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Study suggests new tack in treating, caring for Alzheimer's patients

Don't treat them like children, study suggests

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Researchers from Kansas are offering a rare glimpse into the interior world of Alzheimer's patients with a new study set to be presented at a major international conference in Chicago this week.

The study, while small, is highly suggestive. Key findings indicate that patients—even those who may seem deeply disoriented or cognitively impaired—dislike being patronized or treated as if they are children.

This suggests that a sense of adult identity remains intact in people with dementia, even when individuals aren't able to remember how old they are, where they are, what day it is or which family members are alive and present.

How people experience Alzheimer's disease, especially in its latter stages, is a mystery because those who suffer the illness lose the ability to articulate their thoughts and feelings.

In the Kansas study, researchers tried to get around this hurdle by videotaping 20 elderly men and women living in three nursing homes during the course of a day as aides helped them bathe, brush their teeth, dress, eat and take their medicines, among other activities.

Researchers then analyzed the tapes, assessing how the manner in which staff interacted with patients influenced patients' behavior and the quality of care.

They discovered that when nursing aides communicated in a kind of baby talk for seniors—using a high-pitched sing-song tone, comments like "good girl," diminutives like "honey" and language that assumed a state of dependency ("are we ready for our bath?")—Alzheimer's patients were twice as likely to resist their efforts to help.

Patients would turn or look away, grimace, clench their teeth, groan, grab on to something, cry or say "no"—behaviors that can be read as indications of distress at being patronized or infantilized, said lead researcher Kristine Williams, an associate professor at the University of Kansas School of Nursing.

"Communication can really impact care," she said.

The observation applies equally to people with Alzheimer's disease being cared for at home, a group making up the vast majority of the estimated 5.2 million men and women living with this illness in the U.S., other experts suggest.

"What this new study does is really validate anecdotal evidence and folk wisdom about how we should communicate with people with dementia," said Dan Kuhn, director of the professional training institute at the Alzheimer Association's Greater Illinois chapter.

Twenty years ago, a very different vision prevailed, Kuhn said. Then, it was thought that if an Alzheimer's patient seemed disoriented—if a woman thought she was in her 20s, for instance, or that she was speaking to her brother instead of a son—it was important to point out the mistake and correct her, lest she regress.

Today, the approach is to "enter into a patient's reality instead of forcing that person into our reality," Kuhn explained. "Don't remind them of their disability. Don't tell them they're wrong. And by all means, don't be condescending or critical."

Kathleen Ustick, who oversees Alzheimer's services at Lutheran Life Communities in Arlington Heights, gives an example. If a man with dementia asks repeatedly for his mother, who is deceased, she tells staff to listen closely to his tone of voice and try to read his body language.

If the man seems agitated or panicked, "I think the meaning behind his words is, 'I don't feel safe right now.' Mom represents safety, security, love. And the message for staff is, we have to help calm this person down," she said.

A good way to do that would be to say something like, "No, I haven't seen your mother. But why don't you stay with me for a while?" Ustick suggested.

When Darby Morhardt ran a support group for men and women in the early stages of Alzheimer's disease at Northwestern University's Feinberg School of Medicine, members would frequently talk about how painful it was when people talked down to them or "marginalized" them by leaving them out of conversations.

"They were very angry when they felt they were treated as if they were incompetent," said Morhardt, now education director at Northwestern's Cognitive Neurology and Alzheimer's Disease Center. "They wanted to be treated with respect."

One of those patients was Les Dennis, who lives in Bloomington with his wife, Barbara, and has progressed to moderate Alzheimer's. The Tribune profiled Dennis in an article on early-stage Alzheimer's several years ago, when he was still able to answer questions in an interview.

Today, Barbara Dennis is convinced her husband "understands things 80 to 90 percent of the time," but Les Dennis has lost the ability to express himself consistently, especially when he feels pressured, hurried, displaced or uncomfortable with people around him.

A small incident recently at an adult day-care center illustrates the point. That day, staff moved Dennis from a table where he was making a puzzle because another activity was scheduled. He came home angry and downcast, with the puzzle undone. Putting two and two together, Barbara Dennis arranged for a small table to be set aside for his puzzle work—an activity that makes him feel successful.

It would have been easy to interpret Les Dennis' irritated mood as a symptom of dementia, not an expression of a frustrated need, his wife said.

Barbara Dennis made another important connection with her husband last week as he was watching a nightly news report about Sens. Barack Obama (D-Ill.) and John McCain (R-Ariz.), the presumptive presidential nominees.

"Where are the girls?" Dennis called out to his wife, according to her account.

What girls, she asked herself, running through the possibilities. "Oh, you mean the girls on CNN," she volunteered.

"No, the girls, the girls who were on," she remembers him responding.

Then it clicked. Obama, McCain, girls . . . it must be Sen. Hillary Clinton (D-N.Y.) he was talking about, the "girl" who was no longer there. "The girl you're talking about, you mean Hillary, don't you," Barbara remembers saying, at which point Dennis brightened.

"Yes, yes, that's who," he answered. His wife had understood his thoughts, when another person might think he was being silly or lost in a fantasy.

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Read more about communicating with Alzheimer's patients at Judith Graham's blog ,TRIAGE, www.newsblogs.chicagotribune.com/triage

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