EDITORIAL



Falling Short of the First 90: HIV Stigma and HIV Testing Research in the 90–90–90 Era

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Despite great strides forward, several countries are far from achieving the goals of the UNAIDS 90-90-90 initiative, aimed toward identifying and diagnosing 90% of people living with HIV, distributing antiretroviral therapy (ART) to 90% of people diagnosed, and achieving viral suppression in 90% of people receiving treatment. HIV stigma is likely a contributing factor in failing to achieve these goals, particularly the first 90—identifying and diagnosing 90% of those infected. Since the 2014 launch of the 90-90-90 initiative, major advances in global access to ART have culminated in half of the world's people living with HIV now receiving treatment [1]. There has also been marked progress in the infrastructure needed to distribute HIV treatments worldwide [1, 2]. However, treating HIV starts with diagnosing HIV, making the first 90 the critical cornerstone in efforts to end HIV epidemics. Shortfalls in achieving 90% HIV diagnoses are apparent throughout sub-Saharan Africa, where the vast majority of the world's HIV infections are concentrated [3]. In some countries with the most devastating HIV epidemics, progress has been slowest in achieving the first 90 [3]. In 2017 an estimated 76% of people with HIV in this region had been diagnosed, 79% of whom were receiving ART, and 83% of those receiving ART had achieved HIV suppression. These averages, however, mask the disparities that exist among countries. HIV stigma is most certainly one of numerous factors at play in failing to achieve the first 90.

HIV stigma is a ubiquitous and pervasive barrier to every point along the HIV continuum of care [4–7]. Societal

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devaluation of people with HIV and intersecting characteristics, such as gender, sexual orientation and substance use, adds to the burden of receiving an HIV diagnosis [8]. Prejudice, stereotypes, and discrimination against people living with HIV create a social context in which personal concerns for safety, a sense of shame, social exclusion and other adverse social conditions accompany the prospect of receiving a positive HIV test [9]. Harsh structural expressions of HIV stigma, particularly criminalization of HIV, can also undermine efforts to scale-up HIV testing [10]. People who endorse prejudicial attitudes towards people living with HIV are themselves less likely to accept HIV testing [6]. Having witnessed discriminatory acts and other forms of enacted stigma leads to expectations or anticipation of stigma following an HIV diagnosis. Anticipating future stigma is linked to lower rates of testing uptake in multiple populations [8, 11–13].

Having not achieved the 90-90-90 targets in any country with a substantial HIV epidemic, we asked to what degree may stigma be impeding HIV testing? We therefore took a cursory look at the state of research on the role of stigma in HIV testing in sub-Saharan Africa. We examined published studies between 2014 and 2019 that reported on the relationship between HIV stigma and HIV testing. We purposefully selected the African countries with the highest HIV prevalence by total population: South Africa, Nigeria, Mozambique, Kenya, Tanzania, Uganda, Zimbabwe, Zambia, and Malawi [14]. Together, these nine countries are home to an estimated 20.1 million people living with HIV. We did not set out to conduct a comprehensive review. Rather, this Editorial is intended to provide a thumbnail sketch of research on the relationship between HIV stigma and HIV testing in high-HIV prevalence countries to inform the next steps toward achieving the 90-90-90 targets.



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The State of the Literature on HIV Stigma and HIV Testing in Sub-Saharan Africa

Relevant publications were searched in PubMed in March of 2019, with independent searches for each of the nine countries. We used combined free-text search terms "HIV" AND "test" AND "stigma" AND [name of country]. We only reviewed studies published between 2014 and 2019, the 90-90-90 era, that measured HIV stigma in relation to HIV testing uptake. We only included studies that directly assessed stigma and uptake of HIV testing, omitting policy analyses, studies of HIV testing experiences, studies of stigma experiences in people living with HIV as well as other studies that fall outside of stigma in relation to testing. Studies that sampled participants across countries were included if they reported results individually for each country. We collected qualitative, quantitative, and mixed-method studies. A detailed summary of the studies we examined, country by country, is reported as electronic supplementary material. Below we briefly summarize the state of research for each country.

South Africa

Our search yielded 18 studies conducted in South Africa, encompassing both quantitative and qualitative studies of varying size, scope, and designs. Stigma was consistently identified as a barrier to HIV testing across a diverse range of participants. Of five studies that included quantitative measures of stigma [6, 15-18], three used stigma scales that had previously been used in South Africa. Perceived stigma and discrimination were found to vary across study populations, with higher rates of stigma and overt discrimination occurring in socioeconomically disadvantaged urban and rural communities relative to betterresourced settings [19–22]. With respect to HIV testing, women tended to report more frequent testing than men, with men often indicating hesitation to attend primary health clinics due to concern that they may be perceived as less masculine [23, 24]. Two large quantitative surveys, however, reported conflicted findings with regard to gender, stigma and HIV testing. One study of young adults showed a strong negative relationship between perceived HIV stigma and testing in women but not in men, while another study in urban commuters showed a negative relationship between perceived stigma and testing in men but not in women [21, 23]. In contrast to most findings, one study showed that women who held more stigmatizing attitudes regarding people living with HIV were more likely to report having been HIV tested [21]. Concerns regarding

breaches of confidentiality about test results by health care providers were a common source of hesitancy to get tested, particularly among men. Other themes regarding the impact of stigma on testing included perceived risks for social ostracism, loss of primary romantic relationships, and employment discrimination [22, 25]. As such, a number of studies indicated greater acceptability of hometesting or self-testing than facility-based testing, especially among men [22, 25–27].

Tanzania

Next to South Africa, the greatest amount of HIV stigma— HIV testing research was reported from Tanzania, with 13 studies published since 2014. Results consistently suggest that HIV testing uptake has increased in Tanzania among both men and women. Nevertheless, stigma remains a key barrier to achieving optimal testing rates. Among women, stigma is experienced across multiple contexts, including community members, family, and healthcare professionals [28–30]. Studies find that integrating HIV testing services with antenatal care may shield potential stigma by disguising the type of services being sought. However, women receiving antenatal services still reported fear of testing positive as a barrier [28, 30]. Among men, research in Tanzania has focused primarily on stigma in social networks as potential barriers to HIV testing. One study found that making HIV testing appear more normative may reduce stigma and increase men's HIV testing [31]. Another study found that peer support that encouraged testing reduced anticipated stigma among male peers and community members and resulted in higher testing uptake [32].

Nigeria

Published research regarding stigma and HIV testing remains scant in Nigeria, as our search found only four studies, all of which implicated stigma as a barrier to HIV testing [33–36]. Two quantitative studies with men who have sex with men (MSM) found that sexual orientation stigma served as a barrier to HIV testing and healthcare utilization [33, 34]. One cohort of men found that stigma derived from the passage of laws prohibiting same-sex marriage and fear of judgements for engaging in same-sex relations were linked to poor engagement in HIV testing among Nigerian MSM [33]. Another study of men involved in exchange sex found that fear, public harassment, and the experience of sexual violence were associated with low testing uptake [34]. A qualitative study among pregnant women and their male partners indicated that fear and shame of being diagnosed with HIV and its subsequent impact on family functioning



inhibited HIV testing [35]. Furthermore, testing hesitation resulted from anticipating HIV stigma from family and the community, triggering concerns about losing social support and being abandoned [34].

Mozambique

Only four studies examined barriers to HIV testing in Mozambique, and all found an association between low-testing rates and stigma [36–39]. Two studies were conducted exclusively in Mozambique, and the other two examined testing throughout several African countries, including Mozambique. A multi-country study by Fleming et al. was specifically conducted to provide insight into the barriers to reaching 90-90-90 goals [36-38]. Fleming et al. found that approximately 35% of men aged 15-49 endorsed stigmatizing views of people with HIV, and these men were significantly more likely to report never testing for HIV. The other three studies found stigma to be the among the most pervasive barriers to testing [36–39]. However, in Mozambique stigma was a robust barrier to HIV testing for women but not men, suggesting that other factors may impede testing for men over and above stigma, such as access to health services and masculinity [36, 38].

Kenya

Eight studies conducted research on the impact of stigma as an impediment to HIV testing in Kenya [39–44]. Results showed that women tested more frequently than men, despite holding more stigmatizing attitudes towards people living with HIV [40]. In a multi-country study discussed above, Fleming et al. found that Kenyan men who endorsed more stigmatizing attitudes towards people living with HIV were less likely to have tested for HIV [39]. In addition, Nyblade et al. [41] reported that female sex workers who anticipated stigma from their healthcare provider were more likely to avoid HIV testing. Similar concerns were expressed among university students, adolescents, and young adults [44–46]. Romo et al. found a similar effect among long distance truck drivers, where anticipated stigma was associated with lowrates of HIV testing [42].

Uganda

In Uganda, only four studies evaluated stigma as an impediment to HIV testing [36, 40, 47, 48]. The limited amount of research on stigma and testing in Uganda was surprising given the decades of focused attention this country has received in research. All of the studies we found confirmed

stigma as a barrier to HIV testing. Like other countries in the region, the relationship was stronger among women than men, suggesting that men may encounter additional barriers contributing to their low HIV testing rates. In rural communities, both men and women greatly underestimated the number of persons tested, and that those who perceived testing as less normative were less likely to have been tested [47].

Zimbabwe

Four studies examined the associations between HIV-related stigma and HIV testing in Zimbabwe [39, 49-51]. Each study found that HIV stigma was associated with lower likelihood of HIV testing. Studies in both men and recent mothers found that those who held prejudicial views of people with HIV were less likely to have ever been tested for HIV [39, 49]. A longitudinal qualitative study interviewed participants embedded within the multi-national Project Accept community-level randomized trial intended to reduce HIV-related stigma, increase HIV testing, and reduce HIV infections [50, 51]. While participants identified stigma as a cause of low HIV testing for women in antenatal care, results also suggested decreases overtime in stigmatizing attitudes. In particular, decreases were observed in blaming people with HIV as well as fearing casual contact with those who have HIV infection.

Zambia

Three qualitative and one quantitative study assessed the impact of stigma on HIV testing in Zambia [39, 52–54]. A large survey using population-based data found a negative relationship between endorsing HIV-related prejudice and HIV testing in men [39]. A qualitative study identified anticipated stigma from healthcare workers and peers as a barrier to testing in female sex workers [52]. One study of midwives examined their perspectives of why male partners of pregnant women do not participate in the prevention of mother-to-child transmission of HIV or HIV testing [53]. Midwives cited stigma from healthcare services, society, and other individuals as barriers to men's testing. However, another study found that men themselves denied that anticipated stigma was a barrier to testing in Lusaka, but instead reported that self-stigma did impede testing [54]. Similarly, healthcare workers and lay counsellors reported that shame and self-stigma were experienced by people with HIV. These data suggest that stigma remains a primary barrier to testing in Zambia, although it remains unclear which types of stigma inhibit testing.



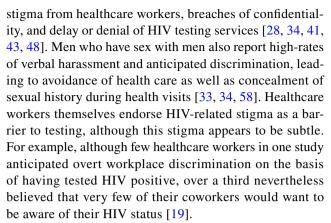
Malawi

Results from three studies in Malawi suggest that structural support may play an important role in the relationship between stigma and HIV testing [39, 49, 55]. For instance, one study found that prejudicial attitudes towards people living with HIV predicted lower odds of lifetime HIV testing in young mothers. However, this association was no longer significant after controlling for whether mothers were offered antenatal HIV testing [49]. In another study utilizing a national dataset, HIV prejudice was associated with higher odds of never having been tested for HIV among men. Although structural factors were not considered in further models, the association between stigma and testing remained significant when other factors were considered, including HIV-related knowledge and acceptance of gender-based violence [39, 55]. Findings in Malawi suggest that it is the experience of going to testing sites that deters testing among men, who prefer home testing [55].

Conclusions

Our admittedly cursory review found 62 studies examining the relationship between HIV stigma and HIV testing in nine African countries representing among the highest HIV prevalence in the world. A majority of the research was conducted in two countries, South Africa and Tanzania. This startling dearth of research is perhaps the major finding from our review. We did not observe any change in the number of annually published studies over the years representing the first phase of the 90-90-90 initiative. The studies varied in methodological quality and used a wide range of self-report instruments to measure HIV-related stigma. Quantitative studies ranged from large multinational surveys including tens of thousands of participants, to smaller survey studies and studies using single-item or idiosyncratic stigma measures [19, 26, 39]. The qualitative research also varied, with studies examining stigma across heterogeneous populations, using a variety of methods that included focus groups, participant observation, and in-depth individual interviews [25, 42, 56]. Only two studies reported data from research designed to evaluate interventions to reduce the impact of stigma as a barrier to HIV testing [51, 57].

Stigma manifests differently across populations, with differing forms of stigma conferring uneven HIV testing uptake. Sex workers, both female and male, experience exceptionally high-rates of overt discrimination, with sex workers in several countries reporting experiences of



The limited amount of research we reviewed did elucidate avenues to address HIV stigma among men and women. First, men were more likely to endorse prejudicial attitudes towards people living with HIV than women across countries, and prejudicial attitudes were shown to be associated with a lower likelihood of engaging in HIV testing in both men and women [39, 40]. HIV testing norms also appeared to be an especially influential correlate of men's testing behavior, with low perceived social support for testing posing a major obstacle [31, 32]. Qualitative research suggests that for men, the prospect of receiving an HIV diagnosis is associated with fears of discrimination and loss of material resources through lost employment, rejection from family and community, and threats to masculinity [24, 59]. Women also anticipated stigma reactions from their partners in response to an HIV diagnosis; with some women reluctant to test or ask partners to test due to concerns that their partners may force them to leave their home based on the test results [37].

The studies we examined show a need for a research agenda on adverse social conditions driven by stigma that impede HIV testing. This research agenda should go beyond descriptive studies, which represent the majority of those conducted thus far in the 90-90-90 era. One conclusion that is so obvious it can go without saying is that there is far more data on HIV stigma than there is HIV stigma theory. And while theory alone will carry little public heath meaning, a stronger conceptual grounding will go a long way toward promoting higher quality research to inform interventions. Longitudinal studies are needed to identify mechanisms and points of intervention. Studies that examine stigma in social relationships using dyadic, community, and multi-level models are needed. Methods are needed to harmonize data from multiple stigma measures. A stigma research agenda should also advance our measurement and knowledgebase of intersectional stigma, specifically the unique experience of stigma faced by individuals with multiple stigmatized characteristics. Research on stigma and testing should also be extended to stigma as an impediment to HIV prevention, including



pre-exposure prophylaxis (PrEP). This Editorial should not be mistaken as a comprehensive review. Indeed, systematic reviews and meta-analyses will be critical to advancing a research agenda on HIV stigma and testing. Publishing quality original research on HIV stigma and testing will remain a high priority at *AIDS and Behavior*.

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