Author’s response to reviews

Title: Participatory Praxis as an Imperative for Health-related Stigma Research

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Author’s response to reviews:

The coauthors and I wish to thank the editor and both reviewers for your thoughtful engagement with our manuscript and for indicating important and concrete ways that we can improve the manuscript. We note that your concerns align with our own and center around deepening the analysis and discussion of what it means to truly engage with stigmatized communities in participatory research praxis to address health stigma. We are grateful for the opportunity to expand our discussion by revising the manuscript so that it is an opinion article instead of a commentary. We will respond to each of the reviewers comments below. Our changes are tracked in the manuscript.

1) (Reviewer 1) Discuss how participatory research can shape and mitigate community stigma surrounding many health issues - specifically, more in-depth discussion about how the goal and process of community participatory research could contribute to the revolution of social acceptance and removal of social stigma, which is often implicit, surrounding health issues. Moreover, discussion about how community participatory research influences stigmatizers and stigmatized individuals is much needed.

We appreciate this question and agree heartily with Reviewer 1 that articulating how the process and goal of participatory praxis can mitigate health stigma, both for those who are stigmatized and those who stigmatize. We appreciate the attention brought by Reviewer 1 to the ways in which participatory praxis in health stigma research can ameliorate stigma faced by communities
through the research outcomes and also through the practice of engaging as equal partners in the research.

We have drawn from our own research and the literature to discuss this issue in greater depth in the revised manuscript. In the section that describes key benefits from a participatory approach, we added a fourth category: Undoing stigma.

This section includes a description of the People Living with HIV Stigma Index research and qualitative results that explore the effects on the peer researchers and steering committee members, who were themselves living with HIV, as they move from being perceived as “consumers” of services to researchers. The section also highlights research on the health benefits of engaging in participatory research as well as research on the benefits of participating in action for social change - which is a key component of participatory praxis.

Certainly more research into this question is warranted and we have added this concern into our proposed research agenda.

2) (Reviewer 2) More detail on the 'how-to' practicalities for each of the steps along the continuum (Figure 1), but most importantly for the ideal point of shared leadership, particularly in repressive and dangerous contexts.

On behalf of the coauthor group, we thank Reviewer 2 for raising the importance of providing more practical and concrete direction for readers. We have addressed this concern in two ways. First, in the manuscript text, we have nuanced our discussion of the continuum, with particular attention to shared leadership. We have sought to highlight the key values, principles, and orientations needed to move toward greater participatory praxis. We add that research projects may initiate at any stage on the continuum and move toward greater participation if the research team is working from the values described. We have also extended our analysis in the section on values, to offer a deeper discussion on power and privilege. In addition, we have added to the section on addressing risks to community members incurred through their participation in research.
Second, we have expanded the list of resources in Table 3. As much as we would like to do so, it is not possible for our piece to closely detail all of the approaches, methods, and examples that are needed for researchers to learn to engage in participatory praxis. However, a strong literature exists on participatory praxis specific to health stigma research and we have sought to compile what we see as the best of the field.

3) (Reviewer 2) And more examples of how participatory praxis has been done successfully.

To address this concern, we have included an additional example from the PLHIV Stigma Index as well as additional resources in Table 3. The resources in Table 3 provide a wide range of good examples of participatory praxis with different marginalized communities and different health conditions.

4) (Reviewer 2) I think as researchers, we may also need some basic awareness building around participatory praxis--we may think we're engaging in it, but in reality we are not. So I was left wanting more concrete details on specific details of how to achieve participatory praxis (and what not to do), particularly if one is not a member of the community. How do we practically go about un-learning practices that instill hierarchy and distance?

We thank Reviewer 2 for this thoughtful comment, which allowed us to also deepen the analysis in the paper. We have now included greater discussion in the section on values to address this question. As Reviewer 2 rightly notes, there can be serious concerns and hesitations by researchers who do not come from the communities where they conduct research but who do want to work collaboratively with those communities. The additional discussion that we added in the Values section seeks to address this concern. In addition, we have added a section on structural changes required in order to see a change in research practices. In that section, we also include a short discussion of the kinds of training that researchers need that are different from most current university requirements.

We would also like to note again here that we have expanded the resources in Table 3. We have selected resources that give specific and concrete direction for how to approach participatory praxis and that offer multiple examples of participatory praxis in action, including examples of how research teams made missteps and needed to recover.
5) (Reviewer 2) What are the specific structural changes in funding, training, promotion, publication and tenure processes that need to happen? How do you see those coming about/what needs to be done to achieve those?

We appreciate the opportunity to expand on our brief mentions in the original manuscript of the need for structural changes to facilitate a change in research praxis. We have added a section on Structural Changes to this version of the manuscript in which we address these questions.

6) (Reviewer 2) I was also left wondering--while striving to achieve shared leadership, are there ever any situations where it is acceptable to land somewhere along the continuum?

This was a gap in our previous manuscript to which we are glad that our attention was directed. This question deserves more attention and discussion among participatory researchers than we have seen to date. We have provided our approach to this question in the new paragraph added to the section on the continuum of participation (which is the first section under Discussion). In short, we answer in the affirmative and argue that the underlying values and orientation of health stigma research should always be grounded in the values and orientation of participatory praxis, while the actual activities and processes may vary from project to project. Even research projects that initially have little ownership by communities can move in the direction of greater engagement and shared leadership.