

# Many Patients Not Told of Dementia Diagnosis

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STOCKHOLM — Clinicians shy away from disclosing a diagnosis of mild cognitive impairment and its potential to convert to Alzheimer's disease.

They also differ in how they word the disclosure when they opt to share the diagnosis and prognosis with the patient and relatives. For their part, families may not want patients to know when they

have been diagnosed with Alzheimer's disease, according to reports presented at the 12th Congress of the International Psychogeriatric Association.

"In dementia, disclosure is not common clinical practice"—only about 15% of professionals disclose the diagnosis to patients—"but there seems to be a trend toward more openness about the diagnosis," said Els Derksen, R.N., a researcher at the Alzheimer's center at St. Radboud University Medical Center, Nijmegen, the

Netherlands. But in contrast to several studies of disclosing a diagnosis of dementia, no studies have been published about disclosing a diagnosis of mild cognitive impairment (MCI).

Ms. Derksen discussed the responses of physicians who completed an optional appendix to a questionnaire that was a part of the European DESCRIPA (Development of Screening Guidelines and Diagnostic Criteria for Predementia Alzheimer's Disease) multicenter study.

The study included patients with suspected MCI.

In discussions with 101 patients with MCI or possible early dementia, physicians told 28% that they had MCI, 62% that they had abnormal memory or cognitive problems, 4% that they had worrisome symptoms or depression plus memory problems, 3% that they had normal memory problems or forgetfulness, 2% that they had amnesic symptoms, and 1% that they had mixed and vascular dementia.

Among 100 patients who received information about their prognosis, physicians told 4% nothing, 18% that the prognosis was unknown or uncertain, 20% that the condition probably would remain stable, 10% that it probably would progress, and 66% that follow-up would be indicated. (The percentages do not add to 100% because follow-up was included with other information for some patients.)

When physicians were asked to describe their use of the term Alzheimer's disease in their interactions with a total of 80 patients, they reported that they did not use the term at all in 23%. Physicians told 72% that they could possibly convert to Alzheimer's disease. They told 4% of the patients that they had Alzheimer's disease or predementia, and 1% that Alzheimer's was not present or detected.

In nearly all instances, the same information about diagnosis, prognosis, and specific use of the term Alzheimer's disease was given to patients' families.

Alzheimer's disease in its predementia stage was suspected in 77 of 101 patients. A physician's decision to inform a patient of the diagnosis was most often guided by the patient's wish to know, a belief in shared decision making between physician and patient, and initiation of medication.

In a separate study, family members of patients with Alzheimer's indicated that they did not wish to reveal the diagnosis to patients primarily because of a concern for causing anxiety and depression.

Filip Bouckaert, M.D., of the department of old age psychiatry at University Centre St. Jozef, Kortenberg, Belgium, interviewed 50 family members of outpatients with Alzheimer's disease and 50 family members of inpatients with the disease. Their results, reported during a poster session at the congress, showed that 57% did not want the patient to be told the diagnosis; this included 42% of family members of outpatients and 72% of family members of inpatients.

Half of family members who did not want the patients to know about the diagnosis cited the possibility of causing anxiety or depression as the main reason not to tell. Similarly, half of those who thought the patient should be told said that his or her right to know was the primary reason to tell the patient the diagnosis.

More family members approved of the disclosure of diagnosis in patients with mild dementia (86%) than in those with moderate (39%) or severe (31%) dementia.

Despite the wish by most family members not to disclose the diagnosis to their affected relatives, 90% of family members wanted to be told their diagnosis if they developed Alzheimer's disease. ■

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