Author’s response to reviews

Title: Challenges in diagnosing dementia in patients with a migrant background - A cross-sectional study among German general practitioners

Authors:

Judith Tillmann (judith.tillmann@ukbonn.de)
Johannes Just (johannes.just@ukbonn.de)
Rieke Schnakenberg (rieke.schnakenberg@uni-oldenburg.de)
Klaus Weckbecker (klaus.weckbecker@ukbonn.de)
Birgitta Weltermann (birgitta.weltermann@ukbonn.de)
Eva Münster (eva.muenster@ukbonn.de)

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Author’s response to reviews:

First of all we would like to thank both reviewers for the extensive and very helpful comments and corrections. Thank you so much for putting so much time into reviewing our manuscript. It has increased its quality a lot. Therefore we also included special thanks in the acknowledgements of the article (ll.370-373).

Editor Comments:

When taking into account the reviewers' comments, please ensure you pay a particular attention in addressing the potential link between low health literacy, socio-economic factors and migration

- Thank you so much for this important remark. We added and discussed these aspects at several passages in the manuscript to make the link clear (see ll.67-68; ll. 296-300).

In addition the choice of the wording "patients with a migrant background" to describe the target population seems somewhat over-inclusive and vague. Please consider replacing if by "migrants", or else please justify using such a broadly defined concept.

- Thank you very much for that important remark. We realised that we have to describe our concept of wording in more detail. We used the term "patients with a migrant background" because, according to the german definition, it includes both people who have emigrated themselves and their direct descendants, and we included both groups in the study. “Migrants",
on the other hand, are usually only people who have emigrated themselves (first generation). However, the terms are not quite clear because there is no international consensus. We have therefore adhered to the definition of the German Federal Statistical Office, as described in lines 76-78: “The German Federal Statistical Office (Destatis) defines a migrant background as follows: Either the person in question or at least one parent is born without the German nationality [19].” and added further explanations both in the background and methods part: “However, there is no internationally official, uniform definition.” (l.80) and “The definition of a migration background of the German Federal Statistical Office was used: Either the person or at least one parent is born without the German nationality [19].”(ll.109-111). We also paid attention to the use of the terms in the background (ll.91-92).

Reviewer reports:

Athina Tatsioni (Reviewer 1):

Tillmann et al., have conducted a cross-sectional study on challenges in diagnosing dementia in patients with a migrant background among German general practitioners. The topic is quite interesting and relevant to family practice. The authors have adequately recognized several limitations especially in the generalizability of the study results. However, I think that this effort is helpful providing the challenges raised by GPs in a densely populated state in western Germany. I think that the reporting would merit a more detailed description of the process of the survey questionnaire development. In addition, there are several comments below that authors may find useful to address:

- Many thanks for this great feedback. We added more details about the questionnaire development as requested (ll. 117-120): “The most common problems in the diagnostic process and in dealing with patients with a migrant background described in the international literature were included in the questionnaire as questions or answer categories. In addition, free text fields were added to name additional aspects not yet described.” We also added a list of questions that were used for the present analysis in lines 134 to 158 to show the exact content. Besides there is a more detailed description of the questionnaire development available in the methods paper of the study, we added the following reference to literature: “More detailed information on the process of questionnaire development are provided in the methods paper [25].” (ll.126-127).

1. Abstract, Results: Besides percentages, authors are suggested they provide absolute numbers and 95% CIs for percentages for a complete presentation of the information.

- Thank you for mentioning that. We added the absolute numbers and 95%-confidence intervals for percentages in the figures two and three as well as the tables to give a more complete overview.
2. Abstract, Results: At the beginning of each sentence, authors should spell out the number instead of starting with a numerical figure.

- Thank you so much. We changed the spelling of the figures as proposed and changed the sentences slightly in the abstract and results section to prevent too long spellings (see markings, ll.41-46, ll.187-191, l.196, l.200, l.237).

3. Methods, Study design: "The standardised, self-administered, written survey included questions about GPs' experience in diagnosing dementia in patients with a migrant background and ways to improve diagnostics and support physicians." Please also provide the full questionnaire version that was used as well as the cover letter distributed to the participants. Both items may be included as supplementary material.

- Thank you very much for that remark. We added the exact questions of the questionnaire used for this analysis in lines 137 to 155 to give a really detailed insight into the questionnaire. However, since the questionnaire should also be used in further research projects, we are relying on controlled distribution. Upon request, we will of course be pleased to make the full questionnaire available for scientific purposes. We hope you will understand. We have additionally added these aspects in detail in the Declarations section (Availability of data and materials) (ll.353-355).

4. Methods, Study design: Authors are recommended to provide psychometric properties of reliability (consistency from one measurement to the next) and validity (accurate measurement of the concept) of the questionnaire as calculated in the pilot phase (line 115).

- Thank you so much for this recommendation. Due to financial reasons, we were not able to validate the entire questionnaire and check its consistency. Since the research area of this study is still new and unknown, there were hardly any questionnaires we could use as orientation. Nevertheless, we were able to adopt some questions from the above-mentioned questionnaire of an Australian research group which already tested for psychometric properties and validity during the pilot phase (doi: 10.1186/s12875-016-0506-z) (ll.120-123). We added this limitation in the manuscript (ll. 125-126): “The validity and reliability was not further investigated.”.

5. Methods, Participants: Authors need to explain the technique used for "random" sampling, which is reported previously (line 102). In addition, authors need to clarify the following: (a) how many and what type of attempts were made to contact subjects; (b) who approached potential subjects; (c) where were potential subjects approached; and (d) how was informed consent obtained.

- Thank you for this important remark. Since there is no information on whether the procedures and possible problems differ due to the characteristics of GPs (e.g. gender, age, region), a simple random sample without replacement was taken among all GPs in the area. We added this information in line 105.
- Thank you so much for these remarks. We added the following information to make these aspects clearer:

A) “Address data of the physicians were provided by the ‘Association of Statutory Health Insurance Physicians North-Rhine’ upon request. The target population was contacted by the institute of general practice using a postal mail with the questionnaires enclosed. Two written, postal reminder procedures were carried out, each with a waiting period of four weeks.” (ll.127-130)

B) As described in the methods part and added in ll. 128-129, GPs were contacted “by the institute of general practice using a postal mail with the questionnaires enclosed”. We hope that this aspect has been made clearer because of this addition.

C) As described in the methods section (ll. 106-107), the study “took place in North Rhine-Westphalia, the most densely populated state in the west of Germany (17.87 million inhabitants)”. In order to make the place where the study was conducted clearer, we added that it took place “in the general practitioners’ practices” (l.106).

D) We added: “Informed consent to participate in the study was documented by answering and returning the pseudonymised questionnaire.” (ll.130-132). Doctors were free to decide whether they wanted to take part in the study and the results were used in pseudonymised form.

In addition, we included a reference to the study protocol, which provides all further information on the methodology of the study (ll.126-127).

6. Methods, Participants: The phrase “The exact process of inclusion and exclusion of GPs is shown in figure 1.” Including the figure should be placed in the Results section.

- Thank you for this remark. We changed the position of the phrase and figure 1 as suggested (ll. 185-186, 1.193).

7. Methods, Statistical analysis (lines 137-140): The percentage of missing data should be removed and presented in the Results section. However, the way authors decided to handle the missing data should remain as is. In addition, the phrase "Missings in independent variables were allocated to the reference category (category with the highest n) since they did not exceed 6% (age: n=9 (2.8%), gender: n=0, migrant background of the GP: n=4 (1.2%), percentage of patients with a migrant background: n=10 (3.1%))" is confusing as to whether the decision on allocating missing data to the reference category was taken ad- or post-hoc. Please clarify.

- Thanks so much for this important remark. We removed the precise amount of missing data from the methods part and added it in the results section as suggested (ll.217-219; ll. 222-224).
- The decision to allocate missing values in the independent variables to the reference category was taken before the data were reviewed. The 6% cut-off is a common limit under which missing values are not listed as a separate category. We changed that description to make the aspect clearer “…because they did not exceed a predetermined limit of 6%” (ll.175-176).

8. Methods, Statistical analysis (line 140): "To control for confounding…” Authors need to clarify which variables were considered as potential confounding factors.

- Thank you so much for mentioning this point. We added a clearer description of these aspects to the methods part (ll. 177-180): “To control for confounding, odds ratios adjusted for age, gender, migration background and percentage of patients with a migrant background (aOR) with 95% CI were computed for all participants as well as stratified for men and women to consider potential effect modification.”. Since we do not have any prior information about special risk groups of physicians regarding the safety in dementia diagnostics, we considered the age, gender and migrant background of the GP as well as the estimated percentage of patients with a migrant background as possible confounders in our analysis and adjusted for these aspects. We also considered gender as a possible effect modifier and stratified for it.

9. Results: Throughout the Results section, authors are suggested the provide 95% CIs for each percentage both in the text and in the corresponding Tables and Figures.

- Thank you for this remark. As suggested, we added 95%-CI for percentages in the figures and tables. We also added absolute numbers. Since the addition of intervals in the text would cause too much complexity, we have not additionally added them in the text.

10. Results: Throughout the Results section, authors are suggested they avoid starting a sentence with a numerical expressing (spelling out the number when it is at the beginning of a sentence is highly recommended).

- Thank you very much for that suggestion. As you proposed, we rewrote and modified these sections (ll.184-185, ll.189, ll.196-197, ll.200, ll.206-207, ll.233-237).

11. Results, Characteristics of the study population: Please add a +/- sign before the number corresponding to each SD.

- Thanks so much for mentioning this important aspect. We added the sign as proposed (ll.187-188).

12. Results, Characteristics of the study population: Is there any information available on how those who agreed differed from those who did not agree? If yes, authors are encouraged to report it.
- You mentioned an interesting point. Since we only had information about the gender of all participating and non-participating doctors, we could only report the differences regarding this aspect, as mentioned in ll.184-185: “Thirty percent of male and 36.2% of female GPs answered the survey.”

13. Results, Characteristics of the study population: The Table 1 title does not correspond to what is reported in the text "Table 1: GPs lack of confidence in diagnosing dementia in patients with a migrant background" vs. "Characteristics of the study population are summarised in the first column of table 1." Please report results from logistic regression in another Table (i.e., Table 2). In addition, for each estimate please provide both unadjusted and adjusted ORs, and explain in the footnote for which variable(s) the analyses were adjusted. If subgroup analyses were used, please clarify that and provide formal between group interactions as well as correction of P-values for multiple comparisons.

- Thank you. As you recommended, we divided table 1 and provided the description of characteristics of the study population and the ORs in separate tables (ll.215-226). We also added crude ORs for both the total population and stratified for women and men to give a more precise overview in table 2. We also adapted the methods section for this change (ll.176-180). We also added the description in the footnote as requested: “adjustment for the other sociodemographic and practice-related determinants of the model, method: enter)” (ll.228-229). Subgroup analyses were carried out for men and women in the regression analysis and can be found in the results section (ll.221-226). We chose the 95% confidence interval common in epidemiology.

14. Discussion, Key findings and interpretation: The phrase "Uncertainties were more frequently reported by GPs aged 50 years or older, those without a migrant background themselves and those treating many patients with migrant background in their practices, although no proof of significance was established" is itself conflicting. Since no statistically significant difference was found, GPs reported difficulties in addressing migrant population regardless of age, migrant background, and proportion of treated migrant patients in the practice. Please rephrase.

- Thank you for this remark. We rephrased that part of the discussion section as follows: “More frequent uncertainties were identified in descriptive analyses among GPs aged 50 years or older, those without a migrant background themselves and those treating many patients with migrant background in their practices. However, no proof of significance of these differences was established in logistic regression analysis.” (ll.248-251).

J. van den Broeke (Reviewer 2):

Overall this study is important as it may form the base for further developments that will lead to an equal chance to good dementia care for migrants. Also, not being able to treat all your patients in what you think would be the best way, is frustrating for GPs. Helping GPs performing better is of great importance both for GPs, for patients and for their family members.
However, it would not be helpful if the study fuels stereotyping. It can be a challenge to get the balance right between useful information about (treatment for) a patient group and assuming generalities for all people within 'one group'. Many good and important studies that have been held and published about so far, may unintentionally discriminate. It is a challenge for scientific writing and research in this day and age to treat all respondents and study subjects in an ethical responsible manner based on equity. I hope you will reconsider some of the sentences with this ambition.

- Thank you very much for your feedback. It is very important to us to avoid any form of discrimination in this manuscript. We have therefore considered your feedback extremely carefully and have further adapted the article. In addition, we have also had colleagues with migration background check the manuscript for these aspects. We hope that it will fulfil this requirement.

Methods: What exact questions did the survey contain? In figure 3: What was meant by 'Patient's refusal because of cultural attitude'? What is 'cultural attitude'? Can it be stated that it always is the physicians' responsibility to approach a patient in a way that fits the patient? Eg providing a patient with the choice for an operation using very difficult medical jargon may also result in refusal. Would it be proper in this case to mention 'patient's refusal because of cultural attitude' if the patient would have gone through with undergoing the operation if it were explained in understandable clear words?

- We really appreciate this great remark. In order to give a really detailed overview of the questions asked and analysed within this article, we have listed them in lines 133 to 155 now. Besides, to give a more detailed insight in the methods and precise structure of the survey, we've provided the methods paper of this study: “More detailed information on the process of questionnaire development are provided in the methods paper [25].” (l.126-127).

- Thank you. In our study, GPs have reported themselves that their diagnostic recommendations were rejected due to cultural attitudes. So it takes deeper research and investigations to see if this perception is correct, or if the barriers are not cultural, but some patients’ lack of knowledge about dementia or because of incorrect perceptions. It is interesting to see, however, that doctors describe this as a cultural problem and do not consider other explanations. We already described possible cultural circumstances that have already been identified in former studies in lines 289 to 296. However, since the assessment of the doctors should be considered with caution, as mentioned by you, we have added the following passages after this section: “At this point, however, it should also be considered that cultural differences and other barriers mentioned by GPs are merely the subjective view of the GPs. Diagnostic problems such as shame and rejection may also be due to other factors such as a low level of education and poor health literacy and could possibly be removed by having more knowledge about the disease [39]” (ll.296-300).

In the summary, lines 41-42, please clarify whose 'socio-demographic characteristics' are of no influence.
- Thank you for this important remark. We added “with no significant influence of GP’s sociodemographic characteristics.” (ll.42-43) to make this aspect clear.

Please rewrite the first paragraph. Please explain diagnosing dementia in individuals with migrant background can be associated with various difficulties from the perspective of the person diagnosing.

- Thank you. As suggested, we added “from the perspective of the diagnosing person” in line 59 to clarify.

In line 59 e.g. who is meant with ‘they’? The GPs who diagnose?

- Thank you so much for this important remark. We added “People with a migrant background” in line 59 to clarify the reference of the following aspects.

And why would a taboo cause difficulties with diagnosing? Please explain or not mention it.

- We added the following aspects to the sentence you mentioned to explain the cultural components in a more precise way: “Often it is tabooed, marked with shame and therefore difficult to address; diagnosis, therapy options and outside help is sometimes not accepted [7-11]” (ll.62-64). There are some cultures where mental diseases are not yet accepted as illnesses and treated with shame, are not discussed or seen as a sign of weakness. Dementia is part of these diseases. That’s why it often happens that the diagnosis is not accepted and no further treatment or help from outside the family circle is accepted.

Also it is mentioned that understanding dementia can be 'culturally shaped'. In my experience, many migrants do not know about dementia, as many other people who have received little education and have low health literacy. The symptoms can be quite difficult to understand if you do not know about the disease and this may cause feelings of shame. Once families know about the disease and have gotten information about it, they understand it is a disease and feelings of shame go away. But is it correct to state this is 'culturally shaped'? (thesis Seeleman 2014: "Many difficulties experienced in healthcare in a multiethnic population are not a result of the patient's ethnicity, but result from universal determinants such as low socio-economic status or low health literacy.")

- Thank you very much for mentioning this important aspect of the influence of education and especially health literacy and also adding the really useful reference. We do fully support what you explained. We only have the information from previous studies and the data of the participating GPs who often indicated that cultural aspects were the underlying cause. It is completely true, however, that this impression of GPs can be biased by a low level of patient’s education and an associated lacking knowledge of the syndrome, and was wrongly referred to cultural aspects by the GPs. We added these aspects in the discussion section: “The results as well as findings of recent studies highlight a strong need for information of patients about dementia and underlying diseases [4,12].Providing material in different languages and native-language regional information centres and care facilities are necessary to ensure high-quality health care for the entire population” (ll.303-306) but also added further aspects in this section:
“At this point, however, it should also be considered that cultural differences and other barriers mentioned by GPs are merely the subjective view of the GPs. Diagnostic problems such as shame and rejection may also be due to other factors such as a low level of education and poor health literacy and could possibly be removed by having more knowledge about the disease [39].” (ll.300-302). Besides we rewrote the lines at the beginning of the background section to make clear that there can be other important underlying reasons: “Handling dementia and mental diseases can be influenced amongst others by cultural aspects.”(ll.61-62).

Methods/Objectives: Why were socio-demographic data of GPs included? What do the patient populations look like in North Rhine-Westphalia? Are there relatively many people who migrated there from Turkey, Russia and Poland?

- Thank you for this inquiry. Socio-demographic data of GPs were included in the study to define the characteristics of the study population and to investigate in the analyses carried out whether these “characteristics of GPs and their practices are connected to problems in diagnosing dementia.” (ll.170-173). Since this is a exploratory study and there have been no previous studies on exactly this topic, we wanted to investigate whether aspects such as age, gender, professional experience in the form of years of work as a general practitioner etc. are connected with the outcome. We added this aspect in the manuscript to make it clear (l.106).

- As described in lines 78-79, most people in Germany migrated “from Turkey (15.1%), Poland (10.1%) and Russia (6.6%) [17]”. We added a more detailed description of the migrant population in the region of study conduction, North Rhine-Westphalia, in lines 108-109 to describe the patient population in more detail: “North Rhine-Westphalia is by far the federal state with the highest share of people with migrant background (5,036,000; 28.4%) [23].”.

Discussion, lines 210 and the following: which references support stating 'lack of knowledge about regional services'?

- Thank you so much for this annotation. The lack of GPs’ knowledge about regional services for patients with dementia has been stated by GPs themselves in our study (77.0% for patients with a migrant background, 22.7% for dementia patients in general) (see figure 2) and has also been reported by Pathak et al. (2015) and Turner et al. (2004). We added some sentences about these study results in lines 265-268: “Pathak et al. report about more than half of the GPs in their study among 380 GPs who are unaware of any dementia care services in their local area [32]. Turner et al. also found that more than half of the GPs respondents said that they do not know about dementia patient’s support groups in their area [33].”.

Lines 224-226: these findings were not significant. If you want to mention this, what supports your assumption that the age of the GP and the number of migrant patients do matter? Could it be possible that GPs who do not have many migrants as their patients are unaware of their incompetence? (thesis Seeleman https://pure.uva.nl/ws/files/2005219/135897_thesis.pdf)
Thank you for mentioning that aspect. Only in descriptive analysis it is possible to see a tendency of older GPs without a migrant background and those treating a large number of migrant patients having stating more need for support. But there was no significant connection in logistic regression which probably is due to the sample size. In order to avoid confusion however, we removed the sentence from the paper.

Lines 227-234 preferably are mentioned in the introduction (perhaps right after lines 74-76), because it is already known that educational level complicates diagnosing (see for instance Goudsmit et al. 2017 https://www.rug.nl/research/portal/files/43810937/The_Cross_Cultural_Dementia_Screening_CCD_A_new_neuropsychological_screening_instrument_for_dementia_in_elderly_immigrants.pdf)

- Thank you so much for this annotation. We added some knowledge about these connections in the introduction to enlight them just at the beginning (ll.67-68).

Line 245: clear, accessible and understandable materials/information --> information in different languages still will not help if it is provided in a too difficult manner (medical jargon) not suitable for people who are illiterate or have low health literacy.

- Thank you so much for mentioning that important aspect. We added the more detailed characteristics of the material needed in lines 300 to 302: “The results as well as findings of recent studies highlight a strong need for clear, accessible and understandable information for patients about dementia and underlying diseases [4,12].”

Lines 254-256: This sentence seems not to be fitting in with the article, because it touches upon an other subject. If the German language would be acquired, problems with the tests would still be present.

- Thank you for mentioning that. Being able to speak German fluently always simplifies the application of dementia tests but it is correct that this would not completely eliminate the problem. To avoid confusion, we have removed this sentence from the article.

Conclusion: To my knowledge the tools in diagnosis of dementia among migrants is for a large part that these tools are not suitable for people with low education, low health literacy and a certain degree of illiteracy, which many migrants have. Therefore I would not put 'culturally independent' in the conclusion so prominently. (Also see Goudsmit et al. 2018: https://www.karger.com/Article/FullText/490174)

- Thank you for this important remark. This sentence is not precise enough. We changed the expression to “diagnostic tools suitable for all population groups (ll.333-334)”.