Reviewer’s report

Title: Ethical Challenges in Global Health-related Stigma Research

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Reviewer: Gillian Craig

Reviewer's report:

I would like to thank the authors for the amendments. However I’m still struggling to see how this article relates to stigma as a substantive topic and the claim the authors make that stigma research raises unique ethical challenges over and above what you might experience with research with hidden or marginalised populations.

The motivation for the article came from a health stigma research workshop where people discussed ethical issues - but it is uncertain that these issues differ to the challenges of conducting research with marginalised groups. Maybe a clear statement upfront about what these differences are is necessary, what the barriers are and how you will illustrate these through your case studies. There is an attempt to do this p8 but I feel it needs to be made clearer. More signposting of what is to come may help here (Eg we will discuss 4 scenarios - name them with bullet points - and state why chosen upfront.

Thank you for clarifying your definition of stigma. The definition of stigma given on line 33 is a little incomplete. Link & Phelen are clear stigma arises as a relational entity involving:

"In our conceptualisation, stigma exists when the following interrelated components converge. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labelled persons to undesirable characteristics—to negative stereotypes. In the third, labelled persons are placed in distinct categories so as to accomplish some degree of separation of "us" from "them." In the fourth, labelled persons experience status loss and discrimination that lead to unequal outcomes.

The authors need to contemplate the role of power in who/what decides which characteristics are undesirable and why. Stigma is socially constructed and in using a partial definition the authors are in danger of essentialising stigma as something inevitable regardless of context. The authors have also omitted felt stigma (fear of discrimination) which is generally accepted to have implications for stress & coping. Why have some forms of stigma been chosen over others or was this an oversight? Power is alluded to (p9) in relation to HIV so the authors do focus on power, moreover the example on PREP is actually alluding to courtesy stigma - where stigma transfers to others by virtue of association - which comes from Goffman's work, but this is not included or discussed in the introduction. The role of power, class and privilege as mediators of stigma are however alluded to in the discussion. It is these kinds of omissions that leads me to
believe that this article really is a discursive piece which addresses research with marginalised communities and sensitive topics - some of which involve stigma - or how research/clinical praxis inadvertently excludes certain groups and produces stigma. I do not think stigma is the substantive topic addressed here.

Lines 19-24 comparisons are made between HIV stigma and a genetically inherited disease. I think these are very different conditions; research suggests that HIV will incur blame and call into question people's moral identities as they will be seen as culpable whereas a genetically inherited condition may attract sympathy (i.e., people will not be seen as morally culpable but this could depend on context. Stigma is not therefore universal). The universalism of stigma that the authors claim conflicts with a growing body of research on the need to contextualise experience. The authors do allude to difference on page 7 with phrases such as "socially accepted status" so there is a slight tension in the authors' conceptual argument. For example, page 11, line 59 they allude to the effects of context with their discussion of vulnerability and layering. These tensions need to be addressed.

Lines 47-50 in the discussion do look at blame in relation to lung cancer.

Line 39 in the results, the authors state, could lead to isolation. Can the team give an example?

Line 25 maybe better to talk about transferable learning form one type of stigma scenario to another rather than use the term "struggling researchers" as I'm not clear what researchers are struggling with at this stage. We all struggle to recruit and conduct research with marginalised and other groups more generally.

SCENARIOS

HIV and PREP

Is it not the case that all children enrolled in research clinical trials who are under the age of 18 need the consent of parents to participate. Lack of representation in PREP trials is not completely about stigma - but lack of guardianship also and the legal issue of capacity to consent. I wasn't therefore convinced this example reflected solely on a stigmatising topic.

Case 2 reflects a problem most researchers experience - the legalese and incomprehensibility of project information sheets. While schizophrenia may be a stigmatised condition I don't see this example as one that really reflects on the working of stigma. Most researchers are required to work with affected communities to get their input into developing project information sheets although RECs often set in stone how these should be written with little room to manoeuvre. It's something we all struggle with.
Case 3 is left unfinished and I'm not clear how this relates to stigma. I assume the authors want to say that in raising awareness we risk stigmatising communities. Yes! This is not a new problem. Identifying, labelling any marginalised community at risk, risks stigmatising them hence the need for service user input to the design, implementation and reporting of interventions. There is a need for greater discussion on the overprotection angle. Page 15 lines 25-29 probably need to be included here rather than in the discussion.

The idea of layering being similar to intersectionality.- the latter needs explain and referencing please so people can see the points of cross over.

Structure of article

It still makes for a difficult read (sorry!). As well as more signposting in the introduction I wonder if the flow of the article could be attended to. Perhaps more theorisation should follow each case which would avoid the problem of some cases appearing a little "thin" (eg case 3), followed by one brief, critical discussion which synthesised all the learning across the different scenarios would help.

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