Reviewer's report

Title: Experiences of patients identifying with chronic Lyme disease in the healthcare system: A qualitative study

Version: 1 Date: 18 February 2014

Reviewer: Joanna Brooks

Reviewer's report:

Overall, an interesting paper with potential, particularly in relation to exploring patients’ use of varied CAMs in CLD. Thank you for letting me read your work. I hope the remarks below will be useful for the authors.

1. (discretionary revision):
Final paragraph of the introduction:
‘The focus of this study was. ... on perceptions of disease burden and of their healthcare providers’.
Was this an initial focus of the study - a study aim - or did these themes emerge from the data? I think perhaps the latter - the aim of the study would be more accurately described as exploring patient experiences using the constructs of the Health Belief Model (HBM).

2. (compulsory revision):
Related to this point, given that the HBM was used to conduct interview schedules, there is insufficient detail with regards to how this model guided analysis and interviews construction – it is not clear to me from the table how some questions are exploring/ related to the model constructs. There should also be some explanation of the HBM somewhere in the piece (perhaps in the background section) for readers unfamiliar with this model.

3. (compulsory revision):
Data analysis. Qualitative methods are appropriate to explore patient experiences of this contested illness condition, but the authors need to be much clearer about their data analysis. What is the difference between themes, codes and categories in the authors’ use of these terms? How many emerged? Why are just two discussed here? What do the authors mean when they say their analysis is based on a phenomenological approach? The two references cited describe a number of approaches to qualitative data analysis and from the authors’ description of their own work, I am not really clear which approach they themselves used. It would be really useful if they could provide clearer detail here.

4. (minor essential revision):
‘Results’ - ‘Recruitment’ – first paragraph. Details of the interviews and process of data analysis should be in the methods section, not in results.
5. (compulsory revision):
The results section generally needs some significant reworking. I have therefore labelled this as a compulsory revision, but I would not wish to dictate to the authors exactly how to do this - so what follows is suggestions as to how they might go about this.

Currently there is just too much under the two themes presented and the thematic headings used / codes presented thus fail to really represent the data. One approach to remedy this might be better use of subheadings within sections (e.g. 'social impact'; 'timeline/ the future' etc. etc. rather than just the current overarching 'patient burden'). The authors might also like to tabulate the codes/themes that emerged through their analysis of the data – this would additionally perhaps strengthen their data analysis section. Various statements are made with no evidence presented to support these claims – e.g. ‘Eight participants noted social limitations.... etc. etc.’. Throughout, the authors seem to be relying on numbers to support their statements – I find this inappropriate in a piece of qualitative research and feel assertions would be better supported through wider use of verbatim quotes from participants. In relation to this, they currently seem heavily reliant on a small subsection of their participants for most quotes provided, and the quotes used are sometimes rather lengthy and not terribly illuminating of the points made – perhaps they might like to revisit their data to strengthen this section?

6. (discretionary revision):
Discussion – literature discussed mainly centres on healthcare professionals' attitudes to medically unexplained symptoms rather than patients' experiences of these encounters (there is lots of relevant qualitative research in other contested illness conditions that could be drawn on). Similarly, what about the use of CAM in other illness conditions? The authors could draw on plenty of relevant existing research.

7. (compulsory revision):
Conclusions. The authors state ‘many participants sought out and were treated by highly invasive (long term antibiotic regimens)’ – where is this evident from the rest of the paper, specifically your results section? How does this relate to the findings presented – please clarify/ explain.

8. (discretionary revision):
Conclusions: Could the authors be clearer about how their research might assist clinicians in creating ‘active and sympathetic clinical encounters’?

Level of interest: An article whose findings are important to those with closely related research interests

Quality of written English: Acceptable

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.