Dementia- is it high time to replace the term in Neurological nosology?

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Recommended Citation
Khan, Qurat ul Ain (2018) "Dementia- is it high time to replace the term in Neurological nosology?," Pakistan Journal of Neurological Sciences (PJNS): Vol. 13 : Iss. 4 , Article 1.
Available at: https://ecommons.aku.edu/pjns/vol13/iss4/1
Dementia is a term used universally by clinicians and researchers for cognitive impairment that affects a person’s ability to function (1). This is the term used by the American Academy of Neurology (AAN) in their nosology. Diagnostic and Statistical Manual of Mental Disorders V (DSM V) has replaced the term with Major Neurocognitive Disorder (2). The term HIV- associated dementia (HAD) was also replaced by HIV- associated neurocognitive disorder (HAND) by the AAN AIDS Task force (3).

As a clinician practicing in a developing country Pakistan, I find it challenging to use the term dementia. Not only do other medical professionals but general public also has a specific connotation attached to this term. Practitioners generally believe that dementia is a benign, “not so significant” condition that predominantly affects an older person’s short term memory but does not cause any other impairments. General public also has a ubiquitous belief that dementia is synonymous with “forgetfulness” and is an acceptable condition in old age without any major consequences.

If we stick to common neurodegenerative dementias, we know that they are progressive (4). We also know that short term memory is only one of the five domains of cognition and is not the only domain or the first domain to get affected in many dementias especially sub cortical dementias (5). Often times behavioral and psychiatric symptoms of dementias are labelled as primary psychiatric illnesses, one of the reasons being absence of standardized neuropsychological testing and lack of expertise in this area in Pakistan. Often times neurological and motor deficits and symptoms such as atypical parkinsonism, dysautonomia, and cerebellar features are also present in some dementias which are not usually thought to be caused by neurodegenerative dementias. Many providers are not familiar with less common neuropsychiatric syndromes such as apraxias and agnosias. Bio markers for diagnosing dementia such as tau and Abeta 42 are not routinely and commonly available Pakistan to help in diagnosing these conditions. Structural imaging (Brain CT and MRI) is the most commonly used modality for making a diagnosis however unfortunately it does not aid much in including or excluding dementia as the final diagnosis for several reasons. Many a times just general cortical atrophy or age related atrophy is reported in imaging reports along with chronic ischemic or vascular changes. Like in other neurological conditions, clinical correlation is extremely important and the clinician needs to look at the images and correlate the extent, pattern, and anatomical distribution of atrophy with the type of cognitive deficits similar to what is done in cases of stroke. I also believe that vascular dementia is over diagnosed in Pakistan due to age related ischemic changes that are commonly present and routinely reported in brain imaging results however they may not necessarily explain the type of cognitive deficits present. As in the case of Parkinsons disease which is mostly a clinical diagnosis, dementia often times is also diagnosed based on clinical presentation and neuropsychological or cognitive deficits. It also needs to be emphasized that dementia is a non-specific term and does not suffice as a stand-alone diagnosis; the type and severity of dementia needs to be determined for proper diagnosis and management. Contrary to the common belief of health care providers and general public, dementia if properly diagnosed can also be treated and managed well which can result in better prognosis and quality of life.

I believe that it is important to reconsider the term dementia and devise an alternative term to be used in neurology nomenclature and also to devise a word in Urdu that reflects the neurological aspect of this condition and is easily understandable.
Dementia is a term used universally by clinicians and researchers for cognitive impairment that affects a person's ability to function. This is the term used by the American Academy of Neurology (AAN) in their nosology. The Diagnostic and Statistical Manual of Mental Disorders V (DSM V) has replaced the term with Major Neurocognitive Disorder. The term HIV-associated dementia (HAD) was also replaced by HIV-associated neurocognitive disorder (HAND) by the AAN AIDS Task force.

As a clinician practicing in a developing country Pakistan, I find it challenging to use the term dementia. Not only do other medical professionals but general public also have a specific connotation attached to this term. Practitioners generally believe that dementia is a benign, “not so significant” condition that predominantly affects an older person’s short term memory but does not cause any other impairments. General public also has a ubiquitous belief that dementia is synonymous with “forgetfulness” and is an acceptable condition in old age without any major consequences.

If we stick to common neurodegenerative dementias, we know that they are progressive. We also know that short term memory is only one of the five domains of cognition and is not the only domain or the first domain to get affected in many dementias especially subcortical dementias. Often times behavioral and psychiatric symptoms of dementias are labelled as primary psychiatric illnesses, one of the reasons being absence of standardized neuropsychological testing and lack of expertise in this area in Pakistan. Often times neurological and motor deficits and symptoms such as atypical parkinsonism, dysautonomia, and cerebellar features are also present in some dementias which are not usually thought to be caused by neurodegenerative dementias. Many providers are not familiar with less common neuropsychiatric syndromes such as apraxias and agnosias. Biomarkers for diagnosing dementia such as tau and Abeta 42 are not routinely and commonly available in Pakistan to help in diagnosing these conditions. Structural imaging (Brain CT and MRI) is the most commonly used modality for making a diagnosis however unfortunately it does not aid much in including or excluding dementia as the final diagnosis for several reasons. Many times just general cortical atrophy or age related atrophy is reported in imaging reports along with chronic ischemic or vascular changes. Like in other neurological conditions, clinical correlation is extremely important and the clinician needs to look at the images and correlate the extent, pattern, and anatomical distribution of atrophy with the type of cognitive deficits similar to what is done in cases of stroke. I also believe that vascular dementia is over diagnosed in Pakistan due to age related ischemic changes that are commonly present and routinely reported in brain imaging results however they may not necessarily explain the type of cognitive deficits present. As in the case of Parkinson disease which is mostly a clinical diagnosis, dementia often times is also diagnosed based on clinical presentation and neuropsychological or cognitive deficits. It also needs to be emphasized that dementia is a non-specific term and does not suffice as a stand-alone diagnosis; the type and severity of dementia needs to be determined for proper diagnosis and management. Contrary to the common belief of health care providers and general public, dementia if properly diagnosed can also be treated and managed well which can result in better prognosis and quality of life.

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References: