UNIVERSITY of
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Florida Policy Exchange Center on Aging
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Policy Brief **April 2021**

What You Don’t Know *Will* Hurt You: The Need for Increased Knowledge of Dementia

> ***“What the mind doesn’t understand, it worships or fears.” - Alice Walker***

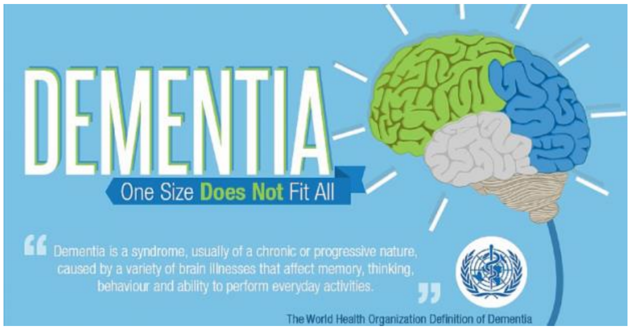
BACKGROUND

Alzheimer’s disease is one of the most feared conditions of older adulthood[1,2]. That fear likely stems from the fact that Alzheimer’s disease and related dementias (ADRDs) are only fairly or moderately well understood in the general population[3]. For example, a vast majority of individuals believe that dementia is a normal part of aging[3,4]. Knowledge about dementia is especially poor among racially and ethnically diverse populations, who hold many misperceptions regarding dementia[3]. This is concerning, given that racial and ethnic minorities, specifically African Americans and Hispanic older adults, have the highest prevalence rates of ADRDs[5]. Poor understanding of ADRDs in the general public can lead to worse outcomes if these individuals subsequently avoid treatment.

In addition to misconceptions, poor understanding of ADRDs is related to higher rates of stigma towards ADRDs[2]. Presence of self-stigma can lead to delayed treatment seeking[6], and stigma about ADRDs from healthcare professionals can lead to poorer outcomes for the treatment-seeking person with an ADRD[7]. Education is one common method used to address stigma, and has been shown to be an effective strategy to reduce stigma towards ADRDs[8].

SUMMARY:

1. There is poor knowledge of ADRDs which can lead to stigma, delayed diagnoses, and poorer outcomes for the person living with ADRD.
2. Two bills in Florida Congress propose to enhance the knowledge of ADRDs in healthcare providers and should be supported.
3. Implications of increasing knowledge of ADRDs in the general public and for healthcare providers include more accurate and earlier diagnoses which would result in better outcomes for the individual living with ADRD, their family and caregivers, and social benefits including cost savings and better research capabilities.



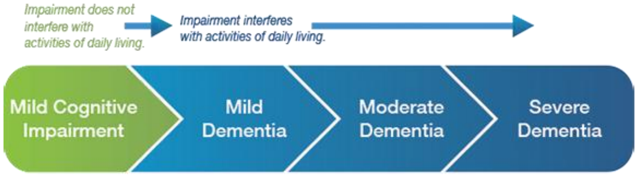
“Dementia is a syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities.”

The World Health Organization Definition of Dementia

Even within the healthcare sector, there have been reports of discomfort with making a dementia diagnosis, due in part to perceived lack of knowledge on dementia[9]. Evidence suggests that primary care providers often miss or delay appropriate dementia diagnoses[9], and that less severe presentations of dementia (or being in a pre-dementia stage of impairment) are related to the highest likelihood of missing the diagnosis[9,10]. Further, correctly noting the diagnosis in medical records is even poorer than clinical judgements, with only about 10% of individuals with mild cognitive impairment being correctly identified in medical notes[10].

However, primary care providers may be best positioned to give dementia diagnoses since they are often the first point of contact for persons expressing concerns with cognition[11], primary care providers have access to the person's medical history, and could reduce stigma associated with cognitive screening by implementing it as part of a typical office visit[2]. Therefore, it is imperative that the knowledge about ADRDs in the general public and healthcare are increased, with special attention given to racial and ethnic minorities.

Not only is it crucial to increase knowledge of ADRDs in the general population and for healthcare providers such that individuals affected by ADRDs have better quality of life, but it would also benefit our understanding of ADRDs. Research on ADRDs is extensive, but within and among the different dementia subtypes there is vast variability regarding clinical progression, biological contributors, and areas of cognition affected[12–15]. Whether our current knowledge on ADRDs translates well to diverse samples is unknown, as racial and ethnic minorities are poorly represented in ADRDs research[16,17]. Increasing knowledge of ADRDs in the general public and among healthcare providers could provide access to individuals earlier in their stages of impairment and could subsequently enhance our abilities to better characterize pathological aging in pre-impairment or early stages of the disease.



POLICY RECOMMENDATION

My policy recommendation focuses on increasing education, but the target of the education is twofold. This twofold approach for the policy recommendation fits well with national guidelines of the Healthy Brain Initiative 2018-2023 Road Map, of which two components include assuring a competent workforce and educating and empowering the nation[18].

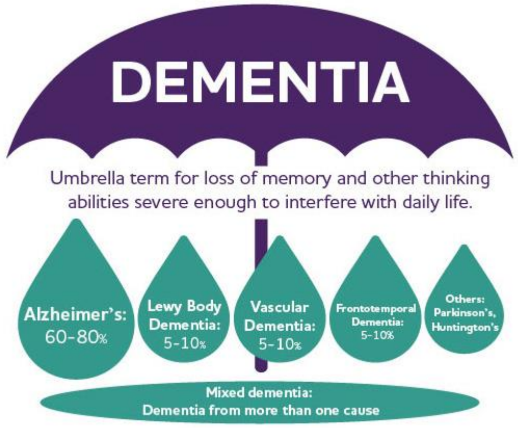
> ***"Education is a critical element to the success of public health in addressing dementia[18]."***

Healthy Brain Initiative 2018-2023 Road Map

First, additional education is needed for healthcare providers such that individuals providing care to older adults at risk of ADRDs will have the necessary knowledge needed to adequately assess the cognitive abilities of their patients. Two pieces of legislation are currently in Florida's Congress: specifically, Florida Senate Bill: SB 874 Alzheimer's Disease Awareness[19] and Florida House of Representatives Bill: HB 627 Alzheimer's Disease and Dementia-Related Disorders Education[20].

These bills in the Florida Congress are proposing to require information be provided to healthcare providers in Florida that covers the importance of early detection/diagnosis, utilizing a validated cognitive assessment tool, emphasizing Medicare's annual wellness visit to address cognitive screening, using Medicare bill coding for cognitive impairment, methods to detect ADRDs early, and methods to reduce risk of ADRDs especially in diverse communities. It would be beneficial for these bills to pass so that the geriatric workforce would be better prepared to assess and diagnose potential cognitive impairment.

A second, related need is for education on ADRDs in the general population. Currently, general screening for cognitive impairment is not required by policy; rather, timely diagnosis is supported (i.e., when older adults or their proxies present concerns about cognitive or functional impairment)[6]. Even when older adults have concerns about their cognition, they often do not discuss these concerns with their healthcare providers[18]. Ensuring that older adults are seeking treatment from a healthcare professional is imperative so that timely diagnoses can be made. Therefore, I would recommend that these policies be amended, or additional bills be introduced focused on the education of the general public, to also ensure the general public is receiving needed education regarding ADRDs.



Both of these policy recommendations also stress the fact that special attention is given to making sure knowledge about ADRDs is provided in culturally sensitive ways so that diverse populations are benefitting.

POLICY IMPLICATIONS

It is believed that enhanced education will prepare the geriatric workforce to be able to accurately diagnose dementia and distinguish it from reversable causes of dementia-like symptoms (e.g., depression or medical conditions[21,22]), and to be confident in diagnoses early along the progression of cognitive impairment. Increased education will result in the general public being more likely to seek treatment with their healthcare providers since they would be able to recognize when cognitive issues seem to diverge from normal aging. By leading to earlier and more accurate dementia diagnoses, implementation of enhanced education for ADRDs will have positive outcomes for individuals with ADRDs, their families, and society.

BENEFITS FOR INDIVIDUALS WITH ADRDs

Individuals living with ADRDs would have improved outcomes regarding quality of life, autonomy, and survival. For example, individuals diagnosed with ADRDs would have the ability to plan future financial, legal, and healthcare decisions while they still have the cognitive capacity to make these decisions[2]. Individuals with ADRDs may also be able to remain in the community longer, have enhanced quality of life, and extended survival time by receiving this early diagnosis[2]. Individuals may also have higher quality healthcare if healthcare providers understand the diagnosis, progression, and treatment options available for ADRDs.

BENEFITS FOR FAMILIES AND CAREGIVERS

The caregivers of persons with ADRDs will also have better outcomes through increased time to process the diagnosis and by having answers to questions about the health of their loved one. Being able to adjust to the diagnosis before significant impairments are faced by the person with an ADRD can lead to better outcomes for the care providers[2]. The families of persons with ADRDs will also be able to appreciate the time they have with their loved one. For families or caregivers, having the person with ADRD receive the dementia diagnosis can improve the caregivers' quality of life and reduce anxiety[6]. The caregivers and families also have additional time to make necessary arrangements for future outcomes and can include the person with ADRD in these decisions.

BENEFITS FOR SOCIETY

Social benefits include adequate planning for future service utilization, reduced costs, and the ability to seek better understanding of ADRDs. Having early and accurate ADRD diagnoses allows community support services to plan for future utilization needs[6]. There are also many economic cost-savings associated with early diagnosis that would likely result from increased education. For example, early diagnosis has been found to be associated with both reduced costs from care needs and reduced institutionalization[2,6]. Cost savings also result from the ability to avoid unnecessary hospitalizations[18]. If individuals with ADRDs are able to avoid or delay nursing home placements, then there would be Medicare/Medicaid savings. Finally, increasing knowledge of ADRDs in the general public and by healthcare providers could contribute to our ability to better understand the complexities of ADRDs. Specifically, by encouraging collaboration between research institutions and primary care providers who have the medical history of persons with ADRDs, we could better characterize the onset and progression of cognitive decline in diverse populations.

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