

APA GUIDELINES for the Evaluation of Dementia and Age-Related Cognitive Change

APA TASK FORCE ON THE EVALUATION OF DEMENTIA AND AGE-RELATED COGNITIVE CHANGE

APPROVED BY APA COUNCIL OF REPRESENTATIVES
FEBRUARY 2021



**AMERICAN
PSYCHOLOGICAL
ASSOCIATION**



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INTRODUCTION

Dementia, or major neurocognitive disorder as it is termed in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5®) (American Psychiatric Association, 2013), is a leading cause of cognitive and functional decline among older adults worldwide and will continue to ascend in global health importance as populations continue to age and effective cures remain elusive (Mathers & Loncar, 2006). By 2060, 13.9 million Americans age 65 and older are projected to be diagnosed with Alzheimer's disease and related dementias (Matthews, et al., 2019), although the incidence of dementia may be decreasing (Knopman, 2020). The incidence for mild cognitive impairment (MCI) or mild neurocognitive disorder (DSM-5®) (American Psychiatric Association, 2013) may be twice as high as dementia (Plassman & Potter, 2018). African Americans and Latinx have higher rates of dementia (Mehta et al., 2017) due in part to historical, sociocultural, and healthcare inequities (Plassman & Potter, 2018).

What follows are professional practice guidelines developed for psychologists who perform evaluations of dementia, MCI, and age-related cognitive change. Although the DSM-5 uses the terms mild neurocognitive disorder and major neurocognitive disorder, the broader research and practice literature typically uses the terms mild cognitive impairment and dementia, and this document follows that convention. Their goal is to promote proficiency and expertise in assessing dementia and age-related cognitive decline in clinical practice. Although dementia and MCI occur in individuals under age 65, the majority of cases occur in older adults, who are the population of focus in these Guidelines.

Additionally, given the stark racial and cultural disparities in dementia outcomes (Stokes et al. 2020), multicultural competence in all aspects of assessment of cognitive decline in older adults is applicable to all the guidelines and is their ideal aspiration.

Guidelines are statements that suggest or recommend specific professional behavior, endeavors, or conduct for psychologists. Guidelines differ from standards in that standards are mandatory

and may be accompanied by an enforcement mechanism. Guidelines are aspirational in intent. They are intended to facilitate the continued systematic development of the profession and to help facilitate a high level of practice by psychologists. Guidelines are not intended to be mandatory or exhaustive and may not be applicable to every professional situation. They are not definitive, and they are not intended to take precedence over the judgment of psychologists. Further, professional practice guidelines are developed based on consensus within the field and thus differ from clinical practice guidelines that rely on systematic reviews and strength of evidence rules (APA, Professional Practice Guidelines, Guidance for Developers and Users, 2015b). These guidelines conform to the "Ethical Principles of Psychologists and Code of Conduct" (APA, 2017a). The guidelines may not be applicable in certain circumstances, such as some experimental or clinical research projects or some forensic evaluations. The guidelines are developed for use in the United States but may be appropriate for adaptation in other countries.

Psychologists are uniquely equipped through training, expertise, and the use of specialized neuropsychological tests to assess changes in cognitive and behavioral functioning and to distinguish typical changes from early signs of neuropathology. Neuropsychological evaluation and cognitive testing remains the most effective differential diagnostic methods for discriminating pathophysiological dementia from age-related cognitive decline, cognitive difficulties that are depression related, and other related disorders. Although biomarkers are used broadly in research and in some clinical settings, neuropsychological evaluation and cognitive testing are necessary to determine the onset of dementia, the functional expression of the disease process, the rate of decline, the functional capacities of the individual, and eventually response to disease-modifying therapies. That is, while biomarkers can detect the underlying neuropathologic changes, cognitive testing is necessary to determine how the disease is impacting one's functioning (Block et al., 2017; Weissberger et al.).

Development Process

Professional practice guidelines on this topic were originally developed by an APA Presidential Task Force, approved as policy by the APA Council of Representatives, and published in 1998 (APA Presidential Task Force on the Assessment of Age-Consistent Memory Decline and Dementia, 1998). The guidelines were reviewed, updated and renamed the *Guidelines for the Evaluation of Dementia and Age-Related Cognitive Change* in 2011 (APA, 2012c).

In 2019, the Board for the Advancement of Psychology in the Public Interest (BAPPI) and the Committee on Aging (CONA) received notification from the Policy and Planning Board that the 2011 guidelines were set to expire in 2021. After conferring with BAPPI and Board of Professional Affairs (BPA) staff, CONA reached out to its collaborators on the 2011 guidelines, Division 20 (Adult Development and Aging), Division 40 (Society of Clinical Neuropsychology), and Division 12-Section II (Society for Clinical Geropsychology). Together they reviewed the 2011 guidelines and determined that there was a clear need to revise this policy. They also prepared a slate of experts to serve as Task Force members for BAPPI's consideration. In November 2019, BAPPI appointed the Task Force to Update the Guidelines for the Evaluation of Dementia and Age-Related Cognitive Change. Its members are: Benjamin T. Mast, PhD, ABPP (Chair), Andreana Benitez, PhD, Shellie-Anne Levy, PhD, Mary M. Machulda, PhD, ABPP, Glenn E. Smith, PhD, ABPP and Kelsey R. Thomas, PhD. The members selected represent multiple, diverse, constituent groups – practice, science, multicultural diversity, early career psychologists, and experience in APA guideline development. The Task Force convened monthly via teleconference, supplemented by small group discussions through December 2020 to complete the update.

A preliminary review of the 2011 guidelines commenced in January 2020 with a 60-day public comment period during which 10 APA Boards and Committees provided input on issues for consideration by the crafters of the guidelines' revision. In addition, eight subject matter experts provided extensive comments that informed the revisions. The draft of the updated guidelines was reviewed by the Office of General Counsel and posted online for the final, 60-day public comment period in September, 2020. The Task Force made its final revisions to the guidelines in response to comments received and the final draft was reviewed by the Office of General Counsel that found no issues of concern. There was no financial support for this effort as all Task Force meetings were held remotely. Nor was financial support received from any group or individual, and no financial benefit to the Task Force is anticipated from approval or implementation of these guidelines.

An update of the guidelines is warranted at this time as psychological science and practice in dementia and age-related cognitive change have evolved rapidly. The current document serves to update the 2011 guidelines based upon recent research and emerging practice trends.

Each guideline includes a Rationale section that provides content relevant to the guideline topic and an Application section that provides recommendations for the clinician to follow when enacting these guidelines in clinical practice.

Guidelines for the Evaluation of Dementia and Age-Related Cognitive Change

THE GUIDELINES

Overview of the Guidelines

GENERAL GUIDELINES: COMPETENCE

- **Guideline 1:** Psychologists gain specialized competence in assessment and intervention with older adults.
- **Guideline 2:** Psychologists performing evaluations of dementia are familiar with the prevailing diagnostic nomenclature and specific diagnostic criteria.

GENERAL GUIDELINES: ETHICAL CONSIDERATIONS

- **Guideline 3:** Psychologists are aware of the special issues surrounding informed consent in older people living with cognitive impairment.
- **Guideline 4:** Psychologists seek and provide appropriate consultation in the course of performing evaluations of dementia and age-related cognitive changes.
- **Guideline 5:** Psychologists are aware of cultural perspectives and of personal and societal biases and engage in nondiscriminatory practice.

PROCEDURAL GUIDELINES: CONDUCTING EVALUATIONS OF DEMENTIA AND AGE-RELATED COGNITIVE CHANGE

- **Guideline 6:** Psychologists strive to obtain all appropriate information for conducting an evaluation of dementia and age-related cognitive change, including pertinent medical history and communicating with relevant health care providers.
- **Guideline 7:** Psychologists conduct a clinical interview as part of the evaluation.
- **Guideline 8:** Psychologists are aware that standardized psychological and neuropsychological tests are important tools in the assessment of dementia and age-related cognitive change.
- **Guideline 9:** When evaluating for cognitive and behavioral changes in individuals, psychologists attempt to estimate pre-morbid abilities.
- **Guideline 10:** Psychologists are sensitive to the limitations and sources of variability and error in psychometric performance and to the sources of error in diagnostic decision-making.
- **Guideline 11:** Psychologists make appropriate use of longitudinal data.
- **Guideline 12:** Psychologists recognize that dementia and cognitive impairment are often accompanied by changes in mood, behavior, personality and social relationships, and attend to these in the assessment process.
- **Guideline 13:** Psychologists recognize the importance of assessing family caregiver health and well-being.
- **Guideline 14:** Psychologists recognize that providing constructive feedback, support, and education as well as maintaining a therapeutic alliance are important parts of the evaluation process.
- **Guideline 15:** As part of the evaluation process, psychologists recommend appropriate, empirically-based interventions available to people living with cognitive impairment and their family caregivers.
- **Guideline 16:** Psychologists are aware that full evaluation of possible dementia is an interprofessional, holistic process involving other health care providers. Psychologists respect other professional perspectives and approaches. Psychologists communicate fully and refer appropriately to support integration of the full range of information for informing decisions about diagnosis, level of severity, and elements of the treatment plan.

GENERAL GUIDELINES: COMPETENCE

GUIDELINE 1

Psychologists gain specialized competence in assessment and intervention with older adults.

Rationale

A central ethical tenet for psychologists is that they practice only within their area of competence (APA, 2017a). In addition to meeting general competency benchmarks for the practice of professional psychology (APA Competency Benchmarks in Professional Psychology, 2012a), psychologists who conduct evaluations of dementia and age-related cognitive changes are encouraged to obtain special competencies required for this activity. Specialized training in geropsychology and/or neuropsychology and/or rehabilitation psychology provide conceptual and clinical foundations for practice in this area.

Application

Psychologists engaged in evaluation of dementia and age-related cognitive change have a solid foundation in clinical psychology. In addition, they are encouraged to obtain and maintain fundamental education, training, and supervised experience in specialties and subfields including but not limited to geropsychology, neuropsychology, rehabilitation psychology, psychopharmacology, neuropathology, and psychopathology. Competence in gathering clinical history; conducting clinical interviews; administering, scoring, and interpreting psychological and neuropsychological tests; and delivering interventions to people living with dementia or age-related cognitive impairment and their families is necessary but may not be sufficient. Psychologists obtain training in cultural psychology and strive for multicultural competence in clinical practice with older adults. Psychotherapy and other intervention training, as well as training in interprofessional consultation is beneficial for psychologists working with older adults and their families as they navigate the challenges that dementia and cognitive impairment have on daily living, particularly interventions designed to help individuals to adjust to diagnosis and its implications, assist family caregivers, reduce unmet needs, and address behavioral and psychological symptoms that occur in the context of dementia. Psychologists also strive to stay abreast of state laws pertinent to dementia evaluations and diagnosis.

GUIDELINE 2

Psychologists performing evaluations of dementia are familiar with the prevailing diagnostic nomenclature and specific diagnostic criteria.

Rationale

A clear understanding of how cognitive disorders are defined and diagnosed is important for developing assessment plans, providing feedback to individuals and their family members, and communicating effectively with other professionals involved in an individual's care. Differential diagnosis requires knowledge of a broad range of psychological and medical conditions that can affect an individual's cognitive and behavioral functioning and an appreciation of both the general trends and individual differences that characterize typical cognitive aging. Because diagnostic nomenclature and criteria evolve in response to clinical and scientific advances, updating of knowledge is important to sustain a high level of proficiency in assessing cognitive disorders.

Application

Psychologists are encouraged to obtain training and continuing education to enhance and maintain their expertise and to utilize current diagnostic methods, concepts, criteria, and nomenclature in their evaluations of older adults.

The *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5; American Psychiatric Association, 2013) outlines diagnostic criteria for the clinical syndromes of major neurocognitive disorder and mild neurocognitive disorder. Although the nomenclature of the DSM-5 is different from ongoing research definitions and prior DSM diagnoses, in general, a major neurocognitive disorder that is thought to be due to a likely neurodegenerative etiology is consistent with a classification of dementia and mild neurocognitive disorder is consistent with the concept of mild cognitive impairment (MCI; note it is also possible to have a major or mild neurocognitive disorder due to non-degenerative etiologies such as Traumatic Brain Injury (TBI), infection, or other disease processes). The DSM-5 now includes additional criteria for determining the likely etiologies of a neurocognitive disorder due to Alzheimer's disease (AD), (e.g. frontotemporal lobar degeneration, vascular disease, dementia with Lewy bodies).

Separate from the DSM-5, familiarity with other diagnostic schemes for dementia and MCI such as the International Classification of Diseases (ICD) codes and disease-specific task forces is encouraged. For example, for Alzheimer's disease, slightly different classification guidelines for dementia and MCI due to AD, as well as preclinical AD, have also been provided by task forces jointly established by the National Institute on Aging (NIA) and the Alzheimer's Association (AA; Albert et al., 2011; Jack et al., 2018; McKhann et al., 2011; Sperling et al., 2011). The NIA-AA guidelines

provide criteria for identifying cognitive impairment (dementia, MCI) of probable and possible AD etiologies, with greater certainty in etiology when biomarker information is available. Neuropsychological testing to confirm the presence and nature of cognitive decline is an important part of the NIA-AA criteria for AD, particularly in questionable cases. Indeed, the use of comprehensive neuropsychological testing has been shown to improve diagnostic accuracy and improve the prognostic value of an MCI classification relative to methods that rely more heavily on brief cognitive screening measures and/or clinical ratings (Bondi et al., 2014; Edmonds et al., 2015).

Neuropsychological testing also figures prominently in the consensus panel guidelines for assessing other forms of dementia. Consensus groups have offered detailed and clinically useful diagnostic criteria for several other major causes of late-life dementia, including vascular cognitive impairment (Gorelick et al., 2011; Sachdev et al., 2014), behavioral variant frontotemporal dementia (Rascovsky et al., 2011), and dementia with Lewy bodies (McKeith et al., 2017). All diagnostic criteria require confirmation of dementia by a clinical evaluation to exclude other explanations for the cognitive impairment that may be determined by history, clinical examination, or specialized tests.

The diagnosis of MCI and/or mild neurocognitive disorder has increased over the last two decades and is thought to occur in a period prior to dementia in which one exhibits cognitive difficulties that are greater than expected based on demographically appropriate normative data, but not so severe as to warrant a diagnosis of dementia given relative sparing of everyday functioning. Although individuals with MCI often remain stable or revert to cognitively typical ranges, MCI classification does generally confer a greater risk for progression to dementia (Manly et al., 2008; Roberts et al., 2014; Smith & Bondi, 2013). Separate from the DSM-5 mild neurocognitive disorder criteria, specific criteria for defining MCI in clinical and research settings vary (Albert et al., 2011; Jak et al., 2009; Petersen, 2004, 2010; Winblad et al., 2004). However, subtypes of MCI (e.g., amnestic vs. non-amnestic; single vs. multiple domains) may provide additional information about disease severity and breadth

of cognitive domains impacted that may be useful in determining etiology and brain regions/systems affected, likelihood of reversion to cognitively unimpaired, or risk of future progression to dementia (e.g., Edmonds et al., 2020; Yaffe et al., 2006).

The use of biomarkers in both research and clinical settings has drastically increased in recent years. In research, the concept of preclinical AD has garnered increasing attention and is thought to represent a stage when AD pathologies are accumulating, but frank cognitive impairment consistent with MCI or dementia is not yet observed. The NIA-AA has put forth a research schema for the biological classification of preclinical AD that focuses on amyloid (A), tau (T), and neurodegeneration (N) such that individuals are characterized as positive or negative for each biomarker and are given an A/T/N profile (Jack et al., 2018). However, this framework has yet to be implemented into clinical practice. Research evaluating its utility for clinical use across populations as well as the nature of the subtle cognitive changes that likely occur during this preclinical phase of AD is ongoing. Practitioners are encouraged to maintain up-to-date knowledge of the status of the research and recommendations for use of biomarkers in clinical practice.

Cognitive decline or complaints often co-occur with mental health conditions, such as depression and anxiety. Declines in attention, concentration, or increased indecisiveness and slowed thinking are included in the DSM-5 diagnostic criteria for generalized anxiety disorder and a major depressive episode. Given the complex relationship between mood/psychiatric symptoms and cognitive changes, familiarity with the cognitive impact of common psychiatric disorders is essential for differentiating between psychiatrically-related cognitive impairments, mood and behavioral changes that may sometimes signal early stages of a neurodegenerative process, and late-life mood and behavior changes that may develop in response to experiencing declining cognition (Geda et al., 2013; Krell-Roesch et al., 2019).

GENERAL GUIDELINES: ETHICAL CONSIDERATIONS

GUIDELINE 3

Psychologists are aware of the special issues surrounding informed consent in older people living with cognitive impairment.

Rationale

Psychologists recognize that informed consent can be a special challenge in dementia evaluations. Informed consent requires that one's agreement to assessment and treatment be competent, voluntary, and informed (American Bar Association [ABA] & APA, 2008; Moye & Wood, 2020). Informed consent implies the person has the capacity to understand the significant benefits, risks, and alternatives of the proposed assessment and to make and communicate a health care decision (Uniform Health-Care Decisions Act, 1994). Yet cognitive impairment in the context of dementia may limit one's capacity to make healthcare decisions without support. This dilemma creates the appearance of a double bind regarding obtaining informed consent for dementia evaluations.

Application

The ABA and APA's (2008) *Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists* provides guidance to help the clinician when assessing persons who may have diminished capacity. This handbook notes,

"The person may have capacity to consent to the evaluation, and either agrees or refuses. In this case, the person has provided a valid agreement or refusal, and this can be documented. Alternatively the person may not have the capacity to consent to the evaluation, and either agrees or refuses. If the person agrees, [they are] generally said to have "assented" and the assessment process goes forward. If the person disagrees, and refuses to comply with an interview, then the psychologist must document why the person is believed

to lack the capacity to refuse the evaluation. In some situations, the capacity evaluation stops there. In other situations, where a capacity evaluation is court ordered, the psychologist may be asked to provide an opinion based on his or her observations of the person (ABA & APA, 2008, p.35)."

The presence of dementia alone does not imply that the person lacks decision-making capacity.

Questions of capacity are addressed with focused capacity evaluations that address specific capacity domains (e.g., medical and financial decision making capacity) through assessment procedures described by the ABA and APA (2008). These include not only assessment of cognitive change, but also functional elements relevant to the capacity domain, other psychological disorders, value and preferences, as well as steps that can enhance capacity including supported decision-making (ABA & APA, 2008; Moye, 2020). Supportive decision-making enables older adults with cognitive impairment to make decisions about their life and care, while receiving help and guidance from a trusted network of people (Moye & Wood, 2020). Psychologists also recognize that exploitation of older adults does occur and evaluate the possibility that an assessment may be requested for reasons that may not be in the best interest of the client (e.g., a family member hoping to take control over finances for their own gain).

Consistent with the APA Code of Ethics, when conducting evaluations of dementia and cognitive change, psychologists seek to balance the person's autonomy and protection (Bush, Allen, & Molinari, 2017). The development of dementia may threaten one's autonomy and increase the need for greater protections to enhance safety such as supported decision-making; however, psychologists also seek to promote as much autonomy as possible, recognizing that overprotection and inappropriate removal of one's rights also carries risks to the well-being of people living with dementia.

When describing the purpose, nature, and procedures of the evaluation with the older adult, the psychologist uses terms in a manner that will foster optimal understanding. To do this, psychologists consider the many factors that may impact decision-making (e.g., educational background, culture, experience in healthcare settings) and tailor their language accordingly. In securing informed consent, psychologists explain to individuals and their legal proxies the following issues, including but not limited to:

- what to expect in the evaluation (e.g., the length of the appointment, how and to whom feedback will be provided, the absence of invasive or painful procedures, the challenging nature of cognitive testing),
- the financial costs of an evaluation (e.g., what insurance will and will not pay for, who is ultimately responsible for paying costs),
- the benefits and risks for the person being assessed,
- limitations to confidentiality (including reporting suspected elder abuse),
- constraints on release of raw test data, and
- mandatory reporting requirements.

Benefits of the assessment may include gathering of helpful clinical information to be used in diagnosis and treatment planning including ways to develop supports that would optimize their autonomy, while potential risks may include the loss of decision-making rights, preclusion from certain services or nursing home placement, potential lack of confidentiality, and the possible need for a guardian or conservator. Psychologists recognize these potential risks and inform the patient/client what documentation will arise from an evaluation (e.g., written report, verbal communication, note in chart) and ways the information from the evaluation may be used by a recipient of that information

(even if the use is unknown). In some situations, supported decision-making with a trusted family member, friend, or professional may provide people living with dementia the opportunity to better understand the options and communicate with their providers while also supporting their autonomy. In certain situations, psychologists may need to offer an expert opinion regarding capacities regardless of whether or not the person consents to a full evaluation (Moye & Wood, 2020). In these situations, psychologists are encouraged to inform the individual that the evaluation must be conducted whether or not they are willing participants and that a refusal to participate will result in the evaluation being compiled from other sources.

The laws for determining capacity as well as the rules and requirements of legally authorized persons vary from state to state. If the individual does not have legal capacity to provide consent, the psychologist must obtain consent from a legally authorized person (see Section 3.10 of the APA's "Ethical Principles of Psychologists and Code of Conduct"; APA, 2017a) to carry out the evaluation and to gather information from other health professionals and family members. Psychologists understand that legally authorized persons can take several forms (i.e., power of attorney, medical power of attorney, guardian), with each form having different levels of control; psychologists understand the permissible actions and timeframe of the representative as outlined in the documentation granting authority (and may ask for a copy when appropriate). Psychologists document the consent, assent, or refusal of the individual as appropriate. Psychologists also document evidence regarding the person's capacity or lack thereof to consent to the assessment.

GUIDELINE 4

Psychologists seek and provide appropriate consultation in the course of performing evaluations of dementia and age-related cognitive changes.

Rationale

Complex issues arise during the evaluation of suspected cognitive decline or dementia. These issues may include multiple medical comorbidities or medication side effects, sociohistorical background and cultural origins, genetic and heritability factors, abuse or neglect, questions of legal competence or guardianship, conflicting or unclear assessment results, and families overwhelmed or divided by the potential diagnosis. For these reasons, integrated health care approaches are particularly well-suited for cognitive decline and dementia care (Galvin, Valois, & Zwieg, 2014).

Application

Psychologists providing services to this population strive to be particularly sensitive to the multiple health conditions that impact cognitive function. In all of these areas, the clinician, individual, and/or family may benefit from and contribute to the expertise or services of other professionals, including but not limited to a range of health professionals such as physicians (e.g. neurologists, geriatricians, psychiatrists, primary care providers), speech therapists, occupational therapists, genetic counselors, adult protective and social service workers, attorneys, and other psychologists (ABA & APA, 2008).

When the psychologist is the first professional the individual contacts, the psychologist seeks to gather existing medical records to complement and inform the assessment. Generally, the individual will have had or will be referred for a thorough medical evaluation to discover any underlying medical disorder or any potentially reversible medical conditions associated with dementia or cognitive decline. When the psychologist is a consultant to other providers, the psychologist seeks to contribute unique and high-value information provided by psychological methods in a thorough, integrated, and efficient manner. Psychologists recognize the need for efficient practice to improve

access to services that are highly valued by referring professionals (Mahoney et al, 2017).

If issues of abuse or neglect arise, psychologists notify appropriate authorities and make referrals for appropriate services. To do so, psychologists remain abreast of local legal reporting requirements and processes (Mosqueda & Olsen, 2015). Psychologists seek to be attentive to issues of financial exploitation, undue influence, and loss of financial capacity (Lichtenberg, 2016; Marson, 2016; Wood & Lichtenberg, 2017) and use well-validated tools to assess these issues (Lichtenberg et al, 2015; 2016; 2017; Marson et al, 2009). In addition, psychologists are encouraged to inform the individual of the reporting requirement prior to services being rendered. In matters of legal capacity and guardianship, psychologists seek additional legal consultation, supervision, and/or specialized knowledge, training, or experience as appropriate to address these issues (Moye & Wood, 2020). Psychologists communicate their findings to other health care professionals with sensitivity to issues of informed written consent that is compliant with the guidelines of the Health Insurance Portability and Accountability Act of 1996 (U.S. Department of Health and Human Services, Office for Civil Rights, 1996). In addition to engaging in nondiscriminatory practice (as described in Guideline 5), psychologists seek consultation from colleagues with multicultural competence, when possible, to appropriately contextualize results and recommendations to all recipients of the information obtained from the assessment.

Psychologists are encouraged to help educate other health care professionals who administer mental status examinations or other brief psychological tools regarding the benefits and limitations of these instruments and their clinical utility for particular applications as well as appropriate referrals, and the importance of well-articulated referral questions. Education can also be provided about the utility and limitations of more comprehensive psychological or neuropsychological assessment in dementia evaluations.

GUIDELINE 5

Psychologists are aware of cultural perspectives and of personal and societal biases and engage in nondiscriminatory practice.

Rationale

The population of the United States is becoming increasingly older and heterogeneous, with the growth of racial and ethnic minorities outpacing that of Whites (US Census Bureau, 2017). The trend for increased neuropsychological referrals for racially and ethnically diverse older adults has been known for approximately 15 years (Byrd & Manly, 2005); the racial diversity of client referrals is even greater today. There is some evidence to suggest that dementia prevalence is higher in ethnic minorities (i.e., African Americans and Hispanic/Latinx) relative to Whites, in part due to genetic risk factors and disproportionate rates of cardiovascular disease, but also in part due to sociocultural factors that may influence diagnosis and treatment (Chin et al., 2011; Fernandez & Johnson, 2020). Therefore, it is paramount that psychologists engage in culturally sensitive assessment of cognitive changes and dementia for their diverse clients. Despite the current sense of urgency, culturally competent provision of services and nondiscriminatory practice is already an established ethical mandate for all psychologists who work with diverse populations (APA 2017a; Boundaries of Competence).

Application

APA's 2017 *Multicultural Guidelines: An Ecological Approach to Context, Identity, and Intersectionality* recommend psychologists practice within their boundary of competence, which includes assessment of culturally and linguistically diverse groups. The psychologist is alert and sensitive to differing roles, expectations, and normative standards within a sociocultural context. In practice and when appropriate, the psychologist discusses and counters potential biases to ensure optimal client performance is achieved for the assessment. Adapted from Mindt et al.'s (2010) "call to action", the following practices may be useful to consider when evaluating diverse older clients:

- Strive to use the best available

neuropsychological tests and most appropriate norms. For example, the most appropriate norms may be from Mayo's Older African American Normative Studies (MOAANS) instead of the more familiar Heaton norms. When appropriate norms are unavailable for a particular client, the psychologist clearly documents the limitations of their assessment and diagnoses in this regard. Research to establish norms on commonly used clinical tests for specific ethnic and racial populations is growing (e.g., advances in norms for Spanish-Speaking individuals from several South American countries (Arango-Lasprilla, 2015, Sayegh & Piersol, 2020), but representative norms are still lacking in many cases. Psychologists assessing older adults from racial and ethnic minority groups use the best available tests with norms appropriate for each individual's background and consult with expert colleagues as needed regarding battery construction and interpretation (Fujii, 2017; Robbins et al., 2016). The neuropsychological report contains caveats related to cultural considerations and limitations of measures used, standardization of administration, normative data available, and if an interpreter was used which raises many ethical considerations that need to be considered (Pedraza, 2018; Rabin, et al., 2020). For cultural considerations in the evaluation process including test selection and interpretation, see Fujii (2017) and Robbins et al., (2016).

- Strive to contextualize neuropsychological findings and recommendations with as much sociocultural information as possible (e.g., quality of education, degree of acculturation and immigration history, language proficiency/fluency, and perspectives on caregiving and use of support resources).
- Strive to control biases through reviewing relevant research, relying on evidence-based practice guidelines, and by seeking additional consultation or, in some cases, withdrawing from the evaluation. The psychologist is encouraged to be aware of their own personal biases, acknowledge them, and work to minimize their impact while working with

diverse clients. If the psychologist is unable to conduct the evaluation fairly, the ethical psychologist seeks to refer the individual to other psychologists capable of providing services.

- Strive for continued growth in cultural competence. In their seminal work, Sue and colleagues (1992) describe cultural competence as 1) awareness of one's own assumptions and biases, 2) understanding the worldview of culturally dissimilar clients, and 3) the ability to develop culturally appropriate assessments or interventions. This can be facilitated through educational opportunities and/or self-directed study through published books and articles (Rabin, et al., 2020). Performing culturally sensitive assessments requires a life-long process of self-reflection and analysis, checking one's biases and assumptions when interacting with diverse clients (Chang, et al. 2020; Dugbartey, 2014).
- Psychologists are advised to carefully evaluate test quality and appropriateness for individual circumstances, especially when the test is being administered to individuals with different cultural and linguistic backgrounds (American Educational Research Association [AERA], APA, & National Council on Measurement in Education [NCME], 2014). For example, the noose item in the Boston Naming Test (BNT) may be culturally inflammatory for African Americans, who have a history of generational trauma related to slavery, violence, and discrimination. Because this item may assess different constructs in African Americans vs. Whites and lacks cultural sensitivity, the noose item has been suggested as inappropriate for continued inclusion in the BNT (Horwitz & McCaffey, 2010). Notably, a replacement item can now be obtained free of charge from the test publisher.

Ageism towards older adults is pervasive in society and is also prevalent in healthcare practice, of which psychologists and other mental health care professionals are not immune (APA, 2020b). These negative biases include assumptions that older adults are dependent, depressed, socially isolated, and will inevitably become

cognitively impaired (APA, 2014, 2020b). With regard to clinical practice, older adults are screened less for functional abilities and cognitive changes, and late life depression is often overdiagnosed. Diagnoses and recommendations may not be clearly communicated (Hirnichsen, 2020), which may be related to an assumption of low competence. Psychologists are advised to be vigilant for stereotype threats which may activate internalized ageism and to work with older individuals to better understand the evaluation procedures and purposes to ensure accurate and optimal performance. For example, older clients may underperform on memory tests and other cognitive measures due to age-based stereotype threat (APA, 2020b; Lamont, Swift, & Abrams, 2015). Lastly, ageism may compound the deleterious effects of other biases related to one's level of education attainment, racial/ethnic background, disability, or other aspects of diversity (Chang et al., 2020). Psychologists strive to consider how the interaction of their own actual/perceived identities and that of their clients may affect performance. Furthermore, psychologists strive to consider how the family histories and intersectional identities of their older clients may affect their health status, risk factors, and access to services.

Ethnically diverse older adults experience disparities in aging and dementia outcomes that are influenced by a variety of sociocultural factors including disparate rates of poverty, lower educational attainment, cultural beliefs in the understanding of dementia and caregiving that may limit service utilization, bias and discrimination based on race, religion, age, sex, disability, sexual orientation, or gender identity, and limited healthcare access and/or inadequate provision of healthcare services (Chin et al., 2011; Connell et al., 2009; Hernandez et al., 2010; Mahoney et al., 2005; Mehta et al., 2005; Roberts et al., 2003; Wallace, 2012; Yeo et al., 2019; Zuckerman et al., 2008). Indeed, there are significant differences in knowledge and awareness of dementia, specifically Alzheimer's disease, in ethnically diverse older adults (Cahill et al., 2015; Ayalon, 2013; Milani et al., 2020). Psychologists are encouraged to work for health equity in diverse populations, and strive to increase awareness of

sociocultural factors that influence dementia rates and outcomes. For example, with regard to cultural beliefs, African American, Hispanic/Latinx, and Chinese Americans may perceive memory loss and dementia as typical parts of aging; without overgeneralization, some African Americans, in particular, may believe in spiritual causes for illness with reliance on spirituality or religion for health and well-being (Connell et al., 2009; Mahoney et al., 2005). Psychologists aim to clarify possible cultural factors that may influence their client's understanding and perceptions of dementia and cognitive impairment (e.g., normalizing cognitive loss; viewing illness as retribution for past sins).

Outreach and psychoeducation in at-risk communities can improve their clients' knowledge base; however, mistrust of healthcare providers, including fears that their concerns may not be acknowledged or fear of institutionalization when family-centered care is preferred, may play a large role in whether ethnic minority clients seek care or even report symptoms of cognitive changes (Mahoney, 2005). In this vein, trust and rapport with their clinicians, including psychologists who aim to be culturally aware and sensitive, is vitally important. While there may be multiple cultural and institutional barriers to care that require time and nuanced approaches for remediation, financial barriers may be more readily amenable for speedier resolution. Ethnic minority populations are often un- or underinsured at greater rates than Whites (Fiscella et al., 2000), having poorer access to health insurance that covers neuropsychological services. Psychologists may wish to offer reduced fees or pro bono services for individuals who are un- or underinsured.

For additional guidance on culturally informed psychological practice, see the APA *Guidelines for psychological practice with older adults* (2014), *Multicultural Guidelines: An ecological approach to context, identity, and intersectionality* (2017), *Guidelines for psychological practice with boys and men* (2018a), *Guidelines for psychological practice with girls and women* (2018b), *Guidelines on race and ethnicity in psychology* (2019b), *Assessment of and intervention with persons with disabilities* (2012b), *Guidelines for psychological practice with lesbian, gay, and bisexual clients* (2012d), *Guidelines for psychological*

practice with transgender and gender nonconforming people (2015a), and *Guidelines for psychological practice for people with low-income and economic marginalization* (2019a).

PROCEDURAL GUIDELINES: CONDUCTING EVALUATIONS OF DEMENTIA AND AGE-RELATED COGNITIVE CHANGE

GUIDELINE 6

Psychologists strive to obtain all appropriate information for conducting an evaluation of dementia and age-related cognitive change, including pertinent medical history and communicating with relevant health care providers.

Rationale

Cognitive function and change are associated with several medical and psychosocial conditions that must be considered in any evaluation of current cognitive performance. However, individuals and even knowledgeable informants may be imperfect historians or lack information regarding the individual's past and current medical status, neuroimaging findings, medication use, and daily function. Medical, occupational, and educational records and family history documents can provide important contextual and functional information pertinent to the evaluation (ABA & APA, 2008).

Application

Prior to conducting the evaluation, psychologists seek to clarify the referral question by reaching out to the referral source. Psychologists strive to fully understand all facets of the referred individual's context, including the perspective of the person who has been referred for evaluation. Psychologists are encouraged to consult with other health care providers and seek relevant records, particularly concerning the individual's health status, medical history, dementia-related biomarkers such as neuroimaging or cerebrospinal fluid information, and current medications. Recent medical evaluations provide critical data concerning the onset and course of cognitive changes.

Psychologists strive to utilize supported decision making approaches when the person's ability to recall and communicate personal and medical information is limited by cognitive impairment. When an individual is able to give only limited self-report, psychologists seek consent or assent from the individual to gather corroborative information from other informants including family members and care providers. Psychologists inform these sources of the potential uses of the information and the limits to confidentiality. In obtaining collateral information, the psychologist considers the interpersonal/family dynamics and cultural contexts as well as the potential motivations of informants. For example, depression can influence the reports of both the person referred for assessment and their family caregivers. Utilization of multiple sources of data helps offset these issues.

In practice, the amount of reliable information available to the psychologist for the evaluation may be highly variable, depending in part on the availability of relevant records as well as knowledgeable family, friends, and other professionals. Conclusions and recommendations from the evaluation may be constrained by the need for further information or a follow-up evaluation.

dementia (ABA & APA, 2008; Mackinnon & Mulligan, 1998). Obtaining contextual and historical information from interviewing the client and knowledgeable informants improves diagnostic accuracy and, ideally, considered in combination with performance-based measures and self-report (Edmonds et al., 2014; Galvin et al., 2005; Mast & Yochim, 2018; Monnot, et al., 2005). Interview data from a corroborative source, such as a caregiver or knowledgeable family member, can provide information on everyday cognitive functioning (Waite et al., 1998). A potential advantage of informant history is the ability to assess change in functioning from earlier in life, which also provides an important context from which to interpret the objective test scores (Jorm, 1996). Finally, obtaining data from informant interviews can add greater precision in the design of appropriate behavioral, environmental and pharmacological treatments of dementia (Hartman-Stein et al., 2002; Mast, 2011; Waite et al., 1998).

Application

Clinical interviews with the client and knowledgeable informants (e.g., family, close friends) provide a more complete picture of the person's history, daily functioning, support systems, and other social and psychological resources. Directly interviewing the person being evaluated for dementia communicates respect for the person's perspective and life history, while evaluating firsthand the level of cognitive function and the individual's awareness of any cognitive and behavioral changes (Mast, 2011). It also enables the psychologist to discern psychosocial stressors or other mental health problems that may be contributing to cognitive change. Such data obtained from direct interviews are invaluable for both diagnostic and intervention planning purposes, and enables the psychologist to tailor

GUIDELINE 7

Psychologists conduct a clinical interview as part of the evaluation.

Rationale

Although objective testing provides valuable data for diagnostic purposes, the clinical interview remains one of the central elements of an in-depth assessment for

person-centered care recommendations to the individual.

In order to accurately diagnose conditions that are associated with cognitive decline and functional disability, psychologists also strive to obtain corroboration from knowledgeable informants whenever possible. Psychologists consider the pros and cons of interviewing the individual and collateral sources separately versus interviewing them together at the same time. Psychologists also carefully consider the reliability of information obtained from interviews and how client and informant characteristics influence what is reported (e.g., family caregiver burden, client memory or communication impairment). Key information obtained during the interview includes but is not limited to the following:

- the onset and course of changes in cognitive functioning,
- response to prior or current interventions,
- level of functioning in instrumental and basic activities of daily living,
- pre-existing disabilities,
- educational and cultural background that could affect testing,
- general medical and psychiatric history,
- past neurological history including prior head injuries or other central nervous system insults (e.g. strokes, tumors, infections),
- current psychiatric symptoms and significant life stressors,
- current prescription and over-the-counter medication and supplement use, as well as home remedies,
- current and past use and abuse of alcohol and drugs,
- family history of dementia (including type and source of diagnosis).

Psychologists may choose to incorporate structured, evidence-based clinical dementia rating tools, brief mental status examinations, and formal measures of functional status and capacity in their clinical interviews. Some clinical information may be gathered from interviews conducted by other professionals as part of an

interprofessional team. Additionally, psychologists may consider a referral for a neuropsychological evaluation, particularly when results from brief mental status evaluations are unclear, that includes comprehensive testing alongside a full clinical interview as a way to integrate multiple sources of information when determining a diagnosis or etiology for cognitive decline and to best understand cognitive strengths (see Guideline 8).

In order to design practical, person-centered recommendations for treatment planning purposes, during the clinical interview the psychologist strives to obtain, whenever possible, an assessment of the person's remaining strengths, unmet needs, quality of life, psychological well-being, social resources, employment, and functional information regarding the individual's ability to manage the important aspects of self-care and the potential utility of compensatory techniques (Molony et al., 2018; ABA & APA, 2008; Mast, 2011). In evaluating suspected dementia, psychologists are encouraged to:

- be sensitive to families' and individuals' understanding of the potential diagnosis of dementia and its ramifications,
- attend to and seek to assess a person's goals, values and preferences regarding care, daily activity, habits, and awareness of resources for care and advance planning (Allen et al., 2019; Jennings et al., 2018; Van Haitsma et al., 2013; Whitlatch, 2010),
- assess the individual's past and current coping skills as well as resources from which the individual can receive support, including cultural, racial/ethnic, and religious communities.

GUIDELINE 8

Psychologists are aware that standardized psychological and neuropsychological tests are important tools in the assessment of dementia and age-related cognitive change.

Rationale

The use of psychometric instruments may represent the most important and unique contribution of psychologists to the assessment of dementia and cognitive change (AERA, APA, & NCME, 2017). Psychometric assessment provides objective information on cognitive strengths and weaknesses necessary for diagnosis. Testing provides reliable information for tracking cognitive change over time or in response to interventions.

Application

Psychologists select appropriate measures to address the referral question and are encouraged to use standardized, reliable, and valid tests. Whether traditional, technology assisted, or teleneuropsychology, appropriate tests have normative data for the age range of the person being assessed and are suitable for the individual's gender, ethnicity, culture, language, and educational background.

Psychologists strive to understand the differences between cognitive screening, cognitive testing, and neuropsychological testing and to carefully evaluate if they have the requisite competency to complete each type of evaluation through their training and education prior to performing cognitive evaluations (Block et al., 2017; Roebuck-Spencer et al., 2017). This information is available in the education and training taxonomies and standards established by each recognized specialty (APA, 2020a).

Brief mental status examinations are used to screen for dementia and other cognitive impairments and track cognitive change in individuals with more severe levels of impairment (e.g., Mini-Mental State Examination (MMSE), Montreal Cognitive Assessment (MoCA)). Brief cognitive screening tools should be standardized and have good positive predictive values for identifying possible cognitive

impairment. Psychologists strive to be aware that not all screening tools are equally sensitive for detecting cognitive impairment and appropriately research the strengths and weaknesses of each instrument prior to use. Psychologists strive to be familiar with the positive and negative predictive values of these tools for identifying cognitive impairment in populations with age, educational, and ethnic and racial characteristics similar to those of the persons to be assessed. A majority of studies reviewed showed that brief mental status examinations generate adequate sensitivity and specificity to dementia but less so for MCI (Moyer, 2014). Importantly, these tools may perform differently based on educational background (Rossetti, 2011) and in ethnic/racial minorities groups resulting in different cut-scores for determining impairment (Rossetti et al., 2018). Moreover, brief mental status tests are insensitive to subtle cognitive changes typical of pre-clinical stages. For these reasons, there may be poor concordance between a brief mental status score and functional status or clinical concern. Thus, both positive and negative results on brief mental status testing may require follow-up with more in-depth neuropsychological testing.

Comprehensive neuropsychological evaluations are used to address more complex referral questions for dementia and cognitive change and typically include tests assessing multiple cognitive domains, such as memory, attention, processing speed, perceptual and motor skills, language, visuospatial abilities, and executive functions. Psychologists are encouraged to include measures of mood in the assessment of dementia and cognitive change. Personality measures may also be warranted depending on the clinical question. Neuropsychological evaluations may also benefit from some form of assessment of strengths/coping assets, which can help the client and care provider in receiving and adjusting to the diagnosis. Conducting neuropsychological evaluations requires training and competence in neuropsychology.

There are many tests and approaches that are useful for assessments, and the number of tests with normative data for older age ranges has increased. The number of tests with specific demographic

adjustments has also increased. Psychologists strive to use sex-adjusted norms when possible because women may be diagnosed with dementia later than men given their verbal memory advantage (Maki & Henderson, 2012; McCarrey, et al., 2016; Sundermann et al., 2019). Supplementing standard age norms with normative data obtained from samples where the absence of dementia has been established longitudinally (i.e., robust norms) may help to increase reliability in identifying mild levels of cognitive impairment. Regarding age norms, psychologists are aware of the relative stringency with which people living with mild cognitive impairment or early dementia were excluded from the standardization samples for a given test. Psychologists assessing cognitive function and change among older adults of ethnic and racial minorities strive to be familiar with the adequacy of the normative data for ethnic and racial minorities for the various measures they employ. Psychologists seek to understand the psychometric properties of measures used in evaluations and take into account the base rates of low scores and account for this in clinical decision making (Kiselica et al., 2020).

Technology assisted assessments, telepsychology and teleneuropsychology (TeleNP) are rapidly evolving (Bilder et al., 2020; Germine, Reinecke, & Chaytor, 2019; Hewitt & Loring, 2020). These approaches to assessment will undoubtedly improve access to service, especially in underserved areas and for individuals who have difficulty leaving their homes. Although there appears to be good support for TeleNP assessments in older adults (Marra et al., 2020), there are also many challenges in implementing these services with older persons due to lack of access to reliable equipment and broadband service, limited experience and proficiency interacting with technology among some older individuals, and reliance on caregivers for those with more severe cognitive impairment. Psychologists are encouraged to use extra caution when administering measures and interpreting results of remote assessment, including but not limited to some of the commonly used instruments (e.g., TICS; telephone-MoCA) in lieu of formal, in-person assessments. The most recent and representative data about aging and

technology use/adoption is available from the Pew Resource Center (2020). Regarding telepsychology and TeleNP, psychologists aim to utilize the most up to date information provided in online resources prior to providing these services such as the APA Guidelines for the Practice of Telepsychology (2013a), APA Ethical Principles of Psychologists and Code of Conduct (2017a), and the Interorganizational Practice Committee (IOPC)'s Tele-Neuropsychology Models and Tools (2020) that are available online at no cost.

GUIDELINE 9

When evaluating for cognitive and behavioral changes in individuals, psychologists attempt to estimate premorbid abilities.

Rationale

The diagnosis of dementia requires evidence of decline from a previously higher level of cognitive function. Ideally, psychologists assessing for cognitive declines in older persons would have baseline test data from earlier years against which current performance could be compared.

Unfortunately, this information rarely exists, so psychologists must try to estimate premorbid abilities.

Application

Psychologists strive to use premorbid functioning estimating methods that are appropriate to each individual. Psychologists are encouraged to be aware of the limits of various approaches to premorbid ability estimation and to appropriately qualify their clinical judgments about premorbid function. Factors commonly considered include socioeconomic status, educational quality and attainment, occupational history, multilingualism, acculturation or immigration experience, and information from collateral informants. This demographic and historical information can be supplemented by contemporaneous tests such as tests of crystallized abilities or word reading ability. Tests of word reading ability are frequently used due to their expediency and ability to account for differences in test performance

between racial/ethnic majority and minority groups, indicating literacy or educational quality (Cosentino et al., 2007; Fyffe et al., 2011). Nonetheless, limitations include measurement imprecision (Bright & van der Linde, 2020; Lowe & Rogers, 2011) and attenuated scores even in early prodromal stages (Weinborn et al., 2018). It may also be challenging to estimate change from premorbid functioning among individuals with language-predominant impairments (e.g. primary progressive aphasia), individuals for whom English is not their native language, or those with intellectual disabilities (cf. McGlinchey et al., 2019; Prasher, 2018; Strydom et al., 2010).

GUIDELINE 10

Psychologists are sensitive to the limitations and sources of variability and error in psychometric performance and to the sources of error in diagnostic decision-making.

Rationale

Psychometric instruments and clinical interpretations of these instruments are subject to error. Instruments have known or knowable limits to their reliability and validity (AERA, APA, & NCME, 2017). Clinical decision-making must contend with limits to test classification accuracy (Chelune, 2017). These psychometric properties are impacted by varying factors such as demography (e.g., age, education, ethnicity) and context, including clinical settings in which performance validity may be at question (Davis, 2018; Lippa, 2018; Martin et al., 2020). In addition, decline in sensory acuity (particularly hearing and vision loss) is frequently comorbid with cognitive decline in aging (Whitson et al., 2018) and may impact performance on psychometric testing (de Haan et al., 2020; Wong et al., 2019), potentially decreasing the diagnostic specificity of these findings. Psychologists strive to be cognizant of the ongoing efforts to disentangle the unique and shared influences of aging, sensory loss, and cognitive decline, as this information impacts psychometric test interpretation, prognostication, and recommendations for

compensatory or rehabilitative strategies (for reviews see Albers et al., 2015; Hill-Briggs et al., 2007; Rutherford et al., 2018; Wayne & Johnsrude, 2015).

Application

Psychologists strive to understand sources of variability and error in their instruments and judgments about cognitive change. They strive to maximize the reliability and validity of the assessment process through appropriate collection of history and selection of instruments, norms, and procedures, including accommodations for potential sensory changes. Psychologists are encouraged to recognize limitations in the evaluation process by appropriately qualifying their judgments and conclusions.

2018). In most cases, a one-year follow-up interval is adequate for monitoring changes in cognitive performance, unless the individual, family, or other health care professionals report a more rapid decline or improvement, emergence of new symptoms, changes in life circumstances, or the individual is 85 years old or older given the higher likelihood of dementia (Patnode et al., 2020).

Because test means may decline with age, it is important that tests selected for use in the evaluation of dementia and age-related cognitive change have adequately accounted for uncomplicated age-related changes in cognitive function. Although better and larger standardization samples of older adults are now available for many commonly used clinical tests, longitudinal norms for older adults are limited, especially those that have more than two assessments. Psychologists recommend follow-up testing only as appropriate (e.g., for diagnostic clarification, treatment planning, and monitoring intervention response) and recognize that interim follow-up not involving formal testing may also be useful in many cases.

Psychologists are strongly encouraged to use statistical methods to assess reliable change so that the extent of change can be interpreted appropriately (Duff, 2012; Stein et al., 2010). There are several statistical methods to assist the psychologist in determining if a reliable change has occurred across time: (1) Simple discrepancy score; (2) Standard deviation index; (3) Reliable Change Index (RCI); (4) RCI controlling for practice effects; (5) Regression-based change formulas (Duff, 2012).

GUIDELINE 11

Psychologists make appropriate use of longitudinal data.

Rationale

Psychologists are frequently asked to perform repeat assessments to follow progression of a condition, track recovery, or track responses to intervention. Psychologists make use of longitudinal data whenever possible, instead of relying exclusively on premorbid estimates. Existing cognitive data can serve as a baseline against which to measure future changes in cognitive functions, whereas magnitudes and rates of cognitive change can be determined by follow-up testing.

Application

Psychologists are strongly encouraged to utilize prior cognitive data when available. Psychologists also strive to be knowledgeable of the stability parameters of the instruments they use over specific inter-test intervals and become familiar with patterns of practice or learning effects and accommodate these effects in their test selection and application. Many cognitive instruments are insensitive to changes over shorter periods, and true cognitive decline may be underestimated if practice effects are not taken into account (Elman et al.,

GUIDELINE 12

Psychologists recognize that dementia and cognitive impairment are often accompanied by changes in mood, behavior, personality and social relationships, and attend to these in the assessment process.

Rationale

People living with mild cognitive impairment and dementia may experience a variety of

changes in mood, behavior, and social interaction including depression, anxiety, wandering, hallucinations, delusions, sleep disturbance, verbal and physical aggression, and apathy. Although these have typically been subsumed under broad categories of behavioral and psychological symptoms of dementia (BPSD) or neuropsychiatric symptoms, they likely reflect an interaction among a variety of factors including cognitive impairment, unmet needs, symptoms of distress, unrecognized pain and discomfort, under- or over-stimulating environments, and caregiver responses (Ballard et al., 2000; Cohen-Mansfield, 2015; Lyketsos et al., 2011; Massimo et al., 2018; Mast, 2011). Most people living with dementia will experience at least one behavioral and psychological changes at some point (Steinberg et al., 2008), although these are more common later in the progression of dementia (Kales et al., 2015).

Although these are not always part of the dementia syndrome itself, they occur more often in the context of dementia and some dementias (e.g., frontotemporal dementias [FTD] and Lewy body dementia [LBD]) have these symptoms as core features (e.g., disinhibition, apathy in FTD and visual hallucinations in LBD). Pre-existing psychological disorders can also contribute to mood and behavior changes in people living with dementia. Regardless of etiology, psychologists are encouraged to evaluate and address these behavioral expressions since they contribute to lower quality of life, higher caregiver burden, and can lead to negative outcomes such as early nursing home placement (Kales et al., 2015; Feast et al., 2016). Recognition and treatment of BPSD can be influenced by health disparities, with recent research suggesting that prevalence and knowledge may be affected by ethnicity and culture (Babulal et al., 2019).

Application

Psychologists strive to be aware of the type of behavioral and psychological changes that can accompany dementia and MCI, and understand their impact on the person, their caregivers, and health care utilization. Whether in the context of initial diagnostic work-up, ongoing intervention, or consultation in long-term care and hospital settings, psychologists assess changes in mood, behavior, and personality in the clinical

interview and in collateral interviews with family and other caregivers. Psychologists may also incorporate well-validated measures in the evaluation process to assess for symptoms and track the effectiveness of interventions (Clarke et al., 2020; Cohen-Mansfield, 2015; Cohen-Mansfield et al., 1989; Cummings, 1997; Curyto et al., 2008; Gitlin et al., 2014; Griffiths et al., 2020; Kolanowski et al., 2017; Malloy & Grace, 2005; Teri et al., 1992).

Application

Clinicians strive to become familiar with assessment approaches and interventions that address family caregiver mental health and resources. Psychologists working with older adults with cognitive impairment seek opportunities to also address family caregiver needs and characteristics that can affect quality of life and well-being. This may include but is not limited to caregiver knowledge and understanding of dementia syndromes, availability of social support, and access to care resources for those with low income and/or social isolation (Zarit & Heid, 2015). Psychologists are also attuned to issues of stress and burden, but also to positive aspects of caregiving and resilience. A variety of nonpharmacological interventions have been developed to improve outcomes with family caregivers, including interventions aimed at promoting benefit finding and resilience (Cheng et al., 2017; Cheng et al., 2020). Caregiver interventions address the provision of education, support and self-care, training in managing challenging behaviors and addressing unmet needs. Psychologists may also recommend engagement in caregiver support groups and the utilization of day center and respite services that can lower stress and improve quality of life (Zarit et al., 2014). Psychologists may encounter clinical situations where evaluation of a family caregiver's capacity to provide care is necessary (Hinrichs & Smith, 2020). The APA Caregiver Briefcase provides an updated collection of clinical practice tools for assessment, intervention, education, and advocacy, as well as research resources (<https://www.apa.org/pi/about/publications/caregivers>).

Enabling family members to accept, support, and engage the person living with dementia is an important challenge to address. It is also critically important that therapeutic goals be discussed directly with the individual who has dementia. This not only provides the respect and dignity that any individual deserves but also provides highly relevant information regarding the individual's understanding and attitude about the goal, their motivation in achieving the goal, and willingness to expend time and energy working toward the goal. Many psychological interventions aimed at helping people living with dementia directly involve family caregivers, who

learn the intervention approach and implement it under the guidance of psychologists and other mental health professionals (Teri et al 2020; Teri et al, 2003).

GUIDELINE 14

Psychologists recognize that providing constructive feedback, support, and education as well as maintaining a therapeutic alliance are important parts of the evaluation process.

Rationale

Individuals and/or family members of individuals concerned about MCI/dementia generally come to the evaluation process seeking information as well as emotional support. Provision of both information and support while maintaining a sense of respect and dignity for the individual, regardless of level of cognitive impairment, reflect both professional ethics and sound clinical practice. Establishing a therapeutic alliance is critical for accurate assessment, development of efficacious intervention, and increased likelihood that interventions will be effectively implemented with good adherence. Early diagnosis and feedback can enable a greater window for legal, financial, and health care planning.

Application

Providing meaningful feedback can be especially challenging given the complexity of communicating dementia diagnoses (Dooley et al., 2015), as evidenced by the fact that many people living with dementia are either undiagnosed or unaware of their diagnosis (Amjad et al., 2018). Other research suggests that up to 50% of patients and families are not informed of a dementia diagnosis (see Carpenter & Gooblar, 2018 for review). People living with dementia have a right to diagnostic information and an explanation for their symptoms, although psychologists are encouraged to consider disclosure preferences of the person and their family. On the other hand, cognitive impairments may limit how much people living with dementia understand and recall their diagnosis. High

levels of fear and low levels of education concerning dementia can also contribute to poor understanding and follow-up care. Feedback highlights strengths and weaknesses and connects the person and family to community support that is both culturally sensitive and person-centered. Psychologists carefully consider the meaning and ramifications of the diagnostic implications for the person (e.g., loss of autonomy, prospect of further decline and disability). It is important to be knowledgeable of the recommendations regarding follow-up and daily living that are typically provided (Meth et al., 2019) and to convey such feedback in a manner that ensures comprehension (Postal & Armstrong, 2013). Post-evaluation feedback has been shown to result in improvements in quality of life, understanding of the diagnosed condition, and coping (Rosado et al., 2018), and even decreased healthcare utilization (Van Kirk, et al., 2013).

Feedback is provided to individuals in language they can understand. Psychologists are encouraged to exercise clinical judgment and take into consideration the needs and capabilities of the particular individual when feedback is provided. The presence of a significant support person during feedback allows the psychologist to assist with differences of opinion, respond to individual questions, and facilitate the interactions between the individual and persons in their support network (Green, 2006). Providing feedback, education, and support to persons significant to the individual, with the individual's informed consent, can also enhance their value and applicability. Psychologists are encouraged to provide feedback to others involved in the person's care, including professional staff in long-term care and home-based care settings. Knowledge regarding levels of impairment, the expected course, and expected outcomes can help these significant others to make adequate preparations and provide individualized care based upon the person's strengths and weaknesses, and level of functioning. Working with the individual's support network in this way can provide them with effective means of responding to the challenges posed by behavior changes stemming from a diagnosis of dementia. Healthy older adults who have had concerns about their cognitive functions can benefit from reassurance

based on results of testing and from suggestions for how they may enhance their everyday cognitive function.

With regard to feedback, education, and support, psychologists are encouraged to be sensitive to issues of marriage, partnerships, family relationships, and friendships of each unique individual. Psychologists strive to acknowledge and accord full respect to these relationships, including those of sexual minority, transgender, and gender nonconforming people, even if these relationships are not recognized by law or acknowledged by individual institutions.

GUIDELINE 15

As part of the evaluation process, psychologists recommend appropriate, empirically-based interventions available to people living with cognitive impairment and their family caregivers.

Rationale

In addition to cognitive decline, people living with dementia experience a wide range of changes in daily functioning, mood, behavior, and social relationships. Psychologists play an important role by incorporating a broad range of interventions to enhance functioning and quality of life. A variety of psychosocial and behavioral interventions focused on the person living with dementia and their caregivers have been developed which can reduce behavioral problems, enhance quality of life, and address unmet needs (Ballard et al., 2018; Beck et al., 2002; Cohen-Mansfield et al., 2007; Cohen-Mansfield et al., 2012; Livingston et al., 2014; Kovach et al., 2006; Meeks et al., 2015; Teri et al., 2003; Teri et al., 2020). Caregiver interventions improve the health and well being of caregivers (Cheng et al., 2020; Elliott et al., 2010; Gallagher-Thompson et al., 2020; Gitlin et al., 2003; Qualls & Williams, 2013), and also reduce nursing home admission and the negative impact of behavioral and psychological changes exhibited by the person living with dementia (Kales et al., 2015; Mittelman et al., 2006; Mittelman & Bartels, 2014).

Application

Psychologists strive to educate themselves regarding currently approved medical and behavioral treatments of dementia and remain abreast of available community, web-based and technological resources. This is a rapidly evolving area, and both families and health care professionals can benefit from learning about best practices based on sound empirical evidence. Cognitive impairment alone does not preclude the ability to benefit from various forms of psychotherapy. It is important to note that cognitive/behavioral interventions are effective in addressing dysphoria, agitation, anxiety, and apathy in people living with dementia (Orgeta et al., 2014). Psychologists strive to recommend appropriate interventions to maximize individual function, balance autonomy and safety, and minimize challenging behavior and emotional distress associated with dementia. Psychologists seek to determine underlying environmental, social, historical, psychological, functional, and medical causes of emotional and behavioral disturbance associated with dementia. Individuals and families can be educated about these treatments, which can be offered to individuals as appropriate. This includes greater awareness of lifestyle factors associated with greater risk for cognitive decline and interventions aimed at preventing cognitive decline and delaying the onset of dementia. (Livingston et al, 2017; 2020; Ngandu et al, 2015).

People living with cognitive impairment often have impaired daily function. Functional challenges can be addressed with a variety of cognitive, behavioral, psychosocial interventions and support services. Technological supports are nascent but rapidly emerging (Moyle, 2019). These interventions may rely on retained abilities, such as preserved procedural/non-declarative memory and preserved reading abilities, social history, and environmental cues. It is therefore critical not only to be aware of the declines associated with a diagnosis of dementia but also to be knowledgeable of those abilities that are relatively spared in dementia, as well as the individual's personal history, background, and current levels of functional capacity. Functional difficulties associated with cognitive decline can sometimes be

partially mitigated through the use of cognitive training paradigms (e.g., errorless learning, spaced retrieval) (Hampstead, 2020) or external aids (e.g., planners or medication dispensers (Greenaway, et al., 2013). However, both approaches require intensive training. Moreover, caregivers and other environmental supports are crucial in maintaining the positive effects of these interventions.

People living with cognitive impairment may also display mood disturbance and challenging behaviors. Antipsychotic medications have been linked to negative outcomes for people living with dementia, and as a result, multiple organizations including the FDA have discouraged their long-term use in this population (Maglione et al, 2011; Reus et al., 2016). Psychosocial and behavioral interventions can frequently mitigate many of these issues (Livingston et al., 2014). Challenging behaviors (e.g., agitation, aggression, anxiety, and apathy) are considered by some an attempt to communicate unmet human needs in people living with dementia and related disorders (Cohen-Mansfield, Libin, & Marx, 2007).

Psychologists work directly with family caregivers to address mental health issues that arise in the midst of caregiving. A variety of caregiver interventions have been developed to enhance caregiver health and well-being, many of which have demonstrated empirical support (Burgio et al., 2009; Cheng et al, 2020; Elliott et al, 2010; Gallagher-Thompson et al, 2020; Mittelman & Bartels, 2014; Pot et al, 2019; Zarit & Heid, 2015). Central features of these approaches include: dementia education, skills training, caregiver self-care and stress management, social support, addressing behavioral changes, and connecting families with community resources. Interventions aimed at incorporating professional caregivers in long-term care settings have also been developed and represent an important practice area for psychologists (Meeks, et al, 2015). The APA Caregiver Briefcase (APA, 2020c) includes a variety of intervention resources.

Psychologists strive to consider financial constraints when making treatment recommendations, as well as the person's comfort with recommendations. The level of trust in healthcare professionals will

invariably impact whether or not patients pursue important treatments (Kennedy et al., 2007).

GUIDELINE 16

Psychologists are aware that full evaluation of possible dementia is an interprofessional, holistic process involving other health care providers. Psychologists respect other professional perspectives and approaches. Psychologists communicate fully and refer appropriately to support integration of the full range of information for informing decisions about diagnosis, level of severity, and elements of the treatment plan.

Rationale

Traditional health care may be provided in isolated settings with outdated systems of manual record keeping. This exacerbates older adults' vulnerability to fragmented care. Receiving conflicting diagnoses and care advice from different providers can increase the burden of chronic and acute medical conditions for individuals and caregivers, and result in disempowering individuals and providers alike (McWilliam et al; Brown et al., 1994). The increased use of electronic medical record systems has allowed for improved ease of communication among providers within the same healthcare system. No single provider is ever likely to have all the essential information that can contribute to making an accurate diagnosis. An interdisciplinary team is most likely to provide all the essential information necessary to make an accurate diagnosis and develop a comprehensive treatment plan. Interdisciplinary teams adopt an "approach to care...characterized by a high degree of collaboration across the various health professionals serving patients in assessment, treatment planning, treatment implementation, and outcome evaluation" (APA Blueprint for change: Achieving integrated healthcare for an aging population, 2008, p. 22). An integrated approach to health care benefits

older adults. These concerns apply to diagnoses of dementia and to intervention decisions regarding people living with dementia and their caregivers.

With the initiation of the Affordable Care Act (ACA), increased emphasis has been placed on preventative and early detection measures, and the primary physician now has a larger role in directing and integrating medical care. Under ACA, Medicare pays for an Annual Wellness Visit that includes the development of a personalized plan for prevention and detection of psychological changes as well as cognitive impairment.

Application

Psychologists strive to ensure that every effort is made to involve all relevant providers in the diagnostic and treatment process. Psychologists are encouraged to take proactive steps to develop collegial, interdisciplinary relationships with other health care providers serving the population for whom they routinely receive referrals for dementia assessment (APA Guidelines for Psychological Practice in Health Care Delivery Systems, 2013b). In addition to communication surrounding assessment, psychologists are also well-positioned to work closely with interprofessional treatment teams (e.g., occupational, physical, speech-language therapists) to promote optimal management of dementia. With appropriate informed and written consent, information can be shared across providers as needed to reach an accurate diagnosis and coordinate appropriate interventions. Psychologists are encouraged to make appropriate referrals to other members of an integrated healthcare team.

CONCLUSION

In 2018, approximately 52 million people in the United States were age 65 or older. This number is expected to nearly double by 2060, increasing the population of individuals, and their families, facing cognitive change and decline. As this cohort grows in number, it also grows in diversity (Centers for Disease Control and Prevention, 2018). Psychologists must be prepared to serve the needs of this population. Psychologists adhering to the guidelines enumerated herein can make significant contributions to the care and well-being of the rapidly expanding number of older persons confronting age-related cognitive change or dementia, as well as their family caregivers.

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