Author's response to reviews

Title: Pre-dialysis patients’ perceived autonomy, self-esteem and labor participation: Associations with illness perceptions and treatment perceptions. A cross-sectional study

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

Re; “Pre-dialysis patients’ labor participation, perceived autonomy and self-esteem: Associations with illness perceptions and treatment perceptions. A cross-sectional study”, manuscript id: 1336861601393280

Thank you very much for giving us the opportunity to revise our manuscript. Please find attached the revised manuscript “Pre-dialysis patients’ labor participation, perceived autonomy and self-esteem: Associations with illness perceptions and treatment perceptions. A cross-sectional study”.

In our Revision Note (below) we have addressed all issues raised by the reviewers. We are grateful to the reviewers for their constructive comments on our manuscript.

We look forward to receiving your editorial decision.

Sincerely,
also on behalf of the co-authors,

Daphne Jansen

Revision Note:

Response to reviewer’s comments regarding the manuscript “Pre-dialysis patients’ labor participation, perceived autonomy and self-esteem: Associations with illness perceptions and treatment perceptions. A cross-sectional study”

In the revised version of the manuscript the changes are highlighted by means of track changes. General comment: we have made some changes throughout the text with respect to the terminology regarding chronic kidney disease, end-stage renal disease, and pre-dialysis phase since the terms used were not always consistent.

Reviewer 1

Major Compulsory Revisions

In the background there are’t data usefull for comparation of results, only general results.

We have compared our study findings with findings from other studies in the discussion section instead of the background section. By doing so we can describe both the study results as well as results from other studies in the same section, giving a clear overview.

Sample
It's small considering that the study was performed in 25 clinics. Data are quite old (2006). I suggest to include patients treated until 2009. Response rate is quite low, it could be a bias. Average age is quite high, with 58% of participants who could be formally retired. Education
level is quite low, which was their work before renal disease? I would like to have some comparations with a healthy population.

The data were collected in 2006 by means of an additional study which was carried out only one time. So no data are available for patients treated until 2009. We have investigated whether there were differences between the responders and non-responders with respect to age, gender and number of co-morbid diseases, and have found no significant differences between the two groups regarding these aspects.

We agree that comparison with a healthy population would be very informative, though it is not our aim to compare this population to the general population or other illness populations, rather to show the state of affairs within this group of patients and to investigate the role of the study predictors in this. With respect to age, we do have included extra information in the discussion section in order to place the data with respect to employment into perspective (page 19). Furthermore, we have information on the sector in which people were working or had worked, and we have included this information in the results section (page 13).

**Minor Essential Revisions**
Measures: insert min-max value of CASP, Current Thoughts Scale, IPQ...

We have inserted the minimum and maximum values on the scales in the text on page 12 and table 2 on page 29.

**Discretionary Revisions**
Discussion/conclusion with more clear indications for multi-professional team.

In the conclusion section we have stated that education should be given by a multi-professional team comprising of nephrologists, dialysis nurses as well as employment experts and social workers (page 20/21). Furthermore, we have added a reference to an article on a psychological intervention which we have developed for patients with chronic kidney disease and their partners (Jansen et al., 2010) (page 21).

**Level of interest:** An article whose findings are important to those with closely related research interests

**Quality of written English:** Acceptable

**Statistical review:** Yes, but I do not feel adequately qualified to assess the statistics.

**Declaration of competing interests:**
I declare that I have no competing interests

We thank Reviewer 1 for her constructive comments.
Reviewer 2

Using a relatively small, convenience dataset this paper aims to answer three questions:
1) To what extent do pre-dialysis patients experience autonomy, and state self-esteem, and to what degree do these patients participate in the work domain?
2) Which perceptions do pre-dialysis patients have about their illness and treatment?
3) To what extent are illness perceptions and treatment perceptions of pre-dialysis patients related to perceived autonomy, state self-esteem and labor participation?

Overall the paper is well written, although the style is somewhat different from the usual nephrology literature. The topic is interesting and important. I would, however, suggest several changes and I would ask the authors to attend to some of the concerns listed below.

Major Compulsory Revisions

1. I believe the overall aims of this manuscript are a bit too ambitious given the limited data. I suggest to leave out analysis related to paid work since the dataset is not designed to answer that specific question. The number of individuals between 18-60 yrs old is very small, the analysis lacks power. The data are very limited and the conclusions drawn in this regard from the very limited analysis seem a bit far fetched. The question raised, is important but a study carefully designed to specifically answer that question needs to be performed.

We would like to include the topic paid work and the associated analyses, since we think that the results on this topic are informative. However, we do agree that the dataset is not sufficient to answer our research question thoroughly. Therefore, we adjusted the (running) title and rewrote the discussion section in such a way that the topic ‘labor participation’ takes up a less prominent role. In the discussion section we also state that the relationship between perceptions and labor participation should be investigated once again in a larger sample of pre-dialysis patients (page 20).

2. Question 2. is very general, very difficult to interpret. Furthermore, the general nephrology readership may not be familiar with the common sense model therefore this aspect need a more thorough description and interpretation. What do the individual illness perception dimensions exactly mean? What do authors consider “positive” or “realistic” perceptions in the context of the particular tool? More information to compare illness perception data obtained in this survey to data obtained in other patient populations, perhaps in patients with CKD should be provided.

We have included more information on the Common Sense Model (page 6). No official cut-off point has been determined for the IPQ-B scores, but on a scale from 0 to 10, scores of 7 and above can be regarded as positive/negative (depending on the formulation of the items). On the basis of the tool it is not possible to indicate whether the positive perceptions are realistic. Here lies a role for health care providers. When exploring the perceptions of their patients it is important to take into account whether these perceptions are
realistic or not, based on the patients’ individual circumstances, since unrealistic positive perceptions can be counterproductive. In empirical studies where IPQ-B scores have been reported, higher scores on the scales that reflect ‘control’ appear to be associated with more positive outcomes in various domains (e.g., van der Kloot et al., Arthritis Care & Research, 2010, 62, 251 – 257; Daleboudt et al., Lupus, in press; Kaptein et al., Health Psychology, 2010, 29, 56 – 64). Please note that the B-IPQ was published in 2006. Therefore, empirical studies using this scale start to appear only now. Empirical data on illness perceptions assessed with the IPQ-R are abundant (see the Hagger & Orbell reference in our manuscript), where the evidence is quite clear in outlining how high scores on Personal control, and low scores on Identity, Chronic timeline, Consequences are associated with better outcomes.

In the discussion section we have added information on (the relevant) illness perceptions of patients on dialysis, this information is included on page 17.

3. In general, use specific quantitative terms when describing the results. Leave the interpretation of the numerical results for the Discussion. Try to avoid non-specific description of the results (e.g.” The average autonomy levels were not very high, but the average level of self esteem was rather high”). Put this in context instead.

With respect to the autonomy and self-esteem results: we have removed the interpretation of the numerical results in the results section. With respect to the illness and treatment perception results: we would like to interpret these results in the results section, in order to provide a general picture on how patients experience their illness. This is now addressed in the revised manuscript on pages 12-14.

4. Using one or a few questions taken from a validated scale (health related autonomy) is unusual and need justification. It seems also somewhat difficult to interpret what the two questions used to assess “global autonomy” may mean. Since these are not validated tools, their analysis seems to be of limited value.

We used the five item autonomy subscale of the CASP-19 (Hyde et al., 2003). However, principal component analysis showed no evidence for the five items to be loading on one single factor. On the basis of statistical evidence, the two new autonomy measures (global autonomy and health related autonomy) were developed out of the original subscale. Though the measures are brief, we believe that the items used, do reflect the construct of perceived autonomy as defined in this study (the feeling that one can do the things in life according to one’s wishes). As these adaptations have been outlined in our paper, our methodology here can be replicated, if other researchers would want to do so, strengthening the value of our adaptation.

With respect to the global autonomy measure: the correlation between global autonomy on the one hand and self-esteem on the other hand is present (r=.55), which is in concordance with other research findings and supports the construction of the construct. Because of limited space, we do not show the correlations between the autonomy measures and self-esteem in de text. The correlations with the other variables used in this study are also plausible.

We have decided to raise the issue of the use of single-item measures (IPQ-B and health related autonomy) in the discussion, in order to justify the use of these measures (page 20).
5. Has the Brief Illness Perception Questionnaire been validated in Dutch? How was it translated and validated?

The English version of the IPQ-B has been translated by three researchers independently, and the results of this translation were compared. The reconciled version is the product of this process. The Dutch version has not been validated.

6. Why were the given comorbid conditions selected for this analysis? Were additional information not available about e.g. amputation, COPD, malignancy?

All included conditions are cardiovascular co-morbidities which are particularly important with respect to patients with CKD. These are standard used comorbid conditions and are relevant for both pre-dialysis and dialysis patients (see Van Manen et al. 2002, 2003 for more information).


7. What was the proportion of missing values?

We included the number of cases with valid values for the self-esteem and autonomy measures on page 12. The valid values with respect to the illness and treatment perceptions and background characteristics were already inserted in table 2 (page 29) and table 1 (page 28) respectively.

8. How were the regression models constructed? What is the rationale to include all the variables authors had? The number of variables seem to many given the relatiel small sample. Have you checked for collinearity? I suggest to formulate specific hypothesis you want to test with the multivariable model and include only relevant variables.

The correlations between the perceptions were below .70, which indicates that there is no collinearity (see table 3 page 30). We agree that the number of variables included in each of the regression analyses may be rather large. We have performed new regression analyses with fewer variables, given the concerns of the Reviewer here. We removed the illness perceptions ‘timeline’ and ‘understanding’ since these perceptions did not correlate with global autonomy, health related autonomy and self-esteem (see table 3 page 30), unlike the other illness perceptions variables. Furthermore, we removed the background variable ‘living status’, since ANOVA analysis showed that people who lived with a partner and people who lived without a partner did not differ with respect to their autonomy and self-esteem levels. ANOVA analysis showed that educational level was related to self-esteem and therefore we included this variable in the regression analyses (for both autonomy and self-esteem, since we prefer to use exactly the same variables in both analyses for reasons of clarity). We consider age, gender and number of comorbid diseases as standard correction variables and therefore we
have included these variables as well. The results of the regression analysis remained the same after removing the three variables, reinforcing the stability of our analyses.

9. Have you used corrections for the multiple comparisons?

Multiple comparisons are no issue in our multiple regression analyses, furthermore we have not performed multiple comparisons, such as many t-tests, anova’s.

10. In the discussion state your main findings instead of repeating the research questions, please. refrain from general statements like: “Moreover, the average reported levels of perceived autonomy are not very high, which implicates that patients feel less autonomous because of their health condition or otherwise”.

We would like to include the research aims/questions in the discussion section so that the discussion can be easily linked to the aims of the study. With respect to the statements about the findings on the autonomy measures: no norm data are available on the autonomy measures. By comparing the mean scores on the autonomy measures of the total group with the answer scale (0=never, 1=sometimes, 2=not so often, 3=often) the results indicate that patients feel less autonomous because of their health condition or otherwise. In the discussion we have made it clearer that the statements are derived from these scales (page 16).

11. How to interpret the finding that health related autonomy is unrelated to illness perceptions? Would this not raise concerns about the validity of the instruments used?

An explanation for the finding that the illness perceptions are not related with health related autonomy might be that patients interpret ‘health’ as ‘physical health’. (My (physical) health stops me from doing the things I want to do). At this stage of the disease process the kidney disease – in most cases – will not yet be associated with severe physical symptoms. This is also reflected by the mean score on the ‘identity’ dimension. We have added this explanation in the text (page 18/19). In addition, as the IPQ-B was published only recently, intercorrelations between IPQ-B and other questionnaires/concepts, such as Health Related Autonomy, are still largely unexplored territory. Future research certainly should address the issue the reviewer raises here.

12. An association was found between illness perceptions versus self-esteem and autonomy. These associations need to be interpreted very cautiously since the association may be explained by common underlying factors rather than direct interaction. These complex relationships may need a bit more detailed discussion.

We realize that the relationships between the psychological constructs are complex. We in particular would like to address the relationship between the illness perception ‘personal control’ and feeling autonomous. Therefore we added information on this relationship in the discussion section (page 17/18).

**Level of interest:** An article of importance in its field

**Quality of written English:** Acceptable

**Statistical review:** No, the manuscript does not need to be seen by a statistician.
Declaration of competing interests:
'I declare that I have no competing interests'

We thank Reviewer 2 for his constructive comments.

Reviewer 3
Thank you for the opportunity to review this interesting article pertaining to labor participation, perceived autonomy, self-esteem and associations with illness and treatment perceptions for pre-dialysis patients. This cross-sectional study provides further evidence for educative and supportive interventions for this population as well as contributing to our understanding of the psychosocial well-being of individuals in the pre-dialysis stage.

Minor Essential Revisions
The authors do not comment on the reliability and validity for all measures in this study specifically perceived autonomy.

We used the five item autonomy subscale of the CASP-19 (Hyde et al., 2003). However, principal component analysis showed no evidence for the five items to be loading on one single factor. On the basis of statistical evidence, the two new autonomy measures (global autonomy and health related autonomy) were developed out of the original subscale. Therefore no information is available on reliability and validity. We felt justified to combine two autonomy items since both items loaded highly on one single factor. Though the autonomy measures are brief, we believe that the items used, do reflect the construct of perceived autonomy as defined in this study (the feeling that one can do the things in life according to one’s wishes).

With respect to the global autonomy measure: the correlation between global autonomy on the one hand and self-esteem on the other hand is present (r=.55), which is in concordance with other research findings and supports the construction of the construct. Because of limited space, we do not show the correlations between the autonomy measures and self-esteem in the text. Furthermore, the correlations with the other variables used in this study are also plausible.

With respect to the Current Thought’s scale: the developers of the scale have found substantial evidence that the scale is psychometrically sound and has a high degree of construct validity. We have added this information in the methods section (page 9).

With respect to the TEQ: no information is available on reliability and validity. The TEQ however has been used before in a study with ESRD patients (Griva et al., 2009).

There is no mention of sample size justification for the number of variables in the regression analysis. Given the sample size of 109 it is important to know that the data met the assumptions for the use of multiple linear regression. A statement to this would be important to include.

We agree that the number of variables included in the regression analysis is rather large for this sample size. We excluded three variables on the basis of bivariate relationships with the dependent variables. We removed the illness perceptions ‘timeline’ and ‘understanding’ since
these perceptions did not correlate with global autonomy, health related autonomy and self-esteem (see table 3 page 30), unlike the other illness perceptions variables. Furthermore, we removed the background variable ‘living status’, since ANOVA analysis showed that people who lived with a partner and people who lived without a partner did not differ with respect to their autonomy and self-esteem levels. ANOVA analysis showed that educational level was related to self-esteem and therefore we included this variable in the regression analyses (for both autonomy and self-esteem, since we prefer to use exactly the same variables in both analyses for reasons of clarity). We consider age, gender and number of comorbid diseases as standard correction variables and therefore we have included these variables as well. The results of the regression analyses remained the same after removing the three variables, reinforcing the stability of our analyses.

The following sentence in the results section is unclear "Differences between the responders and the non-responders with respect to age, gender and number of comorbid diseases were examined and no significant differences were found". There is no mention of ethical approval for this analysis.

The Prepare study was approved by an ethical committee (including the procedure of data collection with respect to the background variables).

Discretionary Revisions
I agree with the authors regarding the limitations of this study in regards to the replacement of the missing data (n=13/109) in 12.8% of the cases for the comorbidity variable and the very small sample size of the individuals who participate in the labor force. It is not mentioned if any individuals were in the labor force who were beyond the age of 64 years of age.

This did not occur.

Two-thirds of the sample was male-is this representative of ESRD in The Netherlands?

This is representative of ESRD in the Netherlands. In 2005, 61% of the population of ESRD patients in the Netherlands were male (Stichting Renine, 2005). We have added this reference in the discussion (page 19).

I look forward to reading the final version of this publication.

Level of interest: An article whose findings are important to those with closely related research interests
Quality of written English: Acceptable
Statistical review: No, the manuscript does not need to be seen by a statistician.
Declaration of competing interests: I declare that I have no competing interests.

We thank Reviewer 3 for her constructive comments.