

# With Dementia Diagnosis, Knowledge Is Power

*Anxiety and depression levels may go down after diagnosis is disclosed to patients and caregivers.*

BY KATE JOHNSON  
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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 also asked about their diagnostic expectations in the first survey.

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.

The picture was less straightforward for caregivers. Regardless of their expectations, depression levels decreased with a diagnosis of dementia and remained unchanged when it was not diagnosed. Anxiety levels were influenced by their 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 towards more services so they get a better sense of what they can do to manage their disease."

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.

"Our hypothesis is that we will see that patients' depression and anxiety either remains stable or gets better, and the caregivers are actually the ones we are expecting will experience more stress" as patients deteriorate, he said.

"This raises difficult issues for clinicians about who their patient is," Dr. Carpenter said. "The patient is the person they are diagnosing, but it is the caregivers who have to provide more and more services, while watching this person [who] they care about slowly decline. And so the burden of responsibility for clinicians, we think, is to think more broadly about who the patient is." ■

## Acetaminophen Increases Activity Levels in Patients With Dementia

BY MARY ANN MOON  
Contributing Writer

Regular administration of acetaminophen raises levels of general activity, social interaction, engagement with media such as television or magazines, and worklike activity in elderly patients with moderate to severe dementia, reported John T. Chibnall, Ph.D., of St. Louis University School of Medicine, and his associates.

Regular dosing with the analgesic presumably addresses untreated pain in these patients, who often cannot report pain and who have a high prevalence of comorbidities, including arthritis, fractures, and diabetes, which can generate significant pain, the researchers said.

Their study findings imply that untreated pain inhibits dementia patients' active engagement with the environment and promotes their withdrawal, Dr. Chibnall, a professor of psychiatry at the university, and his associates added (*J. Am. Geriatr. Soc.* 2005;53:1921-9).

The researchers evaluated behavioral changes in 25 elderly (mean age 85.9 years) nursing home residents with moderate to severe dementia during an 8-week study. The subjects had

Alzheimer's disease, degenerative dementia, or multi-infarct dementia and had resided in nursing homes for a mean of 35 months. All had moderate to severe cognitive decline and impairment in the activities of daily living.

The subjects were given either two 500 mg tablets of acetaminophen or two placebo tablets at mealtimes every day for 4 weeks, then switched to the other treatment for 4 weeks, following a 1-week washout period between the two phases.

Their behavior was evaluated under both conditions using the Dementia Care Mapping (DCM) tool, in which trained "mappers" observed patients for 5 hours between 9 a.m. and 2 p.m., when subjects were likely to be most active. At 5-minute intervals, the observers quantified a wide range of behaviors across 24 domains such as direct or passive social involvement, creative activities, exercise, listening to music, and eating.

The subjects also were evaluated using the Cohen-Mansfield Agitation Inventory (CMAI), a 29-item scale in which nursing home personnel assessed how often the patients had displayed a variety of agitated behaviors during the preceding 2 weeks.

With acetaminophen, subjects clearly showed higher levels of general activity, spent more time in direct social interactions and in engagement with media, and participated more in worklike activity. They also spent significantly less time alone in their rooms.

However, subjects also spent more time in passive social involvement, more time talking to themselves or to imaginary others, and slightly more time experiencing unattended distress while on acetaminophen.

Agitation did not decrease, and the use of both routine and as-needed psychotropic medications did not decrease, while the subjects were taking acetaminophen. However, the levels of agitation and the frequency of agitated behaviors were quite low in this study, which may have confounded the results. Similarly, the use of psychotropic drugs was quite low overall, leaving little room for the intervention to show an effect, the researchers noted.

Overall, the results support the contention that pain dampens dementia patients' activity and restricts their engagement with the environment, while prophylactic treatment of that pain reverses these effects. ■

## Testosterone Replacement May Improve QOL in Alzheimer's

BY MARY ANN MOON  
Contributing Writer

Testosterone replacement improved the quality of life for men with Alzheimer's disease and low serum testosterone levels in a small preliminary study, reported Po H. Lu, PsyD., and associates at the University of California, Los Angeles, David Gefen School of Medicine.

Testosterone therapy has been shown to improve mood, muscle mass, strength, bone density, libido, and certain cognitive functions in hypogonadal men who are otherwise healthy, but this is the first study to report that testosterone may exert positive effects in Alzheimer's disease (AD), the researchers said (*Arch. Neurol.* 2006;63:1-9).

They assessed testosterone's effects on a variety of cognitive, behavioral, mood, and quality of life (QOL) measures in 16 men with mild to moderate AD and 22 healthy elderly men who served as control subjects. The study subjects were randomly assigned to apply either testosterone patches (7 patients and 10 controls) or placebo patches (9 patients and 12 controls) every day for 6 months.

Five of the AD patients and six of the control subjects were hypogonadal at baseline, with

serum testosterone levels below 298 ng/dL.

As a group, AD patients who received testosterone showed a significantly better QOL, as assessed by their caregivers using the 13-item Quality of Life-Alzheimer's Disease scale, than AD patients who received placebo. This effect occurred because the testosterone recipients showed a nonsignificant trend toward improved QOL over the 6-month study period, while the placebo group showed significant declines.

Similarly, the AD patients who received testosterone showed either greater improvement or less decline in three measures of visual-spatial cognitive functioning, compared with the AD placebo group and the control groups.

Both the improved QOL and the improved cognitive functioning were correlated with increased serum testosterone levels.

Two AD patients and four control subjects withdrew from the study because of adverse effects, including skin rash at the testosterone patch application site. None of the AD patients who received testosterone showed more aggression or agitation than placebo subjects, and caregivers did not observe any marked changes in patients' sexual behavior. ■