PEER REVIEW HISTORY

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ARTICLE DETAILS

<table>
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<th>TITLE (PROVISIONAL)</th>
<th>‘The phone reminder is important, but will others get to know about my illness?’ Patient perceptions of an mHealth antiretroviral treatment support intervention in the HIVIND trial in South India</th>
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<tr>
<td>AUTHORS</td>
<td>Rodrigues, Rashmi; Poongulali, S; Balaji, Kavitha; Atkins, Salla; Ashorn, Per; de Costa, Ayesha</td>
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VERSION 1 - REVIEW

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<tr>
<th>REVIEWER</th>
<th>Free, Caroline</th>
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<td>London School of Hygiene and Tropical Medicine, Public Health interventions Unit</td>
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<th>REVIEW RETURNED</th>
<th>17-Mar-2015</th>
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GENERAL COMMENTS

My scores given above come across more negatively than they are as I put 'no' in response to areas that need further detail or clarification or if one aspect of the criteria had not been addressed even if mostly the criteria had been addressed.

Objectives. Whilst it can be true that exploring patient perspectives can increase understanding of how an intervention works, it would be more appropriate here to say: exploring patient perspectives can increase understanding of why an intervention works or why it does not work.

Methods:

The authors should clarify why they only interviewed 16 participants. It is difficult for someone external to the project to judge if saturation of the data has been achieved but my impression is that they may not yet have achieved saturation of the data or do they think they had?

Results.

The authors clearly describe some key themes.

My impression is that further analysis of the data might provide richer findings regarding why reminders don't work. e.g. the written text stating that patients wanted to discuss their disease and drug regimen with a health care provider is illustrated by just one quote which refers to patients wanting to clarify things. Was this explored in depth in the interviews? are there any further insights into what patients wanted to clarify? Does this have implications for future interventions? Could some of what patients want be delivered via automated interventions or is interaction with a health care provider essential? Thi could also be discussed in relation to other trial reporting positive findings.
Some of the English needs correcting e.g second paragraph line 5 and line 7 of the introduction.

The paper would be improved by more clearly drawing out some of the other implications for future interventions. Further discussion of the findings could be done in relation to trials of adherence interventions delivered by mobile phone that report beneficial effects and those that don’t. It might be appropriate to reference Haynes cochrane review on adherence alongside ref 28 in the sentence that states that external reminders used in isolation may not be able to improve adherence as in his review (which has now been updated) Haynes concluded that single strategies for adherence were not effective.

I remain curious. The trial was preceeded by qualitative work with participants - do the authors have any insights we might all learn from regarding why the feedback about messages during intervention development seemed more positive than their views collected in the qualitative interviews? Could this be discussed in the discussion section? e.g. perhaps the qualitative interviews were done by someone independent whilst the intervention development interviews might have been perceived to be done by someone aligned to the intervention?

other refs Douglas N, Free C. ‘Someone batting in my corner’ participant’s perspectives regarding the Txt2stop intervention .BJGP 2013;63:588-589

REVIEWER
Mbuagbaw, Lawrence
Centre for Development of Best Practices in Health, Yaounde Central Hospital

REVIEW RETURNED
19-Mar-2015

GENERAL COMMENTS
1. Please provide the reference number for Ethics approval in the manuscript
2. Where the participants selected from the control or intervention arm
3. In the methods section teh participansts were purposefully selected based on their residence, but residence is not reported in the results section.
4. A lot of interesting discussions may arise regarding extending the role of text messages to other patient needs, who will benefit from them and the role of literacy/education. I am adding some references which the authors may choose to use or ignore:
Reviewer 1: C Free

I enjoyed reading this paper which explores patient perspectives of IVR and text message reminders for medication.

Thank You!

My scores given above come across more negatively than they are as I put 'no' in response to areas that need further detail or clarification or if one aspect of the criteria had not been addressed even if mostly the criteria had been addressed.

Abstract:

Question 1. Objectives. Whilst it can be true that exploring patient perspectives can increase understanding of how an intervention works, it would be more appropriate here to say: exploring patient perspectives can increase understanding of how an intervention works or why it does not work.

This has been revised in the “Objectives” under the abstract as follows:

Exploring patient perspectives enhances understanding of how an mHealth intervention works or why it does not.

Methods:

Question 2. The authors should clarify why they only interviewed 16 participants. It is difficult for someone external to the project to judge if saturation of the data has been achieved but my impression is that they may not yet have achieved saturation of the data or do they think they had?

Response: Yes we believe we did reach data saturation with 16 interviews.

We have included this in the methods section of the manuscript on page 7 (paragraph 2) as follows:

We achieved data saturation around the 16th interview and therefore decided to stop the interviews, as no new information was forthcoming.

Results:

Question 3. The authors clearly describe some key themes. My impression is that further analysis of the data might provide richer findings regarding why reminders don't work, e.g. the written text stating that patients wanted to discuss their disease and drug regimen with a health care provider is illustrated by just one quote which refers to patients wanting to clarify things. Was this explored in depth in the interviews? are there any further insights into what patients wanted to clarify?

Response: Participants also reported that they would like to discuss their health problems and share their feelings, their disease progression, advice regarding medication and its side effects, nutrition, interactive behaviour and any recent advances in HIV treatment.
Participants reported a desire to speak to the person calling them. They also wished to discuss their health problems and share their feelings, their disease progression, advice regarding medication and its side effects, nutrition, interactive behaviour and any recent advances in HIV treatment and cure with the caller if given an opportunity

… I am a patient, I could have asked detailed information about that about taking tablets, about eating food, how to mingle with everyone, how to work … it may help

Question 4. Does this have implications for future interventions? Could some of what patients want be delivered via automated interventions or is interaction with a health care provider essential? The paper would be improved by more clearly drawing out some of the other implications for future interventions.

Response: We have now discussed the implications for designs of future interventions including automation and personal interaction within mHealth interventions on page 22 (paragraph 3) and 23 (paragraph 1 and 2) as follows:

Considerations for future design of mHealth interventions: Interventions personalized to the beneficiaries’ need should be developed [32]. Multicomponent interventions could be designed such that two-way communication with physicians/ counselors, along with information on nutrition, medication side-effects and advances in HIV care are incorporated. Though interactive communication may engage patients for longer durations, it needs to be balanced against the resources needed for intervention scale-up.

Sensitivity to the disease and socio-cultural contexts, given the possibility of stigma if sensitive information were intercepted is needed. Targeting those with poor adherence, as suggested by participants in our study, could improve efficacy of mHealth interventions [40]. Furthermore, qualitative assessments prior to and during a trial can help develop and contextualise such interventions [32] These considerations could be extrapolated onto chronic non-communicable disease and tuberculosis [42]

Question 5. Further discussion of the findings could be done in relation to trials of adherence interventions delivered by mobile phone that report beneficial effects and those that don’t. This could also be discussed in relation to other trial reporting positive findings.

Response: We have discussed the results of our study in relation to other trials as follows:

1. Support and concern (Page 17 last paragraph and page 18 paragraph 1 line 1):

Reports of mHealth interventions providing support and making the recipient feel valued were also observed in Kenya [5, 9, 29]. These interventions, however, involved a component of personal interaction via the phone unlike our automated intervention.

2. Regarding two way communication (Page 18, paragraph 2):

Two-way communication involving text messages was found to open communication channels and address unmet needs of HIV patients in the Cameroon Mobile Phone SMS (CAMPS) trial. Expressing
gratitude, requesting counselling, financial support and advice regarding medication side-effects - reasons for using two way communication in CAMPS trial were also mirrored in our study [34]. Though the content of communication was identified during the design phase in three mHealth trials from Sub-Saharan Africa (SSA), none explored the need for interaction [9, 10, 13]. Further, though the WelTel and CAMPS trials provided an opportunity for personal interaction with the healthcare provider, only the WelTel trial was successful [9, 10]. The other Kenyan trial was successful even though the intervention was completely automated [10]. The lack of interaction is therefore unlikely to be a major reason for the negative trial results in our study.

3. Stigma from the intervention: (Page 21 and 22)

Requests to code content that prevented disclosure of HIV sero-status and minimized stigma were observed in the development phase of the CAMPS intervention [39]. Stigma as barrier to mHealth adherence support was identified in the design phase of the WelTel trial [40].

The perceived risk of unintended disclosure of HIV status due to others viewing participants’ text messages was also reported from China, SSA and Peru [13, 29, 31, 36, 41].

Question 6: Some of the English needs correcting e.g second paragraph line 5 and line 7 of the introduction.

Response: These have been corrected.

Question 7. It might be appropriate to reference Haynes Cochrane Review on adherence alongside ref 28 in the sentence that states that external reminders used in isolation may not be able to improve adherence as in his review (which has now been updated) Haynes concluded that single strategies for adherence were not effective.

Response: This is done in the manuscript as follows: i.e. Reference number 28 on page 17, paragraph 2 as follows:

However, studies have shown that external reminders used in isolation may not be able to improve adherence [27, 28]. Effective adherence support interventions need family or peer support, counseling and daily treatment support reflecting their complexity [28].

Question 8: I remain curious. The trial was preceded by qualitative work with participants - do the authors have any insights we might all learn from regarding why the feedback about messages during intervention development seemed more positive than their views collected in the qualitative interviews? Could this be discussed in the discussion section? e.g. perhaps the qualitative interviews were done by someone independent whilst the intervention development interviews might have been perceived to be done by someone aligned to the intervention?

Response: This has been discussed in the manuscript on page 19 (last paragraph) and page 21 (1st paragraph) as follows:

The intervention in our study was designed subsequent to a survey that used a semi structured interview schedule. One in three participants in the survey indicated a strong preference for voice calls. However, the survey did not explore the preferred content of communication or the extent of its interactiveness. Qualitative exploration of the while piloting the HIVIND trial intervention may have
helped identify issues that could have been addressed before the trial. Also, those who participated in our study were exposed to the intervention for approximately two years. First hand experience with the intervention probably enabled participants to identify more ‘negatives’ regarding the SMS reminder than were perceived by potential trial participants.


Response: We have cited this as reference 32 on page 18 in relation to the anthropomorphic nature of mHealth interventions as follows:

Similar reports are available from an mHealth smoking cessation trial in United Kingdom [32].

Reviewer 2: Lawrence Mbuagbaw

Institution and Country McMaster University, Canada
Please state any competing interests or state ‘None declared’: ‘None declared’
Please leave your comments for the authors below

This is a well written qualitative study on a subset of participants in the HIVIND trial. The study covers the issue adequately. I have minor contributions:

Thank you very much!

Question 1. Please provide the reference number for Ethics approval in the manuscript

Response: The ethics approval for the trial are as follows:
(i) St. John's Medical College Hospital, Bangalore: IERB 1/369/08 – 92/2008 (All studies) (ii) Mysore Medical College and Research Institute: NO/PS/173/2010 (Studies II, III and IV) (iii) YRGCare Medical Center, Chennai: IRB April18/2009

These have been mentioned in the “Ethics Statement” page 10 paragraph 1 of the manuscript.

Question 2. Where the participants selected from the control or intervention arm

Response: Participants were selected from the intervention arm only. This has been clarified in the following sections in the manuscript:

a) Abstract: Methods: line 3 and 4 as follows:
Sixteen purposively selected participants from the intervention arm in the HIVIND trial were interviewed.

b) Manuscript: Methods: Page 7, paragraph 2:
We conducted in-depth interviews with 16 participants in the intervention arm of the trial

c) Manuscript: Findings: Page 10, paragraph 2:
Sixteen participants from the intervention arm of the HIVIND trial participated in this study.
3. In the methods section the participants were purposefully selected based on their residence, but residence is not reported in the results section.

Response: Six participants were of rural residence. This has now been mentioned under: Findings: page 10 paragraph 2-last line in the manuscript.

Question 3. A lot of interesting discussions may arise regarding extending the role of text messages to other patient needs, who will benefit from them and the role of literacy/education.

This has now been discussed under the section “Considerations for future design of mHealth interventions” on page 21 paragraph 1 and 2. The details of this may also be found in the response to comments from Reviewer 1 (C. Free) above.

Question 3a: Role of literacy/education:

This has been discussed on Page 19 in paragraph 1, as follows:

Literacy: The lower English language literacy in our context in comparison to some of these study contexts could have resulted in the preference for voice calls over text messages. It would be of value to identify the preferred mode of communication and incorporate it into the intervention design. Verbal communication has the potential to overcome the literacy barrier for text messaging, and could be used in low-middle income contexts such as ours. The combined effect of education and text messaging in improving adherence, and the literacy barrier to the use of text messages, reflect the need for alternatives such as voice calls and picture messages for adherence support [37].

Question 4. I am adding some references which the authors may choose to use or ignore:


Response: the above ref has been added. Ref 37 on page 19 paragraph 1 as follows:

The combined effect of education and text messaging in improving adherence, and the literacy barrier to the use of text messages, reflect the need for alternatives such as voice calls and picture messages for adherence support [37].


Response: Ref 39 on page 20 paragraph 2 as follows: the above ref has been added.

Requests to code content that prevented disclosure of HIV status and minimized stigma were observed in the development phase of the CAMPS intervention [39].

Response: Ref: 34 on page 18 paragraph 2 as follows:

Expressing gratitude, requesting counselling, financial support and advice regarding medication side-effects - reasons for using two way communication in CAMPS trial were also mirrored in our study [34].