

# Reducing stigma and discrimination: new evidence and its implications

Janet Seeley<sup>a</sup> and Ann K. Blanc<sup>b</sup>

*AIDS* 2020, **34** (Suppl 1):S1–S4

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]. The heterogeneity in response to universal test and treat initiatives, and the role different types of stigma play in this response, has been seen in many settings [12]. Context matters in the effectiveness of stigma-reduction interventions as men and women, older and younger, respond differently to efforts to address stigma and discrimination [13]. These differences present a continued challenge for standardized stigma measures to facilitate comparisons between different approaches to intervention [14], and the ways in which data on stigma are interpreted [15]. In this collection, we bring together articles that address innovation in stigma measurement, speak to the importance of understanding context in intervention design and implementation and highlight the emergence (or re-emergence) of different forms of stigma that have a profound impact on how individuals and groups of people engage with HIV-services. There are reasons to hope that further progress is possible, but

also reminders of how fragile success may be in the face of resource constraints and other urgent health priorities.

We have grouped the articles to present those that address the measurement of stigma first, before moving to articles which provide programmatic insights and evidence of impact. The articles cover a diversity of populations that experience stigma across a range of geographic settings and epidemic context.

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.*

<sup>a</sup>London School of Hygiene & Tropical Medicine, London, UK, and <sup>b</sup>Population Council, New York, NY, USA.

Correspondence to Janet Seeley, London School of Hygiene & Tropical Medicine, London, UK.

E-mail: janet.seeley@lshtm.ac.uk, janet.seeley@mrcuganda.org

Received: 18 July 2020; accepted: 22 July 2020.

DOI:10.1097/QAD.0000000000002647

ISSN 0269-9370 Copyright © 2020 The Author(s). Published by Wolters Kluwer Health, Inc. This is an open access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

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 Siraprasiri *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 (Siraprasiri *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.

## Acknowledgements

We thank Barbara Friedland for her role in facilitating our work on this special issue.

## Funding

This special issue was funded by both the Population Council and Project SOAR. Project SOAR was made possible by the generous support of the American people through the United States President’s Emergency Plan for AIDS Relief (PEPFAR) and the United States Agency for International Development (USAID) through Cooperative Agreement AID-OAA-A-14-00060. The contents of this publication do not necessarily reflect the views of PEPFAR, USAID, or the United States Government.

## Conflicts of interest

There are no conflicts of interest.

## References

1. Castro A, Farmer P. **Understanding and addressing AIDS-related stigma: from anthropological theory to clinical practice in Haiti.** *Am J Public Health* 2005; **95**:53–59.
2. Rosenfeld D, Ridge D, Catalan J, Delpech V. **Age and life course location as interpretive resources for decisions regarding disclosure of HIV to parents and children: findings from the HIV and later life study.** *J Aging Stud* 2016; **38**:81–91.
3. Maughan-Brown B, Beckett S, Kharsany ABM, Cawood C, Khanyile D, Lewis L, *et al.* **Poor rates of linkage to HIV care and uptake of treatment after home-based HIV testing among newly diagnosed 15-to-49 year-old men and women in a high HIV prevalence setting in South Africa.** *AIDS Care* 2020:1–10. <https://www.tandfonline.com/doi/abs/10.1080/09540121.2020.1719025>.
4. Ngwenya N, Gumede D, Shahmanesh M, McGrath N, Grant A, Seeley J. **Community perceptions of the socio-economic structural context influencing HIV and TB risk, prevention and treatment in a high prevalence area in the era of antiretroviral therapy.** *Afr J AIDS Res* 2018; **17**:72–81.
5. Logie CH, Turan JM. **How do we balance tensions between COVID-19 public health responses and stigma mitigation? Learning from HIV research.** *AIDS Behav* 2020; **24**:2003–2006.
6. Stangl AL, Lloyd JK, Brady LM, Holland CE, Baral S. **A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: how far have we come?** *J Int AIDS Soc* 2013; **16** (3S2):18734.
7. Ekstrand ML, Raj T, Heylen E, Nyblade L, Devdass D, Pereira M, *et al.* **Reducing HIV stigma among healthcare providers in India using a partly tablet-administered intervention: the DriSti trial.** *AIDS Care* 2020; **32** (Sup2):14–22.
8. Mak WW, Mo PK, Ma GY, Lam MY. **Meta-analysis and systematic review of studies on the effectiveness of HIV stigma reduction programs.** *Soc Sci Med* 2017; **188**:30–40.
9. Pulerwitz J, Bongaarts J. **Tackling stigma: fundamental to an AIDS-free future.** *Lancet Glob Health* 2014; **2**:e311–e312.
10. Sullivan MC, Rosen AO, Allen A, Benbella D, Camacho G, Cortopassi AC, *et al.* **Falling short of the first 90: HIV stigma and HIV testing research in the 90–90–90 era.** *AIDS Behav* 2020; **24**:357–362.
11. Mahajan AP, Sayles JN, Patel VA, Remien RH, Ortiz D, Szekeres G, *et al.* **Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward.** *AIDS* 2008; **22** (Suppl 2):S67.

12. Green D, Tordoff DM, Kharono B, Akullian A, Bershteyn A, Morrison M, *et al.* **Evidence of sociodemographic heterogeneity across the HIV treatment cascade and progress towards 90–90–90 in sub-Saharan Africa – a systematic review and meta-analysis.** *J Int AIDS Soc* 2020; **23**:e25470.
13. Bonnington O, Wamoyi J, Ddaaki W, Bukenya D, Ondenge K, Skovdal M, *et al.* **Changing forms of HIV-related stigma along the HIV care and treatment continuum in sub-Saharan Africa: a temporal analysis.** *Sex Transm Infect* 2017; **93** (Suppl 3): e052975.
14. Nyblade L, Stockton MA, Giger K, Bond V, Ekstrand ML, Lean RM, *et al.* **Stigma in health facilities: why it matters and how we can change it.** *BMC Med* 2019; **17**:25.
15. Cordes JL, Stangl A, Krishnaratne S, Hoddinott G, Mathema H, Bond V, *et al.* **Trends in responses to DHS questions should not be interpreted as reflecting an increase in ‘anticipated stigma’ in Africa.** *J Acquir Immune Defic Syndr* 2017; **75**:e22.
16. Global Network of People Living with HIV. *PLHIV stigma index: Global Network of People Living with HIV*; 2020, Available from: <https://www.stigmaindex.org/>. Accessed 5 July 2020.
17. Camlin CS, Seeley J. **Qualitative research on community experiences in large HIV research trials: what have we learned?** *J Int AIDS Soc* 2018; **21**:e25173.
18. Mann J. *The third epidemic; repercussions of the fear of AIDS*. London: Panos Institute; 1990.