Reviewer’s report

**Title:** Ethical Challenges in Global Health-related Stigma Research

**Version:** 1  **Date:** 04 Feb 2019

**Reviewer:** Ellen Mitchell

**Reviewer's report:**

This version responds to several pleas to focus on stigmatization as an action and to give additional clarity on the scope and flow of the piece. The authors have made editorial adjustments in this iteration which have improved the text incrementally.

The authors could demonstrate more familiarity with and (ideally) alignment with mainstream stigma scholarship:

1. I feel as if both reviewers are repeating ourselves on this central point: populations that are stigmatized are by definition marginalized and vulnerable. Yet the authors continue to make statements that suggest marginality is only a correlate or consequence not a requisite aspect of stigma. Claims such as "populations who experience stigma are often marginalized and…" are used throughout in ways that I think are (at best) not consistent with stigma theory.

2. On what basis do authors claim that stigmatized conditions "are often severe and hard to treat or prevent"? Why is this claim necessary? Is it not enough to justify research on the basis that being shunned is rotten? What difference does it make whether the stigma is permanent or transient? Here is where I feel that the authors could do more to demonstrate their grasp of stigma theory. If it were easy to prevent - wouldn't that make it MORE stigmatizing (i.e. more susceptible to blaming and shaming??) according to stigma theorists? Think, for example, of fat shaming and slut shaming which are forms of stigmatization that people (especially HCWs) regularly practice because they claim obesity and sexual behavior are essentially choices -- if one practices correct abstemious, moral restraint they won't experience stigma.

3. It is not quite enough to claim that denormalization of alcohol use in pregnancy would "exacerbate the stigmatization of people with FASD and their parents "it is that the intent of denormalization would be to literally to stigmatize them. Stage 1 Stigmatization begins with marking something as non-normative and indeed bad (again link to classical stigma theory).
4. "Layered vulnerability" and "engagement" are awkward (and in the case of "engagement" outdated) framings to the ethical challenges presented in my view. I would prefer to see it squared with GIPA principles, Denver Declaration, Paris Declaration and other ethical frameworks that the stigmatized have a right to be included and engaged in deciding things intended for their benefit. I think that type of argumentation would make this correspondence align better with contemporary discussions of stigma research and the ownership and leadership of stigmatized populations in the fight against their marginalization, stigmatization.

In the abstract authors state "we consider ways in which stigma research can unintentionally result in harms." This is misleading, because, as pointed out previously, none of the case studies is about research on stigma. So, this needs to be removed. I believe you mean simply that stigmatized groups are special when it comes to ethics.

Responding to reviewers' requests for nuance and contextualization has led to some opaque phrasings that suggest the answers to the questions raised are far in the distance. This undermines the article's premise of offering readership insights and direction.

1. "In each case, the solution to such outstanding ethical challenges is likely to be specific to the context in which it arises."

2. "Some ethical challenges are amenable to resolution using existing resources; others will require further work by stigma researchers and ethicists."

There are still a few spots that offer very elementary practical advice that seem almost too basic for the readership of BMC Medicine:

1. Again, to grasp the potential risks, researchers need to learn about the local social and cultural context and how affected individuals themselves perceive potential risks.

2. Where the risk to participants of being identified from research data is high, full anonymization should be considered and implemented as soon as the scientific goals of the research allow.

Finally, on the matter of originality - I think the authors may have overlooked the existence of some stigma and ethics work. They should be careful not to overstate the claim that no one is really delving into the issues of stigma and research ethics. I have tried to dig into it a little myself to see what else is out there. I see quite a bit actually. I do not include these examples because I think they all should be cited. I include them rather to show the authors that this ground they are covering is more well trodden that stated, so the authors should consider how to make it clearer to readers what their unique contribution is in drafting 6 case studies.
Some additional examples of stigma, denormalization and ethics literature:


Some examples of stigmatized populations' critiques of research ethics


Mechanics of protecting stigmatized populations


A lot of work on consent and adolescents' stigmatized sexuality


Ethics of intervention trials

Ethics of mental health research


Ethics of genetic testing


Evaluation of harms and risks and risk mitigation


* Fisher CB. Enhancing the Responsible Conduct of Sexual Health Prevention Research Across Global and Local Contexts: Training for Evidence-Based Research Ethics. Ethics Behav. 2015;25(2):87-96.


Secondary stigma research ethics papers


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Needs some language corrections before being published

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I am starting to see the potential for developing a conflict of interest, because I fear this protracted back and forth on this manuscript without resolution is holding up the special issue on stigma, of which I am a time sensitive stakeholder. That is not affecting me at present, but if it drags on, it will represent a conflict for me. For these reasons, this will be my last round of feedback.

Maybe someone else can look at it with fresh eyes and perhaps more objectively.

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