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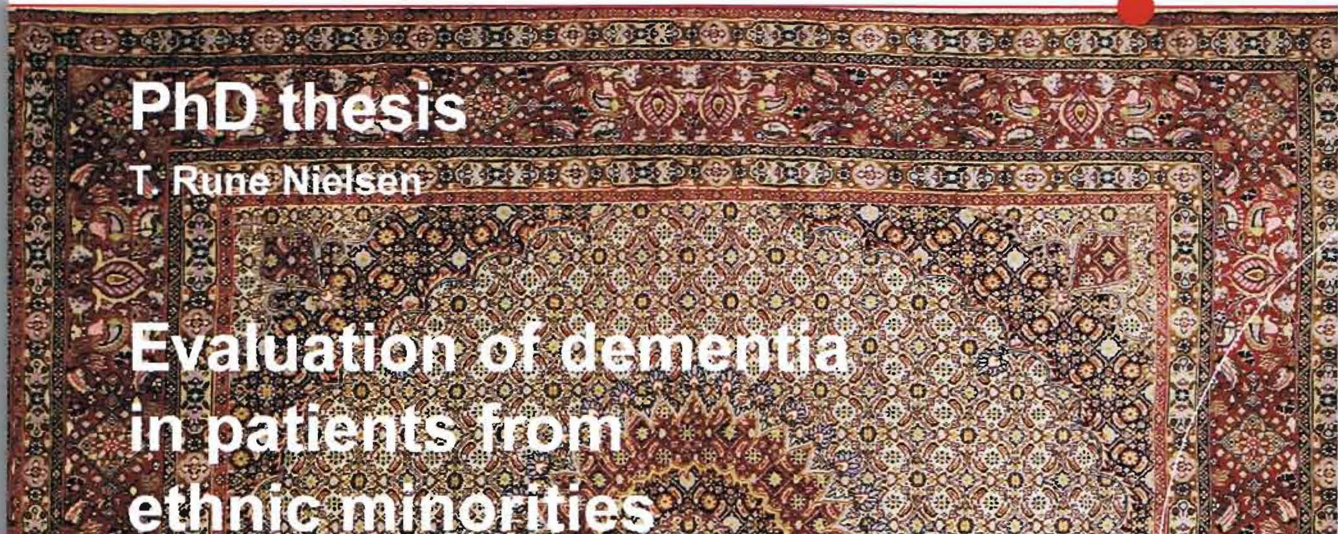

PhD thesis

T. Rune Nielsen

Evaluation of dementia in patients from ethnic minorities

A European perspective

Rigshospitalet

DANISH DEMENTIA RESEARCH CENTRE

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PREFACE

The present thesis is based on three and a half years (2007-2011) PhD study at the Department of Psychology, Faculty of Social Sciences, University of Copenhagen, Denmark. However, I had my office and performed all studies at the Danish Dementia Research Centre, Department of Neurology, The Neuroscience Centre, Copenhagen University Hospital, Rigshospitalet, Denmark. I am very grateful for the invaluable help I have received from my supervisors, my skilled colleagues and co-authors during my research. Without their contribution and support the study would not have been possible.

I am grateful to all the staff at the Danish Dementia Research Centre and the Memory Clinic, Rigshospitalet for the friendly atmosphere and the inspiring working environment. Most of all I am grateful to my supervisor, Gunhild Waldemar for believing in me from the very beginning, and for making my PhD study possible. Her knowledge, vision and contributions to the field of dementia are truly inspiring, and she has repeatedly managed to take my ideas to higher levels. I am also very appreciative for all the scientific inspiration provided to me by my supervisor Asmus Vogel. I am thankful for his valuable scientific feedback on my research project and my manuscripts, and for offering excellent help and advice with statistical analyses. Also, I am grateful to my supervisor Anders Gade for guiding me through life as a PhD student at the Department of Psychology, and for meticulous proof reading of my manuscripts. In addition, I appreciate the time Sarah E. Hvidberg used to proof read the thesis to improve the English language and grammar.

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The cognitive test study would not have been possible without my two Turkish and Kurdish speaking research assistants, Mustafa Olgun and Dilek Pinar Atici Secilmis. I am deeply grateful for their continuous enthusiasm and invaluable help in recruiting participants for this study, and for interpretation during interviews and testing. Also, our many pleasant conversations have been an invaluable source of information about Turkish and Kurdish history, culture and language. In the same spirit, I am thankful to all the elderly Turkish immigrants who participated in the study; they taught me so much through their diverse personal histories and descriptions of life as elderly immigrants in Denmark, and their test performances challenged my understanding of cognitive testing.

I am also grateful to Oliver Peters and his team for letting me visit the Memory Clinic at the Department of Old Age Psychiatry, Charité Universitätsmedicin Berlin, Germany, where I had a brief research visit in April 2011. Especially, I would like to thank Ulrike Beinhoff for her kind hospitality during my visit at the Memory Clinic and for taking time to discuss her work and plan a future publication.

I would like to express my gratitude to the Danish Council for Independent Research in the Humanities (FKK) for financing my PhD scholarship, and the Danish Health Insurance Foundation and the Ministry of Health for financial support to the Danish Dementia Research Centre.

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T. Rune Nielsen, Copenhagen, December 2011

SUMMARY

Symptoms of dementia are relatively invariant across ethnicities and races. Dementia is defined as a syndrome of acquired impairment in several cognitive domains, which must be of a severity to affect social and occupational functioning. However, evaluation of dementia in patients from ethnic minorities is associated with a wide range of challenges, including the lack of appropriate methods for cognitive testing. Although several biomarkers for Alzheimer's disease and other dementias have been developed, at the present time the use of biomarkers in the diagnostic evaluation is secondary to the clinical evaluation of cognitive impairment.

The need for evaluation of dementia in elderly ethnic minority populations is increasing in most European countries but research in the area is limited. There is no European consensus on good clinical practice with patients from ethnic minorities and it is unknown whether European countries are prepared for the increasing demand for assessment and care of these patient groups, who often have different needs and expectations to the dementia service.

In Europe, studies on clinical evaluation of dementia in ethnic minorities have not previously been undertaken outside the United Kingdom. This study from Copenhagen University and the Danish Dementia Research Centre applied several methods, including a survey questionnaire, register-based studies, and a cognitive test study.

The overarching aim of this study was to investigate the clinical practice for diagnostic evaluation of dementia in patients from ethnic minorities in Europe and to develop methods for cross-cultural assessment of cognitive dysfunction.

A survey in clinical centers of expertise of the European Alzheimer's Disease Consortium and two register-based studies using the Danish national hospital registers were used to investigate the clinical practice for diagnostic evaluation of dementia in patients from ethnic minorities in Europe. Our results indicate that European dementia clinics are not well-prepared for the increasing number of elderly patients from ethnic minorities, and that significant ethnic disparities exist in the quality of diagnostic evaluations of dementia. Problematic issues highlighted by the studies were the widespread use of family members for interpretation, and the general lack of suitable methods for cross-cultural assessment of cognitive dysfunction.

A cognitive test study was undertaken in 73 elderly cognitively healthy Turkish immigrants. We assessed the cross-cultural applicability of a range of cognitive tests, including the Rowland Universal Dementia Assessment Scale, the Recall of Pictures Test, the Clock Reading test, and Supermarket Fluency. We found the four tests suitable for cognitive testing of elderly Turkish immigrants and consider them to be important cognitive tests, when assessing dementia in elderly patients from ethnic minority migrant populations.

Although the elderly ethnic minority populations in Europe are relatively small, they should receive the best standard of care. It is important to improve diagnostic rate, diagnostic accuracy and appropriate follow-up for these patient groups to ensure them accurate diagnoses and proper treatment for their specific dementia disorders, especially considering the fact that these populations are expected to increase considerably during the next 20 years. Future studies should focus on the development of clinical guidelines for cross-cultural evaluation of dementia, and attempt to assess the discriminative validity of the four tests, and apply the tests in other ethnic minority populations.

DANSK RESUMÈ

Symptomer på demens er relativt ensartede på tværs af etnicitet og racer. Demens defineres som et syndrom med nytilkomne svigt inden for flere kognitive domæner, der har en sværhedsgrad som påvirker social og arbejdsmæssig funktionsevne. Udredning af demens i patienter fra etniske minoriteter er dog forbundet med en lang række udfordringer, herunder manglen på adækvate metoder til neuropsykologisk testning. Selvom adskillige biomarkører for Alzheimers sygdom og andre demenssygdomme er blevet udviklet, er biomarkører til diagnosticering af demens på nuværende tidspunkt sekundære til den kliniske udredning af kognitive svigt.

I de fleste europæiske lande er der et stigende behov for udredning af demens i populationer af ældre fra etniske minoriteter, men forskning inden for området er begrænset. Der findes ikke nogen europæisk konsensus om god klinisk praksis med patienter fra etniske minoriteter, og det er uvist om europæiske lande er forberedte på det stigende behov for vurdering og pleje af disse patientgrupper, som ofte har anderledes behov og forventninger til demensfaciliteter.

I Europa er studier af klinisk udredning af demens i etniske minoriteter ikke tidligere foretaget uden for Storbritannien. Dette studie fra Københavns Universitet og Nationalt Videnscenter for Demens benyttede en række metoder, herunder et spørgeskema survey, register-baserede studier og et kognitivt test studie.

Det overordnede formål med dette studie var at undersøge den kliniske praksis for udredning af demens i patienter fra etniske minoriteter i Europa, og at udvikle metoder til tværkulturel vurdering af kognitive svigt.

Den kliniske praksis for diagnosticering af demens i patienter fra etniske minioriteter i Europe blev undersøgt ved hjælp af et survey i kliniske ekspertisecentre i European Alzheimer's Disease Consortium og to register-baserede studier, som benyttede danske hospitalsregistre. Vores resultater antyder, at europæiske demensklinikker ikke er velforberedte på det stigende antal ældre patienter fra etniske minoriteter, og at der findes betydelige etniske uligheder i kvaliteten af den diagnostiske udredning af demens. Problematiske forhold, som blev fremhævet af studierne var den udbredte benyttelse af familiemedlemmer som tolke, og den generelle mangel på adækvate metoder til tværkulturel vurdering af kognitive svigt.

Et kognitivt test studie blev foretaget i 73 ældre kognitivt raske tyrkiske indvandrere. Vi vurderede den tværkulturelle anvendelighed en række kognitive tests, herunder Rowland Universal Dementia Assessment Scale, Recall of Pictures Test, Clock Reading test, og Supermarket Fluency. Vi fandt, at de fire tests var adækvate til kognitiv testning af ældre tyrkiske indvandrere og anser dem for at være vigtige kognitive tests, når man vurderer demens i ældre patienter fra etniske minoriteter.

Selv om populationerne af ældre etniske minoriteter i Europa er relativt små, bør den behandling de modtager være af den bedst mulige standard. Det er vigtigt at forøge diagnostisk frekvens, diagnostisk præcision, og adækvat opfølgning for disse patientgrupper for at sikre dem præcise diagnoser og korrekt behandling for deres specifikke demenssygdomme. Specielt i betragtning af, at disse populationer forventes at vokse markant i løbet af de næste 20 år. Fremtidige studier bør fokusere på at udvikle kliniske retningslinjer for tværkulturel udredning af demens, og forsøge at vurdere de fire tests diskriminative validitet, samt anvende dem i andre populationer af etniske minoriteter.

LIST OF PAPERS

The thesis is based on the following papers, referred to in the text by their Roman numerals:

I. **Nielsen TR**, Vogel A, Riepe MW, de Mendonca A, Rodriguez G, Nobili F, Gade A, Waldemar G. Assessment of dementia in ethnic minority patients in Europe: a European Alzheimer's Disease Consortium survey. *International Psychogeriatrics* 2011; 23: 86-95.

II. **Nielsen TR**, Vogel A, Phung TK, Gade A, Waldemar G. Over- and under-diagnosis of dementia in ethnic minorities: a nationwide register-based study. *International Journal of Geriatric Psychiatry* 2011; 26:1128-1135.

III. **Nielsen TR**, Andersen BB, Kastrup M, Phung TK, Waldemar G. Quality of diagnostic evaluation of dementia in patients from ethnic minorities: A nationwide study. *Dementia and Geriatric Cognitive Disorders* 2011; 31: 388-96.

IV. **Nielsen TR**, Vogel A, Gade A, Waldemar G. Cognitive testing in Turkish immigrants – comparison of RUDAS and the MMSE. *Submitted.*

V. **Nielsen TR**, Vogel A, Waldemar G. Comparison of performance on three neuropsychological tests in elderly Turkish immigrants and elderly ethnic Danes. *Submitted.*

In addition, aspects of dementia in ethnic minorities have been reviewed in:

VI. **Nielsen TR**, Waldemar G. [Dementia in ethnic minorities]. [Article in Danish] *Ugeskrift for Læger 2010;* 172:1527-31.

ABBREVIATIONS

AD	Alzheimer’s disease
ADL	Activities of daily living
ASASH	A Short Acculturation Scale for Hispanics
CDT	Clock Drawing Test
CPR	Unique national personal identification
CRT	Clock Reading Test
CSF	Cerebrospinal fluid
CT	Computed tomography
CTT	Color Trails Test
DCRS	Danish Civil Registration System
DLB	Dementia with Lewy bodies
DPCR	Danish Psychiatric Central Register
DSM-IV-TR	Diagnostic and Statistical Manual of Mental disorders, 4th Edition. Text Revision
EADC	European Alzheimer’s Disease Consortium
ECR	Enhanced Cued Recall
FDT	Five Digit Test
FTD	Frontotemporal dementia
GDS	Geriatric Depression Scale
IADL	Instrumental activities of daily living
ICD-10	International Classification for Diseases, 10th Revision
MMSE	Mini Mental State Examination
MRI	Magnetic resonance imaging
NIA-AA	National Institute of Aging and Alzheimer’s Association
NPR	National Patient Register
PET	Positron emission tomography
RPT	Recall of Pictures Test
RUDAS	Rowland Universal Dementia Assessment Scale
SD	Standard deviation
SF	Supermarket fluency
SES	Socioeconomic status
SPECT	Single-photon emission computed tomography
UK	United Kingdom
USA	United States of America
VaD	Vascular dementia

1. INTRODUCTION

In European countries, the proportion of the elderly in ethnic minority migrant populations is increasing. Consequently, dementia is gradually becoming a more important concern among these populations. In Denmark the number of non-Western immigrants aged 60 or more is expected to increase from approximately 25,000 in 2011 to 74,000 in 2030 and 115,000 in 2050 (Statistics Denmark, 2001).

During the last two decades, there has been an increasing interest in the study of ethnic differences in prevalence, assessment and care of dementia in multicultural countries such as the United States of America (USA) and the United Kingdom (UK). The need for evaluation of dementia in elderly ethnic minority populations is increasing in most European countries but research in the area is limited. There are no guidelines for clinical practice with patients from ethnic minorities and it is unknown whether European countries are prepared for the increasing demand for assessment and care of these patient groups, who often have different needs and expectations to the dementia service.

Dementia is defined as a syndrome of acquired impairment in several cognitive domains, which must be of a severity to affect social and occupational functioning. There are numerous different underlying disorders that may cause dementia. The most prevalent among these is Alzheimer’s disease (AD), which is thought to account for more than 60% of all cases (Berr et al., 2005). Other common dementia disorders include vascular dementia (VaD), dementia with Lewy bodies (DLB) and frontotemporal dementia (FTD). The criteria for dementia and AD have recently been revised by the National Institute of Aging and the Alzheimer’s Association (NIA-AA) (McKhann *et al.*, 2011). In the revised criteria, cognitive impairment remains the core criterion and this should be detected and diagnosed through a combination of history-taking from the patient and a knowledgeable informant and an objective cognitive assessment, preferably based on neuropsychological testing. At the present time the use of biomarkers (based on magnetic resonance imaging (MRI), positron emission tomography (PET) or cerebrospinal fluid (CSF) assays) in diagnostic evaluation of AD are secondary to the clinical evaluation of cognitive impairment. However, evidence from biomarkers increase the certainty that the basis of the clinical dementia syndrome is the AD pathophysiological process (McKhann *et al.*, 2011). Nevertheless, at the present time cognitive screening and neuropsychological testing are essential for the diagnostic evaluation of dementia.

Based on the clinical experience in the Memory Clinic at Rigshospitalet and on input from neuropsychological colleagues working with diagnostic evaluation of dementia, our impression was that patients from ethnic minorities were generally underrepresented in Danish dementia clinics. At the same time, clinical evaluations of referred patients from ethnic minorities were often associated with a wide range of challenges, including communication problems and a lack of appropriate methods for testing. There were no obvious answers to questions such as how to carry out the testing, which specific tests to use, and how to interpret the test results. Although symptoms of dementia are relatively invariant across ethnicities and races, cognitive testing may be difficult because the existing test instruments are affected by factors such as culture, language and education.

The aim of this Ph.D. project was to investigate the clinical practice for diagnostic evaluation of dementia in patients from ethnic minorities in Europe and to develop methods for cross-cultural assessment of cognitive dysfunction.

2. THEORETICAL AND EMPIRICAL BACKGROUND

Evaluation of dementia in patients from ethnic minorities has not previously been studied in continental Europe. The existing studies on diagnostic evaluation of dementia in ethnic minorities have primarily been conducted in the USA and to a lesser extent in the UK. Although this evidence may not readily be applied to other countries, the central themes highlighted by this research seem to be of general relevance to the situation of elderly ethnic minorities in Europe.

In this chapter, first the terminology and classification of ethnic minorities will be introduced and the composition of ethnic minorities in Europe and Denmark will be presented. Then the existing evidence from studies in the USA and the UK relating to evaluation of dementia in ethnic minorities will be reviewed, and challenging issues in clinical evaluation of ethnic minority patients, including cognitive testing will be discussed.

2.1. Terminology and classification of ethnic minorities

Various definitions of ethnicity are used in the research literature, and the terminology and classification regarding ethnic minorities are not generally agreed on internationally. Constructs of race, ethnicity and culture are all important facets of the terminology of ethnic minorities, and the terms are generally used interchangeably in the literature.

Race is a term implying genetic homogeneity, and racial distinctions are generally based on physiognomic features (eg. skin colour, hair type and colour, eye colour, and facial structure). The term race generally refers to broad groupings of people based on area of descent such as Asia, Europe, or Africa. However, the term gives little information about immigrant status or ethnic group (Harwood and Ownby, 2000).

The term *ethnicity* refers to a self-described identity of belonging to an ethnic group that may share geographical origins, culture, religious traditions and language (Helman, 2000). As people may view themselves differently at different times, the term is not a static concept. Thus, the concept of ethnicity can be problematic when investigating descendants of immigrants, as classification becomes less clear. People from ethnic minorities are also increasingly likely to marry someone from the majority population or another ethnic minority, which further complicates the construct of ethnicity. In medical research, ethnic minorities are typically classified according to self-perceived ethnicity or according to country of origin (Norredam *et al.*, 2011)

Culture represents an important component of ethnicity, and may be conceptualized as “a group’s way of life: the values, beliefs, traditions, symbols, language, and social organization that become meaningful to the group members” (Aranda and Knight, 1997). Culture can be regarded as a lens through which a person perceives and understands the world (Helman, 2000). Like ethnicity, culture is not a static concept. When immigrants settle in another country, their original culture will inevitably be influenced by the culture of the host country. The term *acculturation* refers to the complex “process whereby the attitudes and/or behaviors of persons from one culture are modified as a result of contact with a different culture” (dela Cruz *et al.*, 2000). Acculturation is a dynamic and multidimensional process that occurs in different paces and degrees in different individuals, reflecting intraethnic and intracultural differences (Berry, 1990). It is important to recognize that with regard to the constructs of race, ethnicity and culture no one definition is agreed upon internationally[1].

2.2. Ethnic minorities in Europe[2]

The pattern of immigration and the history of ethnic minorities are heterogeneous in European countries. Most ethnic minority populations in Europe are constituted by immigrants who arrived in the 20th century, and their descendants. Commonly, the countries of origin are former colonies of the British, French and Spanish empires. Depending on the definition used, approximately 22-29 million non-Western immigrants reside in Europe, or 3% to 4% out of a total population of approximately 728 million people. Populations of North African Arab and Berber minorities (approximately 5 million), primarily migrants from Morocco, are mainly found in southern European countries, but also in the Netherlands and Sweden. Populations of sub-Saharan African minorities (approximately 5 million) are mainly found in the UK and France, but smaller numbers are also found in the Netherlands, Germany, Italy, Portugal and other countries. Populations of Latin American minorities (approximately 2.2 million) are mainly found in Spain and to a lesser extent in Italy and the UK. Populations of Indian subcontinent minorities (approximately 3-4 million) are mainly found in the UK, but also reside in smaller numbers in Germany and France. However, with approximately 9 million people, the Turkish immigrant population constitutes the single largest ethnic minority in Europe (see Figure 1). Populations of Turkish minorities are mostly found in Germany, but considerable populations also reside in Bulgaria, France, and the UK. Although smaller in numbers, Turkish immigrants constitute the largest ethnic minority in several other European countries.

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[1] Because there is no international consensus regarding the terminology and classification of ethnic minorities, in the following review of studies on dementia in ethnic minorities, the terminology used in the original publications will be adopted.

[2] All numbers based on the article *Ethnic groups in Europe*, Wikipedia, the free encyclopedia. Localized 06.12.2011: http://en.wikipedia.org/wiki/Ethnic_groups_in_Europe#Ethnic_minorities_of_non-European_origin)

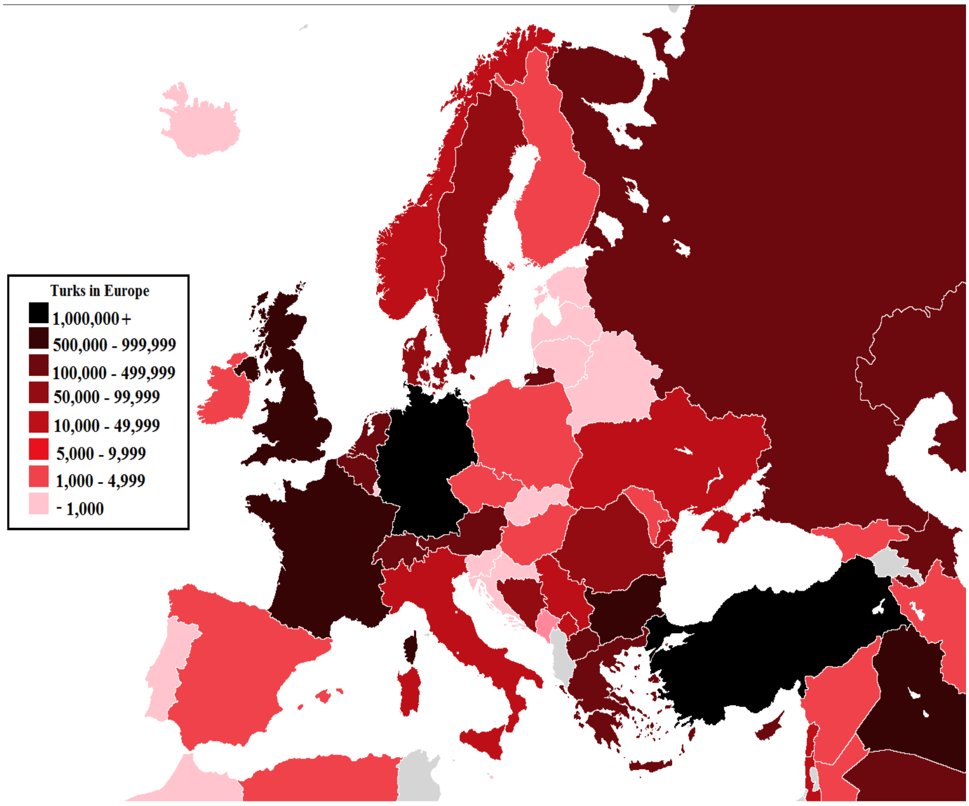

Figure 1. Distribution of Turks in Europe

Reproduced from http://en.wikipedia.org/wiki/Turks_in_Europe.

2.2.1. Ethnic minorities in Denmark

Denmark has traditionally been a culturally homogeneous country with the vast majority of the population consisting of white urban Protestants with a minimum of seven years of education from public schools. In 2011, approximately 380,000 non-Western immigrants[3] and descendants resided in Denmark, or 6.7% out of a total population of approximately 5.6 million people (extracted from Statistics Denmark, Statistics Bank, July 2011). Although there are no official estimates, the number of illegal immigrants in Denmark is generally considered to be very small. The Faroe Islands and Greenland are part of the Kingdom of Denmark, and close and continuous cooperation exist between the Danish government and Faroese and Greenlandic home rule governments. However, compared to the net immigration in Denmark, immigration from these countries has been limited. Similar to other countries in northern Europe, immigration from non-Western countries is a relatively new phenomenon in Denmark, and the majority of people from ethnic minorities are relatively young. Immigrants from Turkey form the largest ethnic minority in Denmark with a population of approximately 60,000 people, followed by immigrants from ex-Yugoslavia (including Bosnia-Herzegovina) with approximately 39,000 people, Iraq with approximately 30,000 people, Lebanon with approximately 24,000 people, and Pakistan with approximately 22,000 people (see Table 1). However, it is primarily among ex-

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[3] According to Statistics Denmark (Statistics Denmark, 2001), non-Western immigrants are immigrants or refugees from countries outside the extended EU, Canada, USA, Australia and New Zealand.

Yugoslavian, Turkish and Pakistani immigrants who came to Denmark as working migrants in the 60s and 70s that elderly persons aged 60 or more are found today.

Table 1. Non-Western immigrant populations in Denmark

	Total population			**Elderly population[†]**	
	Country of origin	***n***		**Country of origin**	***n***
1	Turkey	60,181	1	Ex-Yugoslavia[#]	4784
2	Ex-Yugoslavia[#]	38,962	2	Turkey	3683
3	Iraq	29,859	3	Pakistan	1983
4	Lebanon	24,196	4	Iraq	1260
5	Pakistan	21,507	5	Iran	1210
6	Somalia	17,070	6	Vietnam	1054
7	Iran	15,936	7	Morocco	784
8	Vietnam	14,228	8	Lebanon	740
9	Afghanistan	13,913	9	India	663
10	Sri Lanka	11,041	10	Sri Lanka	650
11	Philippines	10,228	11	Philippines	546
12	Thailand	10,230	12	Afghanistan	523
13	Morocco	10,131	13	Somalia	473
14	China	9767	14	China	469
15	India	7258	15	Thailand	420
	All non-Western immigrants	377,797		All non-Western immigrants	25,225

Non-Western immigrant populations in Denmark in 2011 ranked by size of total population (left column) and by size of elderly population (right column) (extracted from Statistics Denmark, Statistics Bank, July 2011).

[†] Population aged ≥ 60 years.

[#] Including Bosnia-Herzegovina.

2.3. Dementia in the elderly from ethnic minorities

2.3.1. Epidemiology

Epidemiological studies generally find similar age-adjusted rates of dementia in populations in different continents of the world (Daker-White *et al.*, 2002;Rodriguez *et al.*, 2008). However, the distribution of dementia subtypes may be different as some studies suggest that VaD may be more prevalent than AD in Asia (Graves *et al.*, 1994;Ikeda *et al.*, 2001). Most epidemiological studies of dementia in ethnic minorities originate from the USA, and focus has primarily been on African-American and Hispanic populations. In the UK, a number of studies have been performed in Black and South Asian populations.

The overall prevalence of dementia in Western populations is generally found to be between 5.4% and 6.4% of those aged 60 years and above (Ferri *et al.*, 2005;Lobo *et al.*, 2000). Research on the prevalence of dementia in ethnic minority populations in USA have indicated that older African-American and Hispanic people may be at increased risk of developing dementia (Demirovic *et al.*, 2003;Fitzpatrick *et al.*, 2004;Gurland *et al.*, 1999), with proportionally more vascular dementia in the African-American population compared to other ethnic groups (Adelman *et al.*, 2009;Harwood and Ownby, 2000). Higher rates of dementia have also been described in African Caribbean and South Asian populations in the UK (Adelman *et al.*, 2011;Livingston *et al.*, 2001;McCracken *et al.*, 1997) and a Turkish population in Denmark (Rosenbaum *et al.*, 2008). These findings have typically been speculated to be related to the greater prevalence of vascular risk factors that is typically found in these ethnic minorities (Adelman *et al.*, 2011;Harwood and Ownby, 2000;Livingston *et al.*, 2001;Mukadam *et al.*, 2011b;Rosenbaum *et al.*, 2008). Such vascular risk factors may be expected to increase the risk of both VaD and AD (Skoog, 2008). Overall, incidence studies from the USA are in accordance with the prevalence studies in showing a heightened risk of dementia in ethnic minority populations (Gurland *et al.*, 1999;Perkins *et al.*, 1997).

Some studies find the prevalence of dementia in ethnic minority groups to be more than twice that of White populations (Heyman *et al.*, 1991;Livingston *et al.*, 2001;Perkins *et al.*, 1997;Mukadam *et al.*, 2011b;Rosenbaum *et al.*, 2008;Demirovic *et al.*, 2003). However, caution should be taken when interpreting these results as the studies have generally used cognitive screening instruments of unknown cultural validity, and typically did not correct for differences in educational level, language proficiency and other social factors (Adelman *et al.*, 2011;Daker-White *et al.*, 2002). However, a more recent study from the UK that used a culturally sensitive screening instrument and adjusted for differences in age and socioeconomic status found a prevalence of dementia of 9.6% in elderly African-Caribbeans compared to 6.9% in elderly Whites (Adelman *et al.*, 2011). Factors that may contribute to the observed ethnic differences in the prevalence and incidence of dementia and dementia subtypes include different frequency of the apoliprotein E 4 allele, differences in vascular risk factors, differences in lifestyle related factors, and different explanatory models for the symptoms of dementia (Valle and Lee, 2002;Shadlen *et al.*, 2002).

Taken together, the epidemiological studies appear to suggest an elevated risk of dementia in the elderly from ethnic minorities compared with White populations. The factors responsible for these ethnic differences have still not been fully elucidated.

2.3.2. Utilization of dementia services

In spite of the higher prevalence of dementia in some ethnic minority groups, recent systematic reviews have found that patients from ethnic minorities and their caregivers are not utilizing dementia services to the same extent as others (Cooper *et al.*, 2010;Lampley-Dallas, 2002;Mukadam *et al.*, 2011b). Also, people with dementia from ethnic minorities tend to present to diagnostic services when their illness is more severe compared to people with dementia from the general population (Cooper *et al.*, 2010;Mukadam *et al.*, 2011b). The findings from studies in the USA and the UK are remarkably similar. The main difference in the findings from the USA and other countries is the issue of economic constraints. In contrast to most European countries, the USA does not have free access to healthcare.

A number of studies suggest that common barriers for seeking help for dementia among some ethnic minorities include stigma associated with mental disease, different models of caregiving with a strong familial responsibility, discrimination or the feeling that symptoms are dismissed by health care professionals, language barriers, lack of clarity about where and how to access help, and lack of knowledge about dementia and beliefs that nothing can be done to help (i.e. memory loss is a normal part of aging) (Hinton *et al.*, 2004;La Fontaine *et al.*, 2007;Zhan, 2004; Mahoney *et al.*, 2005;Elliott *et al.*, 1996;Lee *et al.*, 2010;Morhardt *et al.*, 2010;Dilworth-Anderson and Gibson, 2002;Liu *et al.*, 2008; Braun *et al.*, 1996; Lawrence *et al.*, 2008; Morhardt *et al.*, 2010; Neary and Mahoney, 2005;Purandare *et al.*, 2007).

Dementia caregivers from ethnic minorities generally report less burden than White caregivers, and a different model of caregiving (Janevic and Connell, 2001;Lawrence *et al.*, 2008). However, a systematic review contested previous assertions that caregivers from ethnic minorities have more intrafamilial support available, so that they need fewer services (Janevic and Connell, 2001).

Altogether, these barriers may explain why ethnic minorities are generally underrepresented in dementia diagnostic services and present to the services at a later stage in their illness.

To sum up, research in the USA and the UK has found a higher prevalence of dementia in some ethnic minorities compared to the general population. In spite of this, ethnic minority patients and their caregivers are not utilizing dementia services to the same extent as others.

2.4. Diagnostic evaluation of dementia in patients from ethnic minorities

According to the recommendations from evidence-based North American and European clinical guidelines for diagnosing dementia (Waldemar *et al.*, 2007;Knopman *et al.*, 2001), a basic dementia diagnostic work-up should include the following: a history of cognitive symptoms, cognitive testing, psychiatric evaluation, blood tests, computed tomography (CT) or MRI scan of the brain, physical examination, neurological examination, and assessment of activities of daily living (ADL). These investigations are all important to establish the diagnosis of dementia and exclude other causes of cognitive impairment. The commonly used diagnostic criteria from the International Classification for Diseases, 10th Revision (ICD-10) (World Health Organization, 1993) and the Diagnostic and Statistical Manual of Mental disorders, 4th edition – Text Revision (DSM-IV-TR) (American Psychiatric Association, 2000) are presented in Table 2.

Although development of efficient biomarkers for AD and other dementias is currently a strong research focus, for now, the diagnostic evaluation of dementia is largely a clinical discipline relying on verbal communication and observation of behaviors (Knopman *et al.*, 2001). However, clinical evaluation of elderly patients from ethnic minorities presents a wide range of challenges, which are related to cultural background, language and literacy skills (Lindesay, 1998;Uzzell, 2007;Ardila, 2005;Teng, 2002;Chandra *et al.*, 2001;Daker-White *et al.*, 2002).

In this section, first the effect of communication problems on the clinical interview will be described. Then, the impact of cultural differences on psychiatric evaluations and assessments of ADL will be presented. Finally, the existing literature on cultural, linguistic and educational influences of cognitive test performance will be reviewed.

Table 2. Diagnostic criteria for dementia

	ICD-10 criteria for dementia
G1.	Evidence of each of the following: (1) A decline in memory, which is most evident in the learning of new information. (2) A decline in other cognitive abilities characterized by deterioration in judgment and thinking, such as planning and organizing, and in the general processing of information. The severity of the decline, with mild impairment as the threshold for diagnosis, should be assessed as follows: Mild: The decline in cognitive abilities causes impaired performance in daily living, but not to a degree making the individual dependent on others. Moderate: The decline in cognitive abilities makes the individual unable to function without the assistance of another in daily living. Severe: The decline is characterized by complete inability to retain new information and an absence, or virtual absence, of intelligible ideation.
G2.	Preserved awareness of the environment during a period of time long enough to enable the unequivocal demonstration of G1.
G3.	A decline in emotional control or motivation, or a change in social behavior, manifest as at least one of the following: (1) Emotional lability (2) Irritability (3) Apathy (4) Coarsening of social behavior
G4.	For a confident clinical diagnosis, G1 should have been present for at least six months.

	DSM-IV-TR criteria for dementia
A	Development of multiple cognitive deficits that include both: (1) Memory impairment (impaired ability to learn new material, or recall previously learned material). (2) At least one of the following cognitive disturbances: a) Aphasia (deterioration of language function) b) Apraxia (i.e., impaired ability to execute motor activities despite intact motor abilities, sensory function, and comprehension of the required task) c) Agnosia (i.e., failure to recognize or identify objects despite intact sensory function) d) Disturbances in executive functioning (ability to think abstractly and to plan, initiate, sequence, monitor, and stop complex behavior).
B	The items in both Criterion A1 and Criterion A2 must be severe enough to: (1) Cause significant impairment in social or occupational functioning. (2) Represent a decline from a previous level of functioning.
C	The cognitive symptoms do not occur exclusively during the course of a delirium.
D	The condition is not better explained by another Axis I disorder (i.e. affective disorder, schizophrenia).

For both ICD-10 (World Health Organization, 1993) and DSM-IV-TR (American Psychiatric Association, 2000) criteria, it is required that all the criteria must be fulfilled to make a diagnosis of dementia. Both criteria stress that evidence of cognitive decline should be obtained when possible from interviewing an informant, supplemented, if possible, by neuropsychological tests or quantified objective assessments. Recently, revised criteria for dementia have been introduced by the National Institute of Aging and Alzheimer's Association (NIA-AA) (McKhann *et al.*, 2011). However, these revised criteria have not yet been implemented in clinical practice.

2.4.1. Clinical interview

Poor communication between clinicians, patients and caregivers from ethnic minorities may lead to poor expression and recognition of symptoms of cognitive impairment (Shah, 2007;Uzzell, 2007). A significant part of ethnic minority elders have little or no fluency in the language of the host country (Lindesay *et al.*, 1997a;Kritz *et al.*, 2000). Although many elderly immigrants have mastered the language of the host country earlier in life, many revert to their original mother tongue as they grow older and no longer need to speak the language of the host country at work (Shah, 2007). Also, bilingual dementia patients tend to have asymmetrical language impairment with preferential deterioration of the last acquired language (Mendez *et al.*, 1999). Therefore, ensuring good communication between clinicians, patients and caregivers from ethnic minorities is vital for the outcome of the clinical interview (Shah, 2007;Uzzell, 2007). This can be achieved through different methods. Ideally the clinician assessing the patient comes from the same culture as the patient. This would allow for direct ascertainment symptoms of cognitive impairment by a clinician with expertise in dementia and direct knowledge of the patient's culture (Shah, 2007). However, in clinical practice this is not always possible (Phelan and Parkman, 1995). Thus, interpretation services are often needed. Both professional and non-professional interpreters are used (Phelan and Parkman, 1995;Uzzell, 2007). Non-professional interpreters are usually family members but may also be non-clinical staff, and non-dementia clinical staff.

The inherent difficulties and limitations in using interpreters have been well described (Shah, 2007;Uzzell, 2007;Griffin-Pierce *et al.*, 2008). There may be difficulties in eliciting appropriate symptoms of cognitive impairment and dementia when non-professional interpreters are used because they lack formal training in interpretation, and may inaccurately interpret the content of questions and answers, may interpret their opinions rather than facts, and may be emotionally biased. Moreover, patients may be cautious in revealing signs and symptoms of cognitive impairment and dementia because they may not feel reassured about confidentiality. Although similar difficulties can occur with professional interpreters, they are generally less common (Phelan and Parkman, 1995).

The gender of the clinician and interpreter can also be important for the outcome of the clinical interview (Shah, 2007;Ardila, 2005). For example, women in some ethnic minorities (e.g. Pakistani women) may not feel comfortable disclosing personal details and clinical information to male clinicians or interpreters. Also, in the same female group, male interpreters may feel unable to interpret questions relating to certain sensitive issues.

Good communication between clinicians, patients and caregivers from ethnic minorities is not only vital for the process of the clinical interview but may also have consequences for the communication of information about treatments and services (Flores, 2005;Lindesay, 1998).

2.4.2. Psychiatric evaluation

Psychiatric disorders are common differential diagnoses to dementia. Therefore, in the clinical evaluation of dementia it is important to rule out that change in cognition, mood and behavior are not better explained by psychiatric disorders. Depression and anxiety may present with different clinical features in patients from ethnic minorities (Lindesay, 1998), which may make it even more difficult to differentiate between psychiatric disorders and dementia.

Emotional expression in different cultures can be influenced by several overlapping concepts: the context of disclosure, available vocabulary and language of emotional expression, selective expressions of emotion and definitions of self (Lindesay, 1998). For instance, the vocabulary and language required to express emotional symptoms are not equivalent and are variable in different cultures (Lindesay, 1998;Tseng, 2003;Abas *et al.*, 1998). Also, the styles of expressing biological and physical symptoms of affective disorders vary in different cultures (Lindesay, 1998;Livingston and Sembhi, 2003;Lindesay *et al.*, 1997a;Livingston *et al.*, 2002). People from Western cultures typically present with predominant symptoms of sadness and low mood during depression, whereas people from some non-Western cultures may present with pain and somatic symptoms (Lindesay, 1998).

Because different cultures experience and express affective disorders in different ways, the diagnostic procedures designed for the general population may not be applicable to patients from ethnic minorities. Although culture adjusted versions of commonly used screening instruments for depression in the elderly, such as the Geriatric Depression Scale (GDS) (Yesavage *et al.*, 1983) have been developed (Ertan and Eker, 2000;Broekman *et al.*, 2011;Mui, 1996;Ganguli *et al.*, 1999) and alternative cut-off values have been recommended for some ethnic minorities (Abas *et al.*, 1998), these are rarely used in Denmark.

In summary, psychiatric evaluation of patients from ethnic minorities may be challenging due to cultural differences in the expression and interpretation of mood and behavior. However, the impact of culture on the psychiatric evaluation may be influenced by the patients' level of acculturation.

2.4.3. Assessment of activities of daily living

The commonly used ICD-10 (World Health Organization, 1993) and DSM-IV-TR (American Psychiatric Association, 2000), and the recently revised NIA-AA (McKhann *et al.*, 2011) diagnostic criteria for dementia and AD include functional impairment in ADL as one of the requirements. However, members of different ethnic or cultural groups may have different thresholds for cognitive impairment to impact on ADL due to different expectations of its elderly members (Teng, 2002;Lindesay, 1998). For example, for an elderly White couple who live by themselves in a modern city, many complex skills are needed in their daily life, such as cooking, driving or using public transportation, banking, shopping, using the telephone, and operating a variety of appliances. Impairment in any of these skills may draw attention and cause concern. On the other hand, for elderly Turkish or Pakistani immigrants who live with their extended family, most of the chores of managing daily life are taken care of by the younger generations. Mild or even moderate deteriorations in cognitive abilities or social behaviour may be unnoticed (La Fontaine *et al.*, 2007;Ardila and Rosselli, 2007;Mahoney *et al.*, 2005;Zhan, 2004;Neary and Mahoney, 2005;Purandare *et al.*, 2007) or accepted as signs of normal aging (Lawton and Brody, 1969). Conversely, apparent deficits in the performance of ADL and instrumental activities of daily living (IADL), such as those measured by commonly used IADL scales (Lindesay, 1998), may simply reflect age- and gender specific norms for that ethnic group (Mukadam *et al.*, 2011a).

2.4.4. Cognitive testing

Performance on cognitive tests is one of the most important pieces of data considered in the clinical evaluation of dementia (World Health Organization, 1993;McKhann *et al.*, 2011;American Psychiatric Association, 2000). However, the vast majority of cognitive tests have not been properly validated for use with ethnic minorities (Manly, 2005;Shah, 2007;Pedraza and Mungas, 2008), and cognitive testing of elderly patients from ethnic minorities may be challenging as cognitive tests designed for dementia standardized in one ethnic group may not be appropriate for use in another. For instance, an elderly immigrant woman from a rural area in Turkey may excel at cooking, sewing, growing vegetables, tending farm animals, caring for children, and getting along with members of her extended family. All of these reflect good cognitive abilities, yet she is likely to score in the "impaired range" on commonly used cognitive screening instruments for dementia, such as the Mini Mental State Examination (MMSE) (Folstein *et al.*, 1975) or the Clock Drawing Test (CDT) (Shulman, 2000).

Studies comparing both healthy and clinical samples from different ethnic and cultural groups have found differences in performance on various neuropsychological tests and cognitive screening instruments (Sosa *et al.*, 2009;O'Rourke *et al.*, 1997;Murden *et al.*, 1991;Black *et al.*, 1999;Storey *et al.*, 2002;Manly *et al.*, 2002;Lucas *et al.*, 2005;Welsh *et al.*, 1995;Nell, 2000). The factors responsible for the divergence in performance between and within ethnic and cultural groups on cognitive tests have repeatedly been demonstrated to be related to cultural, linguistic and educational differences.

2.4.4.1. Culture

The basic cognitive processes are universal. However, cultural differences exist in the situations to which particular cognitive processes are applied. Culture prescribes what should be learned, and at what age, and by which gender. Consequently, different cultural environments lead to the development of different patterns of abilities (Ardila, 2007). Cognitive abilities usually measured in cognitive tests represents, at least in their content, learned abilities whose scores correlate with the subjects' learning opportunities and contextual experiences (Ardila, 1995).

Cultural influences have been described on a variety of cognitive abilities, including perceptual abilities, spatial abilities, memory, language, abstraction, and attention (Rosselli and Ardila, 2003;Nisbett and Miyamoto, 2005;Bernard, 1989;Masuda and Nisbett, 2001;Nisbett and Masuda, 2003;Ardila and Keating, 2007;Lim *et al.*, 2009;Ardila and Moreno, 2001;Ji *et al.*, 2004;Uzzell, 2007;Nell, 2000). For example, experimental studies have found individuals from East Asian cultures to be more attentive to contextual information and to prefer to rely on dialectical reasoning methods compared to individuals from Western cultures which have been found to be more attentive to focal objects and prefer to rely on logical reasoning methods (Nisbett and Masuda, 2003).

Also, culture dictates what is and what is not relevant and significant in a particular context or situation. A culture provides us with specific models for ways of thinking, acting and feeling (Ardila, 1995). Current cognitive testing uses specific conditions and strategies that may not only be unfamiliar to elderly people from ethnic minorities, but may also violate some accepted cultural norms (Ardila, 2005). In an analysis of the influence of culture on cognitive testing, the Colombian born neuropsychologist Alfredo Ardila has proposed that at least the following eight culture-dependent values underlie conventional cognitive testing (Ardila, 2007;Ardila, 2005): 1) *One-to-one relationship*. There is an examiner and an examinee. Usually no one else is allowed to be present, 2) *Background authority*. The examinee has to follow the instructions given by the examiner irrespective of the examiners personal characteristics relative to the examinee (e.g. age, gender, ethnicity, class or caste), 3) *Best performance*. It is assumed that the examinee will perform at best, 4) *Isolated environment*. Testing is often done in an isolated room with doors closed or even locked, 5) *Special type of communication*. The examiner and examinee do not maintain a normal everyday life conversation. The examiner uses a stereotyped language, repeating the same phrases over and over again in a rather formal language, and the examinees are not allowed to talk about themselves, 6) *Speed*. In many tasks the examiner warns that the examinee must perform "as fast as possible" and time may even be measured. For many cultural groups, speed tests are inappropriate (Rosselli and Ardila, 2003). Speed and quality may be contradictory, as good products are the results of a slow and careful process. Speed, competitiveness, and high productivity are important cultural values in literate Western societies, but this is not always the case in other cultural groups, 7) *Internal or subjective issues*. The examiner may ask questions that can be perceived as a violation of privacy. Questions about cognitive issues (e.g. how is your memory?) are also questions about internal subjective representations, the most personal private sphere, 8) *Use of specific test elements and strategies*. The examiner uses figures, blocks, pictures, etc. as part of the test materials. These elements may be unfamiliar to the examinee, or at least not equally familiar for examinees with different cultural backgrounds.

The specific elements used in cognitive testing may disadvantage elderly from ethnic minorities. Cognitive tests using the discrepancy between age and date of birth disadvantage ethnic minority elders born in rural areas with poor birth registration facilities, and those who may have altered age and date of birth to facilitate migration (Bhatnagar and Frank, 1997;McCracken *et al.*, 1997). Culture dependent elements are evident in many commonly used cognitive tests. For example, the Boston Naming Test (Kaplan *et al.*, 2001) includes naming a beaver, an acorn and a pretzel. These items are familiar to most Europeans and North Americans. However, they may be unfamiliar or virtually unknown to people who have migrated from a different geographical area. Culture specific questions about national royalty or political leaders may also disadvantage certain ethnic or cultural groups (Bhatnagar and Frank, 1997;McCracken *et al.*, 1997). Differing concepts of orientation in time and place in different cultures and preferential use of the Western or traditional calendar may also influence performance on cognitive tests (Lindesay *et al.*, 1997b;Ardila, 2007;Teng, 2002;Bhatnagar and Frank, 1997).

Many of the studies comparing cultural influences on cognitive abilities and cognitive testing have compared cultural groups in different countries. However, although elderly ethnic minority migrants grew up in another country, they have typically lived in the host country for a large part of their lives. Therefore they will to various degrees have acquired knowledge of the host culture and adopted some of the values, beliefs and practices of this culture. Acculturation has proven to be a statistically significant correlate of performance on a wide range of cognitive tests (Baird *et al.*, 2007).

To sum up, culture may affect both cognitive abilities and the skills required to solve the tasks typically presented in cognitive tests. However, the impact of culture on cognitive test performance in ethnic minorities may partly be related to the level of acculturation.

2.4.4.2. Language

As described in section 2.4.1., good communication between clinicians and patients from ethnic minorities is vital for the process of clinical evaluation of dementia. This may be even more crucial when performing cognitive testing. However, test instructions are often given in a formal language, which may be very difficult to understand for individuals with limited education (Ardila, 2007), and it is not uncommon that cognitive testing of patients from ethnic minorities takes place in the second, or even third, language, of the examinee. Lower skills in these languages can affect test performance (van de Vijver and Poortinga, 1997;Gasquoine *et al.*, 2007;Gollan *et al.*, 2007;Gollan *et al.*, 2002;Harris *et al.*, 1995;Rosselli *et al.*, 2002).

Often interpreters are used during cognitive testing. In these circumstances, problems appear when interpretation is not given verbatim to the examinee or to the examiner. The interpreter may feel the need to assist the examinee in making a response. When this happens, the true response of the examinee remains unknown and the test is invalid. Likewise, the interpreter may feel the need to simplify the examinee’s response in making an interpretation to the examiner, resulting in the elimination of critical information or missed information (Uzzell, 2007). Also, the validity of test norms from test instruments after being interpreted from one language to another language in a clinical situation is unknown (Uzzell, 2007). Even easy and accurate translation between two languages does not necessarily result in test items of comparable difficulty level. For example, reciting the months of the year is a much easier task in Chinese than in English or Danish, because in the Chinese language the twelve months are simply called “month one”, “month two”, “month three”, etc. (Teng, 2002).

Also, languages conceptualize the world in different ways (Ardila, 2007). For instance, language has been found to affect linguistic categories. In European languages, linguistic categories are typically formed by categorical-abstract principles, whereas concrete-situational principles for linguistic categories have been described in other languages (Nell, 2000;Nisbett and Masuda, 2003;Ji *et al.*, 2004;Uzzell, 2007). For example, when Chinese children were presented with drawings of a chicken, a cow, and a bundle of grass, they tended to group the cow and the bundle of grass because the cow eats grass (Nisbett and Masuda, 2003). Cross-cultural studies on linguistic categories have typically been performed in less educated or illiterate people in rural areas. The ability to form categorical-abstract categories may to a large extent be a school dependent skill.

Different languages differ in phonology, lexicon (semantic field of the words), grammar, pragmatic and reading system. These differences may affect cognitive test performance (Ardila, 2007). For example, when the Digit Span test (Wechsler, 1981) was administered to four groups of immigrants in the USA who spoke Chinese, English, Spanish and Vietnamese, respectively, the Chinese and the Vietnamese groups scored the highest and the Spanish group scored the lowest (Kempler *et al.*, 1998). These differences were attributed to the fact that digits from “1” to “9” are monosyllabic in Chinese and Vietnamese, only “7” has two syllables in English, but six of nine digits have two or three syllables in Spanish (Teng, 2002). In the same study, Vietnamese speakers produced significantly more animal names in animal fluency compared to Spanish speakers, which was attributed to the predominance of one-syllable animal names in Vietnamese and multi-syllable animal names in Spanish (Kempler *et al.*, 1998). It thus appears that test performance can be affected by the articulation time of words in different languages, a phenomenon that has been labelled the *word-length effect* (Ellis and Hennelly, 1980).

Effects of language have also been described on phonological verbal fluency tests. For example, phonological fluency is not possible in Chinese or Berber (the language spoken by most Moroccans) as there are no letter equivalent linguistic units in the Chinese language, and Berber is only a spoken language. The choice of letters may also affect the results in phonological fluency because of differences in letter difficulty and word frequency for each letter in different languages (Ardila, 2007;Oberg and Ramirez, 2006).

In summary, effects of language on cognitive testing are partly related to communication problems and the necessity of interpretation during assessment. However, idiosyncratic characteristics of different languages may also have a more direct impact on cognitive test performance.

2.4.4.3. Education

Education significantly influences cognitive test performance. Empirical findings have repeatedly shown that higher education is associated with better performance on most kinds of cognitive tests (Ardila *et al.*, 1989;Sosa *et al.*, 2009;Crum *et al.*, 1993;Rosselli *et al.*, 1990;Ostrosky-Solis *et al.*, 1998;Ostrosky-Solis *et al.*, 1999). Ethnic minorities in Europe generally have a lower socioeconomic status (SES) compared to the general population (Stronks *et al.*, 2001). Many older individuals from ethnic minorities have migrated from developing countries and have had little or no formal schooling (Teng, 2002). Illiteracy is frequently higher in women due to cultural attitudes found in some countries. This is more pronounced in elderly women, as it is generally easier and considered more important to attend school today than it was several decades ago (Ardila and Rosselli, 2007). In Denmark, nearly all of the Danish-born elderly have had seven or more years of formal schooling, and systematic knowledge of test performance in individuals with less than seven years of schooling is not available. This makes it extremely difficult to interpret test results from individuals with limited or no schooling, as less educated individuals are likely to perform like brain injured subjects on commonly used cognitive tests (Ardila, 1995).

It has been shown that the effect of education on cognitive test performance is not a linear one. Instead, it represents a negatively accelerated curve tending to a plateau (Ostrosky-Solis *et al.*, 1998;Liu *et al.*, 1994). Performance increases rapidly in the low education range of 0-4 years, less rapidly in the education range of 5-9 years and little further beyond 9 years of education. This excludes the possibility of extrapolating expected scores for individuals with limited or no schooling by regression of existing test norms. Also, the length, quality, and content of the school day and year vary considerably from country to country and even from school to school (Ardila *et al.*, 2010;Nell, 2000). It may not be fair to compare the educational level of someone who has completed nine years of education in a rural Koranic school in Pakistan with someone with an equivalent period of schooling in London or Copenhagen, or to compare the educational level of someone educated in a rundown inner city school with someone educated in a school in a resourceful suburban area. In many studies from the USA, oral word reading has emerged as a more powerful determinant of differences among ethnic groups on cognitive test performance than years of formal education. Oral word reading has been used as a proxy of literacy and educational quality in these studies (Manly *et al.*, 2002;Baird *et al.*, 2007;Manly *et al.*, 2005;Manly *et al.*, 2003).

Education not only imparts specific knowledge and skills, but also enhances information-processing proficiency and test taking skills in general (Teng, 2002;Ardila, 2007;Nell, 2000;Ardila and Rosselli, 2007). *Test-wiseness* refers to the examinee’s knowledge of how tests are designed, the expectations behind tests, and strategies for taking tests independent of the content the tests are designed to measure (Ardila *et al.*, 2010). Low scores on cognitive tests in illiterates can be due to differences in learning opportunities of those abilities tested (i.e. calculation, reading, writing), but also to the fact that illiterates are not test-wise; that is, they are not used to being tested, and may not know how to behave in a test situation (Ardila and Rosselli, 2007).

A recent literature review reported a significant schooling effect on cognitive test performance for different types of cognitive abilities (Ardila *et al.*, 2010). Although the impact of schooling on test performance is not uniform, there is converging evidence that illiterate subjects score drastically low on most of the tests used to assess global cognitive function, memory, language, executive functions, and visuospatial functions in the evaluation of dementia (Ardila *et al.*, 2010).

The MMSE (Folstein *et al.*, 1975) is one of the most widely used cognitive screening tests in dementia. However, the MMSE has been found to be biased against those who have limited or no education (Escobar *et al.*, 1986). Illiterates not only differ from schooled individuals on items related to writing and arithmetic, but also on several other items (Ostrosky-Solis *et al.*, 2000;Laks *et al.*, 2003;Brucki *et al.*, 2003;Liu *et al.*, 1994;Kucukdeveci *et al.*, 2005).

Illiterates generally perform more poorly than schooled literates on conventional neuropsychological memory tests, such as word list learning and recall, story learning and recall, verbal paired associates, and complex figure drawing (Ardila *et al.*, 1989;Folia and Kosmidis, 2003;Ostrosky-Solis *et al.*, 1998;Nitrini *et al.*, 2004;Ostrosky-Solis *et al.*, 2007;Reis and Castro-Caldas, 1997). These differences may partly be due to different memorization strategies used by schooled literates and illiterates to structure recall (Cole and Scribner, 1974).

Several studies have reported significantly lower scores on a variety of language tests in illiterates, including category fluency using the category “animals” and phonological fluency, which has proved to be extremely difficult for illiterates (Manly *et al.*, 1999;Kosmidis *et al.*, 2004;Reis and Castro-Caldas, 1997;Ostrosky-Solis *et al.*, 1999;Rosselli *et al.*, 1990). With increasing education, the number of items produced in verbal fluency tests progressively increases. Differences in naming abilities between literate and illiterate people have also been described. When schooled literates and illiterates were compared on a task of naming real objects, naming photographs of these objects, and naming drawings on them, illiterates performed poorly on naming photographs and even more poorly on naming drawings. In contrast, literates and illiterates performed similarly in naming real objects (Reis *et al.*, 2001;Reis *et al.*, 1994).

Difficultues performing executive tests have also been documented in illiterate individuals (Ostrosky-Solis *et al.*, 1998;Manly *et al.*, 1999;Ostrosky-Solis *et al.*, 1999). For instance, low scores in illiterates on the WAIS Similarities Test (Wechsler, 1981) have been documented in several studies, and as mentioned before, phonological fluency it is extremely sensitive to education.

Various studies have shown significant differences between schooled literates and illiterates in performing spatial and visuoperceptual tests (Rosselli and Ardila, 2003;Matute *et al.*, 2000;Ardila *et al.*, 1989). In particular, copying drawings have been emphasized (i.e. copying a cube, a house or Rey’s Complex Figure) to be difficult for illiterates. This is caused by difficulty in both manual control and by difficulty in perceptual analysis (sees Figure 2). Individuals who are inexperienced with using a pen or pencil tend to hold the instrument in an awkward manner and have trouble drawing straight lines toward intended directions. In addition, many illiterates are unable to interpret figures represented on a paper in three dimensions (i.e. a cube or a house). For individuals who have not studied geometry, these figures may appear to be a meaningless juxtaposition of line segments of two-dimensional shapes (Teng, 2002;Ardila *et al.*, 1989).

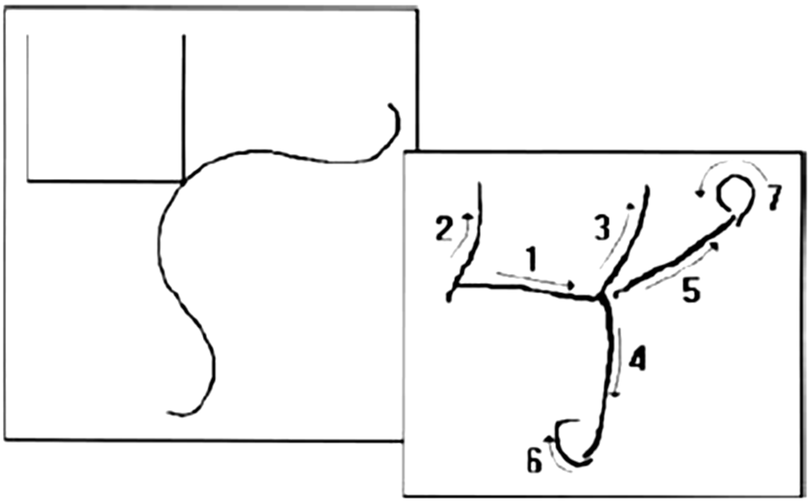

Figure 2. Example of an illiterate woman's copy of a Bender model

Numbers indicate the drawing sequence following the direction of the arrows. Reproduced from (Castro-Caldas, 2004).

Education has also been shown to be an important variable on a variety of motor performance tests. Illiterates demonstrate poorer performance in a diversity of motor tests, including reproducing movements (e.g. ideomotor praxis) and sequences of movements (e.g. Luria's fist-edge-palm test), alternating movements with both hands, and imitating meaningless movements (Rosselli *et al.*, 1990;Nitrini *et al.*, 2005;Ostrosky-Solis *et al.*, 1999;Ostrosky-Solis *et al.*, 1985). Differences in performance on tests requiring fine finger movements in illiterate and literate subjects may be due to the absence of training and practice in fine movements (particularly writing) (Ardila and Rosselli, 2007).

To summarize, less educated and illiterate individuals present significant difficulties in cognitive tests meant to assess different cognitive functions. The magnitude of the educational effect, however, is variable.

To sum up, the existing evidence suggests a higher prevalence of dementia in some ethnic minorities compared to the general population. In spite of this, patients from ethnic minorities and their caregivers have generally been found to be underrepresented in dementia diagnostic services and to present at a later stage in their illness. Further, clinical evaluations of dementia in patients from ethnic minorities have been found challenging due to issues related to cultural, linguistic and educational differences.

3. AIMS AND HYPOTHESES

The overarching aims of this study were to investigate the clinical practice for diagnostic evaluation of dementia in patients from ethnic minorities in Europe and to develop methods for cross-cultural assessment of cognitive dysfunction.

It was hypothesized that a) elderly patients with dementia from ethnic minorities are underrepresented in European dementia clinics, b) that evaluation of dementia in patients from ethnic minorities is associated with a wide range of challenges, including the lack of appropriate methods for cognitive testing, and c) that it is possible to develop valid methods for cross-cultural cognitive testing.

4. METHODOLOGICAL CONSIDERATIONS

Several different methods were applied in this study, including a survey questionnaire, register-based studies, and a cognitive test study.

In this chapter, first the European Alzheimer's Disease Consortium and the Danish national registers will be introduced as resources to investigate the clinical practise for diagnostic evaluation of dementia in patients from ethnic minorities in Europe. This will be followed by a description of a neuropsychological test battery developed for cross-cultural assessment of cognitive dysfunction, and a description of the procedures used to recruit elderly Turkish immigrants for the cognitive test study.

4.1. The European Alzheimer's Disease Consortium as a platform for surveys

As assessment of dementia in ethnic minorities in Europe was an overall undescribed area at the time of this study, in Study I we conducted a survey in clinical centers of expertise of the European Alzheimer's Disease Consortium (EADC) to get an impression of the current status and practice in the field. A questionnaire on the clinical assessment of dementia in patients from ethnic minorities and the perceived challenges of solving this task was mailed to a leading dementia expert in each of the EADC centers. Planning and implementation of the survey followed general guidelines for questionnaire methods (Stone, 1993). Careful consideration was taken in the design of the questionnaire, including question content, phrasing and response format, and question sequence and layout. Piloting of the questionnaire was performed prior to the survey.

At present, the EADC is a network of more than 50 European centers of excellence in 19 European countries specializing in Alzheimer's disease. The development of EADC was funded by the European Union with the purpose of defining operational standards of excellence for the diagnosis and treatment of patients with cognitive and behavioral disturbances. Surveys in the EADC have previously been used to investigate aspects of clinical practice in European dementia centers (Paulino Ramirez *et al.*, 2005).

An apparent advantage of using the EADC for surveys is that it is possible to reach clinical dementia experts across Europe in a relatively short time and at low costs. On the other hand, a limitation of the questionnaire method is that data is based on the subjective perceptions of the respondents. This may lead to over- or under-estimations in the responses. Also, as respondents were not anonymous in this survey, it is possible that some results reflect that respondents wanted to demonstrate a high quality of care for patients from ethnic minorities that were in accordance with international standards (see section 5.1.3.). Another limitation is that the sample may not be representative, because only dementia experts from the EADC were queried. The questionnaires were not mailed to a random selection of clinical dementia centers in European countries. However, we believed that the descriptions of experts from leading dementia centers in Europe could give a valid impression of the status and practice of assessment of dementia in ethnic minorities in Europe.

To further investigate some of the issues highlighted by the survey, we conducted two studies using the Danish national registers.

4.2. The Danish national registers as a unique resource for nationwide studies on dementia in ethnic minorities

In study II, the Danish national registers were used to investigate the diagnostic rate of dementia in the main ethnic minorities in Denmark, and in study III, the quality of clinical dementia diagnoses in patients from the same population was evaluated by review of medical records (see Figure 3). In both studies, the results were compared to previously published data for the general Danish population (Phung *et al.*, 2009;Phung *et al.*, 2010a).

Denmark has a long and exceptional tradition for developing nationwide registers based on unique national personal identification numbers (CPR) through which an individual can be precisely identified. The registers have existed for more than three decades and have recorded extensive data about individual socioeconomic, demographic, and health factors. The CPR makes it possible to precisely and efficiently link data from different registers to facilitate studies about multiple risk factors, the effect of treatment, and the use of resources (Phung, 2008). The registers used in this study were the Danish Civil Registration System (DCRS) (Pedersen *et al.*, 2006), the National Patient Register (NPR) (Andersen *et al.*, 1999), and the Danish Psychiatric Central Register (DPCR) (Munk-Jorgensen and Mortensen, 1997).

The Danish registers have previously been used in studies on dementia and ethnic minority health. A series of papers have been published on the association between mood disorders and dementia (Kessing *et al.*, 2009;Kessing *et al.*, 2008;Korner *et al.*, 2008;Korner *et al.*, 2009), and on epidemiological aspects of dementia (Phung *et al.*, 2007;Phung *et al.*, 2010a;Phung *et al.*, 2009;Phung *et al.*, 2010b). Register-based studies on migration, ethnicity, and health have primarily focused on cancer (Norredam *et al.*, 2007;Norredam *et al.*, 2008), mental disorders (Norredam *et al.*, 2009;Norredam *et al.*, 2010a;Norredam *et al.*, 2010b), healthcare contacts (Norredam *et al.*, 2004), injuries in children (Laursen and Moller, 2009), and reproductive health (Villadsen *et al.*, 2009). Dementia in ethnic minorities has not previously been the focus of register-based research.

Register-based studies require rather little human resources, time, and finance. Therefore, the Danish registers represent a unique resource to study the diagnostic rate of dementia and the quality of clinical dementia diagnoses in ethnic minorities on a national scale. However, there are certain limitations to register-based studies. Data in the national registers is collected primarily for administrative purposes. Therefore, before embarking on a study it should be considered carefully whether the register-based data concerning the risk factor and the outcome are valid and suitable to study the association in question (Phung, 2008). For example, data on education has proven to be problematic in immigrants as data on education from the country of origin is poorly registered in the DCRS. Individuals with no available information on education are pooled with individuals with no education, and education completed in Denmark replaces data on education from the country of origin irrespective of the previous educational level. Also, there is great variation in the validity of registered medical diagnoses (Phung, 2008). However, in a previous study it was found that diagnoses of dementia and AD among elderly in the Danish hospital registers have good validity with positive predictive values of 86% and 81%, respectively (Phung *et al*., 2007).

The national hospital registers do not routinely contain information on ethnicity. To obtain information on ethnicity it is therefore necessary to link these registers with the DCRS. Objective definitions of ethnicity in register-based studies are usually based on data about own and/or parents' country of birth and date of arrival to Denmark. This makes it possible to differentiate between immigrants and descendants (Norredam *et al.*, 2011). However, this definition is just a rough proxy of the complex concept of ethnicity. As described in section 2.1., another way of conceptualizing ethnicity is by self-perceived ethnicity. However, such data are not included in the DCRS or the Danish hospital registers.

A general problem with register-based studies in ethnic minorities is the limited number of migrants, which make sub-classifications difficult. It is often necessary to analyze heterogeneous groups of migrants together, although they present different cultural backgrounds (Norredam 2011). On the other hand, the register-based design allows a sampling of all cases on a national scale. The results from register-based studies in ethnic minorities are not estimates based on a sub-sample of a larger population.

4.3. Development of methods for cross-cultural assessment of cognitive dysfunction

In this study, a pragmatic stance was taken to the development of methods for cross-cultural assessment of cognitive dysfunction. For our purposes, the methods should be applicable to elderly ethnic minorities living in larger cities in Europe. As the Turkish minority is the largest single ethnic minority in Denmark, and in Europe (see section 2.2.), we chose to focus on this ethnic minority group. However, the aim was to develop a brief neuropsychological test battery with potential applicability across diverse ethnic minority groups as we recognized that designing unique tests for every ethnic minority group in Europe would not only be too costly, but also hamper cross-cultural comparisons.

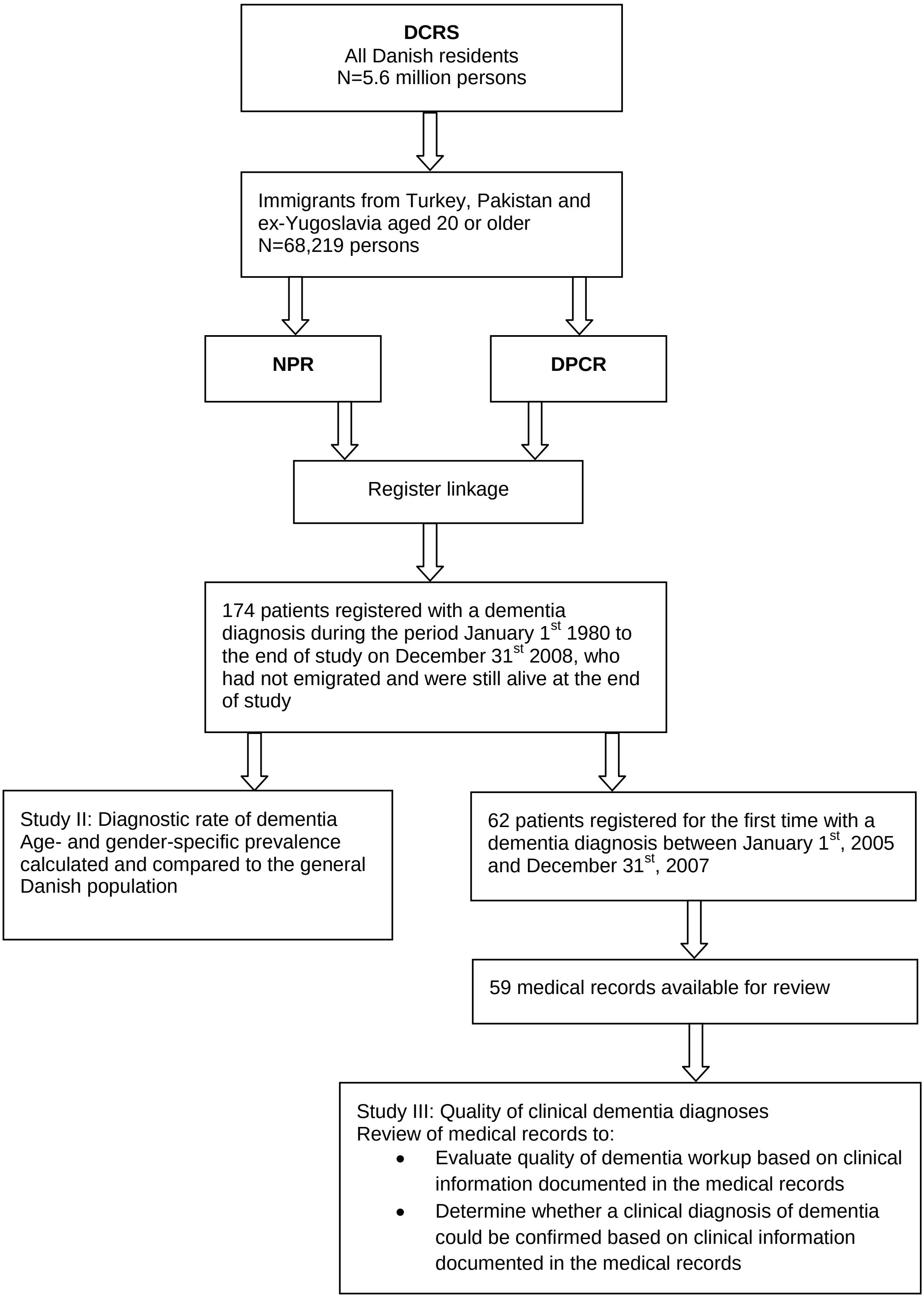

Figure 3. Flow-chart for study population in studies II and III

DCRS: Danish Civil Registration System, NPR: National Patient Register, DPCR: Danish Psychiatric Central Register.

Our goal was to compile a battery of tests that could accurately a) characterize the primary manifestations of AD in ethnic minority patients, b) discriminate between cognitive changes associated with normal aging and those seen in dementia, and 3) measure progression of cognitive impairment.

4.3.1. Neuropsychological test battery

Several guidelines governed the compilation of the neuropsychological test battery. First, to minimize administration time the battery was limited to 14 short tests. Second, to facilitate comparisons between the wealth of existing data on Western populations and the performance of ethnic minorities, five well established tests were included in the test battery. Thirdly, it was sought to reduce the effect of illiteracy or low education on performance. To achieve this, we primarily included tests using oral rather than printed instructions, required oral or nonverbal responses rather than written answers, and presented pictorial rather than verbal stimulus information. Fourthly, as many ethnic minority families do not seek help until late in the course of dementia (see section 2.3.2.), tests which can be performed by persons with moderate to severe impairment were included. Finally, to obtain valid data, it was emphasized that the test battery should be administered in the examinees' primary language. For examinees whose primary language was not Danish, the test battery should be administered with the help of an interpreter trained for the purpose. Therefore, a requirement of the included tests was that they with relative ease could be administered with an interpreter.

Potential tests for the battery were identified through a comprehensive literature review. The literature identified through the review can be broadly grouped into three general areas: 1) Norm development – development of norms for cognitive tests in different ethnic groups; 2) Modification of existing tests – translation and adaption of existing instruments for different linguistic, cultural and educational groups; 3) *De novo* test construction – construction of new tests specifically designed for cross-cultural purposes. Appropriate instruments were selected from the pool of tests generated from the literature review. Five tests which did not violate the guidelines were Enhanced Cued Recall, Supermarket fluency, the Color Trails Test, serial threes, and the Clock Reading Test. The five well established instruments included in the battery were Animal Fluency, Digit Span, the Clock Drawing Test, and copying of simple figures (Greek cross, four-pointed star). To supplement these tests, the Recall of Pictures Test and a simplified version of the Rey Complex Figure were developed. In addition to the 12 measures of specific cognitive abilities, a translated and adapted Turkish MMSE, and the Rowland Universal Dementia Assessment Scale were included as global measures of cognitive functioning. The neuropsychological test battery taps five cognitive domains: Global cognitive function, memory, language, executive functions, and visuospatial functions. The 14 tests comprising the neuropsychological test battery are listed in Table 3 according to the cognitive domain being assessed.

Table 3. Neuropsychological test battery

Test	Primary reference
Global cognitive function	
Mini Mental State Examination[†]	(Folstein *et al.*, 1975)
Rowland Universal Dementia Assessment Scale[†]	(Storey *et al.*, 2004)
Memory	
Recall of Pictures Test[#]	Developed for this study
Enhanced Cued Recall	(Solomon *et al.*, 1998)
Recall of simplified Rey figure	Developed for this study
Language	
Animal fluency	(Strauss *et al.*, 2006)
Supermarket fluency[#]	(Strauss *et al.*, 2006)
Executive functions	
Digit Span[‡]	(Wechsler, 1981)
Color Trails Test	(D'Elia *et al.*, 1996)
Five Digit Test	(Sedó, 2007)
Serial threes	(Ostrosky-Solis *et al.*, 1999)
Visuospatial functions	
Copying of simple figures (Greek cross, four-pointed star)	(Lezak *et al.*, 2004)
Copying of simplified Rey figure	Developed for this study
Clock Drawing Test	(Shulman, 2000)
Clock Reading Test[#]	(Schmidtke and Olbrich, 2007)

[†] Test included in study IV.

[#] Test included in study V.

[‡] Pilot testing revealed Digit Span to be too difficult to administer with an interpreter. As a consequence, Digit Span was excluded from the test battery.

It should be noted that many of the tests measure several cognitive domains (e.g. animal fluency can be considered a measure of language as well as of executive functions).

Descriptions of the five well-established tests in the neuropsychological test battery can be found in their primary references. The eight tests identified through the literature review and the tests developed for this study are described in the following.

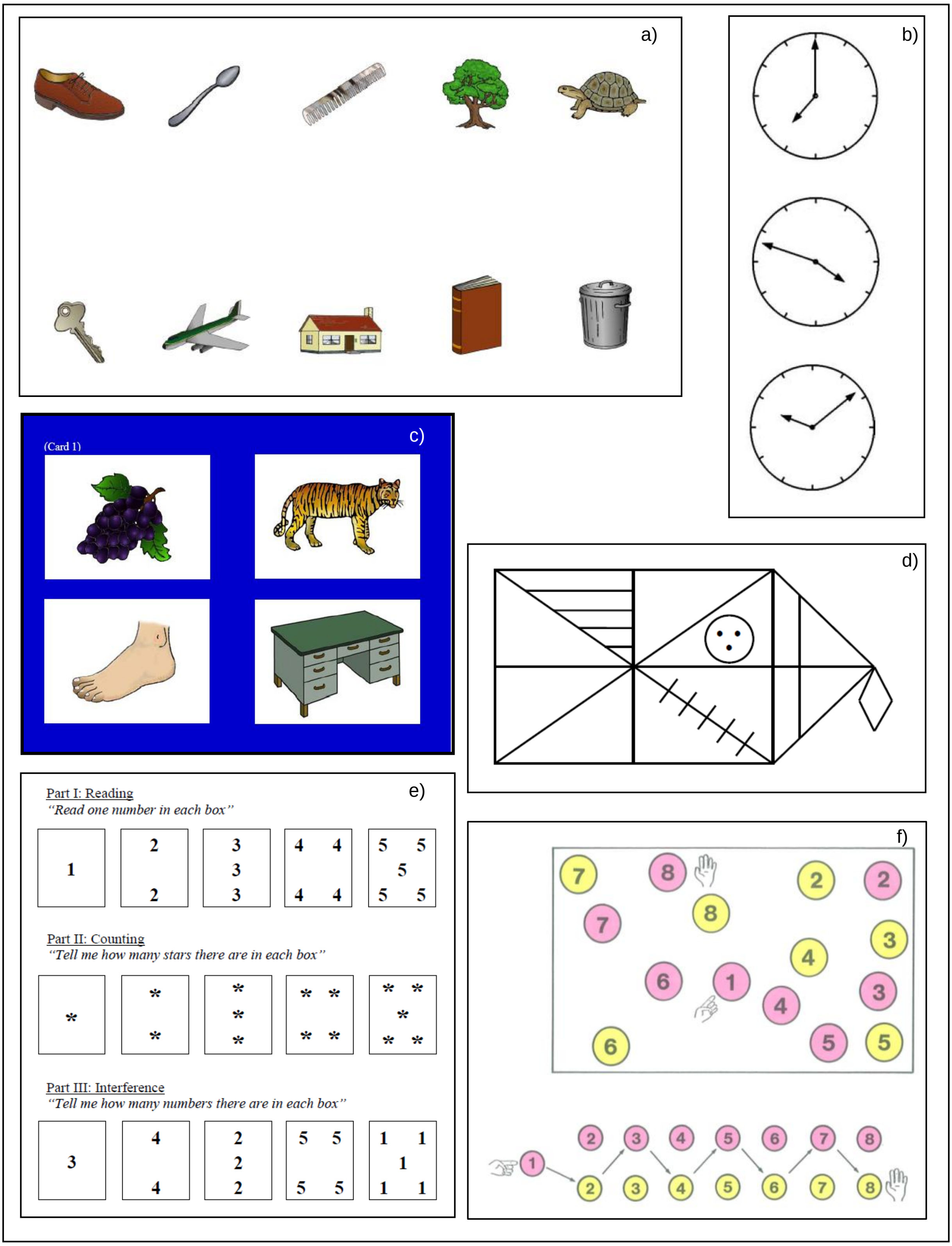

Figure 4. Examples of stimulus materials

Examples of stimulus materials for tests included in the neuropsychological test battery; a) stimulus material for the RPT immediate recall; b) example of clock faces from the CRT; c) Stimulus card I of the ECR; d) stimulus for copy of simplified Rey figure; e) example of stimulus material for part I-III of the FDT (all parts should be read 1, 2, 3, 4, 5); f) test trial from Color Trails 2 with nonverbal instruction below the test stimulus.

Global cognitive functioning was assessed with the *Rowland Universal Dementia Assessment Scale* (RUDAS) (Storey *et al.*, 2004). The RUDAS is a brief cognitive screening test that has been developed for multicultural populations. It contains six items that assess body orientation, praxis, drawing, judgment, memory, and language. Like the MMSE it has 30 points, is portable, easy to administer, and takes about 10 minutes to complete. It has been translated into more than 30 languages without need to change the content (Storey *et al.*, 2004), and it is claimed to be culturally and educationally fair. The original study reports a sensitivity of 89% and specificity of 98% for detecting dementia in a multicultural sample in Australia (Storey *et al.*, 2004).

Evaluation of memory was performed with three memory tests, of which the two were developed for this study.

The *Recall of Pictures Test* (RPT) was developed to assess immediate and delayed recall. The test is similar to a word list learning test. But instead of learning and recalling a word list, examinees are required to learn and recall 10 pictures. The test is similar to a test of delayed recall of 10 simple objects from the Brief Cognitive Screening Battery (Nitrini *et al.*, 2004). However, instead of presenting black and white line drawings we used the colorized Snodgrass and Vanderwart pictures (Rossion and Pourtois, 2004), as it has been suggested that introducing color information can improve the recognition of pictures in illiterate and less schooled individuals (Reis *et al.*, 2001) (see Figure 4). The test of delayed recall of 10 simple objects from the Brief Cognitive Screening Battery was found to be unaffected by illiteracy in a Brazilian study (Nitrini *et al.*, 2004).

In *Enhanced Cued Recall* (ECR) 16 pictures presented four at a time on four individual cards have to be recalled shortly after presentation, and a semantic cue is given for those pictures that are not freely recalled. The test is part of the Seven Minute Screen, developed for the detection of AD (Solomon *et al.*, 1998). We used slightly modified versions of the original tests in which the colorized Snodgrass and Vanderwart pictures (Rossion and Pourtois, 2004) had replaced the original black and white line drawings. Comparable performance data have been reported for the ECR in samples of various educational and national backgrounds (Saka *et al.*, 2006;Solomon *et al.*, 1998;Del *et al.*, 2006;Meulen *et al.*, 2004;Skjerve *et al.*, 2007;Sungkarat *et al.*, 2011;Tsolaki *et al.*, 2002;Drake *et al.*, 2003;de Jager *et al.*, 2008;Ijuin *et al.*, 2008).

For evaluation of nonverbal memory, we developed a *simplified Rey figure.* The figure is similar to the Rey Complex Figure (Meyers and Meyers, 1995), but has only 22 points to make it more suitable for less educated examinees (see Figure 4). A similar approach has been described in development of the NEUROPSI cognitive test battery for less educated Mexican populations (Ostrosky-Solis *et al.*, 1999).

Language function was evaluated with semantic verbal fluency. *Supermarket fluency* (SF) is similar to other semantic verbal fluency tests. Examinees are required to generate as many different “things you can buy in a supermarket” as possible within a one-minute interval. Compared to the commonly used “animal” category, the supermarket category has been found to be more ecologically relevant for illiterate examinees (da Silva *et al.*, 2004).

Aspects of executive functions were evaluated with two culturally and ecologically modified versions of well-established tests.

The *Color Trails Test* (CCT) is a non-alphabetical parallel form of the Trail Making Test (Reitan, 1955) that has been developed for use in cross-cultural populations. An advantage of the CTT is that it is not necessary to use any specific language in its administration and scoring (D'Elia *et al.*, 1996). The test has two parts. In Color Trails 1, examinees are required to connect numbered circles in sequential order. In Color Trails 2, examinees are required to switch between the colors while connecting circles in an ascending sequence (i.e. red 1, yellow 2, red 3, yellow 4 and so on) (see Figure 4).

The *Five Digit Test* (FDT) (Sedó, 2007) was developed to provide a relatively culture-fair means of assessing response inhibition and mental flexibility. Modelled after the Stroop Color and Word Test (Golden, 1978), but designed to minimize the need of reading ability, the FTD can be administered to individuals with minimal literacy skills or whose primary language differs from that of the examiner. The test is comprised of asterisks and numbers (1-5) arranged in the visual array of playing cards (see Figure 4). Examinees are exposed to three conditions as they name a series of 50 digits, count a series of 50 asterisks, and count a series of 50 digits where the numeric value of the digits is incongruent with the number of digits (e.g. two 5's, three 4's, five 1's, etc.). A fourth condition where examinees have to switch between counting and naming incongruent digits as visually cued was not included in this study.

Serial threes is a simpler version of the serial sevens subtest of the MMSE. Examinees are required to count down from twenty by threes. Serial threes is included in the NEUROPSI cognitive test battery for less educated Mexican populations (Ostrosky-Solis *et al.*, 1999).

Visuospatial functions were evaluated with the *Clock Reading Test* (CRT) (Schmidtke and Olbrich, 2007). In the CRT, examinees are required to read the time on a series of 12 clocks showing different times (see Figure 4). In this study, we used a slightly modified version of the original CRT, in which each clock face was presented on a separate page in a small booklet instead of being arranged in three lines on one sheet of paper. In contrast to commonly used tests of visuospatial function (i.e. clock drawing and figure copying tests) the CRT is a pure perceptual task that does not require visuoconstructional abilities. The authors have proposed the test to be independent of cultural, language and education bias (Schmidtke and Olbrich, 2007).

After compilation of the neuropsychological test battery, elderly Turkish immigrants were recruited for the cognitive test study to investigate the cross-cultural applicability of the tests.

4.3.2. Recruiting elderly Turkish immigrants for dementia research

The choice of our focus on Turkish immigrants was mainly pragmatic. It was based on the fact that this group is the largest immigrant group in Denmark, has a large elderly population compared to other immigrant groups, and has a long history of residence in the country (see section 2.2.1.). The focus on a single immigrant group was chosen both for practical reasons and as an effort to control the influence of diverse cultural and linguistic factors on test performance.

Approximately two thirds of the Turkish immigrants in Denmark are of Kurdish ethnicity. The vast majority originate from the Konya area in the central Anatolia region of Turkey. For historical and political reasons the Konya area has a large Kurdish minority that is relatively integrated in Turkish culture. Most ethnic Kurds from the Konya area speak Turkish (either as a first or second language), and if literate, this will usually be in the Turkish language. However, illiteracy is widespread among elderly Turkish immigrants, especially among women. In the Turkish immigrant community in Denmark the common language is generally Turkish, irrespective of ethnic background.

Our aim was to include 100 cognitively healthy elderly Turkish minority participants in the study. To attain this goal, we obtained addresses on a random sample of 500 elderly community dwelling Turkish minority subjects (50 men and 50 women in each of the age groups 50-54 years, 55- 59 years, 60-64 years, 65-69 years, and 70 years or older) from the DCRS according to the following criteria: the subject was an immigrant from Turkey, had lived in Denmark for a minimum of 10 years, was 50 years or older, had a current address in the greater Copenhagen area, and was not registered with a dementia diagnosis in the national hospital registers (see Figure 5). Supplemental inclusion and exclusion criteria were later checked by a structured interview (please refer to the Methods section in paper IV for a detailed description of the inclusion and exclusion criteria). The age limit of 50 years can be regarded as rather low in the context of dementia. However, we chose to include participants from this age based on our clinical impression that patients with ethnic minority backgrounds referred to the Memory Clinic at Rigshospitalet are often in their 50s.

Challenges recruiting and retaining ethnic minority participants in dementia research have been described in several studies (Connell *et al.*, 2001;Eaves, 1999;Olin *et al.*, 2002). These challenges include identifying potential ethnic minority participants, logistic issues in terms of the need for stipends and arrangement of transportation, and linguistic and cultural barriers when the researcher is not culturally connected to the targeted ethnic community. Therefore, we tried to take various precautionary measures to increase the response rate. These measures included employment of trilingual (Danish, Turkish and Kurdish) research assistants, translation of instruments and letters into Turkish, multiple contact attempts by telephone, and application of oral interviews as opposed to questionnaires. Also, participants were visited at home or could chose another location if they preferred that, and all visits were planned outside the periods of Summer Holidays, Ramadan and Christmas. In spite of these precautions the participation rate was low (see Figure 5).

Difficulties in contacting and recruiting older Turkish immigrants for mental health related research have previously been reported (Ertan *et al.*, 1999). In line with the reports of Ertan and coworkers, the impression from our contacts with potential participants was that the main reasons for declining participation were lack of familiarity with participation in research in the Turkish community, risk of social stigma of being considered “mad” if visited and tested by a psychologist, and suspicion that the data could be used by the state or others for non-research purposes. In contrast to the reports of Ertan and coworkers, we did not encounter any problems in having participants sign consent forms.

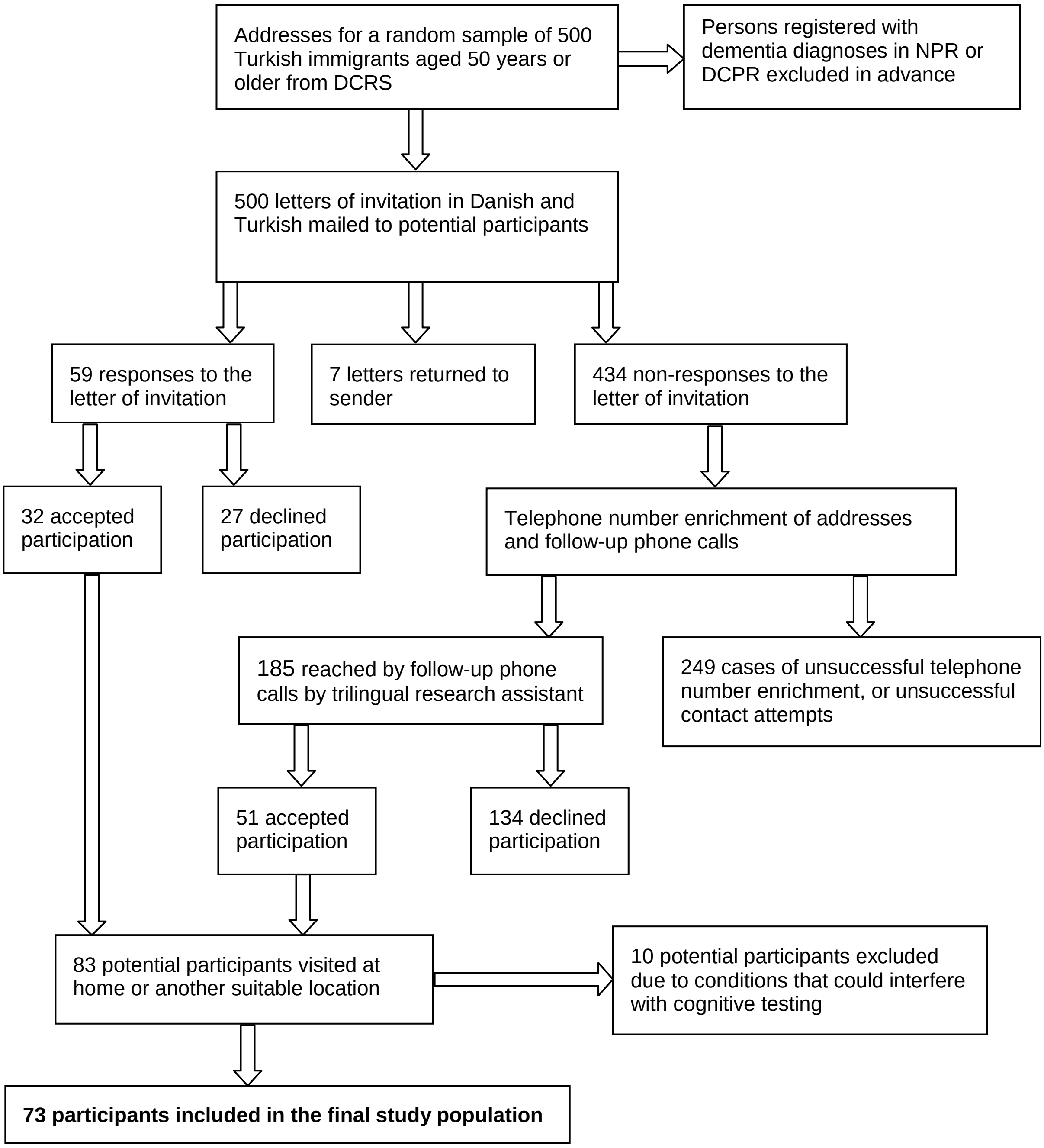

Figure 5. Flow-chart for study population in studies IV and V

DCRS: Danish Civil Registration System, NPR: National Patient Register, DPCR: Danish Psychiatric Central Register.

A significant shortcoming of the procedure used for recruiting participants was that no contact was ever made with about half of the potential participants. This was either due to unsuccessful telephone number enrichment because potential participants could not be identified in internet-based phone books that include landline telephone numbers, mobile telephone numbers, and telephone numbers for phones with prepaid phone cards (www.nno.dk), or because potential participants were never reached in spite of several contact attempts by telephone. A better strategy may have been to contact and recruit potential participants by systematic door knocking of all addresses extracted from the DCRS. Such a strategy has been adopted with success by the 10/66 Dementia Research Group in epidemiological studies in middle- and low income countries (Prince *et al.*, 2007).

For detailed information about materials and methods for each study, please refer to papers I-V in the appendix.

5. RESULTS AND DISCUSSION

5.1. Clinical practice for diagnostic evaluation of dementia in patients from ethnic minorities in Europe

5.1.1. Evaluation of dementia in patients from ethnic minorities in European clinical centers of expertise (Study I)

We found that the majority of the surveyed clinical centers of expertise of the EADC (69%) had regular contacts with patients from ethnic minorities. They generally considered diagnostic evaluation of the patients to be challenging because of communication problems and lack of adequate assessment tools, and they were generally unprepared to ensure adequate services for patients and families with ethnic minority backgrounds. Not surprisingly, strategies for overcoming cultural and linguistic barriers were suboptimal. Most centers performed cognitive assessment with instruments that are only validated in Western cultures, and they frequently relied on family members for interpretation, although professional interpreters were also commonly used.

Although ethnic minorities are prevalent in all European countries, almost one third of the surveyed centers reported that they did not receive referrals of patients with ethnic minority backgrounds. Reasons for ethnic disparities in access and use of health services are complex and often poorly understood (Mayberry *et al.*, 2000). Though ethnic minorities in Europe generally have a lower SES (Stronks *et al.*, 2001) this should not exclude them from the dementia services as these were covered by compulsory health insurance in practically all centers. However, as discussed in section 2.3.2., elderly patients from ethnic minorities may face a number of linguistic and cultural barriers when approaching the health care systems.

Two thirds of the centers reported diagnostic evaluation of dementia in patients from ethnic minorities to be more challenging compared to majority patients, and in more than half of the centers less than 20% of referred patients from ethnic minorities ended up with a dementia diagnosis. However, it seems unlikely that this is due to the challenges of diagnosing dementia in patients from ethnic minorities alone. It probably also reflects that some of the referred patients had cognitive symptoms associated with psychiatric disorders. In line with several other studies (Lindesay, 1998;Daker-White *et al.*, 2002), the main challenges in diagnostic evaluation of dementia in patients from ethnic minorities were reported for clinical investigations relying on verbal communication, i.e. clinical interview, psychiatric evaluation and cognitive testing (see Figure 6).

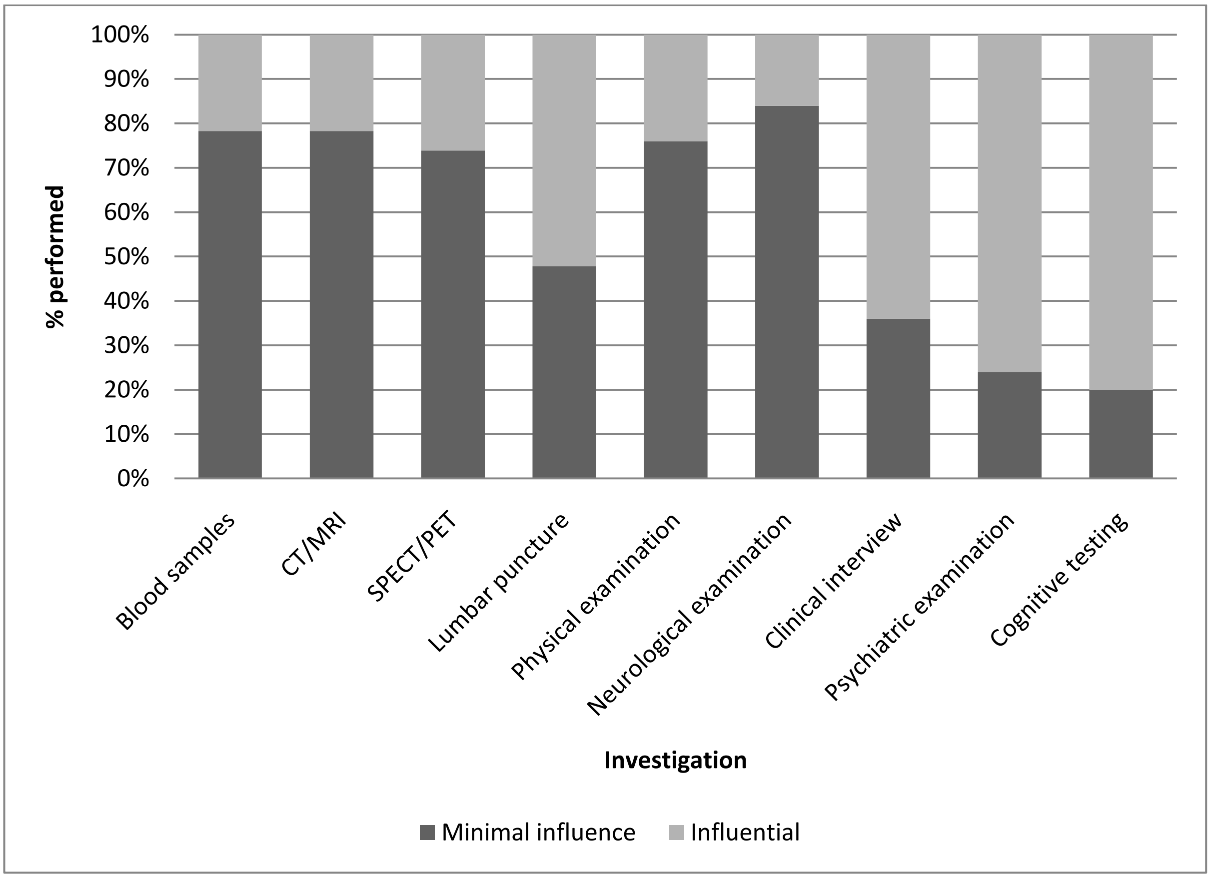

Figure 6. Challenging issues in clinical evaluations of patients from ethnic minorities

Data based on surveyed EADC centers who received referrals of patients from ethnic minorities.

CT: Computed tomography, MRI: Magnetic resonance imaging, SPECT: Single-photon emission computed tomography, PET: Positron emission tomography.

Challenging issues in clinical evaluations of ethnic minority patients highlighted by the centers were the way the patients presented their dementia symptoms and their often limited linguistic abilities and educational level. Another important challenge to good clinical evaluations was the lack of suitable cognitive test instruments and dementia rating scales (see Figure 7).

Overall, the results of Study I indicate that European dementia centers are not well-prepared for the increasing demand for diagnostic evaluations of patients from ethnic minorities. We found strategies for overcoming communication problems to be suboptimal and adequate assessment tools to be lacking.

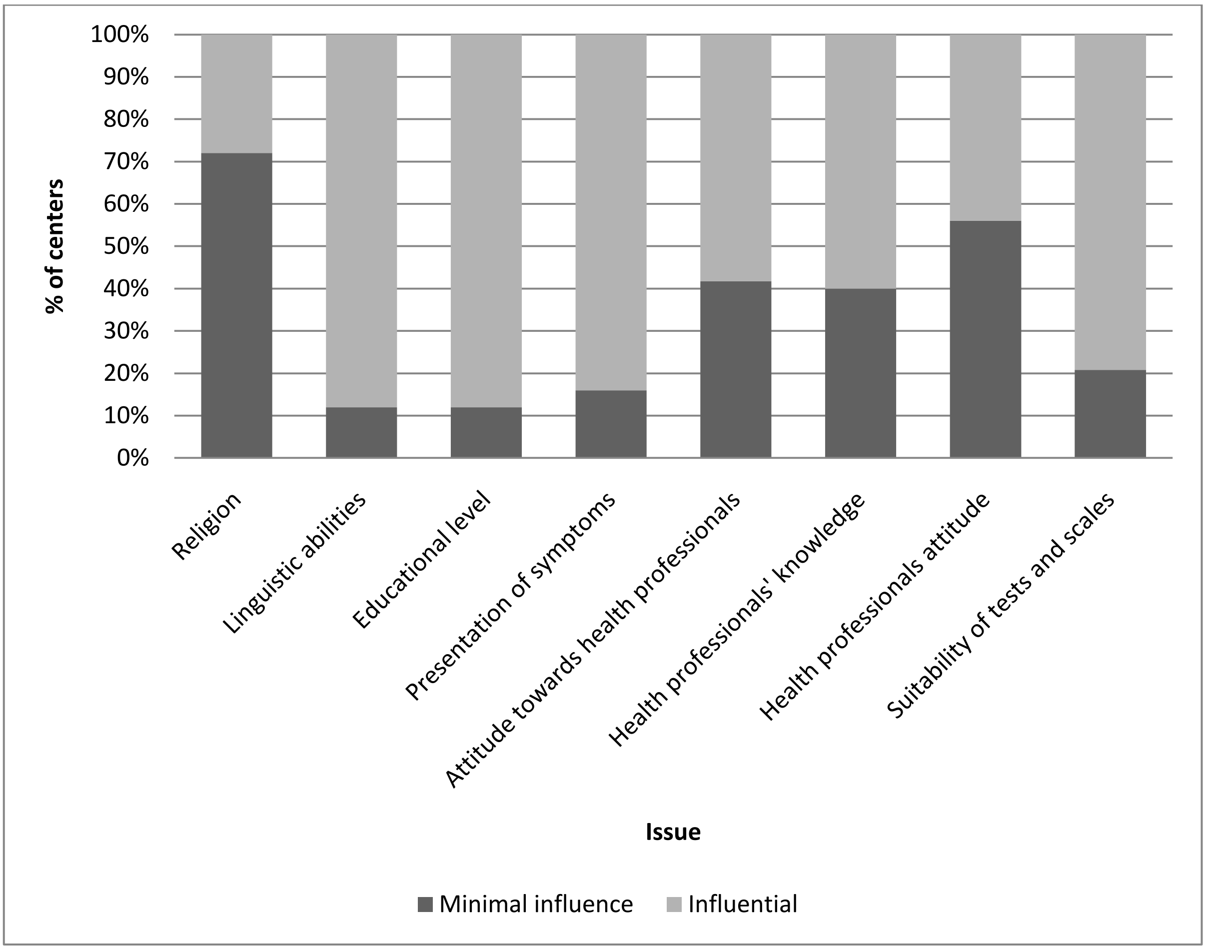

Figure 7. Influence of ethnic minority background on diagnostic investigations

Data based on surveyed EADC centers who received referrals of patients from ethnic minorities.

5.1.2. Diagnostic rate of dementia in ethnic minorities in the Danish hospital registers (Study II)

Based on a population of 68,219 persons aged 20 and older, no more than 174 dementia cases were identified in the Danish hospital registers. The mean age at the time of dementia diagnosis was 57.7 years (SD 16.2), which was considerably lower compared to patients from the general population (mean age 78.5 years, SD 9.8) (Phung *et al*., 2010). The prevalence of registered dementia diagnoses in the ethnic minority population was 0.2% in ages 20 to 59 years and 0.9% in ages 60 years or older with the prevalence rising with increasing age. Comparing the gender-specific prevalence rates to those of the general Danish population, we found no differences in males in the age group 40-59, whereas the prevalence was more than double in females from ethnic minorities. In age groups 60 years or older the prevalence was much lower in both males and females in the ethnic minority population (see Figure 8).

Taking the very young age at the onset of dementia into consideration in some of the cases, the validity of the diagnoses seems doubtful, as dementia is typically not seen in such young individuals. The high prevalence rate in younger age groups could reflect a higher proportion of misdiagnoses in ethnic minority patients, which has previously been suggested by other authors (Lindesay, 1998;

Parker and Philp, 2004). Especially, the high prevalence of dementia in age groups as young as 20-39 years supports this notion.

Several factors may contribute to the under-diagnosis of dementia in the older age groups. As discussed in section 2.3.2., elderly patients from ethnic minorities may face a number of linguistic and cultural barriers to utilizing the health care systems. Furthermore, as pointed out in Study I and several other studies (Lindesay, 1998;Uzzell, 2007;Ardila, 2005;Teng, 2002;Chandra *et al.*, 2001;Daker-White *et al.*, 2002), cross-cultural assessment of dementia can be difficult because of language barriers and cultural variations in the expression of symptoms, and because the cognitive instruments used to assess dementia are affected by cultural variations. Most likely the diagnosis rate of dementia in age groups 60 years or older in the ethnic minority sample is affected by several or all of these factors.

The results of Study II indicate that dementia is probably over-diagnosed in younger ethnic minority populations and highly under-diagnosed in elderly ethnic minority populations.

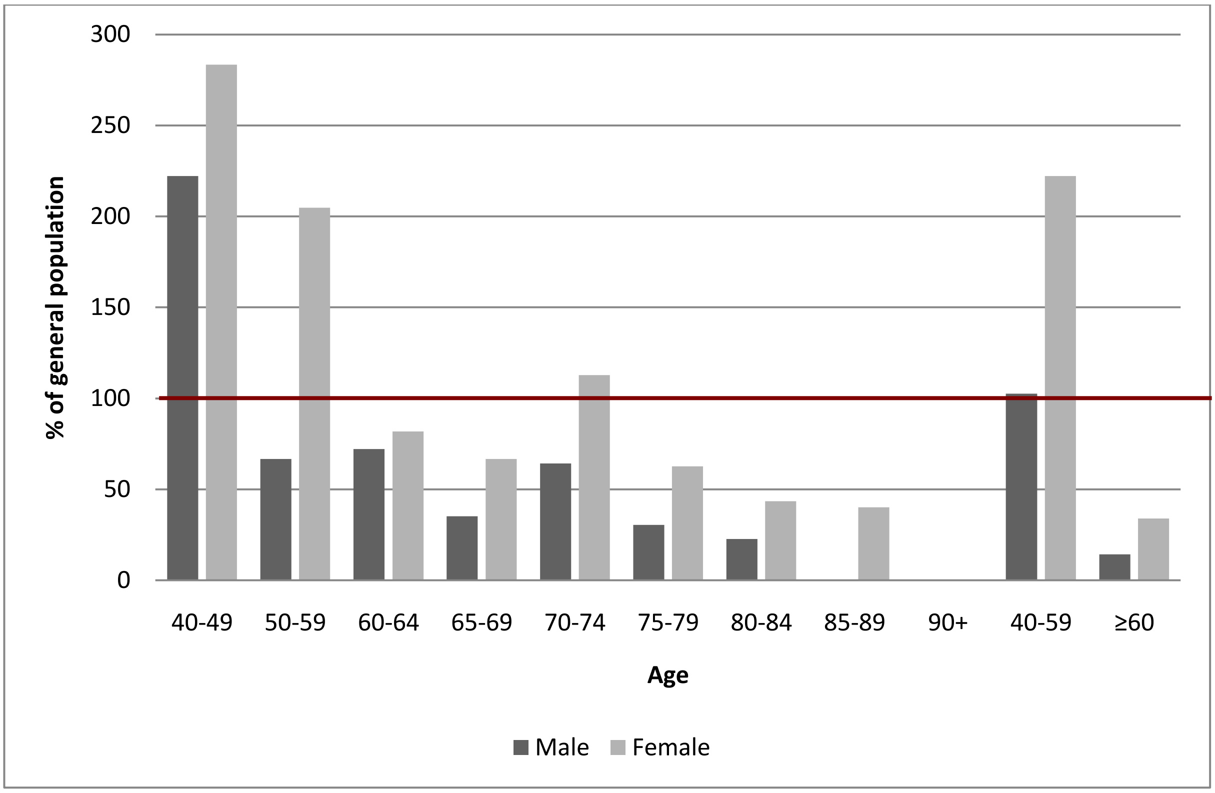

Figure 8. Age- and gender specific prevalence of registered dementia diagnoses compared to the general population

The red line indicates 100% coherence between age- and gender adjusted prevalence of registered dementia diagnoses in the ethnic minority sample and the Danish general population sample.

5.1.3. Quality of clinical dementia diagnoses in patients from ethnic minorities (Study III)

Using the same study population as in Study II, we reviewed the medical records of 59 patients registered for the first time with a dementia diagnosis in the Danish hospital registers between January 1st, 2005 and December 31st, 2007. The results of the review process indicated that patients from ethnic minorities received substandard diagnostic evaluations of dementia compared to patients from the general population, and as a consequence misdiagnoses may be more prevalent.

The impression of the majority of the participating EADC centers surveyed in Study I was that the diagnostic evaluation of dementia in patients from ethnic minorities was in accordance with evidence-based clinical guidelines (Waldemar *et al.*, 2007). However, this was not supported by the results of Study III. When comparing the quality of the dementia work-up performed by dementia specialists for patients from ethnic minorities and patients from the general population, significant ethnic disparities were evident. The presence of valid clinical information was significantly lower on five of eight items of an evidence-based dementia work-up in the ethnic minority sample (see Figure 9).

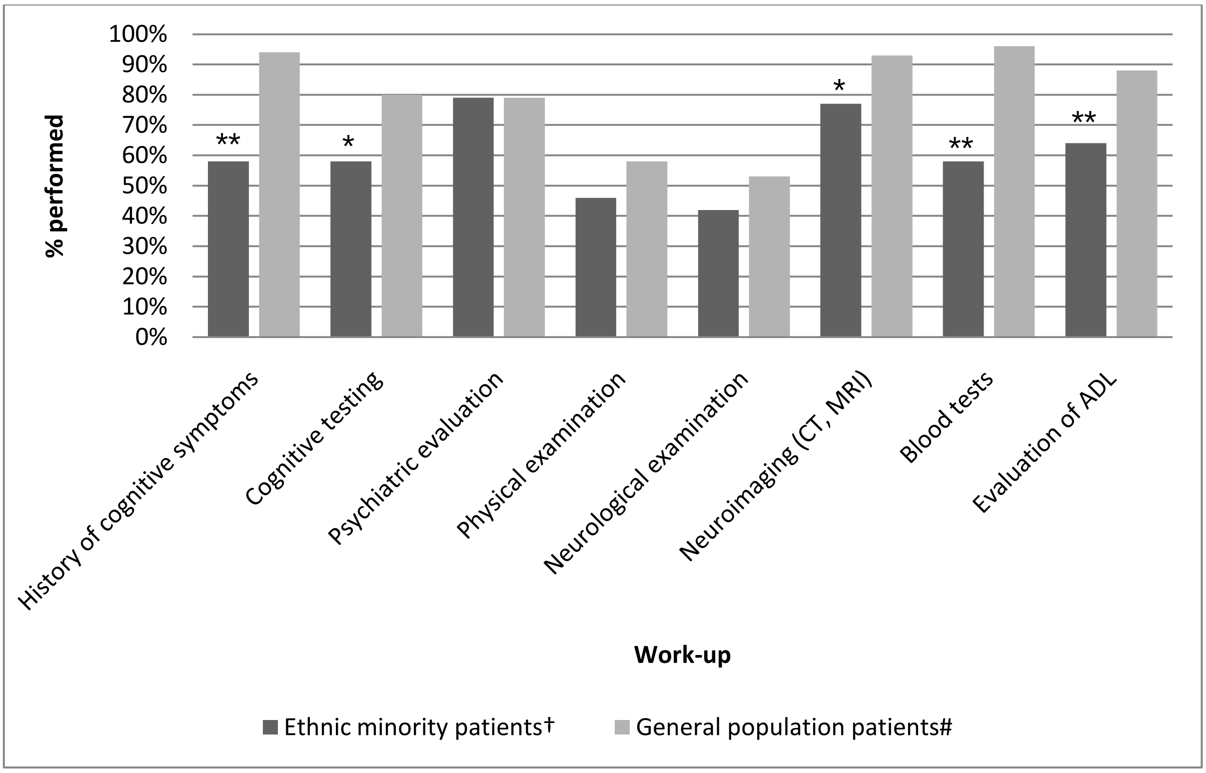

Figure 9. Quality of diagnostic evaluations in patients from ethnic minorities compared to patients from the general population

* *p*<0.01

** *p*< 0.001

† Ethnic minority patients: Immigrants from Turkey, ex-Yugoslavia, and Pakistan.

Data on patients from the general population from (Phung *et al.*, 2009).

CT: Computed tomography, MRI: Magnetic resonance imaging, ADL: Activities of daily living.

The poor quality of the dementia work-up probably affected the validity of the clinical dementia diagnoses, which could only be confirmed in 35% of the patients. This was considerably lower compared to patients from the general population, where clinical diagnoses of dementia in a previous study were confirmed in 89% of the patients (Phung *et al.*, 2009). Not surprisingly, the proportion of dementia diagnoses that could be confirmed in patients younger than 60 years were even lower. Lack of performed investigations highly affected the results of the evaluation process, where it was not possible to determine whether a clinical diagnosis of dementia was valid or not in half of the patients. Nevertheless, as suggested by the results of Study II and previous studies (Lindesay, 1998;Parker and Philp, 2004), our results strongly indicate that dementia is misdiagnosed to a greater extent in patients from ethnic minorities.

As discussed in section 2.4., and highlighted by the European dementia experts in Study I, the main challenges in clinical evaluations of dementia are communication problems and cross-cultural cognitive testing. Therefore, we had a particular interest in the use of interpreters and the methods applied for cognitive testing. At the initial contact, interpreters were used in diagnostic evaluation of 74% of the patients, and half of the time it was family members who assisted with interpretation. This may have resulted in poor communication between clinicians, patients and caregivers from ethnic minorities (please refer to section 2.4.1. for a detailed discussion). Unfortunately, the use of professional interpreters is generally poorly implemented in the Danish healthcare sector. At the same time, many patients are uncomfortable with professional interpreters and prefer to rely on a relative.

In a more in-depth evaluation of the methods applied for cognitive testing we found that satisfactory cognitive testing was performed in no more than one third of the cases. In many cases, it had not been possible to perform all test items due to cultural, linguistic, or educational reasons, which is not a surprise considering the fact that all cognitive assessments were made with instruments that have been developed for educated Western populations (e.g. the MMSE). The use of interpreters and methods used for cognitive testing documented in the medical records in clinical evaluations of patients from ethnic minorities supported the practices described by European dementia experts in Study I.

The results of Study III indicate that significant ethnic disparities exist in the quality of diagnostic evaluations of dementia in the secondary healthcare sector. Generally, we found that dementia diagnoses in patients from ethnic minorities were based on insufficient investigations, and consequently the validity of the diagnoses was often uncertain.

Overall, the results from our studies on clinical practice in diagnostic evaluation of dementia in patients from ethnic minorities in Europe indicate that European dementia clinics are not well-prepared for the increasing number of elderly patients from ethnic minorities. Problematic issues highlighted by the studies were the widespread use of family members for interpretation, and the general lack of suitable methods for cross-cultural assessment of cognitive dysfunction.

5.2. Development of methods for cross-cultural assessment of cognitive dysfunction

5.2.1. Turkish minority study participants

Between September 2009 and December 2010, a total of 73 elderly Turkish minority participants were included in the cognitive test study. Of these 44 (60%) were ethnic Kurds, 27 (37%) were ethnic Turks, and two (3%) had other ethnic backgrounds. The demographic characteristics of the study population are summarized in Table 4.

Generally, the study population consisted of individuals who had grown up in rural areas in Turkey and had limited or no schooling. Despite the fact that the mean time of residence in Denmark was 32 years, the participants generally had low levels of acculturation (i.e. they were primarily orientated towards Turkish and/or Kurdish culture) and had only limited fluency in Danish. Compared to females, males were generally more likely to have attended school, to be more fluent in Danish, and to have a higher level of acculturation (i.e. a higher degree of orientation towards Danish culture).

For a detailed description of the study population, please refer to the Results section in paper IV.

Table 4. Demographic characteristics

Characteristic	
n	73
Age (years) (mean ± SD [range])	61.5 ± 7.2 [50-81]
Female gender (%)	56
Years of schooling (mean ± SD [range])	3.9 ± 4 [0-16]
Literate (%)	65
Years resided in Denmark (mean ± SD [range])	31.7 ± 8.6 [11-43]
Acculturation score (mean ± SD [range])†	1.8 ± 0.4 [1.2-3.3]
No fluency in Danish (%)	36
Interpreter used (%)	93
Rural background (%)	88

† Acculturation was measured with A Short Acculturation Scale for Hispanics (ASASH) (Marín, 1987) adapted for use with Turkish immigrants. Please refer to the Methods section of paper IV for a description of the scale.

5.2.2. Comparison of the RUDAS and the MMSE as tools for cognitive testing in Turkish immigrants (Study IV)

The RUDAS and the MMSE were administered to a community-dwelling sample of 72 elderly immigrants from Turkey residing in the Greater Copenhagen area in Denmark.

When groups with different demographic and acculturation characteristics were compared striking differences, favoring the RUDAS, were found in groups with less than five years of schooling and with lower levels of acculturation, and in women (see Table 5).

Regression analyses revealed years of schooling to predict performance on both tests, although age also had a significant impact on RUDAS performance. That level of schooling profoundly affected

MMSE performance was in accordance with previous findings (Kucukdeveci *et al.*, 2005;Crum *et al.*, 1993). However, the finding that performance on the RUDAS was also affected by level of schooling contrasts with the reports of previous studies in Australian multicultural populations (Rowland *et al.*, 2006;Basic *et al.*, 2009;Storey *et al.*, 2004). This discrepancy is most likely explained by the fact that our sample had a mean of less than four years of formal schooling, and 35% of the participants were illiterate. In comparison, more than half of the participants in the initial study had more than six years of formal education (Storey *et al.*, 2004), and in later studies the median years of education of control samples were 6.5 years and 9 years (Basic *et al.*, 2009;Rowland *et al.*, 2006).

Table 5. Mean (SD) [range] performance on the RUDAS and MMSE stratified by age, years of schooling, gender and level of acculturation

Variable	n	RUDAS	MMSE
Total score	72	26.8 (2.4) [19-30]	23.7 (4.3) [13-30]
Age			
50-59	36	27.6 (2.3) [22-30]	24.5 (3.6) [14-30]
≥60	36	26.0 (2.2) [19-30]	22.9 (4.7) [13-30]
Schooling			
0-4 years	34	25.9 (2.2) [19-29]	20.7 (4.0) [13-27]
≥5 years	38	27.6 (2.2) [22-30]	26.3 (2.3) [22-30]
Gender			
Male	32	26.9 (2.2) [22-30]	25.6 (2.5) [19-29]
Female	40	26.7 (2.6) [19-30]	22.1 (4.8) [13-30]
Acculturation†			
Lower	39	26.0 (2.3) [19-30]	21.6 (4.4) [13-30]
Higher	33	27.7 (2.4) [22-30]	26.2 (2.3) [22-30]

† Lower acculturated participants were participants who scored at or below the median acculturation score on A Short Acculturation Scale for Hispanics (ASASH), and higher acculturated participants were participants who scored above the median on the ASASH.

RUDAS: Rowland Universal Dementia Assessment Scale, MMSE: Mini Mental State Examination.

Previous studies have found the RUDAS to have a sensitivity and specificity for dementia between 81-89% and 76-98%, respectively (Rowland *et al.*, 2006;Iype *et al.*, 2006;Basic *et al.*, 2009;Storey *et al.*, 2004), and the specificity of the RUDAS has consequently been reported to be higher compared to that of the MMSE (Rowland *et al.*, 2006;Iype *et al.*, 2006;Basic *et al.*, 2009).

Similar to this, in Study IV the RUDAS performed considerably better in classifying participants as cognitively normal compared to the MMSE. While 40% of our sample scored below the originally proposed cut-off for cognitive impairment on the MMSE (Folstein *et al.*, 1975), only 4% scored below the proposed cut-off for dementia on the RUDAS (Storey *et al.*, 2004). Thus, compared to the MMSE an important advantage of the RUDAS in screening for cognitive dysfunction in less schooled ethnic minority populations is a reduction of false positive test results and an improved specificity for dementia. In other words, the RUDAS is less likely to classify normal individuals with low schooling as cognitively impaired.

5.2.3. Investigation of the cross-cultural applicability of three neuropsychological tests in samples of elderly Turkish immigrants and elderly Danes (Study V)

In this study, the cross-cultural applicability of three short tests of memory, visuospatial function and semantic verbal fluency were investigated; namely the Recall of Pictures Test (RPT), the Clock Reading Test (CRT) and Supermarket Fluency (SF) (please refer to section 4.3.1. for descriptions of the tests). A total of 109 subjects were included in the study, 73 Turkish minority subjects and 36 Danish subjects.

No differences between the Turkish minority and Danish samples were found on any of the RPT measures, whereas the native Danish sample performed slightly better on the CRT and SF. Data analysis showed that increasing age had a significant impact on test performances in the Turkish minority sample, while no effect of years of schooling and gender were found. No influences of demographic variables were found on any of the tests in the Danish sample. The last finding was expected since the impact of demographic variables on even more complex cognitive measures is limited in elderly, healthy Danes (Vogel *et al.*, 2011).

In general, test performances in the Turkish minority and Danish samples were comparable to previously reported normative data for the three tests in other cultural and linguistic groups with similar levels of schooling (Nitrini *et al.*, 2004;Kempler *et al.*, 2010;Schmidtke and Olbrich, 2007;Garces-Redondo *et al.*, 2004), providing evidence for broader cross-cultural applicability. As illustrated in Table 6, especially the cross-cultural applicability of the RPT seems very promising. In Table 6, the Brazilian samples scored between ½ and 1 point lower on immediate and delayed recall of common objects compared to the samples in the other two studies. This may partly be due to the fact that the test of recall of common objects in this study was based on black and white line drawings. In contrast, coloured drawings or photographs were used in the other two studies. The introduction of colour information may have provided extra cues to improve learning and recall of the objects.

Several studies report the three tests to present good qualities in discriminating between the early stages of dementia and normal aging (Kempler *et al.*, 2010;Liu *et al.*, 2002;Takada *et al.*, 2006;Schmidtke and Hull, 2002;O'Rourke *et al.*, 1997;Tuokko *et al.*, 1992;Schmidtke and Olbrich, 2007;Gomez and White, 2006;Strauss *et al.*, 2006). At the same time the test materials and administration procedures for the tests were appropriate for even unschooled Turkish migrant participants who spoke no Danish, when they were administered with the help of an interpreter. This makes the tests highly relevant for assessment of cognitive dysfunction in elderly Turkish migrant populations in Europe. In particular, the tests could be a valuable supplement to other “culture reduced” cognitive screening tests, such as the RUDAS, in cross-cultural evaluations of dementia.

Table 6. Performance on tests of recall of common objects in samples with different cultural, linguistic, and educational background

	Denmark (Study V)		**Brazil (Nitrini *et al.*, 2004)**		**USA (Kempler *et al.*, 2010)**				
	Turkish	Danish	Illiterate	Literate	African-American	Caucasian	Chinese	Hispanic	Vietnamese
n	73	36	23	28	54	70	71	80	61
Gender (M/F)	41/32	17/19	7/16	20/8	12/42	24/46	34/37	16/64	35/26
Age (mean ±SD)	61.5 ± 7.2	72.1 ± 6.7	74.0 ± 5.0	73.6 ± 5.9	72.7 ± 9.1	77.0 ± 7.4	72.6 ± 7.2	71.9 ± 7.4	71.5 ± 5.8
Education (mean ±SD)	3.9 ± 4.0	8.8 ± 1.9	0	3.8 ± 3.3	11.6 ± 4.7	11.4 ± 3.9	11.2 ± 5.6	8.3 ± 5.3	8.6 ± 4.1
Immediate recall (mean ±SD)	7.6 ± 1.2	7.4 ± 1.3	6.6 ± 1.3	6.6 ± 1.2	7.3 ± 1.3	7.0 ± 1.2	7.4 ± 1.5	7.2 ± 1.6	7.4 ± 1.4
Delayed recall (mean ±SD)	8.2 ± 1.5	8.3 ± 1.7	6.9 ± 1.5	7.3 ± 1.6	7.4 ± 1.8	7.2 ± 1.5	7.9 ± 1.8	7.5 ± 1.9	7.9 ± 1.8

6. CONCLUSIONS AND IMPLICATIONS

The need for evaluation of dementia in elderly ethnic minority populations is increasing in most European countries, but until now European research in the area had not been conducted outside the UK. Diagnostic evaluation of patients from ethnic minorities is associated with a wide range of challenges, but there are no guidelines for clinical practice with these patient groups who often have different needs and expectations to the dementia service.

In this study we investigated the clinical practice for diagnostic evaluation of dementia in patients from ethnic minorities in Europe and developed methods for cross-cultural assessment of cognitive dysfunction. The key points from the conducted studies are:

- European dementia centers are not well-prepared for the increasing demand for diagnostic evaluations of patients from ethnic minorities. Challenging issues in clinical evaluations of ethnic minority patients highlighted by the studies were communication problems and a lack of suitable cognitive test instruments. Generally, strategies for overcoming communication problems in European dementia centers were found to be suboptimal and adequate assessment tools were lacking.

- In the Danish hospital registers there is a higher prevalence of dementia in younger ethnic minority populations, which may be due to a higher rate of misdiagnoses in younger patients with ethnic minority backgrounds.
- Dementia is highly under-diagnosed in elderly ethnic minority populations. This indicates that dementia diagnostic services may be under-utilized by elderly from ethnic minorities with dementia and their caregivers and/or that it is more difficult recognize symptoms of cognitive impairment and diagnose dementia in these patient groups.

- Significant ethnic disparities exist in the quality of diagnostic evaluations of dementia in the secondary healthcare sector in Denmark. Generally, we found that dementia diagnoses in patients from ethnic minorities were based on insufficient investigations, and consequently the validity of the diagnoses was often uncertain.

- Compared to the MMSE an important advantage of the RUDAS in screening for cognitive dysfunction in less schooled ethnic minority populations is a reduction of false positive test results. In other words, the RUDAS is less likely to classify normal individuals with low schooling as cognitively impaired.

- We found the RUDAS, the RPT, CRT and SF suitable for cognitive testing of elderly Turkish immigrants, and we consider all the tests to be important cognitive tests, when assessing dementia in elderly patients from ethnic minority migrant populations. Future studies should assess the discriminative validity of the tests, and apply the tests in other ethnic minority populations.

Taken together, the results from this study indicate that the current practice for diagnostic evaluation of dementia in ethnic minority patients in Europe is suboptimal. When evaluating patients from ethnic minorities, most European dementia clinics perform cognitive assessment with instruments that are only validated in Western cultures and frequently rely on family members for interpretation. Culture sensitive dementia services are lacking and the specialized dementia services are generally not prepared for an increasing demand for assessment and care of patients from different cultural and linguistic backgrounds. There is a general need to increase health professionals’ awareness of the implications regarding cross-cultural assessment of dementia, and there seems to be a profound need to develop appropriate assessment methods for patients from ethnic minority populations in Europe. Although the elderly ethnic minority populations in Europe are relatively small, they should receive the best standard of care. It is important to improve diagnostic rate, diagnostic accuracy and appropriate follow-up for these patient groups to ensure them accurate diagnoses and proper treatment for their specific dementia disorders, especially considering the fact that these populations are expected to increase considerably during the next 20 years

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APPENDIX

Paper I-VI

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Assessment of dementia in ethnic minority patients in Europe: a European Alzheimer's Disease Consortium survey

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ABSTRACT

Background: In most European countries the ethnic minority migrant populations are currently reaching an age where dementia becomes an increasingly important issue. There is no European consensus on good clinical practice with these patient groups, who often have special needs and expectations with regard to dementia services.

Methods: A survey was conducted in clinical dementia centers in 15 European countries. Questionnaires focusing on different points in the clinical assessment of dementia in ethnic minority patients were mailed to leading dementia experts of the European Alzheimer's Disease Consortium.

Results: Thirty-six centers from 15 countries responded to the survey. Ethnic minority patients were seen on a regular basis in 69% of these centers. The diagnostic evaluation was in accordance with evidence-based clinical guidelines in 84–100% of the centers, but most centers performed cognitive assessment with instruments that are only validated in Western cultures and frequently relied on family members for interpretation. Diagnostic evaluation of the patients was considered to be challenging in 64% of the centers, mainly because of communication problems and lack of adequate assessment tools. In general, there were few indicators of culturally sensitive dementia services in the centers.

Conclusions: Ethnic minority patients are seen on a regular basis in European dementia clinics. Assessment of such patients is difficult for a number of reasons. Results from this study show that the most challenging issues are communication problems and assessment of cognitive function where there is a need to develop specific tests for ethnic minority patients.

Key words: Ethnic minority, dementia, survey, questionnaire, assessment, diagnosis

Introduction

Within European countries a substantial and still increasing part of the general population consists of non-Western migrant populations. In most European countries the ethnic minority migrant populations are currently reaching an age where dementia is becoming a significant issue. Symptoms of dementia are similar in all races and ethnicities, but cross-cultural assessment of dementia can be challenging because of language problems and lack of cross-culturally validated cognitive instruments and dementia rating scales (Daker-White *et al.*, 2002). Moreover, there is a stigma and taboo attached to mental health problems in some ethnic minorities (Liu *et al.*, 2008), which may affect the communication of problems, and prejudices on both parts may influence the doctor-patient and the doctor-caregiver relationship (Michaelsen *et al.*, 2004). These challenges have been acknowledged in traditional multicultural societies such as the U.S.A., Canada and Australia for many years. Dementia in elderly ethnic minority populations is, however, still a relatively new phenomenon in most European countries and research in the area is limited. In Europe, research published in English is largely restricted to studies of Indian subcontinent and African Caribbean elders in the U.K.

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(McCracken *et al.*, 1997; Bhatnagar and Frank, 1997; Lindesay *et al.*, 1997a; 1997b; Shah *et al.*, 1998; Lindesay, 1998; Parker and Philp, 2004; Lawrence *et al.*, 2008). Population-based studies from both the U.S.A. (Demirovic *et al.*, 2003; Fitzpatrick *et al.*, 2004) and the U.K. (McCracken *et al.*, 1997; Livingston *et al.*, 2001) have found a higher prevalence of dementia in some ethnic minorities compared to the background population, while other studies have found that ethnic minority patients and their carers are not utilizing dementia services to the same extent as others (Lindesay *et al.*, 1997a; Janevic and Connell, 2001). There is no European consensus on good clinical practice with ethnic minority patients and it is unknown whether European countries are prepared for the increasing demand for assessment and care of these patient groups, who often have different needs and expectations of the dementia service.

Various definitions of ethnicity are used in the literature, and there is little international consensus on terminology regarding ethnic minorities. In Europe most ethnic minorities are first or second generation immigrants. Ethnic minorities cannot be defined by immigrant status alone, however, as indigenous people and ethnic minorities from former colonies may have lived in a European country for generations. Also, not all immigrants may necessarily be perceived as ethnic minorities, e.g. people migrating from one European country to another. For operational purposes, in this study we defined ethnic minority patients as persons who are first generation immigrants or refugees from countries outside the extended EU, Canada, U.S.A., Australia and New Zealand. By choosing this definition, an ethnic minority patient in Europe is restricted to a person who was born in a country outside one of these countries.

The aim of this study was to evaluate the current status and practice for assessment of dementia in ethnic minority patients in clinical centers of expertise of the European Alzheimer's Disease Consortium (EADC). The EADC is a network of 53 European centers of excellence in 18 European countries specializing in Alzheimer's disease (AD). The development of EADC was funded by the European Union with the purpose of defining operational standards of excellence for the diagnosis and treatment of patients with cognitive and behavioral disturbances.

Methods

A questionnaire was mailed to a leading dementia expert in each of the EADC centers. The experts were asked to reply on behalf of their center, or to delegate completion of the form to an equally or better qualified colleague in their center.

The questionnaire form was mailed in a printed format with a request for it to be returned after completion. A pilot study evaluating the questionnaire was conducted in four participating centers prior to initiation of the survey. The questionnaire items investigated different points in the clinical assessment of dementia in ethnic minority patients and the perceived challenges of solving this task. The questionnaire consisted of five main sections: organization of the center, assessment techniques, culture and language, use of interpreters, and assessment of ethnic minority patients (see Appendix 1 for the questionnaire items). The first section concerned the center and the service delivered, especially whether it received referrals of patients from ethnic minority backgrounds. The second section concerned the current practice of assessing ethnic minority patients and the staff's perceived influence of ethnic minority background on various clinical investigations and procedures. The third section focused on the influence of cultural and linguistic factors on the clinical evaluation of dementia in ethnic minority patients. The fourth section focused on issues in interpretation, and the fifth section focused on the staff's general perceptions of challenges and skills in assessment of dementia in ethnic minority patients. Additional items concerned the cognitive screening instruments and dementia rating scales the centers would prefer to be available for ethnic minority patients. The questionnaire form contained space at the end for additional comments.

In the first section of the questionnaire respondents were asked to give approximate percentage values for the description of their center; the rest of the questionnaire required scores on three versions of five-point Likert scales: "Never", "Rarely", "Sometimes", "Often", "Always"; or "Very difficult", "Difficult", "Not different", "Easy", Very easy"; or "Very bad", "Bad", "Neither good nor bad", "Good", "Very good".

To analyze differences between countries with different histories of non-Western immigration, countries were grouped into countries with a long history of immigration (France, Netherlands, Spain, Portugal and the U.K.), and countries with a more recent history of immigration (Belgium, Denmark, Finland, Germany, Greece, Italy, Poland, Romania, Sweden and Switzerland). Countries with a long history of immigration were countries that, for historical and political reasons, had a tradition for influx of non-Western immigrants from former colonies. In countries with a recent history of immigration, non-Western immigration was a more recent phenomenon.

Using SPSS statistical software (Version 15.0 SPSS Inc., Chicago, IL, USA), the responses from countries with different histories of immigration were compared. Fishers Exact Test was used to investigate the significance of differences in whether or not regular referrals of ethnic minority patients were received. Mann-Whitney U test was used to examine the level of significance of responses concerning cognitive testing and use of interpretation.

Results

Of the 53 EADC centers contacted, 36 (68%) centers from 15 countries responded to the invitation to participate in the survey. The geographical distribution of EADC centers and the distribution of centers responding to the survey are shown in Figure 1. The participating centers were generally large centers with 82% receiving more than 300 new referrals per year. The medical specialties of neurology, psychiatry and geriatrics were equally represented (39%, 25% and 36% respectively). Ethnic minority patients were seen on a regular basis in 69% of the surveyed centers. In 80% of these centers, ethnic minority patients comprised less than 5% of the total number of referred patients, while 8% reported ethnic minority patients to comprise more than 20% of all referred patients. Though there were apparent differences in the ethnicity of patients referred for assessment in the centers, the most commonly referred ethnic minority patients were immigrants from Middle Eastern and North African countries (especially immigrants from Turkey and Morocco) followed by immigrants from non-EU East European countries. This reflects the general immigration pattern in Europe. Sixty percent of the centers reported that less than 20% of newly referred ethnic minority patients received a dementia diagnosis. This number was much lower than the percentage of dementia diagnoses given to all newly referred patients (both minority and majority patients), which was generally in the range of 41–80%.

The services of the centers were fully or partly covered by compulsory health insurance in 80.6% and 13.9% of the centers respectively.

b)

Country	EADC centres (n)	Responding centres (n)
Belgium	3	2
Bulgaria	1	0
Denmark	1	1
Finland	2	1
France	8	5
Germany	5	4
Greece	1	1
Ireland	1	0
Italy	4	4
Netherlands	3	3
Poland	2	2
Portugal	1	1
Romania	1	1
Serbia	1	0
Spain	5	4
Sweden	3	2
Switzerland	3	1
United Kingdom	8	4
Total	53	36

Figure 1. Distribution of participating EADC centers. a) Geographical distribution of EADC centers. The gray color denotes countries with an EADC center. The numbers in each country denote the number of participating centers within that country in this particular study. b) A list of countries with EADC centers and the number of centers responding to the survey.

Table 1. Diagnostic evaluation of ethnic minority patients in EADC centers (n = 25)

	PERFORMED WITH ETHNIC MINORITY PATIENTS (%)					
INVESTIGATIONS	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS	NOT APPLICABLE/ DON'T KNOW
Clinical interview	0	0	0	4	96	0
Physical examination	0	0	0	0	100	0
Neurological examination	0	0	0	0	100	0
Psychiatric evaluation	0	4	8	16	68	4
Cognitive testing	0	4	4	20	68	4
Blood samples	0	4	0	8	88	0
CT/MRI	0	0	4	4	92	0
SPECT/PET	0	12	52	20	12	0
Lumbar puncture	8	20	36	16	8	12

CT/MRI = computerized tomography/magnetic resonance imaging; SPECT/PET = single photon emission computed tomography/positron emission tomography.

Table 2. Use of interpretation during diagnostic evaluation of ethnic minority patients in EADC centers (n = 25)

	PERFORMED WITH INTERPRETATION (%)					
INVESTIGATIONS	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS	NOT APPLICABLE/ DON'T KNOW
Clinical interview	4	12	24	24	32	0
Physical examination	16	20	16	20	24	4
Neurological examination	12	24	16	20	24	4
Psychiatric evaluation	4	16	28	16	28	8
Cognitive testing	8	12	20	20	32	8
Blood samples	24	12	20	16	20	4
CT/MRI	24	12	12	16	28	8
SPECT/PET	20	16	12	12	24	16
Lumbar puncture	20	12	12	12	16	28

CT/MRI = computerized tomography/magnetic resonance imaging; SPECT/PET = single photon emission computed tomography/positron emission tomography.

Diagnostic evaluation of ethnic minority patients in Europe

Diagnostic evaluation of ethnic minority patients in the participating EADC centers receiving referrals is summarized in Table 1. The diagnostic evaluation was in accordance with evidence-based clinical guidelines (Waldemar *et al.*, 2007) in 84–100% of the centers. Table 2 summarizes the use of an interpreter with ethnic minority patients during diagnostic evaluation. Interpretation was always or often used during clinical investigations in 44–56% of the centers and in 28–44% of the centers when giving information about ancillary investigations. When interpretation was necessary 71% of the centers always or often relied on family members, 46% on professional interpreters and 13% on staff members.

Indicators of culture sensitive dementia services in the centers were generally sparse. Sixteen to thirty two percent had information sheets, cognitive screening instruments or dementia rating scales directed at commonly referred ethnic minority patients and no more than 8% had knowledge of specialized dementia services for patients with ethnic minority backgrounds in their area. The cognitive screening instrument most centers would prefer to be available for their ethnic minority patients were ethnically modified versions of the Mini-mental State Examination (MMSE; Folstein *et al.*, 1975).

The apparent lack of culture sensitive dementia services in the index centers could not be explained by availability of other better services in their areas.

Influence of ethnic minority background on the diagnostic evaluation

The influence of the patients' ethnic minority background on various investigations is illustrated

Table 3. Influence of ethnic minority background on clinical and ancillary investigations (n = 25)

	INFLUENCED BY ETHNIC MINORITY BACKGROUND (%)					
INVESTIGATIONS	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS	NOT APPLICABLE/ DON'T KNOW
Clinical interview	20	16	20	36	8	0
Physical examination	36	40	16	8	0	0
Neurological examination	32	52	12	4	0	0
Psychiatric evaluation	16	8	32	20	20	4
Cognitive testing	12	8	36	20	24	0
Blood samples	48	24	16	4	0	8
CT/MRI	40	32	12	8	0	8
SPECT/PET	40	28	12	8	0	12
Lumbar puncture	28	16	28	4	4	20

CT/MRI = computerized tomography/magnetic resonance imaging; SPECT/PET = single photon emission computed tomography/ positron emission tomography.

Table 4. Issues influencing clinical dementia evaluation (n = 25)

	INFLUENCE ON CLINICAL DEMENTIA EVALUATION (%)					
ISSUE	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS	DON'T KNOW
Patients' religion	32	40	16	4	4	4
Patients' linguistic abilities	4	8	24	32	32	0
Patients' educational level	4	8	20	44	20	4
Patients' presentation of symptoms	8	8	40	32	12	0
Patients' attitude towards health professionals	12	28	40	12	4	4
Health professionals' knowledge of patients' culture	20	20	24	20	0	0
Health professionals' attitude towards ethnic minority patients	40	16	24	20	0	0
Suitability of test instruments and rating scales	12	8	24	28	16	12

in Table 3. As expected most centers reported that the ethnic minority background affected those clinical investigations that relied more on verbal communication. Some 20–52% of the centers also reported that the ethnic minority background frequently affected obtaining consent for ancillary investigations. Challenging issues in the clinical evaluation of ethnic minority patients that were highlighted by the centers were the way the patients presented dementia symptoms and their often limited linguistic abilities and educational level. Another important challenge to good clinical evaluation was the lack of suitable cognitive test instruments and dementia rating scales. Religious issues were reported to influence the clinical evaluation at a few centers (Table 4).

Based on the results of this survey it is not surprising that the majority of centers (64%) found assessment of dementia in ethnic minority patients to be more challenging than in majority patients. However, 48% still found their skills to be good in assessing dementia in ethnic minority patients.

Comparison of countries with different histories of immigration

When comparing countries with a long history of immigration, no significant differences were found in whether or not regular referrals of ethnic minority patients were received (Fishers Exact Test, $p = 0.588$). However, when comparing issues concerning cognitive testing, and use of interpretation, significant differences were found. In countries with a more recent history of immigration, cognitive testing was found to be more challenging ($U = 39$, $p = 0.028$), and available cognitive test instruments and dementia rating scales were found to be less suitable (Mann-Whitney $U = 26$, $p = 0.019$). No significant differences were found in the use of interpreters during clinical investigations.

In countries with a more recent history of immigration interpretation was used significantly more when giving information about SPECT or PET scans ($U = 23$, $p = 0.021$), blood tests ($U = 32$, $p = 0.036$) and lumbar punctures ($U=26$, $p = 0.019$).

Discussion

This is the first European survey to evaluate the status and practice of assessing dementia in ethnic minority patients. We found that most centers had regular contact with ethnic minority patients. They generally considered diagnostic evaluation of the patients to be challenging because of communication problems and lack of adequate assessment tools, and they were generally unprepared to provide adequate services for patients and families with ethnic minority backgrounds. Not surprisingly, strategies for overcoming cultural and linguistic barriers were suboptimal. Most centers performed cognitive assessment with instruments that are only validated in Western cultures and they frequently relied on family members for interpretation, although professional interpreters were also commonly used.

Nonetheless, use of translated instruments and efforts to develop adequate assessment tools were identified in some centers, indicating that efforts to create better conditions for ethnic minority patients do exist. Evidence-based clinical guidelines (Waldemar *et al.*, 2007) were followed for ethnic minority patient referrals in practically all centers, indicating that discrimination regarding the application of clinical and ancillary investigations was not an issue. On the other hand, it is obvious that the available clinical investigations were often inadequate for evaluation of ethnic minority patients. Two-thirds of the centers reported evaluation of dementia in ethnic minority patients to be more challenging compared to majority patients, and in more than half of the centers less than 20% of referred ethnic minority patients received a dementia diagnosis. It seems unlikely that this is due to the challenges of diagnosing dementia in ethnic minority patients alone. It probably also reflects the fact that some of the referred patients have cognitive symptoms associated with psychiatric disorders. In line with several other studies (Lindesay, 1998; Daker-White *et al.*, 2002), the main challenges in evaluation of dementia in ethnic minority patients were reported for clinical investigations relying on verbal communication, i.e. clinical interview, psychiatric evaluation and cognitive testing. Surprisingly, more than one-fifth of the centers also reported difficulty in gaining consent to do blood tests, brain scans and especially lumbar punctures.

Though ethnic minorities are prevalent in all European countries almost one-third of the surveyed centers reported that they did not receive referrals of patients from ethnic minority backgrounds, and no differences were found between countries with a relatively recent history and those with a long history of immigration. Reasons for ethnic disparities in access and use of health services are complex and often poorly understood (Mayberry *et al.*, 2000). Although ethnic minorities in Europe generally have a lower socioeconomic status (Stronks *et al.*, 2001) this should not exclude them from accessing dementia services as these were covered by compulsory health insurance in practically all centers. Ethnic minority patients do, however, often face linguistic and cultural barriers when they try to access the health care systems. Studies have found that ethnic minority patients are under-represented in specialized health care (Lindert *et al.*, 2008) and have different pathways to a diagnosis of dementia compared to others (Hinton *et al.*, 2004), which suggests that patients with ethnic minority backgrounds may not be referred to specialized dementia services to the same extent as others. At the same time, several studies do, however, indicate that patients and families from ethnic minorities may not seek medical help for dementia symptoms to the same extent as others because of differences in perceptions of dementia and help-seeking behavior (Dilworth-Anderson and Gibson, 2002; Purandare *et al.*, 2007; Lawrence *et al.*, 2008). Furthermore, disparities in access to health services might be attributed to a lack of knowledge about specialized services, or a reluctance to get into contact with the health-care sector, whose services may be perceived as inappropriate (Lindesay *et al.*, 1997a; Daker-White *et al.*, 2002). Most likely all of these factors contribute to the ethnic disparities in access and use of specialized dementia services.

Cognitive deficits are the cardinal symptoms in dementia (World Health Organization, 1993) and clinical assessment and cognitive testing are essential for its correct evaluation. However, certain pitfalls are associated with assessment of elderly ethnic minority patients because they often have limited linguistic abilities in the dominant language (Lindesay, 1998; Daker-White *et al.*, 2002) and often present their dementia symptoms in a different way to other patients (Chandra *et al.*, 2001). Issues concerning cross-cultural cognitive assessment were found to be less problematic in countries with a long history of immigration, which probably reflects the fact that the main ethnic minority populations in these countries are immigrants from former colonies. Because of the historic ties between the countries of origin and the receiving country, these ethnic minority populations generally have a better understanding of the dominant language and culture compared to ethnic minority populations in other countries. However, this survey strongly suggests that referred ethnic minority patients in European dementia centers often have limited or no schooling and thus are unfamiliar with the test or assessment situation (Ardila, 2005). It can be inappropriate to use cognitive tests developed in Western cultures to assess cognitive function in these patients and the test scores will often be misleading (Lindesay, 1998) as the majority of the available cognitive instruments used to assess dementia are affected by cultural variation (Parker and Philp, 2004; Ardila, 2005). Norms adjusted for sociodemographic variables, including cultural background and educational level, are essential in the evaluation of dementia. Some immigrants can read and write in a non-dominant language while others are virtually illiterate. Also, recent immigrants from rural areas have probably never had any reason to learn about complex geometric figures or exact dates. Therefore, if the patients' educational level and cultural background are not taken into account, the interpretation of cognitive test scores will most likely lead to misdiagnoses (Parker and Philp, 2004).

Both structural imaging and cognitive testing are standard requirements in the guidelines for good clinical practice. But while practically all centers always performed CT or MRI with ethnic minority patients, this was only the case in approximately two-thirds of the centers when it came to cognitive testing. This most likely reflects the aforementioned challenges of performing cross-cultural cognitive assessments without suitable cognitive test instruments and dementia rating scales.

The most widely used cognitive instrument is the MMSE and this was also the cognitive screening instrument most centers had available or would prefer to be available for their ethnic minority patients. Several studies have, however, reported the MMSE to be highly influenced by ethnicity and educational level (Parker and Philp, 2004). The mean score on the MMSE for 64–69-year-old Americans with 0–4 years of education is, for example, 22/30 points (Crum *et al.*, 1993). The MMSE has been translated into numerous languages and different modifications and strategies have been proposed to make the instrument more suitable for different ethnic groups and people with limited education (Lindesay *et al.*, 1997b; Parker and Philp, 2004). As an example, a Gujarati version of the MMSE has been developed and validated in the U.K. (Lindesay *et al.*, 1997b; Shah *et al.*, 1998). It is not feasible, however, to translate, make cultural modifications and validate the MMSE in all ethnic minority populations in Europe. A better solution would be to make efforts to develop cognitive screening instruments that are less affected by culture and language or implement already existing examples of such instruments (Storey *et al.*, 2004).

Evaluation of dementia is mainly a clinical discipline relying on verbal communication and observation of behavior. Efficient interpretation is thus crucial when seeing patients from other linguistic backgrounds. European countries differ in their health care policies regarding interpretation. While patients have a formal right to an interpreter in some countries, the use of interpreters is generally poorly facilitated by national governments (Meeuwesen *et al.*, 2009).

Interpretation was used routinely in approximately half of the centers during clinical investigations with ethnic minority patients and in about one-third of the centers when informing them about ancillary investigations. Interpretation was used less frequently when giving information about ancillary investigations in countries with a long history of immigration, which probably reflects better familiarity with the dominant language. Family members were routinely used for interpretation in more than two-thirds of the centers and professional interpreters in almost half of the centers. The reasons for using relatives as interpreters are mostly practical and organizational (Greenhalgh *et al.*, 2007). The literature on medical interpretation recommends the use of professional interpreters, because of fewer mistakes as well as greater physician and patient satisfaction (Flores, 2005). Although studies on communication in informal interpretation are scarce (Aranguri *et al.*, 2006), there is a generally negative attitude regarding the use of informal interpreters because of the lack of professional standards and greater risk of miscommunication (Flores, 2005).

Numerous studies have shown that patients' satisfaction and outcomes are positively affected by the use of professional interpreters (Flores, 2005) and we suspect that the reported challenges of obtaining consent for ancillary investigations reflect the fact that professional interpreters were rarely used when giving information about these procedures.

A limitation of this study was that the data were based on a survey and therefore reflect the perceptions of the respondents. This may have led to over- or under-estimations in the responses. Also, as respondents were not anonymous, it is possible that some results reflect the fact that respondents wanted to demonstrate a high quality of care for patients from ethnic minorities in accordance with international standards. Another limitation was that the sample might not be representative, because only dementia experts from the EADC were sent the survey rather than a random selection of clinical dementia centers in European countries. Thus, we cannot be certain that our results would have been the same had we conducted the survey in a sample of smaller, less specialized centers. The descriptions from experts based in leading dementia centers in Europe does, however, give an impression of the current status and practice of assessment of dementia in ethnic minorities in Europe, which is an area that has not yet been properly described. The main strengths of the study were the high response rate to the survey (68%), and the fact that European countries were broadly represented in the sample. Also, the neurological, psychiatric and geriatric medical specialties were all well represented in the sample.

In conclusion, the current practice of assessment of dementia in ethnic minority patients in Europe is suboptimal. Culture-sensitive dementia services are lacking and the specialized dementia services do not appear to be prepared for an increase in demand for the assessment and care of patients from different cultural and linguistic backgrounds. There is a general need to increase health professionals' awareness of the implications regarding cross-cultural assessment of dementia, and there appears to be an urgent need to develop appropriate assessment methods for patients from the ethnic minority populations in Europe.

Conflict of interest

None.

Description of authors' roles

T. R. Nielsen designed the study, collected the data, analyzed the data and wrote the paper. Asmus Vogel and Gunhild Waldemar assisted in designing the study, supervised the data analysis and assisted in writing the paper. Matthias W. Riepe, Alexandre de Mendonça, Guido Rodriguez and Flavio Nobili assisted in designing the study and assisted in writing the paper. Anders Gade assisted in writing the paper.

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Appendix 1

Survey questions

ORGANIZATION OF CENTER

1. In which medical specialty is your center based?
2. How is the dementia service from your center delivered?
3. As much as you can tell, is there a specialized service for patients from ethnic minority backgrounds in your area?
4. How many new patients were examined in your center last year?
5. How many new patients were diagnosed with dementia in your center last year?
6. Do you receive referrals of ethnic minority patients for diagnostic evaluation of dementia in your center?
7. Do you have staff members from ethnic minorities employed in your center?

ASSESSMENT TECHNIQUES

8. How often do you and the staff in your center attempt to include the following clinical investigations when evaluating ethnic minority patients?
9. How often do you and the staff in your center attempt to include the following procedures when evaluating ethnic minority patients?
10. How often do you and the staff in your center use interpretation during the following clinical investigations when evaluating ethnic minority patients?
11. How often do you and the staff in your center use interpretation in giving information about the following procedures with ethnic minority patients?
12. Does your center have information sheets and consent forms in the languages of ethnic minority patients?
13. Do you and the staff in your center find that the success of performing the following clinical investigations may be influenced by patients' ethnic minority background?
14. Do you and the staff in your center find that the success of getting consent to any of the following procedures may be influenced by a patient's ethnic minority background?
15. Do you use translated versions of the MMSE in your center?
16. Do you use separate cognitive screening instruments or dementia rating scales when evaluating ethnic minority patients?
17. Which cognitive screening instruments or dementia rating scales would you prefer to be available for the ethnic minority patients in your center?

CULTURE AND LANGUAGE

18. Do you and the staff in your center find that any of the following issues influence the clinical evaluation of ethnic minority patients?

INTERPRETATION

19. When interpretation is necessary who will interpret?

ASSESSMENT OF ETHNIC MINORITY PATIENTS – GENERAL

20. In general, how do you and the staff in your center find assessment of dementia in ethnic minority patients compared to ethnic majority patients?
21. In general, how do you and the staff in your center consider your skills in assessing dementia in ethnic minority patients?

RESEARCH ARTICLE

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Over- and under-diagnosis of dementia in ethnic minorities: a nationwide register-based study

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Objective: Among dementia professionals in several European countries, it is believed that dementia is under-diagnosed and under-treated to a greater extent among ethnic minorities than in the native population. It is unknown whether this belief holds true. The objective of this study was to compare the prevalence of register-based dementia diagnoses in the largest ethnic minority groups in Denmark with the prevalence of register-based dementia diagnoses in the general Danish population.

Methods: By linking the Danish hospital registers with the Danish Civil Registration System, nationwide dementia cases for three main ethnic minorities were identified. Age- and gender-specific prevalence rates for dementia were calculated and compared to previously published data for the general population.

Results: The study population consisted of 68 219 persons aged 20 and older. A total of 174 dementia cases were identified. The mean age at diagnosis was 57.7 years (SD = 16.2). Compared to the general population, there was a higher prevalence of dementia among those younger than 60 years, and a markedly lower prevalence of dementia among those 60 years and older.

Conclusions: Dementia is under-diagnosed to a greater extent among ethnic minorities in the age group 60 years and older but is over-diagnosed in the age group younger than 60 years. Several factors may contribute to this pattern, including cultural differences in help-seeking behaviour, and problems in navigating the health-care system. Furthermore, cross-cultural assessment of dementia can be difficult because of language barriers and cultural differences. Copyright © 2010 John Wiley & Sons, Ltd.

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Introduction

During the last two decades, there has been an increasing interest in the study of ethnic differences in prevalence, assessment and care of dementia in multicultural countries such as the United States, Canada and Australia, but very few European studies have focused on these topics. Population-based studies have found a higher prevalence of dementia in some ethnic minorities in the United States compared to the background population (Demirovic *et al.*, 2003; Fitzpatrick *et al.*, 2004), while other studies have found that ethnic minority patients and their caregivers are not utilizing dementia services to the same extent as others (Braun *et al.*, 1995; Janevic and Connell, 2001). This has led some authors to suggest that dementia in ethnic minority patients may be under-diagnosed and under-treated (Mehta *et al.*, 2005; La *et al.*, 2007). This statement has not, however, been validated in European countries.

The Danish hospital registers, which have previously been used in dementia studies (Korner *et al.*, 2008; Kessing *et al.*, 2009; Phung *et al.*, 2009), offer a unique opportunity to address this issue on a national scale. Data from the Danish hospital registers are based on inpatient admissions and visits to hospital-based outpatient clinics in all public hospitals, capturing the vast majority of all contacts with the secondary healthcare system for the whole population. Free access to medical care is available for all Danish residents. Although there are no official estimates, the number of illegal immigrants in Denmark is generally considered to be very small. There are only a few small private hospitals in Denmark and none of these offer services for patients with dementia.

In a previous study, it was found that a diagnosis of dementia among elderly in the Danish hospital registers had a good validity with a positive predictive value of 86% (Phung *et al.*, 2007). Register linkage between the Danish Civil Registration System (DCRS) (Pedersen *et al.*, 2006) and the Danish hospital registers (Munk-Jorgensen and Mortensen, 1997; Andersen *et al.*, 1999) makes it possible to study the nationwide prevalence of dementia diagnoses in the secondary healthcare sector among ethnic minorities.

The pattern of immigration and the history of ethnic minorities are heterogeneous in Western countries. Denmark has traditionally been a culturally homogeneous country with the vast majority of the population consisting of white urban Protestants with a minimum of 7 years of education from public schools. Similar to other countries in northern Europe, immigration from non-Western countries is a relatively new phenomenon in Denmark, and the majority of people from ethnic minorities are relatively young. It is primarily among the Turkish, Pakistani and ex-Yugoslavian immigrants who came to Denmark as working migrants in the 1960s and 1970s that elderly persons aged 60 or more are found today.

Various definitions of ethnicity are used in the literature, and there is no international consensus about the terminology for ethnic minorities. For operational purposes, we define ethnic minorities as non-Western immigrants who, according to Statistics Denmark, are ‘persons born abroad, whose parents are either foreign citizens or born abroad themselves. If information on parenthood is not available, and the person was born abroad, he or she is also defined as an immigrant’ (Statistics Denmark, 2001). According to this definition there are currently approximately 18 500 people from ethnic minorities aged 60 or more living in Denmark (0.03% of all persons aged 60 or more). According to Statistics Denmark, this number is expected to rise to approximately 74 000 in 2030 and 115 000 in 2050. The aim of this study was to carry out a nationwide register-based study of prevalence of dementia diagnoses recorded in the Danish hospital registers for three main ethnic minorities and compare the results with the previously published prevalence of dementia diagnoses recorded in the Danish hospital registers for the general population (Phung *et al.*, 2010).

Methods

Study population

The study population consisted of all Danish residents who had immigrated from Turkey, Pakistan or ex-Yugoslavia, who were registered in the DCRS, who were born before 1980 and were alive at their 20th birthday. We focus exclusively on these three groups because there are very few persons aged 60 or more among other ethnic minorities in Denmark ($n < 1000$).

Identification of dementia cases in the Danish hospital registers

Since 1968, DCRS has assigned unique national identification numbers to all Danish residents and recorded individual demographic data such as age, gender, immigration, emigration and death. Through the same identification numbers, health data of the entire Danish population have been recorded in the national hospital registers (Munk-Jorgensen and Mortensen, 1997; Andersen *et al.*, 1999), allowing accurate and efficient linkage of data from different registers.

We linked the DCRS with the National Patient Register (NPR) (Andersen *et al.*, 1999) and the Psychiatric Central Research Register (PCRR) (Munk-Jorgensen and Mortensen, 1997) to identify dementia cases. NPR has recorded admissions to somatic hospital departments since 1977, and PCRR admissions to psychiatric hospital departments since 1969. Since 1995, NPR and PCRR have also registered data from hospital-based outpatient clinics and emergency departments. Dementia diagnoses are registered in NPR and PCRR by WHO International Classification of Diseases (ICD) codes, ICD 8 from 1970 to 1993 (Danish National Board of Health, 1971) and ICD 10 from 1994 onwards (WHO, 1993). ICD 9 was never used in Denmark.

Date of dementia onset was defined as the first day of a hospital contact (in- or outpatient) when a discharge diagnosis of dementia, either as primary or secondary diagnosis, was recorded for the first time in NPR or PCRR. The term dementia was used in this paper to denote dementia syndromes of any cause, covering all ICD codes for dementia diagnoses (Alzheimer’s disease (AD), vascular dementia (VaD), frontotemporal dementia (FTD) and dementia without specification). The ICD codes for dementia were: AD: ICD 8—290.10 and ICD 10—F00.0-9 and G30.0-9; vascular dementia (VaD): ICD 8—293.09-19 and ICD 10—F01.0-9;

Frontotemporal dementia (FTD): ICD 8—290.11 and ICD 10—F02.0; and dementia without specification: ICD 8—290.09-19 and ICD 10—F03.9.

The prevalence of dementia cases in 2008 were those diagnosed with dementia during the period 1 January 1980 to the end of study on 31 December 2008, who had not immigrated and were still alive at the end of study.

Statistical analysis

Using SPSS statistical software (Version 15.0 SPSS Inc., Chicago, IL, USA), the characteristics of dementia cases with Turkish, Pakistani and ex-Yugoslavian backgrounds were compared. Analysis of variance was used to test the level of significance of age between different countries of origin. For other variables the significance of differences between groups (different countries of origin) was analysed using χ^2-test.

Because of small numbers of cases in each ethnic minority group, they were pooled for further analyses. Although the groups have heterogeneous cultural backgrounds, they share a number of similar characteristics that differ from those of the general population. All groups are mainly constituted by working migrants who lived and worked in rural areas before coming to Denmark. The majority have little or no education and limited fluency in Danish.

Gender-specific prevalence of dementia in the hospital registers was calculated for the three major ethnic minorities in Denmark for different age groups (20–39, 40–49, 50–59, 60–64, 65–69, 70–74, 75–79, 80–84, 85–89 and 90 and over) for the year 2008. Both prevalence of diagnoses with specific dementia subtype (AD, VaD, FTD) and dementia without specification were calculated. The prevalence rates were calculated based on the total population of the three ethnic minorities residing in Denmark on 1 January 2009, which was provided by Statistics Denmark.

The age- and gender-specific prevalence of dementia in the hospital registers for the ethnic minorities was compared to the previously published register-based prevalence for the general Danish population (Phung *et al.*, 2010).

The study was approved by the National Board of Health under licence 7-505-29-1046/1, the Danish Data Protection Agency under licence 2008-41-2311 and by the Danish National Committee on Biomedical Research Ethics under licence H-C-2008-117.

Results

Study population characteristics

The study population consisted of 68 219 persons aged 20 or older. Of these, 30 627 were immigrants from Turkey, 26 399 from ex-Yugoslavia, and 10 086 from Pakistan. From 1 January 1980 to 31 December 2008, a total of 174 dementia cases were identified. The mean age at dementia diagnosis of the cases was 57.7 years (SD = 16.2); 53% of the cases were younger than 60 years. The sex distribution of the cases was 46% male and 54% female. The characteristics of the three ethnic minority groups are summarized in Table 1. No significant differences were found between the three groups in terms of mean age, male to female ratio or distribution of dementia subtypes.

Register-based prevalence of dementia in ethnic minorities in Denmark

Table 2 summarizes the age-specific prevalence rates for dementia for the study population. Both prevalence

Table 1 Characteristics of the dementia cases in ethnic minority patients

Population characteristics	Country of origin						
	Turkey (*n* = 63)		Pakistan (*n* = 31)		Ex-Yugoslavia (*n* = 80)		Level of significance[a]
Age (mean, SD)	58.2	14.5	53.4	16.3	58.9	17.2	NS
	n	%	*n*	%	*n*	%	
Male	28	44.4	19	61.3	33	41.3	NS
Registered diagnosis							
AD	13	20.6	2	6.5	20	25.0	NS
VaD	17	27.0	13	41.9	25	31.3	NS
FTD	0	0.0	0	0.0	0	0.0	NS
Dementia without specification	33	52.4	16	51.6	35	43.8	NS

[a] ANOVA was used to test the level of significance of age between countries of origin. For other variables the significance of differences between countries of origin was analysed using χ^2-test.

Table 2 Age-specific register-based prevalence rates for ethnic minorities in 2008

Population			Prevalence of dementia					
			Specific dementia subtype[a]		Dementia without specification		Total	
Age	Male (*n*)	Female (*n*)	*n*	%[b]	*n*	%[b]	*n*	%[b]
20–39	15 060	14 544	7	0.02	17	0.06	24	0.1
40–49	10 461	8291	19	0.10	16	0.09	35	0.2
50–59	5383	5150	16	0.15	17	0.16	33	0.3
60–64	2060	1654	8	0.22	7	0.19	15	0.4
65–69	1363	1148	9	0.36	2	0.08	11	0.4
70–74	817	786	9	0.56	17	1.06	26	1.6
75–79	534	490	15	1.46	3	0.29	18	1.8
80–84	143	220	4	1.10	5	1.38	9	2.5
85–89	36	66	3	2.94	0	0.00	3	3.0
90+	4	9	0	0.00	0	0.00	0	0.0
20–59	30 904	27 985	42	0.07	50	0.15	92	0.2
≥60	4957	4373	48	0.51	34	0.87	82	0.9

[a] Specific dementia subtype indicates an aetiological diagnosis of AD, VaD or FTD.
[b] Prevalence within age groups.

of diagnoses with specific dementia subtype (AD, VaD, FTD) and dementia without specification diagnoses are given. In age groups younger than 60 years the prevalence was 50% higher in females compared to males. In age groups 60 years or older the prevalence was almost three times higher in females than in males (Table 3). The distribution of dementia subtypes in the population were 20% AD (35 cases), 32% VaD (55 cases) and 48% dementia without specification (84 cases). The prevalence of diagnoses with specific dementia subtype was approximately half of that of dementia without specification diagnoses in both younger and older age groups.

Register-based prevalence for ethnic minorities compared to register-based prevalence for the general population

The age- and gender-specific prevalence rates of dementia for the ethnic minority population in 2008 were compared with results from a register-based study for the general Danish population (Table 3). The register-based prevalence rates for the ethnic minorities were based on a population of 68 219 persons. The prevalence in the age group 40–59 years was similar to that of the general population for males and more than double for females. In the age group 60

Table 3 Age- and gender-specific register-based prevalence rates for the ethnic minorities in 2008 compared to the general Danish population

Age	Male			Female		
	Sample (%)[a]	General population (%)[a]	Sample prevalence as percentage of general population's	Sample (%)[a]	General population (%)[a]	Sample prevalence as percentage of general population's
40–49	0.2	0.1	222.2	0.2	0.1	283.3
50–59	0.2	0.3	66.7	0.4	0.2	204.8
60–64	0.4	0.6	72.1	0.4	0.4	81.8
65–69	0.4	1.1	35.2	0.5	0.8	66.7
70–74	1.2	1.9	64.2	2.0	1.8	112.7
75–79	1.1	3.7	30.4	2.5	3.9	62.7
80–84	1.4	6.2	22.8	3.2	7.3	43.4
85–89	0.0	9.0	0.0	4.6	11.3	40.2
90+	0.0	9.7	0.0	0.0	13.0	0.0
40–59			102.6			222.2
≥60			14.2			34.0

General population register-based prevalence from Phung *et al.* (2010).
[a] Prevalence within age groups.

years or older the prevalence rate of dementia was one-seventh of that of the general population for males and one third for females. The biggest differences were found in the age group 40–49 years where the prevalence rate was more than twice that of the general population in males and almost three times more in females. Data for age groups younger than 40 years were not available for comparison.

Discussion

To our knowledge, this is the first study to report the nationwide prevalence rates of dementia and dementia subtypes in an ethnic minority population. The mean age at the time of dementia diagnosis was 57.7 years (SD = 16.2), which was considerably lower compared to patients from the general population (mean age 78.5 years, SD = 9.8) (Phung *et al*., 2010). The prevalence of dementia in the ethnic minority population was 0.2% in ages 20–59 years and 0.9% in ages 60 years or older with the prevalence rising with increasing age. Comparing the gender-specific prevalence rates to those of the general Danish population, we found no differences in males in age group 40–59, whereas the prevalence was more than double in females from ethnic minorities. In age groups 60 years or older the prevalence was much lower in both males and females in the ethnic minority population. This indicates that dementia is probably over-diagnosed in younger ethnic minority populations and highly under-diagnosed in elderly ethnic minority populations.

Registry-based studies in Sweden (Andreasen *et al*., 1999) and the United Kingdom (Harvey *et al*., 2003) have found the prevalence rate of dementia to be very limited below the age of 65 in the general population. In our sample, more than half of the cases were younger than 60 years. In the age group 40–49, the prevalence rate was more than two times higher in males and almost three times higher in females than the prevalence rate for the general Danish population. Taking the very young age at the onset of dementia into consideration, the validity of the diagnoses seems doubtful, as dementia is typically not seen in such young individuals. The high prevalence rate in younger age groups could reflect a higher proportion of misdiagnoses in ethnic minority patients (Lindesay, 1998; Parker and Philp, 2004). Especially, the high prevalence of dementia in age groups as young as 20–39 years supports this notion. Furthermore, the register-based prevalence for females in age groups younger than 60 years in our ethnic minority population was more than twice the prevalence found in community-based cohort studies (Hofman *et al*., 1991). This is a rather disturbing finding, as a register-based prevalence rate is not expected to be higher than a community-based prevalence rate. This could indicate that the prevalence of dementia diagnoses in younger age groups is highly elevated in ethnic minority populations due to misdiagnosis. In order to examine this, we compared the ratio of diagnoses with a specific subtype, where clinicians had been confident enough to make an eatiological diagnosis, to the ratio of diagnoses of dementia without specification in younger and older age groups. However, no clear picture emerged. A number of factors could contribute to misdiagnoses in these patients. Several studies have reported an excess of hypertension, diabetes and cerebrovascular disease in some ethnic minority populations, including Pakistani and Turkish minorities in Europe (Wild and McKeigue, 1997; Uitewaal *et al*., 2004), and some patients may have reacted to these diseases with subjective cognitive complaints. On the other hand, an increased incidence of stroke has been described in young adults from ethnic minorities in the United States (Pathak and Sloan, 2009) and the United Kingdom (Stewart *et al*., 1999; Banerjee *et al*., 2010) with vascular risk profiles comparable to our ethnic minority population. An increased rate of stroke could inflate the prevalence of VaD and dementia diagnoses in younger age groups. Also, some patients may have had psychiatric disorders, which could explain their cognitive symptoms. Depression is a common differential diagnosis to dementia, and in the early stages of dementia it can be very difficult to discern between the two. When cultural and linguistic differences are present the task can be extremely challenging for the clinician. Several studies have found higher rates of depression and anxiety in Turkish and Pakistani immigrants in Europe, and especially in females (van der Wurff *et al*., 2004; de Wit *et al*., 2008;Gater *et al*., 2009). Thus, the high prevalence of dementia diagnoses in young females could be related to misdiagnosis of depression. However, the same studies tend to find even higher rates of depression and anxiety in older age groups, so this does not seem to be the whole explanation. Also, legal (e.g. regarding citizenship) or economic (e.g. regarding social benefits) issues may have been incentives for subjective cognitive complaints in some patients. These are important questions to address in further studies.

In the age groups 60 years or older, the prevalence of dementia diagnoses was considerably lower in the ethnic minority sample compared to the general population. This finding was more pronounced in males. Prevalence studies from Turkey (Gurvit *et al*., 2008), ex-Yugoslavia (Stefanova *et al*., 2004) and the Indian subcontinent (Rodriguez *et al*., 2008) have found age-specific prevalence rates comparable with those seen in Europe (Lobo *et al*., 2000). Thus, ethnocultural variations in dementia are not likely explanations for differences in prevalence rates. Rather, it indicates that dementia is under-diagnosed compared to the general population in these age groups, and consequently these patients do not receive specialized treatment and care to the same extent as others.

If we compare the prevalence rate of diagnosed dementia in the study population in age groups 60 years or older with the estimated prevalence rate based on data from the pooled analyses of several large European community-based cohort studies (Lobo *et al*., 2000), the discrepancy is even more pronounced with the prevalence rate of diagnosed dementia being just one-sixteenth of the estimated prevalence in males and one-sixth in females. These very low numbers are, however, partly explained by the fact that there were very few individuals older than 84 years in our population, and none of these had received dementia diagnoses.

Several factors may contribute to the under-diagnosis of dementia in older age groups. The ethnic minorities may not seek medical help for dementia symptoms to the same extent as others due to differences in perceptions of dementia and help-seeking behaviour (Dilworth-Anderson and Gibson, 2002; Connell *et al*., 2007; Purandare *et al*., 2007; Lawrence *et al*., 2008), a lack of knowledge of the specialized services, or a reluctance to get into contact with the healthcare sectors, whose services may be perceived as inappropriate (Braun *et al*., 1995). Studies have found that ethnic minority patients have different pathways to a diagnosis of dementia (Hinton *et al*., 2004) and are under-represented in specialized healthcare (Lindert *et al*., 2008), suggesting that patients with ethnic minority backgrounds are not referred to the secondary healthcare system for dementia symptoms to the same extent as others. Furthermore, several studies have found cross-cultural assessment of dementia to be difficult because of language barriers (Lindesay, 1998) and cultural variations in the expression of symptoms (Chandra *et al*., 2001), and because the cognitive instruments used to assess dementia are often not sensitive to cultural variations (Ardila, 2005). Most likely the diagnosis rate of dementia in age groups 60 years or older in the ethnic minority sample is affected by several or all of these factors.

The majority of cases were registered as dementia without specification (48%), followed by VaD (32%) and AD (20%). The high proportion of dementia without specification diagnoses probably reflects that dementia diagnoses in the medical registers are made in both dementia specialist settings and non-specialist settings. Often the diagnostic evaluation is incomplete, and subtypes of dementia cannot be determined (Phung *et al*., 2007). The distribution of dementia subtypes was similar to the register-based distribution in the general Danish population (Phung *et al*., 2010), though there was an indication of a higher prevalence of VaD in our ethnic minority population. We did not find any ethnic minority patients with FTD diagnoses in the Danish medical registers, which probably reflects the major challenge of detecting and interpreting behavioural changes across cultures (Papatriantafyllou *et al*., 2009).

The main strength of the study is that the prevalence rate of dementia is not an estimate based on a sub-sample of a larger population. Rather, the register-based design allows a sampling of all dementia cases on a national scale and thus gives the actual prevalence rate of diagnosed dementia. The main weakness of the study is that the design does not give an accurate picture of the prevalence of dementia in the population. As the results from the study are based on data from the Danish medical registers, the prevalence of dementia does not represent the real prevalence of dementia in the Danish population. Rather, it is a measure of how well the secondary health care sector captures dementia cases in the whole population.

Our study supports the belief that dementia is under-diagnosed and under-treated in elderly ethnic minority populations. Moreover, the majority of cases received a diagnosis of dementia without specification without subsequent follow-up or treatment. This picture is likely to be similar in other countries with a comparable pattern of immigration and universal health coverage. Although the elderly ethnic minority populations in Denmark are relatively small, they should not receive substandard care. It is important to improve diagnostic rate, diagnostic accuracy and appropriate follow-up for these patients to ensure them accurate diagnoses and proper treatment for their specific dementia disorders, especially considering the fact that this population is expected to quadruple within the next 20 years.

The study also highlights the differences in prevalence rates between ethnic minority populations and the general population in age groups younger than 60 years. Although the prevalence of dementia is high

Key Points

- Dementia is highly under-diagnosed in elderly ethnic minority populations, and is probably over-diagnosed in younger females from ethnic minorities. Further research is needed to clarify the over-representation of dementia diagnoses in females in younger age groups.
- The majority of registered dementia diagnoses for ethnic minority patients were ‘dementia without specification’ and plans for subsequent follow-up or treatment were not provided.
- There is an urgent need to find appropriate assessment methods and effective ways of implementing preventive strategies for ethnic minority populations. Future studies should address these issues.

in these age groups in our sample, it is unknown how accurate these diagnoses are. More research is required not only to clarify the over-representation of dementia diagnoses in younger age groups among ethnic minority populations but also to validate dementia diagnoses recorded in the hospital registers for young patients in general. Also, there seems to be an urgent need to find appropriate assessment methods and effective ways of implementing preventive strategies for ethnic minority populations.

Conflict of interest

None declared.

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Quality of Dementia Diagnostic Evaluation for Ethnic Minority Patients: A Nationwide Study

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Key Words
Ethnic minority · Immigrants, dementia · Diagnostic evaluation

Abstract

Background/Aims: Diagnostic evaluation of dementia for ethnic minority patients may be challenging. This study aimed to evaluate the quality of diagnostic evaluation of dementia for patients from ethnic minorities in Denmark. ***Methods:*** The Danish national hospital registers were used to identify patients from the main ethnic minority groups in Denmark, who were diagnosed with dementia in the period 2005–2007. Three raters independently reviewed the patients' medical records. Data were compared to data from a previous similar study in the general Danish population. ***Results:*** Fifty-seven medical records were reviewed. An acceptable diagnostic workup was documented in only 23% of the patients. Dementia diagnosis was confirmed in 35%. Significant differences in the quality of the diagnostic evaluation were found between patients from ethnic minorities and the general population. ***Conclusion:*** There are significant ethnic disparities in the quality of diagnostic evaluations and outcome of dementia in the secondary healthcare sector.

Introduction

In European countries, the proportion of the elderly in ethnic minority migrant populations is increasing. Consequently, dementia is increasingly becoming an important concern among these populations. Although symptoms of dementia are similar across races and ethnicities, dementia may be difficult to diagnose in elderly patients from ethnic minorities. The patients often have limited linguistic abilities in the dominant language [1, 2], they often present their dementia symptoms in a different way than other patients [3], and cross-culturally validated cognitive instruments and rating scales are lacking [2, 4]. Moreover, there is a stigma and taboo attached to mental health problems in some ethnic minorities [5], which may affect the awareness and communication of problems. Prejudices on both parts may influence the doctor-patient and the doctor-caregiver relationship [6]. All of these features may pose important barriers to diagnostic evaluation, referral and follow-up.

In two earlier studies, we found that European dementia centers were generally unprepared to ensure adequate services for patients and families with ethnic minority backgrounds [4], and that a higher proportion of misdi-

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agnoses may be present in patients from ethnic minorities compared to others [7]. A diagnosis of dementia, especially a specific subtype such as Alzheimer's disease (AD) or vascular dementia (VaD), opens the possibilities for treatment and support. On the other hand, the stigma attached to a dementia diagnosis may affect how the patients are treated in their social life, in the medical system and at the workplace. Therefore, it is crucial that patients get the correct diagnosis, and on a solid basis by applying a sufficient diagnostic workup [8].

The pattern of immigration and the history of ethnic minorities are heterogeneous in Western countries. Denmark has traditionally been a culturally homogeneous country with the vast majority of the population consisting of white urban Protestants with a minimum of 7 years of education from public schools. Similar to other countries in northern Europe, immigration from non-Western countries is a relatively new phenomenon in Denmark, and the majority of people from ethnic minorities are relatively young. It is primarily among the Turkish, Pakistani and ex-Yugoslavian immigrants who came to Denmark as working migrants in the 1960s and 1970s that elderly persons aged 60 years or more are found today. At the end of the study period, the total number of immigrants from these areas was 71,546 (numbers extracted from Statistics Denmark, Statistics Bank, January 2008).

Free access to medical care is available for all Danish residents. Although there are no official estimates, the number of illegal immigrants in Denmark is generally considered to be very small. There are only a few small private hospitals in Denmark, and none of these offer services for patients with dementia. Patients with limited or no fluency in Danish have free access to professional interpreters who can assist them during contacts with the healthcare sector. Professional interpreters work for the healthcare sector on a consultancy basis.

Various definitions of ethnicity are used in the literature, and there is no international consensus about the terminology for ethnic minorities. For operational purposes, we define ethnic minorities as non-Western immigrants who, according to Statistics Denmark, are 'persons born abroad, whose parents are either foreign citizens or born abroad themselves. If information on parenthood is not available, and the person was born abroad, he or she is also defined as an immigrant' [9], and focused exclusively on the 3 main immigrant groups.

There is no European consensus on good clinical practice with patients from ethnic minority backgrounds. However, several evidence-based clinical guidelines for evaluation of dementia have been developed [10, 11]. To date, no studies have addressed how well physicians in the secondary healthcare sector adhere to these guidelines when diagnosing dementia patients from ethnic minorities. Based on the recommendations from evidence-based clinical guidelines, the aim of this study was to evaluate the quality of dementia diagnostic evaluation for patients from ethnic minorities and compare the results with previously published results for patients from the general population [8].

Materials and Methods

The Registers

The Danish Civil Registration System [12] assigns unique national identification numbers to all Danish residents and records individual demographic data such as age, gender, immigration, emigration and death. Using the same identification numbers, all Danish residents' contacts with the secondary healthcare system have been recorded in two national medical registers. Since 1969, all psychiatric contacts have been recorded in the Psychiatric Central Register (PCR) [13], and since 1977, all somatic contacts have been recorded in the National Patient Register (NPR) [14]. Dementia diagnoses are registered in the NPR and PCR by WHO International Classification of Diseases (ICD) codes [15].

Study Population

The study population consisted of all Danish residents who were registered as immigrants from Turkey, Pakistan or ex-Yugoslavia in the Danish Civil Registration System, and who were registered for the first time with a dementia diagnosis as primary or secondary discharge diagnosis in the NPR or PCR from January 1, 2005, to December 31, 2007. This population included both in- and outpatients from public hospitals in all regions of the country. The ICD-10 codes for dementia were: F00.0–9 and G30.0–9 for AD, F01.0–9 for VaD, F02.0 for frontotemporal dementia (FTD) and F03.9 for dementia without specification.

Evaluation Process

Letters were sent to all relevant hospital departments to request a copy of the 62 medical records. All available information in the medical records was used in the evaluation process.

For the purpose of this study, a 'registered diagnosis' was defined as the diagnosis registered in the NPR or PCR through which the study population was selected. A 'clinical diagnosis' was defined as the diagnosis the clinician had actually documented in the medical records. A 'rater diagnosis' was defined as the consensus diagnosis reached by the raters through the evaluation process.

Evaluation of the Diagnostic Workup

The evaluation was carried out in two steps. First we evaluated the diagnostic workup that the dementia diagnoses were based on. Using evidence-based clinical guidelines for diagnosing dementia [10, 11], an evidence-based basic workup was defined as: history of cognitive symptoms, cognitive testing, psychiatric evaluation, blood tests (complete blood count, renal function test, liver function test, thyroid-stimulating hormone, glucose, calcium, sodium, potassium and C-reactive protein, or blood sedimentation rate), computed tomography or magnetic resonance imaging scan of the brain, physical examination, neurological examination and assessment of activities of daily living [8].

Three raters – a consulting neurologist (B.B.A.) and a neuropsychologist (T.R.N.) at the Copenhagen Memory Clinic at Rigshospitalet, and a consulting psychiatrist (M.K.) at the Center for Transcultural Psychiatry at the Psychiatric Center Copenhagen – independently reviewed and rated the medical records according to a predefined protocol. The quality of each item of the evidence-based basic dementia workup was rated according to 4 categories: (1) well documented, (2) sufficiently documented, (3) insufficiently documented, (4) not documented. To be considered as valid clinical information, items had to be rated as categories 1 or 2. A written summary of positive findings from cognitive tests, physical examinations, neurological examinations, psychiatric evaluations and neuroimaging were accepted as sufficient. For blood tests, 1 or 2 missing blood tests were accepted if there was no indication that they were necessary to rule out systemic illnesses that could cause cognitive dysfunction. However, blood tests of complete blood count, thyroid-stimulating hormone, blood glucose and serum creatinine were considered obligatory.

Clinical information from earlier contacts was used to supplement the information from the contact when dementia was first diagnosed within predefined time limits. However, psychiatric evaluation had to be done at the time of diagnosis to rule out depression. The rating procedure and the rationale behind the adopted time limits have been described in detail in a previous study [8].

To be considered as an acceptable completion of the evidence-based basic dementia workup, all items of the workup had to be rated as valid clinical information, or if omissions of cognitive testing, evaluation of mental status, physical examination or neurological examination were present, the available clinical information should leave no doubt that the patient fulfilled criteria for dementia [8].

Evaluation of Dementia Diagnoses

Guided by the quality of the clinical information about the dementia workup, the 3 raters independently determined whether dementia could be confirmed according to ICD-10 [15] or DSM-IV criteria [16]. The results were compared, and any disagreement was clarified at consensus meetings. The patients concluded to have dementia were further classified into subtypes according to diagnostic research criteria: AD according to NINCDS-ADRDA for probable AD [17], VaD according to NINDS-AIREN for probable VaD [18], FTD according to Work Group on Frontotemporal Dementia and Pick's Disease [19], and Lewy body dementia according to consensus guidelines for the clinical and pathological diagnosis of dementia with Lewy bodies [20].

The clinical diagnoses documented in the medical records were then compared to the rater diagnoses to determine the extent to which the clinical dementia diagnoses and dementia subtypes could be confirmed.

Evaluation of the Methods Applied for Cognitive Testing and Interpretation

When valid clinical information on cognitive testing was documented in the medical records, the methods applied were evaluated. The methods applied were rated as unsatisfactory if the performing physician or nurse had noted concerns regarding the validity of the cognitive test results in the medical records, or if one or more items of the test instrument had been omitted (i.e. MMSE: 17/22 points). Methods applied for cognitive testing were rated as satisfactory if all items of the instrument were performed (i.e. MMSE: 17/30 points) and no concerns regarding the validity of the test results were noted in the medical records.

The use of interpreters was registered at the initial contact, when the plan for the diagnostic workup was made. If interpretation was applied at the initial contact, it was registered whether health professionals, professional interpreters or relatives performed the interpretation.

Comparison with Data for Patients from the General Population

The presence of valid clinical information for each item of the basic dementia workup for the ethnic minority sample was compared to the results from a previous study in patients from the general population [8]. Comparable methods were used in the two studies, making direct comparisons possible. Because the proportion of diagnoses made by dementia specialists (psychiatrists, neurologists and geriatricians) compared to other medical specialists in the two samples differed (91 vs. 9% in the ethnic minority sample compared to 74 vs. 26% in the general population sample), only the clinical information from dementia specialists was compared.

The Committees on Biomedical Research Ethics for the Capital Region of Denmark, the Danish Data Protection Agency and the National Board of Health approved the study.

Statistical Analyses

Using SPSS statistical software (version 18.0, SPSS Inc., Chicago, Ill., USA), Pearson's χ^2 test was used to compare differences between ethnic minority patients of Turkish, ex-Yugoslavian and Pakistani descent concerning the presence of valid clinical information for each item of the evidence-based basic dementia workup.

The proportion of clinical dementia diagnoses that could be confirmed by the evaluation process was calculated by dividing the number of rater dementia diagnoses by the number of clinical dementia diagnoses. In the same manner, the proportions of clinical diagnosis of AD, VaD and dementia without specification that could be confirmed by the evaluation process were calculated.

Mann-Whitney U and Kruskal-Wallis test statistics were used to compare differences between patients older and younger than 60 years, and between dementia subtypes concerning the proportion of clinical dementia diagnoses that could be confirmed by the evaluation process (the rater diagnoses). Fisher's exact test was used to compare differences between the ethnic minority sample and a sample of patients from the general population concerning the presence of valid clinical information for each item of the evidence-based basic dementia workup.

Table 1. Completeness of the basic dementia workup for patients from ethnic minorities

	Turkish	Ex-Yugoslavian	Pakistani	All 3 ethnic minorities	p value
Patients, n	27 (47%)	22 (39%)	8 (14%)	57 (100%)	
Population base, n	31,433 (44%)	29,496 (41%)	10,617 (15%)	71,546 (100%)	
Workup, %					
History of cognitive symptoms	44	59	88	56	0.092
Cognitive test	52	55	50	53	0.970
Psychiatric evaluation	67	82	75	74	0.486
Physical examination	52	46	63	51	0.704
Neurological examination	48	27	63	42	0.153
Neuroimaging (CT, MRI)	85	64	75	75	0.219
Blood tests	52	55	75	56	0.502
ADL	48	73	76	61	0.148

Valid clinical information was defined as categories 1 and 2 (rated as well documented or sufficiently documented by the evaluation process). Ethnic minorities refer to immigrants from Turkey, ex-Yugoslavia and Pakistan. Population data are from Statistics Denmark, Statistics Bank, January 2008. ADL = Activities of daily living. Level of significance based on Pearson's χ^2 test.

Results

Background Information

Sixty-two patients from the included ethnic minorities were identified with dementia diagnoses in the NPR and PCR in the study period. All 62 patients were included in the study population.

Medical records of 59 of 62 patients (95%) were obtained. We were not able to obtain a copy of the medical records from the 3 remaining patients. Sixty-one percent of the included patients were females and 39% were males. The median age at the date of diagnosis was 67 years (range 23–86), with 39% being younger than 60 years. During the medical record reviews, 2 cases were excluded because of evident misclassification in the registers. A total of 57 medical records were then available for review by the raters. Forty-seven percent of the patients were immigrants from Turkey, 39% were immigrants from ex-Yugoslavia, and 14% were immigrants from Pakistan (table 1). The patients were diagnosed in 24 different public hospitals, covering all regions in Denmark. The distribution of registered dementia diagnoses for the 57 patients were: 53% dementia without specification, 25% VaD and 23% AD.

Review of Medical Records

The clinical diagnoses documented in the medical records were: 28% dementia without specification, 28% VaD, 23% AD, 2% FTD and 19% no dementia (dementia ruled out or no certain conclusion). In 28% of the patients, the clinical diagnoses differed from the registered diagnosis in the hospital registers. Of these cases, 25% had specific subtypes (AD, VaD or FTD) instead of dementia without specification, 6% had VaD instead of AD, and 69% had no dementia (dementia ruled out or no certain conclusion; table 2). Dementia specialists made the majority of the diagnoses. Psychiatrists, neurologists and geriatricians made 58, 21 and 12% of the diagnoses, respectively, while other medical specialists had diagnosed 9%. The majority of the patients were outpatients (83%).

Different use of interpretation was found during different contacts in the course of the diagnostic evaluation. During the initial contact, when the plan for the diagnostic workup was made, interpreters assisted in the diagnostic evaluation for 74% of the patients. Relatives were used as interpreters for 50% of these patients, professional interpreters for 45% and health professionals for 5%.

For each item of the evidence-based dementia workup, the percentage rated as valid clinical information according to ethnic minority group is summarized in table 1. Pearson's χ^2 tests showed no significant differences between ethnic minority groups and the presence of valid clinical information for each item of the basic dementia workup (table 1).

The completion of an acceptable evidence-based basic dementia workup was documented in 23% of the patients. Of the patients with an incomplete workup, 16% were referred for follow-up to a memory clinic or specialist department.

Table 2. Clinical diagnoses documented in the medical records compared to the results of the evaluation process

Clinical diagnosis	Rater diagnosis							
	dementia without specification	AD	VaD	FTD	other dementia	dementia ruled out	unable to conclude[1]	total
Dementia without specification		1				2	13	16 (28%)
AD		9					4	13 (23%)
VaD	1		7		1		7	16 (28%)
FTD	1							1 (2%)
Dementia ruled out						4	1	5 (9%)
No conclusion						2	4	6 (10%)
Total	2 (3%)	10 (18%)	7 (12%)	0	1 (2%)	8 (14%)	29 (51%)	57 (100%)

[1] Through the evaluation process, it was not possible to determine whether dementia was present or not.

In 49% of the patients with valid clinical information on cognitive testing, the methods applied were rated as unsatisfactory during the evaluation process. When correcting for this, the proportion of patients with valid clinical information on cognitive testing dropped to 33%.

Quality of Diagnostic Evaluation of Patients from Ethnic Minorities

The clinical diagnoses documented in the medical records were compared with the results of the evaluation process (the rater diagnoses). Dementia was confirmed in 35% of the patients: 18% with AD, 12% with VaD, 3% with dementia without specification and 2% with other causes of dementia. Only 1 patient had a clinical diagnosis of FTD, and this was not confirmed during the evaluation process (table 2). In 14% of the patients, the raters ruled out dementia, and in 51% it was not possible to determine whether dementia was present.

Dementia was more often confirmed in patients aged 60 years or more (53%) compared to patients younger than 60 years (21%; $p = 0.048$). Concerning dementia subtypes, dementia was confirmed in 69% of the patients with a clinical diagnosis of AD, in 44% of the patients with a clinical diagnosis of VaD and in 6% of the patients with a clinical diagnosis of dementia without specification ($p = 0.002$).

Comparison with Data for Patients from the General Population

The quality of the diagnostic evaluation performed by dementia specialists with patients from ethnic minorities compared to patients from the general population is summarized in table 3. Fisher's exact tests showed significant differences between the two samples in documented valid clinical information on 5 of 8 items of the evidence-based basic dementia workup.

Discussion

To our knowledge, this is the first study to evaluate the nationwide quality of diagnostic evaluation of dementia for patients from ethnic minorities. Based on a population of 71,546 people from ethnic minorities, no more than 62 patients were identified with dementia diagnoses in the medical registers. Elderly patients from ethnic minorities have previously been described to be underrepresented with dementia diagnoses in the Danish medical registers, and proposed explanations for this include that patients from ethnic minorities may be less likely to seek medical help for dementia symptoms compared to others and often face linguistic and cultural barriers when they try to access the healthcare system [7].

The completion of an acceptable evidence-based basic dementia workup was only documented in 23% of the patients, and only 35% of the patients with a clinical diagnosis of dementia were confirmed to have dementia by our raters in the evaluation process. These figures were considerably lower compared to patients from the general population, where an acceptable evidence-based dementia workup was documented in 71%, and clinical diagnoses of dementia were confirmed in 89% [8]. Thus, compared to patients from the general population, the basis on which the dementia diagnoses were made was significantly poorer. This indicates that patients from ethnic minorities received substandard diagnostic evaluations of dementia compared to patients from the general population, and as a consequence misdiagnoses may be more prevalent.

Valid clinical information on each item of the evidence-based basic dementia workup was present in 42–75% of the patients. The most frequently performed investigations were psychiatric evaluations and neuroimaging. When comparing the quality of the dementia workup performed by dementia specialists for patients from ethnic minorities and patients from the general population, significant ethnic disparities were evident. The presence of valid clinical information was significantly lower on 5 of 8 items of the evidence-based basic dementia workup in the ethnic minority sample (table 3).

Table 3. Quality of diagnostic evaluations performed by dementia specialists with patients from ethnic minorities and patients from the general population

Workup	Patient group, %		p value
	ethnic minority (n = 52)	general population (n = 145)	
History of cognitive symptoms	58	94	<0.001
Cognitive test	58	80	0.002
Psychiatric evaluation	79	79	0.544
Physical examination	46	58	0.097
Neurological examination	42	53	0.120
Neuroimaging (CT, MRI)	77	93	0.003
Blood tests	58	96	<0.001
ADL	64	88	<0.001

Valid clinical information was defined as categories 1 and 2 (rated as well documented or sufficiently documented by the evaluation process). ADL = Activities of daily living. Ethnic minority patients: immigrants from Turkey, ex-Yugoslavia and Pakistan. Data on patients from the general population from Phung et al. [8]. Level of significance based on Fisher's exact test.

Cognitive impairment is the cardinal symptom in dementia [15], and clinical assessment and cognitive testing are essential for its correct evaluation. However, the dementia specialists had documented a history of cognitive symptoms and performed cognitive testing in only 58% of the patients in whom they had diagnosed dementia. Patients from ethnic minorities often present symptoms in a different way than other patients [3], and valid tools for cross-cultural cognitive assessment are currently lacking in Europe [2], which may have contributed to the poor documentation of a history of progressive cognitive decline that was supported by cognitive test results. Based on previous studies that report significant challenges in cross-cultural cognitive assessment [2, 4, 21], we had a particular interest in the methods applied for cognitive testing. After a more in-depth evaluation of the methods applied for cognitive testing, we found that satisfactory cognitive testing was performed in no more than one third of the patients. In many cases, it had not been possible to perform all test items due to cultural, linguistic or educational differences, which is not a surprise considering the fact that all cognitive assessments were made with instruments that have been developed for educated Western populations (e.g. MMSE) [22] or Addenbrooke's Cognitive Examination [23]). If the patients' educational level and cultural background were not taken into account in the interpretation of test results, these challenges may have contributed to misdiagnoses [24]. Also, faced with these challenges, the specialists may have opted not to perform any cognitive testing.

Dementia specialists performed psychiatric evaluations in 79% of the ethnic minority patients, which was similar to the rate in patients from the general population. Physical and neurological examinations were performed with less than half of the patients, and were the least performed investigations. However, this was similar to the rate in patients from the general population. For both the ethnic minority and the general population sample, this seems inadequate. The high rate of psychiatric evaluations and the low rate of physical and neurological examinations are most likely because the majority of the diagnoses in both samples were made by psychiatrists, who are more likely than other dementia specialists to focus on mental status evaluation [8]. Following psychiatric evaluations, neuroimaging was the second most frequently performed investigation and was done in 77% of the patients. However, neuroimaging was more frequently performed in patients from the general population. Blood tests were done in 58% of the patients and assessment of activities of daily living in 64%, which were both significantly less compared to patients from the general population. The extent to which the specialists carried out the investigations of the evidence-based basic dementia workup for patients from ethnic minorities is highly unsatisfactory as each investigation is essential to help determine whether dementia is present, and to diagnose the correct subtype.

The poor quality of the dementia workup probably affected the validity of the clinical dementia diagnoses, which could only be confirmed in 35% of the patients. Not surprisingly, the proportion of dementia diagnoses that could be confirmed in patients younger than 60 years were even lower. Lack of performed investigations highly affected the results of the evaluation process, where it was not possible for the raters to determine whether a clinical diagnosis of dementia was valid or not in half of the patients. Diagnoses of a specific subtype (AD or VaD) were confirmed significantly more often than diagnoses of dementia without specification, which could only be confirmed in 6% of the patients. This most likely reflects the fact that in order to make firm assumptions about a specific subtype, dementia specialists need to be more certain of the presence of dementia. Nevertheless, as suggested by several other studies [1, 7, 24], our results strongly indicate that dementia is misdiagnosed to a greater extent in patients from ethnic minorities. We suspect that some of the patients may have had psychiatric disorders, which could explain their cognitive symptoms. Depression is a common differential diagnosis to dementia, and in the early stages of dementia it can be hard to distinguish between the two. Several studies have found elevated rates of depression and anxiety in Turkish and Pakistani immigrants in Europe [25–27], and although psychiatric evaluations were performed with the majority of the patients, cultural and linguistic differences pose significant challenges for the clinician in the evaluation of mental status. Also, we cannot rule out that legal (e.g. regarding citizenship) or economic (e.g. regarding social benefits) issues may have been incentives for subjective cognitive complaints in some patients. Thus, the quality and outcome of diagnostic evaluations was considerably poorer in patients from ethnic minorities.

Several potential explanations for our findings should be considered. One possibility is that the quality of the dementia workup was affected by communication problems that clinicians often face when seeing patients from ethnic minorities [1, 2, 4]. Evaluation of dementia is mainly a clinical discipline relying on verbal communication and observation of behaviors. Thus, efficient interpretation is crucial when seeing patients from other linguistic backgrounds. At the initial contact, interpreters were used in diagnostic evaluation of 74% of the patients, and half of the time it was relatives who assisted with interpretation. A similar practice of using relatives for interpretation has previously been described in a survey on the assessment of dementia in ethnic minority patients in European dementia centers [4]. Unfortunately, the use of professional interpreters is generally poorly implemented in the secondary healthcare sector. Also, many patients are uncomfortable with professional interpreters and prefer to rely on a relative. A second possibility is that patients from ethnic minorities and patients from the general population receive different treatments when being evaluated for dementia due to a more nihilistic approach from healthcare professionals towards patients from ethnic minorities. Like most European countries, Denmark has universal health coverage for all residents, and patients from ethnic minorities should not encounter any financial barriers for receiving medical procedures or diagnostic tests. Although dementia specialists in Europe believe that patients from ethnic minorities receive the same treatments as other patients [4], studies of elderly Medicare patients in the USA have found ethnic disparities in the use of a wide range of medical procedures and diagnostic tests in other medical areas that were not explained by financial or organizational barriers to specialized treatments alone [28–30]. Rather, linguistic and cultural barriers faced by most patients from ethnic minorities may have impacted on dementia specialists' clinical decisions [31].

A third possibility is that the same linguistic and cultural barriers may have influenced the patients' compliance to the investigations of the evidence-based basic dementia workup. If the patients have not understood the importance of the prescribed medical procedures and diagnostic tests or do not agree with them, we must expect them to be less likely to comply with them.

This study has certain limitations. First, the evaluation of dementia diagnoses was only based on the documented clinical information in medical records. This may have underestimated the actual work of medical specialists and may not account for patient compliance. However, we tried to minimize underestimation by including available clinical information prior to the contact when dementia was first diagnosed within predefined time limits and allowed documentation of some investigations to be omitted if the available clinical information left no doubt that the patient fulfilled the criteria for dementia. This has most likely led to an overestimation of the completion of the evidence-based basic dementia workup. Second, the evaluation of dementia diagnoses was based on whether the investigations of the evidence-based basic dementia workup had been performed or not, but for most investigations we were unable to evaluate the quality of these investigations. Although rarely documented or commented on in the medical records, clinical interviews, psychatric evaluations and assessments of activities of daily living may suffer the same linguistic and cultural challenges as described for cognitive testing. Therefore, the quality of the diagnostic evaluations may have been overestimated.

In conclusion, significant ethnic disparities exist in the quality of diagnostic evaluations of dementia in the secondary healthcare sector. Generally, we found that dementia diagnoses in patients from ethnic minorities were based on insufficient investigations, and consequently the validity of the diagnoses was often uncertain. Of special concern was the very poor validity of diagnoses of dementia without specification, and of dementia diagnoses in patients younger than 60 years. We believe that many of these patients may have had psychiatric disorders, for which they did not receive an appropriate diagnosis or treatment. We suspect that the problems identified in this study can be found in other Western countries with comparable patterns of immigration and similar healthcare standards. However, this has never been investigated.

More research is required to clarify the reasons behind the poor quality of the diagnostic workup with patients from ethnic minorities, and effective strategies for improving diagnostic accuracy are urgently needed. Our results call for specific healthcare programs for patients from ethnic minorities with cognitive impairment. Future studies should focus on the development of valid cognitive assessment methods for patients from ethnic minorities, and the development of clinical guidelines for the cross-cultural evaluation of dementia.

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RESEARCH ARTICLE

Title page

Title:

Cognitive testing in Turkish immigrants - comparison of the RUDAS and the MMSE

Running title:

Cognitive testing in Turkish immigrants

Key words:

Neuropsychology, cognitive testing, immigrants, ethnic minority, cross-cultural, Turkish

Key points:

- Although not entirely free of educational bias, we recommend the RUDAS over the MMSE as a tool for cognitive testing of elderly Turkish immigrants.
- Compared to the MMSE, an important advantage of the RUDAS in screening for cognitive dysfunction in less schooled ethnic minority populations is a reduction of false positive test results. In other words, the RUDAS is less likely to classify normal individuals with low schooling as cognitively impaired.

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ABSTRACT

Objective: Methods for culturally and linguistically appropriate cognitive testing of elderly minority populations are lacking in Europe. The objective of this study was to compare the Rowland Universal Dementia Assessment Scale (RUDAS) with the Mini Mental State Examination (MMSE) as a tool for cognitive testing in Turkish immigrants in Denmark.

Methods: A random sample of elderly non-demented community-dwelling Turkish immigrants was recruited from the greater Copenhagen area. All participants completed a structured interview regarding demographic, physical and mental health status, as well as a measure of acculturation, and cognitive testing with the RUDAS and the MMSE.

Results: A total of 72 non-demented participants aged 50 or more were included in the study. The mean performance on the RUDAS and the MMSE was 26.8 (SD 2.4) and 23.7 (SD 4.3), respectively. Compared to the MMSE the RUDAS performed considerably better in classifying participants as cognitively normal. Regression analyses revealed years of schooling to be the main predictor of performance on both tests, although age also had a significant impact on RUDAS performance.

Conclusions: Compared to the MMSE, the RUDAS is a considerably more robust measure of cognitive function and we recommend its use over the MMSE for cognitive testing of elderly Turkish minority populations.

INTRODUCTION

Methods for culturally and linguistically appropriate cognitive testing are becoming increasingly important with the changing demographics in European countries. The elderly population is increasing, and the same trend is seen in residing ethnic minorities.

European countries differ in their histories of immigration and receive immigrants from many parts of the world. However, migrants from Turkey constitute the largest foreign nationality in Western European countries, with more than 3 million Turkish immigrants. Most Turkish migrants live in Germany (approximately 2 million), but also in the Netherlands and Denmark they form the largest ethnic minority group, with approximately 400,000 and 70,000 persons respectively. Moreover, large Turkish minority populations are found in France, the United Kingdom (including Turks from Cyprus), Austria, Belgium, Switzerland and Sweden. In Denmark the majority of Turkish immigrants are ethnic Kurds from the Konya area.

The diagnosis of dementia may be problematic in culturally diverse populations as there is no golden standard for diagnosis (Nielsen *et al*., 2011a; Prince, 2000). In general, diagnostic evaluation of patients from ethnic minorities in Europe is considered to be challenging because the patients often have limited fluency in the dominant language, the presentation of dementia symptoms is different from that of other cultures, and because of lack of adequate assessment tools (Daker-White et al., 2002; Nielsen et al., 2010). Cognitive deficits are the cardinal symptoms in dementia (World Health Organization, 1993). However, in a recent survey we found that only few European dementia clinics had cognitive tests and dementia rating scales available in languages relevant to ethnic minority populations, and most clinics performed cognitive tests with instruments that are only validated in Western cultures (Nielsen et al., 2010). This may result in a higher rate of misdiagnoses in patients from ethnic minorities (Nielsen et al., 2011a). Misdiagnoses may unduly cause emotional distress on patients and family members, lead to unnecessary treatments, and potentially result in increased health care burden and costs (Pedraza and Mungas, 2008). Thus, as the diversity in ethnic, linguistic and cultural backgrounds in the elderly population increases, there is a growing need to develop reliable ways of assessing cognitive dysfunction in patients from different cultural and linguistic backgrounds.

The Mini Mental State Examination (MMSE) (Folstein et al., 1975) is one of the most widely used cognitive tests in Europe (Maruta et al., 2011; Nielsen et al., 2010). However, limitations inherent in this test are even greater when used with patients from ethnic minorities, as MMSE scores are influenced by age, education, ethnicity and language of interview (Escobar et al., 1986). Although translated versions of the MMSE have been developed in languages relevant to ethnic minorities in Europe (Al-Rajeh et al., 1999; Gungen et al., 2002; Lindesay et al., 1997; Xu et al., 2003), and although age- and education-adjusted normative values have been developed (Crum et al., 1993; Kucukdeveci et al., 2005) and alternative cut-off values for illiterate and less educated individuals from ethnic minorities have been proposed (Black et al., 1999; Murden et al., 1991), none of these seem to be widely used in clinical practice (Nielsen et al., 2010).

The Rowland Universal Dementia Assessment Scale (RUDAS) (Storey et al., 2004) is a brief screening test that has been developed for multicultural populations in Australia as an alternative to the MMSE. It has six items that assess body orientation, praxis, drawing, judgement, memory, and language. Like the MMSE it has 30 points, is portable, easy to administer, and takes about 10 minutes to complete. It has been translated into more than 30 languages without need to change the content (Iype et al., 2006; Storey et al., 2004), and it is claimed to be culturally and educationally fair. The RUDAS has a reported sensitivity of 89% and specificity of 98% for detecting dementia in a multicultural Australian sample (Storey et al., 2004). Compared to other brief tests of general cognitive function, the RUDAS has gained credibility due to improvements in sensitivity, addressing frontal/executive functioning, and decreasing susceptibility to cultural and educational biases (Ismail et al., 2010).

The aim of this study was to compare the RUDAS with the MMSE as a tool for cognitive testing in Turkish immigrants in Denmark, and to determine the impact of demographic and acculturation variables on MMSE and RUDAS performance.

METHODS

Subjects

All Danish residents are assigned a unique national identification number by the Danish Civil Registration System (DCRS) (Pedersen et al., 2006), by which individual demographic data, including age, gender, current address and information on immigration (date of immigration and country of residence before immigration), is recorded. Using the same identification numbers, all Danish residents' contacts with the secondary healthcare system have been recorded in two national medical registers (Andersen et al., 1999; Munk-Jorgensen and Mortensen, 1997) that have previously been used in several dementia studies (Nielsen et al., 2011b; Phung et al., 2010).

A random sample of 500 elderly community dwelling Turkish minority subjects was obtained from the DCRS according to the following criteria: the subject was an immigrant from Turkey, had lived in Denmark for a minimum of 10 years, was 50 years or older, had a current address in the greater Copenhagen area, and was not registered with a dementia diagnosis in the national medical registers. Brief letters of invitation in Danish and

Turkish explaining the study were sent to all subjects. A research assistant fluent in Danish, Turkish and Kurdish made follow-up phone calls to subjects who did not respond to the letter within two weeks. Supplemental inclusion and exclusion criteria were checked by a structured interview. Participants with a history of significant memory problems, neurological or psychiatric disease, stroke, traumatic head injury or substance abuse were excluded. In addition, all participants had to be independently living and be free of any physical disabilities that could interfere with neuropsychological testing (e.g. movement disorders, uncorrected hearing, or vision problems). Subjects who reported histories of conditions that could potentially affect cognition, e.g. mild head trauma with loss of consciousness, previous history of depression or chronic medical disease such as cardiovascular disease, diabetes, hypertension or thyroidal disorders were included if they had no cognitive complaints associated with those conditions.

All potential participants were visited by a research neuropsychologist and an interpreter in their home (93%) or another suitable location (3%), or were seen in the Danish Dementia Research Center at Rigshospitalet, Copenhagen (4%), depending on their preference. Written informed consent was obtained from all subjects. The study was approved by the Danish National Committee on Biomedical Research Ethics and the Danish Data Protection Agency.

Procedure

All participants completed an interview and assessment of approximately 90 minutes that included a structured interview regarding demographic, physical and mental health status, as well as a measure of acculturation and neuropsychological tests.

Since specific standardized acculturation measures are unavailable for Turkish minority groups, A Short Acculturation Scale for Hispanics (ASASH) (Marín, 1987; Nielsen et al., 2010a) was adapted and administered to the participants. ASASH has been widely adopted in acculturation research. The scale measures acculturation according to three dimensions on a five-point Likert scale, namely use and preference for a specific language in a number of settings, use and preference for media language, and ethnic preference in social relations (Marín, 1987). The scale has previously been reliably and validly adapted for other ethnic groups (dela Cruz et al., 2000). Using methods similar to those of dela Cruz *et al.* wordings such as "English" and "Americans" were changed to "Danish" and "Danes", and "Spanish" and "Latinos/Hispanics" were changed to "Turkish" and "Turks" or "Kurdish" and "Kurds" depending on the ethnicity and language applicable to the participant.

A Danish research neuropsychologist administered the RUDAS and the MMSE with the assistance of an interpreter trained for the purpose. The items of the RUDAS were translated and back translated from English to Danish by bilingual investigators without need to change the structure or format of any of the items. The interpreters did not encounter any problems translating the items of the RUDAS into Turkish during assessments. Translation of some items of the MMSE has previously been noted to be problematic (Escobar et al., 1986); the repetition of a sentence and backward spelling items in particular. Therefore, only the continued subtraction scoring method (100-7) was used for the attention item, and the original phrase in the repetition item was substituted by "Eğer ve fakat istemiyorum" from the Turkish standardization of the MMSE (Gungen et al., 2002).

A number of binary variables were created to analyze the impact of demographic variables on test performances. Participants were divided into a younger group and an older group. Primary schooling was five years at the time the participants attended school in Turkey, and participants were divided into a group with primary schooling or more and a group with less than primary schooling. Participants were also divided into a higher acculturated group, who scored above the median acculturation score on the ASASH, and a lower acculturated group who scored at or below the median on ASASH.

The ability of the two tests to classify participants as non-demented was evaluated by examining the proportion of participants that were misclassified as cognitively impaired when the originally proposed cut-off values of <23/30 on the RUDAS (Storey et al., 2004) and <24/30 on the MMSE (Folstein et al., 1975) were used. Also, an alternative cut-off value of <18/30 for the MMSE was examined as this cut-off has been proposed for less educated individuals from ethnic minorities (Black et al., 1999; Murden et al., 1991).

Statistical analyses

For continuous variables the Mann–Whitney U Test was used to compare groups due to skewed distribution of data (ceiling effects). Pearson's chi-square test was used to compare frequencies between groups. The linear association between performance on the RUDAS and the MMSE, and between RUDAS and MMSE performance and age, years of schooling and acculturation score, was assessed using Spearman's rank-order correlation coefficient. The impact of demographic and acculturation variables on RUDAS and MMSE performance was investigated using step-wise linear regression analysis with plots of residuals as model control. A p-value of less than 0.05 was considered significant.

RESULTS

Participant characteristics

Between September 2009 and December 2010, 83 elderly Turkish minority subjects were recruited. A total of 59 subjects responded to the letter of invitation, and of these 32 accepted participation in the study. Another 185 subjects were contacted by follow-up phone calls, and of these 51 accepted participation in the study. No contact was ever made with the remaining 260 subjects, mainly because the subjects were not listed in phonebooks.

Of the 83 included subjects, 49 (59%) were ethnic Kurds, 32 (39%) ethnic Turks and two (2%) had other ethnicities. A total of 11 subjects were excluded from the study. Although not registered with a diagnosis of dementia in the medical registers, two participants were suspected of having dementia (based on information from relatives); three subjects were in antidepressive treatment, and one subject refused to complete the test protocol. Other reasons for exclusion included traumatic head injury, stroke, brain tumor and Parkinson's disease. In total, 72 elderly Turkish minority participants aged 50 or more were included in the study. Of the included participants, three (4%) reported a history of mild head trauma with loss of consciousness, nine (13%) reported a previous history of depression, 20 (28%) had diabetes, 30 (42%) had hypertension, 10 (14%) had cardiovascular disease and two (3%) had thyroidal disorder. Diabetes (X^2=4.240, p=0.039), hypertension (X^2=4.346, p=0.037) and a previous history of depression (X^2=8.224, p=0.004) were more prevalent in women. Details of the study participant characteristics are shown in table 1.

Insert table 1 here

Comparison of RUDAS and MMSE performance in groups with different demographic and acculturation characteristics

The mean performance on the RUDAS and the MMSE for the whole sample was 26.8 (SD 2.4) and 23.7 (SD 4.3), respectively. Performances on the two tests were significantly correlated (rho=0.491, p<0.001). Means, standard deviations and ranges for RUDAS and MMSE scores stratified by age, years of schooling, gender and level of acculturation are presented in table 2.

Insert table 2 here

RUDAS scores were higher than MMSE scores in all groups. However, strikingly low MMSE scores were found in the group with less than five years of schooling, in women and in the lower acculturated group.

By using the originally proposed cut-off for the RUDAS, three (4%) of the non-demented participants were classified as cognitively impaired. In contrast, 29 (40%) of the participants were classified as cognitively impaired when the originally proposed cut-off for the MMSE was used. When an alternative cut-off of <18/30 was used for the MMSE, the number of participants classified as cognitively impaired dropped to eight (11%).

Effects of demographic and acculturation variables on RUDAS and MMSE performance

Performance on the RUDAS was significantly correlated with a number of demographic and acculturation variables: age (rho=-0.408, p<0.001), years of schooling (rho=0.464, p<0.001) and acculturation score (rho=0.388, p=0.001). RUDAS performance was not affected by gender (U=621, p=0.828). MMSE performance was also significantly correlated with age (rho=-0.270, *p*=0.022), years of schooling (rho=0.756, *p*< 0.001) and acculturation score (rho=0.580, *p*< 0.001), and men outperformed women (*U*=353, *p*=0.001).

When the demographic and acculturation variables that were significantly correlated with RUDAS and MMSE performance were entered into step-wise linear regression models of RUDAS and MMSE performance, years of schooling and age were included in the final model with RUDAS as dependant variables, and years of schooling in the final model with MMSE as the dependant variable (table 3).

Insert table 3 here

In group comparisons, correlation analyses and regression analyses, level of schooling represented a more significant variable for RUDAS and MMSE performance than any other demographic or acculturation variable. However, the impact of schooling was considerably more pronounced on the MMSE.

DISCUSSION

This study was performed to compare the RUDAS with the MMSE as a tool for cognitive testing in Turkish immigrants in Denmark, and to determine the impact of demographic and acculturation variables on MMSE and RUDAS performance. This is the first study to evaluate the utility of the RUDAS in a European country, and to the best of our knowledge it is the first study to focus on cognitive testing of individuals from a Turkish minority outside Turkey.

The RUDAS and the MMSE were administered to a community-dwelling sample of 72 elderly immigrants from Turkey residing in Denmark. When groups with different demographic and acculturation characteristics were compared, RUDAS scores were consequently higher compared to MMSE scores. However, striking differences (more than four points) were found in the groups with less than five years of schooling and with lower levels of acculturation, and in woman.

Overall, the RUDAS performed considerably better in classifying participants as cognitively normal compared to the MMSE, even when a reduced cut-off for the MMSE of <18/30 that has been suggested for less educated individuals from ethnic minorities was used (Black et al., 1999; Murden et al., 1991). Also, this approach has been criticized for being insufficient, as lowering the cut-off will lead to an unacceptable reduction of the sensitivity of the MMSE in diagnostic assessment of dementia (Ostrosky-Solis et al., 2000). Therefore, the practice of reducing the cut-off for less educated individuals from ethnic minorities must be discouraged. With a cut-off of <23/30 on the RUDAS, previous studies have found sensitivity and specificity for dementia between 81-89% and 76-98%, respectively (Basic et al., 2009; Iype et al., 2006; Rowland et al., 2006; Storey et al., 2004), and the specificity of the RUDAS is consequently reported to be higher compared to that of the MMSE (Basic et al., 2009; Iype et al., 2006; Rowland et al., 2006). When non-demented elderly from ethnic minorities are incorrectly classified as impaired, these errors cast doubt on the diagnostic validity of the test. Thus, compared to the MMSE the RUDAS seems to be a more valid measure of cognitive function in elderly Turkish immigrants.

Although RUDAS and MMSE scores correlated with a number of demographic and acculturation variables, regression analyses revealed years of schooling to predict performance on both tests, although age also had a significant impact on RUDAS performance. That level of schooling profoundly affected MMSE performance was in accordance with previous findings (Crum et al., 1993; Kucukdeveci et al., 2005). However, the finding that performance on the RUDAS was also affected by level of schooling contrasts with the reports of previous studies in Australian multicultural populations (Basic et al., 2009; Rowland et al., 2006; Storey et al., 2004). This discrepancy is most likely explained by the fact that our sample had a mean of less than four years of formal schooling, and 35% of the participants were illiterate. In comparison, more than half of the participants in the initial study had more than six years of formal education (Storey et al., 2004), and in later studies the median years of education of control samples were 6.5 years and 9 years (Basic et al., 2009; Rowland et al., 2006). Similar to our findings, an Indian study found RUDAS scores to be significantly correlated with years of formal education in a less educated Malayalam speaking sample (Iype et al., 2006). In their sample the RUDAS had a sensitivity of 88% and a specificity of 76% for detecting dementia compared to sensitivity and specificity of 90% and 48% for the MMSE. Thus, compared to the MMSE it seems that an important advantage of the RUDAS in screening for cognitive dysfunction in less schooled populations is a reduction of the number of false positive test results and an improved specificity for dementia. In other words, the RUDAS is less likely to classify normal individuals with low schooling as cognitively impaired. This becomes highly important if clinical decisions and treatment plans are based on cognitive test results.

We found the RUDAS to be user friendly and easy to administer with an interpreter, and used it without need to change the structure or format of the items. The participants easily accepted all items of the RUDAS, apart from the drawing task, which requires the copying of a cube. This item was very difficult for participants with less than five years of schooling (data not shown). This observation coincides with other studies that report severely affected performance on copying tasks in older less educated and illiterate subjects from different cultural groups (Manly et al., 1999; Rosselli and Ardila, 2003). The cube copying item seems to be the main reason for influence of schooling on RUDAS performance in our sample. We found several of the items on the MMSE to be problematic in our predominantly less schooled sample (data not shown). In line with previous studies, we found items most sensitive to schooling to be those involving reading, writing, calculation and drawing (Escobar et al., 1986). Also, we encountered cultural influences on the orientation questions in that most participants had no concept of regions of Denmark (region was used as substitute for State in the Danish context), and some of the older ethnic Kurdish participants adhered to a Kurdish calendar system with different names and separation of the months.

A limitation of this study was the relatively young age of the sample and the limited number of participants. Because difficulties in contacting and recruiting elderly Turkish immigrants for mental health-related research had been reported in earlier studies (Ertan et al., 1999), we tried to take various precautionary measures to increase the response rate. These included the employment of bilingual research assistants, translation of letters into Turkish, and multiple contact attempts by telephone. Also, participants were visited in their homes or could choose another location if they preferred, and all visits were planned outside the periods of summer holidays, Ramadan and Christmas. In spite of these efforts, the participation rate was rather low, making the generalization of the results to all Turkish immigrants in Denmark uncertain. However, the recruitment of a random sample of elderly non-demented community-dwelling Turkish immigrants rather than a clinical or convenience sample increases the likelihood that the final sample reflects the Turkish community in Denmark. Another limitation is that our study assumes that the sample was cognitively healthy. Although we had several exclusion criteria and screened participants for factors known to affect cognitive function, we cannot rule out the possibility that some participants may have had conditions causing minor cognitive deficits. Strengths of the study include that a Danish research neuropsychologist performed all assessments with the help of an interpreter, rather than a bilingual researcher. This reflects the clinical reality in most European dementia clinics, where cognitive assessments of patients with diverse linguistic backgrounds is usually performed with the help of an interpreter as bilingual clinicians are lacking (Nielsen et al., 2010). Also, the focus on a single, predominantly less educated ethnic minority group with low levels of acculturation and fluency in the dominant language strengthens the cross-cultural validation of the RUDAS and the evaluation of educational and cultural influences.

With the changing demographics in most European countries, there is a need of a reliable method for detecting cognitive deficits that is valid across cultures. Although not entirely free of educational bias, the RUDAS is recommended over the MMSE for cognitive testing of elderly Turkish minority populations. In future studies it will be interesting to establish the diagnostic accuracy of the test in Turkish minority patients with dementia. Also, for wider use the RUDAS needs to be validated in both ethnic minority and multicultural populations in Europe and other parts of the world.

CONFLICTS OF INTEREST

None

DESCRIPTION OF AUTHORS' ROLES

T. Rune Nielsen designed the study, collected the data, analyzed the data and wrote the paper. Asmus Vogel and Gunhild Waldemar assisted in designing the study, supervised the data analysis and assisted in writing the paper. Anders Gade assisted in writing the paper.

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Table 1. Demographic and acculturation characteristics (n = 72)

Characteristic	
Age (years) (mean ± SD)	61.7 ± 7.2
[range]	50-81
Female gender (%)	55.6
Years of schooling (mean ± SD)	3.8 ± 4.0
[range]	0-16
Literate (%)	65.3
Years resided in Denmark (mean ± SD)	31.7 ± 8.6
[range]	11-43
Acculturation score (mean ± SD)	1.8 ± 0.4
[range]	1.2-3.3
No fluency in Danish (%)	36.1
Interpreter used (%)	93.1
Rural background (%)	87.5

Table 2. **Mean (SD) [range] performance on the RUDAS and MMSE stratified by age, years of schooling, gender and level of acculturation**

Variable	*n*	*RUDAS*	*MMSE*
Total score	72	26.8 (2.4)	23.7 (4.3)
		[19-30]	[13-30]
Age			
50-59	36	27.6 (2.3)	24.5 (3.6)
		[22-30]	[14-30]
≥60	36	26.0 (2.2)	22.9 (4.7)
		[19-30]	[13-30]
Schooling			
0-4 years	34	25.9 (2.2)	20.7 (4.0)
		[19-29]	[13-27]
≥5 years	38	27.6 (2.2)	26.3 (2.3)
		[22-30]	[22-30]
Gender			
Male	32	26.9 (2.2)	25.6 (2.5)
		[22-30]	[19-29]
Female	40	26.7 (2.6)	22.1 (4.8)
		[19-30]	[13-30]
Acculturation			
Lower	39	26.0 (2.3)	21.6 (4.4)
		[19-30]	[13-30]
Higher	33	27.7 (2.4)	26.2 (2.3)

		[22-30]	[22-30]

Table 3. Linear step-wise regression analyses: contributions of demographic and acculturation variables to RUDAS and MMSE performance

Test	*Variable*	*B*	*S.E.B*	*t*	*p*	R^2
RUDAS	(Constant)	30.727	2.235	13.159	<0.001	0.232
	Years of schooling	0.212	0.065	3.258	0.002	
	Age	-0.077	0.036	-2.130	0.037	
MMSE	(Constant)	20.950	0.527	39.720	<0.001	0.441
	Years of schooling	0.710	0.095	7.438	<0.001	

Paper V

Title page

ORIGINAL RESEARCH ARTICLE

Title

Comparison of performance on three neuropsychological tests in elderly Turkish immigrants and elderly ethnic Danes

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Key words

Neuropsychology, cognitive testing, cross-cultural, ethnic minority, dementia

Running Title

Three neuropsychological tests in Turkish immigrants and ethnic Danes

ABSTRACT

Background: Appropriate neuropsychological tests for cross-cultural assessment of dementia in elderly ethnic and linguistic minorities are generally lacking in Europe. The aim of this study was to investigate the cross-cultural applicability of the Recall of Pictures Test (RPT), Clock Reading Test (CRT) and Supermarket Fluency (SF) in samples of Turkish immigrants and ethnic Danes.

Methods: Samples of elderly Turkish immigrants and elderly ethnic Danes were recruited from the greater Copenhagen area. All participants were screened for factors known to affect cognitive test performance. Included subjects underwent a two-hour assessment, where the RPT, CRT and SF were applied as a part of a comprehensive battery of neuropsychological tests.

Results: A total of 109 subjects were included in the study, 73 Turkish minority subjects and 36 ethnic Danish subjects. Significant differences were found between the Turkish minority and the ethnic Danish samples in CRT and SF performance, but not in any of the RPT measures. Age was the only demographic variable with significant impact on test performance for all three tests. Performance data for the three tests in the Turkish minority sample is presented as percentiles.

Conclusion: Although small differences were observed between the Turkish minority and ethnic Danish samples on the CRT and SF, we consider the three tests to be important neuropsychological tests for assessment of dementia in elderly patients from ethnic minority migrant populations.

INTRODUCTION

The elderly population is increasing in all European countries, which will lead to an increase in the number of people with dementia. Immigrants from Turkey form the largest ethnic minority in Western Europe, and the proportion of elderly within this population is expected to increase drastically during the next 20 years. With the changing composition of ethnic, linguistic and cultural populations in European countries, the availability of methods for accurate assessment of cognitive functioning in patients from diverse backgrounds becomes increasingly important.

There is no golden standard for cross-cultural dementia diagnostics (Nielsen *et al.*, 2011;Prince, 2000). Cognitive testing is essential for diagnosing dementia, but assessment of cognitive dysfunction in persons from ethnic minority migrant populations may be challenging. Bilingual staff is rarely available in European dementia clinics (Nielsen *et al.*, 2010), and the majority of available neuropsychological tests used in assessment of dementia are affected by cultural factors (Parker and Philp, 2004;Ardila, 2005). This represent a significant challenge when assessing cognitive dysfunction in elderly immigrant patients with limited fluency in the language of the receiving country, and limited or no schooling (Lindesay, 1998;Nielsen *et al.*, 2010;Nielsen *et al.*, 2011;Daker-White *et al.*, 2002).

A number of studies have suggested that tests of recall of common objects (Takada *et al.*, 2006;Liu *et al.*, 2002;Zunzunegui *et al.*, 2000;Nitrini *et al.*, 2004;Kempler *et al.*, 2010), clock reading (Schmidtke and Olbrich, 2007;Schmidtke and Hull, 2002) and supermarket fluency (Reis *et al.*, 2003;da Silva *et al.*, 2004) to a lesser extent than other cognitive tests are affected by culture and language bias. The same studies also found these tests to be sensitive to cognitive impairment in AD and other forms of dementia. Common features of the tests are that they are short, require no reading skills, and are easy to apply with the help of an interpreter.

Appropriate neuropsychological tests for cross-cultural assessment of elderly ethnic and linguistic minorities are generally lacking in Europe (Nielsen *et al.*, 2010). As the diversity in ethnic, linguistic and cultural backgrounds in the elderly population increases, there is a growing need to find appropriate tests for cross-cultural assessment of patients from diverse cultural and linguistic backgrounds. The aim of this study was to investigate the cross-cultural differences in the Recall of Pictures Test (RPT), Clock Reading Test (CRT) and Supermarket Fluency (SF) for assessment of elderly Turkish immigrants and ethnic Danes. Further, we wished to present the distribution of test scores in a sample of elderly Turkish immigrants.

METHODS

Subjects

Contact information on a random sample of elderly Turkish immigrants residing in the greater Copenhagen area was obtained from the Danish Civil Registration System (DCRS) (Pedersen *et al.*, 2006), in which individual demographic data, including age, gender, current address, and country of residence before immigration is recorded. Based on addresses retrieved from the DCRS, Turkish minority subjects were recruited through personal letters of invitation and follow-up phone calls by bilingual research assistants. Ethnic Danish subjects were recruited through newspaper advertisements. The ethnic Danish sample was a convenience sample of elderly subjects that were sampled to have limited educated. Candidates for inclusion were screened by a comprehensive questionnaire including medical history and consumption of alcohol. Subjects were excluded if they had a history of neurological or psychiatric disease or alcohol consumption above recommended national levels. In addition, all subjects had to be independently living and be free of any physical disabilities that could interfere with cognitive testing (e.g. movement disorders, uncorrected hearing, or vision problems). All subjects underwent a two-hour assessment where cognitive screening tests and a comprehensive battery of neuropsychological tests were applied. In assessment of Turkish minority subjects, an ethnic Danish neuropsychologist administered all cognitive tests with the assistance of an interpreter trained for the purpose.

A total of 16 subjects were excluded from the study. Three Turkish minority subjects were excluded because of current medically treated depression, and four because of traumatic head injury, stroke, brain tumour and Parkinson's disease, respectively. One ethnic Danish subject with poor vision (to a degree that would interfere with cognitive testing) was excluded. In six subjects (two Turkish minority and four ethnic Danish), symptoms of possible dementia were detected in clinical interview. These six persons were referred for further diagnostic examination and excluded from the study. In total 109 subjects were included in the study, 73 Turkish minority subjects and 36 ethnic Danish subjects. The mean time of residence in Denmark for included Turkish minority subjects was 31.6 ± 8.6 years. Demographic characteristics of included subjects are presented in table 1.

Insert Table 1 about here

The distribution of men and women in the Turkish minority and ethnic Danish groups was comparable (X^2=0.112, p=0.738), whereas the ethnic Danish group was significantly older (F=53.52, p<0.001) and had more years of schooling (U=2367, p<0.001).

The Committees on Biomedical Research Ethics for the Capital Region of Denmark, and the Danish Data Protection Agency approved the study. Written informed consent was obtained from all subjects.

Instruments

Recall of Pictures Test

The Recall of Pictures Test (RPT) is similar to a word list learning test. But instead of learning and recalling a word list, subjects were required to learn and recall 10 pictures. The test was based on a test of delayed recall of 10 simple objects from the Brief Cognitive Screening Battery (BCSD) (Takada *et al.*, 2006). However, we used a slightly modified version of the test in which the colorized Snodgrass and Vanderwart pictures (Rossion and Pourtois, 2004) had replaced the original black and white line drawings, as it has been suggested that introducing color information can improve the recognition of pictures in illiterate and less schooled individuals (Reis *et al.*, 2001). Subjects were presented with a piece of paper with 10 colored pictures of common objects that had to be named, and immediately thereafter recalled by the subjects (*incidental recall*). Then the pictures were presented for 30 seconds two more times and subjects were asked to memorize and recall the pictures (*immediate recall*). After a 10-minute interference interval with unrelated test activity, *delayed recall* of the pictures was requested, followed by a *recognition* trial, in which the 10 pictures had to be recognized among 10 distracters. The immediate recall score was the mean score on three learning trials rounded to the nearest whole number, the delayed recall score was the number of pictures recalled after 10 minutes, and the recognition score was the number of pictures recognized among 10 distracters. Also, the number of false positive answers on the recognition trial was recorded.

Clock Reading Test

In the Clock Reading Test (CRT), subjects were required to read the time on a series of clocks showing different times. We used a slightly modified version of the Clock Reading Test developed by Schmidtke and Olbrich (Schmidtke and Olbrich, 2007), in which each clock face was presented on a separate page in a small booklet instead of being arranged in three lines on one sheet of paper. Subjects were presented 12 sheets with clocks showing different times. Each clock face had hands to indicate the hour and minutes, and hour markings. There were no digits around the dial. The subjects were asked to read the time. Any correct form was accepted, e.g. “quarter after two” or “two fifteen”. One point was given for each correct reading of the time. A reading less than four minutes off the correct time was accepted as correct. A half point was given to readings which were four to five minutes or exactly one hour off the correct time. All other readings were given a score of zero.

When reading the four first clocks, subjects were encouraged to check their response if an error was committed. If the reading was changed in the first four clocks, the new reading was scored. The score was the sum of 12 clock readings.

Supermarket fluency

In Supermarket Fluency (SF), subjects are required to generate as many different “things you can buy in a supermarket” as possible within a one-minute interval. The score is the number of different supermarket items produced in one minute.

Statistical analyses

The Chi-square test was used to test the significance of differences in the distribution of categorical variables. For continuous variables, analysis of variance (ANOVA) was used to investigate the significance of differences between groups. For nonparametric variables, the significance of differences between groups was tested with the Mann-Whitney *U* test. The linear association between test performance and demographic variables was assessed using Spearman’s rank-order correlation coefficient. The impact of demographic variables on test performance was investigated using step-wise linear regression analysis with plots of residuals as model control. A p-value of less than 0.05 was considered significant.

RESULTS

Neuropsychological test performance

All subjects were able to complete the RPT and SF, whereas five illiterate Turkish minority subjects were unable to complete the CRT, as they did not know how to read a clock. Data from these subjects were excluded from the analyses of CRT performance. On the RPT recognition trial, two Turkish minority and three ethnic Danish subjects had one false positive answer, and one Turkish minority subject had two false positive answers. Means, standard deviations and range for RPT, CRT and SF performance of Turkish minority subjects and ethnic Danish subjects are presented in table 2.

Insert Table 2 about here

Significant differences were found between the Turkish minority and the ethnic Danish groups in CRT and SF performance, but not in any RPT measures. Performance data for the Turkish minority sample is presented as percentiles in table 3.

Effects of demographic variables

In the Turkish minority group, age was negatively correlated with performance on RPT immediate recall (rho=-0.263, p=0.025) and delayed recall (rho=-0.254, p=0.030), SF (rho=-0.369, p=0.001) and CRT (rho=-0.506, p<0.001). Performance on CRT was significantly correlated with years of schooling (rho=0.337, p=0.005). No gender differences were found on any of the tests. When the demographic variables that were significantly correlated with test performance were entered into step-wise linear regression models of test performance, age was the only variable with significant impact for all three tests (data not shown).

In the ethnic Danish group, no significant effects of age, years of schooling or gender were found on RPT, SF or CRT performance.

Insert Table 3 about here

DISCUSSION

In this study, the cross-cultural applicability of three short tests of memory, visuospatial function and semantic fluency was investigated. To our knowledge, this is one of the first European studies to focus on cognitive testing of ethnic minority migrant populations. Test performance of a Turkish minority sample living in Denmark was compared to a sample of ethnic Danes. No differences between the Turkish minority and ethnic Danish samples were found on any of the RPT measures, whereas the ethnic Danish sample performed slightly better on the CRT and SF. Data analyses showed that increasing age had a significant impact on test performances in the Turkish minority sample, while no effect of years of schooling and gender were found. No influences of demographic variables were found on any of the tests in the ethnic Danish sample. The last finding was expected since the impact of demographic variables on even more complex cognitive measures (Rey Auditory Verbal Learning Test (RAVLT) (Schmidt, 1996) and the Rey Complex Figure Test (RCFT) (Meyers and Meyers, 1995)) is limited in elderly, healthy Danes (Vogel *et al.*, 2011).

The test materials and administration procedures for the three tests were appropriate for even unschooled Turkish migrant subjects who spoke no Danish, when they were administered with the help of an interpreter. There was a wide variance in tests performance with no evident floor or ceiling effects. Although the tests are short and simple, they are more complex than common brief cognitive screening tests such as the Mini Mental State Examination (MMSE) (Folstein *et al.*, 1975) and “culture reduced” screening tests such as the Rowland Universal Dementia Assessment Scale (RUDAS) (Storey *et al.*, 2004), and probably have better discriminative value in assessment of dementia. Several studies report high sensitivity of tests of recall of common objects (Kempler *et al.*, 2010;Liu *et al.*, 2002;Takada *et al.*, 2006), clock reading (Schmidtke and Hull, 2002;O'Rourke *et al.*, 1997;Tuokko *et al.*, 1992;Schmidtke and Olbrich, 2007) and semantic fluency (Gomez and White, 2006;Strauss *et al.*, 2006) in discriminating between the early stages of dementia and normal aging. This makes the tests highly relevant for assessment of cognitive dysfunction in elderly Turkish migrant populations in Europe.

In general, test performances in the Turkish minority and ethnic Danish samples were comparable to previously reported normative data for the three tests in other cultural and linguistic groups (Nitrini *et al.*, 2004;Kempler *et al.*, 2010;Schmidtke and Olbrich, 2007;Garces-Redondo *et al.*, 2004), providing evidence for broader cross-cultural applicability. Therefore, the performance data may be used as reference values in clinical practice not only with Turkish minority subjects, but also with other ethnic minority migrant populations with similar age and schooling characteristics. However, this needs to be established in future studies.

In the Turkish minority group, age had a significant impact on RPT immediate recall, CRT and SF performance. This was not surprising since performances on most cognitive tests decline with increasing age (Strauss *et al.*, 2006). However, it is more noteworthy that the tests were little influenced by schooling in a sample of subjects with 0-16 years of schooling. However, our results are in line with previous studies on tests of delayed recall of pictures or photographs of common objects in elderly Spanish (Zunzunegui *et al.*, 2000), Brazilian (Nitrini *et al.*, 2004), Chinese (Liu *et al.*, 2002), and African-American, Caucasian, Chinese, Hispanic and Vietnamese samples in USA (Kempler *et al.*, 2010), and the CRT in an elderly sample of Germans (Schmidtke and Olbrich, 2007). As in our study, previous studies also find SF performance to be influenced by age. But conflicting results have been reported on the influence of schooling on SF performance (da Silva *et al.*, 2004;Reis *et al.*, 2003;Garces-Redondo *et al.*, 2004).

A limitation of the study is the differences in demographic characteristics between the Turkish minority and ethnic Danish samples. However, it was very difficult to recruit elderly Turkish minority subjects with more than five years of schooling. At the same time, it was not possible to include ethnic Danish subjects with less than seven years of schooling since this was required at the time they attended school. Another limitation is the small sample sizes, and consequently the data should be regarded as preliminary. Strengths of the study include that an ethnic Danish neuropsychologist performed all assessments with the help of an interpreter, rather than a bilingual researcher. This reflects the clinical practice in most European dementia clinics, where cognitive assessments of patients with diverse linguistic backgrounds are usually performed with the help of an interpreter as bilingual clinicians are lacking (Nielsen *et al.*, 2010;Nielsen *et al.*, 2011).

There is a need of reliable methods for detecting cognitive deficits that are valid in European ethnic minority migrant populations. The cross-cultural applicability of the RPT seems very promising, and although small differences in CRT and SF performance were observed between the Turkish minority and ethnic Danish samples, we consider all tests to be important neuropsychological tests, when assessing dementia in elderly patients from ethnic minority migrant populations. In particular, the tests could be a valuable supplement to other “culture reduced” cognitive screening tests, such as the RUDAS, in cross-cultural evaluations of dementia. Future studies should attempt to assess the discriminative validity of the tests, and apply the tests in other ethnic minority populations.

CONFLICTS OF INTEREST

None

DESCRIPTION OF AUTHORS' ROLES

T. Rune Nielsen designed the study, collected the data, analyzed the data and wrote the paper. Asmus Vogel and Gunhild Waldemar assisted in designing the study, supervised the data analysis and assisted in writing the paper.

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Table 1. Demographic characteristics of Turkish minority and ethnic Danish subjects

			Age			Schooling		
Ethnic group	*n*	% Female	*M*	*SD*	Range	*M*	*SD*	Range
Turkish	73	56	61.5	7.2	50-81	3.9	4.0	0-16
Danish	36	53	72.1	6.7	62-87	8.8	1.9	7-12

Table 2. Performance on RPT, CRT and SF in Turkish minority and ethnic Danish subjects

	Turkish minority (n=73)			Ethnic Danish (n=36)		
Test	*M*	*SD*	Range	*M*	*SD*	Range
RPT						
Incidental recall	5.6	1.5	2-9	5.1	2.1	2-10
Immediate recall	7.6	1.2	4-10	7.4	1.3	5-10
Delayed recall	8.2	1.5	3-10	8.3	1.7	3-10
Recognition	9.9	0.3	9-10	9.9	0.2	9-10
CRT*	10.8	1.7	3.5-12	11.6	0.6	10-12
SF*	19.9	6.3	7-40	22.9	5.8	12-40

RPT, Recall of Pictures Test; CRT, Clock Reading Test; SF, Supermarket Fluency.

* Significant difference, *p*<0.01

Table 3. RPT, CRT and SF performance in elderly Turkish minority subjects expressed as percentiles (n=73)

Percentile score	RPT				CRT	SF
	Incidental recall	Immediate recall	Delayed recall	Recognition		
90	8	9	10	10	12	28
50	5	8	8	10	11.5	19
25	5	7	7	10	10.5	16
10	4	6	6	9.4	9.0	12
5	3	5	5.7	9	7.3	10.7

RPT, Recall of Pictures Test; CRT, Clock Reading Test; SF, Supermarket Fluency.

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Demens hos etniske minoriteter

Er det en overset problemstilling?

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RESUME

Der findes et stigende antal ældre blandt etniske minoriteter i de fleste vestlige lande, men patienter fra etniske minoriteter er underrepræsenterede i demensudredning og pleje. Dette kan hænge sammen med den kulturelle opfattelse af demens samt manglende viden om de tilgængelige tilbud blandt etniske minoriteter. Samtidig er det være svært at foretage en fuldgyldig klinisk undersøgelse af de etniske minoritetspatienter, som faktisk søger læge for demenssymptomer. Specielt er tolkningen af kognitive testresultater en vanskelig udfordring.

Der er et stigende antal ældre i vestlige lande, og den samme tendens gør sig gældende for disse landes etniske minoriteter. Demens i disse befolkningsgrupper bliver derfor et stadig mere aktuelt emne. Behovet for udredning, behandling og pleje af ældre fra etniske minoriteter eksisterer allerede, men vil blive langt større i fremtiden. Antallet af ikkevestlige indvandrere i Danmark på 60 år og derover er ca. 18.500. Ved fremskrivning, som er foretaget af Danmarks Statistik, kommer dette tal op på ca. 74.000 i år 2030 og ca. 115.000 i år 2050 [1]. I litteraturen benyttes mange forskellige definitioner af etnicitet, og der skelnes ikke altid konsekvent mellem etnicitet og race. Til denne artikels formål har vi valgt at definere etnisk minoritet bredt, som »personer med en anden kulturel baggrund end majoritetsbefolkningen«. Indvandringsmønstret og de etniske minoriteters historie er meget forskellig i vestlige lande, hvorfor det kan være svært at lave direkte sammenligninger. I Danmark er det primært blandt de tyrkiske og pakistanske arbejdsmigranter, som kom til Danmark i 1960'erne og 1970'erne, samt blandt flygtninge/indvandrere fra det tidligere Jugoslavien, at man finder personer over 60 år.

Formålet med denne artikel er at beskrive problemstillinger i opsporing, udredning og pleje af ældre demente fra etniske minoriteter. Desuden analyseres årsager til forskellig forekomst af demens i forskellige etniske grupper. Endelig diskuteres faldgruber i anvendelsen af *Mini Mental State Examination* (MMSE) [2] i forhold til patienter med etnisk minoritetsbaggrund.

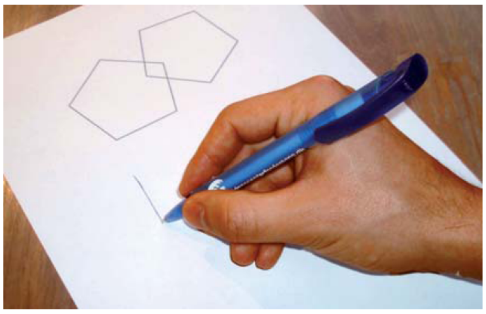
MATERIALE OG METODER

Der er søgt i PubMed (frem til august 2008) ud fra nøgleordene *ethnic minority, ethnicity, immigrant, race, cross-cultural* og *transcultural* kombineret med enten *dementia*, *Alzheimer's disease* eller *Mini Mental State Examination*. Der er desuden inkluderet relevante danske publikationer.

Artikler, som vedrørte etnicitet, MMSE, Alzheimers sygdom og/eller demens hos personer over 60 år, blev udvalgt. MMSE er det mest udbredte kognitive måleredskab inden for demensudredning, og artiklen er begrænset til kun at fokusere på denne. Artikler, der udelukkende fokuserede på neuropsykologisk testning, blev derfor ikke inkluderet. Der blev foretaget manuel gennemgang af referencelisterne i de fundne artikler. Der er søgt i Cochrane-databasen med enkeltordene *ethnicity* og *dementia*, men der blev ikke fundet relevante Cochrane-*review*.

BEHOV FOR DEMENSUDREDNING, STØTTE OG PLEJE I ETNISKE MINORITETSGRUPPER

Flere studier fra England, Frankrig og Danmark har fundet, at demente fra etniske minoriteter og deres familier ikke benytter sig af de tilgængelige tilbud i samme grad som resten af befolkningen. Deres behov synes derfor enten ikke være blevet opdaget, de har



Kopiering af overlappende figurer ved udførelse af *Mini Mental State Examination*.

et mindre behov end resten af befolkningen, eller også har man ikke på tilstrækkelig vis forsøgt at opfylde deres behov [3, 4]. Ved gennemgang af litteraturen foreslås der flere årsager til, at etniske minoriteter er underrepræsenterede inden for demensudredning og pleje. Der kan være forskelle i prævalens af demens mellem etniske grupper, hvilket delvist kan skyldes genetisk variation; de instrumenter, som benyttes til at vurdere kognitive funktioner, er ikke kulturelt følsomme; der kan være forskellig kulturel opfattelse af tegn og symptomer på demens; der kan være forskellig aldersfordeling i etniske minoriteter i nogle lande; der kan være stigma forbundet med demens; der kan være mangel på viden om tilbud og en generel modvilje mod at benytte sundhedssektoren eller den sociale sektor, som nogle etniske minoriteter kan opfatte (eller have oplevet) som kulturelt upassende eller endda racistisk. Blandt førstegenerationsindvandrere er specielt sproglige vanskeligheder et problem i forhold til at diagnosticere og støtte demente patienter [5].

FOREKOMST AF DEMENS HOS ETNISKE MINORITETER

Størstedelen af de studier, i hvilke man har undersøgt prævalensen af demens i forskellige etniske grupper, har fundet mere eller mindre den samme prævalens [5]. Årsagen til demens synes dog at være forskellig, idet den rapporterede prævalens af Alzheimers sygdom (AD) er mindre hos Cree-indianere [6] og personer fra Yoruba i Nigeria [7], og prævalensen af vaskulær demens synes større end prævalensen af AD i Asien [8]. Faktorer, som kan bidrage til de observerede forskelle i årsager til demens, indbefatter forskellig frekvens af ApoE4-allelet, forskelle i vaskulære risikofaktorer, forskelle i livsstilsfaktorer og forskellig kulturel indstilling til hvordan og hvornår, man benytter sundhedsvæsnet [9].

AD ser ud til at være den mest almindelige årsag til demens i alle etniske grupper i USA, men der findes ofte en øget prævalens blandt de afrikansk amerikanske og latinamerikanske minoriteter [10]. Resultaterne fra danske [1] og engelske [11] studier antyder ligeledes, at prævalensen af demens blandt ældre indvandrere kan være op til dobbelt så høj som blandt majoritetsbefolkningen. Meget tyder imidlertid på, at de umiddelbart store forskelle mellem etniske grupper i de sammenlignende studier skyldes, at man ikke har taget højde for forskelle i uddannelsesniveau og andre sociale faktorer [10].

I et engelsk studie fandt man, at prævalensen af demens var højere i afrikansk-caribiske immigranter sammenlignet med etniske englændere og etniske minoriteter, som var født i England, selv om personerne med afrikansk-caribisk oprindelse var signifikant yngre [11]. I dette studie ser fundene ikke ud til at opstå på baggrund af forskelle i sproglige færdigheder eller uddannelsesniveau. Der er ligeledes fundet en højere prævalens af demens hos amerikanske indere sammenlignet med indere i Indien [12] og i amerikanske japanere sammenlignet med japanere i Japan [13]. Prævalensen af demens hos amerikanske japanere var dog på højde med kaukasider. Ved en direkte sammenligning af incidensen af demens i Yoruba i Nigeria og afrikanske amerikanere fra Indianapolis ses en signifikant lavere incidens af AD (1,2% ift. 2,5%) og demens (1,4% ift. 3,2%) i Yoruba [14]. Dette tyder på, at udvikling af demens påvirkes af ændringer, som er relateret til at flytte fra sit oprindelsesland og bosætte sig i Vesten.

Det er veldokumenteret, at der er en overrepræsentation af hypertension, øget dødelighed på baggrund af cerebrovaskulær sygdom og en større forekomst af diabetes hos afrikansk-caribiere og afrikanske amerikanere. Dette kan være med til at forklare den større prævalens af demens i disse grupper, da disse forhold er kendte risikofaktorer for demens [15]. Et lignende billede findes blandt flere af de etniske minoriteter i Danmark [16]. Samlet set tyder resultaterne fra disse studier altså på, at forekomsten af demens hos nogle etniske minoriteter kan være højere end i baggrundsbefolkningen.

DEMENSUDREDNING AF ETNISKE MINORITETER

Kognitive test og klinisk vurdering har en central placering i udredningen af demens, og der er forbundet specielle faldgruber med tværkulturel udredning af demens, som er relaterede til sproglige færdigheder og uddannelsesniveau. Specielt brugen af kulturelt indlejrede kognitive test, som bygger på sprogkendskab og tryghed ved testsituationen, kan være upassende eller vildledende, når de bruges til at vurdere kognitivt funktionsniveau [17]. Kulturelt tilpassede normer er også vigtige i vurderingen af demens. Nogle immigranter kan læse og skrive på et andet sprog, mens andre i praksis er analfabeter. Nyere immigranter fra landområder har muligvis ikke haft meget brug for at tilegne sig viden om, hvordan man tegner komplicerede geometriske figurer eller for nøjagtige datoer. På baggrund af dette vil fortolkningen af kognitive testresultater derfor sandsynligvis føre til en forkert diagnose, hvis man ikke samtidig tager forbehold for den pågældende patients uddannelsesniveau og baggrund [18]. Et studie har således fundet, at 6% af hvide personer uden kognitiv svækkelse og 42% af sorte personer uden kognitiv svækkelse blev forkert klassificeret som demente ud fra MMSE [19]. Det er derfor forsøgt at validere eller ændre testinstrumenterne, så de er bedre egnede til at undersøge kognitiv funktion i forskellige etniske grupper [15].

MMSE er det mest benyttede kognitive screeningsinstrument, men er i de fleste studier fundet at være påvirket af såvel uddannelsesniveau som etnicitet [18] (se **Tabel 1**). MMSE er oversat til mange forskellige sprog, og der er benyttet forskellige strategier til at tilpasse MMSE, så den er bedre anvendelig til forskellige etniciteter og uddannelsesniveauer. I et studie fandt man f.eks., at 25% af personerne i en gruppe med mindre end ni års skolegang scorede 18-23 på MMSE, hvilket normalt opfattes som udtryk for et betydeligt reduceret kognitivt funktionsniveau [20]. Det foreslås derfor at benytte 17/18 som *cut-off*, da det øger testens sensitivitet over for demens hos lavt uddannede personer fra etniske minoriteter. Dette synspunkt støttes i andre studier [21, 22]. En indvending mod denne tilgang er imidlertid, at man risikerer, at lavt uddannede personer fra etniske minoriteter får stillet demensdiagnoser langt senere i forløbet og dermed ikke får tilbudt den relevante behandling.

I flere studier har man fundet, at de enkelte *items* i MMSE har forskellig sværhedsgrad i forskellige sprog og kulturer [23, 24]. Selv mellem lande, som normalt anses for at ligge tæt på hinanden med hensyn til sprog og kultur, har der vist sig at være forskelle. For englændere er flere af MMSE's *items* således sværere, end de er for amerikanere [25]. En anden mulighed har derfor været at lave tillempede versioner af MMSE, hvor problematiske *items* er udskiftet med mere kulturelt passende *items* [26, 27]. Et problem ved denne tilgang er imidlertid, at ændringer i de enkelte *items* ikke altid svarer til de oprindelige *items* i sværhedsgrad eller i, hvad de måler. Eksempelvis har det vist sig, at hvis man erstatter »100-7« med den mindre krævende »baglæns stavning«, så medfører dette gennemsnitligt en forskel i den samlede score på 1,5 point. Desuden tester de to opgaver ikke de samme færdigheder [28]. Det anbefales derfor, at man kun bruger »100-7«-scoringsmetoden, da den bedst mindsker risikoen for falsk negative diagnoser [29].

På trods af disse faldgruber ser de kliniske demensdiagnoser alligevel ud til at være valide, idet et studie har vist, at stabiliteten af demensdiagnoser i en multietnisk population er den samme på tværs af de etniske grupper ved et års opfølgning [30].

PÅRØRENDE TIL DEMENTE FRA ETNISKE MINORITETER

Der er stor forskel på graden af offentlig støtte og mulighederne for pleje i forskellige kulturer. Der er samtidig store forskelle på familienetværkets størrelse i forskellige kulturer, og på hvordan dette inddrages i plejen af ældre familiemedlemmer. Disse forhold har alle betydning for, hvordan det opleves at være pårørende til en dement. I langt de fleste studier har man sammenlignet pårørendes oplevelse af at tage sig af en dement i forskellige etniske grupper i USA. De overordnede temaer inden for emnet dækkes af tre oversigtsartikler [5, 31, 32].

I en amerikansk oversigtsartikel gennemgås 12 komparative studier af racemæssige, etniske og kulturelle forskelle i pårørendes oplevelse af at tage sig af en dement [31]. Forfatterne bemærker, at der er flere metodologiske problemer i disse studier, specielt da der ikke er brugt store repræsentative grup-

TABEL 1

Mini Mental State Examination-score på baggrund af alder og uddannelse er givet ved gennemsnit og standardafvigelse samt median. Data gengivet fra en amerikansk multietnisk befolkningsundersøgelse, n = 6.698 [40].

Mini Mental State Examination-score på baggrund af varigheder af skolegang

	0-4 år		4-8 år		9-12 år		13+ år	
Alder (år)	**gennemsnit (SD)**	**median**	**gennemsnit (SD)**	**median**	**gennemsnit (SD)**	**median**	**gennemsnit (SD)**	**median**
60-64	23 (1,9)	22	26 (2,3)	27	28 (1,7)	28	29 (1,3)	29
65-69	22 (1,9)	22	26 (1,7)	27	28 (1,4)	28	29 (1,0)	29
70-74	22 (1,7)	21	26 (1,8)	26	27 (1,6)	28	28 (1,6)	29
75-79	21 (2,0)	21	25 (2,1)	26	27 (1,5)	27	28 (1,6)	28
80-84	20 (2,2)	19	25 (1,9)	25	25 (2,3)	26	27 (0,9)	28
85+	19 (2,9)	20	23 (3,3)	24	26 (2,0)	26	27 (1,3)	28

SD = standardafvigelse.

per, multivariate analyser, kontrolgrupper og tydelige teoretiske forståelsesrammer. Sammenlignet med kaukasider findes det i disse studier, at afrikansk-amerikanske og latinamerikanske pårørende i højere grad benytter sig af tro, religion og bøn som *coping*-strategier, at børnene i højere grad anses for at være forpligtet til at hjælpe forældrene, at det er mindre sandsynligt, at den pårørende er en ægtefælle frem for et andet familiemedlem eller en ven, og at de pårørende angiver en lavere grad af belastning, »byrde« og depression. Nogle af disse forhold genfindes dog ikke entydigt i senere studier [32]. Der findes aktuelt kun meget få studier af asiatisk-amerikanske pårørendes oplevelse af at tage sig af en dement, og der kan endnu ikke drages samlede konklusioner fra disse studier [32].

Andre interessante fund er, at afrikansk-amerikanere havde lavere indtægter end deres kaukaside modstykke; dem, som benyttede sig af støttegrupper, var primært kaukasider fra middelklassen; kaukaside pårørende havde færre udækkede behov end afrikansk-amerikanske og latinamerikanske pårørende; afrikansk-amerikanske pårørende havde større behov for aflastning end kaukasider, og det var mere sandsynligt, at kaukaside demente kom på plejehjem end afrikansk-amerikanske demente. Disse fund støtter i høj grad den almindelige antagelse om, at etniske minoriteter i højere grad »tager sig af deres egne« [5]. Samtidig viser flere studier imidlertid, at pårørende fra etniske minoriteter ikke modtager mere støtte fra deres sociale netværk end kaukasider, hvilket kan være udtryk for, at de ikke har det store sociale netværk, som det ofte antages, at der er blandt nogle etniske minoriteter [32]. Der kan derfor være tale om, at pårørende fra etniske minoriteter er forholdsvist isolerede i deres hjælp, støtte og pleje af et dement familiemedlem.

ETNISKE MINORITETER OG HOLDNING TIL AT SØGE HJÆLP

Et kvalitativt studie af opfattelsen af demens, pleje og holdning til at søge hjælp blandt vietnamesiske immigranter i USA viser, hvordan demens somme tider ikke prioriteres som et helbredsproblem. Andre problemstillinger, såsom sproglige problemer, overfyldte lejligheder, arbejdsløshed og social isolation var af langt større bekymring [33]. I et andet kvalitativt studie fandt man, at vietnamesiske og kinesiske immigranter syntes, at migration og kulturchok medførte, at symptomer på demens blev mere udtalte [34]. At nogle etniske minoritetsgrupper ikke prioriterer demens som et problem i lyset af andre mere overskyggende eller presserende materielle bekymringer, illustreres bedst af en oversigtsartikel om demens hos australske aboriginere og personer fra Torres Straight-øerne [35]. Der findes ikke noget ord for »demens« i disse samfund eller et andet ord, som beskriver tilstanden på en meningsfuld måde. Personer fra disse samfund står over for mere presserende problemer, såsom utilstrækkelige boligforhold, utilstrækkelig uddannelse og sygehusvæsen og mangel på rent vand. Desuden kan demens i nogle kulturer simpelt hen opfattes som en uacceptabel diagnose [36]. For eksempel har man i kvalitative studier med etniske minoriteter i USA [34, 37], etniske indere i England [38] og etniske tyrkere (og kurdere) i Danmark [1] fundet, at demens i disse grupper i høj grad anses for en naturlig og uhelbredelig konsekvens af alderdom. Endvidere har flere studier fundet, at kinesiske amerikanere anser mental sygdom som ekstremt skamfuld og stigmatiserende [39]. Alle disse forhold kan have betydning for, om etniske minoriteter søger læge pga. demenssymptomer.

KONKLUSION

Der er meget sparsom viden om demens blandt etniske minoriteter i Danmark. Selv om forekomsten af demens i etniske minoriteter ser ud til at være mindst lige så stor som i baggrundsbefolkningen, er patienter fra etniske minoriteter underrepræsenterede inden for demensudredning og pleje. Dette kan dels hænge sammen med, at demente og pårørende fra etniske minoriteter ikke har tilstrækkelig viden om de tilgængelige tilbud. Samtidig kan hukommelsessvigt og andre demenssymptomer træde i baggrunden for mere presserende materielle eller sociale problemer, eller de kan opfattes som en naturlig konsekvens af alderdom. I nogle etniske grupper er der desuden forbundet et stærkt socialt stigma med mental sygdom. Disse forhold kan alle have betydning for, om man søger læge på baggrund af demenssymptomer. Hvis demente fra etniske minoriteter faktisk søger læge på baggrund af demenssymptomer, vil de ofte møde et system, som ikke er rustet til at håndtere deres specielle kulturelle behov, og det vil sjældent være muligt for lægen at lave en fuldgyldig undersøgelse, da de anvendte kognitive måleinstrumenter er kulturelt indlejrede. En uheldig konsekvens af disse forhold kan være, at demente fra etniske minoriteter isoleres i hjemmet, hvor de plejes af den nærmeste familie uden udefra kommende hjælp. Der er derfor behov for mere oplysning om demens til borgere fra etniske minoriteter og for, at sundhedspersonale sætter mere fokus på udredning og social støtte af demente borgere med etnisk minoritetsbaggrund.

Den teknologiske udvikling har medført bedre og bedre muligheder for at påvise patologiske forandringer i hjernen, hvilket kan være værdifuldt, hvor me-

! FAKTABOKS

Patienter med etnisk minoritetsbaggrund er underrepræsenterede inden for tilbud om demensudredning og pleje.

Det er ofte problematisk at udføre kognitiv testning af patienter med etnisk minoritetsbaggrund, da de tilgængelige test er kulturelt indlejrede.

Pårørende til demente fra etniske minoriteter modtager sjældnere støtte eller hjælp uden for den nærmeste familie.

Der er behov for mere viden om demens hos etniske minoriteter blandt læger og sundhedspersonale og for oplysning om demens til borgere fra etniske minoriteter.

ningsfuld kognitiv testning ikke er mulig. Specielt strukturelle (computertomografi (CT), magnetisk resonans (MR)-skanning) og funktionelle (enkeltfotonemissionstomografi (SPECT), positronemissionstomografi (PET)) billeddannelsesteknikker samt spinalvæskeundersøgelser kan vise sig værdifulde i at påvise organisk påvirkning af hjernen og undertiden også være vejledende for en ætiologisk diagnose. På trods af disse fremskridt er kognitiv testning dog fortsat central i demensdiagnostik, hvorfor der er et særligt behov for udvikling af kognitive test, som er målrettet patienter fra etniske minoriteter, som ikke er opvokset i dansk kultur og ikke har dansk som modersmål.

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ANTAGET: 8. marts 2009

FØRST PÅ NETTET: 30. november 2009

INTERESSEKONFLIKTER: Ingen

TAKSIGELSER: Tak til Forskningsrådet for Kultur og Kommunikation for økonomisk støtte til forskningsprojekt vedrørende demens blandt etniske minoriteter. Tak til Sygekassernes Helsefond og Ministeriet for Sundhed og Forebyggelse for økonomisk støtte til Nationalt Videnscenter for Demens.

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