Author's response to reviews

Title: Perceived needs and satisfaction with care in people with multiple sclerosis: a two-year prospective study

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Author's response to reviews: see over
Dear Ms Norton,

Thank you very much for the valuable comments from reviewers regarding our manuscript, ID 1370551694192841, entitled “Perceived needs and satisfaction with care in people with multiple sclerosis: a two-year prospective study”.

The manuscript, which is now resubmitted, has been revised and our responses to the comments from the reviewers are presented below. Furthermore, the abstract is revised to include a more detailed background. The following text is added in the abstract, Background section:
Considering the costs of multiple sclerosis (MS), it is crucial that the health-related services supplied are in accordance with needs as perceived by the people with MS. Satisfaction with care is related to quality of care and can provide health care providers with the means for improvement.

**Reviewer 2**

This study set out to examine the needs of people with MS through time and their satisfaction with care. The paper draws on some interesting conceptual notions of needs and satisfaction based on previous models. Unfortunately the study fails to grapple with what it actually measures. In my view this study has measured people’s satisfaction with a range of current treatment options rather than needs. The study is further weakened by the lack of independence from the service and service user in the data collection process. In addition to the sample being skewed toward people with early disease.

*Authors’ response:*

*This study explored the perceived needs and satisfaction with care in people with MS in contact with specialist MS care on a regular basis. The sample, with a majority of persons with mild MS according to the EDSS, is thus representative of such care and it is likely that our results can be extrapolated to other MS specialist clinics. The study explored the perceived needs of different health-related services that usually are delivered to people with MS by different care givers such as the primary care sector, hospital outpatient departments, the private sector, the local authorities, or other organisations. A recent population-based study of people with MS within the Stockholm County revealed that neurology care contacts constituted only 20% of all outpatient care in people with MS [2]. Furthermore, the research physiotherapists had not previously met the individuals with MS. Needs within the areas of health-related services focused on in this study have been identified by people with MS in previous studies. Nevertheless we understand your concerns and have altered the aim to make it more succinct.*

*The following aim is altered, last sentence in Background:*

The aim of the present study was to explore the perceived needs and satisfaction with care of PwMS during a two-year period, also taking sex and disease severity into consideration.

*The new aim is:*
The aim of the present study was to explore the perceived needs concerning different health-related services and satisfaction with care of PwMS during a two-year period, also taking sex and disease severity into consideration.

*To clarify that only a small part of the MS care is supplied from neurology departments, the following text is altered in Background, line 6 to 7:*
A recent study revealed that the great majority of PwMS in Stockholm use hospital specialist care and primary care in parallel [2]

*The new text is:*
A recent study revealed that the great majority of PwMS in Stockholm use hospital specialist care and primary care in parallel and that neurology care contacts constitute only 20% of all outpatient care [2].

**Abstract: Should include some specific data on findings.**

*Authors’ response:*
*The abstract is altered and the following text is added in the Results section in the abstract:*
Few people with MS perceived a persistent need of a specific service. However, the majority perceived a need for rehabilitation, assistive devices, transportation service for the disabled, psychosocial support/counselling and information on social insurance/vocational rehabilitation at least sometimes.

**Introduction: While an argument is made for the examining health needs, care satisfaction just seems to be tagged on for no apparent reason. The authors need to make some linkage to these different areas and allude to evidence of how satisfied people with MS are with their care. On P4. the authors state that no studies have explored needs through time, in fact study reference (6) did undertake such an analysis.**

*Authors’ response:*
*To provide a rationale for examining care satisfaction the following text and references has been added to Background, line 14 to 17:*
Satisfaction with care is a complicated, multidimensional concept, including both affective and cognitive components [6]. It is related to quality of care [7, 8] and can provide health care providers with the means for improvement.


*The following text is altered in Background, line 19:*
However, no study has explored the variation in perceived needs and satisfaction with care over time in PwMS

*The new text is:*
However, few studies [Forbes et al, 2007] have explored the variation in perceived needs and satisfaction with care over time in PwMS
Method: P6. can the authors give some indication of the reliability and validity of the questionnaire adapted for the study and how it was adapted. Methods section would be enhanced with a clear set of research questions or objectives.

Authors’ response:
The questionnaire was based on the taxonomy of Ware and has been used in previous studies of people with different neurological disorders, as described in Methods, 3rd paragraph.

To provide more information regarding the questionnaire, the following text in Methods, 3rd paragraph, is altered:
In addition, items dealing with diagnosis-related information, information about the disease and participation in planning care were included.

The new text is:
The questionnaire has been found to be feasible including good face validity. In addition to the dimensions suggested by Ware, one item dealing with participation in planning care was included in a previous study of people with stroke [18], since this is included in Sweden’s Health and Medical Services Act. Furthermore, items dealing with diagnosis-related information and information about the disease were included in a previous population-based study of people with multiple sclerosis in Stockholm County [2] as a result of a pilot study exploring the feasibility of the instrument among people with MS [23].


Items dealing with perceived needs addressed areas of different health-related services that usually are delivered to people with MS by different caregivers. The research question presented in the Background section is altered as described previously:
“The aim of the present study was to explore the perceived needs concerning different health-related services and satisfaction with care of PwMS during a two-year period, also taking sex and disease severity into consideration.”

Findings: Would be better organised is related to specific questions, such as what were the perceived needs, perceived needs through time, differences in needs by disease severity etc. The data seem jumbled between satisfaction with care and needs. I would like to see these better differentiated and much more detail on the needs as this is what the paper promised. Are these truly needs are service options.

Authors’ response:
We have chosen not to separate perceived needs and satisfaction with care since they are related. Satisfaction with care was explored for each service among those who expressed a need. Thus, we have chosen to present perceived needs and satisfaction with care as a whole
to present an overall picture and to offer health care providers a base of knowledge regarding areas that need to be improved or further explored. People with MS have indeed many different needs. However, we have chosen to focus on to what extent people with MS experience needs of different services usually supplied within the health care system, and whether they receive the different services to the extent that they perceive necessary. By altering the aim, we hope that the scope of this study is more clear.

Discussion: I think the core problem here is a lack of clarity between needs, treatment options and satisfaction. The discussion should consider different dimensions of need and what has actually been measured by this study, which I think is more about satisfaction with care rather than needs.

Authors’ response:
We have chosen to focus on to what extent people with MS experience needs of different services usually supplied within the health care system, and whether they receive the different services to the extent that they perceive necessary. However, to clarify the limitations of the present study, the following text has been added in Discussion, paragraph 4, line 6: The expectations and knowledge that PwMS have of the different health care providers’ areas of expertise may have an impact on their perceived needs of different services as well as their satisfaction with care.

Reviewer 1
1. Why was satisfaction with care dichotomized (page 7)? If the participants' responses were not concentrated in a way that made dichotomization necessary, it might have been helpful to use more of the information in the Likert scale.

Authors’ response:
Satisfaction with care was dichotomised into satisfied (1-2 on the Likert scale) or not satisfied (3-5 on the Likert scale). The reasons for this dichotomisation were to achieve a robust analysis and not exaggerate the importance of small variations in the Likert scale.

2. "In those with severe EDSS, a statistically significant variation was found concerning occupational therapy" (page 8). Please report the p-value.

Authors’ response:
(p = 0.007) is added in the text.

3. The paragraph at the bottom of page 9 reports on the association between perceived need and severe vs. mild state of MS. How do perceived needs among those with a moderate state of MS fit into this pattern? Were those PwMS not included in these analyses? Also, that paragraph does not mention workplace adaptation.

Authors’ response:
The following text is added:
Between PwMS with mild and severe EDSS there were statistically significant differences with more people perceiving needs among those with severe EDSS. PwMS with moderate EDSS did not differ in perceived needs from those with mild or those with severe EDSS.

The following text is altered:
However, there were no associations between disease severity and perceived need for psychosocial support/counselling and information on social insurance/vocational rehabilitation…

The new text is:
However, there were no associations between disease severity and perceived need for workplace adaptation, psychosocial support/counselling and information on social insurance/vocational rehabilitation…

Discretionary Revisions:
4. Can the authors compare the characteristics of the 36 PwMS who declined to participate against the characteristics of the 219 who were included?

Authors’ response:
We agree that it would be of interest to analyze those who declined participation but the ethics permit and Swedish legislation do not allow the retrieval or the analysis of data from people who declined to participate in the study.

5. In the discussion (bottom of page 11 and top of page 12) the authors suggest that receipt of immunomodulatory treatment accounts for participants’ feeling burdened by the costs of care. It should be possible to examine this question in further analysis. A logistic regression model could use receipt of immunomodulatory treatment as a predictor, along with appropriate covariates (for adjustment).

Authors’ response:
We agree that such an analysis would be of great interest to perform but unfortunately we do not have data on the participants’ financial situation. Furthermore we believe that this research question is somewhat outside the scope of this study.

We hope that you will find the changes satisfactory. Should you have any further considerations and comments, please, contact us again.

We are looking forward to hearing from you.

Yours sincerely,

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