What We Mean When We Talk About Dementia

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As the US population ages and lifespans continue to increase, the number of individuals at increasingly older ages is expected to grow. And so will the number of people with dementia; that is, until treatments are found that can successfully arrest the underlying pathophysiological changes in the brain that are now believed to cause the different clinical etiologies of dementing illnesses.

Unlike many diseases and conditions, clinical expertise in dementia is not "owned" by any one medical specialty. Dementia care is the prototype of a medical condition for which team care, involving multiple medical professions (medicine, nursing, psychology, social work, pharmacy) and a range of community-based social service providers, is essential. Dementia diagnosis, management, and care can be provided by clinicians working across a range of medical specialties, such as geriatrics, neurology, psychiatry, family medicine, internal medicine, and along the full continuum of medical care from hospital, emergency room, clinic/outpatient office, and nursing home, to home and community.

For those of us who work in geriatrics, the association between cognitive health and aging is evident every day, but effectively diagnosing and managing the wide array of dementia presentations is an ongoing challenge. In addition, as a geriatric medical provider, one must be competent in managing other chronic and acute medical conditions common in older adults along with dementia symptoms. This new column will focus its discussion on the issues and trials encountered by those caring for individuals with dementia and declining cognition.

Dementia can be a frightening word that carries with it a connotation of "crazy" or "insane." The word's Latin roots, as a quick Google search reveals, means madness, coming from de- "without," and *ment*, the root of *mens*, which means "mind." Say the word "dementia" or "Alzheimer's" and the picture that comes to mind is a very elderly man or woman who is forgetful, maybe wandering, or demonstrating other behavioral changes. Say the word "geriatrics" and people may think about an older person (usually a woman), slumped over in a wheelchair sitting in a corridor of a nursing home or other long-term care facility. It is important to understand that dementia and aging are not synonymous but are closely associated. While the prevalence of cognitive impairment and dementia increases with age, the majority of older adults do not have dementia. Only one in seven Americans over age 70 have Alzheimer's disease, the most common type of dementia in older age.[1] But over age 85, the proportion of individuals with cognitive impairment or dementia increases to about half. The reality, however, is one cannot talk about one without the other.

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Much of medical training is devoted to "learning the language," but, in practice, in order to communicate with patients and families, the effective clinician is one who can translate medical terms into words that others can understand. This is part of the challenge when we talk about dementia—ensuring that we communicate clearly, and precisely, what phenomena we are talking about. It is at the root of the confusion many patients and family express when they ask, "Is it dementia or Alzheimer's?" or when they state, "He has a diagnosis of dementia, not Alzheimer's disease." In medical literature, frequently, the word "dementia" and "Alzheimer's disease" too easily become intertwined, as though they are one and the same. It is an easy trap to fall into. As I explain to patients, families, and trainees: all patients with Alzheimer's disease have dementia, but not all patients with dementia have Alzheimer's disease. I point out that dementia is an umbrella term, similar to "infection" or "cancer" for which there are distinct different causes. One of my mentors and role models said, "Words reflect thought, be precise in the words you use."

Language is also important when communicating with fellow clinicians, as well, not just with families and patients. Medical terminology is an attempt to define, explain, and organize what we know. In practice, terminology changes over time, becomes more refined and precise as knowledge

grows. New definitions and criteria emerge in an attempt to improve both diagnostic accuracy and communication, but this can lead to confusion. We now talk about cognitive change or cognitive decline across a continuum that includes normal aging, mild cognitive impairment (MCI), and dementia. The challenge clinically is that there are not definite markers to differentiate normal age-related changes from MCI or to indicate when MCI has progressed into early/mild dementia.

Cognitive change and decline is not isolated to memory, or recall, but that is what many continue to focus on. One cognitive domain may be involved, but more commonly multiple areas of thinking are affected. These can include executive function (judgement, reasoning, planning); verbal memory; visual memory; calculation; language (understanding, production); orientation (time, place, person, purpose); or visual-spatial construction. When there are changes in one or more area of cognitive function without associated decline in function, this is what we now refer to as MCI.

Medical criteria for dementia was codified by the proposed criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM-3, 1980) to include a decline in memory and at least one other cognitive domain associated with a change in occupational or social functioning. This was an advance from initial DSM terminology (1952) of "chronic organic brain syndrome" (chronic OBS).[2,3] The International Classification of Disease (ICD-10) has a more strict definition for dementia that requires impairment in memory and abstract thinking, judgement and problem solving, as well as one additional cognitive domain.[4]

As the understanding of distinct clinical presentations of dementia increased, these criteria became difficult to apply. For example, clinicians realized that in some dementias—eg, vascular, frontotemporal, Lewy body—memory loss is not a primary feature. We now have the new terminology "neurocognitive disorders" (DSM-5, 2013), that recognizes a decline in cognitive function does not have to include memory and may present with declines in other cognitive domains.[5] Neurocognitive disorders are classified as "major"—interferes with independence in everyday function and includes dementia or delirium—or "minor"—impairment that does not interfere with function, which is essentially MCI. Within each of these categories, there are the etiologic subtypes (Alzheimer's, vascular, frontotemporal, Lewy body, etc).

The common dementia etiologies that underlie the major neurocognitive disorders in the elderly are not diseases solely of cognitive decline but of functional and behavioral changes as well. In fact, Alzheimer's disease, the most common etiologic cause of major neurocognitive disorder (dementia) in the elderly, is named for a case in which the behavioral changes (eg, delusions, paranoid thinking) were the prominent complaint. For many families of patients and direct care providers, it is the associated behaviors, not the cognitive defects, that they struggle with, and which we are challenged to help them accommodate, adjust to, and adapt to. Indeed, the more challenging, demanding, and often exasperating aspect of helping families and others to care for a person with a dementing illness is helping them to understand that the behaviors are symptoms of the disease.

Whether we call it a neurocognitive disorder, dementia, or we are able to give it an etiologic label such as Alzheimer's or Lewy body or frontotemporal, we are talking about a brain disorder with symptoms that include changes in cognition, function, and behavior that will appear and change, typically, over many years. The fundamental intent behind new terminology is to help clinicians and other providers communicate better; but does this new terminology help us to fully express the full scope of these diseases to patients and families? I hope so, but I'm not convinced. We need to strive to be precise in our language, to communicate openly and honestly among ourselves, but more importantly with patients and those that care for them about the full scope of these conditions and the challenges they present to us all.

As we continue to discuss neurocognitive disorders in subsequent installments of this column, dementia's history, linguistic evolutions, and intended and unintended connotations are key ideas to keep in the back of one's mind. Together, we will tackle difficult patient/family situations, comorbidity in relation to cognitive decline, and advances in treatments, hopefully contributing to most geriatric clinicians' goals of further refining the evolution of cognitive disorders. ◆

References

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