Author's response to reviews

Title: Development and testing of a self administered version of the Freezing of Gait Questionnaire

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Author's response to reviews: see over
Dear Dr Alam,

Please find enclosed the revised version of our manuscript MS: 2267659744046571, entitled "Development and testing of a self administered version of the Freezing of Gait Questionnaire".

We thank the Reviewers for their comments and suggestions, which we have dealt with accordingly. Below follows our responses and an outline of the modifications made in the revised manuscript (all changes and additions are highlighted in yellow).

**Reviewer 1:**

**Major Compulsory Revisions**

1. In the Results section (paragraph 2) the authors report that 19% of cases had neither FOG or gait difficulty, scoring zero on the FOGQsa. Furthermore, no patient scored a maximum of 24. Could the authors comment on the distribution of scores across the range of FOGQsa to assure the reader that sufficient cases existed across severities for validation with the existing FOGQ. This could perhaps be addressed in quartile ranges?

*Response:* We do report the range of FOGQsa scores (0 to 22) in Table 2. That is, although no patient received the maximum score of 24, the most severely affected people scored very close to the maximum. The observed floor effect is also consistent with observations in previous studies on gait and FOG in PD. Taken together, we consider the range of severities sufficiently covered but recognize (in the conclusion paragraph of the Discussion) that further studies in different samples are needed in order to scrutinize the measurement properties of the FOGQsa in more detail. We have now added some comments regarding the score distribution in the Discussion (top of page 11):

The lack of maximum scores may suggest a bias towards less severe problems in the current sample. However, the highest observed score (22) is very close to the maximum score of 24, and the observed rate of people scoring zero on the FOGQsa is consistent with observations in previous studies (see above).

**Minor Essential Revisions**

1. To aid the reader in the Development of the FPGQsa section, the authors should include a sentence explaining how FOG was demonstrated to the clinical sample in addition to reference 19.
Response: This has now been added to the first paragraph under Procedure in the Methods section (page 6):

The FOGQ was thereafter administered as a clinical interview including a demonstration of FOG [19]. That is, the assessor demonstrated typical manifestations of start hesitation, freezing at the doorway and while turning. Finally, clinical assessments according to the UPDRS and Hoehn & Yahr stages (HY) [23] were conducted by an independent assessor who was unaware of previous test results.

2. It would be helpful in an Appendix to have the explanatory paragraph used to help patients understand the concept of FOG and as well as the final text of the questions used (in English).

Response: We appreciate this but argue that it would be potentially problematic to include this since we do not have a validated English language version of the FOGQsa at this time. Experiences of others and ourselves tell us that provisional translations of rating scales may contain ambiguities that can cause misleading responses and, therefore, compromise validity. An English version of the FOGQsa is under development and will be made available in due time. This has now been added in a footnote at the end of the manuscript (page 11):

1 The Swedish FOGQsa can be obtained from the corresponding author. An English language version is under development and will also be obtainable from the corresponding author when available.

However, if the Editor insists, we could consider adding an Appendix with a provisional English version, but in a format that does not encourage people to use it as it is.

Discretionary Revisions

1. In the Discussion section the authors might like to include a brief sentence identifying the previous literature regarding the difficulties in estimating time that have previously been identified in PD, which might help explain the difficulties that were commented on by patients from the clinical sample.

Response: We acknowledge that this may be of some interest, but since this remark was made by only one patient and did not result in any changes we decided not to include this.

2. I note that reference 29 relates to a presentation to be given later this year by the authors relating to this work, which makes this reference a little circular in nature.

Response: The forthcoming presentation (which is accepted) concerns in part data presented in the current manuscript, but it also includes initial pilot observations regarding test-retest reliability. The reasoning for including this reference is that it provides additional information (i.e. test-retest reliability), which is not reported within the present manuscript. We have therefore kept this reference.

3. The authors could consider commenting on the limitations of any questionnaire unless validated against some form of home ambulatory recording, perhaps using accelerometer technology (e.g. Moore et al Journal of Neuroscience Methods 2008).

Response: We have added a short comment about the validation procedure (Discussion, page 11):
Furthermore, validation of the FOGQsa (as well as the FOGQ) has been based on subjective data. Future studies may therefore consider adding ambulatory monitoring of FOG [36].

4. Although the existing FOGQ was developed for clinical interview the authors could consider whether this instrument could be assessed in its current form as a self-report tool.

Response: This could of course be considered, but the major problem is that the wording of the original questionnaire assumes that the respondent understands the concept of freezing (hence the need for demonstration). Since this is not necessarily the case, particularly not if used in surveys where uncertainties cannot be clarified, we believe that it is not suitable for use as a self-administered tool. In addition, experience tells us that there are also some other expressions in the original FOGQ that can be ambiguous or difficult for patients. This can be particularly true when developing additional language versions of the tool, since some expressions are not easily translated into lay language. It is also fairly well known from research regarding patient-reported outcome measures that the best wordings (and translations) typically are those that are as close to everyday lay language as possible (see, e.g. work by McKenna, Doward and others). In the interest of space, we have not added any comments towards this end in the revised manuscript.

Reviewer 2:
I do not have recommendations for the authors.

In addition to the changes outlined above we have made some minor revisions of language. These are also highlighted in yellow in the new manuscript version.

All Tables are incorporated within the manuscript. We have however also attached Table 2 as a separate file due to its layout.

We hope that the revisions and responses will be sufficient for our manuscript to be accepted for publication in 

BMC Neurology.

On behalf of the co-authors
Sincerely,

Maria H. Nilsson, PhD
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