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Quality of Life Matters®

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

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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*.

As the first in a three-part series of surveys and policy summits entitled, "Living Well at the End of Life: A National Conversation," 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.

Inside:

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

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Checklist Tool Developed to Identify Patients in Need of Palliative Care During Hospitalization

Recognizing the gap that exists between the total pool of hospitalized patients in need of palliative care and the necessarily limited number of such patients that specialists in palliative medicine can provide for, the Center to Advance Palliative Care (CAPC) has developed a checklist approach for hospital staff to use in identifying and treating patients with unmet palliative care needs.

"The need to improve care for patients with serious, complex, and potentially life-threatening or life-limiting medical conditions is unquestioned," write the authors of a CAPC consensus report published in the *Journal of Palliative Medicine*. However, "it is neither sustainable nor desirable that palliative care specialists manage all the palliative care needs of all seriously ill patients."

PALLIATIVE CARE EXPERTISE

Problems requiring the expertise of palliative care specialists include:

- Difficult-to-manage symptoms
- Complex family dynamics
- Challenging care decisions regarding the use of life-sustaining treatment

Routine palliative care problems, however, should be managed by hospital staff involved in day-to-day care of the patient, the authors believe. They recommend that every hospital develop a system for identifying patients at high risk for unmet palliative care needs. A first step in this process would be the use of two checklists — one for screening upon admission and another for screening during daily rounds.

> "Palliative care clinical competencies are basic skills for all clinical staff, hence the need to better equip health professionals to provide standardized and evidence-based primary palliative care services, reserving specialists for truly difficult problems."
>
> — Weissman and Meier,
> *Journal of Palliative Medicine*

"The consensus panel believes that by implementing a checklist approach to screening patients for unmet palliative care needs, combined with educational initiatives and other system-change work, hospital staff engaged in day-to-day patient care can identify a majority of such needs, reserving specialty palliative care services for more complex problems."

COMPONENTS OF ASSESSMENT

The panel designated the following as the most important components of a primary palliative care assessment:

- Pain/symptom assessment
- Social/spiritual assessment
- Determination of patient understanding of illness, prognosis trajectory, and treatment options
- Identification of patient-centered goals of care
- Post-discharge transition of care

Based on a review of the literature and current practices, two checklists, each with two sets of criteria, were identified to trigger a basic palliative care assessment by the primary treatment team. *[See sidebar, left.]* "Primary" criteria are global indica-

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Palliative Care Assessment Checklist Upon Admission

Checklist of primary criteria for a palliative care assessment upon admission of a patient with a potentially life-limiting or life-threatening illness includes:

- The "surprise" question ("Would I be surprised if the patient died within 12 months?")
- Frequent admissions for the same condition
- Admission prompted by difficult-to-control physical or psychological symptoms
- Complex care requirements
- Decline in function, feeding intolerance, or unintended decline in weight

Palliative Care Assessment Checklist for Each Day

Checklist of primary criteria for a palliative care assessment each hospital day for a patient with a potentially life-limiting or life-threatening illness includes:

- The "surprise" question
- Difficult-to-control physical or psychological symptoms
- Intensive care unit length of stay of 7 days or more
- Lack of clarity and documentation of goals of care
- Disagreements/uncertainty among patient, staff, and/or family concerning major medical treatment decisions, resuscitation preferences, or use of nonoral feeding or hydration

— Weissman and Meier,
Journal of Palliative Medicine

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

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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.

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/.***

Checklist Tool Developed to Identify Patients in Need of Palliative Care During Hospitalization

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tors representing the minimum expected standard of care; "secondary" criteria are more specific, designed to be used by hospitals whose systems can incorporate them.

The Center to Advance Palliative Care (CAPC) is a national, non-profit organization providing hospitals and other health care settings with the resources needed to develop and sustain successful palliative care programs. Their web address is **www.capc.org.**

EXTENDING PALLIATIVE CARE BEYOND DISCHARGE

"Presumably, this [use of the checklist of triggers for a palliative care assessment] would let fewer needs go unmet, prevent crises and hospitalizations for manageable problems, and improve quality of life," notes *Journal of Palliative Medicine* editor-in-chief Charles F. von Gunten, in his comment on the CAPC report.

Recent findings that palliative care patients often report a lack of supportive information upon hospital discharge concern von Gunten, however. He urges that primary care physicians and specialists alike extend the reach of palliative care by working to ensure smooth transitions between care settings.

"[C]ommunicating clearly, in speech and in writing, in language the patient and family understand, about their condition and the treatment plan, is a fundamental skill for all managing services," writes von Gunten.

"Palliative medicine can't be the only group who know how to talk about prognosis, pain medications, and whom to call for help."

Source: "Identifying Patients in Need of a Palliative Care Assessment in the Hospital Setting: A Consensus Report from the Center to Advance Palliative Care," Journal of Palliative Medicine; *January 2011; 14(1):17-23. Weissman DE, Meier DE; Medical College of Wisconsin/Froedtert Hospital, Milwaukee; Department of Geriatrics and Internal Medicine, Hertzberg Palliative Care Institute of the Brookdale Department of Geriatrics, Mount Sinai School of Medicine, New York City. "Who Should Palliative Medicine Be Asked to See?" ibid.; p. 2; von Gunten CF; editor-in-chief,* Journal of Palliative Medicine.

RESEARCH MONITOR

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

> "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 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 dysp-

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Advanced Cancer Patients' Self-Reported Performance Status and Nutritional Outcomes May Accurately Predict Survival

A team of Canadian researchers has demonstrated that the majority of cancer patients referred to a community-based palliative care program are able to rate their own performance status, which was found to be as predictive of survival as a widely used physician-reported prognostic tool.

"Accurate prognostication is needed to make decisions regarding patient care, enhance the dying patient's quality of life, and allow patients to prepare for death," write the authors of a report published in the *Journal of Clinical Oncology.* "We demonstrate a high probability of concordance between predicted and observed survival for patients in distinct palliative care settings (home care, tertiary inpatient, ambulatory outpatient) based on patient-reported information."

The team tested the prognostic significance of individual elements of the Patient-Generated Subjective Global Assessment (PG-SGA), a standardized nutrition screening tool, among a population-based data set of 1164 palliative care patients with metastatic cancer in the Edmonton, Alberta, area between 2004 and 2007. "PG-SGA has a dual use as a nutrition screen for referral to nutrition support services and in the collection of data for prognostication," the authors point out.

ELEMENTS PREDICTING SURVIVAL

In multivariate analysis, the following elements predicted survival:

- Primary disease site
- Performance status
- Short-term weight gain or loss
- Dietary intake
- Dysphagia

Disease and performance status dominated the model for predictive accuracy. Concordance was not altered by substituting physician-rated performance status via the Palliative Performance Scale for patient-reported performance status via the PG-SGA.

"Our use of patient-reported outcomes, although they may have some limitations, is a strength of our approach," the authors declare. "Data collection is simple, noninvasive, cost-effective, and only precluded in cases of significant cognitive impairment."

Source: "Prognostic Factors in Patients with Advanced Cancer: Use of the Patient-Generated Subjective Global Assessment in Survival Prediction," Journal of Clinical Oncology; *October 1, 2010; 28(28):4376-4383. Martin L, Watanabe S, Fainsinger R, Lau F, Ghosh S, Quan H, Atkins M, Fassbender K, et al; University of Alberta; Cancer Care, Cross Cancer Institute; Palliative Care, Regional Palliative Care Program; and Education Resources, Alberta Health Services, Edmonton, Alberta; School of Health Information Science, University of Victoria; and Palliative Medicine, Research, and Development, Victoria Hospice, Victoria, British Columbia, Canada.*

Nursing Home Residents with Advanced Dementia

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nea, 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.

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.*

RESEARCH MONITOR

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.*

Monthly Discussion of Patient Deaths Improves Interns' Perceived End-of-Life Care Skills, Provides Peer Support of Emotional Needs

"Death Rounds," monthly, hour-long, moderated sessions in which internal medicine interns are provided with a supportive environment in which to discuss their emotional reactions to patient deaths, are a valuable addition to the resident curriculum, researchers have found. Their report is published in the *Journal of Palliative Medicine.*

The team analyzed pre- and post-intervention survey responses of all participating internal medicine interns on rotation at the University of Washington Medical Center during the academic year 2007-2008 (n = 39). Interns from the 2006-2007 academic year served as the control group (n = 38). Key findings include:

- 97% of respondents thought the opportunity to discuss the emotional aspects of patient death should be included in training.
- 90% of intervention group respondents reported being comfortable discussing end-of-life issues with patients and families, compared with 76% of those in the control group.

"Learning to deal with the strong emotions that arise in the care of dying patients is an important part of physician training," the authors write. "Our study suggests that Death Rounds should be adopted as a standard part of the resident curriculum."

Source: "Using Death Rounds to Improve End-of-Life Education for Internal Medicine Residents," Journal of Palliative Medicine; *January 2011; 14(1):55-58. Smith L and Hough CL; Pulmonary/Critical Care, University of California San Francisco, San Francisco, California; Pulmonary/Critical Care, University of Washington, Seattle.*

CLINICIAN RESOURCES

Palliative Care Curriculum Now Available Free of Charge on CD-ROM

"Education in Palliative and End-of-Life Care for Oncology" (EPEC™-O), a comprehensive, multimedia curriculum aimed at all physicians, nurse practitioners, and physician assistants caring for patients with cancer, can now be ordered at no charge from the National Cancer Institute of the U.S. National Institutes of Health.

Core competencies in palliative care needed throughout the course of comprehensive cancer care are addressed, along with instructions on how to incorporate recommended treatments and approaches into clinical practice. Practitioners in the fields of family medicine, general medicine, and geriatrics — as well as those in oncology and hospice and palliative medicine — are encouraged to participate.

The program is offered in CD-ROM format, also including a DVD with video vignettes, and can be used for self-study or for in-person training. The educational activity has been designated by the American Society of Clinical Oncology for continuing medical education credits.

Also available as a separate set is the "EPEC™-O with American Indian and Alaska Native Cultural Considerations," which contains culturally specific information in addition to the original format.

The EPEC™-O curriculum can be ordered at: www.cancer.gov/aboutnci/epeco.

New Pain Management Book Available for Quick Reference

Clinical Pain Management, based on the International Association for the Study of Pain's clinical curriculum, is designed to provide a practical, interdisciplinary approach to the assessment and management of pain for all clinicians. The authors offer concise template chapters as a quick reference, providing best-practice guidance for primary care physicians, anesthetists, neurologists, as well as other specialists, generalists, and trainees managing pain.

"Pain is the most pervasive and debilitating of all experiences," write the authors, led by Mary E. Lynch, MD, a professor in the departments of psychiatry, anesthesiology, and pharmacology of Dalhousie University in Halifax, Nova Scotia, Canada. "It can be acute and short lived or develop into a chronic condition that destroys quality of life. But most pain can be managed."

Clinical Pain Management offers practical recommendations, algorithms, and best-practice guidelines for:

- Comprehensive assessment of pain
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- Pain in children, older patients, and other special populations

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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
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
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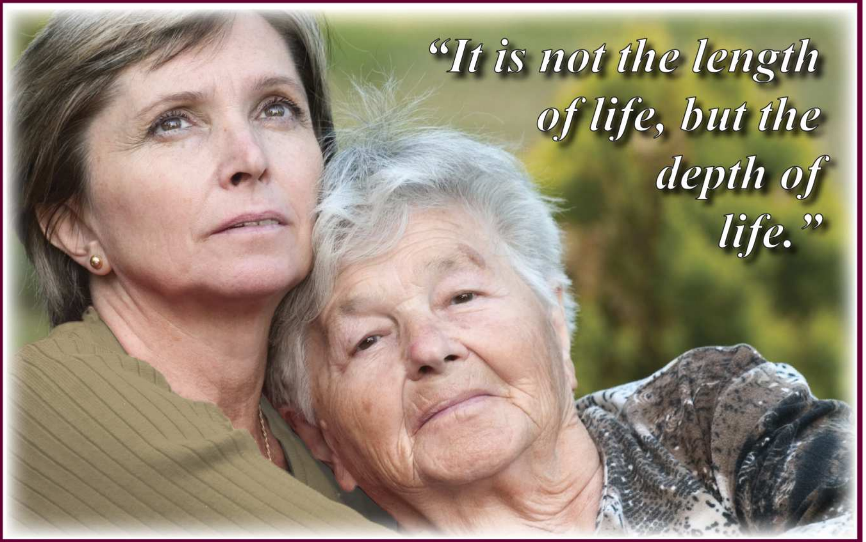

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