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CONTACT: Alzheimer's Association AAIC Press Office, 312-949-8710, aaicmedia@alz.org
Niles Frantz, Alzheimer's Association, 312-335-5777, nfrantz@alz.org

FROM THE ALZHEIMER'S ASSOCIATION INTERNATIONAL CONFERENCE 2018

FIRST PRACTICE GUIDELINES FOR CLINICAL EVALUATION OF ALZHEIMER'S DISEASE AND OTHER DEMENTIAS FOR PRIMARY AND SPECIALTY CARE

Alzheimer's Association workgroup reports recommendations to improve timely and accurate diagnosis and disclosure

CHICAGO, July 22, 2018 – Despite more than two decades of advances in diagnostic criteria and technology, symptoms of Alzheimer's disease and Related Dementias (ADRD) too often go unrecognized or are misattributed, causing delays in appropriate diagnoses and care that are both harmful and costly. Contributing to the variability and inefficiency is the lack of multidisciplinary ADRD evaluation guidelines to inform U.S. clinicians in primary and specialty care settings.

Responding to the urgent need for more timely and accurate Alzheimer's disease diagnosis and improvement in patient care, a workgroup convened by the Alzheimer's Association has developed 20 recommendations for physicians and nurse practitioners. There currently are no U.S. national consensus best clinical practice guidelines that provide integrated multispecialty recommendations for the clinical evaluation of cognitive impairment suspected to be due to ADRD for use by primary and specialty care medical and nursing practitioners.

The recommendations range from enhancing efforts to recognize and more effectively evaluate symptoms to compassionately communicating with and supporting affected individuals and their caregivers. The recommendations were reported at the Alzheimer's Association International Conference (AAIC) 2018 by Alireza Atri, MD, PhD, Co-chair of the AADx-CPG workgroup, and Director of the Banner Sun Health Research Institute, Sun City, AZ, and Lecturer in Neurology at the Center for Brain/Mind Medicine, Brigham and Women's Hospital and Harvard Medical School, Boston. Details of the AADx-CPG workgroup document are being honed with input from leaders in the field, with the goal of publication in late 2018.

At their core, the recommendations include guidance that:

- All middle-aged or older individuals who self-report or whose care partner or clinician report cognitive, behavioral or functional changes should undergo a timely evaluation.
- Concerns should not be dismissed as “normal aging” without a proper assessment.
- Evaluation should involve not only the patient and clinician but, almost always, also involve a care partner (e.g., family member or confidant).

“Too often cognitive and behavioral symptoms due to Alzheimer’s disease and other dementias are unrecognized, or they are attributed to something else,” said James Hendrix, PhD, Alzheimer’s Association Director of Global Science Initiatives and staff representative to the workgroup. “This causes harmful and costly delays in getting the correct diagnosis and providing appropriate care for persons with the disease. These new guidelines will provide an important new tool for medical professionals to more accurately diagnose Alzheimer’s and other dementias. As a result, people will get the right care and appropriate treatments; families will get the right support and be able to plan for the future.”

In 2017, the Alzheimer’s Association convened a Diagnostic Evaluation Clinical Practice Guideline workgroup (AADx-CPG workgroup) of experts from multiple disciplines in dementia care and research, representing medical, neuropsychology, and nursing specialties. The AADx-CPG workgroup used a rigorous process for evidence-based consensus guideline development.

“Our goal is to provide evidence-based and practical recommendations for the clinical evaluation process of cognitive behavioral syndromes, Alzheimer’s disease and related dementias that are relevant to a broad spectrum of U.S. health care providers,” Atri said. “Until now, we have not had highly specific and multispecialty U.S. national guidelines that can inform the diagnostic process across all care settings, and that provide standards meant to improve patient autonomy, care, and outcomes.”

“Whether in primary or specialty care, the recommendations guide best practices for partnering with the patient and their loved ones to set goals, and to appropriately educate and evaluate memory, thinking and personality changes,” Atri added.

The Clinical Practice Guidelines (CPG) recognize the broader category of “Cognitive Behavioral Syndromes” — indicating that neurodegenerative conditions such as ADRD lead to both behavioral and cognitive symptoms of dementia. As a result, these conditions can produce changes in mood, anxiety, sleep, and personality — plus interpersonal, work and social relationships — that are often noticeable before more familiar memory and thinking symptoms of ADRD appear.

“In all cases, there is something we can do to help and support those who entrust us with the privilege of advising and caring for them,” said Atri. “The guidelines can empower patients, families, and clinicians to expect that symptoms will be evaluated in a patient-centered, structured, and collaborative manner. In addition, they help to ensure that, regardless of the specific diagnosis, the results are communicated in a timely and compassionate way to help patients and families live the best lives possible.”

The 20 consensus recommendations describe a multi-tiered approach to the selection of assessments and tests that are tailored to the individual patient. The recommendations emphasize obtaining a history from not only the patient but also from someone who knows the patient well to:

- First, establish the presence and characteristics of any substantial changes, to categorize the cognitive behavioral syndrome.
- Second, investigate possible causes and contributing factors to arrive at a diagnosis/diagnoses.
- Third, appropriately educate, communicate findings and diagnosis, and ensure ongoing management, care and support.

“Evaluation of cognitive or behavioral decline is often especially challenging in primary care settings,” said Bradford Dickerson, MD, MMSc, Co-chair of the workgroup, and Director of the Frontotemporal Disorders Unit at Massachusetts General Hospital, and Associate Professor of Neurology at Harvard Medical School, Boston. “Also, with recent advances in available diagnostic technology, there is a need for guidance on use of such tests in specialty and subspecialty care settings.”

According to the workgroup, a timely and accurate diagnosis of ADRD increases patient autonomy at earlier stages when they are most able to participate in treatment, life and care decisions; allows for early intervention to maximize care and support opportunities, and available treatment outcomes; and may also reduce health care costs. The Alzheimer’s Association encourages early diagnosis to provide the opportunity for people with Alzheimer’s to participate in decisions about their care, current and future treatment plans, legal and financial planning, and may also increase their chances of participating in Alzheimer’s research studies.

“Next steps include reaching out to physician groups and medical societies to encourage primary care doctors, dementia experts, and nurse practitioners to adopt these new best clinical practice guidelines,” Hendrix said.

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- Alireza Atri, MD, PhD, et al. Alzheimer’s Association Best Clinical Practice Guidelines for the Evaluation of Neurodegenerative Cognitive Behavioral Syndromes, Alzheimer’s Disease and Dementias in the United States. Funder: Alzheimer’s Association.
- Alireza Atri, MD, PhD, et al. Details of the New Alzheimer’s Association Best Clinical Practice Guidelines for the Evaluation of Neurodegenerative Cognitive Behavioral Syndromes, Alzheimer’s Disease and Dementias in the United States. Funder: Alzheimer’s Association.

Proposal ID: O1-07-02

Dementia Care Research: Measurement, Outcomes and Policies

Sun, Jul 22, 2:15-2:30 pm

Alzheimer's Association Best Clinical Practice Guidelines for the Evaluation of Neurodegenerative Cognitive Behavioral Syndromes, Alzheimer's Disease and Dementias in the United States

Background: The Alzheimer's Association convened a multidisciplinary Best Clinical Practices Guidelines (CPG) Workgroup charged to evaluate relevant literature, delineate gaps, and integrate evidence and clinical experience to provide consensus recommendations for the clinical evaluation of Cognitive Behavioral Syndrome (CBS) and AD dementia clinical spectrums. The CPG workgroup aimed to delineate best practice points and provide practical and specific U.S. guidelines that were multitiered in approach and relevant to both primary and specialty settings.

Methods: Systematic evidence reviews and literature searches; and a modified Delphi method to develop and grade recommendations.

Results: 20 consensus best CPG recommendations for primary and specialty care settings were developed and graded for the evaluation of CBS, and AD dementia clinical spectrums. The recommendations delineate utilization of tiers of assessments and tests based on individual presentation, risk factors and profile to first establish the presence and characteristics of a CBS; second, to investigate possible causes and contributing factors to arrive at an etiologic diagnosis based on established disease criteria; and third, to appropriately educate, communicate findings, and disclose the syndromic and etiologic diagnosis(es), and ensure ongoing management, care and support.

Conclusions: This talk will present an overview of the CPG workgroup aims, process, rationale, and recommendations.

Alireza Atri, MD/PhD Email: alireza.atri@bannerhealth.com
Banner Sun Health Research Institute/Banner Health, Sun City AZ
Center for Brain/Mind Medicine, Department of Neurology, Brigham and Women's Hospital
and Harvard Medical School, Boston MA

James Hendrix, PhD Email: media@alz.org
Alzheimer's Association, Chicago IL

Maria Carrillo, Ph.D. Email: media@alz.org
Alzheimer's Association, Chicago IL

Brad Dickerson, MD Email: brad.dickerson@mgh.harvard.edu
Massachusetts General Hospital/Harvard Medical School, Charlestown MA

Details of the New Alzheimer's Association Best Clinical Practice Guidelines for the Evaluation of Neurodegenerative Cognitive Behavioral Syndromes, Alzheimer's Disease and Dementias in the United States

Background: Early detection, accurate diagnosis, and appropriate management of neurodegenerative Cognitive Behavioral Syndromes (CBS), Alzheimer's disease (AD) and dementias represent a public health imperative. Despite more than two decades of advances in diagnostics; delineation of syndromic and disease criteria; and management, cognitive behavioral symptoms due to AD and related neurodegenerative dementias too often go unrecognized or are misattributed, causing delays in appropriate diagnoses and care that are both harmful and costly. In the United States, contributing to high variability, inefficiency, and suboptimal rates of timely diagnosis, is a lack of multidisciplinary clinical guidelines to inform evaluation practices for clinicians in primary and specialty settings who encounter and care for affected individuals and care partners (patient-care partner dyads).

To address this gap, in early 2017 The Alzheimer's Association convened a Best Clinical Practices Guidelines (CPG) Workgroup consisting of multidisciplinary clinician experts in dementia care and research. The CPG workgroup was charged to evaluate relevant literature, delineate gaps, and integrate evidence and clinical experience to provide consensus recommendations for the clinical evaluation of CBS and AD dementia clinical spectrums. The CPG workgroup aimed to delineate best practice points and provide practical and specific U.S. guidelines that were multitiered in approach and relevant to both primary and specialty settings.

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Conclusions: This poster will present details of the CPG workgroup aims, process, rationale, and recommendations.

Alireza Atri, MD/PhD Email: alireza.atri@bannerhealth.com

Center for Brain/Mind Medicine, Department of Neurology, Brigham and Women's Hospital and Harvard Medical School Boston MA

Banner Sun Health Research Institute/Banner Health, Sun City AZ

James Hendrix, PhD Email: media@alz.org

Alzheimer's Association, Chicago IL

Maria Carrillo, Ph.D. Email: media@alz.org

Alzheimer's Association, Chicago IL

Brad Dickerson, MD Email: brad.dickerson@mgh.harvard.edu

Massachusetts General Hospital/Harvard Medical School, Charlestown MA

Final Recommendations

Section/Category	Recommendation	Level
Patient Types and Process	RECOMMENDATION 1: For patients who self-report or whose care partner or clinician report cognitive, behavioral or functional changes, the clinician should initiate a multi-tiered evaluation focused on the problem.	A
	RECOMMENDATION 2: For patients with atypical or rapidly progressive cognitive-behavioral symptoms, the clinician should expedite a multi-tiered evaluation and should strongly consider referral to a specialist.	A
	RECOMMENDATION 3: The evaluation process should use tiers of assessments and tests based on individual presentation, risk factors and profile to first establish the presence and characteristics of a Cognitive Behavioral Syndrome (CBS); and second, investigate possible causes and contributing factors to arrive at an etiologic diagnosis.	A
	RECOMMENDATION 4: The clinician should establish a collaborative dialogue with the patient and care partner throughout the evaluation process to appropriately educate; communicate findings; and disclose the syndromic and etiologic diagnosis(es); and ensure ongoing management, care and support.	A
History of Present Illness	RECOMMENDATION 5: During history taking for a patient being evaluated for cognitive-behavioral symptoms, the clinician should obtain reliable information involving an informant regarding changes in A) cognition; B) activities of daily living (IADL and ADL); C) mood and other neuropsychiatric symptoms; and D) sensory and motor function. Use of structured instruments for assessing each of these domains is helpful.	A
	RECOMMENDATION 6: During history taking for a patient being evaluated for cognitive-behavioral symptoms, the clinician should obtain reliable information about individualized risk factors for cognitive decline.	A
Office-Based Examination of Patient	RECOMMENDATION 7: In a patient being evaluated for cognitive-behavioral symptoms, the clinician should perform an examination of cognition, mood and behavior (mental status exam), and a dementia-focused neurological examination, aiming to diagnose the Cognitive Behavioral Syndrome.	A
	RECOMMENDATION 8: In a patient being evaluated for cognitive-behavioral symptoms, clinicians should use validated tools to assess cognition.	A
	RECOMMENDATION 9: A patient with an atypical presentation by history or examination, or in whom there is diagnostic uncertainty, should be referred to a specialist.	A
	RECOMMENDATION 10: A specialist evaluating a patient with cognitive-behavioral symptoms should perform a comprehensive history and office-based examination of cognitive, neuropsychiatric, and neurological functions, aiming to diagnose the Cognitive Behavioral Syndrome.	A

Neuropsychological Evaluation of Patient	<p>RECOMMENDATION 11: Neuropsychological evaluation is recommended when office-based cognitive assessment is not sufficiently informative. Specific examples are when a patient/informant report concerning symptoms in daily life but the patient performs within normal limits on a cognitive examination, or when the examination of cognitive-behavioral function is not normal but there is uncertainty about interpretation of results due to a complex clinical profile or confounding demographic characteristics.</p>	A
	<p>The neuropsychological evaluation, at a minimum, should include normed neuropsychological testing of the domains of learning and memory (in particular delayed free and cued recall/recognition); executive function; visuospatial function, and language.</p>	
Laboratory and Imaging Tests	<p>RECOMMENDATION 12: Laboratory tests in the evaluation of cognitive-behavioral symptoms should be multi-tiered and individualized to the patient’s medical risks and profile. Clinicians should obtain routine Tier 1 laboratory studies in all patients.</p>	A
	<p>RECOMMENDATION 13: In a patient being evaluated for a Cognitive Behavioral Syndrome, the clinician should obtain a magnetic resonance imaging (MRI) (as a first tier approach) to aid in establishing etiology. If MRI is not available or is contraindicated, computed tomography (CT) should be obtained.</p>	B
	<p>RECOMMENDATION 14: When diagnostic uncertainty remains, the clinician can obtain additional (Tier 2-4) laboratory tests guided by the patient’s individual medical, neuropsychiatric, and risk profile.</p>	A
	<p>RECOMMENDATION 15: In a patient with an established Cognitive Behavioral Syndrome in whom there is continued diagnostic uncertainty regarding etiology after structural imaging has been interpreted, a dementia specialist can obtain molecular imaging with FDG-PET to improve diagnostic accuracy.</p>	B
	<p>RECOMMENDATION 16: In a patient with an established Cognitive Behavioral Syndrome in whom there is continued diagnostic uncertainty regarding etiology after structural imaging and/or FDG-PET has been interpreted, a dementia specialist can obtain CSF according to appropriate use criteria for analysis of aβ42 amyloid and tau/p-tau profiles to evaluate for Alzheimer’s disease pathology.</p>	C
	<p>RECOMMENDATION 17: If diagnostic uncertainty still exists after obtaining structural imaging and FDG-PET and/or CSF aβeta and tau/p-tau is unavailable or uninterpretable, the dementia specialist can obtain amyloid PET scan according to the appropriate use criteria.</p>	C
	<p>RECOMMENDATION 18: In a patient with an established Cognitive Behavioral Syndrome and a likely autosomal dominant family history, the dementia specialist should consider whether genetic testing is warranted. A genetic counselor should be involved throughout the process.</p>	A

Communication of Diagnostic Findings and Recommended Follow-Up	RECOMMENDATION 19: Throughout the evaluation process, the clinician should establish a dialogue with the patient and care partner to assess the understanding (knowledge of facts) and appreciation (recognition that facts apply to the person) of the presence and severity of the Cognitive Behavioral Syndrome. The patient and care partner's understanding and appreciation of the Syndrome should guide education, communicating and documenting diagnostic findings, assessment, and diagnostic disclosure.	A
	RECOMMENDATION 20: In communicating diagnostic findings the clinician should honestly and compassionately inform both the patient and their care partner of the following information using a structured process: the name, characteristics and severity of the Cognitive Behavioral Syndrome; the disease(s) likely causing the Cognitive Behavioral Syndrome; the stage of the disease; what can be reasonably expected in the future; treatment options and expectations; potential safety concerns; and medical, psychosocial and community resources for education, care planning and coordination, and support services.	A

Assigning Levels of Strength to a Recommendation

A - Indicates that recommendation must be done.

In almost all circumstances, adherence to the recommendation will improve outcomes.

B - Indicates a recommendation that should be done.

In most circumstances, adherence to the recommendation will likely improve outcomes.

C - Represents a recommendation that may be done.

In some circumstances, adherence to the recommendation might improve outcomes.

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