Reducing stigma and discrimination: new evidence and its implications

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Writing in 2005, Castro and Farmer [1] observed that a ‘transformation of AIDS from an inevitably fatal disease to a chronic and manageable one has decreased stigma dramatically in Haiti’ (p.57). Fifteen years later, hopes that biomedical advances could end HIV-related stigma seem distant. Stigma persists and is made manifest in different ways and at different times in the lives of people living with HIV (PLHIV) [2,3], by whole communities affected by a high burden of HIV-infection [4], and is mirrored in the ways in which people react to new disease threats [5].

Stigma may indeed have reduced in some forms [6,7], but gains from HIV-stigma reduction initiatives have often been modest [6,8] and are rarely implemented at scale [9]. The impact of stigma and discrimination continues to be seen in the variable uptake of HIV-testing and access to care and support [10,11].

Several of the articles in this collection contribute to advances in measurement and, in particular, to the update of the PLHIV Stigma Index, which was originally developed in 2008 [16]. The process of updating and the resulting Stigma Index 2.0 are described by Friedland et al. Notable improvements to the Index include new and refined questions on gender identity, key population membership and other marginalized groups, interactions with healthcare services, anxiety and depression, and internalized stigma. A PLHIV Resilience Scale was also added. The Index was also adjusted to be more reflective of the current context of the epidemic and the response, incorporating indicators that allow a better understanding of intersectional stigma and take advantage of psychometric testing.

Importantly, the Stigma Index 2.0 has been tested and validated across a range of settings, including Cameroon, Senegal, and Uganda. The incorporation of formal statistical techniques for assessing the validity of measures is reflected in the internalized stigma scale across four countries described by Geibel et al. and the Resilience Scale across three countries described by Gottert et al.
Broady et al. and Lyons et al. present new evidence on the conceptualization and measurement of ‘stigma by association’ and intersectional stigma, respectively.

The value of getting measurement right and documenting the ways in which data are used to improve policies and programs is clearly illustrated in the article by Siraprapasiri et al. who highlight the use of data to address stigma and discrimination as one of the ‘three building blocks’ in the national response to HIV/AIDS in Thailand. Specifically, indicators of stigma and discrimination were incorporated into the national monitoring and evaluation plan, and a systematic surveillance system was put in place for tracking progress in health facilities, among key populations, and in the general population.

The intentional use of measurement is also one of the themes of the article by Nyblade et al. They emphasize the importance of the formative research that was used to catalyze action in district level health facilities in Tanzania and Ghana and to inform the design of actions to address stigma. They also describe the integration of stigma measures into performance management systems to track success and make course corrections.

A commitment to participatory research and processes contributed to the success of several of the initiatives described here, including the revision of the Stigma Index driven and administered by PLHIV, the implementation of the Total Facility Approach to reducing stigma in health facilities which utilized participatory workshops with key stakeholders to adapt measurement tools, and in the scale up of stigma interventions in Thailand where stakeholders including PLHIV, key populations, local and international NGOs, development partners and government representatives participated in all stages of the process.

That the experience of stigma (whether due to HIV status or key population status) is both an outcome in its own right with a range of determinants – an indicator of health and wellbeing – as well as a determinant of other health outcomes related to HIV (e.g., incidence, treatment adherence, viral suppression) is tested in several of the articles. For example, Yam et al. show that while results were not completely consistent across communities, PLHIV who were also members of a key population group were significantly more likely to experience some types of stigma and to experience worse treatment outcomes. Geibel et al. show that internalized stigma is associated with depression as well as with antiretroviral therapy (ART) use and viral suppression. Broady et al. demonstrate that experiencing ‘stigma by association’ among Australian gay and bisexual men (whether LHIV or not) has a cross-sectional relationship to several characteristics including the strength of attachment to the community and that this type of stigma is associated with the likelihood of HIV testing and psychological distress.

There is encouraging new evidence about interventions that have shown success in reducing stigma and approaches that may be transferable to other settings. For example, interventions aimed at reducing stigma communicated or enacted by health workers have proven to be effective in Ghana and Tanzania (Nyblade et al.) as well as in Thailand (Siraprapasiri et al.). Both efforts conclude that a ‘total facility’ effort – one that includes both clinical and nonclinical staff – is likely to be most effective at reducing stigma.

Similarly, articles in this collection add to the existing evidence that efforts to reduce stigma experienced by PLHIV are likely to be most effective if interventions occur at multiple levels and in multiple ways. Singh et al. undertook research which explicitly tested and found positive effects of a multilevel approach in India, in which individual, group, and collective interventions were introduced in three different sequences. The randomized controlled trial (RCT) described by Ibrahim et al. on ART adherence among people newly initiating care in the United States points to the need to customize interventions for those who are new to treatment and those who are more experienced. In addition, while the intervention centered on individual level counseling for addressing internalized stigma, it also offered ‘information, motivation, and behavioral skills for adherence to care and ART, focusing on adjustment, problem solving, affect management, and communication.’ The authors conclude that multifaceted interventions can be effective but point to the need for studies that can provide evidence on which interventions are most effective for which people. The results of the RCT described by Lyons et al. underscores the need to address multiple intersecting forms of stigma and multiple identities. While not testing an intervention, Gottert et al. demonstrate in their findings that the determinants of resilience among PLHIV operate at individual, interpersonal, and structural/policy levels (such as legal protections for PLHIV), suggesting that interventions would be most effective if they were designed to address these multiple levels also.

As highlighted in the article describing Thailand’s HIV/AIDS national response, treatment outcomes are also influenced by service delivery issues not related to stigma. The barriers to treatment that are generated by a lack of access to high-quality health services (including trained health workers, drugs and supplies, testing, counseling) need to be overcome in parallel with stigma reduction. The absence of comprehensive models that aim to sort out the relative contributions of each may be due to the demanding data requirements, but it is difficult to assess the significance of stigma reduction efforts in their absence. An example is provided by Yam et al. who did not find an association between stigma and either viral suppression or missing an ART dose among PLHIV of Haitian descent. They hypothesize that the undocumented status of many in that
group may inhibit their access to health services more than HIV-related stigma.

Despite the methodological and substantive advances presented in these articles, several challenges remain for the study of HIV-related stigma. The need to employ nonprobabilistic sampling methods, especially for key populations, due to the barriers to usual probabilistic techniques remains difficult to overcome. As noted by Gottert et al., one problem is that techniques such as snowball and respondent driven sampling (RDS) may result in an overrepresentation of people linked to care, and it is difficult to assess the effect of nonrepresentative sampling on the results. While sampling issues are noted by several authors as a limitation of the research there is little attempt to gauge their effects. More comprehensive assessments of the potential biases should become standard in research that uses nonprobability samples. It is worth noting that this type of sampling (RDS, snowball) may become more difficult during/post the COVID-19 pandemic when the frequency of in-person interaction is likely to be reduced; more alternatives to these methods are urgently needed.

To understand the independent causal effects of interventions on stigma and HIV-related outcomes or simply the causal effects of stigma on HIV treatment outcomes, more studies with rigorous designs are needed. This collection includes two RCTs of interventions (Ibrahim et al. and Singh et al.). Due to their rigorous designs, these studies make substantial contributions to our understanding of the effects of complex interventions. However, because, as with many such trials, participants are not followed poststudy we learn little about the durability of the effects of the interventions. More investment in longer periods of study is sorely needed. Cross-sectional data, as the authors of these articles acknowledge, yield ambiguous results on direction of causality (Yam, Gottert, Broady, Geibel). The one longitudinal study in the collection (Lyons et al.) is able to showcase the advantages of this type of data by tracking incidence and viral suppression over time – and linking these outcomes to changes in stigma.

Finally, only one article in the supplement includes qualitative data (Geibel et al.); the data provide insights that improve our understanding of, in this case, the reaction of participants to the internalized stigma subscale of the Stigma Index 2.0. Overall, however, research using qualitative approaches to better understand the experience of stigma and of related interventions would be a useful addition to many quantitative studies and trial designs [17].

All of the articles in this collection serve to highlight the persistence of HIV-related stigma, while ways in which stigma is experienced and shown may change with time, the ‘third epidemic’, to use the words of Mann [18], remains a stubborn obstacle to testing, treatment, and care for too many people around the world.

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References


