Author's response to reviews

Title: An exploratory study of resilience among asylum seekers living with HIV

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Author's response to reviews: see over
Dear Mr Dizon,

An exploratory study of resilience among asylum seekers living with HIV

Thank you for the considered comments on our original manuscript. Please find, below, a point-by-point response to the concerns raised as well as full details of the changes made to the revised manuscript.

We very much look forward to hearing your response.

Yours faithfully,

Lois Orton PhD MSc BSc ARCS,
On behalf of the co-authors
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<th>Referee comment</th>
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<td>1. Title: I suggest a more appropriate title would be: An exploratory study of resilience factors among asylum seekers living with HIV or Better: (given the emphasis the authors put on threats to resilience) An exploratory study of threats to resilience among asylum seekers living with HIV. DISCRETIONARY</td>
<td>The paper explores resilience with a focus on both resilience processes and their threats. I believe the current title reflects this.</td>
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| 2. Abstract: Results: Based on the operational definition of ‘resilience’ adopted by the study (paragraph 5, last sentence) I would prefer that the authors use a more descriptive term other than making reference to resilience only as ‘tenuous’ and to make specific reference to (all) resilience factors identified by the study, (for example access to HIV treatment) rather than threats to resilience only. MINOR | Abstract has been reworded removing the reference to resilience as being “tenuous” and clearly indicating resilience processes:  
Resilience processes included: staying busy, drawing on personal faith, and the support received through HIV care providers and voluntary organisations. | p.3 |
| 3. Abstract: Conclusions: the conclusions appear redundant, do not reflect the essence of the paper and overemphasize the role of policies. MINOR | Edited to better reflect the main findings and the overall study conclusion (which has been edited in response to comment 16):  
Asylum seekers living with HIV in the UK show immense resilience. However, their isolation means they are often unable to deal with their treatment in the asylum system, with negative consequences for their perceived health and wellbeing. | p.3-4 |
| 4. Background: paragraph 3 The sentence beginning.. ‘The act of migration generates new stimuli and life as an asylum is shaped by new experiences’ is unclear to me and therefore how exactly it follows as pre-migration or posts migration ‘stressor’ DISCRETIONARY | Edited for clarity:  
Both migrating to a new country and experiencing life as an asylum seeker lead to new experiences that could be interpreted as “stressors” | p.6 |
| 5. Background: In the fourth paragraph, I think most readers would know coming to the UK would increase the | I agree. HIV brings new stressors. I referred to these as coming on top of migratory stressors because diagnosis usually comes | p.6 |
chances of one testing for HIV and that it would be difficult to estimate whether or not it was acquired pre or post migration.; I would still consider having HIV as a 'stressor' (irrespective of the opportunities that come with it, such as the possibility of seeing a caring consultant) and not an 'add on' as is implied here. DISCRETIONARY

after migration. This section has been reworded to avoid confusion:

Being diagnosed with HIV is also likely to precipitate new stressors.

We are interested in both; particularly how they compound one another. A sentence has been added to paragraph 6 to make it clear that we are interested in stressors relating to HIV and asylum:

The data presented in this paper derive from a doctoral study exploring the experience of life as an asylum seeker living with HIV. Initially, we were interested in the stressors precipitated by both of these experiences (HIV and asylum) and the ways in which participants responded to them.

6. Background: paragraph 3 and 4: It is not entirely clear to me if this study focuses on the 'ongoing' role of pre-and post-migration stressors for those living with HIV or the independent role of living with HIV (as a stressor) as an asylum seeker. The study results appear to reflect the former rather than the latter.

MINOR

This entire section has been edited for clarity (with the addition of text from the conclusion, as per comment 16).

7. Background: Paragraph 4: sentence 6, 7 and 8 need to be tightened to avoid redundancy.

MINOR

One of the aims of our study was to identify the main stressors for asylum seekers living with HIV. All of the issues mentioned by the referee emerged as important. In the original manuscript, these stressors were detailed in the findings section under the heading “The combined stress of seeking asylum and living with HIV”. The heading of this section has been reworded to enhance clarity and now reads “Seeking asylum and living with HIV: a unique combination of stressors”.

8. Background: The three potential stressors here include: the delay in decision regarding the asylum status for those living with HIV, the event of and implications of an unsuccessful application, and living with HIV (or a positive HIV test result). From the authors' operational definition of resilience… the ability to react positively when things go wrong. Which of these do they refer to?

MINOR

I agree this is an important distinction. Service provider interviews were not designed to provide information on resilience. They were interviewed because the main participants (asylum seekers living with HIV) discussed how important they were as a source of moral support. This is a main theme in the findings (reflected in the focus of this paper, p15 onwards (or p14 onwards in the revised manuscript)). Thus, service provider interviews were not designed to provide information on resilience.
in the results section regarding resilience factors. On the other hand, if the intention of the authors was to measure what the service providers considered resilience factors, then this should be explicitly stated and differentiated, both in the results and discussion sections of this paper. **MAJOR**

Interviews were used to generate contextual data on the types of support provided to patients/service users who were seeking asylum. In order to ensure this is more clear, two edits have been made to the manuscript. In the methods section, the following text has been added:

A brief schedule was used in these interviews to explore their experiences in caring for asylum seekers and the support they provided.

One quote from a service provider was included in the findings section of the original manuscript. This quote highlighted how they felt about serving asylum seekers. It has been removed so as not to detract from the main focus of the paper.

**10. Methods: Data analysis: Study design:** Although it is understandable that HIV and asylum service providers’ inputs were important to guide the design of the study, it is not clear if the resilience or threats to resilience can be measured from the perspective of service providers, as has been referred in the results. The role of the service providers should be clearly defined and little or no reference made in the results section regarding resilience factors. On the other hand, if the intention of the authors was to measure what the service providers considered resilience factors, then this should be explicitly stated and differentiated, both in the results and discussion sections of this paper. **DISCRETIONARY**

Edited methods and findings section as per comment 9.  

**11. Findings:** I think the findings should be stated in a less firm way, for example the combined stress of seeking asylum and living with HIV appear to be post-migration, and therefore reference to pre-migration factors as well as stigma and taboo regarding HIV ‘back home’ may play less of a role if they do not face this abroad. **DISCRETIONARY**

I understand the referee’s concerns, however, stigma and taboo regarding HIV “back home” was an important stressor for study participants (post-migration). It prevents them from revealing their diagnosis to loved ones back home and therefore from receiving their support. It also prevents them from forming relationships with people from their home country in case the
| DISCRETIONARY | word gets back to their friends and family. This is detailed in the findings. For example p.17 “Participants had left behind their community, found themselves unable to confide their diagnosis to those at home, and so to receive their support, and faced difficulties in forming new social bonds in the UK due to their situation as both asylum seekers and the stigma surrounding their HIV diagnosis.” To ensure further clarity the flowing text has been added to the findings section:

Despite most being diagnosed in the UK, home stigma still had a profound social impact. Their condition became a taboo subject that could not be discussed with friends and family both at home and also in the UK. p.12-13 |
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<td>12. Findings: As previously stated it is important to differentiate provider perspectives from those of HIV positive asylum seekers interviewed. DISCRETIONARY</td>
<td>Edited as per comment 9. All perspectives represented are now from asylum seekers living with HIV. As noted in methods section, service providers were interviewed to gain contextual detail on the support they provide to asylum seekers, not to reveal resilience processes (the focus of this paper).</td>
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| 13. Discussion: I think the originality of the study approach and methods should be stated in a less firm way, given the difficulty of differentiating what is pre, migration and post migration and the fact that resilience factors are not stated clearly in this study. MAJOR | Discussion has been rendered more tentative by removing the following text…:

It is also the first study to explore not just the negative impact of such experiences, but also the resilience that those who are exposed to them can demonstrate” and edited section to state the findings more tentatively. p.18

…and revising the following text:

Our study confirms these concerns. It suggests that, despite their immense resilience, those who are living with a long term condition such as HIV, believe their mental and physical health is affected by current legislation. p.19

The rest of the final paragraph has also been edited throughout with the use of more tentative language. p.19-20 |
| 14. Discussion: The study needs to highlight as a limitation the difficulty in delineating what constitutes resilience when contextual stressors are perceived rather than real, how coping is differentiated from resilience as well as the difficulty of collecting reliable data regarding HIV and asylum status. DISCRETIONARY | There are a couple of issues here. In response to the first issue, a couple of sentences have been added to the discussion: 

…Whilst this study did not originally set out to explore resilience, it reveals the capacities of people who are seeking asylum and living with HIV. It makes no effort to measure “actual resilience” quantitatively, but reveals participants’ experiences and their resilience processes. 

In response to the second issue, the reviewer makes a good point. In the context of our study, coping and resilience are in fact the same thing. The text has been edited throughout to ensure consistent terminology (replacing “coping” with “resilience”). 

In response to the third issue, the aim of our study was not to collect data on HIV and asylum status. This would be unethical in a qualitative study of this type. Participants identified themselves as living with HIV and seeking asylum, and described the experiences associated. This has been made more clear in the methods section: 

Potential participants must be adults who identified themselves as seeking asylum at first contact (refugee status was later granted for some), and as living with HIV. | p.18 Throughout |
|---|---|
| 15. Discussion: With reference to UK asylum policies, the authors findings suggest that HIV seropositivity confers added risk, some reference should be made regarding the dual role of HIV and asylum seeking. MINOR | Agree. Final sentence edited: 

…The findings also suggest the need for political action, for reform of the UK asylum system and for changes in the treatment of asylum seekers in the health care system, particularly those living with a long term condition, such as HIV. | p.20 |
| 16. Discussion: The conclusions focus on UK asylum | As suggested, this text has been added to the background | p.7 & 20 |
policies, and need to remain focused on the results of the study and its implications if any for HIV positive asylum seekers. I would be in favour of a paragraph on the relationships among UK asylum policies and HIV in the Background/Introduction section and to leave this section to a more focused reference to conclusions drawn from the study findings.

MAJOR

17. Discussion: Table 2 highlights stressors rather than the real focus of the study, which is resilience factors, which the authors actually measure but do not refer to, even in the discussion section. I would improve this table by adding both resilience and ‘threats’ to resilience factors.

MAJOR

The table was used to summarise the threats to resilience because these are not discussed in much depth in the text. This is because they are not the main focus of the paper (as the referee notes). Resilience factors (or resources as I refer to them) which (as the referee notes) are the main focus of the paper are discussed in more detail in the text. Hence, I did not feel the need to include them in the table. However, for comprehensiveness, I have appended an extra section to the bottom of table 2 to include these. Further, resilience is referred to in the discussion. This has been made clearer with the tightening of terminology (in response to comment 14).

Referee 2

I suggest that the author revises and simplifies her sentence construction. Throughout the text there are instances of long winding sentences and a lot more in the passive verb. I suppose this is a question of semantics to a reviewer for whom the English language is a second language. LO should bear this in mind if she opts to make revisions here.

DISCRETIONARY

The manuscript has been edited throughout to reduce sentence length and complexity.

throughout