



Evaluation tools for Dementia in Follow-Up Neuropsychological Assessments

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Introduction

The autonomy of an individual hinges on their ability to independently make decisions. Many of us have encountered situations where the declining cognitive abilities of a parent, grandparent, or elderly relative have prompted concerns about their capacity to manage their finances or live independently. Clinicians may be tasked with assessing the formal capacity of dementia patients, where cognition plays a central role in determining impaired capability. Various factors such as head injuries, mental illnesses, delirium, depression, and dementia can impact an individual's capacity [1]. Capacity refers to a person's ability to make specific decisions within a given context, and legal capacity is determined through a court process. Society sets thresholds for decision-making abilities in specific activities. It is unjust to assume that individuals with dementia lack decision-making capacity entirely. Those with mild to moderate dementia can still evaluate, interpret, and make decisions about their lives, unless there is evidence suggesting otherwise [2]. The legal framework generally presumes that all adults possess capacity, although capacity must be assessed concerning the specific decision an individual wishes to make at a given time.

Important to evaluate the accuracy of diagnostic tests

It is essential to assess the accuracy of diagnostic tests, especially in the context of Alzheimer's disease dementia. The National Institute on Aging and the US Alzheimer's Association have proposed a revision of the clinical criteria for Alzheimer's disease dementia, which now includes biomarkers such as brain imaging and cerebrospinal fluid analysis to contribute to diagnostic categories. However, it is crucial not to assume the clinical properties of dementia biomarkers; therefore, a formal and deliberate assessment of their sensitivity, specificity, and other properties should be conducted and categorized in Cochrane Diagnostic Test Accuracy (DTA) reviews. Additionally, the diagnostic accuracy of various neuropsychological tests and scales will be evaluated to ensure a comprehensive review of the tests used in the assessment of possible dementia [3]. Our intention is to conduct a comparison and incremental value analysis of all included tests for the diagnosis of Alzheimer's disease dementia and, if sufficient evidence exists, other dementias, following the completion of these individual reviews.

Assessment tools to evaluate competence

An individual lacks capacity if, at the time a decision needs to be made, they are unable to do so due to cognitive impairment or unconsciousness. It's important to recognize that not all abilities are universal; a person either has the ability or lacks it to make a particular choice. While most lifestyle choices are independently made, they are influenced by personal values, relationships, culture, and may not always be solely based on rationality. Factors such as career and education also impact decision-making ability [4]. Reversible conditions can be addressed to improve capacity, and a semi-structured interview with the patient is necessary to assess capacity. The individual must have sufficient information about the issue at hand, and the clinician uses gentle questioning to evaluate decision-making abilities. Capacity

evaluation involves two steps: assessing the individual's decision-making abilities and then making a judgment based on the context and risk-to-benefit ratio of various options, such as obtaining consent [5]. Striking a balance between patient satisfaction and respecting autonomy is essential when assessing capacity. Clinicians have an ethical and scientific duty to accurately assess a patient's decision-making capacity, as these decisions may occasionally be subject to legal review. Capacity tests must be conducted meticulously to avoid harm to the patient due to incomplete assessments, and assessments should be particularly thorough in situations with significant consequences. Each aspect of the assessment carries different weight depending on the situation and context [6].

Capacity can be categorized as adequate, inadequate, or marginal. In situations where individuals affected by dementia refuse evaluations or their family members disagree with them, doctors must handle the situation with tact, caution, and clear communication about the need for further evaluation or the reasons for inadequate capacity, while maintaining accurate records.

The MacArthur Competence Assessment Tools for Treatment is a commonly used tool for assessing competence and has been found effective in dementia patients. This assessment involves reviewing the hospital chart and conducting a semi-structured interview scored for four potential domains [7]. The Evaluation of Limit with regards to Ordinary Decisionmaking is also valuable for identifying individuals with a clear deficit in handling specific issues, understanding the risks and benefits, and making decisions about addressing the issue. Not all affected individuals require a formal capacity assessment, as capacity may vary depending on the severity of dementia. Formal testing is necessary in complex situations where there is conflict among family members or proxy decision-makers, or legal involvement is required.

Understanding the neural basis of decision-making abilities enables interventions, neuropsychological tests, and capacity assessments. Marson and colleagues focused on developing a "neurological version of incompetence" but overlooked the importance of testing executive functions for predicting decisional ability impairment. Bedside examinations such as the government interview and formal neuropsychological tests like conceptualization and fluency tests can assess aspects of executive function. Verbal memory is also crucial, as affected individuals must manage, encode, and recall information [8].

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Individuals' levels of decisional capacity and cognitive function can vary, impacting their assessment by clinicians. The Mini-Mental State Examination (MMSE) is a common cognitive tool in clinical practice, correlating strongly with impaired capability for scores below 16 and retained capacity for scores above 24 [9]. However, relying solely on the MMSE may not provide a comprehensive understanding, and it should be used alongside other neuropsychological tests and interventions to enhance the patient's comprehension of their responsibilities. Decision-making capacity tests should not be based solely on one parameter, as they are often used to determine an individual's level of independence.

There is currently no single test considered a gold standard for capability assessments. A combination of clinician judgment, structured capability interviews, and neuropsychological assessments, including executive function assessments, may be ideal in medical practice. Obtaining consent from the individual and their family, along with approval from the appropriate Research Ethics Board, is crucial to safeguarding the interests of the participating individual. The participant should be adequately informed about the study details and provide unbiased and informed consent. However, as dementia progresses, individuals may lose the ability to make well-informed decisions about research participation [10].

Discussion

When an individual is unable to provide expressed consent, proxy consent may be obtained from their legal guardian. This surrogate decision-maker is tasked with making decisions on behalf of the incapacitated individual. The order of priority for surrogate decision-makers typically includes a spouse, adult children, parents, siblings, and legal guardians. It is essential to thoroughly document the consent process. However, it is important to consider that the surrogate decision-maker may not be familiar with the individual participating in the study and may not be able to accurately represent their preferences. Legal representatives may struggle to provide consent due to feelings of responsibility and the burden of decision-making.

Conclusion

Advanced care planning involves documenting preferences and

appointing a proxy decision-maker through tools such as advance directives or power of attorney. For more detailed information on this topic, please refer to the chapter on "Palliative Care and the Indian Neurologists." Initiating discussions about research participation with patients can allow them to communicate their preferences to their surrogate decision-makers before the need arises. This proactive approach can help ensure autonomy in the decision-making process.

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