Health status of older migrants in the Netherlands: Cross-cultural validation of health scales

Uysal-Bozkir, Ö.

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General discussion
The overall aim of the thesis was to improve health diagnostics for older migrants, with the help of cross-culturally validated scales. To achieve this, in Chapter two we reviewed the literature for available cross-culturally validated scales. We focused on the scales that were adapted for use with Turkish, Arab and Surinamese older people. Chapter three presents the study protocol of the SYMBOL study (Systematic Memory test Beholding Other Languages). In Chapter four and five, we translated and determined the psychometric properties of assessment scales which measure loneliness and depression for use among older migrants. In Chapter six we validated a newly-developed Cross-Cultural Dementia screening (CCD). The prevalence rates of MCI and dementia among Turkish, Moroccan and Surinamese migrants are reported in Chapter seven. The general discussion comprises the main findings of the thesis, along with methodological strengths and limitations and future implications for research and practice.

Main Findings

I. Lack of high-standard cross-culturally adapted health assessment scales

We started our research by reviewing the literature on existing cross-culturally validated health assessment scales. We focused on scales of different health domains; i.e. depression, loneliness, and cognitive decline. Our aim was to assess whether these scales are accurately cross-culturally validated to be used among individuals aged 65 years and older with a Turkish, Moroccan or Surinam descent. Our systematic review demonstrated that the translation and adaptation process was insufficient and that many studies lacked a clear description of the relevant psychometric properties for their translated health assessment scales. There were only a few scales that demonstrated appropriate adaptation for these specific groups of older people. Without appropriate cross-cultural validation of a scale, it is questionable to use an assessment scale in different cultures and settings than it originally was developed. Cross-culturally validated scales are needed in the clinical evaluation of these patient groups in which we face language barriers, and challenges due to cultural differences, low education and illiteracy. This also has implications for the limited test norms. Especially knowing that the group of older migrants will greatly increase, it is likely that the need to address this problem will grow.
II. SYMBOL: a study in the largest migrant groups in the Netherlands

Chapter three presents the design of the SYMBOL study, a population-based, cross-sectional cohort study to assess prevalence of MCI and dementia in the largest migrant groups in the Netherlands. Additional outcomes were prevalence of other relevant health problems in older migrants, e.g. multimorbidity, loneliness, depression, and health-related quality of life. Participants, aged 55 years and older, and of Dutch, Turkish, Moroccan, or Surinamese descent, were recruited via their general practitioners in suburbs of the Netherlands with large migrant populations. Cognitive functioning was assessed by the Cross Cultural Dementia Screening (CCD). Secondary outcomes were assessed through a systematic comprehensive geriatric assessment (CGA). This was composed of cross-culturally adapted, nationally-accepted questionnaires such as the Older Persons and Informal Caregivers Survey Minimum Data Set (TOPICS-MDS)\(^1\). We combined this cross-culturally adapted CGA with the CCD.

III. Cross-Cultural validation of De Jong Gierveld Loneliness Scale and the Geriatric Depression Scale

Given the wide range of serious consequences of loneliness and depression on both physical and mental health, we cross-culturally adapted the De Jong Gierveld Loneliness Scale (DJGLS) and the Geriatric Depression Scale – short version (GDS-15)\(^2,3\). Therefore we first systematically translated the DJGLS and the GDS, including forward- and backward translations, consensus meetings and cognitive pretesting. Afterwards we validated them for use among older migrants of Turkish and Moroccan descent, and the Dutch version was validated for older Surinamese migrants living in the Netherlands.

The DJGLS proved to be internally consistent and to have satisfactory construct validity for a two-factor model reflecting the 6-item emotional loneliness and 5-item social loneliness subscales. The results provided sufficient support for use of the translated version of the 11-item DJGLS among Turkish and Moroccan older migrants and use of the Dutch version for Surinamese older migrants as a reliable and valid measure of loneliness. The GDS-15 proved highly internally consistent among all ethnic groups and results of analyses for construct validity were acceptable. Proper psychometric values were found for the Turkish version, two Moroccan versions (Moroccan-Arabic, Tarifit) and the Dutch version for use among Surinamese (Creole and Hindu). Overall, the results provided support for the use of the (translated version of the) DJGLS and GDS-15 among older Turkish, Moroccan, and Surinamese migrants as adequate assessment scales for loneliness and depression, respectively.

Loneliness, depressive complaints and adverse health outcomes

All four migrant groups reported significantly higher levels of loneliness compared to their native peers. These results were in line with the higher levels of loneliness reported among Turks in Germany\(^4\). Also in line with previous reports, we found an association between
There was also a correlation between depressive complaints and poor health and between loneliness and depression, as was reported in earlier studies. In summary, we confirmed that the earlier-described relation between loneliness and depressive complaints was also present in older migrants.

**Relationship between loneliness, psychiatric disorders and cognitive impairment/dementia**

Emotional (psychiatric) problems, i.e. loneliness, depressive complaints and depression, are associated with memory complaints in older age, which may be early expressions of a dementia process. A previous study showed that loneliness may lead to a greater risk of dementia. Comparable results were found for depression, which has been both proposed to be a risk factor for dementia as well as a prodromal feature for dementia. Because specific risk factors for dementia (i.e. higher prevalence rates of vascular risk factors and psychiatric disorders) are frequently found, a higher incidence of dementia is expected in older migrants. Until now, prevalence rates of dementia among migrants were not known.

Cognitive testing is a key element in dementia diagnostics. However, there are important barriers to assessing cognition in older migrants: language and cultural barriers, and low education or literacy levels. We therefore focused on a newly-developed cross-cultural dementia screening test that was specifically designed to overcome these barriers.

**IV. The Cross-Cultural Dementia screening (CCD): a new neuropsychological screening instrument for dementia in migrant populations**

We assessed the newly-developed CCD. We hypothesized the CCD to be a culture-fair test that could discriminate between demented patients (recruited in memory clinics) and cognitively healthy controls (recruited in SYMBOL). We also expected the CCD to be relatively insensitive to ethnicity and education. Receiver operating characteristic and logistic regression analyses showed that the CCD had good predictive validity for dementia, a good sensitivity (85%) and specificity (89%). There were small to medium associations with ethnicity and education levels, but performance differences between the ethnic groups disappeared after correcting for age and education differences between the groups, which supported our central hypothesis that the CCD is a culture-fair test. Test-retest reliability was good \( r = 0.79 - 0.96 \). Overall we can state that the CCD is a proper dementia screening test for dementia in migrant populations with low education levels. The CCD is a useful addition to the common multidisciplinary diagnostic workup in memory clinics where, until now, a reliably-applicable dementia screening tool for diagnosing dementia among older migrants was lacking.
V. Prevalence of MCI and dementia is much higher in older community-dwelling non-western migrants than in the native Dutch

The aim of chapter seven was to gain some insight into the prevalence of MCI and dementia in the largest migrant groups in the Netherlands, relative to the older native Dutch population, with the use of the cross-culturally validated CGA (the CCD and other questionnaires in SYMBOL). Participants were migrants aged 55 years and older, recruited from the SYMBOL study. MCI prevalence was two to four times higher in the Turkish group, both Moroccan groups, and the Surinamese-Hindustani group, compared to the native Dutch participants. In the same ethnic groups, the frequency of occurrence of dementia was three to four times higher compared to the native Dutch group. Dementia prevalence in the Surinamese-Creole participants was comparable to the native Dutch participants. The dementia prevalence for Dutch participants was comparable to the rates found in previous studies.  

Possible explanations for the high dementia prevalence rates in the migrant groups include primarily socio-environmental factors, like education and SES. However, the association of education with test scores of the CCD is small. Education could therefore not fully explain the differences in dementia and MCI prevalence. Additionally, a higher prevalence of vascular risk factors and psychiatric disorders like depression have been suggested as causes of the higher dementia prevalence in migrants.

In the next paragraph the methodological strengths and limitations will be discussed in more detail, which may further clarify the findings. Specific recommendations for future research are discussed at the end of this chapter.

Methodological considerations

Strengths

Unique
The broad scope of our studies gave us the opportunity to contribute to the limited research in this field, especially in the field of cognitive impairment, in the form of cross-culturally validated health assessment scales for older migrants. These scales would enable health professionals to assess each patient’s health in their own cultural context.

The unique contribution of the SYMBOL is that we attempted to estimate the previously-unknown prevalence of MCI and dementia in the largest non-western migrant groups in the Netherlands with a cross-culturally validated dementia screening. Previous studies used cognitive screening instruments like MMSE, and despite the use of an interpreter, the results were not reliably interpretable. Another quite unique feature of SYMBOL is
that it captures the older migrants, our core study population. This is one of the few studies in Europe which did not exclude, but included them. Another strength of the study was that our method of recruitment via the general practitioner yielded a relatively large sample of the older migrant population, which is generally known to be difficult to include in research \textsuperscript{40,41}. We were able to screen 2308 older people from Turkish, Moroccan, Surinamese and Dutch descent on different health domains.

\textit{Cross-culturally validated assessment scales}

The use of cross-culturally validated health assessment scales has several important advantages. First, with the CCD, we were able to assess cognitive decline in specific domains (memory, mental speed and executive functioning) which are sensitive to cognitive decline due to dementia. Second, the CCD had a high predictive validity for dementia. Third, the CCD is a culture-fair test that is applicable in cases where a language barrier exists, and it was designed specifically for illiterate or poorly educated people. Besides the CCD, we also systematically cross-culturally validated the GDS and the DJGLS, through the essential steps (i.e. translation, pretesting) of cross-cultural adaptation of health assessment scales \textsuperscript{42-45}.

\textit{Limitations}

The specific limitations of each study were discussed in the relevant chapters, but some have more general implications and are therefore noted here.

\textit{Modest certainty about true prevalence}

Although we have made great effort in the study to determine the prevalence of dementia as properly and accurately as possible, there are some additional considerations in interpreting the results:

Modest response rate

Although we recruited a relatively large sample of older migrants, the groups were not large enough to get a good estimate of the prevalence of dementia. This is a limitation of our research. As we attempted to include equal numbers of participants across different ethnicities and age categories, we were not able to include many of the oldest old (≥85) in the Turkish and Moroccan groups. This is a result of the fact that there are few very old Turkish and Moroccan migrants in the Netherlands \textsuperscript{46}. This resulted in small groups (per age category), which give broad confidence intervals and ultimately modest certainty about the true prevalence of MCI and dementia.

Diagnostic procedure

Another limitation of the study is that the “gold standard” for MCI and dementia in our study was the result of a cognitive screening test and not established consensus or research criteria. We assessed MCI and dementia with a screening test, which ideally
should have been followed by a clinical examination by an expert in dementia or a formal neuropsychological assessment, to provide the gold standard (i.e. whether or not the participant was demented). Limited research budgets were the reason we conducted SYMBOL without this better gold standard. Cognitive screening tests should be embedded in a diagnostic process, and findings should be further examined.

Selection Bias
Another reason to be cautious in interpreting the prevalence rates is that, due to the modest response rate, selection bias cannot be ruled out. The response rate was 31%, which is not comparable to other population-based studies. It is possible that this non-response was selective, in particular among older people, people who were very sick or people unfamiliar with research. This is also in turn connected to our method of recruitment (via the GPs in suburbs with large migrant populations) which may also have led to selection bias, as these suburbs are characterized by low SES and worse health. This could have resulted in an under-/overestimation of the prevalence rates of MCI and dementia.
Therefore caution is needed in generalizing the results, as the sampling procedure and low response rates may have resulted in a non-random research population. However, compared with the Dutch national population, our sample was representative regarding age and cultural division (see Additional Figure 1).

Societal relevance
The outcomes of this thesis have a societal impact for the improvement of health care as described below.

Awareness of the association ethnicity with poor (mental) health
As there is an association of both loneliness and depression with adverse (mental) health outcomes, and both conditions occur frequently in older migrants compared to the native Dutch population, it is important that health care professionals are aware of the occurrence of these problems. The negative effects of these problems go beyond the individual, and can be considered a serious public health problem. In a broader perspective older migrants face a lot of health problems, they have a higher risk of unfavorable outcomes, and adverse events are more prevalent.

Optimise diagnostics through cross-culturally validated health assessment scales
Health professionals should be provided with relevant knowledge about common diseases among migrants and be aware of the existence of cross-culturally adapted health scales to assess these. Use of these scales can improve their clinical practice, including diagnosis of both mental health problems and cognitive problems, which leads to optimal care of both patient and caregiver. This thesis provides knowledge and devices to improve cognitive
testing, as well as screening for and diagnosing depression and loneliness. Finally, these scales could be used in future academic research to get a better overview of the health situation and develop tailor-made services of good quality.

Culture-sensitive facilities
This increasing awareness may create a sense of urgency to enable health care professionals and care facilities to provide culture-sensitive health care for older migrant groups in the Netherlands, e.g. in hospital, day care facilities, homes for the elderly and nursing homes. To achieve this awareness, we should work on implementing cultural competencies early in the education of students of medical and other care-related professions. Cultural competencies are the combination of knowledge, attitudes and skills necessary for health care providers to effectively interact with culturally and ethnically diverse patient populations. Ultimately, this will bear fruit in practice and we will be able to fulfill the needs and wishes of patients with a variety of cultural backgrounds.

Future Research
In the current population issues and diseases which come with ageing, such as loneliness and depression, are becoming more prominent. Dementia is already present in the top three most common causes of death worldwide. Knowing that this group will increase, the need to address these issues will be larger and therefore research among older migrants has not come to an end. Some insights for future research are given.

Prospective research

Two-stage research
Although we have tried to answer one of the research questions of the SYMBOL regarding the prevalence of dementia among older migrants in the Netherlands, we needed to work within the aforementioned resource limitations, which resulted in a one-stage diagnostic procedure protocol.
Ideally a two-stage longitudinal study among a larger sample of migrants is needed to definitively determine the prevalence of MCI and dementia among migrants.
We therefore recommend a two-stage diagnostic procedure for identification of memory impairment and dementia. The CCD can serve as an efficient basis for a two-stage study design, to identify participants for more extensive testing that will identify cognitive impairment due to dementia. Follow-up tests for neuropsychological examination should be carefully chosen, including scales which are (cross-culturally) validated or are affected as little as possible by culture and education. The results of the neuropsychological examination should be interpreted cautiously, since many tests are not validated for this group.
Older migrants as part of ongoing initiatives
Additionally, comparable research should be done among migrants in other EU countries to compare prevalence rates. In such studies it is recommended to take the native group to serve as a reference group in the study. As ageing is a major demographic change, it is a driving force shaping the need for health care for older people in Europe, who will be in need of extra care and support in the near future. Therefore ongoing major (inter)national longitudinal studies need to give attention to the ethnic groups in their country. This is especially true in EU countries, as they are inhabited by different groups of migrants. These groups are aging faster than the native population, because of their migration history. Now that the preconditions for proper cross-cultural research are available, particularly cross-culturally validated scales, research results should follow. Ongoing initiatives such as SHARE, LASA, and HELIUS set a good example, by integrating migrants in their study sample. Ultimately, the common purpose is to provide good care to all older people, regardless of ethnic and / or cultural background, language, or literacy levels.

Next generation
In the Netherlands and also in other countries worldwide, the incidence of dementia is appearing to decline because of prevention programs and use of effective methods targeted at reducing the prevalence of vascular risk factors and depression. It is interesting to clarify if there is a comparable trend among older migrants, and if so what the impact is for older migrants, or the second-generation migrants. As the lifestyle and standard of living changes positively for the second generation, we can expect a comparable trend.

Conclusion
This thesis is a necessary step towards the use of the cross-culturally validated scales in health care among Turkish, Moroccan and Surinamese older people in the Netherlands and other EU countries. These scales should be routinely available as a part of the diagnostic process for older migrants. In view of the expansion of the group of older migrants, the current findings may already have implications for health care services. We hope that these studies will trigger awareness of cross-cultural competencies among health care professionals, resulting in culture-sensitive memory clinics, timely diagnosis, better opportunities for counseling, and thereby improving support and quality of life for older migrants and their caregivers.
Appendix

Additional Figure 1: Age dispersion of population aged 55+ years in 4 cultural groups in SYMBOL study (N=2254) and National Population in 2013 (N=4,426,205)

Bron: CBS Statline
General Discussion

References

43. Terwee CB, Bot SD, de Boer MR, et al. Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol 2007;60:34-42.
General Discussion


