Cognitive Assessment in Culturally, Linguistically, and Educationally Diverse Older Populations in Europe

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Abstract

Due to increasing cultural, linguistic, and educational diversity in older populations across Europe, accurate assessment of cognitive functioning in people from diverse backgrounds becomes increasingly important. This paper aims to provide a state-of-the-art review of cognitive assessment in culturally, linguistically, and educationally diverse older populations in Europe, focusing on challenges and recent advances in cross-cultural assessment. Significant work has been carried out on the identification of challenges in cognitive assessment in culturally, linguistically, and educationally diverse older populations and on development and validation of cross-cultural cognitive tests. Most research has addressed the influences of language barriers, education and literacy, and culture and acculturation and in particular, the European Cross-Cultural Neuropsychological Test Battery (CNTB) and the Rowland Universal Dementia Assessment Scale (RUDAS) are well-validated across European countries. However, cross-cultural cognitive assessment is largely still a developing field in Europe, and there is a continuing need for developments within the field.

Keywords

cognitive assessment, diversity, culture, language, education, illiteracy, dementia, Alzheimer's disease

Introduction

Due to demographic aging, the global prevalence of cognitive disorders is expected to increase significantly over the coming decades.¹ At the same time, migration and globalization are currently changing populations throughout most World regions, resulting in increasingly culturally, linguistically, and educationally diverse older populations. Although a certain degree of ethnic diversity has always been present in European countries, this diversity has increased greatly over the last decades. This began with the immigration of labor workers from countries outside the European Union (EU) from 1950 to 1974 and the immigration of people from once-colonized countries, followed by the influx of asylum seekers and refugees in more recent years.² In 2019, non-EU immigrants made up about 5% (21.8 million people) of the total EU population.³ Incidence, prevalence and clinical presentation of cognitive disorders may differ between ethnic or cultural groups depending on their geographical origin, genetic background, gender and age.⁴ At the same time, the presence

of cultural, language and educational barriers may significantly affect diagnosis, treatment and care of cognitive disorders.⁵⁻⁷ Several minority ethnic groups in European countries are at an increased risk of medical conditions that increase risk of cognitive disorders, such as stroke, diabetes mellitus, and hypertension.^{8,9} As a result, patients from minority ethnic groups are increasingly being referred for assessment in European memory clinics and other diagnostic services.¹⁰

Despite recent progress in the development and implementation of biomarkers in the diagnostic workup for Alzheimer's disease (AD) and other cognitive disorders,

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Creative Commons Non Commercial No Derivs CC BY-NC-ND: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs 4.0 License (https://creativecommons.org/licenses/by-nc-nd/4.0/) which permits non-commercial use, reproduction and distribution of the work as published without adaptation or alteration, without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (https://us.sagepub.com/en-us/nam/open-access-at-sage). formal cognitive testing retains a key role in the clinical assessment and is fundamental for early accurate diagnosis and for planning treatment, support and care.¹¹ However, most routinely used cognitive tests originate from Western, Educated, Industrialized, Rich, and Democratic (WEIRD) cultures¹² and may be inappropriate or even misleading when assessing people with different cultural backgrounds. This is particularly evident in the case of older migrants with limited schooling and proficiency in the majority language in the receiving country.¹³ As cultural, linguistic and educational diversity significantly influences cognitive assessment, assessment practices need to be adapted to suit these diverse populations – a need that has been internationally recognized and is reflected in the standpoints of the European Consortium on Cross-Cultural Neuropsychology (ECCroN).¹⁴

The aim of this paper is to provide a state-of-the-art review of cognitive assessment in culturally, linguistically, and educationally diverse older populations in Europe, focusing on challenges and recent advances in cross-cultural assessment.

Challenges in Cross-Cultural Cognitive Assessment

Several issues may pose unique challenges to cognitive assessment in older minority ethnic populations in Europe. However, to date most research has addressed the influences of language barriers, education and literacy, and culture and acculturation.

Language Barriers

Limited proficiency in the host country language is widespread among older people in some minority ethnic groups, including Moroccans and Turks in the Netherlands, South Asians in the United Kingdom, Turks in Germany, and Turks and Vietnamese in Belgium.¹⁵⁻¹⁷ The language in which cognitive tests are administered, as well as the level of formality used, has been shown to significantly impact communication, rapport, and subsequent test scores.¹⁸ As only few European clinicians speak relevant minority languages, interpretation through (formal or informal) interpreters is often needed to assess patients in their native language.¹⁹ Otherwise, cognitive assessment may take place in the second, third or even fourth language, which is likely to affect test performance. Thus, a Swedish study on second language effects on cognitive test performance found that assumptions of Swedish fluency based on a short interview may be misleading and that second language effects may contribute to misclassification of non-native speakers.²⁰ Furthermore, cognitive tests have rarely been developed for interpreter-mediated assessment and the validity of test items after in-situ interpretation from 1 language to another is generally unknown.²¹ For instance, it may be highly challenging to provide quick and accurate translation during a verbal fluency test, or to translate the content of syntactically complex sentences used for repetition tasks in a meaningful way,^{22,23} including the sentences included in the Mini-Mental State Examination (MMSE)²⁴ and Montreal Cognitive Assessment (MoCA).²⁵

Several studies have explored communicative, relational, and ethical issues when informal interpreters are used in clinical contexts and the use of relatives as interpreters is generally discouraged.^{14,26} However, this is complicated by the fact that access to interpreter services and the training of formal interpreters differ greatly between and within European countries.^{19,22} Thus, the use of formal interpreters may be challenging as well, especially for cognitive tests with high demands on the abilities of the interpreter or when interpreters have received little formal training.^{22,23} Despite these limitations of conducting interpreter-mediated cognitive assessments, involvement of formal interpreters in cognitive assessment of linguistically diverse patients is generally recommended by ECCroN.¹⁴

Education and Literacy

Although the level of education is heterogeneous both across and within minority ethnic groups, low education levels or illiteracy are common among older people from various minority ethnic groups in Europe.^{16,17} For example, 17%-36% of older Turkish and Moroccan first-generation immigrants in the Netherlands are illiterate, and more than half (50%-90%), especially women, have not completed any form of formal education.²⁷ Illiteracy, a limited number of years of education, as well as a low quality of education significantly impact cognitive tests scores across several cognitive domains.²⁷⁻³⁴ Patients who are illiterate may also experience more discomfort in testing situations due to unfamiliarity with the setting, the content of the tests, or differences in what is considered a good response.³⁵ Several studies indicate that the effect of schooling and education on cognitive test performance is not linear but rather represents a negatively accelerated curve tending to a plateau.³⁶⁻³⁸ For instance, a Danish study found MMSE and clock drawing test performances in middle-aged and older Turkish migrants in to increase rapidly between groups with no formal schooling and (some) primary schooling, less rapidly between groups with primary schooling and secondary schooling, and little further beyond secondary schooling.³⁷ Also, as the length, quality, and content of the school day and year may vary considerably from country to country and even from school to school in some countries,³⁹ it may be inappropriate or even misleading to apply European norms to immigrants who have their education from a school system that differs greatly from the Western ones.

Illiteracy is frequently higher among migrant women due to cultural attitudes found in some countries. This is more pronounced in older women as it is generally easier and considered more important to attend school today than it was several decades ago.³³ As most cognitive tests originate from

WEIRD cultures, information on the normal or expected range of test performance in people with very little or no formal schooling is generally not widely available. This may make it challenging to interpret test results from people who are illiterate and without formal schooling as they are likely to perform like patients with cognitive disorders on routinely used cognitive tests.³⁹ Striking examples from studies in unschooled illiterate Turkish migrants in Denmark are performances on visuocontructional tests such as the clock drawing test, overlapping pentagons and Necker cube included in the MMSE,²⁴ MoCA²⁵ and Addenbrookes Cognitive Examination (ACE),⁴⁰ which may be extremely difficult for people without formal school experience due to little geometric knowledge and experience with using a pen.³⁹ However, it has been suggested that the influence of illiteracy and little formal school experience on test performance can be reduced by using tests with higher ecological relevance for people without formal school experience; that is, tests relying on elements and strategies from everyday life rather than the classroom.^{31,41,42}

Culture and Acculturation

Minority ethnic groups and immigration patterns differ between European countries. However, the largest minority ethnic groups across Europe originate from South Asian, Middle Eastern, and North African, predominantly collectivist Muslim, cultures.⁴³ Other significant minority ethnic groups are mainly found in specific European countries, including groups of Sub-Saharan African origin in the United Kingdom and France and of Latin American origin in Spain. Additionally, notable minority ethnic groups include the Roma, who are found across most of Europe, indigenous peoples such as the Saami in Sweden, Norway, Finland, and Russia, and Irish Travelers. Acculturation toward the dominant culture differs greatly between and within minority ethnic groups and is closely associated with other factors, such as generation in the country, language proficiency, migration history, and level of education.⁴⁴ In particular the "guest workers," who came to Europe as labor migrants in the post-World War II period, generally have limited levels of acculturation toward the dominant culture as they were initially expected to return to their countries of origin after a number of years - often resulting in a delay of decades in the development of policies promoting social integration and acculturation.²

It often poses a significant challenge to European clinicians to determine which tests and normative data are most appropriate for these heterogeneous populations.¹⁹ Cultural differences may impact the cognitive assessment in several ways. The patient may have different expectations of (the purpose of) the assessment, of what is relevant information, and of what information may be shared with a stranger.⁴⁵ A clinician from the majority group may not automatically be trusted. Some patients and families fear unfair treatment or misunderstanding of their complaints and way of life. For

example, if asked about the burden of providing informal care for an older family member, relatives from collectivist, familyoriented, cultures may object to this as they do not consider themselves to be caregivers. They just do their expected duty as a daughter or son.⁷ Additionally, culture influences communication styles, idioms of distress, and the way symptoms may manifest themselves.^{6,35} Also, a Danish study showed found lower levels of acculturation towards mainstream Danish culture to be associated with poorer performance on tests of mental speed and executive functioning - even when tests were administered in the person's native language and scores were corrected for other demographics.⁴⁴ Finally, culture and acculturation may influence test scores when tests include "Western items" or when the tests involve culturespecific testing elements and strategies.^{13,18} Culturedependent elements are evident in many cognitive tests, including the figures, pictures, words, sentences, etc. included in widely used cognitive screening tests such as the MMSE, MoCA and ACE⁴⁶⁻⁴⁸ Questions about national royalty or political leaders may be familiar to most people in the majority culture. However, they may be unfamiliar or virtually unknown to people from minority cultures, including those who have migrated from a different geographical area.⁴⁹ Also, cognitive assessment using the discrepancy between age and date of birth may disadvantage older people born in rural areas with poor birth registration facilities, and those who may have altered age and date of birth to facilitate migration.⁴⁹ Different concepts of orientation in time and place in different cultures and preferential use of the Western (Gregorian) or another calendar system may also influence performance on the orientation questions included in many commonly used cognitive screening tests.¹⁸

All these factors related to language barriers, education and literacy, and culture and acculturation pose challenges to the assessment of older patients from minority ethnic groups and have initiated recent developments in cross-cultural cognitive assessment in Europe. In contrast to most North American initiatives that have generally focused on adapting and standardizing well-established tests or batteries for specific languages or ethnic groups (eg, Hispanics or African Americans),^{50,51} European efforts have generally aimed at developing and validating cognitive tests and batteries for use across diverse ethnic groups.

Advances in Cross-Cultural Cognitive Assessment

Strategies for overcoming some of the challenges associated with cognitive assessment in diverse older populations include the use of cross-culturally validated cognitive tests. Internationally, several cognitive tests have been adapted, validated and normed for cognitive examination in *specific* languages, cultures and educational groups, including cognitive screening tests such as the MMSE, MoCA, and ACE⁴⁶⁻⁴⁸ However,

to develop a feasible solution for the clinical reality in Europe, in which patients may differ widely in their cultural, language, and educational characteristics, the general approach has been to design and/or validate instruments with potential applicability across groups with diverse sociocultural characteristics. A recent Delphi expert study found that considerable work has been carried out in the development and validation of crosscultural cognitive tests for older minority ethnic populations in Europe¹⁹ (See Table 1). In particular, the European Cross-Cultural Neuropsychological Test Battery (CNTB)⁴³ and the Rowland Universal Dementia Assessment Scale (RUDAS).⁵² which was originally developed for multicultural populations in Australia, were found to be well-validated across European countries. These instruments have been studied in people from numerous minority groups, with a wide variety of education in studies from across multiple European levels. countries.^{27,30,31,44,53-59} More recently, the RUDAS has also been validated in an older Innuit population in Greenland.⁶⁰ Together, these instruments measure a variety of cognitive functions including general cognitive functioning (RUDAS), memory (Recall of Pictures Test, Enhanced Cued Recall and recall of a semi-complex figure), language (Picture naming and semantic verbal fluency), executive functions (Color Trails Test, 5 Digit Test and Serial Threes), and visuospatial functions (Clock Reading Test, Clock Drawing Test and copying of simple and semi-complex figures). For some of the other instruments identified in this study, only few validation studies had been published for the target population.¹⁹ However, better cross-culturally validated instruments used in some countries include the Cross-Cultural Dementia screening,⁶¹ modified Visual Association Test,⁶² and Naming Assessment in Multicultural Europe⁶³ in the Netherlands, the Multicultural Cognitive Examination⁵⁷ in Denmark, Norway and Sweden, and 9 Images test of the district of Seine-Saint-Denis,64

Memory Associative Test of the district of Seine-Saint-Denis,⁶⁵ and Switching Verbal Fluency Test⁶⁶ in France.

In order to make them suitable for use across diverse ethnic groups, languages, education, and literacy levels, these instruments were designed without using culture- or languagespecific stimuli,¹⁸ black-and-white line drawings,^{62,67,68} or test elements that require skills learned in school.³³ Generally, the influence of limited education and illiteracy has been reduced by using test procedures with higher ecological relevance for people without formal school experience; that is, test procedures relying on elements and strategies from everyday life rather than the classroom.^{13,41} Often, smaller modifications of existing test paradigms have been sufficient to make tests more ecologically relevant. For instance, in the RUDAS the memory subtest requires memorization and recall of a shopping list rather than a list of unrelated words, and in the Multicultural Cognitive Examination the semantic verbal fluency subtest adopts a supermarket category rather than the commonly used animal category. Whereas knowledge about supermarkets is usually obtained through everyday life experience, knowledge about animals and strategies for memorizing and recalling words is largely obtained through formal school experience. 31,32,39,42 Also, efforts to overcome the educational barrier in formal cognitive testing include the use of the informant-report instruments such as the short form of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE).⁶⁹ Thus, a Dutch study found that the IOCODE had slightly better diagnostic accuracy in an older illiterate migrant population compared with the RUDAS. Further, it was found that combining the IQCODE and RU-DAS in a diagnostic algorithm resulted in superior diagnostic accuracy compared to using either of the 2 instruments alone.²⁷ These instruments and approaches all represent important contributions to the field of cross-cultural cognitive

Table 1. Cognitive Instruments Designed and/or Validated for Cross-Cultural Cognitive Assessment in Diverse Older Populations in Europe.

Instrument	Primary reference(s)
Cognitive screening tests	
Rowland universal dementia assessment scale (RUDAS)	52,56
Cross-cultural dementia screener (CCD)	61
EASY	78
Multicultural cognitive examination (MCE)	57
Neuropsychological test battery	
European cross-cultural neuropsychological test battery (CNTB)	43,58
Memory tests	
Nine images test of the district of seine-saint-denis (TNI-93)	64
Memory associative test of the district of seine-saint-denis (TMA-93)	65
Modified visual association test	62
Language tests	
Cross-linguistic naming test	79,80
Naming assessment in multicultural Europe (NAME)	63
Executive functions tests	
Switching verbal fluency test (TFA-93)	66

assessment in Europe. However, many European clinicians are not familiar with these newer cognitive instruments, and there is a need for better publication and implementation of the instruments across Europe.¹⁹

Aside from looking into cognitive tests in themselves, European experts on cross-cultural cognitive assessment have also recognized the importance of taking the cultural context of cognitive assessment into consideration.^{14,19} These contextual factors have neatly been summarized by the acronym of the ECLECTIC framework:³⁵ Education and literacy, Culture and acculturation, Language, Economics (eg, socioeconomic status), Communication, Testing situation, Comfort and motivation, Intelligence conceptualization, and Context of immigration. Although this framework has not been formally assessed or implemented in Europe, several key contextual factors have been included in research and clinical practice. For example, short acculturation scales (C) are used in research and clinical practice in several countries, including a modified version of the Short Acculturation Scale for Hispanics.⁷⁰ Additionally, the effects of language abilities in both native and host country languages (L) are recognized by European experts in the field,^{14,19} as well as the effects of stereotype threat, of being unfamiliar with cognitive testing, and of examinee-examiner ethnic discordance (T) on the assessment. Experts in the field also recognize that it is important to take lifetime (socio)demographic factors and access to and availability of healthcare services into account (E).^{14,19} Some aspects from the ECLECTIC framework, particularly communication styles and intelligence conceptualization, has received less explicit attention among European researchers. Other specific examples of relevant issues to take into consideration in working with minority ethnic groups in the European context are traumatic experiences, migration-related distress or grief,⁷¹ exposure to discrimination,⁷² differences in explanatory models of illness,^{73,74} and differences in symptom manifestation and idioms of distress, such as mixed affective and somatic presentations of depression in Moroccan and Turkish patients.⁷⁴ Consistent with this, a survey among European dementia experts found that 84% perceived cultural differences in the presentation of symptoms to frequently affect clinical assessments of clients from minority ethnic groups.75

Conclusion

With increasing demographic aging, migration and globalization, there is an increasing need for researchers and clinicians to address the challenges of conducting cognitive assessment in culturally, linguistically, and educationally diverse older populations. During the last decade, significant work has been carried out on the identification of challenges in cognitive assessment in culturally, linguistically, and educationally diverse older populations and on development and validation of cross-cultural cognitive tests. However, the field of cross-cultural cognitive assessment is largely still a developing field in Europe, and formal expertise is localized rather than widespread. Thus, there is a continuing need for development of cross-cultural cognitive assessment instruments and normative data, for culture-sensitive clinical training, awareness, and knowledge among European clinicians, and for recruitment of culturally and linguistically diverse clinicians into the field. An important step forward was the establishment of ECCroN in 2019. This constitutes the first collaborative attempt of European experts in cross-cultural cognitive assessment to move the field forward. The first research initiative from ECCroN is the Timely Diagnosis of Dementia in Minority Ethnic Groups in Europe (TIMING) project, which aims to identify enduring challenges in clinical practice for dementia diagnostics in minority ethnic populations in European memory clinics and to validate brief case-finding tools that combine culture-sensitive cognitive assessment with patient and informant report, namely the Brief Assessment of Impaired Cognition (BASIC)⁷⁶ and BASIC Questionnaire (BASIC-Q).⁷⁷ The reviewed challenges and advances in cognitive assessment in culturally, linguistically, and educationally diverse older populations do not seem specific to the European context. Cross-cultural cognitive assessment is a challenge worldwide and some of the advances in Europe may potentially contribute to developments in other world regions characterized by diversity and multiculturalism.

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