

The SYMBOL Study: A Population-Based Study on Health and Cognition in Immigrant Older Adults in the Netherlands

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Abstract

Introduction: In the Netherlands, older adults of Turkish, Moroccan and Surinamese descent form the largest groups of “first-generation immigrants”. Next decade, they will comprise 5% of the general Dutch population. When compared to native Dutch, rates of general health problems and chronic diseases are higher among older immigrants. With the aging of the first generation immigrants and the higher prevalence of cardiovascular diseases, the incidence of mild cognitive impairment (MCI) and dementia are expected to increase as well.

This paper presents the design of a population-based, cross-sectional cohort study to assess prevalence of MCI and dementia in the largest immigrant groups in the Netherlands.

Methods/Design: Participants, aged 55 years and older, of Dutch, Turkish, Moroccan (Arabic and Berber speaking), and Surinamese (Hindi and Sranantongo speaking) background, will be recruited via their general practitioners. Main outcome is the prevalence of MCI and dementia in these largest immigrant groups in the Netherlands. Secondary outcomes are prevalence of other relevant health problems in older immigrant adults, e.g. comorbidity, loneliness, depression, health related quality of life, care needs and use of care by older immigrant adults with diagnosed dementia. Cognitive functioning is assessed by the Cross Cultural Dementia screening, which was designed specifically for illiterate or low-educated people from different cultures speaking different languages. Secondary outcomes will be assessed by means of a systematic comprehensive geriatric assessment.

Discussion: This study will provide important information on the prevalence of MCI and dementia and related comorbidity in older immigrants in the Netherlands.

Keywords Health assessment; Cognition; Dementia; Migrants; immigrants; Older persons; Cross-Cultural; Elderly; Population based

Introduction

A substantial and still increasing part of the general population in European countries consists of non-Western immigrants, who –in general– arrived in the 20th century as labour workers [1]. In the Netherlands, most immigrants came from Turkey, Morocco, and former colony Suriname. Their proportion of the Dutch population will grow from 7.2% in 2003 to 14.6% by 2020. The “first-generation immigrants” are currently aging and in the next decade, the number of non-western immigrants over 60 years of age will increase to 5% of the peer population [2]. The Turks and Moroccans came to the Netherlands during the 1960s and early 1970s, and most of them have difficulties speaking and writing Dutch [3]. The Surinamese migrated to the Netherlands during the process of decolonization which took place around 1975. They are familiar with Dutch society and have good command of the Dutch language, as they were taught Dutch language at school. In general, older immigrants have a lower

educational level and a lower socio-economic status (SES) than the older native Dutch [4,5].

Immigrants often face particular health problems and are vulnerable to a number of threats to their physical and mental health [6]. However, their specific health needs are often poorly understood, communication with health care providers remains poor, and health systems are not prepared to respond adequately to their needs [6]. In the Netherlands, when compared to native Dutch, rates of general health problems are higher among older immigrants. Not only do they experience poorer general health, they also report higher frequencies of chronic diseases at a younger age [3,7-10]. Use of formal health care services, such as home care, is less frequent among older migrants, mostly because of unfamiliarity with the (in)formal procedures [8,11], and because of cultural differences [7]. Because first-generation immigrants are often underrepresented in general health surveys and clinical research, specialised therapy or care cannot be provided, nor can appropriate health care policy be developed [12].

The above-mentioned factors underscore the urgent need for reliable and valid health assessment scales that can overcome language and cultural barriers. Cross-culturally adapted health assessment scales

would enable professionals to assess each patient's health in the patient's own cultural context. However, we recently concluded that there is a lack of high-standard cross-culturally adapted assessment scales [1].

Parallel with the aging of the immigrant population and the higher prevalence of cardiovascular diseases [7,10], mild cognitive impairment (MCI) and dementia might become a common phenomenon in this specific group [13,14]. In western populations, prevalence of MCI differs between 3.0% and 19.0% depending on definition [15]. The most common subtype of MCI, amnesic MCI (aMCI), presents with prominent memory impairment and is likely to progress to dementia with 10 to 15% per year [16]. 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 [17,18]. Higher prevalence of MCI and dementia has been described for older African-American and Hispanic people in the United States of America, and for Africa-Caribbean and South Asian people in the United Kingdom [19-25]. Recent research in Denmark showed a prevalence of dementia of 13.5% among older Turkish immigrants, compared to 7.0% in the Danish population. Dementia was assessed using ICD-10 criteria and the Mini Mental State Examination (MMSE) [26], though the researchers stated that the MMSE had specific shortcomings [27].

The assessment of dementia may be influenced by language barriers, cultural variations in expression of symptoms, and the fact that most cognitive screening instruments themselves are affected by culture [28,29]. Cognitive capacities of low-educated and illiterate persons are generally underestimated by common screening instruments, which can result in overestimation of dementia prevalence [30]. However, it is important to know MCI and dementia prevalence in older migrant adults to prepare health care professionals and care facilities, and to give adequate information about these syndromes to the specific groups of older migrants.

In 2005 Goudsmit et al. developed the Cross-Cultural Dementia screening test (CCD), a nonverbal cognitive screening test battery which can distinguish older migrant adults with mild to moderate dementia from their healthy peers [28,31]. The current version of the CCD can be administered in Dutch, in Turkish, in two Moroccan languages (Moroccan Arabic and Berber), (Al Hoceima dialect) and in two Surinamese languages (Hindi and Sranantongo). The CCD measures multiple cognitive functions and can be used cross-culturally, because the visual test materials are all suitable for persons from different cultures. Language barriers are minimal because instructions are in the patient's own language -spoken by a computer-, and the patient's response is mostly nonverbal.

The aims of the present study are:

- To assess prevalence of MCI and dementia in the largest immigrant groups in the Netherlands by means of the CCD,
- To assess prevalence of other relevant health problems in older immigrant adults, e.g. comorbidity, loneliness, depression, health related quality of life, and
- To assess specific care needs and use of care by older immigrant adults with diagnosed MCI and dementia.

Methods

Design and setting

This population-based, cross-sectional study will be conducted in the four largest cities of the Netherlands, i.e. Amsterdam, Rotterdam, The Hague and Utrecht, and in three medium sized cities: Hoorn, Haarlem and, Zaandam. In the first four cities, Turkish, Moroccan and Surinamese populations are at least twice as dense as compared to other towns and regions in the Netherlands. The latter three cities also have a relative large immigrant population [32]. On a voluntary basis, community-dwelling participants will be recruited from general practitioners' (GP) practices in areas with low socio-economic status (SES) [33]. Inclusion will take place from May 2010 to May 2013.

Participants

Inclusion criteria are: age of 55 years or older, born in Turkey, Morocco, Suriname or the Netherlands, and able to speak and understand either Dutch or one of the languages of the country of origin. The ethnic groups will be represented by their languages: Dutch by the Dutch language, Turkish by the Turkish language, Moroccan by Moroccan Arabic and Berber, and Surinamese by Hindi and Sranantongo. Dutch participants will serve as control group. Exclusion criteria are: previous neurological or psychiatric diseases with possible persisting effect on cognitive functioning, severe sensory deficits that preclude engagement in the assessments, or no informed consent. The exclusion criteria can be obtained from the subject, a family member and/or the GP.

Procedure

All participants will be invited to participate via a (bilingual) letter sent by their GP and the research team, followed by a personal invitation by phone by one of the bilingual and bicultural interviewers. Research appointments will take place either in the GP's practice, in a social center (i.e. primary care health center and community center), or at the participant's home, depending on their preference. After informed consent is obtained, the research appointment exists of an interview, during which a systematic geriatric comprehensive assessment (CGA) by means of an interview is administered, and cognitive testing by means of the CCD. The research appointment takes 60 to 90 minutes. In the informed consent procedure, participants also will be asked permission: a. to register their medical history from the GP's medical charts, and b. to contact a relative in order to collect more information about cognitive functioning of the participant. This last part of the informed consent procedure will be used only when participants score below the pre-defined cut-off of the CCD.

Approval

The study was approved by the local medical ethical committee of the Academic Medical Center of the University of Amsterdam.

Measurements

During the research appointment, trained bilingual and bicultural interviewers will administer the CGA and cognitive testing with the CCD. For Turkish and Moroccan participants, this will be done during an interview in their own mother tongue. The Surinamese and the Dutch participants will complete the CGA as a self-administered

questionnaire in Dutch because of their command of the Dutch language. These participants will perform the CCD in their preferred language (Dutch, Hindi or Sranantongo).

Systematic Comprehensive Geriatric Assessment (CGA)

The CGA is derived from two sources. First, during the design of this study, the Dutch Ministry of Health, Welfare and Sport commissioned the National Care for the Elderly Programme. Under this Programme, The Older Persons and Informal Caregivers Survey Minimal dataset (TOPICS-MDS) was developed. An extensive description of TOPICS-MDS has been published elsewhere [34]. To summarize, TOPICS-MDS gathers the following: demographic characteristics, morbidity, health related quality of life (EuroQol-5D +C) [35,36], functional status, emotional wellbeing, social functioning and health services utilisation. If applicable, from the informal caregiver or relative, information is collected on demographics, hours of informal care, Quality of Life, and Care related Burden.

Secondly, instruments and questionnaires will be added that are relevant for the research questions. For the participant, quality of life will also be assessed with the COOP/WONCA charts [37]. These charts measure six core aspects of functional status: physical fitness, mood, daily activities, social activities, change in health and overall health. The reference period is two weeks. The COOP/WONCA has been translated into at least 19 languages, and is validated in Turkish and Arabic [38]. To the morbidity scale of TOPICS-MDS, bipolar mood disorder and mental handicap are added, as they could influence cognitive functioning [13]. Because depression is a common phenomenon in older migrant persons [8,10], the Geriatric Depression Scale (GDS) will be added. The version with two questions (GDS-2) will be asked first and when the participant answers both questions affirmative, the GDS-15 will be administered [39,40]. Loneliness is another major problem among older persons in the Netherlands and because older migrants have potentially an even higher risk of loneliness, the De Jong Gierveld Loneliness Scale (DJGLS) has been added [41,42]. The DJGLS has recently been used in Turkish people in Germany [43]. Finally, the participant will be asked about use and kind of medical care in the home country. We would like to verify a finding from earlier research, that most people don't seek medical care in their home country because they are dissatisfied with their Dutch GP, but because of new complaints during the stay there [44]. For the relative or caregiver of the participant, two questionnaires will be added, which will be administered only if the participant scores below cut-off at the CCD. First, the abbreviated form of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE-sf) will be taken, in which the informant is asked to compare the participant's current cognitive functioning with cognitive functioning ten years before [45,46]. The IQCODE-sf has been validated in Turkey in 2010 [47]. Second, the NeuroPsychiatric Inventory Questionnaire (NPI-q) will be taken, which assesses behavioural problems in patients with dementia [48,49].

Comorbidity will be scored systematically with the Charlson Comorbidity Index (CCI) [50], the Local and National Health Monitor [51] and the International Classification in Primary Care [52]. CCI scores range from 0 to 31, with a higher score indicating more and/or more severe comorbidity. In the other comorbidity scales, a count is made of the different diseases and/or conditions.

Cross-cultural adaptation of the systematic CGA

For forward-backward translation of the Dutch version of the CGA into Turkish, the two Moroccan languages and the two Surinamese

languages, we followed the guidelines of the European Organization for Research and Treatment of Cancer (EORTC) for cross-cultural adaptation of questionnaires [53]. Two independent forward translators who were native speakers of the target language translated all items. We generated the Moroccan-Arabic version in phonetic Arabic script and the Berber version in commonly used Latin script to make it easier to administer. Differences were reconciled in a consensus meeting, and another translator who was also proficient in Dutch back translated the forward translation. Any discrepancies were discussed and resolved by the Moroccan and Surinamese interviewers and the Turkish research coordinator (ÖU), resulting in a final translation. Five persons per language group were then invited to perform the Three-Step Test-Interview (TSTI) [54]. The TSTI is an instrument for pre-testing a self-completion questionnaire by observing actual instances of interaction between the instrument and respondents (the response process). This process led to some additional minor changes in grammar and wording. Although a large part of the Surinamese population speaks Dutch, their cultural background differs substantially from that of the native Dutch. Therefore we also created two Surinamese versions, for Creole (Sranantongo) and Hindustani (Hindi).

Cross-Cultural Dementia screening (CCD)

The CCD was designed specifically for illiterate and/or low-educated people. It requires almost no general factual knowledge and no reading or writing skills [31]. The CCD consists of three subtests that are sensitive to cognitive impairment due to dementia: visual memory, mental speed and selective and divided attention. Every subtest has multiple examples to ensure that the subject understands the instructions. The test uses visual stimulus material that is suitable for people from different cultures/ethnicities. Furthermore, the subtests require only minimal verbal response or nonverbal responses of the subject, such as pointing to the right alternative. On a computer with sound system, the test instructions can be given by an administrator who selects digitally recorded voice samples in the appropriate language (Dutch, Turkish, Moroccan Arabic and Berber, Hindi and Sranantongo). This way of test administration is generally well understood by older migrants from different cultures. Administration time is approximately 20 minutes. The CCD has high sensitivity and specificity for dementia syndromes (resp. 85% and 89%), the retest reliability is good, and the test is only minimally to moderately sensitive to educational and cultural differences [55], [Goudsmit, M, Uysal-Bozkir Ö, Parlevliet, JL, van Campen, JE, Schmand B 2014. The Cross-Cultural Dementia Screening (CCD): a new neuropsychological screening instrument for dementia in low-educated and illiterate elderly migrants].

Training of the interviewers and correction of data

Bilingual and bicultural interviewers administer the CGA and CCD. All are students of psychology or a related discipline. They will receive 9-12 hrs of extra training in administration and scoring of the CGA and the CCD by the researchers (JP and ÖU). To ensure accuracy of data collection and data entry, trained research assistants will review all questionnaires and CCD-test forms for possible errors. If any errors are identified, these will be discussed with the interviewer and corrected by the research assistant.

Outcomes

Primary outcome

The primary outcome of the SYMBOL study is the prevalence of MCI and dementia in the largest immigrant groups in the Netherlands, aged 55 years and over, as assessed with the CCD in the Turkish, Moroccan Arabic and Berber, Hindi and Sranantongo versions. This prevalence will be compared with the prevalence of MCI and dementia in a matched sample of native Dutch participants, assessed with the CCD in the Dutch language version. Mild cognitive impairment (MCI) is defined as delayed recognition score on the delayed visual memory task of the CCD below the 10th percentile, in the presence of subjective memory problems, i.e. mild or severe problems with cognitive function, as rated in the last question of EQ-5D+C by participant's self-report [35]. Presence of dementia is defined as scoring below the cut-off scores established in the CCD validation study, in which logistic regression analyses showed that a combination of the three subtests generated a sensitivity of 85% and a specificity of 89% in predicting dementia in a group of 108 migrant and Dutch dementia patients (Alzheimer, vascular, frontotemporal, and Lewy Body) and matched healthy controls [Goudsmit M, Uysal-Bozkir Ö, Parlevliet JL, van Campen JE, Schmand, B 2014. The Cross-Cultural Dementia Screening (CCD): a new neuropsychological screening instrument for dementia in low-educated and illiterate elderly migrants].

Secondary outcomes

The prevalence of other relevant health problems in participants, e.g. comorbidity, loneliness, depression and health related quality of life will be obtained from the CGA. Care needs and use of care by immigrants with diagnosed dementia and their care givers will also be obtained from the CGA.

Statistical analyses

Sample size

We will include 2000 older immigrants (500 per ethnic group) and 500 older Dutch natives. Ages range from 55 to 85 years, stratified into five-year age groups. Based on previous research and the composition of the Dutch population, we expect 1. that Turkish and Moroccan participants will be most difficult to include, and 2. that the older they are, the more difficult inclusion will be, so that probably few Turkish or Moroccan participants will be included in the oldest age groups [8,56]. Thus, Turkish and Moroccan participants will determine the composition of all age strata in the other ethnic groups. Furthermore, based on the study of Rosenbaum et al, we hypothesize that dementia prevalence among older immigrants will be twice as high compared to older native Dutch [27].

Based on the expected age distribution and the above-mentioned premises, we expect to find approximately 2% participants with dementia in the Dutch group (N=500), and approximately 4% in the immigrant groups (N=2000). The study will have ca. 90% power to detect the hypothesized differences in dementia prevalence with $\alpha=5\%$ (one-tailed).

Prevalence of MCI and dementia

The prevalence ratios of MCI and dementia in the ethnic groups will be calculated based on the definitions above, and differences between the immigrant groups and the Dutch control group will be analyzed using chi-square tests.

Health problems in participants

Participant's characteristics and outcomes of the CGA will be summarized using descriptive statistics. Distribution of frequencies will be used to describe the patient characteristics, average and standard deviation for continuous variables. Differences in patient characteristics are tested by chi-square test or the Mann-Whitney U test, $p < 0.05$ is considered as statistically significant. In all analyses, statistical differences will be quantified using the corresponding 95% confidence intervals.

Care needs and use of care by immigrants with diagnosed dementia and their care givers

These data will be summarized using descriptive statistics. A comparison will be made between Dutch participants and their care givers and participants from the other language groups. All statistical analyses will be performed Statistical Package for the Social Sciences (SPSS) version 20.0 (SPSS Inc., Chicago, IL).

Discussion

With the aging immigrant population in many countries in Europe, and their higher prevalence of cardiovascular diseases, there is an urgent need to determine the prevalence of MCI and dementia in this specific population. The study will use a promising dementia screening instrument, the Cross-Cultural Dementia screening (CCD), which was designed specifically for illiterate or low-educated people from different cultures and speaking other languages. Other health problems will be assessed with a cross-culturally adapted CGA, and care needs and use of care by immigrant with diagnosed dementia and their care givers will be listed, which are unique features of this study. To our knowledge, this study is the first larger population-based study focusing on prevalence MCI and dementia in immigrant groups in Europe.

Knowledge about the prevalence of MCI and dementia, and knowledge about care needs in the aging immigrant population will enable health care professionals and care facilities to prepare for this new group of patients. Furthermore, the results could lead to improved medical care in MCI and dementia for these specific groups, and could cause adaptation of guidelines regarding comorbidity and possibly prevention of problems like MCI and dementia.

The inclusion of older immigrant might be difficult because of unfamiliarity with and lack of interest in research, suspiciousness towards institutions in general, fear of privacy breach, difficulty to read or understand the invitation and information letter, and shame about possible cognitive decline [11,25,57,58]. However, we will try to improve inclusion by inviting potential participants via the GP. In the Netherlands, virtually all inhabitants have a GP and in general, immigrants groups have a high utilisation of GP services [59]. Trustworthiness of the GP is ensured by liberty of choice of GP and the possibility to change from one GP to another if desired. Furthermore, the invitation letter will be written Dutch and in an appropriate language for the potential participant (Turkish, standard Arabic), and will be followed by a telephone call from a bilingual and bicultural interviewer to give further explanation about the study and its objectives, and to answer any questions. This procedure was applied by the Public Health Service Amsterdam (GGD) in their Health Monitor 2004 which focussed on cardiovascular risk factors among Turkish, Moroccan and Dutch inhabitants of Amsterdam [57]. Further barriers to participation will be lowered by interviewing and testing the participant either in the GP's practice, or in a social center

(i.e. primary health care center or community center), or at the participant's home, depending on the participant's preference.

The generalizability of the results will largely depend on the ability to include sufficient participants in all language groups and of all different ages. Despite the limitations addressed here, we expect that this study will provide important information on MCI and dementia in elderly immigrants in the Netherlands for policy makers, health care professionals, patients and informal caregivers.

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