Author’s response to reviews

Title: Exploring the Parkinson patients’ perspective on home-based video recording for movement analysis: a qualitative study

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Author’s response to reviews:

Dear Dr. Chen,

Thank you very much for reviewing our manuscript entitled "Exploring the Parkinson patients’ perspective on home-based video recording for movement analysis: a qualitative study”. We appreciate the careful and constructive comments of the reviewers, and we believe that these have most certainly helped to further improve our contribution. We are pleased to now resubmit the revised version of our manuscript in which we have been able to accommodate all suggestions.

All changes have been highlighted in one of the copies of the revised document. In addition, we have specified all changes in more detail below.

We hope that our revised manuscript can now be considered for publication in BMC Neurology.

We look forward to receiving your reaction!

With best wishes,

Nienke de Vries
Reviewer reports:

Walter Maetzler, MD (Reviewer 1): De Vries and colleagues present in their manuscript results of a qualitative analysis after interviewing 16 PD patients. The aim of the interview was to explore PD patients` opinion on home-based video recording used for movement analysis in the frame of research or clinical routine. The manuscript reports interesting and new data. I have some comments that may further help to make the structure and content of the MS clearer and potentially more balanced.

- Methods: The authors may present some more details about the selection and recruitment process of the 16 persons interviewed. Were all of them already involved in studies (with / without new assessment technology)? If yes, could the authors slightly downscale the value of their finding that all of the patients were willing to be videotaped? I assume that not all PD patients would accept such an assessment. Could the authors also mention that the high "acceptance rate" may be a geographical phenomenon / elaborate on additional potential reasons?

We thank the reviewer for this comment. The interviewed patients did not, at the time of the interviews, participate in any research or innovation project. We added this to the methods section on page 4: ‘Parkinson’s patients, who previously (but not currently) participated in a research project in our centre and expressed willingness to participate in future research were invited via e-mail to partake.’

We also agree with the reviewer that a potential selection bias may have influenced the results. In our previous version of the manuscript, we only mentioned this in the conclusion section. Now, we have included a short paragraph on limitations (including selection bias) in the discussion section on page 8: ‘Despite the overall positive appraisal of home-based video monitoring by the patients participating in this study, we can not generalize these findings to all patients with PD. First, selection bias may have played a role, because we selected patients that were known to be interested in research. Second, the opinion of PD patients in The Netherlands (where care for patients with PD is generally well organized and innovative) may not necessarily reflect the opinion of patients located in another country. Finally, we did not have access to specific medical details on, for example, disease severity of the participating patients. Therefore we do not know whether these results apply to patients with PD in different disease stages’.

In the conclusion we already mentioned the following ‘careful’ conclusion: ‘The opinions presented here were all positive. However, this does not mean that we can extrapolate these findings to the general population of patients with PD. We included patients who are interested in research and may therefore be positively biased. Yet, the present results do indicate that home-based video measurements do not need to be ruled out in advance because of ethical and privacy considerations.’
- Methods: The authors mention a "set-up" that may have already been in use, or at least produced. It would be helpful to get some more details about this system, and which information the patients got about this "specific" system during the interview. The authors may also mention relatively early in the methods section that the system would be able to adapt the video recordings (figure 1). I assume that this information was also provided to the interviewed persons.

We thank the reviewer for this question. In the proposed set-up, we use a Kinect camera; we added this to the methods section, including a short description on page 4-5: ‘We propose a set-up using a Kinect camera which objectively, continuously and non-obtrusively measures motor functioning (i.e. step length, step width, joint angles, walking speed etc.). The system is based on a 3D depth camera (Kinect 2nd generation), with extension and optimization of the Kinect skeleton detection algorithms in order to enable the assessment of movement parameters including standing up and several gait parameters. These algorithms are currently under development.’

We also elucidated the information that we provided to the patients (page 4): ‘Patients were informed about the proposed set-up with the Kinect camera (which, at the time of the interviews, was in developmental stage). Automated data extraction was discussed as a potential future option. However, we explicitly asked patients to give their opinion on collecting videos without this option of automated data extraction.’

- Methods: Could the authors explain the mechanism of "concept saturation" a bit in more detail? How did the research team make sure that the (obviously continuously performed during the collection of the interviews) process of reaching this saturation did not influence their questions / interview structure / selection of topics during new interviews?

Saturation means that new interviews do not result in new information anymore. Here, we considered reaching saturation as a minimum number of 3 interviews, not giving new information. We added the following on page 5: ‘We considered reaching saturation as a minimum number of three interviews not resulting in new information’.

The researcher performing the interviews followed a semi-structured interview guide including a standard introduction, a standard set of open ended questions and (non-normative) prompts to encourage further discussion. The researcher is trained in qualitative research methods. Moreover, primary analyses were performed by other researchers than the researcher performing the interviews. We added the following texts. Page 4: ‘Interviews were conducted by NMV between November 2015 and February 2016.’ And, page 5: ‘The interviews were recorded by a voice recorder and then transcribed verbatim by KS and JH.’
- Results: How many "first level themes" were defined? If they were more than three, how did the authors define the 3 first level themes that are presented as the most relevant ones?

We only found three first level themes.

- Results: I agree entirely with the authors that home-based camera observation is an important topic, and I am also in favour of this method. However, my feeling is that the authors present the data with a tendency towards "too positive". For example, the "interfering" paragraph reports that half of the participants wanted to see the data before the information goes to the doctor, and half don't. However, only a statement of a participant who did not want to interfere with the data is presented. I also suggest to present data in general with beginning with the most frequent opinion (e.g. privacy protection paragraph).

Thank you for pointing this out and we now recognize that the positive statements may be overrepresented. We have updated the manuscript with some more critical quotes of participating patients. For example on page 6: "It should be possible to watch the record first by yourself and possibly delete parts." (patient 11); and page 7: "I don’t want a camera in every room at the same time, I need to have some privacy somewhere" (patient 8).

We also downgraded the ‘general result’ on page 5: “All interviewed patients agreed that video recording at home is acceptable when a number of requirements are fulfilled.”

Also, we have, when applicable, updated the order, now describing the most frequent opinions first.

- Discussion: automatic analyses can be performed…. : Can the authors add a reference?

We have added a reference.

- Introduction, line 2: "the 20st century"; line 27: "fluctuate" instead of "fluctuations"; line 52/53: "symptoms" instead of "disorders"- Results, last page first line: "turn off"

Thank you for noticing; we have corrected all above mentioned points.
Ming-Kuei Lu (Reviewer 2): de Vries et al. performed semi-structured interviews to explore the Parkinson patients' perception of continuous, home-based video recording. Sixteen PD patients were interviewed. They identified three first-level themes including camera recording, motivation and influence on daily activities. This qualitative report may provide a practical reference for physicians and caregivers because the need for a long-duration behavior assessment has increased recently. The manuscript is well-written and the conclusion is reasonable. This reviewer only has four minor suggestions.

We thank the reviewer for the positive appraisal of our manuscript.

1. The items and the order of the three first-level themes are not same between the Abstract Results and the Results of the text and Table 1. In the text and Table 1, camera recording, privacy protection and perceived motivation were entitled.

We thank the reviewer for this careful observation. The labels of the first-level themes as used in the results section and table are correct. We corrected the wrongly used labels.

2. In Table 1, the authors summarized the second theme as "However, the kitchen may lead to the most useful information because much time is spent there.". Nevertheless, all patients agreed that living room or bedroom would be acceptable and only seven (43%) patients suggested the kitchen.

This is correct and we added this to the text in Table 1: ‘The living room was acceptable for all patients’.

3. Are the extracted statements mostly coming from one or two patient(s)? It would be clear if a patient number can be appended in the end of their statements.

Quotes from different patients were used in the manuscript. We have added the patient numbers to the quotes.

4. In the first page of the Discussion section, the first line "…… or it should be possible to turn of", the "of" is an erratum.

We have corrected this.