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WELL; Treating Dementia, but Overlooking Its Physical Toll

By TARA PARKER-POPE

Dementia is often viewed as a disease of the mind, an illness that erases treasured memories but leaves the body intact.

But dementia is a physical illness, too -- a progressive, terminal disease that shuts down the body as it attacks the brain. Although the early stages can last for years, the life expectancy of a patient with advanced dementia is similar to that of a patient with advanced cancer.

The lack of understanding about the physical toll of dementia means that many patients near the end of life are subjected to aggressive treatments that would never be considered with another terminal illness. People with advanced dementia are often given dialysis and put on ventilators; they may even get preventive care that cannot possibly help them, like colonoscopies and drugs for osteoporosis or high cholesterol.

"You can go to an intensive-care unit in most places," said Dr. Greg A. Sachs, chief of general internal medicine and geriatrics at Indiana University School of Medicine, "and you'll find people with dementia getting very aggressive treatment."

The continued focus on treatment to prolong life often means that pain relief is inadequate, and symptoms like confusion and anxiety are worsened. A new study suggests that family members would be far less likely to subject their loved ones to such treatment if they had a better understanding of dementia as progressive, debilitating illness that ultimately shuts down the body after years of mental deterioration.

Harvard researchers recently followed 323 residents of 22 nursing homes. All had end-stage dementia, meaning that they no longer recognized family members, could speak fewer than six words and were incontinent and bedbound. During the 18-month study period, more than half of the patients died.

During the last three months of life, 41 percent of the patients received at least one "burdensome" treatment, like transport to the emergency room, hospitalization, feeding tubes or intravenous treatments. Advanced dementia patients are particularly prone to infections because of incontinence, risk of bedsores, a depressed immune response and inability to report symptoms.

When the investigators looked more deeply into the reasons for treatment decisions, they discovered stark differences based on what family members knew about dementia. When they understood its progressive and terminal nature, only 27 percent of the patients received aggressive care. For family members who did not understand the disease, the figure was 73 percent.

"When family members understood the clinical course of dementia and the poor prognosis, the patients were far less likely to undergo these distressing interventions," said the study's lead author, Dr. Susan L. Mitchell, senior scientist at the Institute for Aging Research of Hebrew SeniorLife in Boston. "Dementia is a terminal illness and needs to be recognized as such so these patients receive better palliative care."

The study also found that pain control was often inadequate. One in four subjects were clearly suffering from pain, but that number may understate the problem, because the patients were unable to talk about their pain.

Dr. Sachs, at Indiana, notes that care for patients with dementia has changed very little in the past 30 years. As a teenager, he watched his grandmother decline from Alzheimer's disease. During her final months, she was repeatedly treated for infections and put in restraints or sedated to control agitation.

"Seeing my grandmother in that state was so distressing that my mother eventually stopped taking the grandchildren to visit," Dr. Sachs wrote last week in an editorial in *The New England Journal of Medicine*. "My grandmother had little in the way of comfort or company toward the end. In my medical training, I learned how my grandmother's final months were typical for people dying from dementia."