Increasing disclosure of dementia 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, concerns over risk of discrimination, and lack of knowledge of local dementia support services. However, based on published data, perceptions that disclosure of dementia diagnosis is not preferred or cause psychological distress among individuals and family members are indeed challenged. A majority of patients want to know if they have Alzheimer’s Disease (AD).

A recent 5-country survey of common perceptions about AD found that 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 they have AD. This US finding is consistent with previously published reports over the last 2 decades.1-10

Diagnosis does not cause psychological stress in most patients and their families. Physician perceptions that a dementia diagnosis may lead to depression, or may cause distress, is based on a survey conducted in 2005-2006.11 Some diagnostic findings on the same are primarily limited to retrospective or survey studies in populations with concomitant depression, a well-known risk factor for suicide.12-13 To examine psychological stress, Carpenter and colleagues interviewed 96 individuals and their companions before a dementia evaluation and after dementia disclosure using the Geriatric Depression Scale (GDS) and the State-Trait Anxiety Inventory (STAI).

• No clinically significant changes were noted in depressive symptoms in the person diagnosed with dementia or their companion (Figure 2): Anxiety decreased or remained unchanged after diagnostic feedback for most groups (Figure 2).

Most family members appreciate the benefits of diagnosis. Counsel and colleagues surveyed 178 adults who had a family member with AD.

• 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 have a sense of control; and 3) allowed family to plan for the future.

• Only 6% of all respondents strongly agreed that “it is easier to not know what the diagnosis is.”

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References


Supportive Disclosure of Alzheimer’s Disease

• An article in the Times of London on diagnostics. 2012. Available at: http://www.timesonline.co.uk/tol/news/health/article10713121.ece


Follow these diagnostic guidelines in response to patient failure on cognitive screening (e.g., Mini-cog) or other signs of possible cognitive impairment.

### History and Physical

- Previous history, and features of memory and cognitive decline. Alzheimer’s Association Family Questionnaire: available and may be administered by medical or psychological means
- Review RKS and SSRI, including driving, and possible medication interactions with mental status exam
- Conduct unstructured mental status exam (e.g., MoCA, SLUMS, MMSE)

### Diagnoses

#### 1. Functional tests

- **CMMT, MCI, VCI, CI, CHS, Chinese Dementia screening labs**
- **MMSE, MMSE-2, K-MMSE**

#### 2. Neuroimaging

- **CT or MRI when clinically indicated**

#### 3. Neuropsychological testing

- **Indicated on cases of mild cognitive impairment or for differential diagnosis: determination of cause and severity of cognitive dysfunction, and for development of appropriate treatment plan**

#### 4. Typical lab results for the following score ranges:

- **MoCA 19-27; SLUMS 18-27; MMSE 18-28**
- **Kokmen STMS 19-33**
- **MMSE/MMSE-2 = 18–28**
- **MoCA = 19–27**
- **SLUMS = 18–27**
- **Vascular dementia**
- **Frontotemporal dementia**
- **Dementia with Lewy Bodies/Parkinson’s disease**
- **Mild Cognitive Impairment**
- **Vascular dementia**

### Family Meeting

- Family care partners
- Interventions for dementia and other dementia

### Medications

- **Donepezil, rivastigmine patch and galantamine**
- **Memantine (mid-late stage)**
- **Avoid/Minimize**
  - Anticholinergics, antipsychotics, and depression

### Intervention Checklist for Alzheimer’s Disease and Related Dementias

- **Refer to specialist as needed**
  - Neurologist: dementia, frontotemporal
  - Geriatrician: Physical therapy

- **Stimulation/Activity/Maximizing Function**

- **Safety**

- **Driving**

- **Medication Management**

- **Financial/Legal**

- **Advance Care Planning**

- **Mood & Behavior**

- **Behavior Management**

- **Support & Planning**

- **Counseling, Education, Support, & Planning**

- **Follow-up in 1 year**

### Cognitive Assessment

- One of the following: SLUMS, MoCA, Boston 10, MMSE-2 or MMSE (Family Questionnaire)

### Normal & Follow-up

- **Normal**
  - Mini-Cog & or GFCOG > 9 [Family Questionnaire] ≥ 2
  - Score falls outside of normal range

- **Follow-up in 1 year**
  - Mini-Cog or GFCOG < 9 [Family Questionnaire] < 2
  - Start on care plan
  - Include family

### Option 1

- Do complete dementia work-up (see provider checklist)

### Option 2

- Refer to: Changes in your practice, nonorganic, nonpsychological

### Follow-up in 1 year

- One of the following: SLUMS, MoCA, Boston 10, MMSE-2 or MMSE (Family Questionnaire)

### Co-management

- **Daily mental, physical, & social activity**
- **Medications**
- **Neuropsychological testing**
- **Family Meeting**
- **Medication Management**
- **Financial/Legal**
- **Advance Care Planning**
- **Mood & Behavior**
- **Behavior Management**
- **Support & Planning**
- **Counseling, Education, Support, & Planning**
- **Follow-up in 1 year**
- **One of the following: SLUMS, MoCA, Boston 10, MMSE-2 or MMSE (Family Questionnaire)**

### Providers

- **Alzheimer’s Association**
- **National Alzheimer’s Hotline**
- **SeniorLinkAge Line**
- **SeniorLink**

### Resources

- **24/7 Helpline:** 800.272.3900
- **alz.org/mnnd**
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*The diagnostic criteria utilized in this chart are based on the Alzheimer’s Association manual for the evaluation and treatment of Alzheimer’s disease. This manual is typically used as a reference in the following score ranges:

- **SLUMS > 18-27**
- **MoCA 18-27**
- **Kokmen STMS 19-33**
- **MMSE/MMSE-2 = 18–28**

[Source: Alzheimer’s Association](www.alz.org)