

Severity Measures in Advanced Dementia: The Utility of Ecological Assessment in Alzheimer's Disease

José Roberto Wajman*

Clinical Neuropsychologist, Researcher at the Behavioral and Cognitive Neurology Group (GNCC), Department of Neurology at The Hospital das Clínicas from The University of São Paulo (HCFMUSP), São Paulo - SP, Brazil

***Corresponding Author:** José Roberto Wajman, Clinical Neuropsychologist, Researcher at the Behavioral and Cognitive Neurology Group (GNCC), Department of Neurology at The Hospital das Clínicas from The University of São Paulo (HCFMUSP), São Paulo - SP, Brazil.

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Dementias due to degenerative disorders are a worldwide burden to public health systems. Given the demographic changes with a global aging trend, faster in developing countries, estimates on the rising prevalence of these disorders are discouraging, considering associated cost in primary, secondary and tertiary care [1]. Alzheimer's disease (AD) in its advanced stages is an important social responsibility in terms of prevalence, directly and indirectly associated costs, besides the suffering caused in their families and caregivers. In the clinical context of dementias, it has been observed that standardized and interventional methods may have the potential to improve the quality of life for both the patient and caregiver, as it provides more precise information about cognition and functionality [2].

Advanced AD might be an issue difficult to handle. This is important to stress, because there is a predictable increase in AD prevalence, and these subjects will have a longer life expectative, what means there will be more subjects in moderate to severe stages. Taking into account the fact that the stratification within these phases is not investigated, it is not clear in the literature what is the best treatment for each level within each stage and that is a good reason (considering the central point of this study) why a better stratification method of these "floor effect patients" is so important [3].

As suggested by DSM-V [4] guideline, the progressive course of dementia might be classified in three main stages: mild – there is still some capacity for independent life, though there is impact on instrumental activities of daily life; moderate – the capacity for independent life is limited and supervision is needed in many activities, with partial dependence; and severe – dependence involves all activities, including personal hygiene, language is significantly limited, sometimes with mutism and often there is associated neuropsychiatric symptoms.

Along with the forthcoming neurological damage, basic activities and social interaction also become compromised [5]. For cognition, there is a continuum of loss. Taking praxis as an example, there is a progression for all aspects, including gait in which 35% of those with mild, 58% of those with moderate and 98% of those with severe AD will have dyspraxia [6]. Similarly, for executive functions there is a progressive deficit that in turn makes it more difficult to evaluate complex cognitive domains as a whole. Usually, that is a reason why there is some skepticism on the point of evaluating cognition and functionality in more severe stages of dementia, but this evaluation is necessary to better understand the natural history of the disease and to evaluate the effectiveness of new strategies of intervention.

The nature of the relationship between real-life Activities of Daily Living (ADL) and neuropsychological performance has yet to be fully delineated. Further, this relationship may vary across different geriatric populations. Some studies have used informant-based measures

to assess functional status [7], however only a few have applied a performance-based measure method (in which the patient is actually observed and objectively rated on his or her ability to perform various ADL), and yet, no such study has been conducted with moderate, moderately severe and severe AD phases.

When patients with dementia in advanced stage becomes virtually “untestable” (common term used in this area), through the instruments used, it is assumed diffuse cognitive decline, significant and widespread. What happens is that many of the instruments that are used in daily practice do have no applicability or effect of sensitivity for most affected patients in areas such as language, for example. Only in the two last decades, the assessment of cognitive abilities in later stages of AD has received special attention from researchers and pharmacological research in relation to the expansion of new instruments proposed to measure a wider range of cognitive and functional domains, and treatment response within severe dementia [8].

In this sense, adapted and specific neuropsychological instruments used to get an idea of the person's abilities and disabilities are often too demanding for persons with moderate, severely moderate and severe AD patients [9]. Following this perspective, functional and ecological (related to the environment in which the subject is inserted) tools have been incorporated into the clinical set for at least three valuable reasons: interventions on moderate to severe dementia could be more accurately evaluated; demonstration of residual abilities could encourage and inspire caregivers to take advantage of this knowledge to support the person in performing ADL independently or only with some oversight by their caregiver; and, moreover, public and private sectors could invest their efforts in developing new therapies for this expanding population [10].

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