Author's response to reviews

Title: The perseverance time of informal carers for people with dementia: results of a two-year longitudinal follow-up study

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Author's response to reviews: see over
Dear Editor,

We are grateful for the opportunity to revise and resubmit our manuscript, and would like to thank the reviewers for their careful consideration of our submission and their constructive comments that definitively have helped improved the quality of the article. We were also happy to read that both reviewers classified our manuscript as an article of importance in its field.

On the next pages of this letter we provide a point-by-point response to the reviewers’ comments, which we have all addressed carefully. In addition, we have hired a professional copy editor to review the style of written English. A copy of a tracked changes version of the manuscript from the copy editor is available upon request. Finally, we have carefully checked that the manuscript conforms to the journal style.

We apologize for the delay in resubmitting the revised version of our manuscript. We hope this version is acceptable for publication in BMC Nursing, but of course remain willing to consider further comments from the Editor and reviewers.

Kind regards, on behalf of all authors,

Job van Exel
Reviewer: Henriëtte van der Roest

Reviewer's report:

I am not sure about the validity of the Pt measure, the authors state that it is a reliable measure to assess perseverance time of caregivers. However, I would like to see results of psychometric results of this measure reported in the manuscript.

The results of convergent and content validity testing of the Pt measure are presented in detail in: Kraijo H, Brouwer W, de Leeuw R, Schrijvers G, van Exel J. The perseverance time of informal carers of dementia patients: validation of a new measure to initiate transition of care at home to nursing home care. J Alzheimer Dis. 2014;40(3):631-42. This article is included as a reference in our manuscript [reference number 1]. We have added the classification this article provided for the convergent and content validity of the Pt measure to our manuscript (line 108 of the original manuscript).

The authors conclude that measuring Pt has clear predictive accuracy for nursing home admission, I do not agree with this, since in the analysis also deceased patients were taken into account. Without this group the ‘correct’ percentage is only 53% for perseverance time of less than 1 year and deceasing for perseverance time of less than 2 years.

We agree with the reviewer that ‘clear predictive accuracy’ may be exaggerated, especially considering the percentage of 53% when not taking into account deceased patients. We have changed the text and now use a more modest formulation. On line 390, we have changed “fairly accurately” into “reasonably well”. On line 427, we have changed “clear predictive accuracy” into “reasonable predictive accuracy”.

The anticipated Pt seems highly related to burden, while burden is not related to realized Pt. However nursing home admission is in majority caused by overburden of caregivers, also other causes may play a role, like illness or injury of the person with dementia. This is not taken into account in the paper. When data on cause of admission are available, it would be worthwhile to include these in the paper.

Unfortunately we have no data on cause of admission available and can therefore not take it into account. However, we had acknowledge the relevance of such information in this context by including it as important topic for further research (line 386).

Also other analysis are needed, like loglinear regression analysis with adjustment for burden and other factors like duration of caring. The duration of care might also play a strong role in perseverance time of caregivers. When the diagnoses has just been made, caregivers often do not
know yet how burdensome the care can be. The authors are not addressing the this important time effect here.

We agree with the reviewer that additional multivariate analysis might be insightful. We have added the results of logistic regressions in Table 5 and accompanying text at the end of the results section.

The authors should be more clear on what group is used in the analysis. Sometimes it is the total sample, in some the sample minus the carers of persons that died within one year, and is sometimes the sample minus the carers of persons that died within two years. In my opinion, the analyses should be performed without the carers of persons that have died, respectively on t1 and t2. Otherwise the outcomes should be interpreted as 'nursing home admission and decease'.

We use different sub-samples to answer different questions. In each table we describe the sub-sample (including N) we use. The outcome of interest in our analyses is whether the patient is (anticipated to be) at home after one and two years, the reverse of that indeed always is 'nursing home admission and decease'. The only exception was Table 2, which did not contain data of deceased patients. We have changed this and –in line with other tables- now presents data of all three sub-samples of patients (i.e., home, nursing home, and deceased). We have also adjusted the corresponding text in the results section to reflect the changes in the table.

In table 2 also the characteristics of the sample for year 2 should be reported, including test statistics.

The characteristics of the sample for year two are reported in Table 1. Table 2 shows differences between patients at ‘home’ and ‘nursing home’ and ‘deceased’ after one year. Adding similar information to Table 2 for the sample after two years, as the reviewer suggests, would require three additional columns of data (i.e., year 2 data split into ‘home’ (n=44), ‘nursing home’ (n=20) and ‘deceased’ (n=10)). Considering the limited size of these sub-samples, we are of the opinion that adding this information will not add to the legibility of the table and the comprehensibility of the manuscript. As the reviewer also suggests later on, the manuscript is already quite lengthy and contains a lot of information for the reader to digest. For this reason, we originally did not include year 2 data in Table 2. If the Editor and the reviewer nonetheless would like this information included in the table, it is of course no problem to supply these extra columns.
The results shown in table 4 are difficult to interpret and other statistical tests are needed to report on these results.

We agree with the reviewer that the presentation of the results in Table 4 could have been clearer. We have changed the headings of the ‘anticipated Pt’ columns and have reversed the order of the ‘realized Pt’ columns to make the interpretation consistent (in terms of yes/no). In addition, the corresponding text in the results section has been edited.

It is not clear to us what the reviewer means with ‘other statistical tests are needed to report on these results’. Pending clarification, we have left the statistical tests unchanged.

Also the term realized Pt should be changed to 'At home' for reasons given above.

Realized Pt refers to carers meeting their own expectations (i.e. anticipated Pt) and is not the same as the patient still living ‘at home’. It depends on the perspective. For example, at the beginning of the study 80 carers anticipated their Pt to be less than 1 year (Table 3). After 1 year, 16 patients were still living at home. Their carers did not realize their anticipated Pt. The other 64 patients were admitted to a nursing home or deceased. Their carers did realize their anticipated Pt, but these patients were not living at home. In other words, we are of the opinion that the suggested change should not be implemented, as ‘realized Pt’ and ‘at home’ can refer to the same situation, but do not necessarily need to.

Where means are reported in the test statistics, also report sd-values.

SD values were added to tables 2 and 4 and in the results section, as suggested.

The authors have recruited a specific sample, this was addressed in the discussion section, but the authors fail to mention that this sample is also specific, for all of the persons included receive formal care.

We agree with the reviewer that the sample included in this study is specific, which was already addressed in the discussion section. Following this comment, the discussion now explicitly mentions that the sample is also specific in the sense that they were registered as people with dementia receiving formal care (i.e., 73.7% of the sample, thus not all, received formal care (see Table 1)).

The manuscript is lengthy, and could be shortened at places.

The full manuscript was copy edited. Some text was deleted and the style of written English was strongly improved.
Reviewer: Daksha Trivedi

Reviewer’s report:

The research questions are well defined, methods are appropriate and well described. The data and figures appear to be sound and genuine. The conclusions are adequately supported by the data. Limitations are clearly stated and issues of generalisability are considered. The title is acceptable.

Minor Essential Revisions:

1. Abstract – be helpful to put percentages in brackets where numbers are given.

   Percentages were added to the abstract, as suggested.

2. Introduction: Please clarify the sentence lines 117 and 118 “We registered Pt using the proposed instrument [1] next to a number of characteristics of people with dementia, their informal carers and the caregiving situation...” This is somewhat unclear

   The sentence was edited and hopefully now is clearer.

3. Lines 189 and 190: Descriptive statistics of all variables are presented in mean and standard deviation for continuous variables and in percentages for categorical variables.- this should include numbers and percentages

   In tables 1, 2 and 4 numbers were added (and percentages placed in brackets), as suggested.

4. Lines 206-208: As described elsewhere [1], 223 informal carers were included in this longitudinal study at baseline. During the two-year follow-up 25 carers dropped out because of non-response (after208 reminders). – It is not clear what is meant by the 223 ‘included’? The text and figure 1 need to indicate how many were invited? How many responded ? and how many were followed-up into the study?

   A brief description of the data collection procedure, including information about number of invitations and gross and net response, has been added to the methods section, under the heading ‘Sample’.

5. Figure 2 – the axis are not labelled – x and y axis..is it PT on the y axis? All figures need titles and clear labelling

   Labels have been added to Figure 2, as suggested.
6. text line 220 – mean age should be accompanied by standard deviation (as shown in table1). The same needs to be done for other variables discussed in the text.

   *SD values have been added for all mean values presented in the results section.*

7. Line 261...‘commonly varied?’

   *This sentence was edited and now reads ‘usually varies’.*

**Major Compulsory Revisions**

1. There is no mention of sample size calculations? And for subsamples. Was this conducted? If it was done in reference 1 (earlier paper), it still needs to be indicated.

   *No sample size calculations were conducted. The data collection procedure is now better explained in the methods section.*

2. Comment on limitations, if appropriate, in the context of sample size, whether or not it was adequate

   *In the discussion the sample size is mentioned as a potential limitation. Also based on comments of the other reviewer, we now discuss the specificity of the sample in more detail and use a more modest formulation in our conclusions.*

3. The authors need to comment on the findings within the context of the validity of the tool. (published in their early work) so the reader can see why the authors measured the domains they did.

   *We have added an additional paragraph at the end of the discussion relating the findings of the study to the aim of introducing Pt and its validity.*

**Discretionary Revisions**

1. It would be interesting to see whether PT reflected any specific challenges or behaviours of people with dementia that the carer had to deal with?

   *Unfortunately we have little information about specific challenges or behaviours of people with dementia in our data. However, the results presented in table 4 and the new table 5 provide some indication of this by showing that need for constant supervision has a negative effect on whether carers meet their expected Pt. We have added it as a suggestion for further research in the discussion section.*
2. Pt may reflect extended family support – it would be interesting to see whether those with family support had different PTs.

Our questionnaire included a question asking whether the patient also received help from other informal carers, and we found that this was the case in about 55% of the sample (see Table 1). However, this question did not specify the type of caregiver and the answers therefore concern extended support in general, not necessarily from family (although most of the times it is likely to be from family). The results presented in tables 4 and 5 show that having extended support was not associated with Pt.