Author's response to reviews

Title: Living with Myotonic Dystrophy; what can be learned from couples? A qualitative study

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

Please find enclosed a revised version of our manuscript addressing the editorial requests as well as the reviewer’s comments.

Below we give a point-by-point response to all concerns raised.

1. **Editorial requests**

   - The ethical statement is moved to the method section of the manuscript (p 9 highlighted)
   - Manuscript conforms the journal style

2. **Response to reviewer’s report of Axel Rainer Wintzen**

   - The reviewer states that the physical handicap is not a major issue in this study and is not specified. According to the reviewer this is not irrelevant.

**Response**

We agree with the reviewer that the physical handicap is very relevant. And it is one of the major issues in this study. In several themes in the results section this is described: Theme 1: decreasing abilities starts with the experiences of persons with MD1 that they had progressively more limitations in an increasing number of daily activities and roles (p 13 highlighted). These limitations were then described as physical barriers (p 14 highlighted) as well as mental barriers. The physical barriers are definitely major barriers, but not the only barriers. In addition, the couples suffer from cognitive and psychosocial barriers which are often underestimated. Current study has shown that beside the major physical barriers, these cognitive and psychosocial barriers also have large impact on the lives of couples.
• The reviewer states that it should be realized, that the study is restricted to persons aged 53-65 years, who usually have accepted their uneasy situation in some way, in contrast with many younger couples. This restricts the generalisability of the conclusions as well.

**Response**
This is a major point and is addressed in the discussion (p 26/27 highlighted)

• The reviewers feels that the discussion is too long. It is repetitive and it even generalizes to other chronic disorders. In the paragraph 'Implications for clinicians and policymakers' the essential message of the study is given. The reviewers suggests that this could serve as the backbone of a more concise discussion.

**Response**
The length of the discussion is reduced with 530 words with emphasis to the essential messages as described in the paragraph 'Implications for clinicians and policymakers'.

• Recently, Timman R et al have published a similar study, with partly similar findings.

**Response**
We would like to thank the reviewer for the attention to the study of Timman et al. We have referred to this study in the discussion (p 29 highlighted).

### 3. Response to reviewer’s report of Katrin Boström

**Major Compulsory Revisions**
Five couple has been interviewed after a purposive sample. The only information on patients beside being in the register and having the disease are that they have restrictions in activities of daily living and social participation and that some have difficulties in communication. The only information on partners is that the couples have been living together at least ten years. A table with some background information on the restrictions as well as age on both patient and partner and if working or not, etc should help to highlight their live situation and give a context for the result from the interviews.

**Response**
We agree with the reviewer on the value of a table with some background information on the persons with NMD. We had some concerns though about potentially identifiable information and deliberately left out a table with background information in the previous version. We now have included a table (p 10) with some additional information regarding age and gender of persons with NMD and the work status of the persons with NMD and their partners.
In current study we were interested in the meaning of restrictions for couples and how they managed individually and together. We did not collect quantitative data regarding the restrictions, but all couples had considerable problems in the performance of daily activities and participation in life roles. They all had restrictions in mobility with one person being completely wheelchair bound.

- When presenting the results “couples” is used and as a reader you don’t know whether this means that both patient and partner in at least two couples express this or if it is two partners in the interview with couples that tell this.

**Response**
In the results section we refer to ‘couples’ when findings relate to both the person with MD1 and the partner as a (married) couple. We have more explicitly described this in the results section (page 12 and 13 highlighted)

- *Minor Essential Revisions*
  The citation ought to be linked to a person – with so few interviewed persons the reader need to be given an indication that the citations relate to several persons. It is also interesting to know whether the partner is male or female. E.g. male partner, female patient 1, male patient 2.

**Response**
All citations are now linked to the persons who said this in the interviews referring to the couple, whether it is a person with MD1 or a partner and whether male or female.

- *Design*
  Observation on how they live is mentioned but does not show in the result. How was it carried out?

**Response**
Indeed the results did not show how the observations had added to the insights gained. In the revised version, this was more explicitly stated in the method section (page 8) and impressions and observations are also included in the results section (highlighted).

- How was the interview situation in their home – was it carried out in a way that made it possible for each of them (patient and partner) to have a confidential situation?

**Response**
All persons were interviewed in the room and chair where they felt most comfortable and were they could speak freely in a confidential situation. This is added in the methods section (page 8 highlighted).
• **Result**
The introduction could be shortened – the number of codes does not tell anything important. To use percentages get a false impression of something computationally. I think the relevant information is that patients gave less information than partners and that most information was gained related to persons with MD1 and least related to partners.

**Response**
The numbers and percentages in the results section are removed and the relevant information mentioned as suggested (p 12 highlighted)

• **Discussion**
Without having any background information on the couples there are comments on it in the discussion part. The persons interviewed need to be described earlier in the paper.

**Response**
The persons interviewed are described earlier in methods section (page 10 highlighted)

• **Discussion**
It states “…of value for single persons with MD1…” – the link between the result of this study and single persons need to be expressed better or be removed.

**Response**
This support need probably also applies for single persons with MD1. This is often causes an additional burden for the healthy parent who also takes on the responsibility of taking care of and encouraging their child(ren) with MD1. This is added in the discussion (page 27 highlighted).

• **Discretionary Revisions**
On page 13 “participants” is used – is it related only to patients or both patients and partners?

**Response**
The word participants is avoided on page 13 and replaced by persons with MD1 or partners.

We hope that we have adequately addressed all comments and concerns raised.
On behalf of all authors,
Yours sincerely,

Edith Cup