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Cognitive assessment of foreign-born

with focus on interpreter-mediated cognitive assessment and the use of appropriate cognitive screening instruments

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Rozita Torkpoor

DOCTORAL DISSERTATION

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Title and subtitle: Cognitive assessment of foreign-born – with focus on interpreter-mediated cognitive assessment and the use of appropriate cognitive screening instruments

Abstract: Cognitive assessment is complex and dependent on optimal communication. Sweden has become a multicultural society with citizens from different linguistic and cultural backgrounds. This creates new challenges and demands on the healthcare system, which must offer safe and equal care to all residents. Interpreters are an important resource for both patients and healthcare professionals to understand each other and can be crucial in providing safer healthcare encounters. Many dilemmas and challenges arise during interpreter-meditated cognitive assessment, and the conventional tests used in such assessment are also influenced by factors such as language, culture, and education and are not always adapted for use in a multicultural society.

The aim of this thesis was to study interactions between healthcare professionals, interpreters, and patients during cognitive assessment. A further aim was to study the ability of the Swedish version of the Rowland Universal Dementia Assessment Scale and the Multicultural Cognitive Examination, to detect dementia and to validate the tests in the Swedish context. The studies were carried out with the help of four specialist clinics for cognitive disorders.

The results of the studies showed that the competence of the interpreter as well as the ability of the healthcare professional to communicate with the patient and interpreter affected the cognitive assessment. The challenges that arose could lead to misjudgements of the patient’s condition and cognitive functions. The studies also showed that the conventional tests used in cognitive assessment are not always adaptable for use with foreign-born patients. In contrast, the RUDAS-S and MCE-S had good accuracy in detecting dementia, were more adaptable for use during multicultural assessment, and were more appropriate for use with an interpreter.

In conclusion, for a safe and reliable cognitive assessment of foreign-born patients, various supports and improvements are necessary:

- interpreters need support and training for increased understanding of the various parts of the cognitive assessment.
- patients need information about the assessment procedure, content, and rules, as well as the role of the interpreter.
- appropriate tests must be used.
- Healthcare professionals need to increase their knowledge of the use of interpreters and the challenges that may occur, and skills as well as guidelines to be able to work based on patients’ individual conditions.

Offering equal care does not necessarily mean that everyone receives care in the same way, but that the healthcare system has the competence and resources to respond to and offer care based on the patient’s individual conditions and needs.

Key words: Cognition, dementia, assessment, cognitive test, interpreter, foreign-born

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Table of Contents

Abstract

Cognitive assessment, which is crucial for a safe diagnosis and appropriate treatment and support of cognitive disorders, is complex and dependent on optimal communication. Sweden, like many other countries, has become a multicultural society with citizens from different linguistic and cultural backgrounds. This creates new challenges and demands on the healthcare system, which must offer safe and equal care to all residents. Healthcare professionals experience language barriers as one of the major challenges when interacting with foreign-born patients, many of whom need an interpreter when communicating with the healthcare system. Interpreters are an important resource for both patients and healthcare professionals to understand each other and can be crucial in providing safer healthcare encounters. However, many dilemmas and challenges arise during interpreter-meditated cognitive assessment, and the conventional tests used in such assessment are also influenced by factors such as language, culture, and education and are not always adapted for use in a multicultural society.

The aim of this thesis was to study interactions between healthcare professionals, interpreters, and patients during interpreter-mediated cognitive assessment. A further aim was to study the ability of the RUDAS-S, the Swedish version of the Rowland Universal Dementia Assessment Scale, and the MCE-S, the Swedish version of the Multicultural Cognitive Examination, to detect dementia and to validate the tests in the Swedish context. The studies were carried out with the help of specialist clinics for cognitive disorders in Region Skåne.

The results of the four different studies reported in the thesis showed that the competence of the interpreter as well as the ability of the healthcare professional to communicate with the patient and interpreter affected the cognitive assessment. The challenges that arose could lead to misjudgements of the patient’s condition and cognitive functions. The studies also showed that the conventional tests used in cognitive assessment are not always adaptable for use with foreign-born patients. In contrast, the RUDAS-S and MCE-S had good accuracy in detecting dementia, were more adaptable for use during multicultural assessment, and were more appropriate for use with an interpreter.

In conclusion, for a safe and reliable cognitive assessment of foreign-born patients, various supports and improvements are necessary:

- interpreters need support and training for increased understanding of the various parts of the cognitive assessment and for cooperation during the assessment,
- patients need information about the assessment procedure, content, and rules, as well as the role of the interpreter, before the assessment.
- adapted tests must be used.

- Healthcare professionals need to increase their knowledge of the use of interpreters and the challenges that may occur, and skills as well as routines and guidelines to be able to work based on patients' individual conditions.

Offering equal care does not necessarily mean that everyone receives care in the same way, but that the healthcare system has the competence and resources to respond to and offer care based on the patient's individual conditions and needs. The findings reported in this thesis highlight the challenges but also the opportunities for improvement for safer and more equal care to patients with cognitive disease.

Abbreviations

AD	Alzheimer’s Disease
AUC	The Area Under the Curve
CDT	Clock Drawing Test
CNTB	The European Cross-Cultural Neuropsychological Test Battery
CSF	Cerebrospinal Fluid
CRT	Clock Reading Test
CT	Computed Tomography
PET	Positron-emission Tomography
DLB	Dementia with Lewy Bodies
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th edition
ICD	International Statistical Classification of Disease and Related Health Problems
FAQ	Functional Assessment Questionnaire
FTD	Frontotemporal lobe Dementia
GDS	Geriatric Depression Scale
MCI	Mild Cognitive Impairment
MCE	Multicultural Cognitive Examination
MCE-S	The Swedish version of Multicultural Cognitive Examination
MMSE	Mini-Mental State Examination
MMSE-SR	Mini-Mental State Examination- Swedish Revision
ROC	Receiver Operating Characteristic
RPT	Recall of Picture Test
RUDAS	Rowland Universal Assessment Scale
RUDAS-S	The Swedish version of Rowland Universal Assessment Scale
SF	Supermarket Fluency
VaD	Vascular dementia/ Vascular neurocognitive disorder
WHO	World Health Organisation

Populärvetenskaplig sammanfattning

Kognitiv utredning, som är avgörande för en säker diagnos, lägger grunden till fortsatt planering av vården, anpassade behandlingar och stöd till patienten och anhöriga. Utredningen är komplex och beroende av optimal kommunikation. Sverige som många andra länder har blivit ett mångkulturellt samhälle med invånare med olika språkliga och kulturella bakgrunder. Detta innebär nya utmaningar och krav på hälso- och sjukvården som ska erbjuda en säker och jämlik vård till alla invånare. Vårdpersonalen upplever språkbarriärer som en av de stora utmaningarna i mötet med utrikes födda patienter. Tolk är en viktig resurs för att patient och vårdpersonal ska förstå varandra och kan vara avgörande för kvaliteten på vården. Det förekommer dock många dilemman och utmaningar under tolk-mediterade kognitiva utredningar. Sedvanliga tester som används vid utredningen är också påverkade av faktorer som språk, kultur och utbildning och är inte alltid anpassade att användas i dagens mångkulturella samhälle.

Ett syfte med denna avhandling var att studera interaktionen mellan vårdpersonal, tolk och patient vid tolk-mediterade kognitiva utredningar. Avhandlingens ytterligare syfte var att studera kognitiva testerna RUDAS-S och MCE-S och deras kapacitet att upptäcka/särskilja demens, samt validera dessa i en svensk kontext. Studierna gjordes med hjälp av fyra specialistkliniker för kognitiva sjukdomar i Region Skåne.

Resultatet av studierna i avhandlingen visade att tolkens kompetens och vårdpersonalens färdighet att kommunicera med patient och tolk påverkade den kognitiva utredningen. Utmaningarna som uppstod kunde leda till missbedömningar av patientens tillstånd och kognitiva funktioner. Studierna visade också att de sedvanliga testerna som används i kognitiv utredning inte alltid är anpassade att användas för utrikes födda. RUDAS-S och MCE-S hade goda egenskaper att upptäcka demens, var anpassade att användas under multikulturell utredning och lättare att användas genom tolk.

Slutsats: För en säker kognitiv utredning av utrikes födda, säker diagnos och anpassad behandling av utrikes födda behöver vi arbeta med olika delar i kognitiv utredning och i mötet med patienten:

- Tolkar behöver stöd och utbildning för en ökad förståelse för utredningens olika delar och bättre interaktion med patienten och vårdpersonalen under utredningen.
- Patienterna behöver information om utredningens procedur, innehåll och regler, samt tolkens roll, inför utredningen.
- Vilka kognitiva tester som används kan vara avgörande för interaktionen mellan vårdpersonal, patient och tolk samt för kvaliteten och säkerheten av utredningen och diagnosen.

- Vårdpersonal behöver ökad kunskap i användandet av tolk och om de utmaningar som kan förekomma, färdighet i att använda anpassade tester, samt rutiner och riktlinjer för att kunna arbeta utifrån patienternas individuella förutsättningar.

Att erbjuda jämlik vård betyder inte nödvändigtvis att alla får vård på samma sätt utan att vården har kompetens och resurser att bemöta och erbjuda vård utifrån individuella förutsättningar och behov, oavsett bakgrund. Avhandlingen belyser flera utmaningar vid kognitiv utredning av utrikes födda, men också förbättringsmöjligheter för en mer säker och jämlik vård vid kognitiv sjukdom.

List of publications

Study I: Torkpoor R, Fioretos I, Essen B, Londos E. "I Know Hyena. Do you Know Hyena?" Challenges in Interpreter-Mediated Dementia Assessment, Focusing on the Role of the Interpreter. J Cross Cult Gerontol. 2022;37(1):45-67. doi: 10.1007/s10823-021-09439-7

Study II: Torkpoor R, Fioretos I, Essen B, Londos E, “No Ifs, Ands or Buts!” Interaction Under Interpreter-Mediated Cognitive Assessment: Focusing on the Role of Health-Care Professionals. *Manuscript.*

Study III: Torkpoor R, Frolich K, Nielsen TR, Londos E. Diagnostic Accuracy of the Swedish Version of the Rowland Universal Dementia Assessment Scale (RUDAS-S) for Multicultural Cognitive Screening in Swedish Memory Clinics. J Alzheimers Dis. 2022;89(3):865-76. doi: 10.3233/JAD-220233

Study IV: Torkpoor R, Frolich K, Londos E, Nielsen TR. Diagnostic Accuracy of the Swedish Version of the Multicultural Cognitive Examination for Cognitive Assessment in Swedish Memory Clinics. J Alzheimers Dis. 2024;97(2):715-26. doi: 10.3233/JAD-230998

Preface

There was a time the only thing I knew about migration was that birds migrated and could never ever even dream of doing it myself, alone, without my family. In 1986, I migrated to Sweden as a refugee. Barely 20 years old, I had to leave everything that mattered, and everyone I loved to build a new life in Sweden. An important person in my life was my wise, generous, and beloved aunt who was a teacher by profession and as a person was a pillar and role model for many of us in the family. She was one of the people who was happiest about my decision to migrate. Later, in her letters, she continued to encourage me to endure all the hardships of living alone in the new country and made me remember the circumstances that had made me make the decision to migrate. When I met her again in Iran 15 years later, I hardly recognized her; although the friendly smile and warm and loving gaze were the same: she had Alzheimer's disease. I still remember that gaze even though she is no longer in this world. I observed my aunt and those around her during the short time I was there. I observed how they talked to her and about her, how they helped her, and what hopes and future plans they had for her. For me, who was already working with people with dementia in Sweden, this meeting became the first seeds of interest and curiosity in the cultural view of cognitive disorders: how one sought care and support based on cultural background, what expectations one had of healthcare, family, and society, and what challenges might arise for foreign-born people who are suspected of having dementia.

Before I began my PhD studies, I had been working since 2008 with cognitive assessment in primary care and at the Knowledge Center for Dementia, *Kunskapscentrum demenssjukdomar*, in Region Skåne[1], Sweden. We noted various challenges related to the care of foreign-born patients. There were few foreigners who applied for cognitive assessment. There were problems in communication with the few who did seek help and underwent cognitive assessment and experienced difficulties in assessment through an interpreter. Also, the customary tests used in the assessment contained questions that were difficult to ask or interpret. These foreign-born patients were also under-represented in community activities, and they

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[1] Region Skåne is the regional municipality in Skåne County and is primarily responsible for health care, public transport, the development of business, culture, infrastructure, community planning and environmental and climate issues in Skåne.

often sought help when the situation at home had become unmanageable. In sum, care for such patients with cognitive disorders was often inappropriate.

With the support of an EU-funded collaborative project, *Migrations School*, at the Knowledge Center for Dementia in Region Skåne and the National Knowledge Center for Dementia in Copenhagen, we worked with issues related to dementia and foreign-born persons. They experienced the same challenges in Denmark. My role in this collaborative project was to coordinate and participate in various subprojects. The subprojects identified the challenges that occurred in the care of foreign-born patients with cognitive disease in primary care and community operations and were extended, at least in part, to implement the Rowland Universal Dementia Assessment Scale (RUDAS) in Region Skåne. This multicultural cognitive assessment scale was developed in Australia and was designed to be less influenced by factors such as education, language, and culture than other tests.

It was also important to know more about foreign-born patients' experiences of ageing and dementia in a new country. In collaboration with an Iranian organization in Malmö, I was able to listen to the stories of older adults through individual and focus group interviews. My bachelor's degree focused on the experiences of others being elderly in a new country. Loneliness and language difficulties were challenges that most of the interviewees experienced. The quote below represents the situation experienced by many of the elderly men and women interviewed.

> This is a paradise, but not mine! Of course, I will get dementia! Who doesn't go crazy with the loneliness and the dark, here I even hide myself from my neighbour because of the language problems you know… and so with all that we have gone through.

Through various meetings and workshops, we identified several challenges that healthcare professionals experienced within specialist clinics, primary care, and community care in Skåne. A common problem that the majority highlighted was communication difficulties. An obvious intervention was to train interpreters in dementia and cognitive assessment for better interaction and collaboration with healthcare professionals and patients. Together with a colleague from the Knowledge Center for Dementia, we trained interpreters who worked within Region Skåne. Interpreters were recruited with the help of the currently procured interpreting agency. During training sessions, I had the privilege of meeting many interpreters skilled in various languages and learned much about interpreting meetings in healthcare from their perspective. The interpreters, who appreciated the training, drew our attention to the fact that healthcare professionals also need to learn more about communication through an interpreter.

The next step was to organize training for healthcare professionals (both for professionals in specialist clinics, primary care, and community operations) who worked with cognitive assessment and care of patients with cognitive disease in general and their use of interpreters. Thus, the need to study cognitive assessment through an interpreter became obvious. By then, I had also started my master's degree. During 2015–2017, we collected data through 19 videorecorded cognitive assessments that were performed with the use of interpreters at a specialist clinic in Region Skåne.

At the same time, a colleague and I prepared the Swedish version of the RUDAS. I was also involved in Sweden's participation in a European study, the Cross-Cultural Neuropsychological Test Battery (CNTB), in which 15 different tests were used to assess Swedish and foreign-born individuals. The RUDAS and part of the tests found today in the Multicultural Cognitive Examination (MCE) were included in the tests used in the CNTB study. With the accumulated experience from participating in this study together with that of other colleagues, we began to teach about RUDAS to healthcare professionals at specialist clinics and primary care in Region Skåne. We also distributed information about the test and about the assessment through an interpreter in lectures at various national conferences and for two years at Almedalen. We also trained 'RUDAS-certified trainers' to promote the RUDAS nationally.

In November 2017, the National Board of Health and Welfare published an updated version of the National Guidelines for Healthcare in Dementia, and the RUDAS was recommended as a cognitive screening instrument in the basic cognitive assessment for foreign-born individuals. In December of the same year, I entered my PhD studies.

Writing the thesis was very special. It was not entirely easy and not simply writing. It has made me reminisce and go through many chapters of my life, both professional and personal. My education and thesis have given me opportunities for many effective meetings with people who also want to make a difference and create opportunities for improvement. It has given me a deeper understanding of the outside world but also of myself as a person. I am so grateful for the opportunities I have been given but also to have been open and receptive to them. My conclusion is this: with all due respect to skills and tools, nothing is more important than the love and will in the meeting between people because they remove many difficult barriers between us, regardless of who we are and what experiences we carry with us. Understanding each other is much easier than we think if these two elements are present. We become much closer to each other because they provide mutual respect, acceptance, and safety. This can be achieved through an inner peace in our hearts and minds.

Hopefully, this thesis can contribute to thoughts, reflections and new tools that can be useful in improving care for foreign-born patients. I am convinced that knowledge, tools and treatment that are necessary for a patient group can be good for all patients.

Introduction

The number of foreign-born people in Europe is increasing, and there is an expected growth in the prevalence of dementia in this group. Thus, the need for cognitive assessment and diagnosis of foreign-born people with suspected dementia is expanding. Early and accurate diagnosis of dementia can lead to adequate and adapted care and support, increased quality of life for patients and their relatives, and economic gains for society [1]. However, there remains a lack of sufficient methods and healthcare services in almost all European countries, which can lead to a growing population being denied the right to adapted and safe care for cognitive diseases [2, 3]. Healthcare professionals may experience the cognitive assessment and diagnosis of foreign-born people as a challenge, and this issue has been highlighted and researched for more than two decades in the USA and UK. Diverse research has been conducted in various European countries, with discussion of policies for dementia care for foreign-born individuals by various expert groups, and recommendations have been proposed [2, 4-6]. However, there is still a lack of structured guidelines; of validated and appropriate cognitive tests that are not influenced by factors such as culture, language, and education; of the opportunity to work optimally through professional interpreters; and of suitable methods to provide timely and safe assessment and diagnosis of foreign-born people in many European countries [6]. More attention must be given to national dementia plans, and guidelines, routines, and knowledge should be developed and increased to be able to offer appropriate dementia care to everyone regardless of their background.

Cognition

Cognition includes the ability to think, reason, perceive, imagine, and remember [7]. The Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) describes the cognitive domains as memory and learning, language, attention, executive function, perceptual–motor function, and social cognition [8]. Cognitive abilities develop from infancy to young adulthood, peaking in early middle age [9]. Decreases in certain cognitive abilities, such as processing speed and certain memory, language, visuo-spatial, and executive functions, occur with normal ageing. However, these declines do not affect people's daily lives or independence [10].

Dementia/Major neurocognitive disorder

Dementia is the umbrella term for marked impairment in two or more cognitive domains, representing a decline from the individual's former level of functioning. Cognitive impairment is not related to normal ageing and is likely to be severe enough to significantly limit independence in an individual's performance of everyday activities [11, 12]. 'Dementia', which is the most common term, comes from the Latin meaning without mind (*de*, out of; *mens*, mind), which may explain why the word has been replaced with the term 'major neurocognitive disorders' in the DSM-5 [8]. Although the term dementia is still used by many healthcare professionals and by patients, and I have used this term in my published articles, throughout this thesis, I will use both terms interchangeably.

Many different underlying disorders can cause dementia/major neurocognitive disorders, and the criteria have been restricted so that impairments in learning and memory are not necessary for diagnosis. The most common types of dementia, in order of frequency, are Alzheimer's disease (AD), vascular dementia (VaD), dementia with Lewy bodies (DLB), and frontotemporal dementia (FTD). AD is the most common type of neurocognitive disorder and accounts for 60%–70% of all cases [13].

Alzheimer's disease (AD)

Because AD is the best-known and most prevalent type of major neurocognitive disorder globally, I begin with a brief historical background on the discovery of the disease. At the beginning of the 20th century, German psychiatrist Alois Alzheimer was working at a mental hospital in Frankfurt where one of his patients, 51-year-old Auguste Dieter, became particularly notable. She had symptoms that differed from those of the other patients, including a memory that worsened until her death in 1906. At autopsy, Dr. Alzheimer found a severely damaged brain. Among the dead nerve cells, he discovered many microscopic lumps and senile plaques (now called amyloid plaques) inside the cell body, something like small balls of yarn and tangles (now called neurofibrillary tangles, tau). His discovery was published, and the term presenile dementia was introduced. The term was later changed, and the diagnosis was named after him [14, 15].

AD, a neurocognitive disease, causes damage to brain cells and nerves and disrupts cell nuclei, producing neurotransmitters that communicate signals in the brain, especially those responsible for storing memory [12]. People with AD develop slowly progressive problems with memory and concentration, such as forgetting the last conversation, repeating questions, not finding their things, or forgetting recently learned information.

Eventually, the memory problem worsens, and the person forgets important appointments and names of relatives, while other cognitive difficulties emerge, such as language difficulties (e.g., problems in remembering and finding the right words when telling a story); difficulty organizing thoughts and thinking logically; difficulty with everyday tasks (e.g., getting dressed or brushing teeth); difficulties with executive function, planning, and performing an action (e.g., going out for shopping); concentration difficulties (easily distracted by different impressions); and difficulty in learning something new, problems coping with new situations, and visuo-spatial difficulties (e.g., inability in orientation).

In the case of mild symptoms, the problem can be referred to as mild cognitive impairment, but if the symptoms are to the degree that they affect the person's independence in their everyday life, then dementia is suspected [12, 16].

Different biomarkers, including Positron-Emission Tomography (PET) scans and Cerebrospinal Fluid (CSF) (clinical) and plasma analyses (research) for amyloid β and phosphorylated tau, can reflect neuropathology in vivo [17].

Vascular dementia (VaD)

Vascular neurocognitive disorder [8] is the second most common cause of dementia and accounts for 25%–30% of all cases [12]. This disease is called VaD because the symptoms are caused by damage and pathological changes in the blood vessels of the brain. Recent diagnostic criteria for the disease include four categories: subcortical ischemic vascular dementia, poststroke dementia, multi-infarct dementia, and mixed dementia [18]. The symptoms vary depending on which parts of the brain have been damaged. For example, memory is affected by damage to the medial temporal lobe, whereas damage to the frontal lobe can influence personality [19]. Language difficulties have complex backgrounds involving several parts of the brain of different qualities. VaD can affect all aspects of the brain, such as understanding and expression, but failure in execution and slowness can also give rise to language difficulties.

Dementia with Lewy bodies (DLB)

Neurocognitive disorders with Lewy bodies [8] or DLB, such as AD, are caused by the degeneration and death of nerve cells in the brain. The name originates from collections of proteins, known as Lewy bodies, that appear in the brain's nerve cells [12]. This disease is caused by a harmful form of the protein α-synuclein, which is found inside Lewy bodies. Lewy bodies are known to be typical of Parkinson's disease and were first described in 1912. The first clinical criteria for DLB were published in 1996 [20]. It is estimated that DLB accounts for 10%–15% of all dementia cases, but the disease is probably underdiagnosed. Prodromal symptoms include cognitive (attention, executive function, visuo-spatial) disturbances, psychiatric (visual hallucinations, depression) or delirium (episodic confusion) [21]. The core symptoms are visual hallucinations, variations in attention and wakefulness, rapid eye movement (REM) sleep behaviour disorder, and parkinsonism [22]. Language is also affected in DLB because of the slowness of word production.

Frontotemporal lobe dementia (FTD)

Frontotemporal neurocognitive disorder [8] or FTD are rare causes of dementia and are over-represented at earlier ages (40–50 years). FTD can be generally divided into behavioural variants and linguistic variants, primary progressive aphasia, and semantic dementia. In this type of dementia, the frontal and temporal lobes of the brain are particularly affected and can influence the concentration, judgement, personality and behaviour, impulse control, and language of the individual [12]. Memory often works well at the beginning of the disease. Later, the ability to think abstractly and solve problems is also affected. Linguistic symptoms also occur, for example, impairment of word comprehension and the ability to correctly name different things (e.g., a car, keys). The person may also have slow and economized speech (few words) with many grammatical errors [8].

Minor neurocognitive disorder/Mild cognitive impairment (MCI)

MCI is the stage between the expected cognitive decline associated with normal ageing and the more severe decline associated with dementia [12, 23]. MCI is determined based on the assessment and information from relatives, but where the diagnostic criteria for dementia are not met. Minor neurocognitive disorder is similar to major neurocognitive disorder, but patients can still live independently (e.g., where activities of daily living, complex tasks such as paying bills or managing medications, are maintained). It is characterized by a less extreme cognitive decline in one or more areas, such as language, memory, and attention, but individuals may have difficulty in certain cognitive areas. Deficits in cognitive function should not be the result of delirium and are not better explained by other psychological conditions [8].

Epidemiology

The increasing prevalence of cognitive disorders is expected due to the ageing population [24, 25]. It was estimated that 35.6 million people were living with dementia worldwide in 2010, and it is anticipated that this figure will almost double every 20 years, reaching 115.4 million in 2050 [26]. Although dementia is not a consequence of old age, lifestyle factors such as social isolation, low education, high alcohol consumption, physical inactivity, depression, diabetes, hypertension, head injuries, hearing impairment, smoking, air pollution, and obesity can affect cognitive reserve or increase the number of neuropathological lesions, which in themselves increase the risk of dementia [27]. In 2017, the WHO described cognitive disorders as an epidemic, and AD and other cognitive disorders may become major global health concerns [28].

Cognitive assessment

In Sweden, cognitive assessment can be performed in primary care or at specialist clinics. The latter usually prefer that basic cognitive assessments be initiated first, if possible [29]. Early and adequate medical assessment in patients with suspected cognitive disorders is crucial for patients and their relatives [30]. Assessment must initially exclude other diseases or conditions that may cause dementia-like symptoms, such as infections, delirium, hypothyroidism, neurological diseases, and depression, and must establish dementia and identify the type of dementia the patient has. Assessment should also lead to the possibility of offering treatment, care, and support adapted to the individual's condition and needs [29].

The diagnosis of dementia is based on a structured medical history, interviews with relatives, physical and psychological examinations, blood samples, cognitive tests, and a structured assessment of functional and activity ability. The cognitive assessment also includes structural brain imaging with computed tomography. If the basic cognitive assessment is not sufficient to establish a diagnosis or if there are other complicated circumstances, for example, if it is a younger person with suspected dementia, an extended investigation is usually performed in a specialist clinic. In Sweden, for cognitive testing in basic cognitive assessment, testing with the Mini Mental State Examination (MMSE) [31], the Montreal Cognitive Assessment (MoCa) [32] and, in some cases, the Rowland Universal Dementia Assessment Scale (RUDAS) [33], which is supplemented with a Clock Drawing Test (CDT) [34], is recommended [29].

The extended cognitive assessment can include neuropsychological tests, where even more cognitive domains are evaluated, structural imaging of the brain with magnetic resonance imaging, fluorodeoxyglucose positron emission tomography (FDG-PET) to measure glucose metabolism, lumbar puncture for analysis of cerebrospinal fluid (CSF) biomarkers, and single photon emission computed tomography (SPECT) or DOPA PET to measure dopamine transport and blood flow in the brain.

Migration and dementia

People have always migrated for a variety of reasons. In 2020, 281 million people were living in a country other than their country of birth [35].

Sweden has been a country of immigration since the 1930s. After immigration for labour post World War II, other wars and conflicts in the world have had a greater impact on people migrating to Sweden. The number of immigrants has varied every year, and large peaks of immigration have occurred, for example, with immigration for labour in the late 1960s, refugees from Iran among other countries in the late 1980s, and refugees from former Yugoslavia in the early 1990s. The number of asylum seekers increased sharply in 2014, and in 2015, more than 160,000 people sought asylum from war-torn Syria [36]. More than two million people (20%) of Sweden's 10.5 million inhabitants have a country of birth other than Sweden [37]. It is estimated that by 2050, every third person ≥65 years [38] or by 2070 every third person ≥80 years [39] in Sweden will be a foreign-born individual.

The terms 'migrant', 'immigrant', 'ethnic minority', 'cultural and linguistic diversity (CALD)', and 'foreign born' appear in research papers and reports, and the terms may relate to, for example, asylum seekers and refugees [2]. Here, I use the term 'foreign-born', as used by both Statistics Sweden and the National Board of Health and Welfare in several of their reports on people born in another country and who have moved to a new country to stay temporarily or permanently, which is often associated with ethnic minorities or migrants. They usually have a mother tongue other than the language spoken in the new country.

A significant increase in the number of culturally, linguistically, and educationally diverse people with dementia in Europe is expected in the coming decades [1, 2, 40]. In 2017, an estimated 467,500 foreign-born people with dementia were living in the European Union (EU) and European Free Trade Association countries [4]. As noted, this expected increase in dementia is associated with lifestyle and medical conditions that can increase the risk of dementia, which occurs more often in foreign-born individuals [27, 41]. For example, high blood pressure common among Africans living in the UK, USA, and Germany [42, 43] and high blood pressure, diabetes, cardiovascular disease, and socio-economic factors are common among Asians and Black Caribbeans in the UK [44]. In Sweden, an increased risk of diabetes has been noted for foreign-born people from the Middle East compared with the native population [45, 46]. The high occurrence of risk factors for coronary disease in foreign-born people can be attributed to a lifestyle remainder from their country of birth or from migration and acculturation to a new social and cultural environment [41].

Seeking care for cognitive impairment

Views on health and illness differ between cultures. It is affected by both individual and collective beliefs, experiences, knowledge, and education. The perception of well-being and the changes that appear over time are also influenced by cultural values. This in turn affects how and when an individual seeks healthcare, if at all. It is important for healthcare providers in a multicultural society to be aware of these factors for increased understanding when patients are in contact [47].

Despite the increased prevalence of dementia among foreign-born individuals, they do not always seek care to the extent expected, and dementia can be underdiagnosed [48, 49]. This may be related to several factors, such as a lack of knowledge about dementia [50, 51] or the cultural perception of dementia [2, 50, 52-54]. A general challenge is to ensure that people in a multicultural society have sufficient health literacy to recognize basic symptoms of cognitive disorders and to know when and where to seek information and help [55, 56].

Foreign-born individuals tend to seek help for cognitive impairment later in the course of the disease or when the situation becomes unsustainable at home and for relatives [57-59]. Dementia and many other diseases that affect the brain are still associated with stigma in many cultures. Words such as crazy, mad, and insane can be used for mental disorders, and the same is the case for people with dementia [60]. The symptoms of dementia can be interpreted as a natural part of ageing, or it can be considered a mental disorder [53, 55, 61]. It may also be associated with a belief in the evil eye, God's punishment, or spiritual powers [2, 62]. Different beliefs or understanding about the cause of dementia may influence people to seek help from a spiritual leader rather than a physician [2].

Language difficulties, a lack of knowledge about dementia, a belief that there is no help or treatment for the disease, and the traditional belief that relatives have the responsibility to take care of the person may be reasons why people with symptoms of dementia do not always seek care. Previous negative experiences of contact with the healthcare system may also be a factor in not seeking care to the extent expected [50, 52, 63-67]. A person's socio-economic status is another factor that can influence the seeking of care [63, 68]. A low socio-economic status has been identified as a possible risk factor for the development of dementia [27, 69, 70]. The underdiagnosis of foreign-born people with suspected dementia [48, 49] may also result from fewer opportunities to use care [26, 52, 58] and may be related to lower health literacy among individuals with a low social position and in migrant populations [71, 72].

Another perspective is that language difficulties create barriers to sharing information between healthcare professionals and patients [73]. Language barriers can be the greatest problems in providing adequate, appropriate, effective, and timely care to all patients regardless of where they seek care [74, 75]. These barriers are a major reason why healthcare professionals cannot detect or recognize symptoms of dementia in foreign-born people [67].

Cognitive assessment of foreign-born

Despite the increasing role of biomarkers, dementia is still identified by clinical diagnosis. The cognitive assessment and diagnosis of foreign-born patients are associated with challenges related to language, cultural and educational background, and literacy skills [57, 76, 77]. Various studies in Europe and the Nordic countries have shown inequalities and differences in assessment, diagnosis, and dementia care between foreign-born individuals and majority populations. In Norway, a lower proportion of foreign-born people with dementia diagnoses or cognitive impairment was found, especially for those not from high-income countries, compared with the native population. Moreover, foreign-born people do not have dementia diagnoses indicating anti-dementia treatment to the same extent as the majority population [78]. Danish [79] and Swedish registry studies [80] showed that migration background was associated with a lower prevalence of dementia treatment. The Swedish registry study showed that the age at diagnosis of dementia was lower for foreign-born people than for people born in Sweden; foreign-born people had lower odds of receiving a specific dementia diagnosis, lower use of acetylcholinesterase inhibitors and, overall, greater use of neuroleptics than did the Swedish-born group [80]. A Danish study showed that there was an overdiagnosis of dementia in younger (<60 years) and an underdiagnosis in older (>60 years) foreign-born patients [81]. The investigators explained that the underlying reasons for this, in addition to cultural differences in help-seeking performance and difficulty navigating the health care system, were as a consequence of difficulties in cross-cultural assessment of dementia [81].

Studies in Europe have shown that foreign-born people had lower MMSE scores and tended to be younger at dementia diagnosis than did the native population [26, 82]; they also had a greater prevalence of VaD and mixed-type dementia [82]. A higher rate of Parkinson-related cognitive impairment and Lewy body disease was found among European immigrants, while non-European immigrants were more likely to receive a psychiatric diagnosis [26].

Cognitive assessment and testing are dependent on communication and effective interaction between the patient and the healthcare professional. Language and culture (values, beliefs, styles of behaviour) can influence cognitive testing [76, 83]. The usual tests used in cognitive testing were designed and developed in Western countries and are influenced by Western culture and norms [84]. Many neurocognitive tests are verbal and difficult to use in testing where the patient and the healthcare professional do not speak the same language [85]. Ardila [76] describes different strategies commonly used in cognitive testing that can be disruptive and alien to people from certain cultural backgrounds. These strategies can affect how patients interact with healthcare professionals and perform during cognitive assessments. He describes how while testing, healthcare professionals prefer to sit only with the patient (to minimize the person being distracted), which can be contrary to cultural norms if patients are not used to a one-to-one relationship to solve a problem. Relationships and authority can affect the patient's performance in testing. 'Best performance', that is, doing one's best in testing, may be perceived as absurd and pointless if the patient does not truly understand the reason for what is to be done and may result in the person not putting in sufficient effort. During testing, healthcare professionals not only typically sit alone with the patient in a room, but with the door shut. This can be perceived as inappropriate and affects interactions with healthcare professionals. Some tests require speed, which may be difficult to maintain if some patients prefer to take more time and do a better job. There may be questions that may be perceived as inappropriate or images and objects that may be culturally specific and difficult to identify [76].

The most used cognitive screening test in Europe, the MMSE [31], was developed in the USA. The test results are influenced by language and culture [86, 87] and by age and education [87, 88]. Education affects the patient's performance in testing. Patients with limited education or poor literacy have difficulties with cognitive testing. Just one to two years of schooling can significantly influence the patient's performance during testing. Literacy can reinforce some basic cognitive abilities, such as verbal and visual memory, visuo-spatial skills, and visuo-motor skills. Education also affects an individual's problem-solving and day-to-day strategies [84]. Nevertheless, it is important to highlight that a lack of formal education does not mean that people are less intelligent than others but simply that they lack the kinds of abilities that are typically learned through education and schooling [6].

That not all cognitive tests can be used for everyone has recently been discussed, and the development and validation of new tests that are adapted to multicultural societies are encouraged [5, 6].

Various neuropsychological tests have been developed and studied in culturally, educationally, and linguistically diverse populations, such as the RUDAS [33], the European Cross-Cultural Neuropsychological Test Battery (CNTB) [89, 90], and the Multicultural Cognitive Examination (MCE) [91]. Nevertheless, there remains a lack of cross-culturally validated cognitive screening tests and the use of these tests in Europe [5]. Tests such as the MMSE are still widely used. Although many healthcare professionals believe these tests are inappropriate for foreign-born individuals, they are unaware of an alternative test, or they are not sufficiently confident that the appropriate screening tests are adjusted to the needs of foreign-born patients [92].

There is a lack of equity in relation to cognitive assessment, dementia diagnosis, and care for foreign-born people [5], especially due to language difficulties, lack of suitable validated cognitive tests, and difficulties in making a diagnosis [2, 57, 77]. The development, validity, and availability of cognitive tests that are not influenced by language, culture, or educational background are recommended, as is increased knowledge about communication through interpreters for healthcare professionals for equal and safe cognitive assessment, timely diagnosis, and appropriate dementia care for all patients [2, 5, 6].

Interpreter-mediated cognitive assessment

Foreign-born patients may have language difficulties, which leads to linguistic barriers between the patient and healthcare professionals. Interpreters are an important resource for patients and healthcare professionals to be able to communicate with each other [93, 94]. Cognitive assessment requires optimal communication and is dependent on accurate interactions between healthcare professionals, interpreters, and patients [95]. Effective communication is important for offering safe and equal care to all patients [74, 75, 96]. Language barriers between healthcare professionals and patients can lead to unreliable and uncertain medical assessments, diagnoses, and treatment [67, 95, 97] and severe consequences such as mortality [98].

In Sweden, the Patient Act requires healthcare professionals to offer individualized information [99]. The right to an interpreter is regulated by various laws in Sweden, such as the Swedish Administrative Act [100]. The Act provides that when an authority is in contact with someone who has difficulty speaking Swedish, they have the accountability to use an interpreter. Healthcare professionals have a responsibility to make themselves understood and to ensure that the patient understands what is being said in a consultation. Healthcare professionals can procure professional interpreters through various accredited interpreting agencies.

However, in Sweden, there is currently a lack of authorized and qualified interpreters and interpreters with basic education [101]. Interpreters who can be procured from interpreting agencies can be those who are authorized medical interpreters but could also be those who have no adequate or formal interpreter education but may have years of experience in the field [101]. A lack of formal education can lead to ignorance of the guidelines defined in *Good Interpreting Practice* that all authorized interpreters must follow [102]. According to *Good Interpreting Practice*, an interpreter must be neutral and impartial, interpret everything that is said, conform to the laws of confidentiality, maintain professional secrecy, and reproduce what has been said in the first-person singular [103].

Basic education for interpreters is provided through various high schools and universities in Sweden, and subsequently, interpreters can train and become authorized interpreters through the Legal, Financial and Administrative Services Agency, after which they can go on to become authorized legal or medical interpreters. It is only possible to become an authorized interpreter in 45 of the many languages spoken in Sweden [104]. The Institute for Languages and Folklore reports that approximately 200 different languages are spoken in Sweden, but a more precise number of languages is difficult to establish [105]. Interpreting agencies address the great need for interpreters by training bilingual people who want to work as interpreters.

Cognitive assessment is complex and places high demands on interpreters and the quality of interpreting. Interpretation during cognitive assessment requires special knowledge of the context because the patient may not be able to interact during the consultation as optimally as desired but also because there are aspects such as cognitive testing that require good collaboration between the healthcare professional, the interpreter, and the patient [6]. For an interpreter-meditated cognitive assessment, adequate training and competence of the interpreter and good collaboration between the healthcare professional, the interpreter, and the patient are crucial [93, 97, 106].

Aims of the thesis

For this thesis, four studies were conducted. Given that communication and language barriers are recognized challenges in the cognitive assessment of foreign-born patients, it is important to examine closely the interactions between healthcare professionals, patients, and interpreters (Studies I and II). For optimal communication and interaction during the assessment, cognitive tests were required that could evaluate the patient's cognitive ability and not be influenced by other factors, such as language, culture, or educational background. Currently, tests with such characteristics are being developed and used, but how these tests are effective in the Swedish context needs to be investigated (Studies III and IV). The knowledge that emerges from these studies could assist healthcare professionals achieve safer and more equal cognitive assessments of foreign-born patients.

The specific aims of the studies were as follows.

Study I: To clarify the interactions between patients, healthcare professionals, and interpreters during the cognitive assessment, with a focus on how the interpreter may influence the outcome of the evaluation.

Study II: To investigate the interactions between patients, healthcare professionals, and interpreters during cognitive assessments, with a focus on healthcare professionals.

Study III: To compare the Swedish version of the RUDAS (RUDAS-S) and MMSE (MMSE-SR) test scores and their diagnostic accuracy in Swedish memory clinics for foreign-born and Swedish patients.

Study IV: To compare the psychometric properties of the Swedish version of the MCE (MCE-S) with those of the Swedish versions of the RUDAS (RUDAS-S), the MMSE (MMSE-SR), and the Clock Drawing Test (CDT) to determine the ability of the MCE-S to differentiate patients with dementia from those without dementia in a multicultural population at memory clinics in Sweden.

Methods

This thesis is based on two qualitative (I and II) and two quantitative (III and IV) studies (Table 1).

Table 1. Overview of the four studies included in this thesis.

	DESIGN	PARTICIPANTS/DATA COLLECTION
STUDY I	Qualitative Ethnographic observations	19 recorded interpreter-mediated cognitive assessments A specialist clinic in cognitive disorders
STUDY II	Qualitative Ethnographic observations	19 recorded interpreter-mediated cognitive assessments A specialist clinic in cognitive disorders
STUDY III	Quantitative Cross-sectional	123 patients (36 foreign-born, 87 Swedish) Four specialist clinics in cognitive disorders
STUDY IV	Quantitative Cross-sectional	117 patients (30 foreign-born, 87 Swedish) Four specialist clinics in cognitive disorders

Studies I and II

Data collection

To study the interaction between healthcare professionals, patients, and interpreters during cognitive assessment, a specialist clinic for cognitive disorders was the optimal site. The specialist clinic chosen was a clinic with a greater proportion of foreign-born people in its catchment area compared with other specialist clinics in the region, which was an advantage for the collection of material for the studies. At the chosen specialist clinic, the Memory Clinic, patient cognitive assessment included a structured medical history; cognitive testing; physical, psychiatric and neurological examinations; blood tests; and CT or magnetic resonance imaging, MRI, of the brain. Complementary examinations could also be performed, such as Apolipoprotein E (APOE) genotyping, CSF analysis, electroencephalography, EEG, or molecular imaging. The cognitive tests included the MMSE-SR, CDT for all patients as recommended in national guidelines [29], and other complementary tests used as needed and based on the clinic's internal procedures. The clinic had recently started using the RUDAS-S test for patients who needed an interpreter during the cognitive assessment and had little schooling to complement other tests used.

Conducting the study required contact with the contracted interpreting agency from which the clinic appointed an interpreter. The managers of the agency were informed, and information about the study was posted on their internal website. The interpreters appointed for the assignment were directly informed about the study and that audio and video recording and an interview would take place in connection with the assignment. Thus, interpreters who came to the clinic agreed to participate in the study, and they also received oral and written information when they arrived at the clinic before signing a form to document their consent.

All staff at the Memory Clinic were informed about the study. The practical procedures, such as providing information to patients and the appointment of interpreters, were discussed and planned together with the Memory Clinic managers.

Based on the referral, the clinic managers were able to determine whether a patient was a potential study participant. The assumption was that the patient's cognitive state was such that they could understand information and decide. If they came with a family member, the family member also received information about the study. Patients received oral and written study information in their mother tongue. After the patients provided their consent, which was documented by signing a form, the author or co-supervisor started two cameras and an audio recorder to record the cognitive assessment.

We recorded 19 interpreter-mediated cognitive assessments. The healthcare professionals (doctors and nurses) who participated in the study had from 1 to >30 years of experience working with cognitive assessments and had varying experience using an interpreter. Seven of the participating healthcare professionals were women, and three were men. All healthcare professionals were native Swedish speakers except one who was nevertheless fluent in Swedish. The interpreters who participated in the study interpreted Arabic, Bosnian, Finnish, Greek, Macedonian, Persian, Spanish, Somali, and Hungarian in their respective languages. Nine of the 15 interpreters were women. Four of the interpreters involved in the study had never interpreted in the context of cognitive assessment. Although authorised medical interpreters were requested when making an appointment for an interpreter, only two of the interpreters in the study were authorised interpreters or authorised medical interpreters. Four of the interpreters had basic interpreter training, and the remaining interpreters had no formal interpreter training. The patients participating in the study had varying educational backgrounds; four had <4 years of schooling, eight had 5–12 years of schooling, and two had >12 years of schooling. Of the 14 patients who participated in the study, eight were women.

Design

These were qualitative studies with an ethnographic design consisting of observation through audio and video recordings of 19 interpreter-mediated cognitive assessments. In ethnographic studies, observations or interviews are the most common methods for collecting data. These observations made it possible to study how the various participants in the consultation interacted and communicated with each other in the context of the consultation and the natural environment [107-111]. This knowledge would have been impossible to gain through interviews alone.

To observe the interaction between different participants during the cognitive assessment, it is best for the observer to be present at the assessment. However, in this context, two languages were spoken, which could mean that important observations were missed. A combination of video recording and having an observer sit in the room was regarded as optimal. However, in the context of cognitive assessment and cognitive testing, which require high concentration from the patient, it was important to reduce factors that could distract the patient [112, 113]. Based on this, we decided that the observations would be made through video and audio recordings.

After each recorded cognitive assessment, both the healthcare professional and the interpreter were interviewed, and they talked separately about their experience of the cognitive assessment and the interaction with the other participants. Other questions asked during the interviews are shown below (Table 2).

Table 2. Sample interview questions for healthcare professionals and interpreters.

HEALTHCARE PROFESSIONALS	INTERPRETERS
How long have you been working in this clinic?	How long have you worked as an interpreter?
Have you worked through an interpreter before?	What interpreter training do you have?
What are your experiences and perceptions of working through an interpreter?	Do you have previous experience of interpreting in the context of cognitive assessment?
How did you experience the collaboration between yourself and the interpreter?	How did you feel the collaboration between yourself and the healthcare staff worked?
What is your experience of differences between cognitive assessment of foreign-born patients compared with Swedish patients?	

Both healthcare professionals and interpreters were given the opportunity to watch the recorded video together with the author or co-supervisor. Most of them did so and found it rewarding.

After each recorded cognitive assessment, everything that was said in Swedish was transcribed by the author and the co-supervisor. The audio recordings were then given to professional linguists with positions at different universities in Sweden who were fluent in the patient's mother tongue (except for one who worked as an interpreter in another part of Sweden). They independently transcribed and translated what was said verbatim into Swedish. After transcribing the material, we had meetings with the linguists, in which we were given explanations for various incidents or misunderstandings that had occurred during the communication; for example, this could be about the characteristics of the foreign language or that misunderstandings or language difficulties had arisen between the patient and the interpreter because they spoke different dialects. This was important information for us in the data analysis and for a better understanding of what happened in the interactions between participants. Thus, before the process of analysis, we had access to everything that was said in both languages during the cognitive assessment.

Data analysis

The analysis was inductive and based on the observations to gain insight into what was being investigated unconditionally, without any preselected theories or preconceptions [114]. The analysis is consistent with the principles of the constant comparative method in accordance with Hammersley and Atkinson [108] and Glaser and Strauss [115] and was considered appropriate for an unconditional analysis of the data to identify what was important for the observed context [110].

The analysis began with a review of all collected data. Patterns in the material related to parts of the dialogues between the participants that were relevant to the purpose of the study were highlighted. These patterns formed the basis of the analysis [108]. The next step was to condense the patterns for better management. Through coding, the condensed text was abstracted. The coded texts were compared with each other, and those containing similar concepts were similarly classified. Several coded texts with similar content formed a category containing several subcategories. The contents of the categories and subcategories were compared with each other to determine the consistency of all the coded texts. The intention was that the content of all categories and subcategories should be clearly defined and that coded texts, subcategories, and categories should be distinct [108, 115]. The author and co-supervisor independently analysed the material and compared the results together before defining categories and subcategories in consultation with the supervisor and the other co-supervisor.

Table 3. The table shows an example of the approach adopted for the analysis.

PATTERN	Healthcare professional: Let's see… Now you're to do what's written here. (Nurse showing a text on a piece of paper) Interpreter: بدك ايه اتغمض اتغمض عيناك [eh, you're to close your eyes.] Healthcare professional: Yes, that's good
CONDENSED PATTERN	The healthcare professional asks the patient to do what is written on a piece of paper. The interpreter reads what is written and instructs the patient to close their eyes.
ENCODING	Misinterpretation Expanded information
SUBCATEGORY	Content being added and removed during interpretation
MEANING	Alteration of instruction
CATEGORY	Meaning and content of what was being said was altered during the interpretation

During the analysis, the recorded material was examined repeatedly while reading the text to gain an overall understanding and insight into what occurred between the participants in the consultation [108, 116]. We investigated and reflected on the meaning of what was said or happened during the consultation. In this way, body language and how participants related to each other were also observed. Many reflections were written down in connection with this, which strengthened the results based on the text and the credibility of the results. One example was a patient who met with a nurse for the first part of the cognitive assessment. The patient seemed to be motivated to undergo the assessment, was worried about their situation, and talked about difficult experiences in life, including that their son had been executed and that the patient had been interrogated several times. At the next visit, which was with a physician, a medical student was also present, and they and the interpreter were of the opposite sex; the three sat on one side of the desk, and the patient sat on the other side. We could see in the video recording that the patient was anxious and restless. This became more noticeable as time went on; the patient increasingly sank into the chair, and the body language and tone when the patient spoke betrayed that the patient was uncomfortable, sad, or worried. The doctor did not notice or react to this.

Methodical considerations

A qualitative study of observations is a suitable method for investigating interactions between people in the context of cognitive assessment. Collecting data through video and audio recordings was an appropriate method for performing the studies. For qualitative studies, various criteria should be considered to demonstrate trustworthiness, such as credibility, transferability, dependability, confirmability, and reflexivity. Subjectivity and the pursuit of objectivity were important considerations during the analytical process [117]. The author and co-supervisor analysed the material independently. It was important that the researchers were aware of their own impact during both the observations and the analysis. Reflections about the impact the researchers might have during the analysis process were crucial to maintain the trustworthiness of the results [108, 118]. The author had experience working with cognitive assessment and was familiar with the context of being observed, which may have affected the analytical process. Reflection and discussions with the supervisor and co-supervisors were important for reducing subjectivity and increasing the dependability of the results. Reflection is an essential part of increasing the transparency and quality of qualitative studies [108, 117, 118].

The credibility of the study required that any apparent influencing processes be made visible and available so that the credibility, reliability, and generalizability of the findings could be assessed [108, 116]. Using quotes from observations is one way to demonstrate the credibility of the results [117].

The data for Studies I and II were collected in various ways through observations, interviews with healthcare professionals and interpreters, and reflection notes, which complemented each other and provided more insight and understanding into the objectives of the studies from different perspectives [117]. A process of triangulation was used to improve the quality of the qualitative studies. In addition, two of us worked on transcription and analysis and continuously conversed, reflected, and compared our analyses to arrive at the results produced. We subsequently involved two other co-authors with different levels of expertise who were not involved in the data collection and analysis to work further with the analyses and develop the categories and subcategories that are presented in the results [117].

Dependability and confirmability refer to the aspects of consistency and neutrality in the analysis and description of results. The results are consistent with those of previous studies in other contexts. The results could also be identified each time they were presented regardless of context, within units for cognitive disorders or, for example, in psychiatry [117].

Other analytical methods were discussed before the study, including conversation analysis [97, 119], which is an alternative for future studies where the investigators can examine in more detail the conversation strategies between people in interaction. The method is used for detailed studies of spoken interaction and is well suited for use when the material consists of audio or video recordings [120].

Studies III and IV

Design

Studies III and IV were quantitative studies that compared the Swedish versions of two tests, RUDAS [33] and MCE [91], with tests conventionally used during the standard cognitive assessment. The aim was to compare the diagnostic accuracy of the tests and to investigate whether other factors, such as age, sex education, and whether the patient who underwent the cognitive assessment was Swedish or foreign-born, affected the respective test results.

The RUDAS-S and MCE-S were translated and back-translated from the original English into Swedish according to the International Society for Pharmacoeconomics and Outcomes Research Principles of Good Practice: The Cross-Cultural Adaptation Process for Patient-Reported Outcomes Measures [121]. The tests were translated with the help of language experts who were native speakers of English or Swedish and subsequently ratified by an expert group of Swedish-speaking specialists in cognitive assessment, senior doctors, psychologists, and nurses [121].

Data collection

Four of five specialist clinics in cognitive disorders within Region Skåne registered their interest in participating in the studies. They believed that the studies could lead to an improvement in their work with cognitive assessment of their foreign-born patients. The specialist clinics' situations, such as waiting lists for patients, participation in other studies, or staff turnover, affected how many patients they were prepared to include in the studies. Overall, we decided that each clinic could include 30 patients.

Healthcare professionals at each specialist clinic received information about the studies and training to administer the RUDAS-S and MCE-S. In addition, two more opportunities were offered for support if needed. The clinics began participating in the studies after the training day. The period for collecting the material was between 2018 and 2019, as not all specialist clinics started to include patients at the same time. A total of 127 patients participated, but not all had complete study materials, restricting the sample size that could be included in the analysis to <127.

Most patients who visited these clinics for cognitive disorders were referred by primary care, psychiatry, or other specialist clinics. Patients, whether Swedish or foreign-born, with the ability to decide about their participation in the study and could undergo testing, was asked to participate in the study. No other exclusion criteria were used. The clinics sent patients some brief study information together with an invitation to the specialist clinics. If the patient had a mother tongue other than Swedish, the study information was also sent in the patient's native language. More verbal and written study information was provided at the clinic in connection with the visit. Study information and consent forms in various languages were translated with the help of the contracted accredited translation agency.

The clinical diagnoses were based on physical, neurological, and psychiatric examinations; cognitive tests; laboratory tests of blood samples; brain imaging; and interviews with relatives according to the Swedish national guidelines [29]. All participating specialist clinics routinely used the MMSE-SR and CDT for cognitive assessment. The majority also used the Geriatric Depression Scale (GDS-20) and the Functional Assessment Questionnaire (FAQ). During the studies, all these tests and surveys, as well as the RUDAS-S or MCE-S, were used. The MMSE-SR and CDT were used for diagnosis, while the MCE-S was not included in the diagnostic procedure. Table 4 and 5 shows which items can be evaluated through the tests.

Mini Mental State Examination (MMSE)

The MMSE was developed in the USA in an English-speaking population [31], and is the most widely used test for evaluating cognitive function [87], and has been translated into many languages worldwide. The test has become the criterion standard for basic cognitive assessment in cases of suspected cognitive impairment or dementia. Despite its popularity and level of accuracy for identifying people with dementia, the MMSE has been criticized because it is influenced by factors such as language, culture, and education. The test requires the person being tested to be able to write, read, and count, which makes it difficult for people with illiteracy or little schooling [2]. The MMSE contains many words and terms that are not easy to translate and various concepts that are less relevant to people from other cultures. MMSE scores are influenced by patient age, education, ethnicity, and language [122].

Clock Drawing Test (CDT)

In the CDT, the patient must draw a clock, fill in the numbers, and draw the hands of the clock in the correct place. The clock should show 10 minutes past 11. The test is popular because of its simplicity and because it can be performed quickly [34]. However, the test is influenced by educational background and whether the person tested is used to writing/drawing or using a clock regularly [2].

Rowland Universal Dementia Assessment Scale (RUDAS)

The RUDAS is a short cognitive screening instrument [33]. The test was developed in Australia , where almost 31% of the population was born in non-English-speaking countries [123] and more than 80 languages are spoken [33]. The RUDAS is at least as accurate as the MMSE in distinguishing between people with and without dementia [124-126]. The test is easy to translate into a diverse variety of languages with a minimal need for cultural or language adjustment. The RUDAS is easy to administer and is less affected by sex, language, or education [86, 124]. However, people with limited or no education do not perform well on cube drawing and alternating hand movement components [89, 127, 128]. The RUDAS has good diagnostic performance for detecting dementia in different socio-cultural settings [86]. The tests include an assessment of body orientation, praxis (alternating hand movements), drawing (copying a cube), judgement (linked to crossing a busy road), memory (recalling four items from a shopping list), and language (naming animals) [33].

Since 2017, the RUDAS has been recommended in Swedish national guidelines for dementia care for the basic cognitive assessment of patients who need an interpreter during the assessment and those with limited schooling [29]. Since 2018, the test has been registered in SveDem (Swedish Dementia Register). Data from SveDem show that the use of RUDAS has increased in Sweden, but not to the extent expected. QlikView data from the Region Skåne database showed that RUDAS is generally used more in Region Skåne than in other parts of Sweden. In 2022, RUDAS was registered for 274 patients in Region Skåne and 205 patients in SveDem (3% of all registered patients in SveDem) (Personal communication QlikView & SveDem 2023).

Multicultural Cognitive Examination (MCE)

The MCE was developed and validated in Denmark and constructed by adding tests from the CNTB [89], which had previously been found to have excellent discriminative properties while being least affected by ethnicity and education [91]. The test includes the RUDAS [33], the Recall of Pictures Test (RPT) (with immediate recall, delayed recall, and recognition of 10 pictures) [129], Supermarket Fluency (SF) (the number of different supermarket items produced in 1 min) [130], and the CRT (reading of the time on 12 clock showing different times) [131].

Table 4. Tests used in Studies III and IV.

COGNITIVE TEST	COGNITIVE DOMAIN/ITEM		STUDY III	STUDY IV
MMSE	Orientation, Repetition, Verbal recall, Attention and calculation, Language, Visual construction	Total score of 30 [31]	X	X
CDT	Executive function, Attention, Language skills, Frontal lobe function, Visuo-spatial skills	With a range of 0–5 [34]	X	X
RUDAS	Memory, Visuo-spatial orientation, Praxis, Visuo-constructional drawing, Judgement, Language	Total score of 30 [33]	X	X
MCE				
RUDAS	See above, score of 30	Total score of 100 [91]		X
RPT	Memory, score of 30			
SF	Language, Executive, score of 28			
CRT	Visuo-spatial, score of 12			

Table 5. Questionnaires used in Studies III and IV.

			STUDY III	STUDY IV
GDS-20	To identify a depressive component	Range 0–30 points Cut-off ≥6 points [132]	X	X
FAQ	To evaluate the instrumental activities of daily living (IADL)	Range 0–30 points Score ≥9 points, or dependence in ≥3 activities, indicates impaired IADL [133]	X	X

Several doctors and other healthcare professionals from the memory clinics were able to participate in diagnostic rounds where the diagnoses were established by consensus. All diagnoses, including etiological diagnosis and level of cognitive impairment, were determined according to the International Classification of Diseases (ICD-10) diagnostic system [134]. Cognitive impairment was classified as dementia, mild cognitive disorder corresponding to MCI, and unspecified symptoms and signs involving cognitive functions and awareness corresponding to subjective cognitive impairment (SCI). The McKeith criteria were used for the diagnosis of DLB in memory clinics [22]. In Sweden, the code F02.8 G31.8 is used for DLB because it is not specified in the ICD-10.

After all data were collected at the specialist clinics, two focus group interviews with representatives from all clinics were conducted to discuss the study's approach and their experiences and reflections regarding their use of RUDAS-S and MCE-S.

Statistical analyses

For almost all statistical analyses in Studies III and IV, we used IBM SPSS Statistics for Windows (version 27; IBM Corp., Armonk, NY, USA) with two-tailed tests, where $p < 0.05$ were considered significant. Missing data in years of education were substituted by multiple imputations using all test data, age, and education.

Clinical Calculator 1 from the Vassar Stats website (www.vassarstats.net/clin1.html) was used to calculate the sensitivity, specificity, positive predictive value (PPV), negative predictive value (NPV), likelihood ratio (LR)+, and LR– with 95% confidence intervals (CIs) at various cut-off points. Other measures were the Youden Index (YI), defined as the sensitivity (%) +specificity (%) – 100, and accuracy (A) = (true positive + true negative) / all cases. In Study IV, to calculate effect size r, for the Mann–Whitney U test, we used the formula $r = z/\sqrt{N}$ (z = standardized test statistic, N = total N, sample size).

When the data were entered into IBM SPSS Statistics for Windows, all the test results and the scores were checked for accuracy and errors by the author and the second author (of Papers III and IV) and the supervisor. Surprisingly, we found some misjudgements of patients' responses and calculations of scores on tests routinely used in the clinics, which were interpreted to have been caused by human error.

Methodical considerations

The study design and the work before data collection were well planned and thorough. We were sensitive to the participating clinics and attempted to accommodate the conditions they specified for their participation in the study. We were careful with information based on the requirements of each clinic and were available for support where needed. Despite the many measures and our efforts to highlight their importance, we found that there was sometimes a lack of information about the patients' educational background. In hindsight, the question about educational background may have been sensitive and therefore not always asked; alternatively, it might be that the staff did not routinely ask that question.

The basic concept of validation refers to investigating whether a test or measuring instrument measures what it is intended to measure [135], for example, whether a low test score indicates cognitive failure. We analysed the RUDAS-S and MCE-S tests primarily for their ability to distinguish patients who had dementia, whether the test results were influenced by factors such as age or educational background, whether the patient was Swedish or foreign-born, and whether the MCE-S had the ability to distinguish patients with AD. We determined the sensitivity and specificity of the tests. Most of the analyses were performed in comparison with conventional tests such as the MMSE-SR and CDT. For the MCE-S test, which contains four different subcomponents, we also examined how the test correlated with the subcomponents, MMSE-SR and CDT.

There are different types of validation. Construct validity is used when a theoretical logic that is the basis of the test instrument has been developed. Construct validity has two subtypes. Convergent validity requires demonstrating that two measures of a construct that theoretically should be related are indeed related. A stronger correlation indicates greater convergent validity. Discriminant validity requires demonstrating that measures that should not be related are indeed not related. A weaker correlation indicates greater discriminant validity [135].

Criterion validity is the ability of a measure (predictor) to predict an outcome (criterion). Ideally, the criterion should be a well-accepted clinical reference measure.

Content validity is the extent to which a measure represents all aspects of a construct (i.e., whether the measure adequately covers the phenomenon it is intended to cover) and is useful for constructs that have multiple dimensions (e.g., depression). Establishing content validity involves fully defining the construct (e.g., what is the definition of depression?), defining all construct indicators (e.g., what are all the possible symptoms and facets of depression?), and determining the correspondence between the measure's indicators and the construct's facets. Content under-representation occurs when the measure misses important aspects of the construct [135].

Face validity refers to whether items in the scale appear appropriate for its purpose and the nature of the construct it purports to measure [135].

For our statistical analyses, we performed analyses that could address the objectives of the studies and with guidance from previous validations of the RUDAS and MCE. We could then also compare our results with previous findings.

We encountered problems with some journals that required evidence of a licence to use the MMSE when attempting to publish a manuscript including the MCE-S, as the MMSE was included in the study. The MMSE-SR is routinely used in clinical practice and was not included just for our study. This requirement for a licence became a lesson for future studies, as similar requirements are likely to become increasingly prevalent over time.

Ethical consideration

Ethical considerations were made before and during the conduct of the studies. Approval by the Regional Ethics Review Board Authority in Lund, Sweden, was required for all studies according to the Act on Ethics Review for Research Concerning Humans [136]. Approval number for study I and II was 2014/492, and for study III and IV 2016/292 and 2018/109.

The protocols we used complied with the ethical principles established by the World Medical Association in the Declaration of Helsinki [137]. Written and verbal information about the study was provided to all study participants. After participants were informed about the study, their consent was documented by their signature on a consent form. All study participants, patients, interpreters, and healthcare professionals were clearly informed of the reason and purpose of the studies. Their participation was voluntary, and they could withdraw from the studies at any time.

The study participants underwent cognitive assessment at the specialist clinics because they suspected a cognitive disorder; therefore, it was important to determine whether they were sufficiently competent to decide to participate. This competency was sometimes determined through referrals or at the beginning of the visit. Participation in the study was interrupted if the healthcare professionals responsible for the visit had any doubts about the patient's competency or if the candidate patient hesitated to participate. For Studies I and II, in which audio and video recording took place, the author or co-supervisor also informed relatives who were usually present. The patient was informed in writing that personal data would be treated confidentially and reported in such a way that participants could not be identified; moreover, the study would not cause any risk to or suffering for the study participant.

Region Skåne required special written permission for video and audio recording of patients, visitors, or staff who were to be recorded for Studies I and II. This was followed according to instructions for the application of photography, filming, and sound recording within Region Skåne's healthcare operations. Everyone who was recorded on sound and video signed the appropriate consent form. The permit was also signed by the operations manager of the clinic where Studies I and II were conducted (Region Skåne 2013). All audio and video recordings were stored in folders on an external hard drive that was encrypted, and subsequently kept in a locked security cabinet. All material and each folder were anonymized with a code number [110]. Where quotations are presented, a code is used as a reference [137]

We obtained permission from the local consultation group for quality registers, care databases, and preparation in Region Skåne (Samrådsgrupp för kvalitetsregister, KVB), with case number 016-21, for information needed for Studies III and IV (e.g., diagnoses that were made after the cognitive investigation).

The degree of information recorded in interactions between people required the author's awareness when anonymizing the data, in that quotes and behaviours were used with respect and caution and within their context. At the same time, the author could identify shortcomings or opportunities for improvement in communication and interaction during the cognitive assessment [112].

Results

Study I

This study investigated the interaction between healthcare professionals, patients, and interpreters through 19 video and audio recorded observations during cognitive assessment, with a focus on the role of the interpreter. We found that what was communicated between patients and healthcare professionals could change in content and meaning based on the interpreter's competence and how the interpreter perceived what was communicated. The interpreter's proficiency in Swedish and in the other language was crucial for optimal interpretation. Interpreter's language difficulties caused misunderstandings between the patient and the healthcare professional. Patients could also lose trust in the interpreter or in the healthcare professional, which in turn affected the patient's collaboration during their cognitive assessment.

We found that interpreters did not always adhere to the guidelines for *Good Interpreting Practice* [103], for example they did not always interpret everything that was said, they made changes or additions to what was said or they were not neutral or impartial. This led to changes in the information and instructions exchanged between the patient and healthcare professional. These changes could affect important information for cognitive assessments, patient interactions, and healthcare professionals' evaluations of patients' cognitive abilities and conditions. The study showed that interpreter-mediated cognitive assessment could be uncertain. Suboptimal interpretation could lead to suboptimal cognitive assessment and misjudgement of the patient's cognitive abilities.

Comments

In Paper I, we showed through various examples how interpreters influenced cognitive assessment. The observations indicated that some of the interpreters had an attitude and approach whereby they made themselves appear superior to the patient or the healthcare professionals. They showed this both through the way they communicated and through their body language (e.g., the way they sat or used their hands). They could show irritation and impatience when the patient talked about their experiences or symptoms. Some interpreters also created their own dialogues with healthcare professionals or patients without making any interpretation.

Some interpreters wrote no notes to remember and support the interpretation, even if the patient or healthcare professional spoke in long sentences or for a long time. This apparent lack of attention could sometimes result in misinterpretation or no interpretation at all. Interpreters sometimes reported something that neither the patient nor the healthcare professional had said.

We observed that the interpreter could refrain from interpreting if patients expressed themselves in a way that might result from uncertainty, language difficulties, or transient memory failure. For example, one patient often used the phrase *shu ismu* ('what's it called') when he did not remember a certain word or concept, but the interpreter omitted this lapse (Observation 18). Another example was when a patient told the healthcare professional about their fatigue, somnolence, and poor balance. The interpreter translated the information about the patient's fatigue and somnolence but omitted to mention their poor balance (Observation 4). Information that could be important for cognitive assessment was sometimes reduced during interpretation.

During the subsequent interviews with the interpreters, it emerged that the interpreters were often aware of their way of interpreting; specifically, they did not always interpret everything that the patient said because they evaluated it as irrelevant to the context. Conflict of interest was also present in some observations; for example, the interpreter and patient knew each other before, but the interpreter did not report this to the healthcare professional. When it became apparent later during the assessment, the healthcare professional took no action. We found differences between the authorized interpreters and the other participating interpreters. Nevertheless, problems could still occur during the interaction, which depended in part on how the healthcare professionals communicated and in part on the documents or tests used during the cognitive assessment.

The results from Study I provided guidance for Study II, in which we explored the role of healthcare professionals in the interaction between the patient and interpreter during the cognitive assessment.

Study II

We noted that the healthcare professional's approach and way of managing the consultation, interaction, and communication with the patient and the interpreter affected the quality and reliability of the cognitive assessment. We observed that healthcare professionals were sometimes not engaged or distracted in consultations with patients. They were not responsive in contact with the patient and were more focused on the tasks to be done. We saw that some of the healthcare professionals started the consultation directly without patient preparation, they were restrictive when providing information, and took it for granted that patients understood what would happen during the assessment. This could lead to confusion, placing the patient in an uncomfortable situation and affecting the patient's performance during the cognitive assessment.

Sometimes the healthcare professionals did not provide the information or explanations that were required to improve the patient's understanding and cooperation during the assessment. They could also be unclear in the instructions they gave, which could affect the interpreter's interpretation and the patient's interaction and participation during the assessment. The less clear the information or instructions that healthcare professionals provided, the worse was the quality of the interpretation. There was also a greater risk that interpreters would make their own additions to clarify information.

Several of the participating healthcare professionals also gave space to the interpreter and the patient to have their own dialogue without being part of the conversation and requiring interpretation. This led to the healthcare professional having no control over what was communicated and many times to misjudge the patient's responses during the cognitive assessment.

Healthcare professionals sometimes gave the interpreter more responsibility than was agreed in the interpreter's assignment (e.g., the interpreter had to help the patient complete a form while the healthcare professional left the room to get something) (Observation 8) or they made demands on the interpreter that exceeded the interpreter's competence (e.g., when the interpreter was asked to make an assessment of the patient's answer) (Observation 9).

Comments

Sometimes healthcare professionals transfer considerable responsibility to the interpreter and the patient. This may include the responsibility and expectation to make what was unclear understandable to the patient. However, it may also give the interpreter licence to revise [138] and express what was said based on their own understanding and interpretation. Healthcare professionals also sometimes expected patients to understand guidelines and context without having prepared or given them any further explanation. An example was when a patient who was going to perform the counting task in the MMSE-SR test ("Subtract 7 from 80 and continue to do so from the new number until I say stop") wanted help, the healthcare professional replied that they were not allowed to say anything more (Example 1, Observation 11, Paper II). Yet, the healthcare professional had not fully described the task or the guidelines governing the task.

On occasions, healthcare professionals did not provide the patient sufficient time to complete the task and interrupted the patient. The healthcare professional often looked at their papers while the interpreter interpreted and could sometimes miss what was happening between the interpreter and the patient, for example, when the interpreter indicated with his hands that the patient should draw a circle (a clue to the patient who was asked to draw a clock) (Observation 10).

During the subsequent interviews and when healthcare professionals viewed the videorecorded data, many did not reflect on their own role, but several commented on how the interpreter interacted with them and with the patient.

In contrast, two of the healthcare professionals were didactical and thorough in providing information at the beginning of the visit so that the patient and the interpreter understood what would happen at the consultation. They were both clear when giving instructions or asking questions. One of them also gave instructions to the interpreter and mentioned that she expected the interpreter to interpret everything that was said. The healthcare professional was very observant (as assessed by, e.g., how she listened to and looked at the patient and the interpreter when they talked) and sometimes asked control questions or repeated what the patient had said to check if they understood each other correctly. A clear relationship developed between the healthcare professional, and patient and the patient seemed to be comfortable in the consultation.

Observations guide us to future studies

The results from Studies I and II highlighted how both interpreters and healthcare professionals could influence the patient's interaction and performance during the cognitive assessment. The results also revealed that the tests and questionnaires used during the assessment could contain questions and words that were difficult to use through an interpreter. For example, some questions on the MMSE-SR could be difficult to translate or some questions on the Hospital Anxiety and Depression Scale, where phrases such as "Do you feel anxious, like you have butterflies in your stomach?" created difficulties for understanding and interaction between the patient and the healthcare professional. With the knowledge that even the tests used for cognitive assessment could affect the interaction between the healthcare professional, the patient, and the interpreter, we examined the tests that were commonly used in the clinic in comparison with tests that are less influenced by language, culture, and educational background. These are presented in Papers III and IV.

The example below is like one of many that presents results in Studies I and II but also leads us to Studies III and IV.

Example from a dialogue in Study II.

Healthcare professional: If you say after me like this: No ifs, ands or buts. Does it work?

Interpreter: بدي تقول من دون ما تقول فيما لو أو أو ليش ما بدي اياك تستخدم هاي الكلمات

I want you to say without saying any ifs, buts or whys. I don't want you to say these words.

Patient : يعني ليش ايه فيما ليش In other words, say why, er, no one about why.

Interpreter: يعني بدها تحكي معك بس ما بس ما بدها اياك تقول انتِ لو أو ممكن في حال

Ya'ni she wants to talk to you but she doesn't want you to tell, maybe, just in case.

Patient : يعني ما اقول Ya’ni I shall not say.

Interpreter: ما تقول هادي الكلمات كلمات تعجب Do not say these words, words of surprise,

أو ليش ايه ...في حال هادي الكلمات Or why Er ... just in case, these words. (Rustle).

Healthcare professional: Hm? Was that right ?

Interpreter: Hmm.

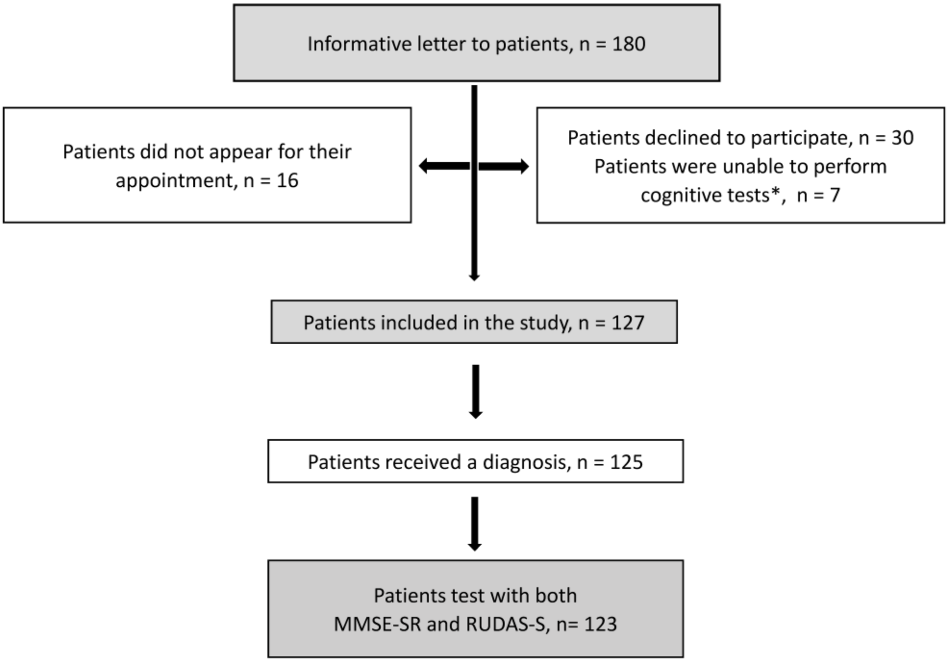
Healthcare professional: Hmm.

The HP then continued to the next question (Example 5, Observation 9, Paper II).

This example arose when the healthcare professional asks the repetition question in the MMSE-SR, where the patient must repeat a sentence spoken by the healthcare professional. Both the patient and the interpreter spoke Arabic but with different dialects, which led to language difficulties throughout the investigation. Neither of them informed the healthcare professional about this problem. The interpreter had never previously interpreted for a cognitive assessment. He did not truly understand the question that he was supposed to interpret, and the interpretation became problematic. The interpreter did not interpret what the patient said and tried on his own to explain and clarify the task for the patient to help the healthcare staff and the patient. The healthcare professional allowed the interpreter and the patient to talk to each other without any requirement for interpretation. The healthcare professional also left the assessment of the patient’s answer to the interpreter by asking the interpreter “Was that right?” instead of seeking an interpretation of what the patient had said. This question in the MMSE-SR is especially difficult to ask through an interpreter and difficult for interpreters to translate.

Study III

The most conventional tests used during cognitive assessment are influenced by factors such as language, culture, and educational background. This will affect the reliability of patients’ performance during cognitive assessments [6, 77]. With this knowledge, the diagnostic accuracy of the RUDAS-S in comparison with that of the MMSE-SR in detecting dementia in Swedish and foreign-born patients in specialist memory clinics was studied. Figure 1 presents a flow chart of the participants included in the study.



* Due to severe cognitive impairment or advanced disease.

Figure 1. Flow chart of the participants in Study III.

In total, 87 Swedish and 36 foreign-born patients from 20 different countries participated in the study. There were no significant differences in age or sex between the groups, but there was a significant difference between the groups in years of education (foreign-born 9.2 ± 4.1 years, min–max 1–17 vs Swedish 11.2 ± 3.6 years, min–max 6–20, *p* = 0.025). The prevalence of dementia diagnoses did not differ between foreign-born and Swedish patients ($\chi^2 = 1.27$, $p = 0.32$).

There was a significant difference in mean MMSE-SR scores between foreign-born and Swedish patients, regardless of whether they had dementia (foreign-born score 19.1 ± 5.5, min–max 4–29 vs Swedish score 24.6 ± 5.2, min–max 10–30, $p < 0.001$); that difference was not evident in the mean RUDAS-S score (foreign-born score 22.6 ± 4.7 min–max 15–30 vs Swedish score 22.6 ± 4.6 min–max 12–30, $p = 0.854$).

Various analyses were conducted to compare the diagnostic accuracy of the RUDAS-S with that of the MMSE-SR, which is routinely used. We found a significant correlation between the RUDAS-S and the MMSE-SR. The probability of dementia diagnosis, according to logistic regression analyses of both the RUDAS-S and the MMSE-SR, was influenced only by age and level of test result but not by the other variables (years of education and whether the patient was Swedish or foreign-born). Receiver operating characteristic (ROC) curve analyses were performed to compare the diagnostic accuracy of the RUDAS-S and the MMSE-SR. The area under the curve (AUC) of the RUDAS-S was 0.81 (95% CI 0.73–0.88), and that of the MMSE-SR was 0.79 (95% CI 0.71–0.87). We suspected that among those with MCI diagnoses, there were patients with dementia, and in a new ROC analysis in which those with MCI were excluded, the RUDAS-S had a greater AUC of 0.93 and MMSE-SR an AUC of 0.84. These findings indicated that the RUDAS-S had moderate-to-good diagnostic accuracy and was at least as accurate as the MMSE-SR for detecting dementia in both foreign-born and Swedish patients. The RUDAS-S had a sensitivity of 0.92 and a specificity of 0.60, with a cut-off of <25/30.

Comments

We found a difference between patient performance on the RUDAS-S and the MMSE-SR. Foreign-born patients had significantly lower scores on the MMSE-SR than on the RUDAS-S, regardless of whether they had dementia. One example that stands out is a patient (foreign-born woman, 10 years of education) with an MMSE-SR score of 4 and a RUDAS-S score of 20. The patient was diagnosed with AD. Although both scores were below the pathological cut-off, they differed substantially.

Three Swedish patients scored highly or attained a full score on the MMSE-SR (28–30/30 points) but scored significantly lower or lower than the cut-off for the RUDAS-S, 28 and 20 points, 29 and 21 points, and 30 and 22 points, respectively. These patients had 8, 17, and 20 years of education, respectively (min–max 8–20). All three patients received a diagnosis of MCI.

The study also included FAQ. During the introduction of the study to the participating clinics, the healthcare professionals were sceptical that relatives of foreign-born people would answer the questionnaire. Contrary to our expectations, the FAQs were answered by 94% of the foreign-born patients and 83% of the

Swedish patients. As expected, numerically higher FAQ scores were found in the group with dementia.

We found no significant difference in the diagnoses between Swedish and foreign-born patients. Nevertheless, the proportions of patients diagnosed with non-specific dementia, VaD, and FTD were greater in the foreign-born group than in the Swedish group. None of the foreign-born patients were diagnosed with DLB or Parkinson-related dementia.

Study IV

In this study, the diagnostic accuracy of the MCE-S was compared with that of the MMSE-SR and CDT, which were used in all clinics in this study for cognitive assessment and diagnosis. Figure 2 presents a flow chart of the participants in the study and their diagnoses.

We found significant differences between foreign-born and Swedish patients for MMSE-SR score (19.8 ± 5.5 for foreign-born vs 24.8 ± 4.8 for Swedish, $U = 613.5$, $p < 0.001$, $r = 0.40$). The CDT score was (2.0 ± 1.8 for foreign-born vs 3.6 ± 1.5 for Swedish, $U = 952.0$, $p = 0.05$, $r = 0.18$). We found no differences between foreign-born and Swedish patients in MCE-S score (63.0 ± 18.0 for foreign-born patients vs 67.0 ± 17.3 for Swedish patients) or in the subcomponents of the test except for SF (12.0 ± 5.8 for foreign-born patients vs 15.0 ± 6.6 for Swedish patients, $U = 941.0$, $p = 0.02$, $r = 0.21$). We found significant differences between patients with and without dementia for all MCE-S components. The MCE-S had a sensitivity of 0.84 and a specificity of 0.74, with a cut-off of <70/100.

The MCE-S, used for the cognitive assessment of 30 foreign-born (from 18 different countries) and 87 Swedish patients, had good accuracy, at least as good as that of the RUDAS-S alone, for identifying dementia in a Swedish context. Furthermore, the test had the ability to distinguish AD patients from non-AD patients with dementia

ROC curves were used to compare the accuracy of dementia diagnoses in cognitive tests, the MCE-S, the RUDAS-S, MMSE-SR, and the CDT. The MCE-S had an AUC of 0.82, which was at least as good as that of the RUDAS-S (0.79), the MMSE-SR (0.76), and the CDT (0.67) for distinguishing between patients with dementia and those without dementia. The MCE-S total score was strongly correlated with all MCE-S subcomponents and the MMSE-SR and CDT.

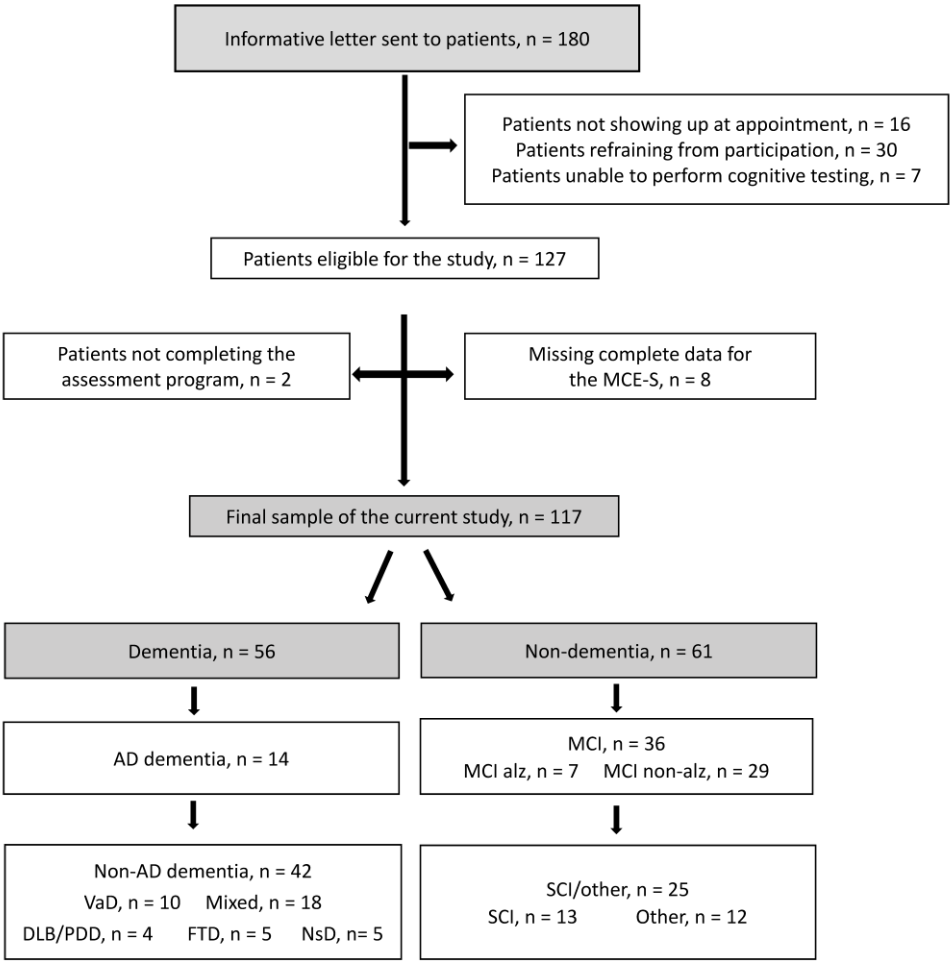


Figure 2. Flow chart of participants and clinical diagnoses in Study IV.
Abbreviations: n, sample size; AD, Alzheimer's disease; VaD, vascular dementia; Mixed, AD/VaD; DLB/PDD, dementia with Lewy bodies/Parkinson's disease dementia; FTD, frontotemporal dementia; NsD, non-specific dementia; MCI, mild cognitive impairment; SCI, subjective cognitive impairment (patient with memory-related subjective symptoms) (R418A); Other, diagnosis of burnout syndrome, depression, post-traumatic stress disorder (PTSD), fibromyalgia, and neurological disorders such as dysphasia and parkinsonism.

Binary logistic regression was used to determine the effect of demographic variables (age, sex, MCE-S, years of education, and whether the patients were foreign-born or Swedish) on the ability of the MCE-S to classify dementia. The probability of dementia was significantly affected only by age and MCE-S score ($p = 0.001$ vs $p < 0.001$).

AD was diagnosed in 14 of 56 patients with dementia. The mean scores for the MCE-S and its subcomponents in the groups of patients with AD and without AD showed that patients with AD had significantly lower RPT-delayed recall scores ($U = 174.5$, $p = 0.02$, $r = 0.31$) and a trend towards significant RPT-immediate recall ($p = 0.06$) and MCE total scores ($p = 0.08$).

Comments

The most unexpected finding was that the MCE-S worked just as well for Swedish patients as for foreign-born patients.

The participating healthcare professionals described their experience using the MCE-S as easy to administer even through an interpreter. They reported that it was easier to maintain patient cooperation and participation during cognitive testing with the MCE-S than with other tests. The MCE-S did not include questions that were difficult to ask. Other cognitive tests, such as the MMSE-SR, contain questions that were usually difficult or impossible to ask, especially through an interpreter (e.g., orientation questions where the patient must state which county they are in, or which season it is). A comment from a healthcare professional from one of the specialist clinics captures the general opinion.

> The MCE-S invites you to have a different conversation with the patient than the conventional tests do, a more everyday conversation. All the questions in the test could be used and were much easier to perform through an interpreter.

An example from Studies I and II is shown here to illustrate how difficult and complex a question from the MMSE-SR could become. This test includes an orientation question where the patient must state which county they are in. On several occasions, based on the video observations, we observed difficulties with the words county or landscape, which became problematic for the interpreters and patients.

Example from dialogues in study I.

Healthcare professional: What landscape are we in?

Interpreter: ا بايه .. منطقة في السويد Eh .. Which area in Sweden?

Patient: Malmö. مالمو Malmö

Interpreter: Malmö.

Healthcare professional: What part of Sweden are we in?

Interpreter: ايه جزء احنا بايه جزء اي منطقة جغرافيا What part, in what part, what geographical area are we in?

Pateint: اوه الدانمرك قريبة علينا ما اعرف انيه oh Denmark is close to us, I can't

Interpreter: We are close to Denmark.

Healthcare professional: Do you know what… this part is called?

Interpreter: يعني هادي المنطقة هادا الجزء من السويد شو اسمه شو اسمه Yani, this area, this part of Sweden - what is it called

Patient: ما اعرف I do not know.

Interpreter: احنا بمدينة مالمو لكن الجزء هادا كله شو بسموه محافظة شو

We are in the city of Malmö, but what is the name of this whole part? It is called a province.

Patient: Skåne. سكونه Skåne

Interpreter: Skåne. (Observation 14)

Discussion

The results of these studies illustrate the complexity of the cognitive assessment of foreign-born patients. The way in which the healthcare professional and the interpreter interacted, as well as with the patient and the test used during the assessment influenced the patient's interaction, collaboration, and response, which in turn affected the quality of the cognitive assessment. The patients were vulnerable when they did not understand what was happening during the consultation and felt they were not truly seen or heard.

We found differences in the patients' test results depending on the test used. The RUDAS-S and MCE-S have good diagnostic properties for detecting dementia and are not strongly affected by language, culture, or educational background. They were thus safer to use through interpreters. If communication during the assessment does not function optimally and adapted cognitive tests are not used, cognitive assessment of foreign-born patients can be inaccurate and may lead to mistakes or misdiagnosis, which can lead to inadequate treatment and care.

Interpreter-mediated cognitive assessment

Language barriers can negatively affect the ability of healthcare professionals to communicate with patients and negatively impact personalized, safe, and effective care to meet patients' needs [74]. It is recommended that patients should preferably be assessed or examined by a bilingual healthcare professional to avoid language barriers [139], but such access is very limited and unrealistic for many languages [5, 138]. Interpreters are an important resource for healthcare professionals to provide communication, increase understanding between patients and healthcare professionals, raise the quality of care and contribute to more effective care, thereby improving clinical outcomes and patient satisfaction [94, 140, 141]. Our studies showed that interpreters who were appointed through interpreting agencies did not always have optimal training and competence. There were shortcomings in the availability of authorized healthcare interpreters and interpreters with basic training [101]. Therefore, even if we requested a trained and authorized interpreter, we did not always get one. As healthcare professionals, it is important to be aware of this potential drawback when interacting with interpreters. This situation places even greater demands on the commitment of healthcare professionals, who are responsible for medically safe patient care, during communication and interaction with the patient.

In addition, the interpreter’s challenges during interpretation, regardless of training and competence, are dependent on the context, complexity, and limitations of the consultation [142, 143]. Based on the results of our study, we highlight how the interpreter’s knowledge of cognitive disorders and cognitive assessment influenced their interaction with healthcare professionals and patients and thus the quality of the interpretation and the assessment.

Cognitive assessment is a complex situation and involves various important elements during a consultation. With all the guidelines governing cognitive testing, the testing itself requires understanding and preparation by the interpreter [106]. After all, the cognitive tests used were not specifically developed or validated for use by an interpreter [77]. A patient with suspected cognitive impairment may have symptoms that are important for healthcare professionals. If the interpreter is not optimally familiar with the context, there may be unconscious shortcomings in their interaction with the patient and healthcare professionals, which may make the cognitive assessment less certain. One example was the interpreter who did not interpret that when the patient said, ‘What’s it called?’ many times, the patient simply could not think of the word to use. An interpreter’s attitude could misrepresent the patient’s failing language and memory and important information for the healthcare professional’s assessment of the patient.

Another example that we reported in Paper I involved a patient being asked “what day is it today?” The patient hesitantly answered “Monday, Tuesday, Wednesday…,” but the interpreter only interpreted “Wednesday”. The interpreter unknowingly or carelessly contributed to a misleading evaluation of the patient’s cognitive ability by not following the guidelines that govern their work but also by not being aware of the importance of verbatim interpretation for that specific assessment. It is extremely difficult for an interpreter to interpret word for word [143], but in the context of cognitive testing, this type of interpretation is crucial. Similarly, when the patient speaks incoherently (without making sense), it must be brought to the attention of the healthcare professional by the interpreter. The results of Studies I and II showed that deficiencies in communication caused misjudgements of the patient’s cognitive ability, which may lead to misdiagnosis.

Based on the results of our study, which confirm those of previous studies, we recommend providing information to the interpreter before the consultation with the patient begins, which could be helpful for the quality of interpretation [142] and, in our case, for the quality of cognitive assessment. The information provided should outline what happens during the consultation and give guidelines for cognitive testing.

Explaining the interpreter’s role to the patient before the consultation can help to establish respectful, flexible, and effective collaboration during the consultation [142].

This may also encourage participants to address any issues directly during the consultation. For example, with reference to our study, we might avoid incidents in which neither the patient nor the interpreter told the healthcare professional when dialect differences occurred.

Moreover, the study showed that the communication technique of healthcare professionals, in relation to clarity, speech, gaze, turn-taking [142], and their ability to communicate through an interpreter are crucial for the quality of communication. In addition, the presence, commitment, and responsiveness of healthcare professionals are important for the confidence of patients, which are important elements in the relationships between patients and healthcare professionals during consultations [144]. Healthcare professionals' openness, flexibility, and curiosity can also contribute to their relationships with patients and increase the quality of their interactions and communication. Martin Buber's relational philosophy describes that people meet each other either based on an I–It relationship or an I–Thou (you) relationship. In the latter, a relationship is created where two individuals meet and achieve a common understanding that is based on trust [145]. When the healthcare professionals do not provide their full concentration during the consultation with the patient, there is a risk that the patient will become an 'It' and perceive the healthcare professional as uninvolved and uninterested. Then, there is a risk that a distance is established instead of a relationship between healthcare professionals and patients, which may affect the patient's motivation and cooperation.

The results of Studies I and II made it clear that when communication between healthcare professionals, interpreters, and patients breaks down, it is usually not because of individual participants in the conversation. Rather, it involves the interaction between all participants in the conversation [97, 143].

Studies conducted in other healthcare contexts/disciplines have shown that healthcare professionals could be sceptical of the quality of communication and care despite the use of professional interpreters. They were unsure if they could trust the interpreter and uncertain of their own role during interpreter-meditated consultations [146]. We found that healthcare professionals were sometimes less committed, flexible, and responsive than might otherwise be expected. This was perhaps a consequence of their finding language barriers challenging [92] and not having faith in interpreter-meditated consultations, resulting in low expectations for the consultation and a feeling of abandonment, powerlessness, and not working with the expected professionalism and commitment. We found that healthcare professionals lacked sufficient clarity in understanding the role of the interpreter and its impact on the cognitive assessment. On the other hand, some healthcare professionals were comfortable with interpreters, often assigning them more responsibility than their role and competence warranted.

In sum, healthcare professionals describe various difficulties in assessing and diagnosing foreign-born patients, with language barriers being the major challenge

[67, 92, 147, 148]. The interpreter still plays a large role in the consultation, and the relationships that exist between the healthcare professional and the interpreter can be decisive for the assessment [95]. Language barriers can negatively affect healthcare professionals' ability to communicate effectively with the patients. This, in turn, has a negative impact on the provision of appropriate, timely, safe, and effective care to meet patients' needs [74]. Therefore, it is important to train healthcare professionals to communicate through an interpreter and to determine what requirements can and cannot be placed on an interpreter. It is also important that healthcare professionals reflect on their own role during communication and interaction with patients and the approach they must take to ensure that patients feel comfortable, safe and understood.

Strengths and limitations of studies I and II

We recognize that the studies would be of greater quality if the translations were reviewed by one more person. The author and co-supervisor were aware of this and tried to optimize the quality by involving the language experts in the purpose of the study and being clear about the requirements placed on their translations.

Another limitation of the studies was that the author wanted to explore nonverbal communication even further, as this is also culturally influenced. However, this would have required further competence on the part of the author to be able to understand and analyse nonverbal communication.

The analysis could have been conducted using a more deductive approach, incorporating theory or prior knowledge throughout the analysis. Previous studies have investigated how interpreters work and influence interaction or communication in different contexts. They described, for example, interpreters' interpretations in various terms, including close, extended, reduced, replaced, and omitted interpretations [143]. This prior knowledge was important and useful for processing, discussing, and confirming the results of our studies.

Because we wanted to study the interaction between healthcare professionals, interpreters, and patients, we chose foreign-born patients as the inclusion factor. In retrospect, it would have been of interest if Swedish patients had also participated in the study to compare healthcare professionals' interactions and communication with patients, with and without an interpreter, which is a suggestion for future studies.

The content of the cognitive assessment was not prepared for the study and represented the clinical reality. It was beneficial for the study that several healthcare professionals with different professions (doctors and nurses) were participants in the study to gain broader insight into how they interact with patients and interpreters. After each recorded assessment, the healthcare professionals and interpreters were interviewed by the author and co-supervisor. It would have been valuable to also interview the patients about their experience of cognitive assessment. This is suggested for future research. The cultural aspects of the interaction between the participants were not discussed in the papers, nor was the sex perspective, which in turn affected the interaction. These factors could be elucidated in future studies.

Diagnostic accuracy of the RUDAS-S and MCE-S

The use of a cognitive screening instrument adapted to the cognitive assessment of patients with various cultural, linguistic, and educational backgrounds is essential for providing timely diagnosis and safe care [5, 6, 77]. We found a difference in the patients' MMSE-SR scores depending on whether they were Swedish or foreign-born, regardless of whether they had dementia. This difference was not observed for the RUDAS-S or MCE-S, which may provide a more reliable evaluation of patients' cognitive abilities without the influence of other factors. The studies showed that the RUDAS-S and MCE-S were at least as good as the MMSE-SR in detecting dementia.

The present study revealed that the MCE-S, like the MCE [91], has the ability to distinguish AD patients from non-AD dementia patients, indicating that the MCE-S is a good screening instrument for the early diagnosis of cognitive impairment. The MCE-S improves the cognitive assessment of foreign-born patients compared to RUDAS-S only since it broadens the assessment of memory, verbal fluency, and visuo-spatial ability [91].

We found that the MMSE-SR can provide a misleading evaluation of a foreign-born patient's cognitive abilities. The MMSE is often not an appropriate test for use in cross-cultural cognitive assessment [87]. This may explain why healthcare professionals reported that they had better contact with patients during testing with the RUDAS-S and MCE-S than with the MMSE-SR. It is not just the test score but also the procedure during testing that is important. Healthcare professionals should also be able to evaluate patients' responses and interactions during testing. How the patient responds to questions can be just as important as the answer they give and may provide additional insight into the patient's cognitive abilities.

Interestingly, several of the patients who underwent assessment had lived in Sweden for more than 50 years and needed an interpreter. This indicates that even if individuals have lived in a country for many years, studied or worked, and been integrated into society, they may still need an interpreter when they become older or develop a cognitive disorder. This also implies that there are citizens who, despite many years in Sweden, have not learned the language sufficiently well to be able to converse on their own when they encounter the healthcare system. Regardless of length of residence in Sweden, the need for an interpreter must be considered based on the patients' needs. Especially in the case of cognitive assessment, patients should be encouraged to communicate through the language in which they have the best mastery [85].

An unexpected result related to the RUDAS-S and MCE-S scores for Swedish patients with a high number of years of education. These assessments seemed to be more sensitive to patients' cognitive abilities and condition in relation to the diagnosis they had received than MMSE-SR scores. There are opinions among specialists who believe that the RUDAS-S or MCE-S should be used for the cognitive assessment of foreign-born patients with few years of education and not for those with a high educational background. In Sweden, the National Board of Health and Welfare recommends the RUDAS-S for patients with low education [29]. Although the RUDAS-S is considered a simpler test, there is no evidence that it is an inadequate test for highly educated patients. A meta-analysis of 26 studies showed that the RUDAS had similar diagnostic performance in high-, low-, and middle-income settings [86]. We did not find that the RUDAS-S was unreliable when assessing more highly educated patients.

We found that most foreign-born patients (58%) received diagnoses that did not lead to treatment with dementia-specific drugs, in contrast to Swedish patients (24%). Other studies have shown that there is a significant difference in the use of dementia drugs among foreign-born patients [80]. Foreign-born patients from non-European countries rarely receive diagnoses such as DLB, but psychiatric diagnoses are more common [26]. Future research should study diagnoses for foreign-born and Swedish patients in a larger study population and investigate the reason for any differences.

The studies showed that more FAQ answers were provided for foreign-born patients than for Swedish patients, which was unexpected for healthcare professionals before data collection. It is important to provide additional information to obtain fairer insight into patients' cognitive ability and whether this ability affects their everyday life and independence. Healthcare professionals are often influenced by prejudices or previous experiences, norms, and values when in contact with patients [149]. All patients must be given the same opportunity and optimal basis for assessment. More information about the patients increases the possibility of a reliable diagnosis, and the person-centred treatment and support that the patients may need.

Strengths and limitations of studies III and IV

To our knowledge, Studies III and IV are the first to validate the RUDAS-S and MCE-S in Sweden. The studies were performed in daily clinical practice in four specialized memory clinics. To be inclusive and reflect real life, no exclusion criteria were formulated. The study included patients with various native languages who were representative of the most common foreign-born groups in Sweden [150], and Swedish patients. There were no significant differences in sex and age between the foreign-born and Swedish patients, which was a strength of the studies.

In general, the number of foreign-born patients who were referred for a cognitive assessment was smaller than expected. Foreign-born patients seek care for memory disorders less often than native-born patients [6], which may indicate a need to increase knowledge about cognitive disorders, dementia, and cognitive assessment in the group of foreign-born patients.

The studies have some limitations that should be considered. This was a cross-sectional cohort study without longitudinal follow-up to support the accuracy of the clinical dementia diagnosis used as a criterion standard. It would have been beneficial to use, for example, the Clinical Dementia Rating Scale as an independent measurement to evaluate the level of cognitive impairment [151]. Currently, we must trust the diagnoses made at specialist clinics as the reference standard. The memory clinics in the study were accustomed to using the MMSE-SR, and the results from the MMSE-SR were used to reach the dementia diagnosis, which was used as the reference standard in the present study. This may have inflated the psychometric properties of the MMSE-SR because of circular logic.

In other validation studies, the test results were compared between patients with suspected dementia and healthy control individuals. In our studies, it may be a disadvantage that we did not include healthy controls but instead included patient controls with other diagnoses. Using patient controls could be beneficial for the study outcomes, as this may better reflect clinical reality. In any case, the use of healthy control groups might have provided us with more information about the tests and is suggested for future research.

The duration of residence in Sweden for the foreign-born patients ranged from 1 to 55 years, with a mean of 30 years. A further limitation of the studies was that a measurement of acculturation was not performed. Acculturation is the process by which the person is integrated and influenced by exposure to another culture [152]. A lower degree of acculturation might be related to poorer performance in cognitive testing [153-155], especially in tests of cognitive speed and executive ability [156].

Conclusions

We found that the quality and accuracy of the cognitive assessment of foreign-born patients depend on several different factors. The assessment is highly dependent on optimal communication and interaction between all participants in the consultation. An interpreter can have a negative impact on cognitive assessment when they are not familiar with the context in which they are interpreting, when the patient and the interpreter speak different dialects, or do not follow the guidelines for their work. Healthcare professionals are responsible for the medical safety and quality of the assessment, and how they communicate with the patient during the assessment is crucial for the relationship and confidence they build with the patient. This is important for the interaction and for the patient to understand what is happening during the cognitive assessment and for them to feel seen, heard, and understood.

How healthcare professionals interact with interpreters increases the quality of communication and provides better conditions for interpreters to perform well, which in turn can lead to better interactions with patients during various parts of the cognitive assessment. Healthcare professionals need knowledge in communicating with patients who do not share the same language, as well as communicating through an interpreter. It is also important that they reflect on their own approach and role in relation to patients and how they themselves can influence the assessment.

The cognitive test used during the assessment can be decisive for optimal communication and interaction with the patient, the reliability of the assessment, and the diagnosis. The RUDAS-S and MCE-S have good diagnostic performance and are at least as good as the MMSE-SR in detecting dementia. These tests have the advantage that they are less influenced by factors such as language, culture, and educational background. The RUDAS-S and MCE-S are as effective for the cognitive assessment of foreign-born patients as they are for Swedish patients.

During cognitive assessment, patients may feel at a disadvantage and exposed, which can affect their interaction and performance. Healthcare needs to address various aspects to increase the patient’s conditions for a safer and more equal cognitive assessment and diagnosis; otherwise, harm can occur while the intention is to do good.

Interpreters need to be trained in cognitive assessment and its special challenges when interpreting in that context. Healthcare professionals need training and awareness regarding cognitive assessment in multicultural society to use interpreters optimally and to have routines including the use of adapted tests. Workplaces and managers must allow and create conditions for their staff to be able to work with a person-centred and holistic approach.

The cognitive assessment of foreign-born patients can be uncertain and unequal, which may lead to misdiagnosis and a lack of treatment and support. Equal opportunities do not always lead to equal outcomes. There is a need for awareness, knowledge, adapted tools, and the opportunity to respond to patients based on their conditions and needs for safe and equal care.

Reflections and clinical implications

The four studies comprising my thesis have given me new insights into cognitive assessment, patients' situations, and healthcare professionals' competence and prerequisites in performing medically and patient-safe work. Assessment of cognitive abilities can be helpful in predicting changes in functional capacity, designing and planning appropriate interventions for the patient, and helping relatives and caregivers meet upcoming care needs [157]. Sweden, like other countries in Europe, is multicultural. All residents have the right to equal and safe prevention, assessment, diagnostics, treatment, and support. The cognitive assessment of foreign-born patients is complex, and there is a need to develop and improve different parts of the process. We need to communicate better with the patients in our multicultural society, improve communication through interpreters, and have routines and guidelines for the use of adapted cognitive tests during the assessment. These studies highlight many challenges but also the potential for several improvement opportunities. This knowledge and awareness will be useful and beneficial for all patients, regardless of whether they are Swedish or foreign-born.

Below are some reflections and recommendations based on the studies and clinical experiences I have gained during my studies.

The patient

During data collection for the studies, there were few foreign-born patients who applied for a cognitive assessment. This finding is consistent with previous studies showing that foreign-born patients access diagnostic services later in their illness or do not seek cognitive disorders to the extent expected [52, 59]. This may be due to the cultural view and stigma associated with dementia, limited knowledge about the disease and its symptoms, a lack of awareness of available services, or previous negative experiences of contact with the healthcare system [65]. Education and socio-economics can also influence how people experience cognitive disease and seek care [68]. Not speaking the same language as healthcare professionals has also been identified as a substantial barrier to seeking care and diagnosing dementia [48, 57]. Language difficulties also create barriers to sharing information between healthcare professionals and patients [73], and may represent the most serious problem in providing adequate, appropriate, effective, and timely care to all patients regardless of where they seek care [74]. Language difficulties are thus a major reason for the failure of healthcare professionals to detect or recognize symptoms of dementia in foreign-born patients [67]. For example, a person attending primary care to assess diabetes may be asked about their memory or other cognitive abilities if the nurse or physician suspects cognitive disorders, and a cognitive assessment can be scheduled if necessary. This observation, question, and opportunity to initiate an assessment may not be provided to people who do not speak the same language as healthcare professionals. A Swedish study showed that the initiative for cognitive assessment for foreign-born patients was more often taken by their relatives [158]. Thus, the possibility of receiving a cognitive assessment and diagnosis may depend on the relatives' view and knowledge of dementia and their ability to seek care. Healthcare professionals in both primary care and specialist clinics should be more observant and provide assessments when cognitive impairment is suspected so that such patients are not missed.

Currently, there is more evidence about the importance of lifestyle and prevention interventions to reduce the risk of factors that can lead to cognitive diseases [27, 159, 160]. Both primary care and specialist clinics should also review the possibility for adapted information and increased awareness of preventive measures for foreign-born persons. For example, physical inactivity, hypertension, hearing loss, and obesity can have great prevention potential [161]. By investing in prevention, we should be able to reduce and influence the risk of cognitive diseases for foreign-born patients, at least in part. We can also establish contact with patients who may need cognitive assessment, making it easier to implement if there is a need. These issues require further study.

Patients are in a disadvantageous situation in many ways, and at different level [162]. Not being able to communicate directly with healthcare professionals and being dependent on an interpreter can put patients in an even more difficult and unsafe situation.

It is important that healthcare professionals take such factors into account when meeting with patients. Brief information about what will take place during the cognitive assessment and the role that interpreters have for both healthcare professionals and the patient are simple measures that make the assessment more meaningful for patients and increase their understanding and cooperation. Questions about medical history provide important information about the patient in the investigation process and can help healthcare professionals build a relationship and trust with the patient. Questions that facilitate patients to describe their symptoms and needs are required. In particular, information that might be uncomfortable or symptoms that might be difficult for the patient to talk about may be related to the cognitive disease, for example, personality changes and altered behaviour or sleep patterns.

To improve the possibility of early assessment for the whole society, there is a need to:

- increase information and awareness about cognitive diseases, symptoms, and the importance and objectives of cognitive assessment
- increase understanding that cognitive diseases, like other diseases, should be investigated so that appropriate treatment and help can be initiated

To increase the patient's understanding, participation, and commitment at the cognitive assessment, it is important to:

- begin the assessment with a short conversation, to provide brief but clear information about what will happen during the assessment
- provide information about testing and guidelines for implementing the tests
- provide information about the interpreter's role
- check that the patient and the interpreter understand each other, for example, that they speak the same language/dialect

The interpreter: a resource for shared understanding

Healthcare professionals have a responsibility for communication, and the interpreter is a resource to help them and the patient communicate, that is, a resource for shared understanding [143]. Various problems arise when the interpreter does not have the competence that is expected and when healthcare professionals are unable to work through the interpreter optimally. A lack of quality in interpreter-mediated cognitive assessment can lead to misjudgements of patients' symptoms, conditions, and misdiagnosis. Questions about communication through an interpreter need more consideration and are a patient safety issue. We should be aware of the importance of developing good collaboration with the interpreting agency [163], should make more demands on interpreter agencies in procurement agreements and improve in reporting deviations when provided with an interpreter who does not have the necessary skills, leading to ineffective communication.

Through dialogue and collaboration with interpreting agencies, opportunities for training and support for interpreters can be identified. A good example involves a collaboration between Cognition and migration[2] in Region Skåne and interpreting agencies. In recent years, we have trained approximately 100 interpreters for cognitive assessment. This intervention has been appreciated by both interpreters and healthcare professionals. In this way, it is possible for interpreters to learn about cognitive diseases and what happens during the cognitive assessment; moreover, information that is accessed through healthcare professionals before the interpretation begins can strengthen the interpreter's role and improve the quality of interpretation [2, 6].

Healthcare professionals can then advantageously appoint these trained interpreters. As healthcare providers, we should also be responsible for creating good conditions for interpreters to be able to work as well as possible. Healthcare professionals should be aware of the challenges that may arise when communicating through an interpreter and have knowledge of how they can best use the interpreter. Communication strategies, the words and terms used, and clarity of information and instructions are important elements for the quality of the interpretation.

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[2] Cognition and migration is a strategic unit within the field of neurology, rehabilitation medicine, memory disorders and geriatrics, within Region Skåne. The unit's mission is to work for care on equal terms for all people with cognitive impairment and dementia, with a focus on foreign-born individuals. https://vardgivare.skane.se/patientadministration/vard-av-personer-fran-andra-lander/migration-asyl/kognition-och-migration/

Training for interpreters on:

- cognition, cognitive disorders, and symptoms
- the importance of cognitive assessment
- the challenges that may occur in interpretation during cognitive testing
- the specific requirements for interpretation that are of value for the quality of the cognitive assessment

For optimal communication through an interpreter, keep in mind to:

- book the interpreter 10–15 minutes before the patient arrives to prepare the interpreter for what will take place during the cognitive assessment
- speak directly to the patient
- speak clearly and in short sentences
- avoid medical terms, and difficult words and concepts
- be clear in the transition from one task to another
- require the interpreter to interpret everything that is said
- control turn-taking and do not allow the patient to speak too many sentences before the interpreter interrupts to interpret
- ask control questions to check that the patient has understood
- not ask the interpreter for opinions on the matter; the interpreter must be neutral and impartial

164

Healthcare professionals and the healthcare system

It is important to have the knowledge to communicate with patients through an interpreter, but it is also important to reflect on our own way of communicating with patients in general. By not being clear or responsive to patients, distance can be created between the healthcare professional and the patient, which puts the latter at a disadvantage. Willingness to understand and commitment are major components of effective communication. Reflection on one's own cultural values and norms, as well as being curious, responsive, present, and flexible in communication facilitates communication across barriers both culturally and linguistically

Our observations gave the impression that healthcare professionals felt a sense of abandonment, which may be because interpreter-mediated consultations are perceived as difficult and challenging. The observations also confirmed that even though language is self-evidently important for communication, so is commitment and a desire to understand. Sensitivity is required to gain understanding, by paying attention and listening to what is said and what is not said with words, observing body language, asking control questions, and being always interested and actively present during the conversation. Healthcare professionals can also be influenced by their prejudices and beliefs, norms and values, which may affect communication and relationships with the patients with whom they come into contact [149]. Foreign-born patients can sometimes experience being treated according to healthcare professionals' prejudices or feel that they are not taken seriously [165]. A person-centred and holistic approach that invites to see the patient, be curious, flexible, and responsive, can help to meet patients regardless of their language and cultural background, in a professional manner and based on patients' conditions. However, for a person-centred approach, a permissive and integrated person-centred culture is required in the workplace with the necessary conditions. Managers' commitment, routines, and guidelines are required for a sustainable work culture [166-169].

Interpreter-mediated cognitive assessments can take longer to complete than other consultations. We have proposed the benefits of providing information to prepare the patient and the interpreter for better communication and interaction to increase the quality of the assessment. How could this work in these times of resource cuts, where productivity must be increased, with more patients seen per work shift to shorten care queues? There is a paradox here. The law says that we must offer safe and equal care to everyone [170], and all patients must receive professional and medically safe care based on their needs. Patients must be involved based on their conditions, and a more efficient healthcare resource must be achieved [171]. The Patient Act aims to promote patient integrity, self-determination, and participation in health and medical care activities [99], but is this achievable for organizations? The healthcare system wants their employees to be professional, but there remains the question whether they are given the conditions, the time, and the opportunities to achieve that.

Future studies could map how the healthcare system allows time and resources towards the goal of working based on patients' individual needs and conditions. Do workplaces enable their staff to work on that premise?

Appropriate cognitive screening instruments

In recent years, awareness of the importance of using culturally and educationally sensitive and appropriate cognitive screening tests has increased [2, 5, 6, 172]. Our studies confirmed a need for cognitive tests that are adapted to today's multicultural societies in which one measure cannot fit all. Despite national recommendations to use the RUDAS [29], tests such as the MMSE are still used in the cognitive assessment of foreign-born patients. Even though the test is deemed unsuitable for foreign-born patients, the reason for its continued use may be a lack of knowledge of the RUDAS or a lack of familiarity with its use [92].

Healthcare systems and professionals should be more open to changes and opportunities for improvement and invest more in training and implementing new knowledge and new tools. The studies we conducted to investigate the diagnostic accuracy of the RUDAS-S and MCE-S cognitive tests for detecting dementia were important steps towards validating these tests in a Swedish context. More research with a larger study population is needed to increase knowledge and evidence for the use of the MCE-S. However, this shift does not preclude the use of the MCE-S in clinical practice. The MCE-S is a good alternative or complement to the cognitive assessment of foreign-born patients in primary care because of its characteristics. All parts of the test are easy to administer both with and without an interpreter, and the test improves the ability to evaluate a patient's cognitive abilities on a broader basis than that covered by the RUDAS-S and can increase the possibility of identifying AD [91]. This in turn can lead to earlier diagnosis and planning of treatment and support.

After knowledge gained from our MCE-S study, through a development project, we also used the MCE-S within eight participating units in primary care in Region Skåne [173]. All participants found the MCE-S easy to administer and it helped them better understand the patients' cognitive functions. Based on this development project and contact with other healthcare professionals (nurses and physicians) in primary care, participants noted that they required more telephone consultation opportunities from specialist clinics for cognitive diseases. This is an organizational issue and it is worth reviewing such opportunities because they represent an important step for early diagnosis and maintaining continuity of care (which has beneficial effects for patients and their care), patient integrity, and participation [171, 174].

Based on clinical experiences, contacts with healthcare professionals and awareness we have gained from our studies, it is recommended that both the RUDAS-S and MCE-S be used for cognitive assessment of foreign-born patients, regardless of educational background and skill or difficulty in the Swedish language. It would have been desirable to have the knowledge and skill to use tests that were adapted to the patients' needs and conditions, and for healthcare professionals to have the competence and opportunity to be able to choose the tests that were needed based on the patients' conditions and to supplement tests with others as needed. Although structure and guidelines are essential for safe and equal care, the ability to understand the patient's condition and individual needs and adapt care based on observations is essential for safe and effective care.

Although the goal of the healthcare system is to provide equal and safe care for all residents of Sweden, care for foreign-born patients with cognitive disorders is not equal and safe. There is a difference in equity and equality, and care requires self-awareness, competence, resources, guidelines and the willingness to achieve equity where all patients are treated according to their conditions, circumstances, and needs.

Conclusions and final reflections

There is a voice that doesn't use words. Listen.
Rumi(1207-1273)

People have been migrating from one place to another for years. The reasons range from security, social and political factors, demographics and human rights to poverty and climate changes. People being forced or choosing to move to other countries, sometimes far from their home countries, where cultural and linguistic differences occur. Healthcare can experience challenges in cross-cultural meetings between people of different sex, age, language, education and socioeconomic background. Effective communication is a necessary complement to the evident professional competence to succeed in building relationships, increasing understanding, and creating security for patients. Healthcare professionals need alternative tools to improve communication and increase the quality of care. Professional interpreters, committed relatives, appropriate information for patients, training for healthcare professionals and interpreters, and adapted tools are among the resources that can increase the quality of care. However, the most important tool is within us. Rumi, the Persian poet (1207–1273), highlights *self-reflection* and *empathy* as important tools for communicating and interacting with people [175].

Influenced by Rumi's life philosophy and timeless wisdom, I want to emphasize the ability to increase understanding of others by listening. Listen hard, listen with the heart, and be open to others' stories that include values, ideas, feelings, and expectations. Have a genuine interest and desire to understand and help others. Ask and not guess. Be fully present, curious, with respect for the other's beliefs and differences, and develop your own ability to reason and understand the other person based on their framework of reference. This requires love, responsibility, perseverance, openness, freedom from prejudice, and open-mindedness. Constant self-reflection about who we are and how our own values and attitudes affect us in our encounters with other people is paramount.

Future perspectives

Based on the knowledge gained from the studies that comprise this thesis, a summary of suggestions for future research is outlined.

- The possibilities and conditions for healthcare professionals to work based on patients' conditions and needs at specialist clinics for cognitive disorders (and primary care) should be determined. Interviews with doctors, nurses/occupational therapists, and their managers are essential.
- The patient's experience of the cognitive assessment regarding understanding and participation before and during the assessment should be sought. Interviews with Swedish and foreign-born patients should be conducted.
- To improve interaction and communication during cognitive assessment through interpreters, we have trained interpreters in various languages about cognitive disease and cognitive assessment. Evaluation of this intervention by interviewing healthcare professionals, interpreters, and patients is required.
- Through a larger national cohort of Swedish and foreign-born patients, the MCE-S and its subcomponent properties for the detection of dementia should be examined.
- Due to lifestyle and the presence of various diseases and conditions, foreign-born individuals may have a greater incidence of diseases that increase the risk of developing cognitive disease. Intervention and evaluation of preventive knowledge and studies on foreign-born individuals will mitigate this risk.

Acknowledgment

As you start to walk on the way, the way appears.
Rumi (1207-1273)

Nothing in life happens by chance. All the people you meet, all the stories you hear and all the moments that make you stop and reflect can become one's tools in a journey you choose to travel on. Early in my education once my supervisor said, “enjoy your journey and make sure not to miss the "Serendipities" (not to miss unexpected discoveries while looking for something unrelated)”. I have stumbled upon many such discoveries, moments and encounters that have made me so heartily grateful, happy and motivated about my journey. It would not have been possible without my supervisor who followed me and guided me not to get lost. My deep appreciation goes to my outstanding main supervisor Professor **Elisabet Londos**. I will forever be grateful to you for everything you have done during my studies and all the opportunities and support you have given me to achieve my goals. You have always been available, engaged, interested and patient. Understood my strengths and confirmed me, saw my weaknesses and supported and encouraged me. I have felt your enthusiasm and confidence throughout my studies. You have let me grow into my role as a researcher. The best thing about my PhD studies, after everything I've learned, is having you as my supervisor. Thank you for all the great conversations, wise advice, kindness, understanding and guidance both in studies and in life.

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