Guideline for Alzheimer's Disease Management

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2 authors:

Debra Cherry
Alzheimer's Association, California Southlan... 19 PUBLICATIONS 404 CITATIONS

Freddi Segal-Gidan
University of Southern California 16 PUBLICATIONS 197 CITATIONS

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Alzheimer’s Disease Management Guideline: Update 2008

Freddi Segal-Gidan, Debra Cherry, Randi Jones, Bradley Williams, Linda Hewett, Joshua Chodosh, for the California Workgroup on Guidelines for Alzheimer’s Disease Management

Abstract

Background: Frequent review and update of guidelines are necessary for them to remain current and useful for clinical practices. This second revision of the postdiagnostic management of Alzheimer’s disease (AD) guideline by the California Workgroup was prompted by significant advances in knowledge about appropriate care management, including pharmacologic and nonpharmacologic approaches to treatment of the disease, accompanying behavioral problems, and functional decline. The focus remains explicitly on primary care, where the majority of it occurs for those with AD and other dementias.

Methods: In all, 40 experts in dementia care were recruited from a variety of disciplines across California. Four workgroups were created that reviewed recent research findings from a total of 569 publications since 2002. The revised Guideline incorporates 305 new references, including 11 state and federal laws, in addition to 78 references from the previous version.

Results: The Guideline is divided into four sections that address postdiagnostic management: (1) assessment, (2) treatment, (3) patient and family education and support, and (4) legal considerations associated with AD. Significant revisions and changes in each area and the underlying research to support the recommendations are presented in this article. New topics related to early stage and end-of-life were identified and recommendations were developed for these specific populations.

Conclusions: The Guideline recommendations provide a framework to inform and improve medical care for AD by primary health care providers.

1. Introduction

Alzheimer’s disease (AD) affects more than 5 million U.S. citizens and their caregivers [1]. It is expensive, resulting in substantially higher medical costs over the course of the disease compared with other patients of the same age but without AD [2–4]. In 2005, an estimated 24.3 million people had dementia, with 4.6 million new cases of dementia each year (one new case every 7 seconds). A doubling of the number of affected people is expected every 20 years, and it could reach up to 81 million by 2040 [5]. Worldwide societal costs of dementia were estimated to be $315 billion in 2005 ($105 billion were for informal care), which are certainly higher in 2010 [6].

Despite the availability of clinical practice guidelines, substantial deficits in quality of care of patients with AD continue to be reported. These include underdiagnosis [7–10], inappropriate use of psychoactive medications [11,12], under-reporting of abusive behavior toward the elderly population suffering from AD [13,14], and limited access to and use of recommended institutional and community resources [15,16]. Safety issues are infrequently addressed, and there are only a few systematic procedures in place to address concerns regarding persons with AD who are driving, who are at risk for wandering or abuse, or who have firearms at home [17]. Moreover, since the earlier publication of these guidelines, we now know that...
systematic guideline-supported approaches to dementia care through care management result in reduced stress to the caregiver and improvement in other psychosocial issues, in addition to reduction in need for institutional care [18,19].

For guidelines to remain current and relevant, frequent review and updates are necessary. Significant advances in the postdiagnostic management of AD have occurred since the California Workgroup’s original guideline was updated in 2002 [20], prompting the need for this revision. These include approval of the medication memantine by the U.S. Food and Drug Administration, widely publicized studies on antipsychotic use [21], a number of research reports on exercise benefits [22,23], and a growing body of published data on care management in AD [18,19]. These recently revised guidelines, like the original, are written for primary care practitioners, as well as for patients and their families. However, the Guideline for Alzheimer’s Disease Management is also a resource for administrators and policy makers who are working to improve the quality of health care for those with dementia.

2. Methods

Experts from the State of California (academic research and education, clinical practice, and administrative leadership) in one or more of the four content areas that formed the structure of the previous Guideline (assessment, treatment, patient and family education and support, and reporting requirements) were identified and invited to participate as Workgroup members. An explicit attempt was made to include all relevant disciplines, with representation from across the state.

A search of the published data was performed using PubMed and PsycInfo databases, which was limited to peer-reviewed journals in English. Search terms included “Alzheimer” or “Alzheimer’s” plus “assessment,” “treatment,” “caregiver,” “capacity,” “elder abuse,” “primary care,” “end-of-life,” “systematic review,” “early-stage,” “late-stage,” “meta-analysis,” and “guideline.” More than 20,000 articles (PubMed search total = 19,793; PsychInfo search total = 13,205) published between 2002 and 2007 were identified. Additionally, the Cochrane Library Database of Systematic Reviews using the term “Alzheimer” identified 61 reviews. Links to related studies as well as additional studies by authors from the initial search, major research programs conducted by those authors, and other references provided by members of the California Workgroup were explored. Additional studies were located using the ancestry method (i.e., searching the references sections of studies from those described earlier in the text). Because of the large volume of published material, content reviewers focused on reviews and meta-analyses, reports of relevant clinical trials, other intervention studies, and other guidelines, published since 2002 and relevant to the content area of that Workgroup. The Workgroup members discussed their reviews in multiple subgroup meetings and presented their findings at an in-person meeting of all four subgroups together. Major areas needing revision were identified, recommendations were discussed, and revisions to the previous Guideline were accepted and/or modified by consensus for each of the four content areas. The four Workgroups developed drafts of their respective sections for the full report, which were circulated among all the Workgroup members for review and editing in an iterative process which, after several rounds, resulted in a consensus document. During this period, members submitted additional articles not found through the initial searches, which were incorporated in subsequent drafts where relevant.

3. Results

A total of 569 publications were reviewed (Table 1). The revised Guideline incorporates 305 new references, including 11 state and federal laws, in addition to 78 references from the previous version.

The Guideline recommendations are based on the best available evidence. When a thorough search turned up insufficient or inconsistent data with respect to a specific aspect of AD management, recommendations were made using expert opinion and Workgroup consensus, as described earlier in the text.

The Guideline is divided into four sections that address postdiagnostic management. These include (1) assessment, (2) treatment, (3) patient and family education and support, and (4) legal considerations associated with AD. Significant revisions and changes in each section are presented in the following sections.

3.1. Assessment

Comprehensive assessment is the foundation of quality of care for affected patients and their families. The profound effects of cognitive decline, along with the complexity of co-occurring comorbid medical conditions, functional impairments, and behavioral and caregiver issues, demand that while making assessments one must be careful and thorough so as to identify how best to address medical issues, improve quality of life, and maximize independence [24]. The assessment section was revised to better address postdiagnostic care, and includes a discussion of screening tools to evaluate the mental status of the patients. The need for careful assessment of comorbid conditions and the relationship between cognitive changes and deterioration of comorbid disease status has been highlighted. Behavioral assessment and living arrangements, especially with respect to safety, medication management, end-of-life issues, and caregiver and capacity assessment, are other areas of focus. Finally, this section contains additional discussion on the frequency of reassessment.

The Guideline recommends periodic cognitive reassessment using a reliable and valid tool. Although the Mini-Mental State Examination [25] is still commonly used, its
The relationship between symptoms of comorbid disease and cognitive impairment is complex and dynamic. A change in functional status may be inappropriately attributed to expectations of the decline. Medical conditions, presenting either as a deteriorating preexisting condition or as a new medical problem, may not include typical signs and symptoms but rather a worsening of cognition, delirium, and/or deterioration in function. Close monitoring of signs and symptoms, such as weight loss, behavioral change, or increased somnolence, is recommended for individuals with or without comorbid disease.

Table 1

<table>
<thead>
<tr>
<th>Work group</th>
<th>Assessment</th>
<th>Treatment</th>
<th>Patient and Family</th>
<th>Legal</th>
<th>Total/item type</th>
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<tr>
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<td>157 (237)</td>
<td>113 (136)</td>
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</tr>
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</table>

NOTE: The 438 total references cited by section include duplications because of overlapping content in the total 383 references in the Final Guideline Report.

An emphasis on medication prescription and administration has been recently added to this version of the Guideline. The need to monitor medications (both prescription and nonprescription) is critical to the quality of care given the more recent recognition of the associated morbidity and mortality in older adults [28,29]. Thus, assessment and monitoring for changes in medication use is recommended for every visit.

The Guideline now highlights the need to assess an individual’s living arrangements in the interest of understanding environmental supports and barriers to enhanced functional independence and reduced stress to the caregiver. Close attention to safety concerns will help structure an environmental assessment. This assessment may also assist in identifying potential neglect and/or abuse of elderly population with dementia. The Guideline includes risk factors (characteristics) for both caregivers and care recipients to assist the clinician in identifying possible abuse (Table 3).

Table 2

<table>
<thead>
<tr>
<th>Name of instrument</th>
<th>Number of items</th>
<th>time required</th>
<th>maximum score</th>
<th>Cognitive functions assessed</th>
</tr>
</thead>
<tbody>
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<td>BOMC</td>
<td>6 items</td>
<td>3 minutes</td>
<td>Maximum Score = 28</td>
<td>Orientation, concentration, short-term verbal recall</td>
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<tr>
<td>CASI</td>
<td>25 items</td>
<td>15–20 minutes</td>
<td>Maximum Score = 100</td>
<td>Attention, mental manipulation, orientation, long-term memory, short-term memory, language, visual construction, word list fluency, abstraction and judgment</td>
</tr>
<tr>
<td>MiniCOG</td>
<td>2 items</td>
<td>3 minutes</td>
<td>Maximum Score = 5</td>
<td>Visuospatial, executive functioning, short term recall (Note: Includes clock drawing)</td>
</tr>
<tr>
<td>MMSE</td>
<td>19 items</td>
<td>10 minutes</td>
<td>Maximum score = 30</td>
<td>Orientation, registration, attention and calculation, short-term verbal recall, naming, repetition, 3-step command, reading, writing, visuospatial</td>
</tr>
<tr>
<td>MoCA</td>
<td>12 items</td>
<td>10 minute</td>
<td>Maximum score = 30</td>
<td>Visuospatial/executive functioning, naming, attention, repetition, verbal fluency, abstraction, short-term verbal recall, orientation (Note: Includes clock drawing)</td>
</tr>
<tr>
<td>SLUMS</td>
<td>11 items</td>
<td>7 minutes</td>
<td>Maximum score = 30</td>
<td>Orientation, verbal recall, calculation, naming, attention, executive function (Note: Includes clock drawing)</td>
</tr>
</tbody>
</table>

Abbreviations: BOMC, Blessed Orientation Memory Concentration Test; CASI, Cognitive Assessment Screening Instrument; MMSE, Mini-Mental State Examination; MoCA, Montreal cognitive assessment; SLUMS, St. Louis University Mental Status Examination.
Caregiver assessment is an important addition to the Guideline. As with earlier versions, the critical need to identify the primary caregiver and the adequacy of support for that caregiver is emphasized. There is additional focus on the health of the caregiver with greater appreciation of the increased risk of serious illness [30], major depression [31], and higher mortality from caregiver strain [32].

Assessment of an individual’s capacity for decision-making is an important new component of the Guideline. “Capacity,” that is, one’s ability to make decisions, is distinguished from “competency,” which is typically used as a legal term. Capacity is decision-specific and must be assessed each time a decision by the individual with AD is needed. There is also evidence that objective cognitive testing can be used to determine the ability to make decisions about medical treatment [33]. The Guideline provides a list of questions to guide clinical assessment of their decision-making abilities.

There is little evidence to support how frequent patients should be reassessed. Thus, the Workgroup relied on a consensus recommendation that visit frequency be left to the discretion of the practitioner, taking into account the patient’s clinical status, as well as the skill and understanding of the caregiver but with minimum intervals at no less than every 6 months unless change in function, behavior, or clinical state warrants earlier reassessment. Consistent use of standardized instruments will guide clinicians in identifying important changes over time.

3.2. Treatment

Medical research on pharmaceuticals, particularly cholinesterase inhibitors, has included several clinical trials and meta-analyses. Transdermal application of rivastigmine is now available with fewer adverse affects compared with oral rivastigmine [34]. A meta-analysis of cholinesterase inhibitors used for at least 6 months showed mild improvement in cognition, daily function, and behavior [35]. Greater effects regarding placement at a nursing home have been noted, with a 20% reduction in placement at 25 months of treatment [36]. Memantine, the only available N-methyl-D-aspartate antagonist, is now approved by the U.S. Food and Drug Administration for treatment of AD. When memantine is added to a cholinesterase inhibitor in patients with moderate to severe impairment, an improvement may be seen in the behavior [37].

Nonpharmacologic therapy continues to be a mainstay of AD treatment. The Guideline contains new information on the use of nonpharmacologic treatment for behavioral symptoms, including recommended activities to treat specific symptoms (Table 4). Just as it is recommended that pharmacologic treatments target specific behavioral symptoms, behavioral approaches should also be similarly applied. Use of nonpharmacologic approaches before pharmaceutical interventions is further motivated by the potential for serious adverse effects with use of antipsychotic medications [40] as well as their questionable effectiveness [41,42].
appropriate referrals for professional assistance. As the importance of basic legal and financial planning and to make a unique position of trust and influence to convey the importance of the disease. Providers of primary care should use their financial decisions should ideally be made early in the course of AD of the ability to make decisions, major legal and financial decisions should not be made. Two new specific recommendations regarding individuals with dementia and driving by those with dementia were added. The section labeled in the previous Guideline version “reporting requirements” has been renamed as “legal considerations” because the latter is considered to be broader in scope. Recommendations on reporting elder abuse of individuals with dementia and driving by those with dementia were retained. Two new specific recommendations regarding the need for legal and financial planning and capacity evaluations were added.

Because cognitive decline over time deprives patients with AD of the ability to make decisions, major legal and financial decisions should ideally be made early in the course of the disease. Providers of primary care should use their unique position of trust and influence to convey the importance of basic legal and financial planning and to make appropriate referrals for professional assistance. As the disease progresses, there may be times when a capacity declaration is required before the patient’s chosen substitute decision-maker can be authorized to act. A “structured approach to the assessment of patient capacity” is recommended, and guidelines for its application have been outlined.

3.5. New topic areas

A new recommendation focuses on the “special needs of early-stage patients,” recognizing that patients with early AD have unique concerns and issues. There is expert consensus that people with early-stage AD require a different approach to care management than those in the moderate or advanced stages of the disease. With early detection and diagnosis, it is vital that the patient be included in decision-making. Affected individuals have much to gain from being involved in treatment planning and expressing their desires related to specific future plans. Recent best practice guidelines for early-stage or newly diagnosed patients recommend follow-up for 2 months after diagnosis, and every 6 months thereafter. Efforts to diagnose patients in earlier stages are supported by demonstrated benefits of earlier treatment. Early-stage AD patients have shown improvements in cognition, mood, and behavior from cognitive stimulation, physical exercise, and psychosocial support.

Also new to the Guideline is a section on palliative and end-of-life care. As with other chronic diseases, treatment goals shift to relief of discomfort as the primary focus as cognitive function worsens. Weight loss from decreased caloric intake is a common and vexing problem for families and clinicians. Although a feeding tube is often considered, there is little evidence that this approach produces a clinically meaningful outcome or that it prolongs life. Primary care providers should initiate discussions of care options that maximize comfort while avoiding futile treatments, taking into consideration the patient’s wishes and values.

4. Discussion

Our approaches to postdiagnostic care for patients with AD continue to evolve. Motivation for revising the 2002 version of the Guideline grew directly from the growth in research, supporting both existing approaches and enhanced treatments and strategies for postdiagnostic assessment and management of AD. There are an increasing number of

<table>
<thead>
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<th>Organization</th>
<th>Telephone</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Association</td>
<td>1-800-272-3900</td>
<td><a href="http://www.alz.org">www.alz.org</a></td>
</tr>
<tr>
<td>Alzheimer’s Disease Education and Referral (ADEAR) Center</td>
<td>1-800-438-4380</td>
<td><a href="http://www.niapublications.org/adear">www.niapublications.org/adear</a></td>
</tr>
<tr>
<td>Alzheimer’s Disease Research Centers of California</td>
<td>1-916-552-8995</td>
<td><a href="http://www.dhs.ca.gov/alzheimers">www.dhs.ca.gov/alzheimers</a></td>
</tr>
<tr>
<td>Area Agencies on Aging</td>
<td>1-800-510-2020</td>
<td><a href="http://www.c4aging.org">www.c4aging.org</a></td>
</tr>
<tr>
<td>Family Caregiver Alliance (Caregiver Resource Centers)</td>
<td>1-800-445-8106</td>
<td><a href="http://www.caregiver.org">www.caregiver.org</a></td>
</tr>
<tr>
<td>Eldercare Locator for Continuum of Services</td>
<td>1-800-677-1116</td>
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evidenced-based management approaches specific to AD care [60]. These include care management, exercise, and nonpharmacological approaches to behavioral management. Primary care providers have access to several organizations for assisting patients and caregivers in need of education and support (Table 6). The increased attention on AD and its increasing prevalence may explain, in part, why more patients are being diagnosed at earlier stages than when this Guideline was last revised. Thus, primary care physicians have greater opportunities for treatment earlier in the course of the disease.

Recent studies have demonstrated considerable gaps in quality of care for patients with AD and for their families and caregivers [39]. A key step to addressing quality deficiencies is the development of clinical guidelines. For practitioners, guidelines may be useful as decision-support resources, particularly in areas of clinical uncertainty. Guideline development may be the initial activity for developing performance measures to facilitate clinical practice improvements. However, guidelines only have utility when practitioners, health care plan administrators, and policy makers directly apply this information to patient care. Additionally, clinical guidelines that are published in an easily accessible form, such as Web-based posting (this guideline can be found at www.alz.org), can be important for patients' and families' self-care strategies as well as for advocating for improved medical care.

The 2008 Guideline for Alzheimer's Disease Management is intended to assist the primary care practitioner in providing medical management to affected patients, managing psychosocial issues, and making appropriate referrals to legal and financial resources within the community. The Guideline can also serve as an educational resource to establish a standard of care, to improve continuity of care, and to raise provider and consumer awareness of the special concerns of patients with AD and their families.

References

Appendix

GUIDELINES FOR ALZHEIMER’S DISEASE MANAGEMENT

- Conduct and document an assessment of:
  - Daily function, including feeding, bathing, dressing, mobility, toileting, continence and ability to manage finances and medications
  - Cognitive status using a reliable and valid instrument (e.g. the MMSE)
  - Other medical conditions
  - Behavioral problems, psychotic symptoms, or depression
  - Reassessment should occur every 6 months or more frequently with any sudden decline or behavioral change
  - Identify the primary caregiver and assess the adequacy of family and other support systems
  - Assess the patient’s decision-making capacity and whether a surrogate has been identified
  - Caregiver’s needs and roles should be assessed and reassessed on a regular basis
  - Assess the patient’s and family’s culture, values, primary language, literacy level and decision-making process

- Develop and implement an ongoing treatment plan with defined goals. Include:
  - Use of cholinesterase inhibitors, if clinically indicated, to treat cognitive decline
  - Appropriate treatment of medical conditions
  - Referral to adult day services for appropriate structured activities, such as exercise and recreation
  - Treat behavioral problems and mood disorders using:
    - Non-pharmacologic approaches, such as environmental modification, task simplification, appropriate activities, etc.
    - Referral to social service agencies or support organizations, including the Alzheimer’s Association’s Safe Return Program for people who may wander
    - Medications, if clinically indicated and non-pharmacologic approaches prove unsuccessful

- Discuss the diagnosis, progression, treatment choices and goals of AD care with the patient and family in a manner consistent with their values, preferences and the patient’s abilities
- Refer to support organizations for educational materials on community resources, support groups, legal and financial issues, respite care, future care needs and options. Organizations include:
  - Alzheimer’s Association 1-800-656-5800 www.alz.org
  - Family Caregiver Alliance & 1-800-445-7800 www.caregiver.org
  - Caregiver Resource Centers
  - or your own social service department
- Discuss the patient’s need to make care choices at all stages of the disease through the use of advance directives and identification of surrogates for medical and legal decision-making
- Discuss the intensity of care and end of life care decisions with the person with AD and the family

- Abuse: Monitor for evidence of and report all suspicions of abuse (physical, sexual, financial, neglect, isolation, abandonment) to Adult Protective Services or your local police department, as required by law (California Welfare Institution Code, Section 15650).
- Driving: Report the diagnosis of AD to your local health officer in accordance with California law (Sections 2800 - 2812 of Title 17, California Code of Regulations).

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California Version: R 01/01/02 2002
Alzheimer's Disease and Its Impact:

As the population ages, the incidence of Alzheimer's disease (AD) becomes greater. One in ten persons over 65 and nearly half of those over 85 have AD. Currently, 4 million persons in the U.S. have a diagnosis of Alzheimer's disease. A person with AD can live from 3-20 years or more from the onset of symptoms and at some point that person will require 24 hour care including assistance with daily activities such as eating, grooming and toileting. The yearly monetary costs of AD exceed $100 billion in the U.S. The social and emotional toll on caregivers and families is immeasurable. Fortunately, there are effective strategies for management of Alzheimer's disease and related dementias that are covered in this guideline.

About the Guideline:

This document was developed by the California Workgroup on Guidelines for Alzheimer's Disease Management through a collaborative effort of healthcare providers, consumers, academicians, professional and volunteer organizations, and purchasers of health care. A companion document is available which explains each of the areas of the Guideline in greater detail. To download a copy of the Guideline and related information, visit the California Council of the Alzheimer's Association website at www.caalz.org.

Purpose of the Guideline:

This clinical practice guideline represents core care recommendations for AD management that are clear, measurable, practical and based on scientific evidence, as available. The California Workgroup has provided its expert opinion when research evidence has been unavailable or when research results were inconsistent. The intended audience of this guideline is primary care practitioners, including physicians, nurse practitioners, physician assistants, social workers, and other professionals providing primary care to AD patients and their families.

*Note: Many of the activities mentioned in the Guideline do not require a physician and can be done by other members of the treatment team.

Guidelines for the Diagnosis of Alzheimer’s Disease:

The guideline suggests care management principles and is based on the assumption that a proper diagnosis of Alzheimer’s disease has been made using reliable and valid diagnostic techniques. For organizations seeking guidance in developing or adopting a diagnostic guideline for Alzheimer’s disease, a useful reference is the Clinical Practice Guideline on Early Alzheimer’s Disease: Recognition and Assessment developed by the Agency for Health Care Research and Quality. To obtain a copy, contact the AHRQ Publications Clearinghouse at 1-800-358-9295 or visit them on the web at www.ahrq.gov. Additional guidelines and references are available from the National Guideline Clearinghouse at www.guidelines.gov.