

A Newsletter for Healthcare Professionals

Spring 2011

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97% of Americans Believe Patients and Families Should Be Educated about End-of-Life Care Options

Hospice care highly respected; 91% of Americans deem it a top priority

Most Americans believe that enhancing life at the end of life is more important than extending it, and they are nearly unanimous in wanting more information and education about the choices available to them in palliative care, end-of-life care, and hospice, according to a national poll released in March by National Journal.

The poll results were presented at a gathering of policy experts in the nation's capital by Brent McGoldrick, general manager and senior vice president of public affairs research at the DC offices of Financial Dynamics, the consulting firm that conducted the National Journal-commissioned survey.

Key Findings Include:

- 97% of respondents agree that it is important to educate patients and families about the palliative and end-of-life options available to them.
- 96% believe that issues concerning palliative and end-of-life care should be a top priority in health care.
- 71% of Americans feel it is more important to enhance quality of life for seriously ill patients than to attempt to extend life through every medical intervention possible.
- Most Americans believe that discussions with physicians about palliative and end-of-life treatment options should be covered by private insurance (86%) and Medicare (81%).

"This is not a political issue," said McGoldrick. "People view the issues surrounding these topics primarily through the lens of personal experience." The results were consistent across all political party affiliations, he pointed out.

There is a sense from the two-thirds of Americans who have had direct experiences with end-of-life care that they have not been particularly well informed, noted McGoldrick. Of the 63% of respondents who reported personal experiences with palliative and/or end-of-life care, almost half said they felt unprepared. "If the threshold question is whether or not Americans are ready and willing to have this conversation, the answer is a resounding 'Yes,'" he concluded.

Americans Support Palliative Care Despite Their Lack Of Knowledge

When asked about the term "palliative care," few respondents (24%) said they were familiar with it. Yet 44% of those surveyed thought it should have top priority in the nation's health care system. Similarly, while 65% said they were familiar with the term "end-of-life care," 86% considered it important. **"Hospice care" was better known and highly respected, with 86% being familiar with the term and 91% deeming it a top priority.**

Following a description of all three terms by an interviewer, 96% of respondents believed it important that these health and life issues have top priority in health care, with 72% believing this priority status to be very important.

A Question of Trust

Although respondents reported receiving most of their information on palliative and end-of-life care from family members, friends, and the news media, the sources they trusted most to provide this information (rated 7-10 on a 10-point scale) were physicians, followed by family and friends. Least trusted sources were news media and politicians.

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Patients Referred from Acute Care to Home Hospice More Likely to Die Within One Week Than Patients Enrolled from Home

African Americans have 83% higher odds of enrolling directly from hospital

African-American patients are more likely than whites to be in a hospital just prior to hospice admission, and patients of both races admitted to home hospice care from an acute care setting have a similarly higher likelihood of dying within seven days of hospice enrollment than do their counterparts who are enrolled from home, a team of researchers has found.

“[T]hese findings highlight the need for efforts to increase length of stay for patients in both racial groups, especially those referred from acute care settings, who are at greatest risk for very short hospice stays,” write the authors of a report published in the *Journal of the American Geriatrics Society*.

Researchers analyzed data on 43,869 hospice decedents who had received routine home hospice care by a national provider in one of 26 programs in eight states between 2000 and 2003. Variables included hospice preadmission location (acute or non-acute

care setting), race (African American or white), and hospice length of stay. Key findings include:

- Race was the single greatest predictor of hospital as a preadmission location, followed by the use of Medicaid.
- African Americans were 83% more likely than whites to be in an acute care setting (hospital or emergency department) one to two days before hospice enrollment (48.6% vs 32.3%).
- Home was the most common non-acute care preadmission setting for both racial groups.
- Both African Americans and whites who enrolled in hospice from acute care settings were more likely than those admitted from home to die in <7 days (24.5% vs 17.2% and 29.2% vs 21.2%, respectively).

“The finding that African-American race is an independent predictor of referral to hospice from a hospital can be understood

in the context of what is known about racial differences in treatment preferences, resource use, and access to care,” comment the authors. Research has shown that African Americans are more likely to want life-sustaining therapies regardless of prognosis, and to have higher rates of hospitalization, cardiopulmonary resuscitation, and in-hospital deaths.

“[I]nitiatives targeting timely discussions about end-of-life care and hospice referrals in settings outside of the hospital may improve access to hospice and increase lengths of stay of African Americans with advanced illness whose goals of care are consistent with the hospice philosophy of care,” they conclude.

Source: “Racial Differences in Location before Hospice Enrollment and Association with Hospice Length of Stay,” *Journal of the American Geriatrics Society*; Epub ahead of print, March 15, 2011; DOI: 10.1111/j.1532-5415.2011.03326.x. Johnson KS, et al; Department of Medicine, Division of Geriatrics, Center for the Study of Aging and Human Development, Center for Palliative Care, Duke University, Durham, North Carolina. Reprinted with permission from Quality of Life Matters®, copyright 2011. Published by Quality of Life Publishing Co., Naples, FL.

97% of Americans Believe Patients and Families...

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Most trusted sources for end-of-life care information included:

- Physicians and other health care providers (76%)
- Family members and friends (69%)
- Clergy and spiritual leaders (46%)
- Social service agencies and programs (39%)

Financial Concerns

The survey found evidence of conflicted emotions regarding expenditure at the end of life, with 79% of respondents reporting that their greatest concern would be the cost of treatment if they or a family member became seriously ill, while 55% felt that the health care system had the responsibility to spend whatever was necessary to extend their lives. Lack of trust in the health care

system and desire for all life-prolonging treatments in the face of serious illness were highest among those with a lower level of education and African-American ethnicity.

Personal Concerns About Serious Illness

Personal concerns regarding serious illness (rated 7-10 on a 10-point scale) included:

- Cost of treatment (79%)
- Lack of sufficient information with which to make decisions (73%)
- Burdens on family and friends (72%)
- Being emotionally or spiritually unprepared for death and dying (48%)

“The issues and choices surrounding health care at the end of life have huge implications for our country, on the personal level, in the health care field, and

for policy-makers,” said summit moderator Ronald Brownstein, editorial director of National Journal Group. “This poll makes it clear that while Americans are wrestling with these issues in their personal lives, the public conversation simply isn’t keeping up. Americans want to learn more about options at the end of life, and it’s time our national discussion shed less heat and more light.”

The survey interviews were conducted by telephone among 1000 adults (male, 48%; Caucasian, 70%; not currently covered by health insurance, 13%) during three days in February 2011.

Results of the survey and a video of the March 2011 policy summit are available at: www.nationaljournal.com/events/event/45/. Reprinted with permission from Quality of Life Matters®, copyright 2011. Published by Quality of Life Publishing Co., Naples, FL.

Nursing Home Residents with Advanced Dementia Have Better Pain and Dyspnea Management, Fewer Unmet Needs under Hospice Care

Approximately 70% of patients with advanced dementia die in nursing homes in this country. Those residents with dementia who receive hospice services are three times more likely to receive opioids for pain and symptomatic treatment for dyspnea, and their families report fewer unmet needs during the last seven days of life, according to a report published in the *Journal of the American Geriatrics Society*.

“It is important for health care providers, family members, and policy-makers to have an understanding of the role of hospice services for patients with dementia, given the numbers of Americans dying with this condition,” state the authors. The mortality rate due to dementia, a leading cause of death in the U.S., is increasing faster than that of any other fatal condition, they point out.

Investigators analyzed data collected on 323 residents with advanced dementia (mean age, 85.3 years; white race, 89.5%; female, 85.4%) living between 2003 and 2007 in one of 22 nursing home facilities with more than 60 beds in the greater Boston area. Follow-up assessments (n = 1394), which included a chart review, nursing interview, and a brief clinical examination, were conducted quarterly for 18 months.

Residents' health care proxies (mean age, 60.0 years; adult child of resident, 67.5%; female, 63.8%) were interviewed at baseline, quarterly, and two months following the resident's death. The research is part of the Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life (CASCADE) Study, supported by the National Institute on Aging of the federal National Institutes of Health.

A key finding is that less than one-quarter of residents with advanced dementia in this study were referred to hospice care. “Research suggests that hospice care is beneficial for patients with dementia,” write the authors. “Nonetheless, the rate of

“This study suggests that promoting greater prognostic awareness of family members is a modifiable factor that may increase the use of hospice services. Moreover, the results strongly support the notion that hospice is a beneficial, but underused, service for nursing home residents with advanced dementia and their families.”

— Kiely et al, *Journal of the American Geriatrics Society*

hospice use observed in this nursing home population (23.3%) supports the widely held view that hospice services largely underserve patients with dementia.”

Hospice Referral Factors

Factors independently associated with hospice referral included:

- Presence of an eating problem (adjusted odds ratio [AOR] = 4.21, 95% confidence interval [CI] = 1.99-8.90)
- Perception by family members that resident had less than six months to live (AOR = 3.83, 95% CI = 1.29-11.37)
- Nonwhite race of resident (AOR = 2.55, 95% CI = 1.36-4.76)
- Better mental health of proxy/family member (AOR = 1.04, 95% CI = 1.01-1.06)

“The onset of eating problems in advanced dementia often indicates that the patient is nearing the end of life,” point out the authors. “Thus, it is not surprising that residents with eating problems were more likely to be referred to hospice than those without this problem.”

Similarly, they note, patients whose families recognized that their loved one was probably in the terminal stage of the disease were much more likely to be referred to hospice. “This finding supports the notion that the challenge of prognostication in

advanced dementia may be an important barrier to delivering hospice services to these patients.”

Barriers To Hospice Care

Major barriers to providing hospice care to dementia patients include:

- The underrecognition of dementia as a terminal illness
- Challenges in prognostication
- Variation in access to hospice services among nursing homes

Pain And Dyspnea Management

- Patients were recorded as having pain in 31.0% of assessments. Of these, only 23.4% received their scheduled opioids for pain treatment.
- In multivariate analysis, treatment with scheduled opioids for pain was significantly more likely for residents under hospice care (AOR = 3.16, 95% CI = 1.57-6.36).
- Dyspnea symptoms were managed somewhat better. Of the 27.3% of assessments recording patients with dyspnea, the provision of oxygen, morphine, scopolamine, or hyoscyamine to treat dyspnea was recorded among 67.5%.
- In multivariate analysis, treatment of dyspnea with one of these modalities was significantly more likely among hospice patients (AOR = 3.28, 95% CI = 1.37-7.86).

Unmet Needs In Last Seven Days Of Life

Among the 137 deceased residents whose proxies completed post-death interviews, 29.9% had received hospice care. Median time between hospice referral and death was 38 days. Unmet needs were analyzed for the following four domains: communication and shared decision making; information received from providers; emotional support provided to the family; and amount of help the resident received with personal care.

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Nursing Home Residents with Advanced Dementia Have Better Pain and Dyspnea Management, Fewer Unmet Needs under Hospice Care

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Of the residents who died without hospice care, 81.3% had at least one unmet need in the last seven days of life, compared with 68.3% of residents who died while receiving hospice services. “Consistent with other reports,” note the authors, “lack of emotional support and inadequate information from providers were the most common unmet needs that bereaved family members reported.”

The authors conclude: “[T]he findings clearly demonstrate that opportunities exist to improve end-of-life care for nursing home residents, not only through greater use of hospice, but also by providing better treatment of pain and dyspnea and addressing unmet needs during the dying process.”

Source: “Hospice Use and Outcomes in Nursing Home Residents with Advanced Dementia,” Journal of the American Geriatrics Society; December 2010; 58(12):2284-2291. Kiely DK, Givens JL, Shaffer ML, Teno JM, Mitchell SL; Hebrew SeniorLife Institute for Aging Research and Department of Medicine, Beth Israel Deaconess Medical Center, Boston; College of Medicine, Pennsylvania State University, Hershey; and Center for Gerontology and Health Care Research, Brown University Medical School, Providence, Rhode Island. Reprinted with permission from Quality of Life Matters®, copyright 2011. Published by Quality of Life Publishing Co., Naples, FL.

As a physician, you know your patient best and when it is appropriate to recommend hospice as an option for care. When that time comes, Hope Hospice is here to support you, your patient and their family.

The Hospice Talk: Steps for Physicians

- Confirm the patient/family understanding of the underlying diagnosis and prognosis. “Tell me what you understand about your illness.” “What are you expecting?”
- Elicit goals. “What are you hoping for in the time you have left?”
- Summarize the patient’s goals, and introduce hospice. “For all my patients at this stage, I recommend hospice.”
- Explain why hospice care would be appropriate. “Hospice helps me take care of people like you and your family when the goals of the medical care are the things you just said you wanted. They take care of you at home; they are my eyes and ears.”
- Offer to contact the local hospice to arrange a meeting. “Let me ask the hospice program to call you. Someone can come out to your home to explain their services.”
- Confirm that you intend to remain involved. “You and I can discuss what they tell you. In my opinion, this is the best care I can give you at this time in your life.”

~ Adapted from Moore and von Gunten, *Chest*

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