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Title: Medical invalidation in the clinical encounter: a qualitative study of the healthcare experiences of women and non-binary people living with chronic illnesses

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Reviewer 1: Fuchsia Howard

Institution: School of Population and Public Health, University of British Columbia
General comments (author response in bold)

1. Focus on young adults: The age range of the participants was 20 to 35 years, representing a unique sample. It is not clear whether this young adult age sample was the result of convenience sampling or whether the focus of the study was on young people from the beginning. Because the sample is young adults, the introduction ought to include a line of reasoning/literature that discusses the experience of young people in particular as these often differ from older individuals with a variety of illnesses, including chronic illness. Similarly, the data analysis/findings would be strengthened by an interpretation of the influence of young adulthood.

This was an intention from the start and didn't get carried through into the writing, so thank you for highlighting this omission. Revised accordingly – see also our response to editor review comments and theme 1.

2. Framing of methodology: The authors describe the methodology as a qualitative, arts-informed participatory approach drawing on feminist disability theory.

A. However, it is not clear how this was participatory research and the intersection with the involvement of patient-partners. When and how were participants involved in the design of the study, aside from the design of the workshop, as well as other study aspects such as analysis or refining of the findings. It seems there is some confusion about how/whether to frame the research as participatory or patient-oriented research.

B. It is unclear what feminist disability theory the authors drew upon or how this informed the various study aspects – from study conception and through analysis. Further details are important to make apparent what and how theory informed this research.

C. It is unclear how Braun and Clarke's approach to thematic analysis intersected with the use of a qualitative participatory arts-informed approach. The authors state that this was informed by the concept of medical invalidation, but I also wondered whether the analysis was informed by feminist disability theory referred to earlier.

Thank you for highlighting this – there is considerable overlap regarding the different methodological approaches, so we revised for clarity and added more details explaining the methodological approach in the methods section to address the methodological concerns outlined here in points a-c.

3. Findings: The 3 themes presented do appear to convey different ideas and it is evident why these are separated in the way they are. However, within the 3 main themes, it is difficult to discern the main ideas and findings, particularly in theme 2. I could not get a handle on the main ideas being presented in this theme and only when I referred to the table did I gain a bit more clarity. However, the headings in the table do not match the text and so adds confusion. Though I suspect the authors presented the participant quotes/examples in table form because of the journal word limit, separating them from the text detracts from the narrative the authors are attempting to provide. I suggest the authors rework the findings by identifying the main ideas in each theme,

grouping the ideas accordingly in the text and then integrating quotes/examples to exemplify what they are attempting to convey. Fewer quotes placed strategically would perhaps be more effective than an abundance of quotes poorly placed in the manuscript. **Revised, see also response to editor comment #11.**

Reviewer 2: Marie-Chantal Fortin

Institution: Centre de Recherche du CHUM

General comments (author response in bold)

Title Page:

1. The authors mentioned that patient partners were involved in the study. They also included the GRIPP2 short form to report the patient involvement in their study. However, why there is no patient partners among the authors?

See response to editor comment #12.

Abstract:

1. In the background section, the authors use the term working relationship for patient-physician relationship. I would suggest removing the word working since it is not a relationship between co-workers.

2. In the background section, the authors should specify that they want to look how medical invalidation is experienced by women and non-binary patients.

3. In the Methods section, the authors should also include that they used an arts-informed participatory research.

Thank you. Revised abstract to include more details accordingly.

Methods:

1. The authors should mention in the Methods section that they used the Standards for Reporting Qualitative Research and refer to the Table at the end of the manuscript.

2. Why the authors chose to include only women aged between 20 and 35?

3. The authors should mention how many patients were interested to participate and how many really participated.

4. It is unclear for me if the discussion happened during the same workshop where the patients created a collage. It should be clarified. Also, why the authors chose to conduct group discussion with two or three participants?

5. Who was leading the group discussion?

6. Did the authors attained data saturation during the analysis?

1. Added this note: line 51. Thank you.

2. Added more information/rationale as this was also brought up by another reviewer – see lines 35-41; 68-74.

3. Added this detail – lines 115-117.

4. More information added, see lines 82-87.

5. More information added – see line 83-84.

6. Our approach is guided more by our theoretical orientation than concepts such as data saturation – See Malterud et al., 2016 for the concept of “information power” as opposed to data saturation.

Results

1. In the Table 1 on participants' characteristics, it would be interesting to know the type of chronic illness, average age, employment status, education level.

2. In the results section, it would have been interesting to hear about the arts-informed research and the visual collage created by the participants. Are there some

topics that were not addressed during the discussion and only expressed in the visual collage?

3. Were there some topics that were different from non-binary patients?

1. I have added a bit of detail on the chronic illnesses, line 118-120. Given the small number of participants we have opted not to include too much demographic information to protect confidentiality. We did not collect information on employment or education level.

2. These are taken up in a separate publication.

3. No – did not end up being as salient as some of the other demographic factors.

Interpretation

1. In the interpretation section about the participants' recommendations, the authors should consider adding medical student training session with patient partners could be an avenue to explore to enhance empathy and listening skills.

Thank you for this suggestion. I think this is a good suggestion, but our aim is to suggest going beyond activities that enhance empathy and listening so would not be an appropriate recommendation based on our conclusion.