

February 8, 2017

Shekhar Saxena, MD Director Department of Mental Health and Substance Abuse World Health Organization CH-1211, Geneva Switzerland SaxenaS@who.int

Dear Dr. Saxena:

We are writing on behalf of the American Psychological Association (APA) to request reconsideration of the World Health Organization's proposal to transfer all of the diagnoses for dementia from the Mental or Behavioural Disorders chapter of the ICD-11 to the chapter of Diseases of the Nervous System. APA is the largest scientific and professional organization representing psychology in the United States, with 115,700 researchers, educators, clinicians, consultants and students as members and affiliates. Our mission is to advance the creation, communication and application of psychological knowledge to benefit society and improve people's lives.

We were surprised and very concerned to learn of this new development as we were aware that a different approach had been jointly proposed by the ICD-11 Mental Health and Neurology Topic Advisory Groups and had previously been reflected on the ICD-11 beta platform. According to that proposal, the syndrome of dementia and associated psychological and behavioral symptoms would be classified under Mental and Behavioural Disorders, while the neurological disease entities that can underlie the syndrome of dementia would be classified under Diseases of the Nervous System. We understand that from a health statistics perspective, this dual-coding approach may seem complicated, but the proposed change reflects a marked divergence from ICD-9 and ICD-10 without a clear empirical justification. APA is concerned that this change is likely to result in a serious reduction in the access to and quality of care for those with dementia by precluding health care professionals from providing critically needed assessment and intervention services to this population.

First of all, it is critical to note that the proposed transfer of ICD-11 diagnoses for dementia is inconsistent with the current placement of the behavioral consequences of other general medical conditions. For example, Psychotic Disorder Due to Another Medical Condition, with delusions, is in the Mental or Behavioural Disorders (MBD) chapter. Placing the behavioral consequences of just Dementia Conditions (Major Neurocognitive Disorder) in the neurology section of ICD-11 is not comparable with how such conditions are treated in the Endocrine, Cardiovascular, or Infectious Disease sections and with how the related delirium and amnesic disorders are addressed.

Secondly, the ICD-10 organization, in which the neurocognitive disorders are located in the MBD chapter and the causative degenerative brain disorders are located in the neurology chapter, continues to reflect a valuable and realistic distinction. It is also concordant with the principles of ICD-11, in which the disorders are listed in the chapter corresponding to their manifestations and not in the chapter covering the causative disorder (e.g., diabetic neuropathy in the neurology chapter, diabetes in the metabolic chapter). Thirdly, there are some dementias due to non-medical, non-neurological conditions – such as HIV, alcoholism, and liver disease – that would not belong in the neurology chapter. Fourthly, the ICD-10 placement of dementia, which acknowledges both the underlying medical condition and the manifestation of that condition, can support reimbursement for the management of both aspects of the disease.

And of particular concern related to the last point above, the proposed change is likely to have the deleterious effect of reducing access to health care services for patients with dementia and other brain disorders in the U.S. and elsewhere. For example, it is anticipated that U.S. health care payers, such as Medicare, Medicaid, and private insurance companies, would deny reimbursement to health professionals for such services as diagnostic assessment, neuropsychological testing, behavioral treatments, and psychopharmacological treatment of cognitive and behavioral manifestations of these conditions.

The science and practice of psychology are integral to efforts to assess, diagnose, treat, and support individuals with dementia, and to lighten the burden of the families and institutions that provide their care. Psychologists are essential members of interdisciplinary health care teams and are experts in the neuropsychological assessment of individuals suspected of having dementia and in the development and delivery of evidence-based interventions to address the mental health and behavioral symptoms associated with dementia across the disease course.

With respect to the assessment of dementia, our first point of emphasis is that the current gold standard for dementia diagnosis involves a neuropsychological evaluation. Psychologists are trained in the integration of measures of cognitive performance with historical, neurological, medical, psychological, behavioral, social, familial, environmental, and other diagnostic information. Current research demonstrates that neuropsychological measures function well as diagnostic, prognostic, and disease progression indicators (Blacker et al., 2007; Gomar et al., 2011; and Tabert et al., 2006). Cognitive measures are critical in the practical and operational level within all three recognized stages of Alzheimer's disease (AD) - pre-clinical, mild cognitive impairment (MCI), and AD dementia - in recently updated diagnostic guidelines by the U.S. National Institute on Aging and the Alzheimer's Association (Albert et al., 2011; McKhann et al., 2011; and Sperling et al., 2011). Neuropsychological measures are more accurate, earlier predictors of progression to AD when compared to MRI, FDG-PET, and amyloid imaging (Gomar et al., 2011). Even as biomarker identification and analysis improve, neuropsychological evaluation and cognitive testing will still be 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, hopefully, response to therapies (APA, 2012).

Neuropsychological evaluation and cognitive testing remain among the most effective differential diagnostic methods in discriminating neurodegenerative changes from normal agerelated cognitive decline, cognitive difficulties that are related to mental health conditions or medical morbidities, and other related disorders. They also provide useful information to individuals with dementia and their families regarding functional capacities and the potential impact of interventions on disease progression (APA, 2012). In addition, these measures are utilized to evaluate the capacity of an individual to independently make medical, financial, and legal decisions (ABA & APA, 2008). Psychologists and other health care providers, who are not neurologists, are currently eligible for reimbursement for the provision of assessment services. The proposed change for ICD-11 would restrict the ability of providers with expertise in neuropsychological evaluation to bill for these critical services. This will likely result in both decreased access to and diminished quality of available services. Experts across health professions agree that a comprehensive neuropsychological assessment is necessary to determine the possible causes of disorders and to earmark appropriate behavioral and environmental interventions.

Our second serious concern is that evidence-based interventions for dementia, and the reimbursement for these services, may likewise be jeopardized with the move from the MBD chapter to the Diseases of the Nervous System chapter of the ICD-11. In addition to the cognitive impairments caused by dementia, the most common symptoms of dementia are behavioral and emotional, including agitation, disinhibition, apathy, depression, social withdrawal, wandering, irritability, anxiety, lability, aggression, delusions, and hallucinations. Behavioral symptoms associated with dementia are a critical component for consideration in its conceptualization. At least half of individuals with dementia exhibit these significant behavioral problems at varied stages of the disease process. These behavioral problems are also exacerbated by numerous comorbid conditions, including pain, delirium, sleep disorders, hearing and vision loss, and preexisting depression and psychosis.

Related to the management of behavioral disturbances in dementia, most reviews of the field suggest that behavioral interventions are preferred, due to their safety, effectiveness, and ability to avoid the serious side effects that are common with pharmacological approaches (Salzman et al., 2008). Extensive reviews of the evidence for psychological and behavioral interventions are available (Brodaty & Arasaratnam, 2012; Cooper et al., 2012). Examples of the efficacy of behavioral interventions in treating dementia are as follows: cognitive/behavioral interventions in reducing dysphoria, agitation, disruptive behaviors, anxiety, and apathy (Teri et al., 2005); behavioral and lifestyle interventions in delaying cognitive decline and loss of function (Logsdon McCurry & Teri, 2007); and sensory stimulation in addressing issues related to agitation or anxiety (Lin et al., 2009).

If access to behavioral interventions is curtailed by the proposed change in ICD-11, treatments for dementia will likely be shifted back to the pharmacological approaches that frequently cause iatrogenic effects. Specifically, the Beers Criteria (American Geriatrics Society, 2012) identification of inappropriate medications for older adults, especially those with dementia disorders, include the medications that have been used to manage behavioral problems associated with dementia, including antipsychotics, benzodiazepines, barbiturates, and some antidepressant medications. Thus, it is important to assure that the ICD-11 structure does not impede access to non-pharmacological interventions.

In conclusion, APA requests the transfer of all the diagnoses for Dementia from the Diseases of the Nervous System chapter back to the MBD Chapter of ICD-11. Such a move would be consistent with ICD-10, the classification of other diseases in ICD-11, and the recommendations from both the Mental Health and Neurology experts (Topic Advisory Groups) that advised your Department on the ICD-11 revisions.

Thank you for your attention to our concerns. We look forward to your response and welcome the opportunity to contribute further to the development of ICD-11 to ensure that it reflects both a diagnostic classification system of high clinical utility, as well as a vehicle to ensure that individuals receive needed health care services.

Sincerely,

antini S. Puente

Antonio E. Puente, PhD President

Cympin O/Sen

Cynthia D. Belar, PhD, ABPP Interim Chief Executive Officer

 cc: Donna Pickett, Classifications and Public Health Data Standards, US National Center for Health Statistics, <u>dfp4@cdc.gov</u> Robert Jakob, Classifications Standards, and Terminology, WHO, <u>jakobr@who.int</u>; Anneke Schmider, Health Statistics and Information, WHO, <u>schmidera@who.int</u> Ties Boerma, Director, Department of Health Statistics and Information Systems, WHO, <u>boermat@who.int</u> Stefanie Weber, Co-Chair, Joint Task Force (JTF) on the ICD-11 for Mortality and Morbidity Statistics, <u>Stefanie.Weber@dimdi.de</u> James Harrison, Co-Chair, Joint Task Force (JTF) on the ICD-11 for Mortality and Morbidity Statistics, james.harrison@flinders.edu.au

## References

Albert, MS, DeKosky, ST, Dickson, D, Dubois, B, Feldman, HH, Fox, NC, ... Phelps, CH. (2011). The diagnosis of mild cognitive impairment due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 7(3), 270-279. doi: 10.1016/j.jalz.2011.03.008

American Bar Association & American Psychological Association. (2008). *Assessment of older adults with diminished capacity: A handbook for psychologists*. Retrieved from <a href="http://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf">http://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf</a>

American Geriatrics Society (2012). American Geriatrics Society updated Beers criteria for potentially inappropriate medication use in older adults. *Journal of the American Geriatrics Society*, *60*, 616-631. <u>http://dx.doi.org/10.1111/j.1532-5415.2012.03923x</u>

American Psychological Association. (2012). *Guidelines for the Evaluation of Dementia and Age Related Cognitive Change*. Retrieved from <u>http://www.apa.org/pi/aging/resources/dementia guidelines.pdf</u>

Blacker, D., Lee, H., Muzikansky, A., Martin E., Tanzi, R., McArdle, J., Moss, M., & Albert, M. (2007). Neuropsychological measures in normal individuals that predict subsequent cognitive decline. *Archives of Neurology*, *64*, 862-871.

Brodaty, H., & Arasaratnam, C. (2012). Meta-analysis of nonpharmacological interventions for neuropsychiatric symptoms of dementia. *American Journal of Psychiatry*, *169*, 946-953. doi:10.1176/appi.ajp.2012.11101529

Cooper, C., Mukadam, N., Katona, C., Lyketsos, C. G., Ames, D., Rabins, P., ...Livingston G. (2012). Systematic review of the effectiveness of nonpharmacological interventions to improve quality of life of people with dementia. *International Psychogeriatrics*, *24*, 856-870.

Cohen-Mansfield, J., Gomar J. J., Bobes-Bascaran, M. T., Conejero-Goldberg, C., Davies, P., & Goldberg, T. E. Alzheimer's Disease Neuroimaging Initiative (2011). Utility of combinations of biomarkers, cognitive markers, and risk factors to predict conversion from mild cognitive impairment to Alzheimer's disease in patients in the Alzheimer's disease neuroimaging initiative. *Archives of General Psychiatry*, *68*, 961-969

Lin, L., Wu, S., Kao, C., Tzeng, Y., Watson, R., & Tang, S. (2009). Single ability among activities of daily living as a predictor of agitation. *Journal of Clinical Nursing*, *18*, 117-123. doi: 10.1111/j.1365-2702.2008.02367.x

Logsdon, R. G., McCurry, S. M., & Teri, L. (2007a). Evidence-based psychological treatments for disruptive behaviors in individuals with dementia. *Psychology and Aging*, *22*, 28-36. http://dx.doi.org/10.1037/0882-7974.22.1.28.

McKhann, GM, Knopman, DS, Chertkow, H, Hyman, BT, Jack, CR, Jr., Kawas, CH, ... Phelps, CH. (2011). The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 7(3), 263-269. doi: 10.1016/j.jalz.2011.03.005

Salzman, C., Jeste, D., Meyer, R. E., Cohen-Masfield, J., Cummings, J., Grossberg, G.,...Maslow, K. (2008). Elderly patients with dementia-related symptoms of severe agitation and aggression: Consensus statement on treatment options, clinical trials methodology, and policy. *Journal of Clinical Psychiatry*, *69*, 889-898. doi:10.4088/JCP.v69n0602

Sperling, RA, Aisen, PS, Beckett, LA, Bennett, DA, Craft, S, Fagan, AM, . . . Phelps, CH. (2011). Toward defining the preclinical stages of Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 7(3), 280-292. doi: 10.1016/j.jalz.2011.03.003

Tabert, M.H., Manly, J.J., Liu, X., Pelton, G. H., Rosenblum, S., Jacobs, M., Zamora, D., Goodkind, M., Bell, K., Stern, Y., & Devanand, D. P. (2006). Neuropsychological prediction of conversion to Alzheimer's disease in patients with mild cognitive impairment. *Archives of General Psychiatry*, *63*, 916-922C

Teri, L., Huda, P., Gibbons, L., Young, H., & van Leynseele, J. (2005). STAR: A dementiaspecific training program for staff in assisted living residences. *The Gerontologist* 45, 686-693.