LISTEN MORE CAREFULLY TO ALZHEIMER’S CAREGIVERS

To the Editor: It is not unusual for caregivers of people with Alzheimer’s disease (AD) such as myself to report that their loved ones were initially misdiagnosed and treated for stress, anxiety, or depression. Maybe this misdiagnosis is because emotional stress often manifest symptoms of confusion and memory loss similar to those associated with AD, and it can be difficult for doctors to differentiate. Maybe it is because doctors know that they cannot effectively treat AD, but they can often successfully treat symptoms caused by emotional stress. Regardless of the reason, many caregivers note that their doctors simply did not take sufficient time to listen carefully to the AD symptoms they were reporting about their spouses.

It is also not unusual for caregivers to report that a contributing factor to their spouses’ misdiagnosis was a high Mini–Mental State Examination (MMSE) score. My wife, who is now in moderate stage AD, repeatedly scored very high on the MMSE. That was another contributing factor to her 2 years of misdiagnosis, despite my noting and reporting obvious AD symptoms to her doctors. My wife now undergoes annual neuropsychological testing each year as a participant in a longitudinal research study at an Alzheimer’s Disease Research Center, and the MMSE continues to be an unreliable diagnostic test for her. With few exceptions, her scores on various assessments of executive function of the brain, memory, language, attention, and visual spatial abilities have declined significantly during these past 3 years, yet whereas nearly a dozen subtest scores were at the 0–1% level on last year’s annual assessment, her MMSE score (25) remained high.

Most doctors are time pressured and understandably want to use an AD screening test that can be administered and scored quickly, but quick screening tests such as the MMSE are simply not always effective. As Dr. Peter V. Rabins, Director of the Division of Geriatric Psychiatry and Neuropsychiatry at Johns Hopkins School of Medicine, noted, “The MMSE cannot be used to diagnose dementia.” Whereas the MMSE can be used to screen for cognition disorders, its limitations include “poor ability to detect minor changes in cognition—that is, mild dementia—and its lack of testing for certain cognitive functions such as executive function.”1

Several journal articles in recent years have questioned the continued use of the MMSE for AD screening. One recent comprehensive review notes how the MMSE “may hide too much about what the person can or cannot do.” The study’s author states firmly, “Above all, a diagnosis of dementia should not rely chiefly on a MMSE total score. The focus should be on the individual, their history, their strengths, and weaknesses.” In other words, the doctor should strongly consider a caregiver’s observations because only the caregiver can provide that history about strengths and weaknesses.2

Researchers at Washington University School of Medicine in St. Louis administered a 2-minute questionnaire (AD8 Screening Interview) to friends and family members of individuals being screened for dementia. When comparing results of the AD8 with results of the MMSE, the AD8 was “superior to conventional testing in its ability to detect early signs of early dementia. It (the AD8) can’t tell us whether the dementia is caused by Alzheimer’s or other disorders, but it lets us know when there’s a need for more extensive evaluations to answer that question.”3 Nevertheless, despite this knowledge about the many failings of the MMSE—and the growing body of research indicating the greater effectiveness of caregiver observations—the MMSE continues to be widely used, and misused, often as the sole screening test for AD, and caregivers continue to report that their observations are being ignored.

Many individuals will present with no discernible AD symptoms during office visits, but doctors must listen more carefully to caregivers’ observations. When a caregiver says that your patient is experiencing serious cognitive or memory problems—even if you do not see these symptoms present in your office—please take these observations more seriously. Such observations should lead to a much more-comprehensive evaluation beyond a simple screening test or a referral to a neurologist or geriatric psychiatrist more familiar with AD symptoms for a complete neuropsychological evaluation.

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REFERENCES

