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Disclosing a Dementia Diagnosis: Why So Important?

Zaldy S. Tan, MD

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Question:

Do patients need to know they have dementia?



Response from Zaldy S. Tan, MD

Associate Professor, Department of Medicine, Division of Geriatrics, University of California, Los Angeles (UCLA); Medical Director, UCLA Alzheimer's and Dementia Care Program, Ronald Reagan UCLA Medical Center, Los Angeles, California

According to the Alzheimer's Association, fewer than half of people with Alzheimer disease (AD) or their caregivers have been told of their diagnosis by their healthcare provider.^[1] There are likely several reasons for this, but an important factor for nondisclosure is delayed or missed diagnosis of dementia. A review of screening for dementia in primary care revealed that an estimated 50% of patients over age 65 years who had dementia were not diagnosed by their primary care physicians.^[2]

The reasons for this are multifactorial; examples include, but are not limited to^[3]:

- Clinician factors
 - Concern about risk for misdiagnosis
 - Lack of training or skills for dementia care
 - Concern about possible burden or stigmatization of patients
- Patient factors
 - Assumption that cognitive changes are part of normal aging
 - Language barrier
 - Forgetting to mention cognitive symptoms
- System-based factors
 - Lack of time
 - Lack of specialists available for consultation
 - Low financial incentives/reimbursement for dementia care

Despite these challenges, physicians and other health professionals have the professional, ethical, and in some cases legal obligation to disclose the dementia diagnosis and to address the issues that go along with the disease.

While dementia remains incurable, its timely diagnosis and disclosure are important for patients and their families for deciding on present treatment and for future planning. In a systematic review of 23 studies on preferences of disclosure of dementia diagnosis, over 90% of individuals without cognitive impairment were in favor of disclosure; among those already diagnosed with dementia, it was 85%.^[4] Thus, even though treatment

options may be limited, the vast majority of patients and families prefer to be informed if they have AD or other forms of dementia.

The ethical principle of truth-telling in medicine, which includes the right of patients and families to receive information about their diagnosis and illness,^[5] obligates the clinician to inform patients of their right to information and invite the patient to decide about the amount of information they want or need.

There are currently five treatments for dementia approved by the US Food and Drug Administration. The acetylcholinesterase inhibitors and memantine have been shown in multiple studies to exert beneficial, albeit modest, effects on cognition, behaviors, and activities of daily living in patients with dementia. While none of the currently available treatments is known to alter the course of dementia, several potential disease-modifying therapies are currently in clinical trials. These include therapies aimed at eliminating or preventing the formation of beta-amyloid or tau proteins, counteracting inflammation, and addressing insulin resistance. Participation in these trials will only be possible if an early diagnosis of dementia is made.

The legal imperative is another reason to diagnose and disclose a dementia diagnosis. Several states require physician mandatory reporting of a dementia diagnosis to the local department of public health and/or motor vehicles.^[6] Twenty-two states have a protocol for voluntary physician reporting, five states encourage self-reporting, and 44 states allow family members to report potentially impaired drivers.^[7] In addition, early diagnosis of dementia will allow the individual to make important legal decisions such as assigning a proxy for future health, legal, and financial decisions, which may no longer be possible if diagnosis were made and disclosed at a later stage of the disease process.

Finally, the disclosure of dementia diagnosis provides the opportunity to offer caregiver education and support. In 2012, a total of 15.4 million Americans provided an estimated 17.5 billion hours of unpaid care for people with dementia.^[8] Only a minority of caregivers of persons with dementia stated that they are confident in managing dementia-related problems, know how to access community services, and perceive that their health providers helped them work through dementia-related problems.^[9] The early diagnosis and disclosure of AD or other dementias will allow clinicians to provide caregiver access to community services and resources as well as monitor for caregiver stress and strain.

In summary, the belief of some health professionals that it is unimportant to seek out and inform a patient of a dementia diagnosis is unfounded. Most patients and families prefer to be informed if they have AD or other forms of dementia, and such disclosure opens the doors for the initiation of appropriate medical, social, and legal interventions that will benefit patients, caregivers, and society.

Developed in association with the [UCLA Alzheimer's and Dementia Care Program](#).

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