Author's response to reviews

Title: Empowerment of patients in online discussions about medicine use

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Author's response to reviews: see over
Response to reviewer’s report

Response to reviewer’s report Neil Coulson

To my knowledge there has been little attention given to exploring the empowerment of patients in online discussions concerning the use of medicine. As a consequence, I was very much looking forward to reading this manuscript and learning more about the study undertaken.

On the whole I feel positive towards this manuscript but would wish to see some revisions before recommending it for publication. These revisions, however, are not insurmountable and I am confident the authors will be able to respond to them appropriately.

Response: Dear professor Coulson, thank you very much for your detailed comments on our article. We highly appreciate the efforts you put into explanations of your comments and the suggestions for improvement. We thoroughly revised the article taking into account your comments and suggestions. Please find our point-for-point response to your concerns below.

Major Compulsory Revisions

1. My main problem with this manuscript is that it draws upon rather outdated work by van Uden-kraan et al and whilst this work was very important at the time there has since been much work which has extended it. This applies to at least TWO main areas:
   a) line 107 - it is argued that previous concerns have been unfounded. However - this work was a message analysis study (like the current one) and it is likely that few problems were identified because patients are now known to actively correct inaccurate information and that moderators are likely to remove any incorrect information. Therefore, we cannot rely on message analysis studies to determine the extent to which there are problems with online message boards. Since van Uden-Kraan et al published this study there have been other message analysis studies but also several questionnaire studies which have directly asked members about any problems. It would be useful and indeed needed to offer a more up to date review of this specific aspect of the literature.

Response 1a: We revised our text to better reflect the possible problems associated with the use of message boards. We have added several sources to elaborate on the possible disadvantages associated with message boards. We give an overview of possible disadvantages, instead of stating that these disadvantages do not occur. This has been described in the following lines (105):

In the case of online resources such as message boards, however, information of good quality is much harder to achieve or to guarantee, as the information is dependent on a large number of often anonymous individuals. Other potential dangers or disempowering effects of using online message boards include negative posts, disadvantages related to the use and evaluation of healthcare services, asynchronous communication, anonymity, lack of physical contact, and the large amount of information generated on message boards (Mo & Coulson, 2014; Uden-Kraan, et al., 2008; White & Dorman, 2001).

In light of the permitted word count, we expect that this issue has been sufficiently addressed in this way. Nevertheless, we will add further references if professor Coulson is still missing any relevant references.

b) line 173 - exactly the same problem in that this work is based on older work by van Uden-Kraan et al on empowerment. Since that study was published there have been many more studies which have shown that there are indeed many more empowering processes, several disempowering processes and together have related them to a range of important psycho-social outcomes. The introduction and indeed the methods section does need to take into account somehow the fact that this aspects of the literature has developed far beyond that which van Uden-Kraan et al originally proposed. Quite what this means for the analysis is up to the authors to consider - but at the very least there ought to be a fuller and more up to date review of the literature with other articles addressing this topic cited, if not discussed.

Response 1b: We have added several references (both older and newer) discussing empowerment processes. We feel like the work of van Uden-Kraan, et. al. (2008) is useful for our analysis for two reasons: (i) it not only explores empowerment processes,
but also explores the positive outcomes of these processes and (ii) recent studies have confirmed that similar processes and outcomes occur on message boards. These changes are reflected in the following lines (216):

Empowerment processes have been discussed in several articles. Finn (1999) has described the following processes occurring in an online self-help group about disability: mutual problem solving, information sharing, expression of feelings, catharsis, mutual support and empathy. Building on this research, Perron (2002) described the following empowerment processes: disclosure, providing information or advice, empathy or support, gratitude, requesting information or advice, computer issues, friendship, creative expression, structure. Van Uden-Kraan, et al. (2008) confirmed the occurrence of these processes in online forums. They also found the following empowerment processes in online support groups about breast cancer, arthritis and fibromyalgia: exchanging information, encountering emotional support, finding recognition and understanding, sharing experiences and helping others, amusement (van Uden-Kraan, et al., 2008). Several studies (Bartlett et al., 2011; Campbell et al., 2013; Mo et al., 2014) have confirmed the occurrence of these empowerment processes and also confirmed the outcomes described by van Uden-Kraan, et al. (2008). Two other studies into social support for weight loss in online communities show similar results (Das et al., 2014; Hwang et al., 2010). The major social support themes found were: encouragement and motivation, information, and shared experiences. These themes are closely related to the processes found by van Uden-Kraan et al. (2008) (Wentzer et al., 2013). An online survey conducted by Holbrey et al. (2013) among 50 participants revealed several other empowerment processes: connecting with others who understand, access to information and advice, interaction with healthcare professionals, treatment-related decision-making, improved adjustment and management.

We chose to use a categorization based on the work of van Uden-Kraan, et al. (2008) because they not only described empowerment processes in online forums, but also described positive empowerment outcomes related to these processes.

2. The analysis concludes that 'we did not see any major disadvantages occur' - however - based on the above comments - are the authors happy that they in fact looked for the potential disadvantages? I would like to see some comment on this so the reader is clear as to the scope of the analysis undertaken.

Response 2: We agree that the discussed disadvantages do not fully reflect more recent literature. Therefore, our analysis is now solely focused on the quality of information, instead of focusing on the disadvantages described in van Uden-Kraan, et al. (2008). We focused on the quality of information as this plays an important role in both patient empowerment and self-management. As professor Coulson mentioned earlier, patients and moderators can correct inaccurate information and therefore might influence our findings. We have seen users actively engage in this type of behavior and have also included this in our discussion. We did not have clear indications that moderators removed disputable information or negative posts. Nevertheless, we acknowledge that our findings could be biased due to any removal of posts. We have clarified this in the article as follows (line 386):

In general, we found that many people respond to and correct posts that include incorrect or disputable information, for example by referring users to a doctor. However, it should be noted that message board moderators may delete disputable information. Although we found no clear indications that such removals occurred in the threads we analysed, our findings may be biased due to the possible deletion of posts. We chose to focus on the quality of information that can be consulted on the Internet at the end. Nevertheless, further research on the effect of moderators on empowerment processes could generate useful information for the strategic application of message boards in healthcare.

3. The comment about negative posts line 332 - this is perhaps explained by the comments above that Ref 11 used groups where moderators removed incorrect or unhelpful replies. In any case, I think the reasons suggested are speculative at best and need to be revised and more evidence based suggestions put forward.

Response 3: Since we have limited our analysis of possible disadvantages to the quality of information, this line is no longer included in the article.
Minor Essential Revisions

4. The authors might wish to include, for information, a statistic concerning the % of patients prescribed medications for long term self-management of a condition. This is implied but would strengthen the rationale for the study.

Response 4: We have added the percentage of patients using prescribed medications for long term self-management (line 61):
It is estimated that around 90% of people with a chronic disease are prescribed medicines for long-term use (Calsbeek, 2007; Heijmans, et. al., 2004) with self-management being sufficient for 70 to 80% of patients (Ouwens et al., 2012).

5. How were the threads randomly selected - please specify which tool was used to do this.

Response 5: We loaded the threads as separate PDF files in the program ATLAS.ti. The first 25 threads listed in the program were selected. Threads that contained only a few posts discussing medicine use were excluded. This has been clarified in the article as well (line 170).

6. In the abstract - the term 'self-efficiency' was used but this felt a little odd. Could the authors reflect on whether this is in fact the correct term and they are happy with what it suggests.

Response 6: We incorrectly used the term self-efficiency interchangeable with self-efficacy. We have changed the term self-efficiency to self-efficacy in this draft, to correctly convey that empowerment could strengthen patients’ their belief to manage their medicine use successfully.

7. I would suggest adding 'online message board' to the keywords if this is possible

Response 7: Thank you for the suggestion, we have added the term 'online message board' to the keywords.

Response to reviewer’s report Samantha Adams

I enjoyed reading this article on empowerment of patients in online discussions about medicine use, a topic of increasing importance. I do, however, have several concerns about the article in its current form.

Response: Dear professor Adams, thank you very much for your comments on our article as well. We acknowledge your extensive discussion on our analysis and have revised the analysis taking your suggestions into account. Please find our point-for-point response to your concerns below.

8. My primary concern is that the paper presents itself as a qualitative study, yet the data is under-analyzed from a qualitative perspective and largely presented in a quantitative style in the text (very summative), backed up with quantitative frequency tables. The discussion also begins with more quantitative terminology. However, there is no explanation in the methods of how the quantitative analysis was done and the authors seem not to understand how to move from the coding of qualitative data to a richer data analysis.

Response 8: We have further clarified our analysis in the methods section. We did not intend to perform a purely qualitative study. The method we used, is known as deductive thematic analysis, based on categories from previous studies of van Uden-Kraan, et al. (2008). This has been clarified in the following line (177):
The posts were coded using a deductive thematic analysis method. This type of analysis is useful in research aimed at answering a specific research question, for the purpose of identifying, analysing and reporting themes or patterns within data (Braun et al., 2006; Vaismoradi et al., 2013). In our study we focused on the type of empowerment processes that occur in online forums. First we familiarised ourselves with the data and read all the threads and we wrote down our initial ideas. We found that these corresponded with the processes described by van Uden-Kraan, et al. (2008) and therefore considered these ideas well-suited as a coding framework for this study. The first author proceeded to code each post. The coding was not based on verbal cues; instead posts (or
fragments of posts) were placed in the predefined coding scheme. To validate the coding, the second and third author checked a random sample of posts in an open coding session to obtain agreement on the coding. The final analysis was performed based on a consensus reached between all three authors. To provide an indication of the relative prevalence of the different empowerment processes, we have also specified how many times these processes occur in the posts.

9. Moreover, the link between the coding categories and empowerment is shaky at best. Most of these categories have been identified in online studies without the framework of empowerment. So how do we know that these are empowering processes? Are there, for example, verbal cues in the text? I understand the reliance on Uden-Kraan from a Dutch perspective, but the authors could also draw on similar, older studies from international literature that more clearly operationalize the link between these notions.

Response 9: We have further elaborated on the framework of empowerment in our method section, as is also discussed in response 1b. We hope this clarifies any confusion about the empowering processes used in this study. We have also further clarified the coding process in the article (line 177). This has been discussed in response 8.

10. In their categories, the authors do not list other types of advice, such as (indirect) encouragement between patients to stop taking medications or to self-regulate the dosage. This point does return in the latter half of the results and the discussion, but without reflection on how this relates to the categories.

Response 10: We did not make a distinction between the different kinds of advice, however we did make a distinction in the quality of information. To avoid possible confusion, we have clarified that the topics discussed in the posts could consist of harmless, correct, disputable and incorrect information (line 375): The most prominent topics discussed concerned the effects of medicines, dealing with medicines or the disorder itself and the use and dosage of medicines. The topics discussed do not necessarily promote patient empowerment, as the posts may contain harmless, correct, disputable or incorrect information. Posts containing disputable or incorrect information could have potentially adverse and disempowering effects when that information is acted upon.

11. The authors also fail to explain how the 'professional with a pharmaceutical background' evaluated quality. These deficiencies in the methodology need to be corrected in a subsequent draft.

Response 11: We have further elaborated how the quality of information was assessed (line 192): After the first coding session, the third author, being a pharmacist by education, evaluated the posts that provided information on medicines and their use. The focus was on assessing whether the information might have harmful effects. The categories were not based on previous research, but emerged from the type of information provided in the posts. For example, advice on discontinuing the use of medicines or changing the dose without consulting a doctor was considered to be poor advice. Advice we considered to be of high quality included the recommendation to consult a medical professional when considering changing medicine intake or use.

12. The authors could give more information on the sites reviewed, including a short description of type of site (the current description is vague) whether or not groups were moderated/monitored (and if so, by whom?) and how the sites and groups were structured, as the structure of a site can also determine the nature of the information posted there.

Response 12: The method section now contains more background information on the sites reviewed (line 151): In total, we selected seven message boards for further analysis (three for ADHD, three for diabetes, one for ALS). The two most active message boards for both ADHD and diabetes were Fok and Viva. The VIVA message board is primarily aimed at adult women, whereas the FOK message board is primarily aimed at young people. As a result, different norms apply on the two message boards. The VIVA message board tends to be more supportive in nature, while discussions on the FOK message board tend to be more challenging. Both message boards are general in nature, which means that they target a broad audience and not just patients. The third most active ADHD message board is Babybrabbel, which is aimed at women who are pregnant or recently had a baby. Babybrabbel is similar to VIVA in the sense that it is a general message board where the
discussions and exchanges are supportive in nature. Diabetesforum was the final message board about diabetes that was selected. This forum is specifically aimed at diabetes patients, and many of the posts are about exchanging experiences of living with this condition. Due to the rareness of ALS, only the ALS-specific message board StopALS.nu contained posts related to the use of ALS medicines. This message board is aimed at patients suffering from ALS and those close to them. Other than posts containing information about selling medicines, we did not have clear indications that actions were taken by moderators. Therefore, we don’t expect them to have much influence on the discussions taking place. This has been clarified in the following text (line 433):

Moderators deleted a few posts where users offered to sell medicines, and gave the user a warning. We found no clear indications that any other actions were taken by moderators; for example, we saw no “edits” in posts. We also found no responses to deleted posts, e.g. quotes from deleted posts. Nevertheless, there is a possibility that our findings could be biased due to the possible removal of posts.

13. They should also reflect on the methodological choices made (search and selection strategies, paraphrasing rather than direct translation, etc) and how this might influence their results and/or conclusions.

Response 13: Posts were translated when we quoted them in the article, for the actual analysis we used the original posts in Dutch. Therefore, we do not expect this to influence the results. We have elaborated on this in line 205:

To protect the privacy of the message board users, the quotes used in this article were translated from Dutch to English to ensure they cannot be traced back to the original source. For the analysis, we used the original text.

In our discussion we have included several limitations associated with our methodological choices. We expect the following limitations to occur based on our search and selection strategy (line 411):

Firstly, we focused on Dutch message boards because we intended to conduct the search from a Dutch perspective. It is likely that Dutch patients will also visit English message boards, as most people in the Netherlands are able to read and write English. People confronted with a rare disease such as ALS are probably more inclined to visit international message boards than patients suffering from a common disorder. Therefore, our search parameters may have excluded some message boards, and also resulted in only one relevant ALS message board to use in this study. Secondly, in our study we used a mix of general message boards and message boards about a specific disorder. This might influence the frequency of the empowerment processes found, although we found a similar order of the processes in both types of message boards. Thirdly, when searches are performed on the same computer, Google offers a consistent way to search all message boards in the same manner. At the same time, we found that Google only displays a specific percentage of its total hits. Because of this, we may have missed some posts. Fourthly, moderators deleted a few posts where users offered to sell medicines, and gave the user a warning. We found no clear indications that any other actions were taken by moderators; for example, we saw no “edits” in posts. We also found no responses to deleted posts, e.g. quotes from deleted posts. Nevertheless, there is a possibility that our findings could be biased due to the possible removal of posts. Fifthly, we selected the first 25 threads shown in the ATLAS.ti program after randomly loading the corpus of files. After coding the selected 25 threads, we concluded that the same patterns occurred in the threads. We therefore do not expect that we have missed information.

14. Overall the analysis feels like a preliminary draft and I am not convinced that they can draw the conclusions currently drawn based on the methodology used and results currently presented. The analysis therefore needs to be entirely reworked. Be sure to analyze quotes properly, not leaving them to speak for themselves and ensure that the analysis and quotes match.

Response 14: We have made several changes to the analysis, which have also been discussed in the previous responses.

First off, we have clarified that we made use of deductive thematic analysis based on existing categories described in van Uden-Kraan, et. al. (2008), rather than a purely qualitative, grounded theory approach. Recent studies have used similar categories and have shown that these categories can indeed be related to empowerment outcomes (Bartlett & Coulson, 2011; Campbell, et. al. 2013; Mo & Coulson, 2014). To provide an indication of the relative prevalence of certain empowerment processes, we have also included how many times these processes occur in the posts.
Secondly, based on the feedback of professor Adams and that of professor Coulson, we decided not to focus on all disadvantages described in van Uden-Kraan, et. al (2008). We did so because they do not fully reflect recent literature. Instead, we focus on the quality of information as this plays an important role in both patient empowerment and self-management. This is also reflected in the results and discussion section of the article. The discussion section has been rewritten and now more focused on the empowerment processes that occur and the quality of information of the posts. The different categories have been discussed more extensively in the results section. Finally, we are aware that our research has several limitations, as we have also discussed in response 13.

Minor Essential Revisions

15. There are English grammar mistakes in the abstract and main text and typographical errors in the reference list. I therefore recommend having subsequent drafts checked by a native English speaker.

Response 15: As suggested by prof. Adams, our manuscript has been edited by a native English speaker.

16. A few references that might help the authors are listed below. They relate to doing qualitative analysis, sharing experiences on the internet and sharing experiences with medications.

Response 16: Thank you for the suggestions; we have incorporated several of the articles in the discussion section of our study. We have included Wu et al. (2013) in the discussion about the topics discussed in the posts (line 366):

Online platforms have become increasingly popular sources for gathering information about patients sharing their medicine use experiences (Adams, 2013), including the possibility to detect possible side-effects at an earlier stage (Wu et al., 2013). In our study users seemed to focus mainly on whether or not medicines had the intended effect. Discussions about side-effects were mostly limited to the ADHD message boards. The type of information exchanged about the use of medicines could help increase the self-efficacy of patients, enabling users to receive information more quickly and tailored to their personal needs (van Uden-Kraan et al., 2008). We found that people were actively exchanging information about medicine use, either by providing information, sharing personal experiences, or requesting information. The most prominent topics discussed concerned the effects of medicines, dealing with medicines or the disorder itself and the use and dosage of medicines.

Adams (2013) & Ziebland, et. al. (2012) have been used in our discussion about the quality of information (line 392):

Although much of the information itself may be considered harmless, this does not necessarily mean that the effects cannot be harmful, as the utility of health information depends on the recipient’s background knowledge that is necessary to evaluate the information adequately (Schulz et al., 2011). The extent to which people rely for information on other people’s experiences as posted on the Internet is a cause of concern as well Ziebland, et. al. (2012). Our study reflects the importance of personal experiences, but we found no indications that these posed more risk than other types of information.

Final remark to professor Coulson and Adams:

Thank you very much again for your helpful and detailed review. It contributed to a more thorough analysis of our findings and better insights.

On behalf of all authors, Jasper van Berkel