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Trends in responses to DHS questions should not be interpreted as reflecting an increase in “anticipated stigma” in Africa

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To the Editor

In sub-Saharan Africa, measurements of change in levels of HIV-related stigma have not been well reported. Years of data have been collected through the Demographic and Health Surveys (DHS) and AIDS Indicator Surveys (AIS) on responses to questions aimed at determining attitudes towards people living with HIV (PLHIV). Chan and Tsai (August 2016 issue) recently analysed the data from 31 African countries between 2003–2013 and we applaud the efforts of the authors for taking on this challenge [1]. The authors conclude that over time there has been an increase in “anticipated stigma,” but a decrease in “social distancing” towards PLHIV.

We recently concluded a similar analysis of stigma trends by examining the same DHS survey data from Africa. We are concerned that the conclusion that anticipated stigma has increased over time in sub-Saharan African countries may not be a sound interpretation of these data. Cognitive interviews of the DHS stigma measures conducted by Macro International and the International Center for Research on Women in Tanzania in 2004 identified problems with the question: “If a member of your family got infected with the AIDS virus, would you want it to remain a secret or not?” used by Chan and Tsai as indicating “anticipated stigma” [1]. A “Yes” response to this question is supposed to reflect the respondents’ anticipation that a family member may experience stigma if their HIV-positive status became known [1]. Conversely, a “No” response is assumed to reflect that the

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respondent does not anticipate that their family member will experience stigma if their status become known. However, the cognitive interviews suggested another interpretation all together. In a few cases, a “No” response was actually a stigmatizing one, with disclosure linked to ‘protecting’ others in the community from being infected with HIV by their family member, *even if* their family member may then experience stigma (Laura Nyblade, oral communication, January 2014) [2]. The potential problem with this question may explain the puzzling significant association with gender but no significant association with country HIV prevalence reported by Chan and Tsai. Given the multiple interpretations of this question possible, it is not a credible measure of “anticipated stigma”, thus we believe serious caution is warranted when considering Chan and Tsai’s interpretation of these data as reflecting an increase in “anticipated stigma” over time [3].

In addition, our analyses support the conclusion of a downward trend in “No” responses to two of the three questions used by Chan and Tsai to reflect “social distancing”. The questions “Would you buy fresh vegetables from a shopkeeper or vendor if you knew that this person had the AIDS virus?” and “In your opinion, if a female teacher has the AIDS virus but is not sick, should she be allowed to continue teaching in the school?” have been shown to be useful measures of discriminatory attitudes [2]. However, we have concerns about the third question used by Chan and Tsai in their composite measure of “social distancing”. Specifically, research in Tanzania suggested that when responding to the question, “If a member of your family became sick with AIDS, would you be willing to care for her or him in your own household?”, men and women interpreted the term ‘care’ differently, with men perceiving ‘care’ to mean ‘financial support’ and women as ‘physical and emotional support’ [3]. Given prevailing social and gender norms in many African settings that place women in charge of providing physical care and support for sick relatives, a women’s ‘no’ response to this question is not comparable to a man’s ‘no’ response. For example, a woman caring for a person living with HIV is likely to come into contact with bodily fluids, which she may fear are infectious. While the virus cannot be transmitted through such contact, this fear may be driving her ‘no’ response. This may explain why more women disagreed with this statement than men. By including this item in their composite measure of social distancing, Chan and Tsai are likely dampening the reductions in social distancing actually occurring in the region and suggesting gender differences in stigmatizing attitudes that may not exist. This question has been removed from the standard DHS questionnaire as of 2015 due to the differing interpretations by gender and should also be excluded from Chan and Tsai’s analysis [4]. In general, while we have some concerns about the use of this question, we agree the DHS data from Africa are supportive of a downward trend in discriminatory attitudes, or “social distancing”, as reported by Chan and Tsai [1].

Our independent and similar analyses of DHS data on stigma-related attitudes support Chan and Tsai’s conclusion of encouraging trends in measures of attitudes reflective of potential “social distancing” of PLHIV. However, we urge caution with respect to their conclusions about trends in “anticipated stigma.” The authors question if there is a casual association between ART scale-up and an increase in “anticipated stigma” and recommend that policymakers support new interventions to deal with “anticipated stigma”. If there is no association of ART scale-up and “anticipated stigma,” it would be inadvisable to direct

resources to this issue. As a supplement to the data available from DHS surveys, further integration of measures of experienced stigma and discrimination within surveys and cohorts of PLHIV incorporating systematic sampling would have great value in assessing trends in HIV stigma over time. Further study is also warranted to help develop survey questions that can accurately measure the general population's attitudes towards PLHIV, and particularly anticipated stigma.

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