experience of illness.

---

**FINDINGS: SIGNIFICANT FACTORS IMPACTING ACP**

**Historical legacy.** Past and present racism in the U.S. influences African Americans’ decision making. This includes the history of slavery, with its legacy of sociodemographic disadvantage; mistrust of the medical community, dating back to mistreatment in the antebellum period; structural racism, which impacts not only education and health literacy, but also access to care, disease burden, and medical outcomes.

“Questions about the potential for care to be withheld or withdrawn, such as those ACP and end-of-life discussions in which procedures are the focus, arouse historically rooted concerns about discrimination,” write the authors.

**Religion and spirituality.** Since the adoption of Christian practices and narratives by early African Americans, religious beliefs have been an inextricable part of the community’s value system, influencing attitudes towards aggressive, life-prolonging care.

“Faith in God’s ability to heal is universal in our data, and both prolonged life and death are understood as forms of deliverance from sickness,” write the authors. “The data suggest that aggressive medical care is often sought to buy time for God to manifest healing.”

**Family and community.** An almost universal trust in the protective power of family was found across a range of decision-making responsibilities, with a strong interaction among the cultural assets of family, community, and religious belief. “Family and community are viewed, in our findings, as both a source of protection from untrustworthy clinicians and as something to be protected from the burdens of end-of-life decision making.”

**Clinic factors.** Because consideration of prognosis shapes the goals and

Continued on Page 5
As Hospice Use Increases, So Also Do Short Lengths of Stay

Terminally ill patients in the U.S. continue to choose hospice care in increasingly high numbers, but the proportion of late enrollments has also continued to increase. In 2014, more than half of hospice patients received services for fewer than 14 days, with over one-third receiving hospice care for less than one week, according to figures in the latest annual report from the National Hospice and Palliative Care Organization (NHPCO).

“The unique interdisciplinary team of hospice is equipped to aid patients through the last months of life,” states NHPCO. “Earlier access to hospice care can reduce emergency room visits and hospitalizations. Additionally, quality of life for patients and family caregivers can be greatly improved.”

An estimated 1.6 to 1.7 million patients were served by hospices in 2014, up from an estimated 1.3 to 1.4 million in 2010. Hospice provides “expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes,” notes the report. Support is provided also to the patient’s family and loved ones. The services are available to patients with any terminal illness, and of any age, religion, or race.

The year 2014 saw a rise in enrollment over the previous year by patients of Hispanic ethnicity as well as those of non-Caucasian race. Compared with 2013, hospice use by patients of Hispanic or Latino origin rose to 7.1% from 6.8%, while enrollment by patients of non-Caucasian race jumped to 24% from 19.1%.

While the majority of hospice users (63.4%) enrolled with non-cancer diagnoses, cancer as an admitting diagnosis stayed steady at about 37%.

Top non-cancer primary diagnoses:
- Dementia (14.8%)
- Heart disease (14.7%)
- Lung disease (9.3%)
- Other (8.3%)
- Stroke or coma (6.4%)

Length of hospice stay has continued to drop over time, from a median of 20.0 days in 2007 and 18.5 days in 2013 to 17.4 days in 2014. Average length of stay decreased to 71.3 days in 2014, down from 72.6 days in 2013. Meanwhile, the trend of increasing proportions of patients with very short lengths of service has continued over time, while the percentage of patients with very long lengths of stay has declined.

Proportion of patients by length of service in 2014 vs 2013, respectively:
- < 7 days, 35.5% vs 34.5%
- < 14 days, 50.3% vs 48.8%
- > 180 days, 10.3% vs 11.5%

The number of U.S. hospices has reached an all-time high at 6100, 92.8% of which are certified to provide services under the Medicare hospice benefit, and 20% of which are part of a hospital system. Hospice services are available in all 50 states, the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands.


African Americans (from Page 4)

An editorial by the guest editor of the special issue distills the implications of the issue’s study findings and the wisdom of the invited editorials into a step-wise approach to finding “the way forward” to ensuring that the needs of African Americans are met at the end of life. [See sidebar, page 4.]

“We can only begin to build trust in an atmosphere of mutual respect between the patient and the provider, respect that is both sincere and evident in all our communication and interactions,” writes Ronit Elk, PhD, research associate professor focusing on EOL care and health disparities at the College of Nursing, University of South Carolina, Columbia.

Regional Variations Persist in Delivery of Evidence-Based Care at the End of Life

As people age and their bodies change, so also do their care preferences and priorities. However, the care currently delivered to older, seriously ill patients frequently does not reflect these changes, often is not consistent with evidence-based practices, and varies widely by geographic region, according to the most recent report from the Dartmouth Atlas Project.

Released in February 2016, the report used Medicare claims data from 2012 to examine health care utilization by hospital referral region among older Americans, “with an emphasis on the patient’s perspective.” By providing data that is more meaningful to older adults, and by illustrating how dependent the intensity of end-of-life care received can be on geographic location, the authors hope to contribute to the effort to improve care.

The population of Americans aged 65 years and older is expected to rise from 43.1 million in 2012 to 83.7 million in 2050, while the number of those aged 85 years and older is expected to nearly quadruple during that same time period. “The aging of the population demands that we improve the delivery of care and improve policies to benefit the older adults of today — our parents, grandparents, and neighbors — and ourselves in the future,” write the authors.

The report acknowledges progress that has been made in recent years in certain areas of health care provision for older adults, such as the reduction of preventable hospital admissions and the lowering of 30-day readmission rates. However, there are still important areas in need of improvement — areas in which older adults continue to receive care that does not meet established guidelines or, in many cases, the patients’ own goals and preferences.

**LATE HOSPICE ADMISSION**

The percentage of beneficiaries enrolled very late in hospice (≤ 3 days before death) varied more than fourfold across geographic hospital referral regions, with a national average of 16.8%. “Rates of hospice referral often do not reflect patient preferences, which tend to favor comfort measures over medical intervention,” states the report. “Referrals to hospice care that are done too late also adversely affect the quality of care, the reported experiences of patients and families, and their satisfaction with the health care system.”

- More than one-quarter of patients were enrolled in hospice within three days of death in Fort Lauderdale, FL (27.3%), Cincinnati, OH (25.7%), Sun City, AZ (25.2%), and Mason City, IA (25.2%).
- Lower rates of late hospice referral were found in Syracuse, NY (7.0%), Grand Forks, ND (7.4%), Anchorage, AK (8.1%), and Bangor, ME (8.6%).

**DAYS IN INTENSIVE CARE UNITS**

The number of days spent in ICUs in the last six months of life averaged 3.6 days nationwide, and “is trending upward, despite patient preferences for less intensive inpatient care and questions about the value of such care. Unnecessarily aggressive care at the end of life can detract from, rather than improve, patients’ quality of life,” write the authors.

- The most days spent in ICUs in the last six months of life were in Miami, FL (9.1), McAllen, TX (9.1), and Los Angeles, CA (7.1).
- The fewest average number of days were found in referral areas of Wisconsin (La Crosse, Neenah, and Appleton), each averaging about one day.

**FEEDING TUBES IN ADVANCED DEMENTIA**

The practice of inserting feeding tubes in patients with advanced dementia has been well established in the literature as inappropriate, delivering little or no benefit and having a high potential for causing harm and decreasing quality of life. In 2012, the average percentage of patients with advanced dementia who received feeding tube placement in the last six months of life was 6% nationwide. There was, however, a tenfold variation by hospital region, from 1.3% to 14%.

- The highest percentages of advanced dementia patients with feeding tube placement in the last six months of life were in Lake Charles, LA (14%), Dearborn, MI (13.3%), and Los Angeles, CA (12.8%).
- The lowest percentages were found in Portland, OR (1.3%), Salt Lake City, UT (1.3%), and Madison, WI (1.4%).

“In people with advanced dementia, loss of interest in food and the inability to swallow mark the final phase of the disease and are irreversible,” comment the authors. “Though once very common..., feeding tube placement in people with advanced dementia is no longer the recommended course of care.”

“The findings from this report will generate meaningful conversation about the care for our aging population and identify areas of action for health systems, advocates, and policy makers,” says Terry Fulmer, PhD, RN, president of The John A. Hartford Foundation, which sponsored the report.

End-of-Life Resource for Physicians
Offers Free Consultations

The Doc2Doc Program from Compassion & Choices, a nonprofit organization committed to improving care at the end of life, offers practicing physicians a free and confidential telephone consultation with one of the organization’s medical directors through its website at www.compassionandchoices.org/doc2doc-program. The program’s aim is to help physicians provide timely care and up-to-date information for their patients seeking answers about end-of-life options.

“Your informed communication about the full range of end-of-life options should be part of a larger conversation surrounding each patient’s health care goals,” suggests the program. “Ideally, these conversations should begin soon after a diagnosis of terminal illness and continue throughout the progression of that illness.” The website provides a toll-free number and email address for “anytime” physician contact.

Consultation topics include subjects such as hospice and palliative care, effective pain and symptom management, how to follow current clinical practice guidelines, communication with patients and family members, the effect of specific state laws on end-of-life care, handling patients’ inquiries about or requests for withdrawal of life-sustaining therapies, and where to direct a patient for reliable information on end-of-life issues and advance care planning.

The site also maintains a comprehensive end-of-life information center for patients and their families. Most of the resources for patients are downloadable and include informational booklets on end-of-life care options, a toolkit for discussing advance care planning with one’s physician and creating an advance directive document, and a list of state-specific advance directives.

Mnemonic Tool for Culturally Aware Advance Care Planning Conversations Introduced

According to a presentation at the 2016 annual assembly of the American Academy of Hospice and Palliative Medicine (AAHPM) and Hospice and Palliative Nurses Association (HPNA), culturally sensitive communication can enhance the effectiveness of advance care planning. A team of hospice and palliative care specialists led by Kathleen Mitchell, MD, of Jamaica Hospital Medical Center in Queens, NY, studied how culture plays an important role in the way individuals respond to illness, receive and impart bad news, and make plans for end-of-life care.

Dr. Mitchell’s team introduced a new tool to help physicians understand and address their patients’ culturally influenced concerns while fostering awareness of the physicians’ own beliefs and biases about illness and dying. “A REFLECTION” is a mnemonic tool representing: Allow, Reflect, Empathize, Facilitate, Listen, Engage, Compassionately bridge, Trust, Inquire, Open, and Name needs.

In the assembly abstract, the team states, “Our country’s population is growing older, becoming more diverse, and surviving longer with chronic conditions. Health care professionals must develop skills to provide culturally sensitive care while practicing in an already overburdened health care system.”

End-of-Life Care Meetings for Clinicians

2016 Annual Scientific Meeting of the American Geriatrics Society. May 19–21, 2016, Long Beach, CA. Website: www.americangeriatrics.org


Selected Topics in Primary Care, Hospice, Palliative Care, and Infectious Diseases. June 18–25, 2016, Seven-night Bermuda Cruise Conference from Boston, MA. Accredited by the Accreditation Council for Continuing Medical Education. Phone: 800-422-0711; Website: www.continuingeducation.net


21st International Congress on Palliative Care. October 17–21, 2016, Palais des congrès (Montreal Convention Centre), Montréal, Québec, Canada. Presented by Palliative Care McGill University. Website: www.palliativecare.ca

Quality of Life Matters®

Now in its 18th year of publication, Quality of Life Matters® is recommended as an educational resource by the American Academy of Hospice and Palliative Medicine.

The periodical is dedicated solely to end-of-life care news and clinical findings and is researched and written by professional medical journalists specializing in covering palliative care issues.

It is an independent publication; it is not affiliated with any health care organization or company. The quarterly newsletter is published by Quality of Life Publishing Co., a firm dedicated to easing the way for patients with life-limiting illnesses and their families.

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

For information, rates, or reprint requests for this and other publications, please contact Quality of Life Publishing Co.

TOLL FREE 1-877-513-0099
EMAIL info@QOLpublishing.com
MAIL Quality of Life Publishing Co. 6210 Shirley St., Ste. 112, Naples, FL 34109

EXPLORE OUR FULL LINE OF BRANDED EDUCATIONAL BOOKLETS at www.QOLpublishing.com
• Tools to address CAHPS® survey questions
• Written to meet health literacy standards
  • Available in multiple languages

EDITORIAL TEAM

Karla Wheeler
Editor-in-Chief & Founder

Jan Carlton Doetsch
Clinical Editor

Gretchen Landolt
Chief Executive Officer

Kelly Brachle
Chief Operating Officer

Katie Jensen
Editor, Production Coord.

Dashia Larimer
VP Customer Relations

Your copy of Quality of Life Matters is provided as an educational service by