Author's response to reviews

Title: Development of an online information and support resource for adolescent idiopathic scoliosis patients considering surgery: perspectives of health care providers

Authors:

Radha MacCulloch (radha.macculloch@sickkids.ca)
Joyce Nyhof-Young (joyce_nyhof-young@uhn.on.ca)
David Nicholas (nicholas@ucalgary.ca)
Sandra Donaldson (sandra.donaldson@sickkids.ca)
James G Wright (james.wright@sickkids.ca)

Version: 2 Date: 20 April 2010

Author's response to reviews: see over
April 20, 2010

To The Scoliosis Editorial Team:

Thank you very much for your careful review of the manuscript entitled, Development of an online information and support resource for adolescent idiopathic scoliosis patients considering surgery: perspectives of health care providers (MS: 1317292791351498).

The authors have read the reviewer’s feedback and comments and integrated suggested revisions into the paper. Changes have been tracked in ‘track changes’ and/or highlighted in yellow. Please find the reviewer’s comments and suggestions below accompanied by our responses.

Sincerely,

Radha MacCulloch
Joyce Nyhof-Young
David Nicholas
Sandra Donaldson
James G Wright
Reviewer Report: Joseph O'Brien

Comment 1:
If the goal of this paper is strictly to build a website for the patients having surgery at the authors’ Institution then I congratulate them and have no further comment on this paper. On the other hand, there is no mention within the paper of any intent to password protect or restrict access in any way. As such, it would appear that the goal extends beyond their Institution and will be viewed by patients worldwide as generally happens with today’s internet. In such case, there appears to be other limitations of this paper and statements that do not live up to the evidence and rigorous standards of trustworthiness applied towards the focus groups. For example, in the background section the authors state, “Unfortunately, most current online resources emulate the deficiencies of current clinical practice by providing incomplete and inconsistent information and minimal or no venue for social support.” The authors cite a paper by Kortum P, Edwards C, Richards-Kortum R in 2008 in support of this statement which is a general paper about the topic of vaccines, and not specifically referring to online resources addressing the topic of surgery for adolescent idiopathic scoliosis.

Response: Thank you for your feedback. This reference has been removed from our paper (see page 4). We have added a paragraph describing a review of traditional (non-web-based) and web-based resources patient information and support literature in scoliosis conducted by our research team prior to undertaking the needs assessment (please see page 4).

Comment 2:
The authors make no mention of existing online scoliosis resources, nor take any measures to ascertain whether or not the focus groups’ needs would be met by such resources. A simple google search results in millions of references, including several that are well known reputable information sources, such as the Scoliosis Research Society, the American Academy of Orthopedics, the NIH, Spine Universe etc. Furthermore, there are several other sites such as iscoliosis and spinekids that are geared specifically for teens and also include the social networking venues the authors refer to. Building another website may help communicate what the authors institution thinks is appropriate as expressed by one of their focus group members, but on the other hand, it is yet another website for a patient to go to which displays potentially contradictory information and more frustration in knowing what to expect or do. The paper would be more meaningful if the existing resources were addressed with appropriate analysis to evidence why spending money and time on another new website resource is warranted.

Response: Thank you for your feedback. As indicated above, and described in the manuscript on page 4, we have previously reviewed tradition and web-based resources.
Reviewer Report: Nachiappan Chockalingam

Comment 1:
The authors indicate that they would like to achieve a professionally moderated online support system. I think the manuscript would benefit from a short discussion on procedures followed in various parts of the world and how the authors would achieve their aim.

Response: This has been addressed on page 13. See: “While the surgical techniques used to correct scoliosis (pedicle screws, hooks, wires etc.) may vary, these variations do not substantially affect the decision-making and information about scoliosis surgery. During website testing, queries from patients and parents will be monitored and technical surgical information will be modified accordingly to address decision-making needs.”

Comment 2:
The manuscript will also benefit from a clear, sign posted discussion on how the proposed website will maintain the quality and the relevance of the content.

Response: This has been addressed on page 13. See: “Website content will be reviewed every 3 years and when major new information becomes available to ensure content quality and relevance.”

Reviewer Report: Jim Raso

Comment 1:
Many of comment given by the focus groups related to their perception of what others, the adolescents or parents, would want/need. These comments are probably correct but not as helpful as they could be if the data from the adolescents and families themselves were also provided. And without the corroboration of the other groups one can not be sure that the suggestions are valid. Although the focus groups are multi disciplinary, they are all from one major acute care centre and may not be sensitive to the needs of patients and families in more remote areas.

Response: Thank you for your feedback. The findings from the larger study were analyzed and interpreted along “subject” or “participant” lines, permitting a detailed examination of the perceived information and support needs of adolescent idiopathic scoliosis surgical candidates from the unique perspectives of both adolescents and orthopaedic clinicians. The previous paper presented the unique information and support
needs of adolescents with idiopathic scoliosis who were considering surgery from the perspective of the adolescents themselves. The findings shared in this second paper have been deliberately presented separately in order to showcase the significance and uniqueness of clinicians’ perceptions and adequately capture the rich feedback from this group elicited through qualitative research methods. We have cited the manuscript which presents feedback from adolescents with AIS in the “Discussion” section of this paper and feel that both papers would be of value to readers. We have acknowledged the fact that data came from one major acute care centre in the “Limitations” section.

Comment 2:
The paper would be much improved if the results of the other 2 focus groups discussion were also included.

Response: Please see response to comment 1.

Comment 3:
The study revealed more mostly what health care providers believe adolescents and parents would want/need in a web site. The conclusions about evidence based, user-centered, etc are correct.

Response: Please see response to comment 1.

Comment 4:
The title should reflect that the paper limits itself to the health care workers.

Response: We have changed the title to reflect that the paper outlines perspectives of orthopaedic health care providers.

Comment 5:
My major concern with this paper is the absence of data from the other two groups. Without those data, I am not sure what value this paper holds for the readers.

Response: As noted above, this manuscript focuses specifically on the health care providers perceptions of patient needs. While users/patients should be the prime focus, understanding and incorporating the health care provider’s views would likely enhance their support for a website and more importantly, increase the relevance based on the valuable input of clinicians who have much experience addressing adolescent and family concerns.

Comment 6:
My personal editorial pet peeve is the use of “in order to” when “to” would do just fine.

Response: This has been changed (see page 6 and page 7).