Author's response to reviews

Title: Informing the Development of an Online Self-Management Program for Men Living with HIV: A Needs Assessment

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Author's response to reviews: see over
To Whom It May Concern:

Thank you for considering the manuscript titled “Informing the development of an online self-management program for men living with HIV: A needs assessment” for publication in BMC Public Health.

The authors would like to thank the reviewer for their comments; we believe they have significantly improved the paper.

I have addressed the reviewers’ comments as follows:

**Reviewer 1**

**Major Revisions**

1. *Literature review of self-management is limited to citing one review that was conducted but not providing any information about the findings from that review. The literature review requires significant expansion.*
   - Expanded the section on self-management of HIV including expanding on findings from the cited systematic review.

   “Self-management involves three tasks: medical management, role management and emotional management, and encompasses six core skills: problem solving, decision making, resource utilisation, the formation of a patient-provider partnership, action planning and self-tailoring [5]. In order to be a successful self-manager, motivation, healthy behaviours and effective collaboration with health professionals is required [6]. Self-management interventions are widely used and have demonstrated effectiveness in improving health related outcomes and quality of life for a variety of chronic conditions including diabetes[7], arthritis[8], vision loss[9], and cardiovascular disease[10]. Benefits to be obtained for people living with chronic conditions from participating in self-management interventions include reduced morbidity, improved health related behaviours and health outcomes, reductions in use of acute medical services and hospital visits and improved quality of life [11].

   Self-management interventions have also been trialled among PLHIV with systematic reviews finding evidence of effectiveness enhancing adherence to cART[12], increasing exercise[13, 14], and short-term improvements in physical, psychosocial and health knowledge and behavioural outcomes[4]. In comparing common factors across chronic diseases and challenges which are specific to HIV, Swendeman and colleagues (2009) report “lack of direct self monitoring of physical status; stigma and disclosure; and criminalization of HIV exposure” as
particularly challenging when it comes to the self management of HIV infection[15]. “

- Also added further explanation of the fourth step of the needs assessment (the systematic review)

“Finally, a systematic literature review was conducted, which examined the effectiveness of existing HIV-specific self-management interventions and identified those programs and models which could be used to inform the intervention targeting the needs of this group. Briefly, this review found that self-management programs for PLHIV result in short-term improvements in physical, psychosocial and health knowledge and behavioural outcomes[4]. The long-term effectiveness of such programs could not be established due to insufficient evidence. The present paper reports on the findings of the survey of quality of life and the focus group discussions.”

2. Definition of self-management by Lorig is ok, but many communities in the USA talk about family management, not just self. Perhaps self works here if this sample is primarily gay, white men. I doubt it works if these are individuals of color.

- Expanded discussion of self-management (as above). Self-management is the applicable term here. The authors concur that a family management model would be more appropriate for various CALD populations.

3. It is not clear that saturation was reached with one focus group with 11 participants. I found the findings very interesting and well presented, but perhaps due only to those who participated and not representing a larger community. There was no discussion of the limitations of this observation of the potential of failing to reach saturation in the questions about self-management.

- Added a paragraph on limitations addressing this issue at the end of the discussion.

“There are several limitations to this study. Firstly, this study included only those who identified as gay or MSM meaning that the results from this study may not be applicable to other PLHIV including women, heterosexual men and people who are culturally and linguistically diverse. Second, the focus groups were conducted with a relatively small sample of participants and saturation was not reached in the timeframe available. The multifaceted approach to the needs assessment including a comprehensive review of literature addressed this limitation, ensuring the findings were representative of the population of gay/MSM living with HIV in Australia as a whole. “

Reviewer 2

Major Revisions

1. Page 4 line 6, who has raised concern about this issue? I would expect this claim to be justified with a citation. Also, I’m not clear on what the author’s mean by “implementation of programs”, please clarify.

- We are talking about health programs that are developed and delivered to client groups without consideration of theoretical models, and the specific
needs/concerns of the client group. The sentence was changed to clarify this (as below).

"Concern has been raised, however, that health education has focused too narrowly on the implementation of programs, rather than on designing and developing programs that are grounded in theory and systematically targeted towards meeting the concerns of the specific client groups[8, 9]."

2. In general I was surprised by limited literature cited in the qualitative results and discussion sections. I know some qualitative traditions advocate for this, but it helps to reader to understand the novelty of the findings, and how the findings fit into overall body of research. Many reading this paper will not be HIV self-management experts and if they only read this paper, they would miss a whole literature on HIV self-management that is directly related to this study. (also, take a look at the literature on post-traumatic growth following and HIV diagnosis - others have looked at this issue before)

- Expanded the literature review on self-management intervention for PLHIV as above (see reviewer 1 comment 1).
- Included additional references throughout discussion as suggested (see p 18-20).

3. Discussion: It seems the purpose is really to develop an online SM program focusing on the psychosocial needs of gay men living with HIV. Not additional SM needs. If correct, please clarify.

- The aim of the needs assessment was to establish the “priority areas” for the intervention to target. Psychosocial needs were identified as being the priority and the intervention will be strongly weighted towards addressing such issues. More general self-management aspects will also be addressed through the intervention but as a secondary priority.

4. Also, I’d like to ask the authors to be clearer in what they mean by support. This word is used throughout the discussion and is very imprecise. Is there anything in their data that can help us clarify what type of support is needed? Specifically, what have we learnt about these needs from this study?

- The word 'support' is used once in the discussion (p18, line 24). The argument we are making is that self-management support particularly surrounding psychosocial issues (such as emotional impact, disclosure and management of intimate relationships) is needed. We have learnt that these needs are not presently being adequately addressed and that the proposed self-management intervention may provide a solution to this.

5. Also, could the authors talk about how the qualitative findings complemented the quantitative findings from the SF12. As it is written, these really appear to be separate data from separate studies and there is little synthesis provided. This would help the reader to understand these findings, and their implications, in greater detail.

- The first paragraph of the discussion has outlined the findings from the survey of QOL and explained how these findings were echoed in the focus groups. This is addressed again in the third paragraph of the discussion linking the survey findings to the findings of the focus group.
**Minor Revisions**

1. I strongly suggest that the author’s look at Dallas Swedenman’s model of integrated HIV self-management. I think it would help to inform the background paragraph on page 3, lines 21-24. It is also more recent than Lorig's work.
   - Included a discussion of Swendeman’s work in the background as suggested.

   “Self-management interventions have also been trialled among PLHIV with systematic reviews finding evidence of effectiveness enhancing adherence to cART[12], increasing exercise[13, 14], and short-term improvements in physical, psychosocial and health knowledge and behavioural outcomes[4]. In comparing common factors across chronic diseases and challenges which are specific to HIV, Swendeman and colleagues (2009) report “lack of direct self monitoring of physical status; stigma and disclosure; and criminalization of HIV exposure” as particularly challenging when it comes to the self management of HIV infection[15]. “

2. Page 5, line 8: while I understand what the author’s mean by “positive men”, I’m not sure an audience member who is not an HIV expert would understand. I recommend changing to HIV-positive or man living with HIV.
   - Done. Changed all to HIV-positive.

3. Style: the authors identify ART as cART in the background and ART in the results. Please be consistent so as to not confuse the reader.
   - Done. Changed all to cART.

4. Focus groups: that all participants identified as gay or MSM may bias the results. I'd like to see the authors discuss this limitation (and its implications).
   - Done. Added a paragraph on limitations at the end of the discussion. See above (reviewer 1 comment 3).

5. Isolation and stigma, page 13- we wrote a paper last year that looked at this issue in men and women that might help provide context for this result and provide further justification for the conclusion. (Webel, 2014, AIDS Care(26) 5.
   - Thank you, we have referenced and described your work in the relevant section of the discussion.
   “This finding is supported in research conducted by Webel and colleagues (2014) who found that HIV-related stigma is a significant predictor of stress and social isolation[29].”

Please contact me if you require any further information.

Kind Regards,

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