Author’s response to reviews

Title: Leishmaniasis patients' pilgrimage to access health care in rural Bolivia: a qualitative study using human rights to health approach

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Dear Editor

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I am enclosing herewith the revised version on the manuscript entitled: “Leishmaniasis patients' pilgrimage to access health care in rural Bolivia: a qualitative study using the human rights to health approach” with reference IHHR-D-18-00063. We thank the reviewers for their relevant inputs regarding our manuscript. Below the point by point responses are presented. Changes made in the manuscript have been marked using track changes.

AUTHORS’ RESPONSE

; We thank the editor and reviewers for their helpful comments, which we think have sharpen the manuscript on several important points.

Reviewers’ comments in bold

; Author comments in normal typeface

Excerpts from manuscript italicized and indented

Reviewer #1:
1) Replace quality of life in abstract, results

Thanks to the reviewer for this comment. The title of the second theme was not updated according to the revisions on the results section. The title of this theme has been corrected and now it reads:

Page 2, line 28:

(2) the severity of symptoms and disruption of functioning drives the search for Western medicine

2) On page 4, lines 86-88, "implied" and "affectation" should be replaced. Consider "resulted in" and "impact" but defer to editor

Thanks to the reviewer for this comment. Following the advisor of the reviewer #2, the background section has been changed to give more emphasis on the right to health approach importance for the study. The new version of the background does not include these words anymore.

3) Table 1. Replace "Type of Problem" with "Form of disease" or "Form of Leishmaniasis"

Thanks to the reviewer for this comment. We accept the suggestion, now in the last cell of Table 1 it reads:

Form of leishmaniasis.

4) On page 6, line 129, replace "well-known experience" with "reputation"

Done; now it reads:

Page 7, line 151:

CUMETROP’s reputation in treating leishmaniasis attracts patients from different regions

5) On page 6, line 134 sentence "The access to these communities..." is redundant with itself

Thanks to the reviewer for this comment. We agree with her observation. We have changed the sentences and now it reads:

Page 8, lines 156-158:

Due to the lack of adequate roads, public transport is scarce and consequently, their options to get access to medical services are limited.
6) On page 9, lines 197-198, the sentence "The majority of..." is grammatically incorrect. Do you mean, "recounted visiting"?

; Thanks to the reviewer for this comment. Now, the sentence reads:

Page 11, lines 218-219:

The majority of the mestizo participants recounted visiting the health post closest to the community or private doctors.

7) On page 13, line 300, replace "they had to go through many difficulties" with "they faced many hardships"

; Done. Now, the sentence reads:

Page 15, line 320:

they faced many hardships to reach them.

8) On page 13, line 302, replace "implied", this does not seem to be an accurate use of the word

; Thanks to the reviewer for this comment. To clarify the meaning, the sentence now reads:

Page 15, lines 322-324:

Poor road conditions and unsafe means of transportation were additional problems to overcome.

9) On page 15, line 350-354, the line "In remote areas..." is somewhat redundant and poorly written

Thanks to the reviewer for this comment. To avoid redundancy the sentence has been rephrased, now it reads:

Page 17, lines 372-374:

Among Tsimane and other indigenous groups from the Amazon region of Bolivia and Peru, the absence of health services resulted in a lack of trust and familiarity with Western medicine as well as more use of traditional medicine.

10) On page 18, line 412, replace "author was" with "author became"

; Thanks to the reviewer for this comment. Now, the sentence reads:
the first author became familiarised with leishmaniasis patients’ experiences related to the disease

11) On page 19, line 453, replace "reinforce" with "strengthen"

; Thanks to the reviewer for this comment. Now, the sentence reads:

we suggest to policy makers to strengthen leishmaniasis care capacity related to laboratory diagnosis and availability of treatments in primary health care centres located in endemic areas.

Reviewer #2:

I thought that this was useful piece of work addressing a disease, and experience of disease, which has relatively little attention.

The authors have done a number of things well. The methodology is sound, the example quotations from the fieldwork are strong, illustrative, and contextualised. The strengths and limitations of the research itself are clearly set out.

As for what needs further work:

1) The English. I have provided commentary and suggestions for the authors via an annotated version of the pdf. I would recommend strongly adopting these, or a version of them.

• Line 28: What does sub-demand mean? Unclear

; Thanks to the reviewer for this comment. To clarify it, the word sub-demand has been replaced by under-utilization, now reads:

Page 2, line 20-21:

there is an under-utilization of treatment in relation to the estimated affected population

• Line 52: Neglected in what sense? It is identified as a concern and as a severe problem by WHO. If you mean neglected in the sense of inadequate funding, or understanding, say this explicitly.
Leishmaniasis is considered one of the most neglected tropical diseases due to lack of funding, political commitment and national and international cooperation.

- Line 64: The paper cited was published in 1992 - you can't claim this as an accurate risk estimate in 2018.


Line 74: Cases do not seek attention, people do. Please rephrase this.

However, it is well known that a high number of people cannot access adequate health care to treat this disease.

Line 75: I don't understand what this means: “To entitle the right to health”

Page 5, lines 89-90:

However, it is well known that a high number of people cannot access adequate health care to treat this disease.

Line 83: Change to the fulfilment.

Page 5, lines 89-90:

However, it is well known that a high number of people cannot access adequate health care to treat this disease.

Line 83: Change to the fulfilment.
importance of the right to health approach for the study. The new version of the
background does not include this sentence anymore.

Line 77-78: This is clumsy. I would suggest simply referring to the ICESCR, as the example.

; Thanks to the reviewer for this comment. However, we consider that citing some of the most important covenants where the right to health is recognized strengthens its principle as a legal duty worldwide.

Line 88: Showed that med described serious affectation on men’s capacity to work

; Following the suggestion of the reviewer, the background section has been changed to give more emphasis on the importance of the right to health approach for the study and this sentence has not been included anymore.

Line 91: I think this phrasing is unfortunate. By "medical services" you mean "western" or "modern". Instead of "regarding" you should use "for". "can be related to the influence of cultural issues" doesn't make sense. I would simply refer to the continuing cultural importance of traditional medicine, and integrate this with the next sentence.

; Since the background section has been changed to give more emphasis on the importance of the right to health approach for the study, the new version does not include this sentence anymore.

Line 95: Change under to through

; This sentence (and word) has been deleted from the new version of the background section, given the same idea has been already developed and included in other previous sentences of the same section.

Line 111: “sylvatic” The readership of the journal will need to know what this means

; Thanks to the reviewer for this comment. To help the understanding of this term, we added an explanatory sentence. Now, it reads:

Lines 132-134:

Because the main mechanism of transmission of leishmaniasis in the country is sylvatic, meaning that the rainforest is the ecosystem of vectors and reservoirs, there are few options to control vector exposure.

Line 118: Change to 11 male and 3 female

; Thanks to the reviewer for this comment. The sentence has been modified; now it reads:
In total, 14 participants (11 male and 3 female)

My wife used to tell me that I could not touch her.

2) More importantly, and more significantly, there is an extensive literature on the human right to health; and although the authors identify four aspects of the right necessary for its full enjoyment, they need to devote more attention to precisely WHY a human rights approach is critical, WHY it is critical for (neglected) tropical diseases, and precisely WHY / HOW it will support those suffering from leishmaniasis. As the article stands it reads rather like a study of the experience of the disease, with human rights "tacked on". The authors need to provide some deeper reflection on the value of a human rights approach, and what it would mean for these people, in this context, at this time. I would specifically recommend and expect the authors to read, think about, and refer to the following at the very least (some of which I realise was published after this piece was written)


https://www.who.int/neglected_diseases/Human_rights_approach_to_NTD_Eng_ok.pdf


It would also be sensible and advisable to contextualise generally with some of the foundational HR and health literature, which is easily accessible.

Thanks to the reviewer for this important comment. We agree that the paper did not show the importance of using a human right to health approach to understanding the problem of leishmaniasis in Bolivia. For this new draft, we have read the suggested articles and incorporate them, as well as, other relevant literature from the rights approach to health is cited in the references.
In this new version, the background section has been changed emphasizing the importance of using a right to health approach. In addition, we included a paragraph in the conclusions section which also remarks the importance of using a human right to health approach to controlling a neglected disease such as leishmaniasis. The new background section now it reads:

Lines 43-120:

Neglected tropical diseases (NTDs) are a group of diseases that affect almost exclusively poor people living in rural parts of low-income countries, and their most important common feature is that they affect disproportionately individuals with little social and political capital (1). In this context, a human rights approach is key to strength health advocacy for the people affected by NTDs and to support control and elimination efforts of these diseases (2).

NTDs are both a cause and consequence of human rights violations. NTDs are more likely to occur where human rights are not guaranteed and they may lead to violations of human rights and fundamental freedoms, including equality and non-discrimination (3).

The right to health defined as “the highest attainable standard of health”, is a legally guaranteed obligation of the States. Several international human rights treaties, as well as regional agreements and national constitutions and laws protect the right to health (4-8). The main global treaty that enshrines this right is the International Covenant on Economic, Social and Cultural Rights (ICESCR) (8). The committee of the ICESCR outlines four essential conditions of health systems necessary for its realization: availability, accessibility, acceptability and quality, also known as the AAAQ framework (9, 10). The World Health Organization (WHO) suggests NTDs program managers and partners to monitor differences in access using this framework to explore barriers and facilitating factors for effective coverage and to understand who is left behind and why (11).

Leishmaniasis is considered one of the most NTDs due to lack of funding, political commitment and national and international cooperation (12). WHO estimates 0.7–1 million annual cases worldwide due to tegumentary leishmaniasis (13) while only in Latin America, by 2016, 48,915 new cases were reported (14). Tegumentary leishmaniasis has several clinical forms ranging from cutaneous leishmaniasis (CL) to mucosal leishmaniasis (ML). CL exists mostly as painless skin ulcers that can take months to years to heal (12) and ML usually appears after a CL episode and produces severe destruction in the mouth, nose and larynx if not treated (15). CL affects patients’ quality of life in addition to affecting work and school activities (16). CL scars produce loss of self-esteem, depression, anxiety and stigma and it is an obstacle to the social integration of those affected by the disease (17). This situation may be even worse in ML due to the disfigurement and mutilation of facial structures. In the most severe cases of ML, there might be an affectation of speech ability as well as vital functions such as breathing and feeding.

Bolivia is in the top five countries in South America with leishmaniasis cases and is considered the country with the highest risk of ML (18). Seven of the nine departments located in the Amazon rainforest are considered endemic and four of them (La Paz, Pando, Beni and Cochabamba) contain most of the reported cases nationally (19).
Leishmaniasis is a growing problem in Bolivia. In the last 33 years, 52,244 cases of leishmaniasis have been recorded, of which 92% were CL and 8% ML (19). To reduce the morbidity and mortality of leishmaniasis, the National Leishmaniasis Control Program (NLCP) was created in 2007 with the aim of improving the access and quality of health care in terms of prevention, diagnosis and treatment. However, it is well known that a high number of people cannot access adequate health care to treat this disease.

Although there are some studies that mentioned something about the difficulties in access to health care for patients with leishmaniasis in Latin America (20-23), these are few, old, do not focus specifically on the problem of access to medical care and none of them has been conducted in Bolivia.

The purpose of the present study is to explore the experiences of patients with leishmaniasis and the challenges they faced when searching for diagnosis and treatment in the Amazon region of Bolivia using human rights to health approach.

; The new paragraph of the conclusion section now it reads:

Lines 469-472:

Public health activities to control leishmaniasis can be benefited from using the human rights to health approach and integrating human rights principles, uncovering health inequities and catalyzing integration focusing on who is left behind and why, in a way that the needs of the most marginalized are fulfilled.