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Increasing Disclosure of Dementia Diagnosis

The issue of disclosure of a dementia diagnosis and what is best for patients and families has been debated around the world over the past 2 decades.¹⁻⁶ Literature reviews continue to show that clinicians who suspect dementia often do not disclose or document a formal diagnosis.^{3,4} As a result, approximately 50% of patients with dementia have no documentation of diagnosis in their medical record (Figure 1).⁷ A recent study of caregivers' experience with the diagnostic process reported that it took >2 years after the initial physician visit for some patients to receive a dementia diagnosis.⁸ Caregivers also reported a sense of reluctance among doctors to disclose the diagnosis.⁸

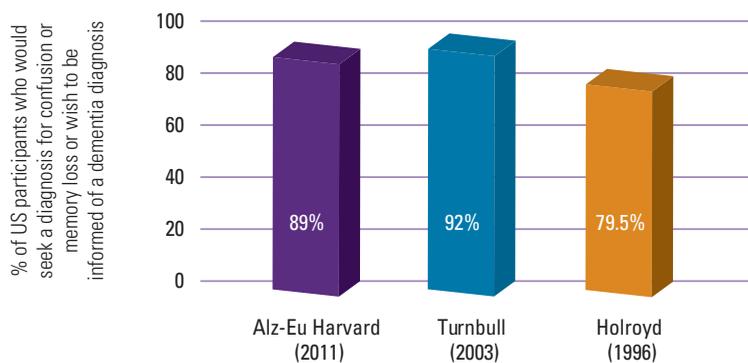
Figure 1. 50% of patients with dementia have no medical record of diagnosis



Divergence Between Common Perceptions About Dementia Diagnosis and Published Data

Physicians have cited many barriers to diagnosing dementia, including doubts about the value of diagnosis given limited treatment options, concern over risk of misdiagnosis, and lack of knowledge of local dementia support services.⁷ However, based on published data, perceptions that disclosure of dementia diagnosis is not preferred or causes psychological distress among individuals and family members should be challenged.

Figure 2. Surveys of US adults
Majority want to know dementia diagnosis



A majority of patients want to know if they have Alzheimer's disease

A recent 5-country survey⁹ (France, Germany, Poland, Spain, and the US) examining public attitudes about Alzheimer's disease found the following:

- More than 80% of all adults (N=2,678) and 89% of US adults (N=639) responded that if they had memory or confusion symptoms, they would go to a doctor to determine if the cause was Alzheimer's disease. This US finding is consistent with previously published reports over the last 2 decades (Figure 2).^{10,11}
- Of the US respondents, 65% said that even if they were asymptomatic they would likely or somewhat likely be interested in getting a medical test that would determine if they would get Alzheimer's disease in the future (if one becomes available).

Most family members appreciate the benefits of diagnosis

Connell and colleagues surveyed 178 black and white adults who had a family with Alzheimer's disease. The purpose of the study was to examine racial differences in the perceived benefits and barriers to a dementia diagnosis.⁶

- More than 75% of family members rated the following benefits of diagnosis as being very or extremely important: 1) let family know what was wrong with relative; 2) allowed family to get information about Alzheimer's disease; and 3) allowed family to plan for the future.
- Black respondents endorsed the above benefits more often than whites and indicated that involving their family members in important decisions, such as making a will and using community services, also were very important to extremely important benefits of diagnosis.
- Only 6% of all respondents strongly agreed that "it is easier to not know what the diagnosis is."

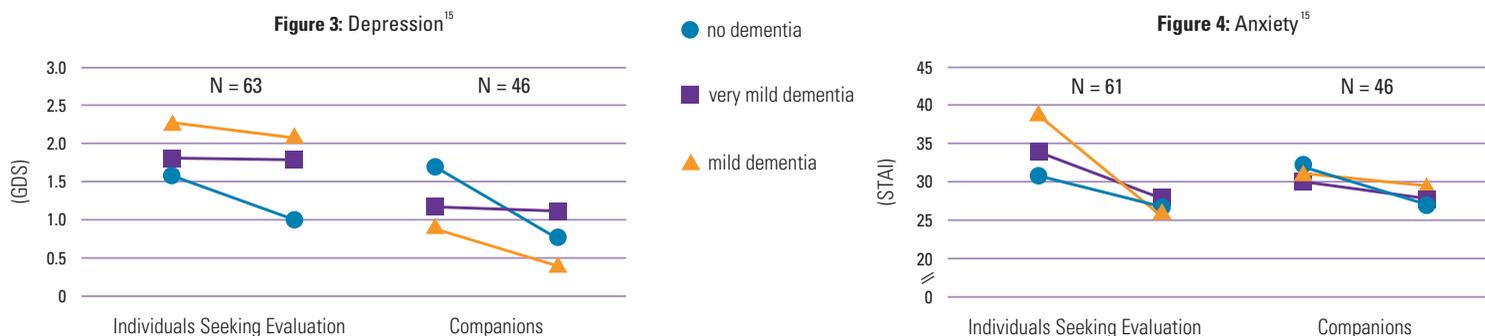
Diagnosis does not cause psychological stress in most patients and their families

Physician conjecture that a dementia diagnosis may lead to depression or even suicide has been reported.¹² Empirical findings on the issue are primarily limited to retrospective or review studies in populations with comorbid depression, a well-known risk factor for suicide.^{13,14} To examine psychological stress, Carpenter and colleagues evaluated 90 individuals and their companions before a dementia evaluation and after dementia disclosure using the 15-item Geriatric Depression Scale (GDS) and the State-Trait Anxiety Inventory (STAI).¹⁵

- Sixty-nine percent of individuals were diagnosed with very mild or mild dementia.
- No clinically significant changes were noted in depressive symptoms in either the persons diagnosed with dementia or their companion (Figure 3).
- Anxiety decreased or remained unchanged after diagnostic feedback for most groups (Figure 4).

Authors noted, "Gaining knowledge and developing a treatment plan, individuals may realize that they can take an active role in managing the illness, enhancing a sense of self-efficacy where before they might have felt helpless."

Changes in depression and anxiety, pre-evaluation vs post-disclosure, in individuals and companions seeking a dementia evaluation.



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