

Half of Dying Long-Term Care Residents Have Pain, Dyspnea

Increased Access to Hospice and Palliative Care Highly Recommended

In their last month of life, one-half of residents who die in a long-term care setting experience pain, one-half have dyspnea, and nearly all have problems staying clean, according to a multi-state study reported in a recent issue of the *Journal of the American Geriatrics Society*.

“In nursing homes and residential care/assisted living facilities, dying residents have high rates of physical symptoms and need for more effective palliation of symptoms near the end of life,” write the authors.

Investigators analyzed the interview responses of staff (n = 674) and family (n = 446) caregivers for residents (mean age, 85 years) who died between July 2002 and December 2004 in 230 long-term care sites in four states.

ON A TYPICAL DAY DURING THE LAST MONTH OF LIFE:

- 47% of residents had pain; 15% had “severe or horrible” pain.
- 48% of residents had dyspnea, with 11% experiencing severe dyspnea.
- 90% had problems with cleanliness.
- 72% had symptoms affecting intake of food and water.

“These symptoms merit attention in the clinical palliative care of patients who die in long-term care,” the authors write. “Their experience of symptoms is a major determinant of quality of life near the end of life.”

OTHER FINDINGS INCLUDE:

- Treatment for pain and dyspnea was rated by staff and family as “very effective” for only half of decedents.

- For 64% of residents, staff members reported they had expected the death either for less than one week or not at all.
- Overall symptom burden, as well as problems with cleanliness and intake, were worse for residents in nursing homes than for those in other facilities.

Staff were more likely to rely on non-verbal than verbal expressions of pain for assessment in residents who were cognitively impaired. “Observation of pain behaviors may contribute to undertreatment of pain,” comment the authors, noting that validated verbal scales for pain in dementia exist, and “staff should be trained in symptom assessment using self-report whenever possible, even for residents with dementia.”

Since one-quarter of older Americans receive their end-of-life care in long-term care facilities — and that percentage is projected to increase — their symptom experience is a major indicator of quality of care delivered at the end of life, the authors note.

“The high prevalence of end-of-life symptoms has implications for direct-care staffing ratios, for staff training, and for targeted use of hospice and specialized palliative care services to augment symptom management” and promote “comfortable and dignified dying.”

Source: “Symptom Experience of Dying Long-Term Care Residents,” *Journal of the American Geriatrics Society*; Jan. 2008; 56(1):91-98. Hanson LC, Eckert JK, Dobbs D, Williams CS, Caprio AJ, Sloane PD, Zimmerman S; Cecil G. Sheps Center for Health Services Research; Division of Geriatric Medicine, Dept. of Medicine; Dept. of Family Medicine; & School of Social Work, University of North Carolina at Chapel Hill; Dept. of Sociology & Anthropology, Erickson School of Aging Studies, University of Maryland, Baltimore County, Baltimore; & School of Aging Studies, University of South Florida, Tampa.

WHAT QUALITY CARE MEANS TO OUR FAMILIES

Over the past twenty-seven years serving the San Ramon, Castro Valley and Tri-Valley areas, we have always valued input and comments from our patients and their families. The feedback we receive regularly from those we serve is an integral part of our quality improvement plan.



Ann Noll, RN, CHPN
Director of Patient Services

From Family Surveys: May 2008

My father left the hospital on a Sunday. Due to late-stage Alzheimer's, he developed aspiration pneumonia. We were with hospice only one week. Between hospice and the wonderful care the owners of the board and care gave my dad, he lived his last week comfortably with respect and dignity. My stepmom passed away 10 days later rather unexpectedly. Hospice was what kept me together. Thank you!!

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When hospice came I was already doing everything that was suggested. Mom had not been coherent since Sat. AM and she died Thurs. AM. Hospice was brought in Mon. AM. It could have been easier if hospice was brought in weeks before when she first stopped eating. I appreciate

(Cont'd on Page 2)



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**AMERICAN COLLEGE OF
 PHYSICIANS CLINICAL
 GUIDELINE AIMS TO
 IMPROVE END-OF-LIFE CARE**

The American College of Physicians (ACP) has released a clinical practice guideline for improving palliative care among patients nearing the end of life. The set of evidence-based recommendations, as well as the report on the literature review upon which it is based, were published in the January 15, 2008, issue of *Annals of Internal Medicine*.

“End of life is defined as a phase of life when a person is living with an illness that will worsen and eventually cause death. It is not limited to the short period of time when the person is moribund,” states the guideline.

RECOMMENDATIONS INCLUDE:

- Regular assessment for pain, dyspnea, and depression
- Individualized attention to such concerns as coordination of care, psychological well being, and caregiver burden
- Use of therapies of proven effectiveness — including opioids — in the management of pain and unrelieved dyspnea
- Use of proven pharmacological or psychosocial interventions for depression
- Implementation of advance care planning with completed directives for all patients with serious illness

All care planning should occur “as early as possible” in the course of serious illness, states the paper, and must make certain to anticipate issues specific to each patient’s disease course and personal values. Reassessment of the care plan is necessary whenever clinical change occurs.

Source: “Evidence-Based Interventions to Improve the Palliative Care of Pain, Dyspnea, and Depression at the End of Life: A Clinical Practice Guideline from the American College of Physicians,” Annals of Internal Medicine; January 15, 2008; 148(2):141-146. Qaseem A, Snow V, Shekelle P, Casey DE, Cross JT, Owens DK, for the Clinical Efficacy Assessment Subcommittee of the American College of Physicians. “Evidence for Improving Palliative Care at the End of Life: A Systematic Review,” ibid., pp. 147-159.

**From Family Surveys:
 May 2008**

(Cont’d from Page 1)

everything that was done. Just the few minutes with hospice were comforting. The pamphlets were very helpful as well. Sincere thanks.

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Each person was an angel from God ... so loving and supportive to my mother and us. We were told to the hour what to expect and how to care for her. The volunteers, social worker, nurse, and minister were all so loving.

**From Bereavement Surveys:
 “Grief Journeys”
 May 2008**

The series of sessions made all the difference in my ability to move forward toward healing. I love the leaders and my fellow mourners. This group is comprised of amazing, empathetic, and insightful individuals. I’m grateful to have been a part of the group.

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I loved it! The Bereavement Counselors were truly amazing. I never thought I would feel this way after losing my husband just 8 months ago. I always looked forward to coming to class because of my new found friends and that I always felt SAFE!

These comments provide a snapshot of the breadth and depth of care provided by the Hope Hospice team and the manner in which we coordinate with families and health-care providers.

Complimentary informational meetings are available for patients and families. Please call: 925-829-8770

Hospice care is available for any end-stage illness including cancer, heart or lung disease, dementia, and ALS.