Author’s response to reviews

Title: Cross-sectional study of prevalence of dementia, behavioural symptoms, mobility, pain and other health parameters in nursing homes in Austria and the Czech Republic: Results from the DEMDATA project

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Author’s response to reviews:

Dear Dr. Meyer,

We thank you for considering our manuscript for publication in your journal and we thank Prof. Halek and Dr. Fleischer for their helpful comments. We revised the manuscript according to the reviewers’ suggestions and think that the comments were very valuable and improved the manuscript considerably. Responses to the reviewers (in the following marked with “RESPONSE: ”) and changes in the revised manuscript are as follows.

Margareta Halek (Reviewer 1):

Abstract:

1. Please state clearly the design of the study in the title and in the abstract
RESPONSE: We added to the Abstract the information about the study design. In line 25, original manuscript (line 26, revised manuscript) a new sentence was formulated.

Also, we changed the title: “Cross-sectional study of prevalence of dementia, behavioural symptoms, mobility, pain and other health parameters in nursing homes in Austria and the Czech Republic: Results from the DEMDATA project”
Introduction:

2. I am not convinced by the information provided in the background section that there are only few epidemiological studies carried out in nursing homes. The nursing home sector is in generally the most examined. Is there no reviews abostatement? For example there are several reviews regarding behavioral symptoms of people with dementia living in long term care (e.g. Wetzels et al 2010; or Seitz et al. 2010). The authors should describe more precisely what is known about the topic and what gaps are addressed by this study. Is this for example the issue that there are no data from Austria or Czech Republic until now?

RESPONSE: We thank the reviewer for this comment. We agree with the reviewer that there are already studies existing that have a special focus – for example behavioural symptoms. We also mentioned in line 92 of the original manuscript one existing study. We now added the two citations mentioned by the reviewer (line 92 of the original manuscript; line 97 of the revised manuscript). There are however few studies informing about prevalence and severity of dementia. Further, prevalence rates differ considerably between studies. We describe the studies on prevalence in the introduction and our intention was to contribute data for Austria and the Czech Republic for which there are no data available up until now.

We now added a sentence clarifying this issue on page 4 (line 98-99) of the revised manuscript.

3. Please describe more in detail the objectives of the study. „To explore information" is very unspecific. Formulation of research questions may help the readers to understand which gap is addressed in this study. After reading the manuscript i have the feeling that the manuscript is mainly about the differences and similarities between the two countries. If it is true, please explain why it is important.

RESPONSE: We now provide detailed information about the aims of the study in the introduction (p. 4/5 of the original manuscript; page 5 of the revised manuscript). In particular, we also added research questions: (1) What is the prevalence of dementia, cognitive impairment and different health parameters (such behavioural problems, pain, functioning) in Austrian nursing homes and in nursing homes in the Czech Republic? (2) Do these prevalences differ between the two countries?

To point out the importance of international collaborations in this field two sentences were added in the introduction (p.3, line 57 original, line 59 revised manuscript) and in the conclusion (p. 20, line 480 of the original manuscript; line 606 revised manuscript).
Methods:

4. I recommend starting the section with a clear description of the study design. Is this manuscript the main result paper from your DemData study or is this a kind of secondary analysis of data from this project? Against the protocol i think that the manuscript focuses only a part of the data from DEMDATA. For this reason, it would therefore be important to clarify which questions the main study poses and which ones are addressed here.

RESPONSE: We have revised the presentation of the study design (see Method, p. 5/6 of the original manuscript; p. 6 of the revised manuscript). This paper provides results from the first analysis from parts of the DEMDATA protocol, this has been clarified on page 5 (revised manuscript).

5. According to the protocol the study should be representative. Please provide more information about sampling procedure, sample size calculation etc.

RESPONSE: We thank the reviewer for this comment and have now added details on the sampling procedure and the sample size at the beginning of the method section (see Method, p.5/6 of the original manuscript; p. 6/7 of the revised manuscript). We now also report response rates at the beginning of the results section (p. 9 of the original document / p. 12, line 287, of the revised document).

6. I suggest to reduce the section "Data management" since it is well described in your protocol.

RESPONSE: During the revision we have removed this section.

7. The outcomes/variables published in the protocol (Table 1) are missing in the manuscript. Is there a reason for that? Please state the reason for deviation from protocol.

RESPONSE: For this analysis, only the instruments applying to residents and environmental factors were used. The protocol published still contains variables for relatives, care team and qualitative variables. These will be analysed in subsequent publications. This has now been clarified in the introduction (p. 5, line 111 of the revised manuscript).
Analysis:

8. I think it is important to state which analyses are main analyses and which analyses were not

RESPONSE: The main purpose of the DEMDATA project is the estimation of prevalence of dementia. This is now clearly stated in the definition of our research questions at the end of the introduction on page 6 (revised manuscript)/page 5 (original manuscript).

9. Please state if there are sources of bias and what was done to handle the problems. For example you have a selected group in CZ due to the charts analysis. How do you assess the influence (bias) on the results regarding the missing data?

RESPONSE: In Austria, several motivational measures were taken to optimise adherence to the study protocol and prevent missing data. Especially the method of employing study assistants which were recruited from within the care team of each nursing home was very helpful. Also motivational workshops with nursing home administrators and care team members explaining the study were organized in both countries. However, there might be a bias in the study sample selection especially due to the limited access to potential study participants in the CZ Republic. In the Czech Republic, some wards were not made accessible to the researchers for unknown reasons. There is a possibility that these wards were mainly occupied with residents with dementia. Therefore the estimation of prevalence for the Czech Republic cannot be clarified within this study. This limitation of study is again mentioned in the discussion section under “limitations”. Both issues are now emphasized more strongly in the discussion and limitation of the study (line 464 in the original document, line 597 page 25 of the revised manuscript).

10. How the authors managed the missing data? Is there a defined cut-off for imputation (calf circumstances?)

RESPONSE: For the main point of the study, the prevalence of dementia, the Global Deterioration Scale (GDS) score was used. The GDS score could not be determined in 9 residents in Austria and for 3 residents in the Czech Republic. Since the GDS is a global measure of the severity of Dementia, in some rare cases, a clear rating was impossible (Examples: withdrawal of consent before cognitive testing was completed, inhomogeneous or undeterminable performance patterns due to other medical disabilities (e.g stroke, blindness, inability to speak, extreme deafness). Furthermore, we added information about how many cases were replaced with regard to the calf circumference (p. 9, line 202 of the original, p. 11, line 272 in the revised document).
11. Your have done a lot of tests. How do you handle the problem with multiple-testing?

RESPONSE: We now adjust for the number of tests (Bonferroni correction). This information can now be found on page 11, line 266 of the revised manuscript (sub-section statistical analysis).

Results:

12a. Since your manuscript is about dementia, it would be important to present the data in the table for this population, or to compare both - residents with and without „dementia”.

RESPONSE: The surprising result in our study is the high prevalence of dementia in this population. It was not our intention to specifically compare persons with and without dementia. We believe that the clarification of our research questions also clarify this issue.

12b. I did not found how you define residents with dementia. I know well the problem with the „diagnosis“ in health care studies (see Palm R, et al. People with dementia in nursing home research: a methodological review of the definition and identification of the study population. BMC Geriatr. 16. 2016. p. 78.) and because of that it is important how do you define your population.

RESPONSE: We especially also thank Prof. Halek for this comment. It was not our intention in this study to diagnose persons but to identify persons at risk – exactly following Rebecca Palm’s et al. suggestion. Similar to the method of Lithgow et al (described in our original manuscript) we determined the presence or absence of cognitive and functional deficit. In order to clarify this issue, we now added a definition of dementia on page 6 (line 124) in the original document (line 169ff on page 7 of the revised manuscript). Along these lines, we also clarify that we did not perform a medical diagnostic process (see comments for reviewer 2).

13. I suggest adding confidence intervals to the tables.

RESPONSE: We followed this suggestion and added confidence intervals in all tables of the revised manuscript.

14. I miss information about the data distribution; is all data normal distributed?

RESPONSE: The (continuous) data was not normally distributed and analysis was made accordingly using the Wilcoxon rank sum test. We rephrased the respective sentence (section
statistical analysis p 9, line 196 in the original manuscript, sub-section: statistical analysis) in order to make this clearer (now page 11 line 260).

15. I suggest to structure the discussion alongside the research questions, highlighting the main results

RESPONSE: We ordered the discussion according to the result section.

16. Line 408-409, p. 17: which data indicate that social activities are not systematically implemented or specifically conceptualized? I did not found data on this in the result section.

RESPONSE: The data were collected during an interview with the nursing home managers. Only the frequency and type of activity and the duration, and number of residents participating were assessed. The comment on page 17 in the discussion has no basis in the systematically collected data but rather reflect our observations during the presence of the researchers in the nursing home. Therefore we thank the reviewer and clarified the sentence on page 17, line 407 of the original manuscript (now line 488 on page 20 of the revised manuscript).

17. Due to the problematic of team membership, I am not sure how informative is the comparison of the team ratio. If the social worker are a part of the team in CZ than this will increase the team ratio. This issue has to be discussed in context of tasks of the particular team members and should not be solved only by excluding the social worker, I guess.

RESPONSE: Social worker perform no direct care tasks and mainly work with the family-therefore the social worker was excluded- as was the administration staff. The value of this ratio is rather seen in the possibility for international comparison. We added a clarifying sentence at p 9, line 209 in the original manuscript (now line 279 page 12 of the revised manuscript).

18. I am convinced that the diagnostic practice and medical services should be careful improved but I think that the differences in the numbers might me also there result of inadequate "dementia diagnostic" on both sides - medical practice and the research measurement procedures (see point 12). As you mentioned dementia diagnosed needs more that MMST or GDS. Thus the conclusion regarding the "true" state of the residents should be interpreted with caution.
RESPONSE: We thank the reviewer for the comment and agree that a research procedure such as the one applied in our study where we screen persons with several cognitive, behavioural and functional instruments (in which also the decline of functional abilities of the residents are discussed with knowledgeable care team members) does not replace an in-depth medical diagnostic procedure including a neurological, a radiological and an internal medical examination. Therefore we modified some of our statements. However, our findings are in accordance with other studies such as Lithgow et al and Roen et al as mentioned in the discussion.

However, we agree that diagnosis of dementia and cognitive deficit should not be used interchangeably in our manuscript. We clarified this issue in several sections of the manuscript (see also comment 1 of reviewer 2).

19. I miss the discussion, if the instruments you have chosen for your study are the right one. For example Behave-AD is developed and validated for home care and not for nursing homes- I guess that there are not language specific psychometric studies for the particular instruments and this should be considered as a source of bias.

RESPONSE: Most of the scales were chosen because the teams in Austria and the Czech Republic already had experience with those instruments in nursing homes. Especially instruments such as the Brief Cognitive Rating Scale have shown to be more appropriate than the MMSE since the testing can be presented within a casual conversation (for example for the domain “past memory”, the person is asked about their profession, their children and their country of origin or birth place). Only after a rapport has been established, further questions regarding recent memory or orientation are presented. The BEHAVE-AD which is performed with care team members; it asks for behavioural symptoms which are typical for persons with dementia regardless of residence. Experiences with the scales are now mentioned in the Discussion (on page 24, line 586ff, revised manuscript). We agree with Prof. Halék that some scales are not internationally validated – which poses a problem and this is a potential source of bias. Some scales such as the EQ-5D-3L are developed by an international consortium and have proven very useful in our study as well. This challenge for the future is now mentioned in the limitations of the discussion (p. 25, line 599 of the revised manuscript).

20. What are you recommendation for future research bout the methods your used - what was successful and what should be reconsidered?

RESPONSE: We added recommendation for future research in the discussion (sub-section: “Importance of these findings for practice and recommendations for future research” on page 23 line 553 revised manuscript)
21. I think that the differences between the both countries make visible that the translation of research between different countries should be carefully done. Yes, we can learn from each other but we should be also clear about the differences in which have significant impacts for example on effectiveness of services and interventions.

RESPONSE: We agree with the reviewer. Trans-national studies are important but we need to understand the differences, for which our study provides some insight. This issue is now pointed out in the discussion (section: Importance of these findings for practice and recommendations for future research on page 23 of the revised manuscript)

22. Please provide information if the representativeness was reached and how generalizable are the results (according to your critic in the background)

RESPONSE: For Austria, the sample was stratified and randomly selected. Therefore we consider the results representative. For the Czech Republic representativeness cannot be guaranteed due to sample selection problems. In the discussion we added a sentence to clarify this issue (see also comment 9).

23. Final remark: consider the use of STROBE statement for the revision of the manuscript.

RESPONSE: The Strobe checklist has been used.
Steffen Fleischer (Reviewer 2):

1. It is very positive that the researchers used direct assessment methods to investigate cognitive impairment. Unfortunately they mistake the results of their assessments as diagnoses this is a mistake the authors have to account for throughout the whole manuscript. The GDS used by a psychologist or a "trained evaluator" (line 122-124) definitely is not the gold standard for dementia diagnostics.

RESPONSE: We thank Dr. Fleischer for this comment which is crucial. We did not intend to give the impression that an in-depths medical diagnosis could be replaced by the scoring of the GDS scale performed by a psychologist. Especially did we not intend to set it as a “gold standard”. But we understand the reviewer’s hint and made some changes in the manuscript. We fully agree with the reviewer that in practice, dementia should be diagnosed within an interdisciplinary medical team. We changed parts of the manuscript where cognitive testing results and a medical diagnosis of “dementia” were used synonymously. In detail, we made the following changes in the manuscript:

To make sure that the significance of cognitive deficit is not only based on the scoring of the GDS, we clarified the GDS staging procedure on page 6 (line 134) of the original manuscript, (page 8, line 188, in the revised manuscript) “The GDS is a 7-point Global Scale taking the severity of cognitive, functional and behavioural symptoms of pre-dementia stages and dementia stages into account. The GDS has satisfactory scale quality criteria…”. The GDS staging procedure is supported by the assessment of behavioural symptoms, functional symptoms and cognitive symptoms”.

On page 6 (line 124) of the original manuscript (now on page 7, starting with line 169 of the revised manuscript), the following sentence was added: “The clinical psychologists and evaluators were familiar with the diagnostic criteria for dementia. Dementia was defined according to the DSM V criteria of the American Psychiatric Association [18]) as a) a significant cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, memory, learning); b) the interference of cognitive deficits with independence in everyday activities; c) the cognitive deficits are not due to a delirium or d) due to another mental disorder. In the Czech Republic, evaluators were additionally supervised by a Geriatrician (I.H., senior author of this publication).”

We replaced “prevalence of dementia” by “overall estimation of prevalence of cognitive deficit (suspected dementia)” (see page 19 line 453 original manuscript, page 23, line 565 of the revised manuscript)

2. The authors indicate there is another publication that describes the methods more detailed (line 98-99). I think that does not suffice, I want to read more about the the study design and
sampling (especially a justification for the sample size) in this article (random sampling, stratification etc.).

RESPONSE: We have added more information about the study design etc in the method section (p.5/6 in the original manuscript, page 6 ff revised manuscript)

3. The description of the test instruments is not consistent, some instruments are described very detailed (e.g. specification of reliability) and some not. Perhaps a table could help here.

RESPONSE: We refrained from using a table for the description of the instruments in part because these instruments are well known in the field and now added some more information (sub-section test-instruments, p. 6/7 in the original document; 8/9 ) so the presentation becomes more consistent.

4. In my view, the section data management plan has not to be included in the manuscript.

RESPONSE: During the revision we have removed this section from the manuscript.

5. R-Studio is only a GUI, the analysis software is R (line 200).

RESPONSE: We have updated the information on p 11, line 265 in the revised manuscript

6. Results: There are some redundancies in tables and text. I would rather prefer the tables.

RESPONSE: We checked the text and the tables for redundancies and revised the text accordingly throughout the results sections on pages 9 to 16 (original document)/12-19 (revised document; see also comment 8).

8. In my opinion T-values are not necessary, they have no meaningful additional information

RESPONSE: We agree with Dr. Fleischer and removed the t-values and also Chi-squares and p – values since the tables provide the statistical details; this should also help in removing some of the redundancies (see also comment 6).
9. In this context, cluster-adjusted confidence intervals would be of more use and should be added (totally missing now).

RESPONSE: We added confidence intervals in all tables of the revised manuscript.

9. It should be stated whether the QoL-AD was used as a proxy or self-rating or both.

RESPONSE: In the DEMDATA Protocol, both versions of the QoL-AD (self-rating and proxy rating of a relative) were administered. However, in this analysis only the self-rating by the resident from Austria was used. The proxy rating will be analysed in a different publication. In the Czech Republic, the instrument was not applied (neither the self-nor the proxy version). We have rephrased the sentences in the results section to make this clearer (p.16, line 376 of the original document; p.19, line 452).

10. Generally the term proxy assessment should be used more cautious as most assessments used are "proxy" assessments (e.g. the GDS).

RESPONSE: We totally agree with Dr. Fleischer and now try to be more careful with this term. We have revised the abstract (p.2, line 39 of the original manuscript; p.2, line 40 page 2 revised manuscript) and the sub-section “test instrument used”

11. Discussion: This section is lacking the most as the response rate is not described throughout the whole text and not mentioned in the discus. The value of the results by no mean can be appraised by the reader.

RESPONSE: We thank the reviewer for this comment and now added the response rate in the result section (p.9, line 214 of the original/ p.12, line 287 of the revised document) and the discussion (p.17; line 393/394 of the original manuscript; p.20, line 471ff of the revised manuscript).

12. In line 429 to line 430 care stages are introduced, this has to be explained: What does stage 3 mean?

RESPONSE: We have provided more detailed information on the care stages in the discussion section (p.19, line 427ff of the original document; p.21 of the revised manuscript – line 508ff)
13. In-text citations: have to be revised (e.g. 1440, 57, 80, 81).

RESPONSE: Done.

14. Tables: the GDS in table 1 should be moved to table 2

RESPONSE: We followed the reviewer’s suggestion and moved the results of the GDS to table 2 in the revised manuscript.