Author's response to reviews

Title: Importance Attributed to Components of a Self-Management Program by Individuals with Traumatic Spinal Cord Injury: Pilot Results from a Canadian Survey

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Author's response to reviews:

June 19, 2014
Dr. Giorgio Scivoletto
BMC Neurology

Dear Dr. Scivoletto,

Thank you very much for the opportunity to revise and re-submit our manuscript, “Patient Perspectives on the Components of a Self-Management Program for Individuals with Traumatic Spinal Cord Injury: Results from a National Survey” to BMC Neurology (MS: 2529427871159512). We have responded to the reviewers’ comments and have indicated the page numbers where the changes have been made. Changes to the manuscript itself have been highlighted using track changes.

Reviewer 1 (Elizabeth Dean):

Reviewer's report

Reviewer 1 makes a number of statements indicating that the inclusion of the questionnaire would be helpful: “It is helpful to me to be able to see the questionnaire that was circulated”; “I would like to see the questionnaire to be able to confirm this”; “Before I can make a recommendation about the merit of this work for publication, I would like to see the manuscript re-written in better quality scientific writing and to be able to see the wording of the questionnaire specifically the framing of the survey to the participants and the wording of the questions”.

We appreciate this request and have included the full version of the survey as an additional file. The following sentence has been added on page 5 of the revised manuscript: “The complete survey is included in Additional File 1”.

Reviewer 1 has also indicated, “I would like to see here and in the Introduction, the frame of the work to be extended with respect to people aging with SCIs and lifestyle-related conditions given as a group with a disability, they are at particular risk”.

As such, we have added the following sentence to the Introduction, “Furthermore, individuals with a SCI are at particular risk of lifestyle-related conditions including diabetes and heart disease [6]” (page 3).

Reviewer 1 indicates that, “As a pilot more could be done to relate the patient activation data and the findings, even in a rudimentary way. The exclusion of those who scored high is rather mystifying. It is not clear to me why the voice of those who appear to be highly activated was not considered relevant. Perhaps, it was the quality of their self-management programs? Although this work did not address this relationship specifically, more could be done to speculate about some of the relationships and this informing future studies”.

It should be noted that the exclusion of those individuals with perfect Patient Activation Measure (PAM) scores is consistent with the recommendations of the developers of the PAM (i.e., Hibbard et al., 2004; 2005). This was already noted on page 9: “A further 10 outliers were excluded due to perfect patient activation scores (a measure of self-management behaviour), as per the recommendation of Hibbard and colleagues [15,16] yielding a final sample size of 99 individuals” (no changes made). However, almost two-third of the sample (n=62) were in the “taking action” or highest level of activation, and thus we maintain that those individuals who are considered highly activated are well-represented.

Major Compulsory Revisions

1. Reviewer 1 suggests, “The title needs to be more specific and specify ‘Pilot Results from a Canadian Survey’ (i.e., Importance Attributed to Components of a Self-Management Program by Individuals with Traumatic Spinal Cord Injury: Pilot Results from a Canadian Survey)”.

We very much appreciate this suggestion and have changed the title of the manuscript to the suggested title, “Importance Attributed to Components of a Self-Management Program by Individuals with Traumatic Spinal Cord Injury: Pilot Results from a Canadian Survey” (page 1).

2. Reviewer 1 indicates, “As a questionnaire survey, the sample size is small. The thrust of the study is interesting and constitutes in my opinion pilot data. Second, the management of spinal cord injury varies globally, particularly lofty ideals such as self-management, thus the work needs to be contextualized to country”.

Again, we appreciate these observations (small sample size, global variation in
the management of spinal cord injury) and their implications to the generalizability of our study findings. As such, we have included them in the Limitations section (page 16) of the manuscript:

“Although a national sample was employed, the sample size was small and resulted from a sample of convenience. Thus, it is likely that it was not representative of the broader group of individuals with traumatic SCI... The generalizability of the study finding to individuals with non-traumatic SCI may also be limited as individuals with non-traumatic SCI tend to be older and include more females [32]. Furthermore, the management of SCI varies globally [33], and thus, the current results may be specific to the Canadian context” (page 16).

3. Reviewer 1 indicates,

“As an example of unclear writing, the wording around the objective of the work is blurry and non-specific. The title refers to ‘patient perspectives’. The Likert scale is anchored by ‘importance’ yet in some places in the manuscript the term ‘relevant’ (title) and ‘relevance’ are used. Although these seem related and interchangeable, words are important and how these were used in the questionnaire could elicit varying interpretations and results. Page 10 Line 2 makes reference to ‘suggested’ modules, why is this word needed, and then vague reference in the line below to ‘preferred components’. Page 10 refers to ‘indicated a preference’ however level of ‘importance’ is not necessarily ‘preference’. Further to the wording in the questionnaire, whether the participants are asked the questions about importance ‘in general’ may be different to their perception of importance to them ‘individually’. This is an important discrimination as different responses could be elicited”.

Again, we appreciate Reviewer 1’s attention to detail. The title of the manuscript has since been changed to “Importance Attributed to Components of a Self-Management Program by Individuals with Traumatic Spinal Cord Injury: Pilot Results from a Canadian Survey” (page 1).

Use of the terms ‘relevant’ or ‘relevance’, including in the title, have either been removed or removed and replaced with the terms ‘importance’ (i.e., consistent with the Likert scales used in the survey which used the term “important”).

On page 10 and throughout the manuscript (as appropriate), the term ‘suggested’ has been removed to increase the clarity.

Furthermore, on page 11, the reference to “indicated a preference for” has been removed, and the language used in the survey has been employed: “In terms of modes of delivery, 39.4% (n=39) of the sample indicated that an internet-based self-management program would be best…”

Finally, since we asked participants, “how would you rate the following items in terms of their importance in a self-management support program…”, we assume that the responses that were received relate to the importance to the participants themselves rather than “in general”. Again, we very much appreciate Reviewer
1’s attention to detail on this point.

4. Reviewer 1 indicates that “Some mention is needed of how the sample size was determined. The size I expect resulted from a sample of convenience rather than power analysis, thus lending itself better to pilot data. The size of the sample needs to be addressed in the limitations section”.

As indicated above, this limitation has been added to the Limitation section (page 16): “Although a national sample was employed, the sample size was small and resulted from a sample of convenience. Thus, it is likely that it was not representative of the broader group of individuals with traumatic SCI”.

5. Reviewer 1 indicates that

I have some further suggestions for strengthening the work by editing it to improve its message. First, in my reading of the work, there seemed to be a dis-connect between progressive notions such as ‘self-management’ and a bigger epidemiological frame, and a biomedical tone to the writing, e.g., patients vs. people with SCIs particularly because many were community living and not explicitly receiving active ‘medical treatment’. I also suggest editing ‘medical treatment’ to something more generic such as ‘health care’. Medical has specific connotations; a word that embraces the broad range of program attributes would be preferable. There is no mention of preventive care given people with SCIs can expect to live almost a full life expectancy. Also, I understand that more older people are incurring SCIs which in combination with lifestyle-related non-communicable diseases further complicates the comprehensive care of these individuals. The rationale for the work would be strengthened with some reference to these issues.

We appreciate these points and have changed references to ‘patients’ to ‘individuals’ and ‘medical treatment’ to ‘health care’ on page 3 and throughout the manuscript, as suggested.

Furthermore, the following sentence (with suggested wording), “Given this increasing emphasis on the community management of SCI, strategies that could be developed and implemented in order to empower and engage individuals with SCI in promoting their health and minimizing the risk of health conditions, both those related to their injuries and lifestyle-related conditions, are required [7]” (page 3) is “more specific and consistent with self-management ‘speak’”.

6. Reviewer 1 indicates

There is a decided bias to the writing, in my view. For me, the data set off some alarm bells. From my standpoint, that only three quarters viewed self-management programs as important/very important is curious and almost alarming given the need for all of us to take greater responsibility for our health and wellbeing and particularly if we are living with a chronic condition. Why not 100% particularly in light of lifestyle related conditions given people with
disabilities have greater risks of NCDs? Do the investigators have any insight about the large proportion of participants who viewed self-management as ‘very unimportant’? Given participants had the option of responding ‘neutrally’, the fact so many viewed self-management programs as ‘very unimportant’ is not trivial, and in my view, has major implications for the interpretation or at least implications for future studies. One might predict that nutrition and exercise would be considered ‘very important’ components by all. An interesting question is ‘why not?’ Healthier lifestyles are unequivocally linked to better health care outcomes as well as better health and reduced health risks, and potentially life-saving for these individuals. This point seems to be missing. I believe this point needs to be included and the results framed in this light.

The need for discussion/future research regarding individuals who consider the importance of a self-management program as “very unimportant” is very well taken and as such the following sentences have been added to pages 14-15:

“Lastly, while the majority of the sample rated the overall importance of the development of a self-management program for individuals with traumatic SCI as “very important” or “important”, one-quarter of the sample indicated that the development of a self-management program was “very unimportant”. This finding may reflect health-system level barriers including, access and availability of services and models of care, which limit the ability to create the optimal conditions for self-management among individuals with traumatic SCI (i.e., a self-management program is not viewed as important if the health system does not have the characteristics needed to support the individual’s self-management) [15]. Future studies should aim to understand the reasons why self-management may not be considered as important among particular sub-groups of individuals with traumatic SCI”.

We believe that the fact that almost the entire sample rated both the nutrition and exercise modules as either “important” or “very important” is significant in and of it itself. However, we have added the following sentence to pages 12-13, as outlined by Reviewer 1: “Healthier lifestyles are unequivocally linked to better health care outcomes as well as better health and reduced health risks, and potentially life-saving for these individuals”.

7. Reviewer 1 indicates that “I appreciate the survey questions were informed by previous work, however what about the importance of smoking cessation in smokers, stress management
(although relaxation techniques are mentioned, but stress management is distinct), weight control (although related is distinct from nutrition)”.

Reviewer 1 is correct that based on the findings of our qualitative work, the importance of modules such as smoking cessation and stress management was not assessed (i.e., the findings of our qualitative research provided the rationale for the modules that were included and findings relating to smoking cessation and stress management and self-management did not emerge from our previous qualitative studies) (no changes made).
8. Reviewer 1 indicates that “The Abstract conclusion is weak. i.e., ‘The importance assigned to the modules on exercise and nutrition is consistent with…..and a wellness/health promotion approach for (to) self-management in this population.’”

The conclusion for the abstract has since been revised: “Future research might consider how these preferences change over time, but ultimately, this research could be used to develop and pilot test a self-management program for individuals with traumatic SCI” (page 2).

9. Reviewer 1 indicates

“Page 3 Background. End of para 1. ‘…to increase patients’ involvement and control of their medical treatment and its subsequent effects are required [x].’ As per my suggestion above, the scope is broader than ‘medical treatment’. I suggest something more specific and consistent with self-management ‘speak’, such as ‘to empower and engage people with SCI in promoting their health and minimizing the risk of health conditions, both those related to their injuries and lifestyle-related conditions.’ This brings in the contemporary language of the WHO and the ICF”.

As indicated above (i.e., point #5), the following sentence has been added:

“Given this increasing emphasis on the community management of SCI, strategies that could be developed and implemented in order to empower and engage individuals with SCI in promoting their health and minimizing the risk of health conditions, both those related to their injuries and lifestyle-related conditions, are required [7]” (page 3).

10. Reviewer 1 indicates

Page 4 mid para 1. ‘Collectively, these findings point to the …’ does not follow clearly from the sentence above it.

This sentence has since been changed to: “Thus, there is a need for both greater understanding of self-management in SCI and detail on the specific components of a self-management program for individuals with SCI” (page 4).

11. Reviewer 1 indicates

Page 5. Line 1. How was fluency in English established? How many were excluded on this basis?

It should be noted that no formal process was in place to establish fluency in English. We assumed that if the participant completed the survey that they could understand English (no changes made).

12. Reviewer 1 indicates

Page 6. Para 2. Last line. What does this mean exactly? What is the implication?
Presumably, these questionnaires were included in the survey. Needs to be clear. What’s the rationale? These data and their implications are not described or integrated.

This sentence has since been revised to: “Standardized questionnaires were also used to capture the qualitative themes generated from the first phase of the study [i.e., 15]) as well as the important elements of the CDSMP. These standardized questionnaires were embedded within the larger survey. These questionnaires included the Hospital Anxiety and Depression Scale (HADS) [16] and the short version of the Patient Activation Measure (PAM) [17,18]” (page 6).

That is, the themes generated from the qualitative phase of the study (e.g., depression) informed the content of the survey that was administered (e.g., low mood/depression emerged as a barrier to self-management; therefore, a standardized questionnaire on depression was included in the on-line survey).

13. Reviewer 1 indicates,

“Limitation of self-selected group of those wishing to be contacted for research. It would be helpful to know the proportion of the total number registered with the RHI”.

Thus, the following information has been added: “The current sample of participants was drawn from the RHI SCI Community database. There were a total of 1417 participants. Of the 1417 participants, 71 did not wish to be contacted for future studies, leaving 1346 participants who did want to be contacted for future studies. A random sample of 300 participants was drawn from this sample of 1346 participants” (page 9).

The sentence, “All participants wished to be contacted for research purposes” has been included to provide further support to the fact that the current sample represented a more engaged and healthier group of individuals with traumatic SCI (page 16).

Additional Editorial

14. “Page 8 Line 3. Edit the Ms. entirely for grammar and composition inconsistencies such as this (‘median’ should be ‘medians’ to be consistent with string”).

The entire manuscript has been reviewed for grammar and composition inconsistencies including the example provided which has been changed from median to medians (page 8).

15. “Page 8. SPSS is a proper noun. Capitalize the first letter of Sta Pac for the Soc Sci”.

This suggested change has since been made: “Statistics were calculated using
the Statistical Package for the Social Sciences software [23]” (page 8).

16. “Page 8. Para 2. I do not think ‘suppressed’ is the appropriate word”.

The word ‘suppressed’ has been replaced with ‘numbers not reported due to small sample size…” (page 9).

17. Page 8. Last para. TSCI not spelled out previously. Suggest spelling traumatic out in full, no need to abbreviate.

Traumatic has been spelled out in full (page 9).

18. Page 8 Last para. Although the statement is referenced, but the rationale for excluded ten with perfect PASs is not entirely clear to me? Is it not important to capture individuals across these scores, because it may be their success and access to the self-management modules that was helpful? Certainly a chicken and egg question, but this is what preliminary or pilot data is all about.

In line with the suggestion/instruction of the developers of the Patient Activation Measure, individuals with a perfect score were removed from the sample (Hibbard et al., 2004; 2005).

19. Page 15. Has at least four instances of ‘it is’. Review the manuscript for all such construction and minimize the use of nonspecific ‘it’ as much as possible in scientific writing in general.

As per this suggestion, the use of ‘it is’ has been minimized (see changes on pages 16-17).

Reviewer 2 (Marcel WM Post):

Major Compulsory Revisions

1. Page 2. Results: If 300 individuals with SCI were invited through the RHI, and an additional unknown (!) number were invited through the TWH, the final sample of 99 does not correspond to the reported response rate of 48%

Reviewer 2’s observation on the sample size and subsequent response rate is well taken and the following modifications have been made: “Survey invitations were sent to 300 individuals with SCI including individuals with both traumatic and non-traumatic SCI from the RHI; additional individuals were approached at the Toronto Western Hospital outpatient spinal clinic (numbers not reported due to small sample size i.e., # 5). The number of individuals with non-traumatic SCI
Since we did not know how many individuals there were with non-traumatic SCI (i.e., from the original 300 invitations that were sent), a true response rate cannot be determined.

2. Idem; I am not sure how to interpret the 74% preferring individuals with a similar level of injury, if only a minority preferred a group setting.

Reviewer 2’s point is well taken. Although a minority of the current sample indicated that the best delivery of a self-management program was in a group setting, participants were also asked to consider the important considerations for the make-up of a self-management program if that program had to take into account characteristics of the group.

3. Key words. Please consider more useful keywords than “Program”, “National” and “Survey”

The key words now include the following: Self-management, Exercise, Nutrition, Depression, Traumatic, Spinal Cord Injury, Survey (i.e., Exercise, Nutrition, Depression have been added) (page 2).

4. Page 4. The study lacks specific research questions.

The research objective has since been revised (based on Reviewer 1’s suggestions as well): “Thus, the objective of the current study is to determine the importance attributed to the components of a self-management program by individuals with traumatic SCI”.

The broadness of the research objective reflects the exploratory nature of the current study.

5. Page 6. The HADS is not a diagnostic tool and provides only a number of depressive symptoms, that is considered indicative of possible depression. Literature shows that about half of those scoring above the clinical cut-off point do not have depression as assessed in a subsequent clinical interview. So please refer to the term symptoms of anxiety or depression, or to mood problems, when interpreting scores on the HADS.

We appreciate Reviewer 2’s insights and have since changed references to anxiety to symptoms of anxiety and references to depression to symptoms of depression (e.g., page 7).

6. Page 8. I do not think the non-response analysis is useful in its current form. Since the large majority is known at the RHI and WTH, it will be possible to compare the 114 participants to those who were invited but declined participation or were excluded because they did not complete the questionnaire.
The number of individuals who declined to participate (versus were ineligible to participate) is unknown. Thus, the “non-response” analysis compares those individuals who completed the entire survey with those individuals who did not complete the entire survey (no changes made).

7. Page 8. Please add the number of individuals invited through the WTH.

This number has not been reported due to the fact that it represents less than 5 individuals (i.e., numbers less than 5 are not disclosed due to privacy/confidentiality concerns).

8. Page 11. There is too little attention for the time frame: the sample is heterogeneous in terms of time after SCI, and individuals with relatively recent SCI may have different needs and concerns than those with long-standing SCI.

The following has been added to the Discussion section to address the issue of how these importance ratings might change over time:

“Future research should explore how these perspectives might change over time (i.e., how importance ratings vary based on time since injury)” (page 17).

9. Discussion overall: please discuss the generalizability of the findings and possible implications for individuals with non-traumatic SCI.

The generalizability of our study findings was also raised by Reviewer 1, and accordingly, the Limitations section (page 16) was revised (i.e., see point #2 above). Based on Reviewer 2’s comments we have also included the following sentence with respect to the generalizability of the study findings to individuals with non-traumatic SCI:

“The generalizability of the study finding to individuals with non-traumatic SCI may also be limited as individuals with non-traumatic SCI tend to be older and include more females [32]”. (page 16).

10. Page 12. The authors pay much attention to the low importance ratings of dealing with depression. I do not think this is actually that worrying: 34.3% rated this topic as very important and 42.4% rated it as important. The others might simply feel a self-management intervention is not the best setting to treat depression.

We agree with Reviewer 2’s observation and now have the following sentence:

“Furthermore, more than three-quarters of the sample rated the inclusion of a module on “dealing with depression” as “very important” or “important”. This finding is consistent with our previous findings on the importance of positive and negative mood as either a facilitator or barrier to self-management [15]” (page
Minor Essential Revisions
1. I do not think numbering the headings is according the journal style.
   The numbering in the headings has been removed.

2. Please provide more information on the project as a whole to show how this part fits in the project as a whole, or add a reference to the place where more information can be found.

This is the third of a four part study on the implementation considerations for the development of a tailored self-management program for individuals with traumatic spinal cord injury and was completed as part of the first author’s doctoral research. One of the qualitative studies that is a part of this work has now been cited in the manuscript (i.e., Munce et al., 2014).

3. Page 7. Please add that you used the short version of the PAM.
   We have since added that the “short version” of the PAM was used (i.e., “The short version consists of 13 items…” (page 7).

4. Page 9 and 10. There is no need to repeat numbers that are in a Table in the text.
   For Table 1, there is minimal overlap between the information in the text and in the table itself (no changes made).
   Some of the information that is already contained in Table 2 has been removed from the text of the section “Components of a Self-Management Program”. Specifically, the following information that is contained in Table 2 has been removed from the text: “…information/education on aging with a SCI (n=42; 42.4%), communicating with health care professionals (n=40; 40.4%), problem solving (n=40; 40.4%), transitioning from rehabilitation to the community (n=40; 40.4%)”. (pages 10-11).

5. Page 9. How many participants visited their primary care physician in the previous 12 months?
   The number of participants who visited their primary care physicians for any reason in the past 12 months was 87 (no changes made to the manuscript).

6. Page 15 line 6. Participants rated the importance for individuals with TSCI in general, not for themselves, so I do not feel that it is allowed to infer that this proportion will be higher in individuals who are not as high functioning.
   The sentence, “However, given that three-quarters of this (relatively healthy) sample believed that the development of a self-management program was
“important” or “very important”, it is likely the development of a self-management program in this population is even more warranted among those individuals who are not as high-functioning” has since been deleted (page 17).

Discretionary Revisions

1. Page 9. Please consider to insert an extra Table with the figures on received care.

Since this represents a small component of the study, we have decided to keep this information in text form (i.e., and not highlight it in a Table).

2. Page 13. Is distance/transportation not an important consideration in Canada?

Distance/transportation has been added to the list of examples demonstrating accessibility barriers (page 15).

3. Page 14 mid-page. I wonder why the authors associate physical health issues with a professional and mental health issues with a peer leader?

It should be noted that this is only a speculation that individuals with SCI would seek emotional support from a peer versus physical/medical support from a professional (no changes made).

The manuscript has been reviewed overall for clarity.

Again, we thank the Reviewers very much for their insightful and expert comments and suggestions for this manuscript and hope that these revisions are considered satisfactory.

Respectfully,

Sarah EP Munce, PhD
Fiona Webster, PhD
Michael G Fehlings MD PhD
Sharon E Straus, MD MSc
Eunice Jang, PhD
Susan B Jaglal, PhD