Workgroup on Terminology for Cognitive Impairment and Dementia

A cross-cutting stakeholder discussion on barriers, opportunities and strategies to develop consistent, accurate, and meaningful language for cognitive impairment and dementia, that is useable or at minimum interoperable among scientists, care providers and the public.

Submitted to the Advisory Council on Alzheimer's Research, Care and Services in October, 2018 by
Ronald Petersen, PhD, MD, Mayo Clinic, Angela Taylor, Lewy Body Dementia Association and
Mary Widmeyer, MD, Mayo Clinic

Introduction:

The 2016 and 2017 recommendations in the National Plan to Address Alzheimer's Disease, also recently updated in 2018, call for initiating a national conversation on terminology for cognitive impairment and dementia. Reasons for having such a conversation are summarized in the Alzheimer's Disease-Related Dementias (ADRD) Summit 2017 article in Neurology [1]:, including the following excerpt:

"There are many factors that contribute to unclear and inconsistent nomenclature: undirected evolution of terminology, reductionist tendencies, confounding of clinical syndromes and etiologies, and lack of consensus regarding how to refer to the mildest symptomatic phases of cognitive impairment and dementia."

"In addition, Alzheimer's disease (AD) is often used synonymously with or instead of the term dementia. The result is that some patients and families have not heard of the ADRD diagnoses, and thus lack context for making a connection between AD care and service and their own needs."

Public Perception of Dementia:

There has been an effort to provide appropriate information to the general public, which can be seen in internet educational and advocacy group websites. When performing an internet search on dementia, there is reasonable consistency throughout the top-search sites. They attempt to describe the differentiation of terminology. For example, on the Alzheimer's Association website, it states:

"Dementia is not a specific disease. It's an overall term that describes a group of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities... Dementia is often incorrectly referred to as "senility" or "senile dementia," which reflects the formerly widespread but incorrect belief that serious mental decline is a normal part of aging." [2]

Similar descriptions are seen on other top-search websites, such as Mayo Clinic's Patient Care and Health Information website [3], a discussion of the types of dementia on WebMD [4], and a discussion of "What is dementia?" at the National Institute of aging [5].

These sites are an important vehicle for education, as patients and families frequently obtain direct firsthand knowledge from the internet, prior to evaluation. They can also serve to reinforce information learned through discussions with their physicians. These sites also provide information on the causes of dementia, with sub-topics on Alzheimer's disease, vascular dementia, Lewy body dementia, fronto-temporal dementia, mixed dementia, etc. which can potentially be helpful following diagnosis. Common dementia myths are explicitly addressed on many sites, such as “Memory loss is a natural part of aging”, “only older people can get Alzheimer's”, and “drinking out of aluminum cans or cooking in aluminum pots and pans can lead to Alzheimer’s disease” [6].

However, the access to reliable information about dementia has not yet translated to better public awareness. A study published in 2014 reviewed 40 studies of dementia literacy internationally, and reported only fair to moderate knowledge of dementia. Major misconceptions were recognized, with half of participants across the studies describing dementia as a normal part of aging, with no value in pursuing treatment [7]. Since that time, efforts have been made to change public awareness, including the establishment of dementia as a global health priority by WHO, increase in dementia friendly community' initiatives, and attempts to increase public awareness through social media.

A second review was performed this year, which continues to show the same misconceptions, describing dementia as a normal, non-preventable, part of aging. However, there was an increase in the belief that there was value in seeking treatment for patients with dementia [8]. Both studies note the limited amount of research performed in low- and middle-income countries, and describe that this is particularly concerning, since most people with dementia live in low- and middle-income regions.

The public understanding and perception of dementia has been difficult to shift. Because patients and their families do not have a working knowledge of disease processes, they rely on stagnant perceptions and beliefs. Stigma associated with dementia has been crippling. Frequently, stereotypes describe late stages of disease when a person is most impaired and fully dependent upon others for care [9].

Recent studies conducting surveys to measure the stigma of dementia in the general public showed that people expected that patients with mild-stage AD would not remember most recent events, would be discriminated against by employers, and would be excluded from medical decision-making [10]. The expectations and stigma associated with AD was shown to be related to people’s age, gender and overall beliefs, with older participants describing beliefs about less support and social interactions, and women describing more feelings of sadness and pity [11]. There was also an expectation that health care insurance would be limited due to the diagnosis, genetic testing, or results from brain imaging [10].

The assumptions and stigma of dementia and Alzheimer’s disease can be seen, unexpectedly, in daily life. A study in Belgium starkly highlighted misconceptions about dementia when having participants view mock advertising campaigns for Alzheimer’s awareness. Some advertisements were created with slogans that capitalized on fear of death and debility, whereas others had slogans centered on humor and the ability of patients to maintain some social interactions. Participants described the fear-based slogans as more shocking, but did see them as more credible, comprehensible and impactful [12].

Public assumptions and stigma can be difficult for caregivers to manage, and increase the burden of caregiving. An adult child’s concern about public stigma of dementia has been shown to have an effect on caregiving of their parent, resulting in negative caregiving experiences and increased burden, and ultimately to decreased involvement in the care of their parent [9].

Finally, fear around the risk of having dementia can lead to inaccurate assumptions in the public, despite being given accurate information. A study of participants in the general population who had APOE genotype testing performed showed that almost 70% of participants remembered their risk of dementia as being inaccurately high [13].

Challenges to be addressed:

1. Improvements in the differential diagnosis of AD/ADRDs:

- This requires standardization of diagnosis of clinical syndromes and diseases with known causes.
- This may involve separation of the underlying molecular and cellular causes from risk factors and correlates. Diseases that cause dementia are defined in terms of classical autopsy-based neuropathology, but these terms have been used to also describe clinical phenotypes, and have caused overlap in terminology.

2. Improvement of the precision of treatment of individuals with AD/ADRDs, based on improvements in diagnosis:

- There are implications when redefining terminology - the new use of the DSM-V diagnosis of Major vs. Minor neurocognitive disorder can reclassify patients from prior diagnosis of MCI vs. Dementia [15]. If terminology is adjusted, this can affect the current recommendations of treatment [16].

3. Harmony of terminology used across both clinical and research communities:

- Classifications have been made using clinical symptomatology, the neurohistopathology, characteristics of the patient group, or site of predominant abnormality in anatomy.

4. Improvement the public's understanding of cognitive impairment and the different forms of dementia, over the life course, based on current scientific knowledge. This may require:

- Definition and promotion of a broad understanding, across stakeholders, of preclinical, prodromal, and symptomatic stages .
- Solving the complex ethical challenges, such as the psychological, emotional, social impact of earlier biomarker-driven diagnosis of symptom-free individuals [14].
- Assessment of policy implications and related civil rights issues.
- Improvement of access to care and services, via more refined and accurate diagnoses and public understanding.

5. Management of the unique challenges of communities experiencing health disparities.

- Issues to be addressed include but are not limited to access to healthcare, cultural sensitivities, and diversity in terminology.

6. Reduction of stigma.

- Further understanding of the role of terminology in contributing to or lessening stigma.

Key Stakeholder Groups to Engage:

- Patient and Care Community
  - People with dementia and their families
  - Caregivers
  - Communities experiencing health disparities
  - Service providers
  - Advocacy organizations
- Healthcare System
  - General Medical Practitioners
  - Neurologists
  - Insurance Companies and Payers
- Scientific and Regulatory Communities
  - Researchers (basic, translational and clinical)
  - Federal agencies

Potential Outcomes from Updated Nomenclature:

- Increased understanding of cognitive impairment and dementia across stakeholder groups and the public
- Earlier and more accurate diagnosis
- Easier access to medical care and social services
- More appropriate treatment
- Increased education and support for patients diagnosed
- Better ability of those affected to plan for the future
- Improved sense of well-being for those living with dementia
- Improved ability of research studies to enroll more homogeneous groups of research subjects
- Increased participation in research studies
- Increased rate of scientific progress and development of effective care strategies through better communication among basic, translational, and clinical scientists

Potential Working Group Deliverables:

- ½ day virtual workshop on dementia terminology
- Development of strategy to engage relevant stakeholder groups
- Present developing recommendations at future AD/ADRD summits for public comment
- Engage stakeholders to advance the work in progress
- Refine recommendations for terminology
- Organize a conference for public comment
- Ultimately, publish recommendations on terminology

Acknowledgements: We would like to express our appreciation to Rod Corriveau, PhD of the National Institute of Neurological Disorders and Stroke and Melinda Kelley of the National Institute on Aging for their input on an early draft of this document.

References:

1. Corriveau et al. Alzheimer's Disease–Related Dementias Summit 2016: National research priorities. Neurology Nov 2017, 10.1212/WNL.0000000000004717; DOI: 10.1212/WNL.0000000000004717
2. https://www.alz.org/alzheimers-dementia/what-is-dementia
3. https://www.mayoclinic.org/diseases-conditions/dementia/symptoms-causes/syc-20352013
4. https://www.webmd.com/alzheimers/guide/alzheimers-dementia#1
5. https://www.nia.nih.gov/health/what-dementia
6. https://www.alz.org/alzheimers-dementia/what-is-alzheimers/myths
7. Cahill, S., et al. (2015). "A systematic review of the public's knowledge and understanding of Alzheimer's disease and dementia." Alzheimer Dis Assoc Disord 29(3): 255-275.
8. Cations, M., et al. (2018). "What does the general public understand about prevention and treatment of dementia? A systematic review of population-based surveys." PLoS One 13(4): e0196085.
9. Werner, P., et al. (2010). "Subjective experience of family stigma as reported by children of Alzheimer's disease patients." Qual Health Res 20(2): 159-169.
10. Stites, S. D., et al. (2018). "What features of stigma do the public most commonly attribute to Alzheimer's disease dementia? Results of a survey of the U.S. general public." Alzheimers Dement 14(7): 925-932.
11. Stites, S. D., et al. (2018). "Identifiable Characteristics and Potentially Malleable Beliefs Predict Stigmatizing Attributions Toward Persons With Alzheimer's Disease Dementia: Results of a Survey of the U.S. General Public." Health Commun 33(3): 264-273.
12. Van Gorp, B., et al. (2012). "Toward a more nuanced perception of Alzheimer's disease: designing and testing a campaign advertisement." Am J Alzheimers Dis Other Demen 27(6): 388-396.
13. Linnenbringer, E., et al. (2010). ""I know what you told me, but this is what I think:" perceived risk of Alzheimer disease among individuals who accurately recall their genetics-based risk estimate." Genet Med 12(4): 219-227.
14. Alzheimer Europe Reports. (2016). Discussion paper on ethical issues linked to the changing definitions/use of terms related to Alzheimer's disease.
15. Tay, L., et al. (2015). "New DSM-V neurocognitive disorders criteria and their impact on diagnostic classifications of mild cognitive impairment and dementia in a memory clinic setting." Am J Geriatr Psychiatry 23(8): 768-779.
16. Sachs-Ericsson, N. and D. G. Blazer (2015). "The new DSM-5 diagnosis of mild neurocognitive disorder and its relation to research in mild cognitive impairment." Aging Ment Health 19(1): 2-12.