Reviewer's report

Title: Exploring reasons for non-participation and withdrawal from a randomised controlled trial of telehealth and telecare in England: a qualitative study

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Reviewer: Lance Brendan Young

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Major Compulsory Revisions
None

Minor Essential Revisions
None

Discretionary Revisions

The article, Exploring Reasons for Non-Participation and Withdrawal from a Randomized Controlled Trial of Telehealth and Telecare in England: A Qualitative Study, is well written and makes an important contribution to our understanding of a persistent barrier to healthcare. Although it is publishable in its present form, I hope the authors will consider several proposed changes that would enhance the focus and clarity of the article.

1. In the title and throughout the article the authors refer to participation in a trial. This trial involved telehealth and telecare treatment interventions. In a sense, potential participants were asked simultaneously to enroll in a research study and in a TH/TC program. Yet, participants may have different reasons for non-participation in research studies and non-participation in TH/TC programs. The authors never make the distinction and the article would benefit tremendously if they would, given that the audience is familiar with non-participation in research and one of the keywords is “trial participation”. Refusal to enroll in, or deciding to withdraw from, a research study has been extensively studied due to its methodological implications. At the very least, the authors should acknowledge this literature in the Background section and note that they are studying non-participation and withdrawal rates which cannot be attributed to baseline refusal to participate in research. In fact, when they note the 36.7% non-participation rate on page 6, they might compare it to similar non-participation rates in chronic care interventions which do not involve TH/TC in order to suggest the magnitude of the problem when TH/TC is a component of the intervention. The concluding sentence in the Background section states, “Whilst this study is focusing on non-participation and withdrawal from the WSD trial, it was clear that participants were mostly reflecting on the potential impact of telehealth and telecare if they were to take part in the trial.” This is a key point and belongs in the Results section with an explanation how the researchers determined “it was clear.”
2. The title includes “randomized controlled trial” but the randomized and controlled aspects of the trial have little relevance to the qualitative study described. Further, they would cause search engines to identify the article when searchers are actually looking for (quantitative) RCTs on telehealth. I suggest eliminating the phrase in the title.

3. The authors mention “barriers” to healthcare twice in the article, on pages 5 and 18. Given that “barriers to care” is a common phrase in the literature and that this study focuses on one of the major barriers to widespread adoption of TH/TC as a mode of healthcare delivery, I would urge the authors to use it both in the title and as an organizing framework. In fact, it could serve as a formal research question: “What are potential participants’ perceived barriers to participation in TH/TC interventions for chronic care?”

4. In the Abstract, the authors refer to “non-uptake” but that phrase is never used in the body of the article, and the term “uptake” is used only once, in the Conclusion. They should eliminate it and refer instead to “non-participation and withdrawal” or simply “non-participation”.

5. On page 6, the authors should elaborate on how, “eligible patients within practices were then approached to take part.” Did their physician or nurse attempt to enroll them? In person? Given the potential relevance of the initial presentation to the patients, the authors should clarify communication-relevant information: messenger, message content, medium, timing, and location.

6. On page 7 the authors do a good job of defending a relatively small sample size. In order to anticipate the inevitable objections of quantitative researchers, the authors should note in the sampling paragraph or in the Discussion’s limitations paragraph that qualitative research does not aim for generalizability, but aims rather for transferability. A source citation for transferability and for the small sample size would help to support the sampling method used.

7. On page 8, reference is made to coding for “emerging themes” but coding requires some sort of guiding question, as one could code for a wide range of perceptions, from language used to describe symptoms to the failures of the healthcare system. If the coded themes related to a question about barriers to participation (or something similar) the authors should say so.

8. On page 8, the authors should provide a more detailed description of the analytic technique used for coding. If Atlas.ti software was used, are the authors able to provide a measure of inter-coder reliability? If not, more detail should be provided regarding what constitutes a “theme” and how the discussions resulted in combining or splitting emergent themes.

9. On page 8, the description of the “observational work” deserves a separate, more detailed paragraph because observation is a different method and because the participants observed were apparently different from those interviewed. Interviewing and observation work well together in this study, but they are separate methods and led to separate, though related, results.
10. In the Results section, are the three themes presented the only themes that emerged? On page 14, the article mentions, “a final strong theme” but doing so implies weaker themes also emerged and the reader is left wondering who determined strength and weakness of themes. A numerical calculation of the frequency of themes would convey to the reader that accuracy is important to qualitative research. At present, each of the three broad themes seems to have a number of variant subthemes. For instance, the technical competence theme mentioned the complexity of the modern world, the generation gap, limited English proficiency, lack of technical support, and mechanical problems. Explicitly state why those were all categorized as “requirements for technical competence and operation of equipment”? Providing detailed information about the boundaries drawn between themes indicates rigor was important to the researchers. Further, simplifying theme categories would clarify results. I’d suggest: Perceptions of Technology, Perceptions of Self, and Perceptions of Healthcare.

11. In qualitative studies, the interesting narrative elements often are lost in the body of the text, and the problem is worse in medical journals because the audience is accustomed to reading data in tabular form. Consider presenting one or more tables consisting of several brief excerpts illustrating each theme.

12. On page 13, one participant mentions the burden placed on his wife, and later three caregivers mention the burden for patients who are too ill. In the Discussion section, the authors address the importance of caregivers in determining enrollment, but their influence perhaps merits more explicit exploration in the Results. On that subject, the caregivers’ perceptions on page 13 and 14 seem to fit better in the “disruptions” theme subsection, as they seem to indicate TH/TC could only interfere with a caregiving system that is working. I’d place it on page 15, in the paragraph beginning, “Other respondents who had quite severe problems were often already receiving specialized services.”

13. Overall, the Discussion section is quite good, particularly its integration of the findings with previous research. I’d suggest mentioning explicit practice implications for each of the themes addressed. For instance, the perception of complicated technology suggests TH/TC should be targeted only to those who can use it effectively, should be simplified, or should be introduced in more understandable terms. The authors should not save all the practice implications for the Conclusion.

14. The article would benefit from a Discussion paragraph suggesting areas for future research. The study participants had very intelligent observations which researchers should attempt to prove or disprove. Three avenues of research suggest themselves. First, does TH/TC encourage dependency among (some) participants? Second, are technical issues problematic for (some) TH/TC participants? Third, does TH/TC negatively affect existing healthcare delivery systems?

Level of interest: An article of importance in its field
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.