

Palliative care for patients with dementia more available but still not adequate

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A new national survey conducted by researchers from Indiana University and the Regenstrief Institute has found that while palliative care may be available for those with dementia, there are significant barriers to providing or receiving services to relieve the pain, eating difficulties and other symptoms associated with dementia.

The survey findings are reported in the Nov. 2010 issue of the [Journal of the American Geriatrics Society](#).

"Although the general public and many physicians do not associate palliative or [hospice care](#) with [dementia](#), dementia is a terminal disease and should be respected as such. Palliative care is needed throughout the illness and can provide those who are unable to communicate their needs with a better quality of life as well as lowering the stress the illness places on caregivers and the entire family," said study first author Alexia M. Torke, M.D., M.S., who is an IU School of Medicine assistant professor of medicine and geriatrics and a Regenstrief Institute investigator. She is also on the faculty of the IU Center for Aging Research and the Fairbanks Center for Clinical Medical Ethics.

Palliative care for those with dementia focuses on relieving symptoms such as pain, shortness of breath, fatigue, nausea, loss of appetite and difficulty sleeping. Hospice care provides palliative care at the final stage of life. Palliative care, which is often provided in the patient's home, can be administered through the course of the disease along with medical treatment and does not hasten death.

Hospices provide palliative care to individuals in the final weeks or months of life. According to National Hospice and Palliative Care Organization data, only 11 percent of hospice patients in the facilities had a primary diagnosis of dementia. That may be because it is often difficult to determine how close to the end of life dementia patients may be and they therefore are not provided with hospice care.

In the new study the researchers conducted telephone interviews about the provision of palliative care to patients with dementia with directors of 426 hospice and palliative care programs. A detailed online survey was completed by 80 program directors.

The study found that 94 percent of hospice and 72 percent of palliative care program directors reported that their programs have recently cared for patients with dementia. This is a substantial increase from a 1995 study that found only 21 percent of hospice programs had provided this care.

Non-hospice palliative care programs are relatively new and typically care for patients earlier in the disease before the patient is hospice eligible. To learn more about these programs, the authors asked in-depth questions of palliative care program directors. The directors indicated the existence of significant barriers to providing non-hospice palliative care. These obstacles included inadequate insurance coverage for home services by Medicare and other insurers, home health benefits that expired before the individual was eligible for hospice care as well as insufficient family and healthcare provider knowledge of palliative care for dementia.

Strategies highlighted as critical for successful palliative care for dementia and reduction of caregiver burden were an interdisciplinary team usually composed of a nurse, social worker, physician and chaplain, collaboration with community organizations and campaigns to provide

information to families and physicians.

"While it is heartening to see that most of these programs provide care for patients with dementia, there are many, many more who need this care than are receiving it. Education and policy efforts should focus on communicating with families and providers about palliative care, supporting caregivers who often are frustrated in their efforts to improve quality of life for a loved one with dementia, and reforming reimbursement structures to provide coverage earlier in the disease when patients have high needs but are not hospice eligible," said Dr. Torke.

Provided by Indiana University School of Medicine

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