

## *Dying Patients Get Little Pain Relief, Emotional Support From Staff*

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### ***End-of-Life Care Inadequate***

#### ***Dying Patients Get Little Pain Relief, Emotional Support From Staff***

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WebMD Medical News

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on Tuesday, January 06, 2004

Jan. 6, 2004 -- A new study shows that end-of-life medical care is best with hospice service vs. hospital or nursing home care.

The research shows many patients dying in hospitals and nursing homes get inadequate physical and emotional care from doctors and nurses who treat them. But this is rare when they receive hospice services during their final days, according to the largest study to date measuring the quality of end-of-life medical care.

After reviewing the deaths of nearly 1,600 patients in 22 states and conducting 120 interviews with those patients' relatives, Brown University researchers say that nearly three in four family members report "excellent" care from hospice services -- in which end-of-life care is either provided at a special facility or at home, largely by family members assisted by visiting specially trained medical personnel. Meanwhile, fewer than half of those whose loved ones spent their final days in other institutions were satisfied. Specifically, the researchers report:

- According to respondents nearly 25% dying patients did not get enough pain medication, and sometimes got none at all. This was more likely to occur in nursing homes as compared with hospice care.
- One in three family members say that hospital and nursing home staff didn't provide enough emotional support.
- Families reported more concerns with the patient being treated with respect when dying, when patients were at a nursing home, hospital, or home with home health

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services, compared with persons who died at home with hospice services. In addition, 25% felt the doctor's communication was poor.

- The kicker: Only 15% of respondents said they thought institutional healthcare providers had enough knowledge of the patient to provide the best care possible.

"This lack of support is often someone in the institution who isn't doing the most basic things, even offering common courtesies," researcher Joan Teno, MD, tells WebMD. "When I look at the data, I'm very concerned because by 2020, some 40% of Americans will be dying in nursing homes. This is a major calamity in our healthcare system."

Teno, a professor of community health and medicine at Brown Medical School and associate director of its Center for Gerontology and Health Care Research, says the problems often stem from staffing problems. "Go to any hospital or nursing home and staffing has been cut to bare bones," she says. "Often, they don't have a registered nurse passing out medications, but a licensed practical nurse. That influences choices in care, since a LPN can't give intravenous pain medication." Even when nurses administer medication, they're so busy that they can't tend to the emotional needs of patients or their families.

"The take-home message is that dying patients in a hospital or nursing home need loved ones to act as an advocate, and very clearly, they need to be there in multiple shifts to make sure the patients gets proper care," Teno says. "Based on my own experience as a physician, I can tell you that having someone there who advocates for you improves medical care, since patients can't often do it themselves."

Agreed, says Robert Buckman, MD, an oncologist at the University of Toronto and author of *I Don't Know What to Say* and other books of end-of-life medical care.

"For instance, pain medication often results in constipation and for some dying patients, that's a bigger problem than the pain," he tells WebMD. "Patients often feel embarrassed mentioning it, but a relative can - and better ensure someone can address it. Often, nurses and physicians don't realize this." He recommends that relative "advocates" keep a "shopping list" with the key medical care issues to discuss with caregivers.

Buckman was not involved with Teno's study, published in this week's *Journal of the American Medical Association*, but says he isn't surprised by its findings.

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"One of the biggest stumbling blocks, in all of us, is a difficulty in communicating with end-of-life patients -- and that includes healthcare providers," he says. "It's a very sensitive subject and we just don't know how to talk to them." Recently, Buckman and other end-of-life specialists began producing videos, sold to medical schools and hospitals, which instruct doctors and nurses on how to better treat dying patients.

One thing loved ones can advocate: Getting hospice care for the patient, says another expert not involved in Teno's research.

"This is a wonderful and very important study, and shows there is a very marked difference in quality and satisfaction of care in patients who receive care from hospice as compared to those who do not," says Diane Meier, MD, director of the Palliative Care Institute at Mount Sinai School of Medicine in New York City.

"There are a number of factors for this, but one important one is that when you're with hospice, you can talk about what is really happening and what you want to accomplish. You can actually begin to speak the truth," Meier tells WebMD. "This is of enormous value to families who have often been moving through a healthcare system that pretends the patients are going to get better, when they're really not.

"Hospice is a way for dying patients to live as well as possible, and it's one of the most rational and intelligent insurance benefits. It pays for medications, equipment, doctors, nurses, social workers and aides to come to house and help you -- all at no cost to you."

SOURCES: Teno, J, *Journal of the American Medical Association*, Jan. 7, 2004; vol 291; pp 88-93. Joan Teno, MD, professor, Community Health and Medicine; associate director, Center for Gerontology and Health Care Research, Brown Medical School, Providence, RI. Robert Buckman, MD, professor, medicine, University of Toronto Medical School; physician, Princess Margaret Hospital, Toronto. Diane Meier, MD, director, The Lilian and Benjamin Hertzberg Palliative Care Institute, Mount Sinai School of Medicine, New York City.

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