Author’s response to reviews

Title: Experiences of fear of falling in persons with Parkinson's disease - a qualitative study

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Response to reviewers

We thank the reviewers for their insightful and valuable comments on our manuscript “Experiences of fear of falling in persons with Parkinson’s disease – a qualitative study”. Changes in the manuscript are made by using the “track changes” feature and can be easily found in the manuscript. Below is a point-by-point list where we have addressed and responded to the reviewers’ comments.

REVIEWER 1 (Marie Saint-Hilaire)

Remark 1:

There are several awkward sentences or wording that should be corrected in the manuscript (ie: 1st paragraph of Background) but these are easy to correct.

Response: We have had the revised version of the manuscript checked by a native speaking Englishman and revised the manuscript as appropriate.

Remark 2:

Although the authors compare their results to findings in non PD patients in the literature, it would have been interesting to have also interviewed a group of patients with FOF but without PD to assess if themes would be different.

Response: We agree that this would be interesting, but it is beyond the scope of the present study. FOF in persons with and without PD would be an interesting topic for a future study.

REVIEWER 2 (Colleen Canning)
Remark 1:

The authors make the assumption in the introduction (para 2) that FOF is maladaptive and developing effective methods to reduce FOF is (always) the desired outcome. This does not account for the possibility that the fear of falling reported by a participant may be appropriate, given his/her physical and cognitive capabilities, and that the adaptive and avoidance behaviours employed could be optimal for that person. Another possibility is that an individual's fear of falling may be less than optimal, resulting in risk taking behaviour. I suggest the introduction and discussion of the manuscript be revised to take these possibilities into account.

Response: We are grateful for the reviewer’s comments.

We do in fact not believe that FOF is always maladaptive and always need to be treated, and we have therefore done some revisions in the background section. In order to open up for the possibility that FOF is not necessarily negative, we have changed the wording from “reduce FOF” into “handle FOF”.

Moreover, we now speak of treatment from a more general perspective. See one example below (Background section, page 4, last paragraph, lines 55-59):

"To the best of our knowledge, no study has explored how persons with PD experience FOF. Such knowledge would be of value for the clinical care of persons with PD. That is, an increased knowledge of the experiences of FOF could facilitate the support of persons with PD to handle their FOF as well as the treatment of persons with PD and FOF."

We thus agree that interventions which specifically address FOF may not be needed for all persons with FOF.

This paper highlights that activity avoidance was used as a strategy by the participants. Thanks to the reviewer’s comments, we realized that we need to underline the importance of promoting safe activity performance. This is especially important since we know that people with PD are less physically active than others of the same age. By stressing safe activity performance, risk taking behaviors are taken into account. The following sentence has been added to the discussion section (page 22, first paragraph, lines 14-17) in order to stress the importance of safe activity performance:

“Such interventions should promote safe activity performance as risk taking behavior may increase the risk of falls.”

Moreover, “in a safe way” has been added to the following sentence (discussion section, page 22, second paragraph, lines 27-32):

“(…) persons with PD who experience FOF may need guidance and support from health-care professionals as well as from family and friends to be able to continue their treasured activities in a safe way.”
Remark 2:

The method of data collection (semi-structured individual interviews in participants' homes) is justified and seems appropriate, although the methodological approach is not clearly stated or justified? Please amend.

Response: We have expanded the description of the methodological approach (methods section, page 9, second paragraph, lines 25-38):

“The interviews were analyzed using manifest and latent content analysis conducted in several steps, as described by Graneheim and Lundman [29]. This is a well-structured methodological approach, suitable for exploring variations of a phenomenon. The twelve transcribed interviews constituted the units of analysis that were coded, categorized and interpreted. The first overall analysis of the interviews was performed gradually as the interviews were completed. (…)”

Remark 3:

Recruitment of participants: it is not clear how the additional six potential participants were identified for possible inclusion (page 5, line 10).

Response: The six additional potential participants were identified in the same way as the initial 25 potential participants. That is, all participants were selected among the 56 participants who reported that they were afraid of falling in the previous postal survey study (described in the manuscript). This has been clarified in the following sentence (method section, page 6, second paragraph, lines 12-18):

“(…) an additional six potential participants (who reported high levels of FOF in the postal survey study) were contacted.”

Remark 4:

The recruitment procedures suggest that the researchers were sure that data collection would reach saturation with the 12 identified participants. It is not clear why the 5 non-participants were not put on a waiting list until data saturation was known to have occurred, e.g., this would have allowed the authors to potentially recruit some participants who reported severe PD.

Response: We are thankful for this comment which revealed a lack of clarity in the description of the recruitment process. The decision to omit the five non-participants from qualitative interviews was made after the twelve interviews were completed, i.e., when we decided to terminate the data collection since we found that no new data emerged. That is, we were not sure from the beginning that the data collection would reach saturation with the 12 participants, as the reviewer suggests. We have rephrased this part of the method section into the following (page 6, last paragraph, lines 45-61):
“In order to obtain a heterogenic study sample with various experiences of FOF, the final selection of participants was based on the responses to the questions posed during the phone call (described above). The selection of participants was performed in several steps to ensure the inclusion of information rich cases in relation to the experiences of FOF. The inclusion process continued until no new data of interest for the study aim emerged during the qualitative interviews. This resulted in the inclusion of twelve persons. At the time when the researchers had decided to terminate the data collection, the five non-participants were contacted and informed about the decision not to include them in the study.”

Remark 5:

Participants: please include number of falls each participant reported in the past 6 months, if this information is available, ie, were multiple and frequent fallers included in the sample? This may influence interpretation of results.

Response: Fall frequency varied largely among the nine participants who reported previous falls. The following sentence has been added to the method section of the manuscript (page 8, last paragraph, lines 58-61):

“Of these, 5 participants were single-fallers and 4 were recurrent fallers during the past six months: 1 participant reported 2 falls, 1 participant reported 10 falls and 2 participants reported 2 falls every week (i.e., 52 falls).”

Remark 6:

Data analysis is clearly described. This section could be improved by including the researchers reflections upon their own role and how this may influence data selection and analysis.

Response: This paragraph has been rewritten as follows (methods section, page 9, last paragraph, lines 60-65):

“(…) The first author, who has clinical experience of conducting anamnestic interviews, but limited experience of qualitative research interviews, conducted and transcribed the interviews and performed the initial analysis. Subsequently, the first author discussed the interviews, codes, categories and themes on several occasions with the three other authors, who are senior researchers with extensive research experience of qualitative interviews. (…)”

Remark 7:

Results: Do the authors have any further indicators of risk of falling (other than history of falls and use of mobility aid), in particular, presence or absence of freezing of gait would be an important consideration?
Response: Unfortunately, we do not have any data on presence or absence of freezing of gait. We consider this to be a limitation of the study and have added the following to the paragraph “Strengths and limitations” (discussion section, page 24, first paragraph, lines 12-17):

“The study does not include any descriptive data on the presence or absence of freezing of gait among the participants; future studies targeting FOF should preferably include this, as these phenomena are associated [40].”

Remark 8:

Table 1 - include answers to further questions: dyskinesia, fluctuations, difficulty in ADL.

Response: Descriptive data on the occurrence of dyskinesia and fluctuations have been added to Table 1, as suggested by the reviewer. ADL difficulties are already included in Table 1 as a dichotomization of the Parkinson’s disease Activities of Daily Living Scale (dichotomized into needing help / not needing help from others in daily activities). Please see footnote 3 in Table 1.

Remark 9:

Many statements summarizing the results appear to reflect the authors view that FOF is always maladaptive, eg, Page 10, line 56 "FOF made a variety of activities and environments seem hazardous and frightening". It is possible that the activities and environments described are appropriately perceived as hazardous and frightening for some individuals with PD and FOF.

Response: We agree with the reviewer that the perception of some activities and environments as hazardous and frightening/daunting might be justified for some individuals. However, we do in fact describe the perceptions of the participants. To clarify this further, the sentence is rephrased (Results section, page 12, last paragraph, lines 35-38) to:

“The participants described that their FOF made a variety of activities and environments seem hazardous and daunting.”

The above has also been clarified in the Discussion section (page 19, third paragraph, lines 43-48):

“The participants described that FOF generated a feeling of vulnerability and made various activities as well as environments seem potentially hazardous.”

Remark 10:

The link between FOF and risk of falls (including history of falls) needs to be further considered. For example, page 12, line 8 "their FOF restricted them from fully participating". While there is discussion of what factors underlie FOF it is not linked to the possibilities of inappropriate and appropriate adaptation.
Response: The interviews were performed and are reported from the participants’ perspective. For example, one woman described restrictions in participation since she did not dare to use the escalator with her friends. Instead, she needed to search for an elevator. She explicitly expressed that her FOF was very pronounced when she used escalators and therefore avoided them. She did not describe that her history of falls made her afraid of using the escalators.

It is true that there might be a link between fall risk and FOF, but in the minds of the participants, it was their fear that restricted their everyday life and not their (eventual) fall risk. As this is a qualitative study, the results mirror the participants’ views and experiences.

When it comes to the link between FOF and a history of falls, this is being considered for example in the following statement (Discussion section, page 21, third paragraph, line 23):

“FOF seemed to be affected by one’s own as well as by other persons’ experiences of falls.”

Remark 11:

Discussion Para 1, page 18: the authors conclude that the “results of the present study does not include any indices that FOF implied positive effects, such as decreased fall frequency, but the experiences of FOF were solely described in negative terms”. Please reconsider this conclusion. The word itself “fear of falling” implies negativity. This, combined with the methodology of interviewers leading participants back to the subject of FOF when they diverted to talk about their fall experiences (page 6, line 28), may, in part, explain the negativity of the findings.

Response: It is correct that the words “fear of falling” implies negativity and it is therefore not surprising that the results does not include any indices that FOF implied positive effects. As the results remain, we do not consider this a reason for changing the conclusion. However, we have inserted a comment on this in the discussion section (page 19, last paragraph, lines 57-64):

“The participants expressed their experiences of FOF solely in negative terms. This is not surprising as the words “fear of falling” implies negativity.”

Moreover, as mentioned in the background section of the manuscript, FOF is a predictor of future falls and near falls in persons with PD, already early on in the course of disease (Lindholm et al., PLoS One 2015). However, falls are not independently associated with FOF in people with PD (Franzén et al., Brain and Behavior 2016; Jonasson et al., J Parkinsons Dis 2015; Lindholm et al., BMC Neurol 2014; Nilsson et al., Parkinsons Dis 2012; Mak et al., Parkinsons Dis 2012). The interviews in the present study revealed that FOF affected everyday life in several ways, and it was evident that it negatively affected the participants’ quality of life, which has previously been shown (Grimbergen et al., J Parkinsons Dis 2013; Rahman et al., Behav Neurol 2011). During the interviews in the present study, the participants expressed that their FOF sometimes took the joy out of previously appreciated activities. Also, activities that were still performed were not appreciated in the same way as before, due to the participants’ FOF. As such, FOF has several negative effects for the individual.
As the focus of our study is FOF, it would not serve the cause of the study to allow the participants to talk in detail about their experiences of falls. As already stated above and in the manuscript, falls are not independently associated with FOF in people with PD.

Remark 12:

Para 2, page 18: consider including discussion of the findings of O'Brien et al (2016) who did not report FOF as a barrier to exercise in a group of people with PD.

Response: We thank the reviewer for this valuable comment. We have inserted a comment regarding the article of O’Brien et al. into the discussion section (page 20, second paragraph, lines 12-21):

“Although one previous study of persons with PD did not report FOF as impacting on their decision to engage in physical exercise [30], another study showed that FOF is perceived as a barrier to exercise [31].”

Remark 13:

Also, please note limitation that not all people with PD report FOF and so conclusions should be limited to the group investigated in this study.

Response: We agree that the conclusions are limited to people with PD who experience FOF. Indeed, in the Conclusion section (page 24, third paragraph lines 50-53), we write “This indicates that interventions targeting FOF need to be…”. That is, the sentence refers to interventions targeting FOF which are offered to people with PD and FOF, and not interventions for the PD population at large.

To further clarify that the conclusions are limited to people with PD and FOF, we added “and FOF” in the last sentence of the conclusion (page 25, first paragraph, lines 4-8):

“This study provides new information that increases the understanding of FOF, which has implications for researchers as well as clinicians working with persons with PD and FOF.”

Remark 14:

Given the experience of FOF in people with PD is influenced by their own experience of falling and that of others, it seems that people with PD and FOF would benefit from an assessment of their actual fall risk in order to identify whether their FOF is consistent with their risk of falling. See Paul et al (2013) as an example of a fall risk prediction tool.

Response: We agree that such assessments might be beneficial, not least to those with high FOF and low actual fall risk. However, this manuscript does not focus on which tools to use in clinical practice and/or research.
The relationship between a history of falls and FOF is indeed intriguing in people with PD. Previous research has shown that FOF is a predictor of future falls among people with PD (Lindholm et al., PLoS One 2015). On the other hand, no prior study that used multivariable analysis did in fact identify a history of falls as an independent explanatory factor for FOF in people with PD (Franzén et al., Brain and Behavior 2016; Jonasson et al., J Parkinsons Dis 2015; Lindholm et al., BMC Neurol 2014; Nilsson et al., Parkinsons Dis 2012; Mak et al., Parkinsons Dis 2012).

Remark 15:

Page 20, para 3: The suggestion that people with PD and FOF might not think about FOF or conquer the fear applies only to a subset of people with PD and FOF, ie, those where the FOF is in excess of their actual risk of falling. This approach may result in increased falls for those whose FOF is consistent with their abilities and the environment. Please amend to consider this implication.

Response: In order to clarify that activities might need to be adapted to avoid falls, we have made the following revisions to the discussion section:

- We have added “in a safe way” (page 22, second paragraph, lines 27-33):

  “(…) persons with PD who experience FOF may need guidance and support from health-care professionals as well as from family and friends to be able to continue their treasured activities in a safe way.”

- We have also added the second sentence in the following paragraph (Discussion section, page 22, first paragraph, lines 12-17):

  “Finding ways to utilize intrinsic motivation like this might be beneficial in interventions addressing FOF. Such interventions should promote safe activity performance as risk taking behavior may increase the risk of falls.”

Remark 16:

Page 21, para 2: The authors acknowledge that FOF is a complex phenomenon, but have kept it quite separate from "effort to avoid falls and effects of falls". My view is that this is an oversimplification, and potentially reduces the meaning of the data.

Response: It is not correct that we separate FOF from “effects of falls”. Indeed, we do believe that FOF can be an effect of falls. Instead, in the paragraph mentioned by the reviewer, we write that our participants had difficulties in “separating FOF from actual falls, and efforts to decrease FOF from efforts to decrease the risk of falls” (page 23, first paragraph, lines 4-8).

FOF can be present also among those without a history of falls, which was the case for three participants in the present study and has also been reported in previous studies of persons with
Parkinson’s disease (Jonasson et al., BMC Geriatrics 2014; Matinolli et al., Eur J Neurol 2009). As such, we argue that FOF should be kept separate from “actual falls”.

Likewise, activity avoidance due to the perceived risk of falling has also been reported by persons without a history of falls (Kader et al., BMC Neurol 2016). We therefore argue that “efforts to decrease the risk of falls” is not interchangeable with “efforts to decrease FOF” or vice versa. However, some active ingredients of a potential intervention might affect both aspects.

Remark 17:

Editorial For clarity of reading, I would prefer ‘fear of falling’ to be written in full, rather than the abbreviation FOF (which is easily confused with FoG, a more common abbreviation for freezing of gait).

Response: It is correct that FoG is a common abbreviation for freezing of gait. However, FOF is also a commonly used and well-recognized abbreviation for fear of falling. It has been used in several previous studies, see for example: Landers et al., J Neurol Phys Ther 2017; Auais et al., Age Ageing 2017; Mak et al., Arch Phys Med Rehabil 2014; Visschedijk et al., BMC Geriatr 2015; Hughes et al., Int Psychogeriatr 2015.

As “FOF” appears many times in our manuscript (162 times), we prefer using the abbreviation rather than writing it out in full to enhance readability.