Medical Xpress

Hospice improves care for dementia patients and their families

July 29 2011

Hospice services substantially improved the provision of care and support for nursing home patients dying of dementia and their families, according to an analysis of survey responses from hundreds of bereaved family members. The research comes as hospice funding has received particular scrutiny in the debate over Medicare spending.

"People whose loved ones received hospice care reported an improved quality of care, and had a perception that the quality of dying was improved as well," said Dr. Joan Teno, a Brown University gerontologist and the lead author of the study published online in the Journal of the American Geriatrics Society. "This is one of just a few studies out there that has examined dying with dementia where the predominant site of care is a nursing home and can report the benefits of hospice services. As just one example, for nursing home patients not in hospice, one in five family members reported an unmet need for shortness of breath while that was only 6.1 percent for people in hospice."

Hospice care was a great comfort to Bartley Block, of Providence, when he lost his wife, Janet, to dementia in October 2010. He and Janet received service from Home and Hospice Care of Rhode Island on and off for about a year as her condition wavered, and then ultimately declined. Block said that even after his wife began struggling to eat, she still would get up and walk. Hospice workers would help the couple take walks at the nearby Tockwotton Nursing Home and patiently feed her food that they'd puree.

"It meant a great deal to her and to me," Block said. "It not only was able to calm her, but it was calming to me. There were spiritual sessions for me. They did so much for her to make her life easier."

That kind of experience is reflected in the responses of hundreds of families in the survey. In all, Teno's team asked 538 family members of nursing home patients who died of dementia to reflect on the care and support they experienced and observed at their loved one's end of life. Of that group, 260 received hospice care and 278 did not. Among the report's key findings:

Family members of hospice recipients were 51 percent less likely to report unmet needs and concerns with quality of care.
They were 49 percent less likely to report an unmet need for management of pain.
They were 50 percent less likely to have wanted more emotional support before their loved one's death.
They rated the peacefulness of dying and the quality of dying more positively than families whose loved ones did not receive hospice care.

The survey also found that people who felt their loved one received hospice care "too late" had stronger concerns about care and support in almost every one of the survey's many measures. They felt worse off than people who had no hospice care at all.

"These are people who get slammed around the healthcare system in the last days of life," Teno said. "These are people with transitions who go from an acute care hospital to a nursing home in the last 24 hours. They are reacting to a set of circumstances that shouldn't have occurred."

Dementia is a particularly important area to study, Teno said, because the untreatable condition has only recently gained recognition as being terminal illness. The unpredictability of its progress, however, has led to

a large number of dementia patients staying in hospice for longer than people with other conditions. That has made dementia a focus for scrutiny in discussions of cost.

But the study provides new evidence that hospice provides a meaningful benefit to nursing home patients with dementia and their families, such as the Blocks, Teno said. Policymakers should therefore factor in that evidence as they discuss the future of Medicare funding.

"It is a terminal illness," Teno said. "As we do payment reform we should preserve access and quality of care for those persons dying of dementia."

Provided by Brown University

Citation: Hospice improves care for dementia patients and their families (2011, July 29) retrieved 4 May 2024 from
https://medicalxpress.com/news/2011-07-hospice-dementia-patients-families.html