Author’s response to reviews

Title: Challenges and Support for Quality of Life of Youths Living With HIV/AIDS in Schools and Larger Community in East Africa: A Systematic Review

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Author’s response to reviews:

Editor’s comments

Comment 1

1. Please provide a stronger rationale on why you decided to focus only on the East African region. Of course this region has the highest HIV rates, but is not the only one. For instance, other countries of Africa, may also have high HIV infection rates and were excluded from this study (South Africa?). Rationale should be deeper than just state that there is no information on this specific region.
Response

We recognize that HIV/AIDS is not a major problem only in East Africa but throughout Sub-Saharan Africa and globally. However, since the aim of our review was to inform the design and implementation of interventions to address the Quality of Life of YLWHA in East African communities, we included studies from East African countries because these countries have more or less similar economic and cultural contexts. The history of how these East African countries have dealt with HIV is also different from that of other areas like South Africa or West Africa and therefore Sub-Saharan Africa would be too broad. We also realized that due to the extensive research in HIV in South Africa, our findings and conclusions for the entire Sub-Saharan region would be skewed more towards South Africa and therefore probably less fit for East Africa.

We have included this justification in the inclusion/exclusion criteria as also requested by the first reviewer (lines 189-204) in the revised manuscript.

Comment 2

2. This is a complex review that has 2 research questions. Methods are in some parts mixed up for both. If methods applied to each questions in the analysis, it should be highlighted better. Additionally, the use of evidence from qualitative and mixed methods research approaches relates with important challenges. To improve the understanding of the methods, and the way the QUAL and the Mixed Methods

Response

We had two objectives to achieve in the review but with one research question. The two objectives as quoted directly from the manuscript were;

“The specific objectives of the review are twofold: 1) To review evidence on challenges that YLWHA experience in schools and larger community; 2) To review evidence on support available and interventions programmed for YLWHA in schools and the larger community”.
We formulated one search strategy to answer this research question (What are the challenges or support for YLWHA in schools and larger communities of East Africa?). In our search strategy challenges were separated from supports by a Boolean operator “OR” (Line 174, revised manuscript)

We have stated that one search strategy was formulated under search methods to clarify this (line 172, revised manuscript)

We did not clearly understand the last part of the comment “To improve the understanding of the methods, and the way the QUAL and the Mixed Methods” but we thought this required us to clarify how we used evidence from qualitative research and mixed methods studies.

Response

We included two studies that used mixed methods but the quantitative data reported in these studies were not targeted findings of our review and we therefore did not include this data. We reported this under analysis in the manuscript (Lines 238-239, revised manuscript). Consequently our review turned out to be a qualitative systematic review.

Comment 3

3. Authors did not including EMBASE in their databases search. Authors should consider explaining why they did not considering EMBASE and consider describing how the lack of search in this database might or might not have an impact on the final results.

Response

EMBASE has a large overlap with Medline with additional focus on pharmacology and pharmaceutics. We were convinced that searching EMBASE would yield similar papers that we targeted. However, since this overlap is not 100%, we could have errored in that choice. We therefore realize that not including EMBASE in the search possibly led to missing out of some studies. We have therefore included this in the limitation section lines 683-685.
Comment 4

4. Only One reviewer performed the screening of the first titles/abstracts by one reviewer. Furthermore, Only one reviewer screened the full-texts and consulted with a second. This approach is not recommended, since the screening by one author has shown a higher likelihood of missing eligible studies. This is a major limitation of a review. Please consider explaining why this approach was used and adding this issue as a major limitations in the appropriate section, explaining the potential impact that decision may have on your results.

Response

According to Cochrane guidelines, the initial screening of tittles and abstracts to remove those clearly irrelevant to the review can be done by one author but they strongly recommend that the final selection of studies to include and exclude should be done by at least two.

We clarify that EK and SV collaborated closely and resolved any doubts that arose about studies to included and exclude. Consensus was achieved on all studies that were included and those that were excluded. This is reported in the revised manuscript under lines 211-213

Comment 5

5. It is not clear how the extraction was performed: Was this only one author? Please clearly describe the process conducted. If that is the case (one author) authors should also mention this as a major limitation of their work. That approach has some limitations and is not the actual recommendation by the Cochrane Collaboration. it has shown more errors than duplicate extraction.

Response

We reinforce the measure to extract data by two authors, in order to guarantee the quality of the systematic review. We followed the Cochrane Collaboration guidelines on systematic reviews, but we had removed these details of data extraction to reduce on the size of the manuscript. The process has now been elaborated under the section of data extraction and management as follows;

“Two review authors, EK and SV, independently extracted the data. They then converged and compared the extracted data. In cases of discrepancies in the extracted data, the original articles in which those discrepancies arose were revisited and such discrepancies were resolved by discussion to arrive at a consensus”. Lines 214-218
Comment 6

6. Please consider starting methods clearly stating what type of review are you conducting you considered? (Mixed, Quan and QUAL? Also, what designs of studies: What were the QUAN designs, the QUAL designs and which one were the Mixed Methods research designs).

Response

We planned to include quantitative, qualitative and mixed methods studies but the retained studies were qualitative (14) and mixed methods (2). In the mixed methods studies we only involved qualitative findings because the quantitative findings were not the target for our review. This was explained in the methods section of the manuscript but since it turned out to be a qualitative review, we have included this in the first sentence in the methods section as advised. Lines 147-148

Comment 7

7. So far the search strategy is 18 months old. If this paper is to be accepted, by the time the paper may be published, the search will be almost, or around, 2 years old. Please consider: a) updating the search and include any new evidence that may merge, or, if not possible, b) the potential impact of this "old Search" should be discussed as a limitation.

Response

In the search methods of the original manuscript we included the statement quoted here “In each database, monthly email alerts were created using the email address of EK for updates of new studies that conformed to our search strategies. By the time of submission of this manuscript, no new study merited inclusion”

We have been receiving these emails and we have not received any new study we can include in the review. We have now changed from the time of “submission” to “revision” (lines 184-187) in the revised manuscript. We also know that from the time of revision and publication new evidence may emerge. We have therefore included the potential impact of this as a limitation in the section of limitations lines 685-687
First reviewer’s comments

The authors have conducted a review to synthesise evidence to inform the design and implementation of interventions that support the wellbeing of youths living with HIV/AIDS in an East African context. I think their study meets this aim; their findings provide a potentially valuable contribution to intervention development. I have a number of comments about the methods adopted, particularly around the reporting of methods and analysis of qualitative findings.

Comment 1

1) Abstract.

At the beginning of the abstract, I think it would be better to include the aim of the review that the authors state in the introduction (to inform the design and implementation of interventions that support the wellbeing of youths living with HIV/AIDS in an East African context).

Response

Thank you for the suggestion. We have included this in the abstract of the revised manuscript lines 44-45.

Response

You use an acronym in the abstract without explaining it.

This has been addressed (lines 47 and 60) in the abstract of the revised manuscript

CINAHL was now also written in its original full form as Cumulative Index to Nursing and Allied Health Literature; and SRH as Sexual and Reproductive Health.
From reading the abstract I understood that the review was a synthesis of mixed methods and qualitative studies, so included quantitative and qualitative data; I think a sentence needs to be added to the abstract to clarify that there were no quantitative results that met the inclusion criteria.

Response

We thank you for this suggestion. A sentence has been included in the abstract of the revised manuscript line 51-52

A central purpose of qualitative synthesis is to synthesise new information, rather than only describing what research has been done on a particular topic, so the authors should identify what they are adding in the abstract. What seems to be the 'new' understanding from this synthesis is that although the bulk of challenges studies identify arise in schools, and there are supportive approaches available, there weren't studies that explored how supportive interventions might work in schools. The authors already state this in the abstract, but could frame this findings as important information that they are adding to the field.

Response

We thank you for pointing out this and in a way of addressing it, we have included this new finding in the abstract lines 69-72. Also in the conclusion section we have added this contribution to the field (lines 691-694) as similarly requested by the second reviewer.

Comment 2

2) I think the Introduction section does a good job to contextualize and rationalize the study.

Response

Thank you for appreciating this
Comment 3

3) There are a few points for the Methods section to clarify information reporting. please separate information about 1. the search methods, 2. inclusion/exclusion criteria, 3. Data analysis, 4. Included studies (description of the prisma process, summary about included studies), and 5. Findings (your analysis of qualitative findings) into separate sections. At the moment the search section has search information, inclusion/exclusion information, information about search results and/or included/excluded studies. It will make things much easier to access if these can be signposted and discussed separately within each relevant section.

Response

We had removed these subheadings to reduce on the size/word count/length of the manuscript but for clarity we have re-worked the methods section to include these sections noted above.

Search methods starting line 171

Inclusion/exclusion criteria starting line 189

Data analysis starting line 235

Description of included studies starting line 270

Findings starting line 308

Please explain within the inclusion/exclusion section your rationale to limit studies to those of the past 10 years, and to only include studies from East Africa.

Response

Time restriction

We included a time restriction in our search in order to get the most recent evidence given that research on HIV/AIDS has expanded exponentially over the past decades. But also, access to ART in East Africa has increased in the last decade (Elul, Wools-Kaloustian, Musick, Nuwagaba-Biribonwoha, 2016). This means increased survival of children with HIV and emergence of challenges related to leaving with HIV as a chronic condition. Studies exploring these challenges and support needs would be expected within this time frame.
We recognize that HIV/AIDS is not a major problem only in East Africa but throughout Sub-Saharan Africa. However, since the aim of our review was to inform the design and implementation of interventions to address the Quality of Life of YLWHA in East African communities, we included studies from East African countries because these countries have more or less similar economic and cultural contexts. The history of how these East African countries have dealt with HIV is also different from that of other areas like South Africa or West Africa and therefore Sub-Saharan Africa would be too broad. We also realized that due to the extensive research in HIV in South Africa, our findings and conclusions based on the entire Sub-Saharan region would be skewed more towards South Africa.

We have added this justification for time and geographical restrictions in the inclusion/exclusion criteria of the revised manuscript lines 191-202.

c. I have some concerns about the use of 'outcomes' in this manuscript. Outcomes are effects of interventions and so are relevant to the quantitative evaluation of interventions, and more specifically link to measures. Qualitative studies explore the perceptions and experiences of people in relation to interventions they have received and/or other aspects of their lives, these are not outcomes. Please find any use of 'outcomes' in the manuscript and make sure they are accurate.

Response

We have checked the entire manuscript to ensure accurate use of the term “outcomes”. We have instead used the term “findings” where “outcomes” does not apply. Changes can be found in the table of characteristics of included studies, lines 239, 263, 304, 308, among others.

d. Please extract the included study aims and report them in your table of study characteristics, they make it possible for the reader to understand each study more easily.

Response

The aims have been extracted and reported in the table of study characteristics.
e. Did you conduct quality appraisal? If you did, please report the method and then findings at the beginning of the findings section; if not, please provide a rationale for why you did not conduct quality appraisal.

Response

We conducted a critical appraisal of included studies but we decided not to report the results of the appraisal because we did not want to base our decision to include studies or interpret findings based on the results of the appraisal as justified below.

Critical appraisal of qualitative research is widely debated and currently no consensus exists on methods, tools and whether it should even be done [1 & 2]. In many studies such appraisal has not led to exclusion of papers from the synthesis [3-5]. [6] also noted that critical appraisal was more of an exercise of judging a written report and not the research process and it tends to favor papers published in qualitative oriented journals that allow lengthy papers that enable authors to elaborate on the research process [7 & 8]. On the backdrop of this, we did not include results of the critical appraisal but judged included studies to be of high quality because they were published papers in peer reviewed journals.

We have thus included the justification above under a new section in the methods “Assessment of quality of included studies” lines 226-234. We also have the results of the assessment and we are willing to provide them if it is necessary


Comment 4

4) Findings. The authors seemed to have stopped the analysis process with their initial framework of challenges and supports which I see as descriptive codes rather than themes. This to me is the greatest problem within the manuscript. Usually the analysis would continue by looking at relationships between codes, and potentially developing some explanatory theories (themes). For example, stigma/discrimination seems to be the main explanation around challenges; supports could then be looked at in relation to how they prevent or ameliorate stigma/discrimination. This is a more likely main theme. I would encourage the authors to think further about this. At the very least, if it were possible to create a diagram showing the relationships between codes, this would greatly improve their ability to communicate their findings to others. Discussing 'challenges' and 'supports' in separate sections means there is repetition, as these link to each other in many different ways. The authors could better organise and report their Findings section. Please cite each paper that reported the general theme you are discussing at the beginning of each theme section.

Response

We appreciate the added value a meta-synthesis would have on our findings. However, it was not the aim of this review to develop explanatory theories but rather to aggregate findings on challenges and support as stated in the introduction of the manuscript. We were also constrained by the fact that we did not have sufficient evidence to assume relationships for example between challenges and support strategies since our studies were highly heterogenous in terms of participants, data collection methods and study aims as seen in the table of characteristics of included studies. Quoting directly from Cochrane guidelines;
“Meta-analysis should only be considered when a group of studies is sufficiently homogeneous in terms of participants, interventions and outcomes to provide a meaningful summary” Qualitative evidence synthesis is a process of combining evidence from individual qualitative studies to create new understanding by comparing and analyzing concepts and findings from different sources of evidence with a focus on the same topic of interest. Therefore, qualitative evidence synthesis can be considered a complete study in itself, comparable to any meta-analysis within a systematic review on effects of interventions or diagnostic tests” [9].

In the discussion we however developed hypotheses about these relationships which can be explored in future research.


We have also reworked the entire results section to illustrate how the codes are related according to our findings and also to present challenges and support together for each code (main theme) in order to minimize repetitions. We have also cited each paper reporting on the main theme at the start of the theme as suggested in your comment. See findings starting from line 308
Comment 5

5) I thought the discussion section was good - the authors contextualize and discuss implications of their findings well. I would draw greater attention to the finding that the bulk of challenges are faced within schools, but none of the research on supports was conducted in schools, as this seems to be an important way this synthesis adds to existing knowledge.

Response

Thank you for the appreciation. We have highlighted this contribution to the existing knowledge in the conclusion section that we have added, as also requested by the second reviewer. Starting from line 688.

The changes in the findings section led to slight changes in the discussion section lines 592-594 and line 625 in the revised manuscript.

Comment 6

6) This paper needs a good deal of work on the analysis to be of publication standard, but I think it is worth publishing so would recommend 'major revisions'

Response

We hope we have satisfactorily addressed all issues raised but in case we have not been clear in some we are willing to revisit them in response to your concern.

Second reviewer’s

The following minor comments need to be addressed to improve the quality of the manuscript;

Comment 1

1. Authors should exclude 'Type of included studies' and 'Challenges faced and support available' from the 'search method' subheading and write them also under their respective subheadings to make it clearer to readers.
Response

This has been addressed by creating other subsections as also requested by the first reviewer.

Type of studies section starting at line 151

Phenomenon of interest section starting at line 161

Search methods section starting at line 171

Comment 2

2. Please mention the initials of the two authors who extracted data and also report their level of agreement.

Response

The initials have been included and a statement about how agreement was arrived at has also been included in the methods section. This can be found in lines 211-213

Comment 3

3. How missing date were handled during the data extraction. Authors should mention is in a separate subheading.

Response

We did not encounter any case of missing data in the included studies. We have included this statement in line 220. Since we did not have much to report about this, we decided to integrate this information under the subheading ‘Data extraction and management’.
Comment 4

4. Please mention in the 'data analysis' section that no formal meta-analysis was conducted in this review.

Response

We reported this in the search results section. Lines 265-266; “We finally included 16 studies in the qualitative synthesis [46-61] and none in the meta-analysis”

Comment 5

5. Conclusion of this review should explicitly be mentioned under a subheading.

Response

A conclusion section has been added at the end of the manuscript Lines 688-695. It summarizes the main findings of this systematic literature review, the contribution that this reviews makes to the field, and the main recommendation based on these findings.