

MDS Alert

Research Study: Families Share Their Impressions of Hospice Care in Nursing Homes

While positive, the research findings include a caveat.

In an e-mail interview with MDS Alert, Brown University's **Joan Teno, MD, MS**, described a recent research study that she and colleagues published in the Journal of the American Geriatrics Society as "one of the largest studies looking at the quality of hospice for persons dying from dementia."

In the study, Teno and the other researchers "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," states a Brown University press release on the study. "Of that group, 260 received hospice care and 278 did not." The study found that family members were:

"51 percent less likely to report unmet needs and concerns with quality of care.

49 percent less likely to report an unmet need for management of pain."

Teno noted in her e-mail comments that "screening for and detecting pain is an important skill in this population because you are relying on observed signs of distress. The patient is unable to tell you she is experiencing pain." In addition, "correctly using opiates is an important skill that many physicians and nursing home staff aren't aware of."

Among "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," said Teno in the release.

Family members also "rated the peacefulness of dying and the quality of dying more positively than families whose loved ones did not receive hospice care," states the release.

Caveat: "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," cautions the release. "These are people who get slammed around the healthcare system in the last days of life," Teno said in the release. "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."

In the e-mail exchange with MDS Alert, Teno addressed what prompted her to do the study, which is the increasing "policy focus on rising Medicare expenditures for hospice in the nursing home with limited research focusing on the 'added value' of hospice services for dying patients and their families." Teno pointed out that hospices provide the following extra services:

- A hospice aide who supplements the care provided by the nursing home CNA;
- Spiritual and bereavement counselors who "are there to help the staff and family with one of the most difficult life transitions;"
- Volunteers. Teno reported that her favorite program in the nursing home setting provided by the hospice where she works is called the "Vigil" program. "These are volunteers who work two-to-four hour shifts around the clock so that no patient needs to die alone. Often, families are separated by thousands of miles. For their peace of mind, just knowing that a volunteer is there to sit with their loved one is tremendous relief."