Reviewer’s report

Title: Patient Perspectives on the Components of a Self-Management Program for Individuals with Traumatic Spinal Cord Injury: Results from a National Survey

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Reviewer: Elizabeth Dean

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Patient Perspectives on the Components of a Self-Management Program for Individuals with Traumatic Spinal Cord Injury: Results from a National Survey

Overview

Based on online survey methodology, this study examined the ‘relevant components of a self-management program for individuals with traumatic SCI.’ The investigators recruited participants through email (Rick Hansen Institute registry) and through an out-patient hospital spinal clinic. The rationale for the study was based on the notion of ‘increasing emphasis on the community management of spinal cord injury (SCI).’ They argued that strategies could be developed and implemented in order to increase patients’ involvement and control of their medical treatment …..’.

1. Is the question posed by the authors well defined?

Could be improved.

2. Are the methods appropriate and well described?

Could be improved. It is helpful to me to be able to see the questionnaire that was circulated. I attempted to access it online, however as I expected the site had been closed. Although most editors are not inclined to want to publish complete surveys, access by reviewers is helpful in the review process.

3. Are the data sound?

I would like to see the questionnaire to be able to confirm this. I think a qualitative open ended section could have augmented the findings.

4. Does the manuscript adhere to the relevant standards for reporting and data deposition?

The scientific writing needs to be tighter.

5. Are the discussion and conclusions well balanced and adequately supported by the data?

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.

6. Are limitations of the work clearly stated?

Could be improved. I see this work as a pilot investigation. 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.

7. Do the authors clearly acknowledge any work upon which they are building, both published and unpublished?

I believe so.

8. Do the title and abstract accurately convey what has been found?

The title could be more precisely written although understandable.

9. Is the writing acceptable?

The manuscript needs to be revised in terms of scientific writing to improve the quality of its contribution to the literature. I would be pleased to re-review the work when it is re-written and the points below clarified or addressed.

Recommendation

Major Compulsory Revisions (which the author must respond to before a decision on publication can be reached)

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.

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’).

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.

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.
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.

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.

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.

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.

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).
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.’

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.

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

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

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.

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.

Additional Editorial
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.

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

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

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

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.

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.

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

**Quality of written English:** Not suitable for publication unless extensively edited
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.