

# Lack of diagnosis creates added risks for those with dementia

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A Johns Hopkins study on data from more than 7,000 older Americans has found that those who show signs of probable dementia but are not yet formally diagnosed are nearly twice as likely as those with such a diagnosis to engage in potentially unsafe activities, such as driving, cooking, and managing finances and medications.

The findings, reported in the June issue of *Journal of the American Geriatrics Society*, highlight the need, investigators say, to make patients and their families explicitly aware of the memory disorder so that physicians and loved ones can take protective steps.

"When patients receive a formal [dementia](#) diagnosis, their families are typically aware that, at some point, their loved ones will not be able to drive or will need more help with their medicine," says study leader Halima Amjad, M.D., M.P.H., a fellow in the Johns Hopkins University School of Medicine's Division of Geriatric Medicine and Gerontology. "But when people are undiagnosed, families and friends may ignore or be unaware of functional problems that already exist."

Previous studies have clearly documented safety issues for [dementia patients](#), Amjad notes, but have largely focused on single issues in small patient samples. For a broader look, she and her colleagues used data from 7,609 people drawn from the National Health and Aging Trends Study, an ongoing Johns Hopkins research study begun in 2011 that's gathering health information on Medicare beneficiaries ages 65 and older nationwide. Subjects are periodically interviewed and take cognitive and physical exams to assess their health as they age.

For the new study, Amjad's team classified these volunteers as having diagnosed dementia if they or a companion reported that they received a formal diagnosis from a doctor, or as having probable but undiagnosed dementia if they had no formal

diagnosis but scored below a certain threshold on cognitive tests or interviews with a caregiver responding on their behalf. Two additional groups were classified as having possible dementia or no dementia.

All participants were asked about activities or living conditions that are potentially unsafe in dementia, including providing care to another person, driving, preparing hot meals, handling finances, managing medications, going alone to doctors' visits or multiple falls. In addition, they answered questions about unmet needs—whether they ever went without eating, bathing, clean laundry and groceries, or stayed in the home or in bed because they had insufficient help.

Analysis showed that those with dementia, either diagnosed or undiagnosed, were less frequently engaging in potentially unsafe activities than those with possible or no dementia. For example, about 23 percent of older adults with probable dementia were driving, compared to 59 percent with possible dementia and 84 percent with no dementia. Of older adults with probable dementia, 37 percent managed their own medications at least some of the time, compared to 93 percent of those without dementia. "That in itself is good news, though the numbers are still important from a public health and safety standpoint," Amjad says. "Either the patients themselves or their family members are self-regulating and doing these activities less frequently as their disease is progressing."

However, she says, the results revealed that those whose dementia was undiagnosed were significantly more likely to be taking part in unsafe activities, compared to those with a formal dementia diagnosis. For example, while about 17 percent of the volunteers with diagnosed dementia were still driving, nearly 28 percent of those with undiagnosed dementia were doing so.

Similarly, about 12 percent of those with diagnosed

dementia were still handling their finances, but about 29 percent of those with undiagnosed dementia were. Overall, about 17 percent of those with diagnosed dementia were still preparing hot meals for themselves, but about 42 percent of those with undiagnosed dementia were. And nearly 22 percent of those diagnosed were still handling their own medications, while around 50 percent of those with undiagnosed dementia were.

"There are a couple of important questions we are raising in this research," says David Roth, Ph.D., director of the Johns Hopkins Center on Aging and Health and professor of medicine at the Johns Hopkins University School of Medicine. "First, are those with dementia receiving adequate medical care, including accurate and up-to-date diagnoses? Second, are diagnoses of dementia being properly communicated to patients and their families?"

The findings should be a wake-up call to physicians who care for the elderly and family members whose loved ones might be developing dementia, Amjad says.

"If elderly patients are having difficulty with activities, they may benefit from a physician formally screening them for dementia," she says. "But families are really the front line in recognizing when someone shouldn't be driving or needs more help with managing medicines. That means being watchful and aware as loved ones get older and dementia is more likely."

An estimated 5 million people in the U.S. have some form of dementia, including Alzheimer's disease, and the prevalence is projected to nearly triple by 2050. Multiple studies have suggested that about one-half of those with dementia are undiagnosed.

Provided by Johns Hopkins University School of Medicine

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