



Interlingual and Cross-Cultural Sensitivity in Screening and Diagnosis for Dementia: A Literature Review

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ABSTRACT

Background: Interlingual and cross-cultural sensitivity in screening and diagnosis for dementia: A literature review. Widely used neuropsychological tools, like the MMSE and the MoCA test, have difficulty distinguishing dementia in populations deviating from the norm. Namely: Illiterates, ethnic minorities and Deaf people. This review aimed to show how common neuropsychological tools can be insensitive to the characteristics of these populations and to highlight the efforts that have been done to adapt neuropsychological tools and to create new, less culturally affected ones.

Methods and findings: A review of 38 studies (published between 1960 and 2022) that found the ICMR-NCTB battery suitable for people without typical education and immigrants from developing countries and the RUDAS test less influenced by the language and the education level than the MMSE. Multidimensional equivalence emerged as very important in the procedure of translating or adapting neuropsychological tools. For Deaf people, it is preferable to create new tools in the sign language rather than adapt already existing ones.

Conclusions: The higher prevalence of dementia in people from linguistic, ethnic and cultural minorities is reflected in existing neuropsychological tools, which do not meet the needs of these minorities. The increase in the prevalence of dementia worldwide makes the finding of ways by which we can distinguish dementia cross- culturally necessary.

Keywords: Drug-drug interactions; Knowledge; Medication; Pharmacy professionals

INTRODUCTION

The plethora of neuropsychological tools that have been developed to screen for dementia often fail to distinguish dementia in populations that deviate from the “norm” and to account for how sociocultural differences affect the

manifestation of dementia. For example, citizens of non-Western countries, ethnic minorities in the Western world, people with a low educational background, Deaf people and people belonging to more than one of the above categories are at risk of getting over- or under-diagnosed. The difficulty of these people to respond to neuropsychological tests that

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have been standardized for a population with different collective characteristics and experiences is often perceived as mental weakness and is wrongly attributed to dementia, while sometimes actual mental weakness cannot be noticed early, leading consequently to late diagnosis and late intervention. All of the above, when combined with the increase in life expectancy and the consequent increase in the prevalence of dementia worldwide, make the finding of tools that can distinguish dementia cross-culturally necessary. The effort to develop culturally appropriate neuropsychological tools has moved in two directions: The adaptation of existing tools characterized by cultural bias and the creation of new tools, that are relatively unaffected by culture (C. Parker, I. Philp, 2004).

LITERATURE REVIEW

Adaptation of Neuropsychological Tools

The scientific branches of translationology and cross-cultural psychology are involved in the process of adapting/translating neuropsychological tools and provide a theoretical framework through which this topic can be analyzed. The concept of equivalence in the translation/adaptation of a text does not only have to do with the form, but also with what the form signals in the context of the utterance's environment, just as the meaning of an utterance is not limited to the signifieds that compose it [1]. However, the concept of equivalence has many dimensions that are not limited to translating. When it comes to a neuropsychological test, content equivalence is about whether the test questions are culturally relevant to the background of the person being assessed, semantic equivalence concerns the exact translation of the questions, practical equivalence is about the appropriateness of the way that a test is administered, criterion equivalence assesses the extent to which a test, once adapted, is still suitable for assessing dementia, while perceptual equivalence is concerned with maintaining the level of difficulty of individual questions to assess the same cognitive domains as the original test [2]. In order to meet the needs of this multidimensional equivalence, literature suggests guidelines such as redefining test cut-offs, setting up interdisciplinary committees to undertake initial translation and back-translation into the source language, pilot testing in the target population and feedback by participants, as well as other processes. However, it seems preferable to create individual instructions for the cultural adaptation of each scale, which has been done for the ACE-III test [3], while a recent systematic review combined existing translations and cultural adaptations of the MoCA test to form a single set of specific guidelines for its translation and adaptation [4]. At the same time, as dementia is also characterized by changes in the quality of life, it must be taken into account that the perception of life quality and the expression of health-related problems vary between different cultures [5]. Additionally, functional decline, which is a prerequisite when diagnosing dementia, may differ among elders living in Low and Middle-Income Countries (LMICs) due to the diversity in socio-economic status, family structure and lifestyle of the elderly in

general [6]. What is also interesting is the studying of the Behavioral and Psychological Symptoms of Dementia (BPSD) cross-culturally, in order to identify both genetic and environmental risk factors, which can be achieved through comparisons of the same ethnic group in different societies, with environmental and economic development differences, while maintaining genetic homogeneity [7].

Development of New Neuropsychological Tests

An example of the effort to develop a culturally unaffected neuropsychological instrument is the ICMR-NCTB battery, which was developed in India. India has a high illiteracy rate, 122 spoken languages and the largest diaspora population in the world (United Nations Department of Economic and Social Affairs Population Division, 2017). Therefore, diagnosing dementia in Indians and Indian immigrants who continue to communicate in their native languages is a challenge. Immigrants from developing countries are at a double disadvantage when assessed by gold standard tests, as their educational background is usually low while such tests require a degree of formal education and lack of familiarity with the language and culture of the country in which they currently live is also common [8]. However, in the ICMR-NCTB neuropsychological battery it is taken into account that illiterate people are not familiar with using pencil and paper and therefore the corresponding tests are conducted with wooden sticks. Also, the black-and-white patterns in naming tests are replaced by colored ones, while the numbers are replaced by pictures where the numbers are represented by fingers [9]. These changes are based on research indicative of the different cognitive strategies used by illiterates, which affect their performance on tests aimed at formally educated individuals [10-14]. After all, there is evidence that the organization and development of the cerebral cortex differs between the illiterate and the formally educated [15] and the differences are apparent with just one year of formal education [16]. It is also known that illiterate populations are less familiar with the whole process and experience of a test, which can create anxiety for the exam, while the language in which the neuropsychological test is administered affects significantly the performance and must be taken into account when considering immigrants and people from multilingual countries [17]. It is necessary to pay attention to findings that demonstrate the superiority of bilinguals and multilinguals in tests that assess executive functions and their consequent disadvantage in tests of naming and verbal fluency [18]. The short neuropsychological test RUDAS (Rowland Universal Dementia Assessment Scale), which was specifically designed to screen for dementia in culturally and linguistically heterogeneous Australian populations, appears to have diagnostic success comparable to that of the MMSE, but less influenced by the language and the education level, while found RUDAS to be more accurate than MMSE in detecting dementia in such sociocultural contexts. Nevertheless, a 2017 systematic review concluded that none of the existing neuropsychological tests can be preferable for dementia screening in populations with little or no formal education, as their level of accuracy is unacceptable in the context of LMICs,

where dementia is diagnosed at primary health care centers rather than specialist clinics [19].

Neuropsychological Assessment in Sign Language

A chapter slightly different from all of the above is the screening of dementia in deaf people. The term “Deaf” refers to those who are members of the Deaf community and for whom being deaf is a social bond and not a disability. These people communicate in a sign language, which is not a visual version of a spoken language but is grammatically distinct [20]. The capital letter “D” separates them from the larger deaf population, which also includes people who have lost their hearing due to old age or communicate in a spoken language throughout their lives. In this community awareness of dementia is much lower than in the majority of hearing people, partly because of the limited information about dementia in sign language that is available to the general population. Over and under-diagnosis are common due to the inability of clinicians to communicate directly with deaf patients, the lack of linguistically and culturally appropriate screening and diagnostic tools, as well as the generally poor access of deaf people to preventive and health promotion services. In order to gain awareness of what it means for a deaf person to live with dementia and to design appropriate neuropsychological tools for this population, it is necessary for researchers to gain cultural familiarity with deaf sign language and everyday life. Sign language is a visual language whose messages are created and conveyed in four dimensions: The three usual dimensions of space, as well as time. Research in the field of communication and personality is increasingly interested in the non-verbal part of language; that is the study of behaviours, facial expressions and gestures, from which communicative intent and response can be inferred but they do not officially constitute a part of language. However, the characterization “non-verbal” seems inappropriate for the case of semiotics, where the absence of sound/speech is the norm and therefore the “non-verbal” constitutes a part of the language. Sign languages make use of multichannel symbols, *i.e.*, complex expressions that simultaneously combine a characteristic pattern of the mouth with a facial expression, a specific gesture placed in space or on the body and a detailed movement, all of which together increase and expand the semantic content of what someone is saying and it requires many sentences to be translated into a spoken language. In Deaf culture the visual is the medium of language and language literally “moves” in the environment through spatial and temporal dimensions that produce it. Therefore, the physical environment must be much more modified than in the auditory world in order to facilitate language and communication, and the visual is a prerequisite for language. Also, mediated communication is a lifelong experience for Deaf people in order to interact with the hearing world, and therefore to participate in research. Having an interpreter has been considered acceptable and necessary for data collection, however when assessing for dementia it must be understood that this creates many challenges in maintaining a conversation and engaging in interaction. Having a sign language interpreter not only adds

to the participants' challenges but, more importantly, underscores their own base language and contributes to the invisibility of the language in which they think. Widely used neuropsychological tests, such as MMSE, ACE-R and MoCA use linguistic and cultural objects which do not translate effectively into a sign language, while written instructions in these tests are inappropriate as prelingually deaf people have poor reading ability, with an average reading age of 9 years in the UK. The BSL-CST (British Sign Language-Cognitive Screening Test) has been developed by a team of Deaf neuropsychologists, linguists and a speech therapist for administration in clinical and community contexts, with questions and instructions given in British Sign Language and presented in video format. The video instructions ensure a standardized administration process that would be impossible to achieve using paper-based tests, as the BSL-CST doesn't have a written form. BSL-CST has the potential to form the basis of cognitive screening tools in sign languages around the world, with its format and method being suitable for adaptation to other sign languages and the consequent potential to revolutionize early diagnosis of cognitive disorders and dementia in deaf people who communicate in sign language. Development of tools directly in sign language is essential for clinical accuracy and identification of patterns of cognitive functioning and cognitive impairment in the Deaf, which is either missed or mismeasured when using theoretical frameworks of spoken languages.

DISCUSSION

Scientific findings have consistently shown that dementia has a higher prevalence in people from linguistic, ethnic and cultural minorities. However, this is only reflected in existing neuropsychological tools, which do not meet the needs of certain minorities. The biggest problem with an insensitive neuropsychological tool for dementia screening is not a false positive or negative diagnosis, but rather a lack of interest in the dementia experience both universally and cross-culturally, that hinders the ability to offer help on a larger scale. Ultimately, by learning how to include minorities in dementia we learn a little bit more about all of “us”.

CONCLUSION

The higher prevalence of dementia in people from linguistic, ethnic and cultural minorities is reflected in existing neuropsychological tools, which do not meet the needs of these minorities. The increase in the prevalence of dementia worldwide makes the finding of ways by which we can distinguish dementia cross-culturally necessary.

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