Dementia Diagnosis Brings Patient, Caregiver Relief

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ORLANDO — Contrary to many physicians' fears, disclosing a diagnosis of dementia to patients and their caregivers does not produce negative reactions, and in some cases actually lowers their anxiety and depression levels, according to a survey.

The findings should encourage physicians to be more up front when faced with reporting such a diagnosis, said the study's lead investigator Brian D. Carpenter, Ph.D., of the department of psychology at Washington University, St. Louis.

In a review paper, Dr. Carpenter's team reported that reluctance to disclose a dementia diagnosis is common among physicians (Gerontologist 2004;44:149-58).

"On average, somewhere around 50% of physicians say they don't routinely tell patients and caregivers when there is a diagnosis of dementia because they are worried about an extremely negative, even suicidal, reaction," he said in an interview. "They just tell them it's normal aging."

But in his study, which he presented as a poster at the annual meeting of the Gerontological Society of America, Dr. Carpenter found that, among 80 patient-caregiver dyads, initial reactions within 3 days of a diagnosis of dementia were not negative—even among those who did not expect such a diagnosis.

The longitudinal study recruited patients and their caregivers at the time of their initial contact with the Washington University Alzheimer's Disease Research Center. Surveys assessing baseline data on self-reported anxiety and depression were mailed to all subjects as soon as their initial appointment was scheduled. Similar surveys were then obtained by telephone 2-3 days after a diagnosis had been given.

Depression was measured using the Geriatric Depression Scale, and anxiety was measured using the State-Trait Anxiety Inventory. Participants were asked about their diagnostic expectations.

In total, 67% of patients were diagnosed with dementia (21% with mild dementia and 46% with very mild dementia), and the remaining 33% had no dementia.

Regarding diagnostic expectations, caregivers were more accurate than patients when estimating the likelihood of a dementia diagnosis. More than half (52%) were correct when they said they expected a dementia diagnosis, compared with 32% of patients.

Among those who said they did not expect a diagnosis of dementia, 15% of caregivers were incorrect, compared with 34% of patients. Regardless of their diagnostic expectations, patients experienced no change in depression and a decrease in anxiety after receiving their diagnosis, regardless of what the diagnosis was.

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The picture was less straightforward for caregivers. Regardless of their expectations, depression levels decreased with a diagnosis of dementia, and remained unchanged when dementia was not diagnosed.

Anxiety levels were influenced by their diagnostic expectations and not by the actual diagnosis. Anxiety decreased when caregivers expected a dementia diagnosis (regardless of the actual diagnosis) and remained unchanged when they did not expect a dementia diagnosis.

"We think many of the patients and caregivers feel better after they receive the news because they anticipate that there's something wrong. They're not really sure what in some cases, and then when they have a diagnosis, a label, sometimes that results in a great sense of relief," Dr. Carpenter said.

"When they get the news, they are also shuttled toward more services so they get a better sense of what they can do to manage their disease," he added.

Most of the caregivers in the study were family members: 58% were spouses, 23% were children or in-laws; and 6% were other family. Thirteen percent were friends.

The ongoing investigation will measure if and how the subjects' reactions may change with time. Participants will be assessed 1 month, 6 months, and 1 year after the diagnosis, Dr. Carpenter said. ■