Nursing home residents eligible for palliative care often don't get it

By Lisa Rapaport

(Reuters Health) - Many nursing home residents who might benefit from palliative care to make them more comfortable and improve their quality of life don't receive it, a small U.S. study suggests.

Researchers examined data on 228 residents of three northern California nursing homes and found that 157 of them, or 69 percent, were eligible for palliative care based on the types of health issues they had. But none of them were receiving palliative care, and only two were getting hospice services. "We know from several studies that palliative care is often initiated too late in the disease trajectory and most nursing home residents die without the benefit of palliative care or with palliation delayed until the last days of life," said lead study author Caroline Stephens of the University of California, San Francisco School of Nursing. "We also know that palliative care in nursing homes is associated with improved quality of care, satisfaction with care, enhanced symptom management and fewer trips to the emergency room - especially when such care is initiated earlier in the disease course," Stephens added by email.

By 2030, two out of every five deaths in the U.S. will occur in nursing homes, researchers note in JAMA Internal Medicine. Even though nursing home care costs an estimated \$136 billion a year, it's often associated with poor quality and low patient satisfaction.

Palliative care aims to improve quality of life for seriously ill patients by relieving their symptoms and easing their stress, and it can be provided in addition to treatment focused on curing disease. Hospice care, by contrast, doesn't include active treatment and focuses instead on providing comfort and pain relief.

In the current study, the nursing home residents eligible for palliative care were 81 years old on average and 47 percent of them had Alzheimer's disease or dementia. Another 24 percent had congestive heart failure, 17 percent had chronic obstructive pulmonary disease and 8 percent had cancer.

Nearly all of the patients had completed questionnaires about their preferences for end-of-life care, and about 25 percent of them expressed a desire for comfort-focused treatment.

Overall, about 64 percent of family members thought residents usually or always experienced bothersome symptoms, as did 71 percent of the residents. Only about 4 percent of the residents had received assessments at the nursing home that suggested they had no more than six months to live. This likely means many residents aren't getting an accurate prognosis of their life expectancy, given the severity of their illnesses, and this may contribute to the scarcity of palliative care, the authors conclude.

The study was small and limited to just three facilities, and it wasn't a controlled experiment designed to prove whether or how palliative care might improve the quality of life for nursing home residents.

Even so, the results highlight a need for nursing homes to do a better job of communicating to patients and families about palliative care, said Dr. Gary Winzelberg, a geriatrics specialist at the University of North Carolina School of Medicine in Chapel Hill. "Assessment and treatment of pain and other symptoms is a fundamental patient right independent of whether an individual receives palliative or hospice care," Winzelberg, who wasn't involved in the study, said by email. "Concerns about inadequate symptom management should be addressed with the nursing staff, and if necessary with a nursing home ombudsperson or nursing home licensing authority," Winzelberg added.

Patients and families may be able to improve their odds of receiving palliative care and adequate services to manage comfort and quality of life by asking some key questions when they're shopping for a nursing home, said Dr. Joan Teno, a geriatrics researcher at the University of Washington in Seattle who wasn't involved in the study.

Among other things, people should ask if the nursing home has a contract for hospice services and whether they have palliative care consultation services available, Teno said by email.

"We need improved access to palliative care services in nursing homes," Teno said. "Nurse practitioner-led palliative care consult services are an important means of doing this for nursing home residents."

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