Revision Manuscript ID: ijerph-1077392

The Hague, the Netherlands, January 29, 2021.

Dear Reviewer,

Thank you for your quick response, compliments and the helpful comments on the draft manuscript. We gladly accept the opportunity to revise and re-submit our manuscript entitled *"Participation restrictions among children and young adults with acquired brain injury in a pediatric outpatient rehabilitation cohort: the patients' and parents' perspective."* (Manuscript ID: ijerph-1077392) as an original article to 'the International Journal of Environmental Research and Public Health'. We have addressed the comments on a point-to-point basis and highlighted the changes we made in red. In the full text manuscript, we also highlighted the changes in red. Below, you can find the responses to your comments on a point-to-point basis, including statements on where to find the changes in the manuscript.

COMMENT 1:
The English is very good, there is one spelling mistake on line 64 'which' not 'witch'. Line 457 paired sample data were not available for all patients.

RESPONSE:
Thank you, correction made:
"This rehabilitation-based study in which the primary focus was … ", line 64
"…paired sample data was not available for all patients. …" line 491

COMMENT 2:
I had to read the paper a few times to be clear that **the study started prior to referral to an outpatient rehabilitation facility.** Were the children referred **on the basis of continuing problems** or would any child be referred 6 months after the ABI? A related question - **had the participants received any rehabilitation prior to entry to the study**?

RESPONSE:
In this study, patients were referred to one of the 10 participating (outpatient) rehabilitation centers on the basis of continuing and/or expected problems, related to their brain injury. The questionnaires were filled out prior to, or during the first appointment (with a rehabilitation physician). See: line 102 in the paragraph 'design' and line 122 in the paragraph 'data collection' of the methods section. There were no patients that received outpatient rehabilitation treatment before this first appointment. As we want this to be clear from the start, we made changes throughout the manuscript.

Changes can be found in the following sections and lines:

Introduction, last paragraph, Lines 86-87:

"The present study aims to investigate (the nature and severity) participation restrictions among children and young adults with ABI (5-24 years with TBI or nTBI) who were referred for outpatient rehabilitation treatment (not having received any prior rehabilitation treatment) and to describe..."

Methods, paragraph 'design' Lines 96-98:

"Data from patients with ABI (and/or their parents) that were referred for outpatient rehabilitation treatment on the basis of continuing and/or expected problems, related to their brain injury were analyzed. These patients had not received any outpatient rehabilitation treatment yet. This study was part of a larger multi-center study on family impact, fatigue, participation and quality of life and associated factors in the Dutch ABI population (children and young adults). …"

Discussion, first paragraph, Line 361:

"According to data gathered before/on the first appointment for routine outpatient rehabilitation for children and young adults with ABI and their parents in multiple rehabilitation centers, approximately…"

COMMENT 3:
Part 1: Parents are likely to be more influential on participation with younger children. **It might have been useful to divide the young group into younger/older children.**
Part 2: Also **community involvement may have been different in younger and older children**

RESPONSE:
Part 1: Indeed, we only presented comparisons separately for the groups 5-17 and 18-24 years old. Although the reviewer raises an interesting point. we choose to only analyze the data for above and under 18 years old separately. This is mainly based on the fact that most children in the group below 18 were in primary or secondary school- age, representing a similar developmental stage with age related transitions, that differ from the 18–25-year-old group. The mean age of the 'children' in our population was 14 years (SD: 11-16) and only 29% was under 13 years of age. We agree with the reviewer that the influence of parents on participation may vary with age, but the question remains what age groups should be selected for analysis. Furthermore, we did not look specifically into the influence of parents on participation, nor did we statistically investigate the influence of age on participation restrictions as this has already been done in prior studies by other authors. References: (1-8) We therefore chose not to describe outcomes for more age groups than the present two and we hope that our rationale is clear to the reviewer.

Part 2: When looking into community participation, table 4 shows that scores for community participation were lower than for other scales of the CASP and that this was found in all

groups and did not seem to differ between age groups. However, in general, we agree that this could be better highlighted, therefore we added a sentence in the discussion section.

Changes can be found in lines 395-396:

"For both patient-report and parent-report CASP outcomes and in all (age) groups (< 18 years/> 18 years/total), the lowest scores were found in the domain 'community participation', which …"

COMMENT 4:
Part 1: I would like to see the **rationale for using non-parametric** statistics. As presented you have a lot of wilcoxon comparisons. Part 2: Did you use any **correction to significance levels for multiple tests**?
Looking at your results it seemed that the means may not have been very different from the medians.
Part 3: It would be helpful to provide means. Clearly **using parametric statistics would have been more powerful and would have allowed for consideration of the effects of gender and family characteristics on the results.**

RESPONSE:
Part 1: Our rationale for using non-parametric tests was based on the distribution of the data which we analyzed using Kolmogorov-Smirnoff tests. (also see line 210)
Although we agree that the differences between medians and means were in general relatively small (as seen in the table below), we chose to report medians instead of means, based on the distribution of data. Furthermore, the non-parametric statistics we used according to this distribution are more conservative and less sensitive for outliers making our findings more robust. We therefore prefer to uphold our choices for statistical analysis. However, if requested, it is an option to add means and standard deviations to the table next to the medians and inter quartile ranges.

Table 1 (now including means). Median and mean total and domain scores on the CASP of children and young adults with acquired brain injury (ABI).

Outcome measure	Domain scores / Total scores	Patient report	Patient report	Parent report	Parent report
		n=223	n=223	n=245	n=245
		median (IQR)	**mean (SD)**	**median (IQR)**	**mean (SD)**
CASP	Total Score	82.5 (68-90)	77.9 (16.4)	91.3 (80-98)	87.1 (13.6)
	Home/community living activities	80.0 (63-90)	75.8 (19.6)	90.0 (75-100)	84.4 (16.9)
	Home participation	87.5 (75-96)	83.5 (13.9)	91.7 (83-100)	90.2 (11.1)
	Community participation	75.0 (56-92)	71.1 (21.4)	87.5 (75-100)	83.6 (19.1)
	School/work participation	85.0 (67-95)	78.9 (21.7)	95.0 (83-100)	88.4 (16.7)

*Not presented in the original manuscript

Part 2: Indeed, we did not state in the manuscript that we corrected for multiple testing. However, we used the Bonferroni method to correct for this and found no influence of multiple testing in our outcomes. We added that information to the methods and results sections.

Changes can be found in lines 244-245:

"… paired samples were calculated. A Bonferroni correction was performed to account for multiple testing (the α-value divided by the number of analyses on the dependent variable did not exceed 0.05). Wilcoxon signed-rank tests…"

Part 3: regarding the consideration of the effects of gender and family characteristics on the results: The present study did not aim to investigate the influence on participation of factors other than those represented by the patient (CAFI) and environmental factors (CASE) as well as HRQoL since previous literature already found gender and family characteristic factors to be relevant in this population. References: (1-8)

COMMENT 5:
My major query regards the **rationale for the study.** I assume that these are baseline studies, and that the proposal is to carry out a 2nd round of tests after the outpatient rehabilitation treatment (altho' one might expect some improvement with time anyway). A more important and substantial paper could have contained both of these results.

RESPONSE:
Indeed, this study concerns a baseline study, and we are still in the process of collecting longitudinal follow-up data. This particular study addresses a number of specific research question, with corresponding analyses using a cross-sectional design.
With the use of follow-up data many more research questions can be answered, however the scope of the paper would thus become very broad, and the number of data to be presented too much. Furthermore, believe that the results of our baseline-analyses are interesting to present in a separate paper because of:

1: the large number of patients in this multicenter study that provide insight into participation restrictions in patients with persisting problems in daily life at referral to a rehabilitation center. No comparable study has previously described these results as far as known to us.
2: the use of a new 4-level categorization system,
and 3: the patients' and parents' perspectives which has not been assessed before in an outpatient rehabilitation cohort.

In the 'directions for future research' section (lines 505-517), we have recommended follow up projects with longitudinal data.

References:

1. van Tol E, Gorter JW, DeMatteo C, Meester-Delver A. Participation outcomes for children with acquired brain injury: a narrative review. Brain Inj. 2011;25(13-14):1279-87.
2. Anaby D, Law M, Hanna S, Dematteo C. Predictors of change in participation rates following acquired brain injury: results of a longitudinal study. Dev Med Child Neurol. 2012;54(4):339-46.
3. de Kloet AJ, Gijzen R, Braga LW, Meesters JJL, Schoones JW, Vliet Vlieland TPM. Determinants of participation of youth with acquired brain injury: A systematic review. Brain Inj. 2015;29(10):1135-45.
4. Iverson GL, Gardner AJ, Terry DP, Ponsford JL, Sills AK, Broshek DK, et al. Predictors of clinical recovery from concussion: a systematic review. Br J Sports Med. 2017;51(12):941-8.
5. Lambregts SAM, Smetsers JEM, Verhoeven I, de Kloet AJ, van de Port IGL, Ribbers GM, et al. Cognitive function and participation in children and youth with mild traumatic brain injury two years after injury. Brain Inj. 2018;32(2):230-41.
6. Van Baalen B, Ribbers GM, Medema-Meulepas D, Pas MS, Odding E, Stam HJ. Being restricted in participation after a traumatic brain injury is negatively associated by passive coping style of the caregiver. Brain Inj. 2007;21(9):925-31.
7. Imms C, Mathews S, Richmond KN, Law M, Ullenhag A. Optimising leisure participation: a pilot intervention study for adolescents with physical impairments. Disabil Rehabil. 2016;38(10):963-71.
8. Anaby D, Pozniak K. Participation-based intervention in childhood disability: a family-centred approach. Dev Med Child Neurol. 2019;61(5):502.