Reviewer’s report

Title: Co-producing a shared understanding and definition of empowerment with people with dementia

Version: 1 Date: 25 Feb 2019

Reviewer: Julie Haesebaert

Reviewer's report:

This paper describes the process of co-producing a definition of empowerment specific to the situation of people with dementia, based on literature review and the perspective of end-users, in a collaborative research involving PWD. This paper treats of an interesting topic in an era where patient engagement and empowerment is promoted but for which few data regarding PWD are currently available. The approach combining literature review and coproduction workshop is very relevant and the theory section in the different definitions of power is well documented. However I have concerns regarding the reporting of methods and findings.

1- One of my main concerns regards the 1rst objective stated in the paper which is "1. How can PWD be involved in coproduced research to define empowerment relative to PWD?". To me the research has not been conducted to properly answer this question as first aim. It seems that the questions 2 and 3 are more consistent with the project that has been conducted. The authors did not study the mechanisms, the process nor the impact of engaging PWD in research, no endpoint regarding how PWD were engaged (level of engagement, activities, perceptions, barriers/enablers, impact… for instance) were studied and reported, thus I would only state this as secondary objective. In line with this remark, the first sentence of the discussion should be removed. I propose to begin the discussion on the definition, and to rather mention later that this study showed that PWD engagement in research is feasible, since PWD participated to the workshops and gave valuable insight.

2- The literature review is described as a "systematic search and narrative review". The number of databases screened is correct, but some data are missing to fit with the definition of a systematic approach.

- The questions addressed by the review are not explicitly defined, for instance in the abstract emphasis is put on empowerment measurement which is not clearly addressed in the body of the manuscript as an objective and not presented in the result section.

- Regarding table 1: Where there any boolean operator between empowerment and concepts?

- Did you apply language restriction and date restriction regarding publication date?
- Why limiting your search to peer-reviewed journals? Grey/unpublished literature on this topic, coming from patients associations or institutions would have been very relevant.

- No information is available in the methods on data extraction and analysis process of the review. I would suggest switching the first 2 paragraphs of the results from the results section to the design section because to me they provide information on these points. It would be interesting to present the items covered by the data extraction framework.

- The results section should begin by presented numbers of papers included. The flow-chart of inclusion of papers in the review is not presented and would be interesting as appendix for instance to gain in transparency of the review process (see PRISMA statement for example).

3- Regarding the co-production workshops:

- Who are the 9 co-researchers mentioned p8 118? Do they correspond to the 9 PWD mentioned previously? Additionally to PWD, how many professionals/researchers participated to the workshop? Who facilitated the workshops?

- Description of PWD involved in workshop could be enhanced by presenting briefly their previous experience of involvement in research or their history of participation in the Dementia NL. This would help to appreciate how they are representative of "all" PWD. The authors mentioned it as a potential limitation of the study but additional description of the PWD could help to appreciate this potential bias.

- It seems that no clinician has been included in the process. Why did you choose to not include clinicians/health professionals? This has to be discussed in the paper since, as mentioned in the results from the literature review, they are involved in the design of programs to empower PWD. Co-production usually involves all end-users representatives and professionals could be considered as end-users of the definition.

4 - In the final definition of empowerment, the specification 'about their life' seems to refer only to an individual perspective. Did the members of the workshops talk about organizational or even societal levels?

5- The discussion does not clearly compare the proposed definition to others available in the literature in general or specific of patients with other diseases. Did the authors identified specificities linked to dementia in the proposed definition?
Minor remarks:

- "people with dementia" is inconsistently abbreviated as PWD or PwD, please revise the manuscript to be consistent.

- p16 l39: I think NGO has never been used before in the manuscript so I propose to write it in full length.

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