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Getting to the heart of stigma across the HIV continuum of care

Guest Editors: Lucy Stackpool-Moore, Carmen H. Logie, Allanise Cloete
Supplement Editor: Karoline Soerensen

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EDITORIAL

What will it take to get to the heart of stigma in the context of HIV?

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More than 40 years into the global HIV pandemic, we are still grappling with HIV-related stigma and its intersections with other marginalized identities, health conditions and social practices. HIV-related stigma, conceptualized as the devaluing, mistreatment and constrained access to power and opportunities experienced by people living with and associated with HIV, remains a critical concern inhibiting the HIV response [1]. Indeed, the UNAIDS Global AIDS Strategy explicitly describes the goal that "people living with HIV, key populations and people at risk of HIV enjoy human rights, equality and dignity, free of stigma and discrimination" to realize optimal HIV outcomes [2]. The inclusion of commitments towards eliminating HIV-related stigma and discrimination within the Political Declaration agreed at the 2021 United Nations High-Level Meeting on HIV/AIDS for the first time also signals a conducive global political environment for action at scale [3]. The time is now to renew and innovate responses to HIV-related stigma, including taking the steps needed to ensure an enabling global policy environment.

Reducing stigma and alleviating its harmful effects is an essential ingredient of any effective national HIV response. Approaches can be informed by a focus on human rights, agency and intersectionality, which may be understood as a "discourse about identity that acknowledges how identities are constructed through the intersection of multiple dimensions" [4] and captures the complexities of social identities and social power. Contextual differences can be significant, and as evident from the work of the Global Partnership for Action to Eliminate all forms of HIV-Related Stigma and Discrimination, it can be useful to focus on understanding how and where stigma manifests itself in specific settings for diverse communities in different geographies [5]. To succeed in reducing or alleviating its harmful effects, efforts must remain situated firmly within increased human rights realization for people living with and most affected by HIV. Research that focuses on stigma processes and their harmful impacts can also attend to the ways in which people exert individual and collective agency to resist and dismantle stigma, and form solidarity. A dual focus on stigma's harms *and* the ways in which people and communities navigate stigma can avoid perpetrating binary or simplistic notions of powerlessness, vulnerability and passivity, and instead calls attention to the nuances and fluidity of power dynamics [6]. A focus on "whole" selves can be informed by intersectionality theory to take into account interlocking systems of oppression—including stigma and discrimination [7, 8]. More could be learned from other sectors regarding how to understand and address HIV-related stigma, including social ecologies of resilience [9, 10], activism [11] and civic engagement [12], community mobilization [13], collective impact [14], peer support and solidarity among persons living with HIV [15], and collective and self-efficacy [16].

This Supplement on Getting to the heart of stigma across the HIV continuum of care aims to draw attention to HIV-related and intersecting stigma and discrimination across the HIV prevention and care continuum. The articles contribute to consolidating the evidence base and provide a state-of-the field update about the latest concepts, innovative research methods and strategies to reduce stigma and/or ameliorate its harmful effects. Articles cover a variety of lived experiences of stigma; and at times, include examples of resilience, good practice and community leadership. Language is important, and the authors whose work is published in this Supplement have been encouraged to follow the latest terminology guidance from UNAIDS and to adopt person-centred language, such as avoiding acronyms and using language that puts the person first (see, e.g., the People First Charter). The language used in research may in fact result in practice changes to engage person-centred language in social and healthcare encounters [17]. Several papers in the Supplement include important methodological insights about the co-creation of research and co-production of knowledge, including with marginalized groups (see Brown et al. [18], Gamarel et al. [19], Tun et al. [20] and Collier et al. [21]). A partnership model between researchers and marginalized groups in the co-creation of knowledge is increasingly influencing stigma research and is reflected in some of the studies in this Supplement. Such approaches foster knowledge production for greater impact and social change that are led by community researchers and/or more grounded in lived experiences. It is our hope that this Supplement informs efforts to address stigma and discrimination and ultimately improving quality of life and access to healthcare for people living with and most affected by HIV.

Studies in this issue examine the impact of HIV-related stigma on the HIV prevention cascade. For instance, Hargreaves et al. [22] explore the association between stigma and HIV incidence through a nestled study within the PopART trials in Zambia and South Africa. They found no evidence of an association between HIV stigma and HIV incidence in the trials, suggesting that efforts to reduce new HIV infections and improve HIV prevention and treatment programmes may fail if HIV stigma is considered in isolation and are not complemented by a more holistic approach. In another paper, Atkins et al. [23] evaluated the factor structure of a pre-exposure prophylaxis (PrEP)-related stigma scale as part of a larger prospective cohort study nested within Kenya's Jilinde programme. They identified four dimensions of PrEP-related stigma; and the scale demonstrated strong internal consistency, was positively correlated with depressive symptoms and negatively correlated with uptake of HIV services. Prevention cascade stigma research and practice should consider PrEP stigma alongside other prevention barriers.

Other papers focus on HIV-related stigma impacts among people living with HIV. Johnson-Peretz et al. [24] focus on schools in rural Africa as potential sites of stigma for young people. Authors apply a life-course framework to explore a time of critical life stage transition, finding the young people in the study were already engaged in finding ways to manage their own healthcare, while refusing to internalize stigma, and were becoming invested with greater responsibility for their own, and their families' health. Collier et al. [21] explore multi-dimensional experiences of stigma among people living with HIV and Kaposi's sarcoma in Kenya. The intersection of HIV-related, cancer-related and skin disease-related stigma was better understood using mixed-methods approaches with people living with both HIV and cancer. Other studies explore stigma within broader structural determinants of health, such as poverty. For instance, Logie et al. [25] examined both food and housing insecurity as drivers of HIV-related stigma, and present findings from a longitudinal engagement with a cohort of women living with HIV in Canada, finding resource scarcities linked with increased experiences of HIV-related stigma.

Several papers in this Supplement focus on opportunities to address or reduce stigma among or for diverse groups of people. The paper by Pollack et al. [26] looks at work to reduce HIV-related stigma and discrimination in healthcare settings in Vietnam, and their findings demonstrate the effectiveness of a multi-pronged facility-level intervention. Nyblade et al. [27] suggest that in order to get to the "heart of stigma," efforts must understand and respond to both HIV and other intersecting stigma targeting sexual and gender diversity, and take a non-siloed approach to training healthcare providers. Connecting within a focus on intersectionality, structural processes of stigma and practical opportunities to address biases within the healthcare system, their paper discusses findings and curriculum adaptation for a total health facility approach for stigma reduction. From a community perspective, Tun et al. [20] focus on transgender men and women in Nigeria and discuss how provider awareness of, and respect for individual gender identity is critical for optimal delivery of HIV and other health services for Nigerian transgender men and women.

Peer-support and community leadership in challenging and researching stigma is essential to contributing to the robust evidence base of what works to respond to stigma. Makoni et al. [28] provide examples of the importance of community-led monitoring in promoting accountability and better policy responses that meet the needs of the spectrum of diverse people living with and affected by HIV in Zimbabwe. Gamarel et al.'s [19] commentary proposes a status-neutral approach for research with trans communities in the United States. The authors argue that although interventions focused on PrEP or antiretroviral therapy uptake and adherence have and will continue to benefit communities, these HIV "status-segregated" interventions can perpetuate HIV stigma and other forms of oppression among those in most need of HIV programmes. They argue that segregating people into HIV prevention and HIV treatment research disrupts the organic and close kinship structures, and conclude by calling on funders to develop mechanisms that support the development and testing of HIV status-neutral interventions. Brown et al.'s [18] community-led innovation with systems thinking considers how to get to the heart of addressing stigma at scale. The authors present findings from a study adopting a systems perspective to understand how to tackle structural stigma via the Meaningful Involvement of People with HIV, while highlighting the challenges in demonstrating peer leadership from people living with HIV.

The Supplement also includes papers that review conceptual frameworks and measures used to evaluate stigma, including recommendations for different scales and approaches to robustly measure stigma and track change over time. Ferguson et al. [29] present findings from a global systematic review that highlight the gaps and diversity within existing measures and conceptual frameworks to address stigma. Finally, Golub and Fiskin's [30] commentary suggests that HIV researchers and practitioners have failed to fully specify or examine the mechanisms through which HIV service implementation itself may reinforce stigma and inequity.

Taken together, the articles in this Supplement offer insight into a range of health conditions, social identities, social determinants of health and life stages that shape lived experiences of stigma. It also provides insight into wide-ranging methodologies, including qualitative, quantitative, systems mapping and systematic reviews, that were employed to generate new insights into the complexity of stigma. Getting to the heart of stigma requires engagement across methods, conceptual frameworks and impacted communities to understand what factors are most important to translate research to action to advance human rights and equity.

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COMPETING INTERESTS

The authors declare no competing interests.

AUTHORS' CONTRIBUTIONS

The Editorial was conceptualized by LSM, CL and AC. LSM and CL wrote the first draft of the Editorial. AC and FR reviewed and contributed additional material. All authors reviewed and revised the Editorial before final submission.

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RESEARCH ARTICLE

Tackling structural stigma: a systems perspective

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[#]These authors have contributed equally to the work.
In support of visible GIPA/MIPA principles, co-authors and study investigators GB, BA, CH and JR are openly living with HIV. GB was lead researcher and workshop facilitator, and BA, CH and JR were peer participants in the workshops.

Abstract

Introduction: Structural stigma in the global HIV response is a "moving target" that constantly evolves as the epidemic changes. Tackling structural stigma requires an understanding of the drivers and facilitators of stigma in complex community, policy and health systems. In this paper, we present findings from a study adopting a systems perspective to understand how to tackle structural stigma via the Meaningful Involvement of People with HIV/AIDS (MIPA), while highlighting the challenges in demonstrating peer leadership from people living with HIV (PLHIV).
Methods: Through a long-term ongoing community-research collaboration (2015–2023), the study applied systems thinking methods to draw together the insights of over 90 peer staff from 10 Australian community and peer organizations. We used hypothetical narratives, affinity methods and causal loop diagrams to co-create system maps that visualize the factors that influence the extent to which peer leadership is expected, respected, sought-out and funded in the Australian context. We then developed draft indicators of what we should see happening when PLHIV peer leadership and MIPA is enabled to challenge structural stigma.
Results: Participants in the collaboration identified the interactions at a system level, which can enable or constrain the quality and influence of PLHIV peer leadership. Participants identified that effective peer leadership is itself affected by structural stigma, and peer leaders and the programmes that support and enable peer leadership must navigate a complex network of causal pathways and strategic pitfalls. Participants identified that indicators for effective PLHIV peer leadership in terms of engagement, alignment, adaptation and influence also required indicators for policy and service organizations to recognize their own system role to value and enable PLHIV peer leadership. Failing to strengthen and incorporate PLHIV leadership within broader systems of policy making and health service provision was identified as an example of structural stigma.
Conclusions: Incorporating PLHIV leadership creates a virtuous cycle, because, as PLHIV voices are heard and trusted, the case for their inclusion only gets stronger. This paper argues that a systems perspective can help to guide the most productive leverage points for intervention to tackle structural stigma and promote effective PLHIV leadership.

Keywords: community; peer; PLHIV; stigma; structural; systems

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1 | INTRODUCTION

Despite advancements in HIV care and prevention, HIV stigma and discrimination continue to undermine quality of life for people living with HIV (PLHIV) [1]. In order for multilevel interventions to meaningfully reduce stigma [2, 3], we need to understand stigma at a system level. This was reinforced in a recent consensus statement calling for "health systems and the people who work within them [to] recognize and work to eliminate the multiple forms of structural discrimination that undermine the health of PLHIV" [4].

The Greater and Meaningful Involvement of the People with HIV/AIDS (GIPA/MIPA) [5, 6] has long been recognized as central to an effective response to HIV [7, 8], including in strategies and policies to tackle systemic HIV stigma [9, 10]. GIPA/MIPA is often applied through the involvement of networks of PLHIV, community-based organizations, key population networks and civil society [8]. In turn, opportunities for peer leadership are often enabled by mobilizing and strengthening communities most affected by HIV. This includes peer- and community-led (PCL) responses by gay and bisexual men, people who use drugs, sex workers and PLHIV, navigating highly stigmatized and political contexts around sex, sexuality and drug use. These peer-led responses operate through organizations established and governed by their communities. PLHIV have played a critical role in PCL programmes, including peer support, health promotion, community mobilization, leadership and policy advocacy [11, 12]. Strengthening community systems and PLHIV peer leadership is increasingly recognized in policy and strategy documents as critical to impactful responses to HIV stigma [8, 13–16].

This paper presents findings from the W3 (Understanding What Works and Why in Peer Based Programmes in HIV and Hepatitis C) project, in which we used complex systems theory and methods to investigate the factors that influence the extent to which peer leadership is expected, respected, sought-out and funded in Australia.

The aim of this paper is to better understand how to tackle structural stigma via the Meaningful Involvement of People with HIV/AIDS (MIPA), while highlighting the challenges that must be navigated to demonstrate effective peer leadership in the process.

The W3 project is an ongoing long-term collaboration (stage 1: July 2015–June 2017; stage 2: July 2017–December 2019; and stage 3: January 2020–June 2023). The project sought to deepen understanding of the socio-ecological system(s) in which PCL programmes operate in Australia. This report discusses the first two stages of this project, while the final stage is currently underway.

2 | METHODS

The project uses a qualitative research method adapted from systems thinking [17]. The method and its adaptation are described in Reeders and Brown [18]. Systems thinking views the world as composed of dynamic, interactive networks and systems. It aims to recognize patterns in their overall function, rather than attributing causal effects to their individual components. In this research, we are identifying patterns of interaction that recur often enough, and exert enough influence, to make them worth mapping.

The W3 Project responded to the need voiced by Australian PCL organizations to improve scholarly and policymaker understandings of what works and why in peer-based HIV and hepatitis C prevention and health promotion. In response to recommendations from a subsequent scoping study, conducted in consultation with the community sector [19], a collaboration was formed to improve the evidence base regarding the role that PCL programmes play in the overall HIV and hepatitis C prevention system.

The W3 collaboration (Table 1) formalized existing relationships among HIV and hepatitis C community organizations in Australia. All relevant community organizations were invited to participate at each stage of the study and took part according to their capacity to commit staff time. While organizations self-selected to be part of the project, the study includes organizations of diverse size, location and jurisdictional scope (state/territory and national).

Peer leaders who volunteered to participate from the participating organizations (Table 1) were members of communities of PLHIV, gay and bisexual men, people who use drugs and sex workers. Most peer leaders had multiple intersections across these and other communities impacted by HIV. Most were paid peer staff who had worked in peer organizations for over 3 years, some over 10 years, in a variety of service delivery, outreach and advocacy roles. Organizations in the W3 collaboration and individual participants from each organization provided signed informed consent to participate in workshops at each stage.

Table 1. The W3 collaboration

W3 Project: Understanding what works and why in peer-based and peer-led programmes in HIV and hepatitis C
Australian Federation of AIDS Organisations (the national body for the community-based response to HIV, whose members include peer- and community-led organizations)
Australian Injecting and Illicit Drug Users League (the national body for peer-based drug user organizations)
Harm Reduction Victoria (peer-based drug user organization)
Living Positive Victoria (PLHIV peer-based organization)
National Association of People Living with HIV/AIDS (national peer PLHIV organization)
Positive Life New South Wales (PLHIV peer-based organization)
Queensland Positive People (PLHIV peer-based organization)
NSW Users and AIDS Association (peer-based drug user organization)
Scarlet Alliance – Australian Sex Workers Association (national peer-based sex worker organization)
Victorian AIDS Council (community- and peer-based organization with services for and by gay and bisexual men and PLHIV)
Western Australian Substance Users Association (peer-based drug user organization)
In Australia, “community-based” and “peer-based” are the dominant organizational descriptors. These organizations were established by the communities most affected by HIV from the mid-1980s, and their governance is based within their communities. For a summary of the history of the community response in Australia, see [20]

Abbreviations: NSW, New South Wales; PLHIV, people living with HIV.

Consistent with the system mapping methodology [17, 18] as a form of research co-production, the project followed a dynamic and iterative process in constant conversation between peer practitioners and the research team to develop “system maps.” The system maps and their accompanying text descriptions are the qualitative data analysed in this paper.

The identity of the organizations was not confidential (Table 1). At the request of the peer organizations, workshops in stage 1 and stage 2 were not recorded and transcribed to ensure confidentiality of the participating individuals’ views and experiences, and confidentiality of the discussion of the detailed specific examples of how organizations navigated stigmatized, criminalized and political environments. The project was provided ethics approval by the La Trobe University Human Research Ethics Committee (Approval No: FHEC14/155).

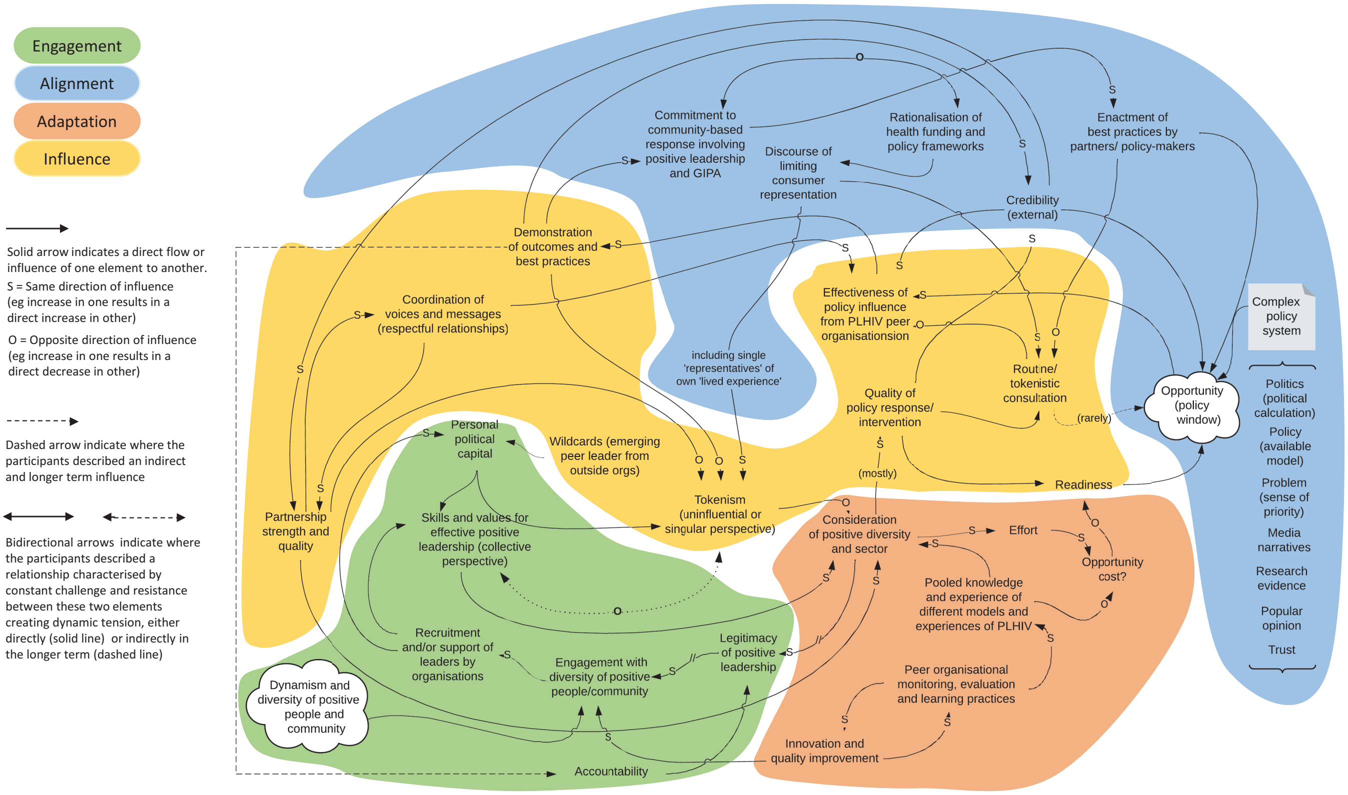

Figure 1. PLHIV peer leadership system map. Abbreviation: GIPA, Greater Involvement of People Living with HIV/AIDS.

2.1 | Stage 1—Systems mapping

Stage 1 (July 2015–June 2017) involved three case studies at different levels of the "prevention system," including a needle and syringe exchange programme working in frontline service delivery; a social network-based health promotion initiative targeting sexually adventurous men; and an HIV-positive peer advocacy strengthening initiative. The three case studies were chosen through consultation within W3 collaboration to ensure a diversity of peer contexts and locations within the relevant HIV and hepatitis C prevention systems, as well as geographic diversity in Australia.

We conducted 18 workshops, ranging from 1 to 2 days each, with 10 PCL organizations across Australia (Table 1). Each workshop featured between 1 and 4 organizations. We drew on the experience and perspectives of more than 90 peer practitioners working in outreach, community development, workshop facilitation, policy reform and leadership, management and governance. All 10 partner organizations involved PLHIV within peer-led programmes. However, four organizations were specifically PLHIV peer-led organizations with strong PLHIV leadership roles. These included three state-based organizations and one national peak organization, which represents state-based organizations in national advocacy.

Workshops used hypothetical narratives, affinity methods and digital drawing tools to develop causal loop diagrams, which visualize the feedback loops that emerge between variables and processes in an ongoing system [17]. This method helped us to identify and understand the complex relationships between all the moving parts of a community and policy system, drawing on complexity science to conceptualize how interactions among actors can generate emergent structures (such as networks, cultures and communities) and effects (including overall prevention efficacy) [21–23].

To validate the maps, the workshops explored system dynamics by participants selecting an issue from their practice and a starting place on the map, and then following the pathways laid out by arrows and items, identifying and discussing the implications for that issue. The workshops tested hypotheticals, asking "if this element suddenly stopped working, what might happen elsewhere in the system?" Participants drew on their peer work experience and the maps were refined where required to reflect the participant's experience [18]. These implications identified through the system mapping formed part of the system descriptions.

Drawing on the realist evaluation work of Pawson and Tilley [24], we analysed the full set of complex system maps (for an example, see Figure 1) to identify the key underlying functions that occurred across all the system maps and which enable peer-led responses to be effective and sustainable in continually changing community and policy environments (W3 framework, Figure 2). The methodology of stage 1 has been described in detail elsewhere [18, 25, 26].

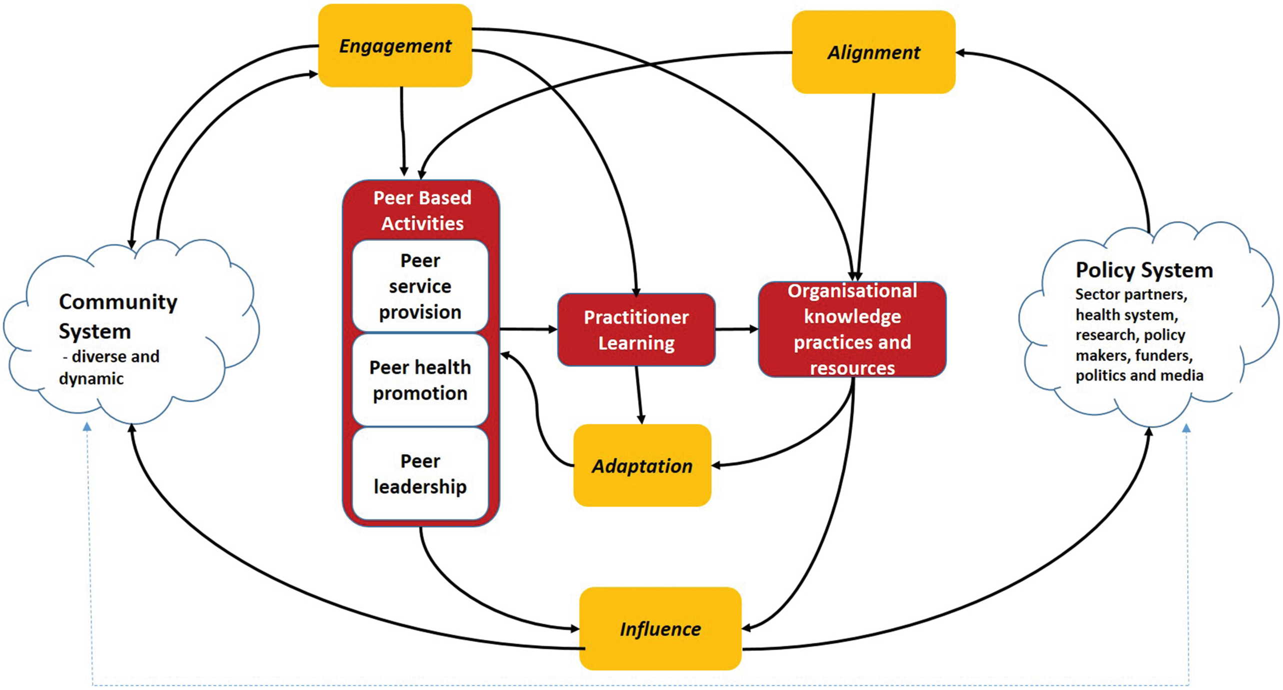

Figure 2. W3 framework.

Element	Definition
Community system	The community system includes the networks and cultures the programme engages with, and the processes of interaction and change that are taking place within them.
Policy system	The policy system includes sector partners and stakeholders, funders, policy-makers, health system, surveillance and research, politicians, news media, and other organisations which interact with the peer programme and its communities.
Engagement, Alignment, Adaptation and Influence	Functions that are required within the system for peer-led programmes to be effective and sustainable in a constantly changing environment.
Peer based activities	Different kinds of peer based approaches that depend on practitioners having and using peer skill-the ability to combine personal experience and real-time collective understanding to work effectively within a diverse community.
Practitioner learning	Staff and volunteers in peer based programmes pick up insights from clients and their own networks, and in their practice over time they develop, test and refine mental models of their environment.
Organisational knowledge practices	Organisational management values and learns from the analysis of insights from peer practitioners, supporting the adaptation process and sharing with stakeholders in the community and policy system.
Arrows	Flows of knowledge or causal influence that constitute the programme as a system.

2.2 | Stage 2—Development of monitoring, evaluation and learning framework (July 2017–December 2019)

In stage 2 (July 2017–December 2019), the project conducted further workshops with W3 collaboration members (more than 35 participants), drawing on the W3 framework to develop tailored indicators for the role, quality and influence of, among other things, peer leadership in their local policy-making and health service provision system [27, 28]. These indicators were then trialled and refined in practice within two peer organizations (one PLHIV peer organization and one people who use drugs peer organization). The approach and outcomes of this stage have been described elsewhere

[29–32]. Further details are available from www.w3project.org.au.

3 | RESULTS

Participants in all the system workshops identified that peer-led responses operate within and mediate between complex and constantly changing community and policy system elements. In this paper, we focus on the results of the PLHIV peer leadership case study, which most clearly illustrates the factors that can either diminish or reinforce the valuation of peer leadership in policy-making and service provision. This section focuses on the feedback loops that relate most directly to structural HIV stigma, and identifies their long-term implications based on workshop discussions held during the co-production process.

3.1 | Orientation to the PLHIV peer leadership map

The PLHIV peer leadership system map in Figure 1 illustrates the relationships and processes that constitute the Australian HIV policy-making and health service provision system from the perspective of a national policy advocacy initiative known as "Poz Action." Participants described how a range of front-line programmes, including peer education, support, outreach, mobilization and advocacy, are interconnected and nested within this broader system. The map developed by the participants visualizes a matured, organized and community-based response to HIV that navigates many pitfalls that can lead to undervaluing peer leadership.

In order to simplify and operationalize the three complex system maps, we developed the W3 framework (Figure 2) as a mid-level theory that presents PCL programmes as *contextual interventions* that operate within and between two interrelated and continually changing complex systems: affected communities (left cloud) and policy system (right cloud). The framework highlights four key functions—engagement, alignment, adaptation and influence—that must be happening for PCL programmes to maintain relevance and influence as these systems change and evolve around them. These four key functions have been used to shade relevant areas of the PLHIV leadership map in Figure 1:

- engagement (green) concerns the embedding of the peer-led programme within affected communities;
- alignment (blue) reflects its relationship with the HIV sector and its policy context;
- adaptation (orange) refers to processes for adapting programmes according to what they learn from engagement and alignment;
- influence (yellow) reflects the outcomes of programme activities in the community and policy systems.

In what follows, we use these functions to describe selected system dynamics identified by participants through the workshops—key feedback loops and longer causal pathways—and the identified implications for the valuation of peer leadership in the policy system. In the discussion below, italicized text refers to textual items on the system map (Figure 1).

3.2 | Function 1: Engagement within the PLHIV community system

Systems thinking reminds us that not only is the environment constantly changing, but changes are often emergent and, therefore, hard-to-predict. Workshop participants identified that PLHIV peer organizations are uniquely positioned to notice cues and patterns in their community and, if they capture and use this knowledge effectively, they can demonstrate peer leadership in policy systems that may struggle to accurately predict the impact of policies on PLHIV. Conversely, failing to use this knowledge can lead to de-valuation of peer leadership.

Participants described that effective PLHIV peer leaders draw on their own experiences and social networks. But they also utilize insights from PLHIV peer programmes that engage with a broader range of PLHIV identities, needs and experiences. Our participants reported that this enables peer leaders to develop and constantly refine a *collective perspective* on the issues affecting different people and groups in the PLHIV community. This collective perspective distinguished charismatic individual advocacy from effective peer leadership in policy reform spaces.

Secondly, high-quality engagement with the diversity of the PLHIV community meant having a mix of formal and informal processes to *recruit and/or support PLHIV peer leaders*. Formal process may include taking part in reference groups or policy committees, or being elected to organizational board or subcommittees. This formal process supports the PLHIV leader to develop *personal political capital* as well as *skill and values for effective positive (PLHIV) leadership*. Informal processes were equally important and included identifying latent potential for leadership among clients and contacts, and then mentoring them or connecting them with opportunities for advocacy. This may be through identifying people with experience of an emerging issue, or who bring a new or underrepresented perspective, or who have charisma or *personal political capital* capable of capturing the attention of community or policy systems.

Effective PLHIV leaders were contrasted by our participants with "*wildcards*" who have significant *personal political capital* based on a strong narrative and personal charisma, but whose advocacy is not supported by a collective perspective and insight into the broader PLHIV community. If PLHIV leadership was characterized with this type of advocacy, participants noted the risk of tokenistic inclusion leading to reduced trust in PLHIV voices in the future. Particular kinds of peer leadership can either challenge or reinforce ongoing structural stigma in policy-making networks and systems.

3.3 | Function 2: Alignment between health system and peer-led responses

The alignment function allows peer-led responses to pick up insights into changes in the policy system (such as health services, legal and regulatory, epidemiology and social research), as well as gauge their own influence within that system. However, as illustrated in the alignment domain in Figure 1, participants identified that the *rationalization of health funding and policy frameworks* can negatively influence a health system's *commitment to community-based response involving PLHIV leadership*. This tension can promote tokenistic inclusion of PLHIV, decreasing the opportunity, credibility and capacity for PLHIV peer organizations and leadership to influence policy at a time when the system most needs their community insights and engagement. This also affects the capacity for the peer leadership to gain early insights into emerging health system changes and to adapt programmes in response. When peer leadership is excluded from policy networks, the quality of alignment suffers, making it harder to engage in the kind of policy advocacy that demonstrates the value of PLHIV peer leadership—thus reinforcing structural stigma.

3.4 | Function 3: Adaptation to changing community, policy and health system contexts

As illustrated in the W3 framework (Figure 2), to drive adaptation in response to the changes occurring within communities, health systems and policy, participants identified that PLHIV peer leaders needed to draw insights from both their communities (engagement) and from their policy environment (alignment). These insights must be used to guide adaptation across the range of programme activities, including peer service delivery, health promotion and peer leadership.

Participants also identified that for insights to be translated into adaptations, the PCL programmes and their partners in the HIV response need to understand these insights and support continuous and rapid adaptation. This included ensuring the formal and informal leadership opportunities for PLHIV responded to the emerging barriers for PLHIV to participate, whether due to stigma, perceived lack of professional experience or minority status.

For example, as illustrated in the adaptation domain in Figure 1, interactions between innovation and quality improvement; organizational monitoring, evaluation and learning practices; and pooled knowledge and experience of different models and experiences of PLHIV were identified by participants to all contribute to the consideration of positive [PLHIV] diversity and sector perspectives in policy-making forums and spaces. These factors all affect the influence domain as well, represented on the map by the quality of the policy response/intervention as well as the peer organizations' readiness to respond to shifting opportunities for policy reform. This demonstrates how quality adaptation is essential for consistently producing policy interventions that demonstrate effective peer leadership and challenge structural stigma.

3.5 | Function 4: Influence on the health and policy system

Insights from PLHIV peer-led responses can be the broader HIV sector's only source of close-to-real-time knowledge about emerging issues and unintended consequences for PLHIV in rapidly changing and hard-to-predict socio-ecological environments. Examples included the emergence of stigma towards PLHIV unable to reach undetectable viral load, the emergence of "PrEP 4 PrEP" sexual sorting based on use of pre-exposure prophylaxis and how changing migration conditions impact upon willingness to access HIV care. Given this unique perspective, findings from formal and informal *community monitoring* [33] were identified as an influential strategic asset for the broader HIV response. This is a key pathway for demonstrating the value and effectiveness of peer leadership.

A second key pathway was identified as requiring careful navigation. Consistent with Kingdon [34], participants described that policy reform requires playing the "long game." This poses *credibility* of peer leadership as an ongoing concern. PLHIV leadership must be seen and endorsed as credible, not just within policy-making spaces, but also within the HIV sector and associated policy and health networks, in order to influence policy-making. Participants describe that often, policy and health system influence is *leveraged* by involving other policy actors, who can advocate for and amplify positions carefully developed through peer leadership. Similarly, demonstrating leadership in whole-of-sector policy responses improves alignment—the ability of peer leadership to tread the shifting sands of policy reform. This requires more than consultation: it depends on relationships and trust and a sectoral culture that values HIV-positive peer leadership in policy-making.

Experienced PLHIV leaders in our study reported their influence on different issues was not independent or "once-off," but rather depended on having ongoing and demonstrable engagement within the PLHIV community, as well as a track record of high quality, timely and relevant previous contributions to policy-making or health service reform. Participants identified that accountability, credibility and institutionalized stigma were constantly negotiated within both community and policy systems. As illustrated in Figure 1, this analysis suggested that the *quality of policy responses* and *effectiveness of policy influence* are only indirectly related. Policy influence is moderated by credibility and stigma, commitment to a community response, trust and past performance. Thus, the system map illustrates valuation as a key leverage point [35] for improving GIPA/MIPA and challenging the structural stigma that persists when PLHIV are excluded from policy-making or health system reform spaces.

Our participants identified a second crucial dynamic in the prevalence of *tokenistic inclusion*. Multiple causal loops in Figure 1 feed into and out of tokenism (centre of diagram), reflecting its central role in a system where PLHIV inclusion is mandatory but listening to PLHIV voices remains optional. Participants identified the quality and impact of PLHIV peer leadership's influence in the policy and health system was mediated by the tension between a sectoral *commitment to a community-based response and GIPA* and the health system-level pressures (such as *rationalization of health funding and policy* and *discourse of consumer representation*).

The latter can shift the system towards tokenism, the inclusion of PLHIV in policy processes without meaningful influence on policy outcomes. In this context, participants described that the appearance of PLHIV "involvement" is what matters, and a policy or health organization may not inquire too closely into whether the position being advanced is based on *peer skill*, *collective perspective* and the *consideration of positive [PLHIV] diversity and sector perspectives*. Structural stigma thrives when the messy reality of the PLHIV lived experience can be treated as unwelcome complications rather than essential considerations. Tokenistic inclusion can lead to relying on individual perspectives at the cost of collective perspectives or balancing community and sector interests. This impacts on the quality of advice and also the credibility of PLHIV participation. In Figure 1, we have used bidirectional arrows to illustrate these relationships described by participants as characterized by constant challenge and resistance between elements, creating a dynamic tension.

3.6 | Indicators of effective PLHIV peer leadership

In stage 2, we drew on the PLHIV peer leadership system map (Figure 1), the W3 framework (Figure 2) and the collaborative pilot work, to identify indicators for effective engagement, alignment, adaptation and influence. Table 2 presents the indicators for the quality and impact of PLHIV peer leadership in ways that can challenge structural stigma.

4 | DISCUSSION

Findings from the W3 project show the pathways—and pitfalls—that must be navigated in order to demonstrate and promote effective PLHIV leadership, and to challenge the structural stigma that devalues peer voices and perspectives in the Australian HIV prevention and health promotion system. In particular, it highlights the complex interplay of factors that can either diminish or reinforce the positive valuation of peer leadership in policy-making and health service provision. It demonstrates that PLHIV inclusion involves a network of actors, relationships and practices, not simply placing a person living with HIV on a committee.

Across all three Australian case studies in stage 1, the study mapped a process by which insights from the daily realities of sex and drug use are captured through peer service provision, shared within peer organizations and repackaged with relevant insights from research or policy other inputs into formats that were able to be understood and recognized in policy forums and research. This process has been described as "translation" [36]. This can contribute to more effective and responsive policy-making, in part because this process offers close to real-time knowledge of rapidly changing situations. However, it depends on valuing the HIV-positive voice in policy.

Structural stigma can occur when peer insights and the positive voice are not valued. Sub-optimal policy, made when peer leadership is not respected, has wide-ranging effects as it is put into practice across the system. But secondly, stigma directly affects the structure of that system itself, as it marginalizes or excludes particular actors from exerting influence. Recognizing these two senses in which stigma is structural helps identify possible solutions. It is not enough simply to include peer voices in decision making. Organizations that facilitate the inclusion of peer voices also need to ensure their involvement demonstrates visible peer leadership—and the benefits in terms of quality policy-making.

The systems perspective provides an insight into the system impact of a model of peer leadership that resists the domination of a single, convenient or tokenistic narrative, but that values and incorporates the diverse and evolving experience of PLHIV. It highlights that both policy-making and health service provision consist of systems—and so systems perspectives and methods are essential for understanding how effective peer leadership can be supported by and exert influence within them.

For example, interventions to improve PLHIV engagement across the HIV continuum of care increasingly recruit PLHIV as peer navigators [37–39]. Peer navigators use their lived experience to help other PLHIV navigate complex systems of care and support provision, and thus build up knowledge of those systems' workings and shortcomings. As health systems endeavour to reduce stigma and enhance the continuum of care, these peer navigators gain unique insights into the experiences of their diverse peers, building a collective understanding of the effectiveness of the changes in the health service system as they occur. For this knowledge to be shared and influential in health system reform, these insights and navigators' potential for policy leadership must be valued and resourced within the health and policy system.

The indicators in Table 2 describe what we should be seeing happening with effective engagement, alignment, adaptation and influence. They provide a starting point for understanding how GIPA/MIPA can reduce stigma and enhance the HIV continuum of care. The W3 framework and indicators help guide answers to the question: how do we *know* if we are demonstrating effective PLHIV leadership in ways that challenge structural stigma?

The findings illustrate that as PLHIV peer programmes and peer leadership, we should be capturing insights from engagement and alignment; we should be able to point to specific adaptations in our peer programmes and identify outcomes of our influence in the health system and policy-making processes. Over time, these insights can inform the confidence of a wide range of stakeholders that the functions are being fulfilled and that effective peer leadership has been demonstrated—confidence which can be monitored quantitatively (e.g. via surveys).

The same approach may be taken to monitor changes in structural stigma over time. Its processes operate and its effects are felt at every level of the socio-ecological system, from individual lives up to policy and legislation. This means stigma is not "one thing" to measure: it is a constantly moving target, motivated by diverse drivers and facilitators, and manifesting in diverse ways and locations. Instead, a range of indicators must be used, monitoring for impacts on different levels, and drawing insights from a diverse array of stakeholders [40]. Our approach here is consistent with the practices of community monitoring [33], which invite PLHIV and members of key populations to participate in combined internal-external evaluation of interventions, funding arrangements, policy-making and healthcare provision.

There are limitations in the applicability of our work to date. The system map and framework have been based on the expertise and experience of participants from 10 PLHIV inclusive peer-led organizations in Australia, and the examples on the expertise of four PLHIV peer-led organizations. The participants may have experiences of systemic stigma, healthcare, social and economic opportunities, organizational support

Table 2. Examples of W3 framework indicators for meaningful involvement of people living with HIV

	Quality actions/process indicators	Indicators of impact towards meaningful involvement
Engagement indicators	• Diverse PLHIV peer leaders are regularly identified, recruited and supported from across peer programmes • PLHIV leaders demonstrate the use of personal experience, cultural knowledge and evidence informed insights to communicate and work effectively with community (i.e. peer skill) • Structures, processes and opportunities are in place to support peer workers to learn from each other's insights and maintain a current overall understanding of their diverse communities	• PLHIV recognize the peer organization as an important part of, participant in and resource to their community • Increasing willingness of PLHIV community to engage in sector consultation and leadership opportunities
Alignment indicators	• The peer organization actively seeks out opportunities for policy contributions and advocates for creating safer and effective ways for community members to participate in the health and policy sector's response • PLHIV peer leaders communicate with policy and sector partners to improve each other's understanding of responses to emerging issues	• The PLHIV peer organization is informed about changes within the health system and policy environment and invited to assess how they might affect its communities and/or its work • Key players from the broader health sector and policy environment recognize the peer organization as credible, trustworthy and an essential partner in the overall public health response • Policy and sector allies publicly demonstrate they value the advice from PLHIV peer leadership and their commitment to a community-based response
Adaptation indicators	• The peer organization's practices are guided by peer knowledge and insights • The peer organization draws on engagement with PLHIV, evaluation of peer programmes and partnerships with the sector to develop evidence-based responses	• Peer leaders demonstrate the ability to apply a peer lens to update their collective perspective of the community and policy systems and pre-empt the implications of changes in the system • The peer organization draws on community and sector insights to improve policy advice
Influence indicators	Policy and health services • Peer leadership is enabled to draw on strength of engagement, alignment and peer skill to respond to opportunities for policy participation and influence • Peer leadership is enabled to be responsive to opportunities for policy participation and provide policy advice when needed • The peer organization maintains control over the use and interpretation of the information they share with external stakeholders Community • The organization supports peer leaders to build their confidence, skill and experience in community and personal advocacy • Expanding community influence is reflected in new and diverse PLHIV engaging in peer leadership opportunities	Policy and health services • Policy makers and health services seek out the advice of PLHIV peer leaders based on quality of past advice • The policy and health system demonstrates that it values the peer approach and has trust in the quality of the insights it generates • The peer organization can demonstrate buy-in from stakeholders to advance community needs and enhance the HIV continuum of care Community • Coordinated peer leadership results in a strong collective community voice that contributes to policy recognition of diverse needs and experiences within the community • PLHIV community looks towards PLHIV peer leadership to provide insights based in the reality of their shared lives

and access to policy makers that may not be generalizable to other countries.

The final stage of the project (January 2020–June 2023) is underway, and is consolidating evidence of the system-level influence of selected peer organizations within the Australia-wide HIV response.

5 | CONCLUSIONS

Structural stigma is pernicious and pervasive, even within the organized response to the HIV pandemic. This Australian system mapping study found that effective peer and PLHIV leadership can reduce structural stigma over time, drawing insights from lived experience and practice wisdom to understand and intervene in its processes and effects. However, effective peer leadership is itself affected by structural stigma, and peer leaders and the programmes that support and enable peer leadership must navigate a complex network of causal pathways and strategic pitfalls to demonstrate effectiveness and maintain positive valuation of their work. Participants identified that incorporating PLHIV leadership created a virtuous cycle, because, as positive voices are heard and trusted, the case for their inclusion only gets stronger. A systems perspective can help to guide the most productive points for intervention to tackle structural stigma and promote effective PLHIV leadership.

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AUTHORS' CONTRIBUTIONS

GB and DR: Conceptualization, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, visualization, writing—original draft, review and editing. AC, BA and CH: Conceptualization, formal analysis, visualization, validation, writing—review and editing. SC, DG and JR: Validation, writing—review and editing. GB, DR, AC, BA and CH were among the participants in the system mapping and indicator development workshops.

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DATA AVAILABILITY STATEMENT

The authors confirm that the data supporting the findings of this study are available within the article. Full description of the protocols and methods, and the detailed system maps and their accompanying full text descriptions (the qualitative data analysed in this paper) are available from www.w3project.org.au Further data requests concerning this study can be made by contacting the corresponding author graham.brown@unsw.edu.au.

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COMMENTARY

The ethical imperative to reduce HIV stigma through community-engaged, status-neutral interventions designed with and for transgender women of colour in the United States

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Abstract

Introduction: In the era of biomedical HIV prevention and treatment technologies, such as treatment as prevention (TasP) and pre-exposure prophylaxis (PrEP), there is momentum to develop and rigorously evaluate interventions focused on PrEP among those at risk for HIV acquisition and antiretroviral therapy (ART) adherence among people living with HIV. While HIV status-specific interventions focused on PrEP or ART provide valuable information, status-segregated interventions can create, perpetuate, and even increase HIV stigma among transgender women of colour and other marginalized communities in the United States (US).

Discussion: Due largely to community advocacy, discourses that support status-neutral approaches have emerged in the scientific literature. Although US-based funding mechanisms have typically designated awards focused on a specific HIV status, intervention developers and implementing agencies find creative ways to design and implement status-neutral programmes despite such restrictions. We present our experience with intervention research in New York, Detroit, New Orleans, Puerto Rico and the San Francisco Bay Area, all Ending the HIV Epidemic (EHE) priority jurisdictions. Kickin it with the Gurlz' was developed to be status-neutral through two grants due to community demands for a unifying approach. The Transgender Women Engagement and Entry to (TWEET) Care Project was designed to improve HIV care engagement for transgender women living with HIV, but developers realized the importance of including participants of any HIV status. Healthy Divas was designed for transgender women living with HIV but subsequent implementing agencies prioritized adapting it to be status-neutral. These examples support the urgency of designing, implementing and evaluating status-neutral interventions.

Conclusions: Community-based organizations strive for inclusivity in their programming and are rightly often reluctant to segregate services based on the HIV status of their clients. As researchers, we have an ethical imperative to work to reduce HIV stigma and respond to the needs of those most impacted by HIV, including transgender women of colour. As such, we call upon funders to develop mechanisms that support the development and testing of HIV status-neutral interventions to reduce HIV stigma and support community building, thereby increasing the possibility of fully realizing the benefits of biomedical HIV prevention and treatment technologies for all.

Keywords: transgender; HIV stigma; intervention; women; HIV prevention; HIV treatment

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1 | INTRODUCTION

There have been incredible strides to prevent human immunodeficiency virus (HIV) transmission and ensure that people living with HIV live longer and healthier lives [1, 2]. In the era of biomedical technologies, such as treatment as prevention (TasP) and pre-exposure prophylaxis (PrEP), there has been global momentum to develop and rigorously evaluate interventions focused on PrEP among those at risk for HIV acquisition and antiretroviral therapy (ART) adherence among people living with HIV. While interventions focused on PrEP or ART uptake and adherence have and will continue to benefit communities, these HIV status-specific or what we have termed "status-segregated" interventions can perpetuate HIV stigma and other forms of oppression among those in most need of HIV programmes [3], especially among transgender women of colour, by inadvertently disclosing HIV status to community members [4], allocating scarce resources to members of a community with a specific HIV status [5] and can increase HIV stigma and reduce social support by imposing artificial divisions in the community [6].

In the United States (US), transgender women of colour have expressed the urgency of grounding HIV prevention and care programming in their lived experiences, noting that oppression rooted in ethno-racism and cisgenderism and resultant social determinants of health (e.g. unmet gender affirmation needs, biased policing and hyper-surveillance that results in overrepresentation in the legal-criminal system, economic vulnerability and immigration experiences) take precedence over HIV [7–12]. For example, one young transgender woman of colour described the importance of addressing social determinants of HIV: "We need jobs, places to stay, doctors. HIV is just one of the many problems we deal with" [13]. Further, segregating people into HIV prevention and HIV treatment research disrupts the organic and close kinship structures among transgender women of colour that are needed to buffer experiences of oppression based on ethno-racism and cisgenderism [5]. Status-segregated intervention research can feel forced, divisive and culturally unresponsive to the needs and experiences of transgender women of colour [5, 11]. That is, dividing community by HIV status can perpetuate HIV stigma among close-knit marginalized communities when resources are already scarce [5].

Evidence also suggests that HIV status-neutral interventions are preferred in community-based settings [14, 15], as programme participants can address shared experiences of intersectional oppression, structural determinants of HIV and mental health challenges driving HIV risk and suboptimal HIV prevention and treatment uptake, and decrease HIV stigma. These interventions are urgently needed to optimize HIV prevention and care outcomes with transgender women of colour [16]. To meet this need, community-based organizations often adapt evidence-based interventions that were designed to be status-segregated to be status-neutral. While these status-neutral approaches are more responsive to their clients as well as their implementation context, these adaptations are being implemented without rigorous evaluation [17]. Building on Myers and colleagues' status-neutral framework, we present evidence from ongoing intervention research in New York, Detroit, New Orleans, Puerto Rico and the San Francisco Bay Area, all Ending the HIV Epidemic (EHE) priority jurisdictions, supporting the utility of designing and implementing status-neutral interventions with transgender women of colour (Table 1).

2 | DISCUSSION

Even though US federal funding mechanisms often designate awards to focus on people of a specific HIV status, intervention developers and implementing agencies can and do find creative ways to design and implement status-neutral programmes despite such restrictions. For example, the Health Resources and Services Administration (HRSA) funded the Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Colour Initiative in 2012. This Special Projects of National Significance (SPNS) initiative supported nine demonstration projects to develop and evaluate innovative interventions to reduce HIV health inequities among transgender women of colour living with HIV [18]. As part of this initiative, the Community Healthcare Network (CHN) in Queens, New York developed and tested the Transgender Women Engagement and Entry To (TWEET) Care Project, a peer-led, group-based educational intervention [19]. During the TWEET development process, CHN realized that to deal with HIV stigma in their community, they needed to include transgender women of any HIV status, such that participating in TWEET did not "out" the participants as living with HIV. As stated by the TWEET developer, it "created a welcoming supportive environment to address HIV stigma. The transgender women in the programme who were living with HIV were able to share their experiences on how they coped with their HIV status, which in turn served as an educational tool for those who were not living with HIV." (Personal Communication with Luis Freddy Molano MD, August 2020). To meet funding requirements, only transgender women living with HIV were included in the initiative's cross-site evaluation, and SPNS resources were not used to incentivize participation for participants not living with HIV.

Three organizations replicating TWEET in HRSA's E2i Initiative (Using Evidence-Informed Interventions to Improve Health Outcomes among People Living with HIV) [20] also adopted CHN's status-neutral approach to TWEET by including transgender women of any HIV status in response to HIV stigma in Ponce, Puerto Rico, New Orleans, Louisiana, Los Angeles, California and Detroit, Michigan. TWEET in these three communities was able to create social cohesion between transgender women regardless of HIV status, and the status-neutral approach facilitated participant recruitment by not requiring participants to self-identify as living with HIV to be included in the TWEET groups. Importantly, many individuals *chose* to share their HIV status over the course of the project, which fostered self-efficacy in communicating about HIV, allowed group members to form deeper connections with each other and provided an opportunity to collectively challenge prevailing HIV stigma. In Detroit, TWEET has continued to be implemented as a peer-delivered status-neutral intervention even after the end of the funding to meet the community demand for such a unifying and supportive group led by transgender women of colour.

Beyond TWEET, status-neutral interventions that simultaneously address trauma are urgently needed in Detroit. As Michigan's HIV epicentre [21], patterns of economic disadvantage, racial segregation and anti-transgender stigma have resulted in limited engagement in both HIV prevention and care among transgender women of colour [22]. We applied to a request for applications to the US National Institutes of Health that was focused on addressing violence along the HIV care continua among transgender women of colour. The few existing services in Detroit are primarily funded by HIV dollars to support people living with HIV. Although these behavioural programmes focused on HIV care are critical, with few exceptions (e.g. TWEET) they have historically excluded transgender women of colour not living with HIV who need these services and inadvertently disclosed programme participants' HIV status [5]. At the time of writing the grant proposal in Detroit, we knew we would need to find additional funds to include transgender women not

Table 1. HIV intervention approaches for transgender women of colour in the United States

Intervention	Eligibility criteria	Theoretical framework	Intervention components	Location
TWEET Original	At least 18 years old	Social cognitive theory	Transgender leaders teach back groups led by peer leaders	Detroit, Michigan, New Orleans, Louisiana, Ponce, Puerto Rico, Queens, New York
	Assigned male at birth and currently identifies as female, trans female, trans sexual and transgender	Social learning theory	Community outreach and recruitment	
	Fluent in English or Spanish	Trans-theoretical model	Supportive retention services (e.g. assistance with name change, gender markers, gender affirming care referrals; patient navigation and benefits counselling; referrals to comprehensive legal services)	
	Identifies as one or more of the following racial/ethnic categories: Hispanic/Latino/Puerto Rican/Cuban, Black or African American, American Indian or Alaska Native, Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian, Native Hawaiian, Guamanian or Chamorro, Samoan, or Other Pacific Islander Living with HIV to be included in the cross-site evaluation. Intervention activities were open to any HIV status			
TWEET Implementation	At least 18 years old	Social cognitive theory	Transgender leaders teach back groups led by peer leaders	
	Assigned male at birth and currently identifies as female or trans female	Trans-theoretical model	Community outreach and recruitment	
	Fluent in English or Spanish		Supportive retention services (e.g. assistance with name change, gender markers, gender affirming care referrals; patient navigation and benefits counselling; referrals to comprehensive legal services)	
	Living with HIV to be included in the cross-site evaluation. Intervention activities were open to any HIV status			
Healthy Divas RCT	At least 18 years old	Gender affirmation model	Six peer-led individual sessions, held weekly, and one group workshop facilitated by a healthcare provider with expertise in HIV care and transgender health	San Francisco and Los Angeles, California
	Assigned male at birth and currently identifies as female or trans female, or another transfeminine identity	Healthcare empowerment model		
	Fluent in English or Spanish			
	Living with HIV, as confirmed be antibody testing			

(*Continued*)

Table 1. Continued

Intervention	Eligibility criteria	Theoretical framework	Intervention components	Location
	Reports suboptimal engagement in HIV care, as indicated by one or more of the following: (1) not on ART, (2) if on ART, reported less than perfect adherence on a validated adherence rating scale, 38 or (3) reported no HIV primary care appointments in the prior 6 months			
Healthy Divas Implementation Study	At least 18 years old	Gender affirmation model	Expanded on Healthy Divas intervention content (described above) to be status neutral and include information relevant to trans women of negative or unknown HIV status	Oakland, California
	Assigned male at birth and currently identifies as female, trans female or another transfeminine identity Fluent in English or Spanish	Healthcare empowerment model		
Kickin' it with Gurlz	At least 18 years old	Gender affirmation model	Integration of three evidence-based interventions: (1) gender affirmation and safety needs screening; (2) at least two peer navigation sessions; and (3) eight peer-delivered culturally adapted group sessions based in cognitive behavioural therapy strategies from the Seeking Safety programme with an explicit focus on intersectional oppression and resistance	Detroit, Michigan
	Assigned male at birth and identifies as female, transgender woman or another feminine gender identity Self-identifies as a person of colour (any racial/ethnic identity except non-Hispanic white) History of trauma (i.e. endorses at least two items on the adapted Trauma History Screener, which includes IPV and experiencing or witnessing other forms of violence) Living or willing to travel to Detroit English speaking	Critical consciousness		
TRIUMPH	18 years or older	Gender affirmation model	Peer health education, peer-led community mobilization and clinical integration of PrEP with hormone therapy to promote PrEP knowledge and acceptability	Oakland and Sacramento, California
	HIV negative (confirmed by rapid test) Report a gender identity different from the sex assigned at birth			

(*Continued*)

Table 1. Continued

Intervention	Eligibility criteria	Theoretical framework	Intervention components	Location
	Currently sexually active or intending to become sexually active, express a desire to use Prep Fluent in English or Spanish			
Triunfo (TRIUMPH) Implementation Study	At least 18 years old Assigned male at birth and currently identifies as female, trans female or another transfeminine identity Fluent in English or Spanish	Gender affirmation model	Expanded on TRIUMPH intervention (described above) to include peer health education and navigation to services relevant to trans women living with HIV	Oakland, California

Abbreviations: ART, antiretroviral therapy; IPV, interpersonal violence; PrEP, pre-exposure prophylaxis.

living with HIV given the documented need for status-neutral programmes. Fortunately, we were awarded the grant to develop and pilot a multicomponent intervention designed to help transgender women of colour living with HIV heal from violence and trauma. After many conversations, we applied for and received an additional grant to develop and pilot the intervention with transgender women of colour not living with HIV. Although funded at the start of the COVID-19 pandemic, the status-neutral approach named "Kickin it with the Gurlz" by our team of Latina and Black transgender women in Detroit has been a success. Across interviews (*n* = 11) and focus groups (*n* = 12) to adapt the intervention content, participants expressed a desire for status-neutral groups citing the importance of "breaking down stigma in community." While only possible through two separate funding mechanisms, our team is in a position to examine the feasibility and acceptability of a status-neutral intervention with transgender women of colour designed to address both HIV prevention and care continua outcomes at the outset.

In San Francisco, the UCSF Center of Excellence for Transgender Health (UCSF CoE) has spent the better part of a decade developing and testing a peer-led, gender-affirming intervention for transgender women living with HIV, called Healthy Divas. Significant funding and resources have been invested in pilot testing and conducting a randomized controlled trial of the intervention (R01MH106373). Based on the urgent need for such a programme, Healthy Divas was selected for national dissemination by HRSA's E2i Initiative [20]. Further, as part of our UCSF Prevention Research Center's core research activities, we are conducting an implementation study of Healthy Divas with Cal-PEP, a community-based organization serving African American transgender women communities in Oakland, California. As part of this implementation study, Cal-PEP expressed a strong preference to adapt Healthy Divas to be status-neutral, similar to the approach used in the TWEET original research and subsequent replication. Additionally, Cal-PEP was facing recruitment barriers due to the fact that the programme is known to serve people living with HIV and may inadvertently disclose a client's HIV status to the close-knit Cal-PEP community. These concerns were so urgent and valid that, in collaboration with Cal-PEP, the UCSF CoE rapidly adapted the intervention's content to include transgender women who are not living with HIV, incorporated information about HIV testing and PrEP in the curriculum and re-trained the peer facilitators to implement the status-neutral version of Healthy Divas. As a peer counselling and client-centred intervention, Healthy Divas was designed to be flexible and adaptive to the concerns of the client and was, therefore, amenable to adaptation. However, without adequate testing, we are unsure of the impact this adaptation might have on the intervention's efficacy.

The UCSF CoE has also been conducting PrEP research with Latina transgender women at La Clínica de la Raza, a community-based clinic in a predominantly Latinx neighbourhood of Oakland, California. Triunfo was designed as a peer-led, PrEP education and community mobilization project to encourage PrEP uptake and adherence among Latina transgender women at risk for HIV acquisition. As a result of the focus on those not living with HIV, anyone in the community who was not able to participate in Triunfo was outed as living with HIV, which resulted in inadvertent reinforcement of HIV stigma and a sense of the programme being unnecessarily exclusionary and divisive. Our university-academic partnership recently received funding to expand the programme at La Clinica to include Latina transgender women living with HIV and study the implementation of a status-neutral version of the intervention designed to improve both HIV prevention and HIV treatment.

3 | CONCLUSIONS

With evidence and advocacy to support HIV status-neutral approaches as a means to eradicate HIV stigma globally [23–25], it is essential that federal funding, such as the recent request for applications by the US Centers for Disease Control (CDC-RFA-PS22-2209) and US National Institutes of Health (PAR-21-344) focused on low- and middle-income countries, provides mechanisms for developing and testing these approaches. Such funding avenues have the potential to result in better science and implementation outcomes in a context in which community-based organizations are currently implementing adapted versions of evidence-based interventions that have not been rigorously tested. Additionally, since evidence-based interventions only have an impact on the HIV epidemic when they are implemented, it is important that these interventions are consistent with the organizational culture, mission and value systems of community-based agencies. Status-segregated interventions can run counter to the needs of many such agencies to create connections across multiple intersections, including HIV status.

Social support, community connection and social capital are important mechanisms that reduce the deleterious impact of HIV stigma on HIV care continua outcomes, including engagement in care and viral suppression [26–28]. There have been a handful of promising status-neutral interventions designed with and for transgender women to increase social support, community connection and increase access to resources. For example, LifeSkills, Couples HIV Intervention Program (CHIP) and Sheroes were designed as status-neutral approaches, all of which were acceptable and feasible; however, the outcomes of these studies relied on self-report and precluded biomedical confirmation (e.g. PrEP adherence and viral load) [29–31]. Additionally, there are several HIV status-neutral interventions developed with community-based organizations that were designed for and by transgender women of colour across the US, including programmes designed by La Clinica del Pueblo in Washington, DC and those developed for Latina trans women at TransLatin@ Coalition. The gold standard for HIV research within the scientific community now requires biomedical confirmation of self-reported behaviours. As highlighted by Myers and colleagues, future efforts are required to consider eligibility criteria and outcome measurement using a status-neutral approach [3]. This advancement will require working closely with community members to secure trust in collecting biomedical samples due to historical and ongoing systemic ethno-racism and cisgenderism and ensuring that we do not place too much burden on study participants without adequate compensation. Additionally, we must develop procedures that ensure HIV status is not inadvertently disclosed in the data collection process.

HIV status-neutral interventions have tremendous potential to reduce HIV stigma through building solidarity and information exchange among trusted peers, as well as addressing pressing needs that undermine successful engagement across both the HIV prevention and care continua [3]. However, HIV status-neutral approaches warrant careful planning with community partners and consideration of the local context. For example, there may be additional types of support needed for HIV disease management and living with a chronic illness compared to HIV prevention programmes. While there may continue to be a need for status-segregated programming, HIV stigma is pervasive and status-neutral approaches can serve as platform for deconstructing HIV stigma and avoid the victim-centric approach that has historically predominated existing individual-level interventions for people living with HIV [32]. There may also be concerns that status-neutral approaches may divert funds from people living with HIV. Our intention is not to advocate for reduced funding or compromise quality of care for people living with HIV but rather to increase funding for all communities who experience intersectional oppression to reduce HIV inequities.

Community-based organizations strive for inclusivity in their programming and are reluctant to segregate their services based on HIV status. We have an ethical imperative to respond to the needs of those most impacted by HIV, specifically transgender women of colour. Our HIV intervention efforts must be designed to decrease or eliminate HIV stigma among marginalized communities who experience multiple and interlocking systems of oppression. Funding priorities focused exclusively on status-segregated intervention research create an ethical dilemma for HIV researchers wishing to collaborate effectively with communities most impacted by HIV. As such, we call upon funders to develop funding mechanisms that support the development and testing of HIV status-neutral intervention research to reduce HIV stigma, support community building and fully realize the benefits of biomedical HIV prevention and treatment technologies for all.

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COMPETING INTERESTS

The authors declare no competing interests.

AUTHORS' CONTRIBUTIONS

KEG, GR and JMS wrote the first draft of the manuscript. BMM, LJC, LAR and MC contributed to the refinement and presentation of the interventions and programmes presented. All authors contributed to the writing of the manuscript, and all approved the final draft.

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SHORT REPORT

A qualitative study of how stigma influences HIV services for transgender men and women in Nigeria

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Abstract

Introduction: Transgender men and women in Nigeria experience many barriers in accessing HIV prevention and treatment services, particularly given the environment of transphobia (including harassment, violence and discrimination) and punitive laws in the country. HIV epidemic control in Nigeria requires improving access to and quality of HIV services for key populations at high risk, including transgender men and women. We assessed how stigma influences HIV services for transgender people in Lagos, Nigeria.

Methods: In-depth interviews (IDIs) and focus group discussions were conducted with transgender men (n = 13) and transgender women (n = 25); IDIs were conducted with community service organization (CSO) staff (n = 8) and healthcare providers from CSO clinics and public health facilities (n = 10) working with the transgender population in March 2021 in Lagos. Content analysis was used to identify how stigma influences transgender people's experiences with HIV services.

Results and discussion: Three main findings emerged. First, gender identity disclosure is challenging due to anticipated stigma experienced by transgender persons and fear of legal repercussions. Fear of being turned in to authorities was a major barrier to disclose to providers in facilities not affiliated with a transgender-inclusive clinic. Providers also reported difficulty in eliciting information about the client's gender identity. Second, respondents reported lack of sensitivity among providers about gender identity and conflation of transgender men with lesbian women and transgender women with being gay or men who have sex with men, the latter being more of a common occurrence. Transgender participants also reported feeling disrespected when providers were not sensitive to their pronoun of preference. Third, HIV services that are not transgender-inclusive and gender-affirming can reinforce stigma. Both transgender men and women spoke about experiencing stigma and being refused HIV services, especially in mainstream public health facilities, as opposed to transgender-inclusive CSO clinics.

Conclusions: This study highlights how stigma impedes access to appropriate HIV services for transgender men and women, which can have a negative impact along the HIV care continuum. There is a need for transgender-inclusive HIV services and competency trainings for healthcare providers so that transgender clients can receive appropriate and gender-affirming HIV services.

Keywords: gender-affirming; HIV; HIV care continuum; stigma; transgender; transgender-inclusive services

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1 | INTRODUCTION

In sub-Saharan Africa (SSA), transgender persons experience a high burden of HIV and sexually transmitted infections (STIs) [1–7], physical and sexual violence [8, 9], stigma and discrimination [10–12], mental health issues [8, 12] and inadequate access to HIV prevention services [13]. In Nigeria, HIV prevalence data among transgender persons are sparse; HIV prevalence among men who have sex with men and transgender women (TGW) (combined) attending community clinics was reported to be 44–66% [14].

Multiple intersecting stigmas related to HIV status, sexual orientation, transphobia and homophobia also influence the experience of transgender people. Evidence of the negative impact of intersectional stigma on HIV risk-reduction behaviours and antiretroviral therapy initiation and retention is growing [15–18]. Transgender populations often navigate several challenges, including various forms of stigma and laws criminalizing same-sex relationships [5, 10, 19, 20], when trying to access services for HIV prevention and care [11, 21, 22]. Nigeria's Same Sex Marriage Prohibition Act (2013) prohibits same-sex relationships and organizations supporting people in such relationships, and creates a challenge to provision of and access to services to anyone believed to be engaging in same-sex relationships, including transgender individuals [20, 23, 24].

In recent years, the number of programmes addressing the needs of transgender populations (primarily HIV services) implemented in SSA countries has increased [25, 26], including the provision of gender-sensitive and stigma reduction trainings for healthcare providers [27–29]. As HIV programmes attempt to expand their services to the transgender population, there is a need to better understand how stigma influences existing services in specific contexts like Nigeria.

2 | METHODS

In March 2021, in-depth interviews (IDIs) and focus group discussions (FGDs) were conducted by trained interviewers/moderators in Lagos State with 25 TGW, 13 transgender men (TGM), 10 healthcare providers who work with transgender clients and 8 community service organization (CSO) representatives working with transgender clients. Table 1 describes the study population and methodology. CSO representatives provided input into all study guides. TGW/TGM guides were pilot tested. Participants provided written informed consent. Some CSO ($n = 4$) and provider ($n = 1$) interviews were conducted by phone; their consent was obtained over the phone and audio-recorded. All interviews were audio-recorded; a notetaker took notes of FGD sessions. All interviews were translated/transcribed. The study coordinator reviewed all transcriptions for accuracy. Thematic content analysis was used to analyse the data using NVivo 12 software to identify stigma-related gaps in HIV service delivery. Four researchers (including one co-investigator) with a good understanding of local context reviewed the data and developed the codebook through consensus. Coding was deductive and *a priori* codes guided the process. These were discussed by the research team through an iterative process. Team meetings were used to resolve disagreement in coding among coders. The investigative team discussed and categorized the codes into three main themes of: (1) challenges with gender identity disclosure to providers; (2) lack of sensitivity among providers about gender identity; and (3) HIV services not being transgender-inclusive and gender-affirming. Data saturation was achieved. The study was approved by the Population Council's Institutional Review Board and the Nigerian Institute of Medical Research.

3 | RESULTS AND DISCUSSION

Three main themes emerged: (1) challenges with gender identity disclosure to providers; (2) lack of sensitivity among providers about gender identity; and (3) HIV services not being transgender-inclusive and gender-affirming.

1. *Gender identity disclosure is challenging due to anticipated stigma experienced by transgender persons and fear of legal repercussions*

Disclosure of ones' gender identity can theoretically help facilitate more tailored HIV prevention services, as sensitized providers could then have a better understanding of the potential needs and vulnerabilities of clients. However, such disclosure to providers remains a great challenge. For example, anticipation of legal repercussions may impede transgender clients from disclosing due to fear of being turned in to authorities if their gender identity was exposed.

> *Like in Nigeria now, we have laws against them. So for them to even come out even if you are telling them we are friendly, we are this, they will still be scared of "I hope you won't report them to 'you know'".* (***Provider, Public Health Facility [PHF]***)

> *You're not encouraged to go [to hospitals]. Because it is not legalized, one. Two, it is not officially known. And you might be seen as a strange person when you start voicing out your problems.* ***(TGW, 21, IDI)***

Some providers reported difficulty in eliciting information about the client's gender identity, even providers who had received transgender competency training and intended to discuss this topic to help meet the clients' needs. Other providers reportedly felt uncomfortable with the topic in general.

> *Sometimes it gets uncomfortable because even the client that is transgender or MSM, they themselves are not comfortable. …They might not really want to come out.* (***Provider, PHF)***

> *A lot of health workers still find it so uncomfortable; you know to treat you, to identify with you as maybe a MSM or transgender. …as you present to them your sexual orientation, they still want to ignore it.* ***(Provider, PHF)***

Because stigma inhibits disclosure of gender identity, it can restrict access to appropriate HIV prevention and care services, as has been reported in related studies in other contexts [30–33]. Relatedly, providers from facilities that have received gender/sexual diversity training indicated that although their facilities offer sensitized HIV services, they are still not well equipped to offer other services that transgender clients need. For example, they refer to transgender-inclusive CSO clinics for certain STIs (e.g. anogenital warts) and mental health counselling.

> *I refer [transgender clients] to [CSO clinic] where there is mental health services. …I would transfer the person where the person will go and get service and come back to continue his medication.* ***(Provider, PHF)***

2. *Lack of sensitivity about gender identity and conflation of transgender men and women with being lesbian or gay/men who have sex with men (MSM)*

Both TGM and TGW spoke about providers not being sensitive to their requested pronoun and that they felt disrespected.

Table 1. Study population, methodology and sample characteristics

	Transgender women (*N* = 25)	**Transgender men (*N* = 13)**	**Transgender-inclusive CSO staff (*N* = 8)**	**Healthcare providers (*N* = 10)**
Type of interviews	10 IDIs 3 FGDs (5 participants per FGD) (in-person)	8 IDIs 1 FGD (5 participants per FGD) (in-person)	8 IDIs (by phone or in-person)	10 IDIs (by phone or in-person)
Eligibility criteria	Self-identify as transgender or have discordant responses to the two-step questions on sex assigned at birth and gender identity; 18 years or older		Having worked at least 6 months for a CSO working with transgender population and being in a position that interacts with transgender community or makes decisions for transgender programmes; 18 years or older	Having worked at least 6 months at one of the transgender-inclusive clinics or public health facilities that have been trained to provide transgender-inclusive services through an Elton John AIDS Foundation-funded programme
Sampling and recruitment	Five transgender-inclusive CSOs used convenient sampling and selected transgender men and women (diversified by age) who use their programmes and services; Participants also referred peers. All participants referred by the CSOs agreed to participate.		Purposively sampled from among five transgender-inclusive CSOs in Lagos; selected participants who had ample knowledge of services for transgender men and women	Convenience sample
Place of interview	At transgender-inclusive community, health clinic operated by CSO serving high-risk key populations		Phone interview or at CSO office	Phone interview or at place of work (health facility/clinic)
Duration	IDIs: 1 hour FGDs: 1.5 hours		IDIs: 1 hour	IDIs: 1 hour
Topics of inquiry	• HIV and sexual health needs of TGM/TGW and challenges in accessing services • Experiences accessing HIV and sexual health services • HIV/STI risk and vulnerabilities of TGM/TGW • Experiences of stigma and discrimination		• HIV/STI risk and vulnerabilities of TGM/TGW • HIV and sexual health needs of TGM/TGW and challenges in accessing services • Strategies to improve HIV and sexual health services for TGM/TGW	• Attitudes towards TGM/TGW and providing services to TGM/TGW • HIV and sexual health needs of TGM/TGW and challenges in accessing services • Challenges in providing services for TGM/TGW
Interviewer	Self-identified cisgender man (*n* = 3) Self-identified cisgender woman (*n* = 2) [Both men and women interviewed TGM and TGW]		Self-identified cisgender male (*n* = 3) Self-identified cisgender female (*n* = 2)	Self-identified cisgender male (*n* = 3) Self-identified cisgender female (*n* = 2)
Language of interview	Mix of English and Pidgin English		English (as preferred by participants)	English (as preferred by participants)
Reimbursement	5000 Nairas (US$ 12)		5000 Nairas (US$ 12)	None

(*Continued*)

Table 1. (Continued)

	Transgender women (N = 25)	**Transgender men (N = 13)**	**Transgender-inclusive CSO staff (N = 8)**	**Healthcare providers (N = 10)**
Cadre of staff			Director (*n* = 4) Programme Officer/Other (*n* = 3) Community mobilizer (*n* = 1)	Doctor (*n* = 4) Counsellor (*n* = 4) Nurse (*n* = 2)
Health facility type				CSO clinics (*n* = 4) Public health facilities (*n* = 6)
Median age (IQR)	24 (22, 27)	27 (25, 31)		
HIV status	2 HIV positive	All HIV negative or unknown		

Abbreviations: CSO, community service organization; FGD, focus group discussion; IDI, in-depth interview; IQR, inter-quartile range; TGM, transgender men; TGW, transgender women.

> *I just feel it's still more of the discrimination. Some people not respecting your pronouns. When you tell them (providers), …when they call you Miss and you are like, no, I prefer to be called Mr, and they look at you like, "ah ah, as you are like this endowed with breast, which one is Mr?" They don't understand you.* ***(TGM, 26, IDI)***

The conflation of TGM with lesbian women and TGW with being gay or MSM was raised frequently even though they were not asked about these different groups. This conflation occurred naturally, even among providers who had received gender/sexual diversity training. This conflation appeared to be more common for TGW than TGM. Some providers assumed that MSM and TGW had similar health needs because they assumed both groups engage in anal sex.

> *…this thing, gay, MSM, transgender …it's still the same thing. …Even though some goes to the extent of changing their reproductive systems …so I think apart from the physical structure, it's the same need because …it's still anal sex all of them do.* ***(Provider, PHF)***

> *They [providers] do not understand the term "trans", so they just stick to the word, "homo" and "gay".* ***(TGW, 27, IDI)***

Studies that have documented the impact of widespread conflation of gender identity with sexual orientation [34–37] highlight how this can limit access to and the effectiveness of HIV prevention services and the need to acknowledge transgender identities and address the unique needs of this population [36]. Provider awareness of, and respect for individual gender identity is critical for optimal delivery of HIV and other health services for Nigerian TGM and TGW [37]. Studies suggest that interventions that increase provider competence in delivering gender-affirming services can facilitate transgender engagement in, as well as retention in, HIV care [38, 39] and can increase patient–provider trust and foster positive interactions [38, 40].

3. *Offering HIV services without tailoring to transgender community needs can reinforce stigma*

Both TGM and TGW reported experiencing stigma related to their gender identity when accessing HIV services. CSO representatives and providers also spoke about the stigmatizing attitudes among HIV providers have towards transgender clients and occasions of provider refusal to attend to transgender clients. This is an example of intersectional stigma, where transgender individuals experience multiple stigmas (i.e. related to gender identity, as well as HIV—resulting in not receiving needed HIV services).

> *That was the first and last time I went to the government hospital to get my HIV test and when the lady saw me, she now ask me for my sex,…I opened up to her that I was a transwoman, she was now saying …it's sinful you are going to hell, that HIV is connected to hell…I was like I wanted to leave that place immediately.* ***(TGW, 22, FGD)***

> *… there was a time I went to get tested for HIV, it was at a public sector…the person was very rude to me on the basis that I was effeminate, and I still couldn't get the test done. Because after being insultive, she still told me that I should go.* ***(TGW, 24, IDI)***

These findings show that stigma acts as a barrier to HIV testing, and as a consequence, transgender people do not have the opportunity to even enter the HIV care continuum. This finding is consistent with other studies that have reported poor care continuum outcomes among transgender populations and that stigma and discrimination is one of the key impediments to better outcomes [38, 39, 41–47].

Transgender respondents and some providers also pointed to a distinction in the experience of stigma and discrimination depending on the type of facility where they accessed HIV services, with negative experiences reported at "mainstream" health facilities and more positive experiences reported at transgender-inclusive CSO clinics.

> *I don't go to normal general healthcare providers, but when it comes to queer health care providers, they treat me well but when it comes to the normal general local health care*

> *providers, they treat me very very bad which I don't even try to go there anymore.* **(TGW, 23, IDI)**

> *The healthcare providers [in 'mainstream' facilities] are not even knowledgeable enough to know that this people exist or even those who knows that they exist are still afraid …that if they provide services to these people, they may face the law.* **(Provider, CSO clinic)**

Transgender clients felt uncomfortable about receiving physical examinations from providers, particularly in mainstream health facilities. Because of anticipated stigma, many transgender individuals are unwilling to access services from providers in mainstream facilities because they feel uncomfortable and disrespected by provider's insensitivity to gender identity and/or specific healthcare needs.

> *Some transwomen are very shy of going to the hospital to meet a doctor and ask doctor I want to check if my ass is okay.* **(TGW, 21, IDI)**

Most providers from the participating public health facilities (i.e. "mainstream"), however, appeared to not be aware of these challenges.

> *If they come here, we'll take them as patients. We treat them normal; we don't look at the, the bad aspect of it in society, or what the law implies, we don't practice that kind of law here, we just take patients as patients. …I told them that ehm your practice is not a sin here.* **(Provider, PHF)**

These findings highlight the varying experiences of stigma experienced by TGM and TGW in different healthcare settings, which seemed to depend on whether the facility was a transgender-inclusive CSO facility and/or providers in the health facility had undergone transgender competency training. Suggestions for future interventions include a recommendation for providers in "mainstream" public facilities to undergo competency training in gender-affirming services, particularly in HIV and STI units, to improve clinical practice. Trainings can include, for example, sessions on non-stigmatizing and respectful care to gain skills to sensitively probe about gender identity and sexual behaviours so that appropriate services can be offered, correctly acknowledge clients gender identity and pronouns, and confidently conduct physical examinations for transgender clients. Moreover, having a focal person who can attend to transgender clients or having transgender peers or key opinion leaders [48] as navigators or case managers to facilitate linkage to services and navigate the appointment can help in creating a safe, enabling environment. Another stigma reduction strategy could be to coordinate more closely with CSOs that already offer gender-affirming services to bring lessons learned to other facility settings.

Turning to study limitations, since the qualitative data were obtained from TGM and TGW who are connected to transgender-inclusive CSOs, the views of those not connected to such CSOs may not be represented. Nevertheless, the findings are consistent with those reported in other settings but more importantly highlight the specific ways in which stigma creates gaps in the provision of and access to services for transgender people in Nigeria. A major strength is that this is one of the few studies about the effects of stigma on HIV services for the transgender population, including their own voices.

4 | CONCLUSIONS

This novel study found that stigma impedes access to appropriate HIV services (such as HIV testing) for the Nigerian transgender population, a community that is highly marginalized and hidden in the Nigerian context. These findings call attention to the need to address clinical practice, and programmatic and policy gaps in availability and access to gender-affirming HIV services for Nigerian transgender persons, especially within healthcare settings. There is also a need for the national HIV and STI service delivery guidelines to include specific language around transgender-inclusive and gender-affirming services. The current guidelines (2020) do not specifically include transgender persons [49]. Additional research to explore and pilot effective stigma reduction and competency skills-building interventions focused on the transgender population could improve services along the HIV care continuum and ultimately HIV prevention and treatment outcomes in this population.

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COMPETING INTERESTS

All authors have no competing interests to report.

AUTHORS' CONTRIBUTIONS

WT, AAA and JP conceptualized, wrote and revised the manuscript. KG conducted literature review and contributed to the manuscript writing. AF oversaw the implementation of the data collection, assisted with data analysis and contributed to the manuscript writing. WT wrote the protocol for the study. OD trained data collectors and conducted the analysis. OS trained data collectors and helped with manuscript revision. ES assisted with data collection implementation, provided feedback on study tools and revision of the manuscript. AA and FE assisted with study tool reviews, data collection implementation and revision of the manuscript. All authors have read and approved the final manuscript.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author.

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RESEARCH ARTICLE

Telling the story of intersectional stigma in HIV-associated Kaposi's sarcoma in western Kenya: a convergent mixed-methods approach

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Abstract

Introduction: The experience of stigma can be multifaceted for people with HIV and cancer. Kaposi's sarcoma (KS), one of the most common HIV-associated cancers in sub-Saharan Africa, often presents with visible skin lesions that may put people at risk for stigmatization. In this way, HIV-associated KS is unique, as people with KS can experience stigma associated with HIV, cancer, and skin disease simultaneously. The aim of this study is to characterize the intersectionality of HIV-related, cancer-related and skin disease-related stigma in people living with HIV and KS.

Methods: We used a convergent mixed-methods approach nested within a longitudinal study of people with HIV-associated KS in western Kenya. Between February 2019 and December 2020, we collected quantitative surveys among all participants and conducted semi-structured interviews among a purposive sample of participants. Quantitative surveys were adapted from the abridged Berger HIV Stigma Scale to assess overall stigma, HIV-related stigma, cancer-related stigma, and skin disease-related stigma. Qualitative data were coded using stigma constructs from the Health Stigma and Discrimination Framework.

Results: In 88 semi-structured interviews, stigma was a major barrier to KS diagnosis and treatment among people with HIV-associated KS. Participant's stories of stigma were dominated by HIV-related stigma, more than cancer-related or skin disease-related stigma. However, quantitative stigma scores among the 117 participants were similar for HIV-related (Median: 28.00; IQR: 28.0, 34.0), cancer-related (Median: 28.0; IQR: 28.0, 34.8), and skin disease-related stigma (Median: 28.0; IQR: 27.0, 34.0). In semi-structured interviews, cancer-related and skin disease-related stigma were more subtle contributors; cancer-related stigma was linked to fatalism and skin-related stigma was linked to visible disease. Participants reported resolution of skin lesions contributed to lessening stigma over time; there was a significant decline in quantitative scores of overall stigma in time since KS diagnosis (adjusted $\beta = -0.15$, $p < 0.001$).

Conclusions: This study highlights the role mixed-method approaches can play in better understanding stigma in people living with both HIV and cancer. While HIV-related stigma may dominate perceptions of stigma among people with KS in Kenya, intersectional experiences of stigma may be subtle, and quantitative evaluation alone may be insufficient to understand intersectional stigma in certain contexts.

Keywords: stigma; Kaposi's sarcoma; HIV/AIDS; cancer; sub-Saharan Africa; mixed methods

Additional information may be found under the Supporting Information tab of this article.

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1 | INTRODUCTION

For people living with HIV and cancer, the experience of stigma is multifaceted, reflecting HIV and cancer-related stigma simultaneously. Stigma is a well-studied social construct, characterized by discrimination against individuals labelled as "other" because of socially undesirable characteristics [1]. Stigmatization of illnesses creates barriers to health equity and decreases quality of life among people with associated diseases [2]. Intersectionality was originally used to describe the marginalization of Black women who were targets of discrimination because of both race and gender identities [3]. The lens of intersectionality can also be used to understand the burden of multiple marginalized identities related to health states, such as HIV and cancer [3, 4]. Although HIV and cancer individually are known to be stigmatized health conditions associated with delayed healthcare-seeking and poor treatment adherence [5–9], little is known about intersectional stigma among people with HIV, cancer, and Kaposi's sarcoma (KS) in resource-limited settings [10, 11].

KS remains one of the most common HIV-associated cancers, even in the era of antiretroviral therapy (ART) [12]. KS often presents with highly visible skin lesions, putting people at risk for stigmatization [13]. The intersectionality of HIV, cancer, and skin disease-related stigma in people with HIV-associated KS is of particular interest, as all three conditions are known to be associated with stigma [10, 13]. The manifestations of these three intersecting stigmas have the potential to impact healthcare engagement at many levels, including delayed diagnosis and treatment of KS.

The goal of this study was to describe the prevalence and experiences of stigma in a longitudinal cohort of adults with newly diagnosed HIV-associated KS in western Kenya using a mixed-methods approach, guided by the Health Stigma and Discrimination Framework [14]. We aimed to characterize: (1) manifestations of stigma in HIV-associated KS; (2) intersectionality of HIV-related, cancer-related, and skin disease-related stigma in KS; and (3) longitudinal changes in the experience of stigma in HIV-associated KS following diagnosis.

2 | METHODS

2.1 | Study population

This study was nested within a parent epidemiologic study using the rapid case ascertainment approach to identify and enrol all people newly diagnosed adults (aged 18 years or older) with KS from 2016 to 2019 at the Academic Model Providing Access to Healthcare (AMPATH) network in western Kenya [15]. KS was diagnosed histopathologically; a clinical diagnosis was made when biopsy was deemed unsafe (e.g. oral/ocular KS). Participants were followed longitudinally at 16-week intervals to assess survival and other measures, including stigma. These time intervals were selected to match clinical care follow-up visits in oncology. The study was approved by the Institutional Research Ethics Committee at Moi University and Partners Healthcare Institutional Review Board; all participants provided written informed consent.

2.2 | Data collection procedures

2.2.1 | Physical examination, questionnaires and blood draws

Eligible participants completed questionnaires on demographics and KS-related symptoms, underwent physical examination (total body skin examination, lymph node palpation, assessment of lymphedema, and pulmonary, abdominal and cardiac examination when indicated), and provided biological samples to assist in KS staging and categorization of co-variates [15].

2.2.2 | Quantitative, abridged Berger HIV Stigma Scale

To measure distinct forms of stigma experienced by people with HIV-associated KS, we adapted the validated abridged 25-item Berger HIV Stigma Scale (Berger-aHSS) to create four quantitative surveys evaluating (1) overall stigma, (2) cancer-related stigma, (3) skin disease-related stigma, and (4) HIV-related stigma [16, 17] (Supplement A). The Berger HIV Stigma Scale (HSS) was selected because the original Berger HSS has been adapted and validated for use around the world [16, 18], in sub-Saharan Africa [19, 20], and has been successfully used to study non-HIV health conditions, including cancer [21, 22]. The adapted quantitative surveys were translated to Swahili, back-translated to English and finally, field tested in western Kenya by research staff (Supplement A).

The Berger-aHSS includes sub-scores of the following four constructs from the Health Stigma and Discrimination Framework [14]: internalized stigma (6-items, range 6–24), experienced stigma (10-items, range 10–40), perceived stigma (4-items, range 4–16), and anticipated stigma (5-items, range 5–20) [16, 17]. Each item on the Berger-aHSS is a 4-point Likert scale (1-strongly disagree, 2-disagree, 3-agree and 4-strongly agree), with a range of composite scores for the entire quantitative survey between 25 and 100; higher scores indicated higher stigma.

Overall stigma was measured at enrolment. At follow-up visits every 16 weeks, participants completed the quantitative surveys (*overall stigma*, *cancer-related stigma*, *skin disease-related stigma*, and *HIV-related stigma*). All living participants in the parent study were asked to complete the adapted Berger-aHSS scales from February 2019 to December 2020. Follow-up study visits to collect the adapted Berger-aHSS scales occurred at 16-week intervals for the first 2.5 years after KS diagnosis.

2.2.3 | Qualitative, semi-structured interviews

From February 2019 to August 2019, a purposive sample of participants with newly diagnosed KS from the parent study were invited to participate in in-depth interviews focused on barriers and facilitators to diagnosis and treatment of KS (Supplement B). The interviews included probes on the role of stigma as a barrier to KS diagnosis, initiation of and adherence to chemotherapy, and the intersection of HIV-related, cancer-related, and skin disease-related stigma in people with KS (Supplement B). Research staff trained in qualitative interview techniques conducted in-person, in-depth, semi-structured interviews. Participants were compensated for transportation to the clinic. All interviews were approximately an hour and audio recorded.

2.3 | Analysis

2.3.1 | Quantitative analysis

We used descriptive statistics to summarize baseline demographic and clinical characteristics. For each of the adapted Berger-aHSS quantitative surveys, we calculated a total additive composite score and categorized total scores based on percentile of total possible composite scores. "Mild" was between 25th percentile and 50th percentile (25–50), where the average response was "strongly disagree" or "disagree," "Moderate" was between 50th and 75th percentile (51–75), where the average response was on the border between "disagree" and "agree," and "Severe" values were greater than

75th percentile (76–100), where the average response was "agree" or "strongly agree" to the questions about stigma in the Berger-aHSS [23]. We used the same percentile criteria to categorize sub-scores for each of the domains in the Berger-aHSS as "Mild," "Moderate" and "Severe."

We performed exploratory analyses focused on understanding missingness in the data, differences in stigma over time and the relationships between overall, cancer-related, HIV-related, and skin disease-related stigma. To evaluate longitudinal changes in overall stigma in people with HIV-associated KS after diagnosis, we used a linear mixed-effects model with a Gaussian link, where the intercept for each participant was assessed as a random effect, and age, sex, KS stage at the time of diagnosis; death at the end of the study period, and baseline CD4⁺ T cell count were included as fixed-effects. Time was parameterized as the time from KS diagnosis (either biopsy date or date of clinical diagnosis, if biopsy was not performed) to the date when the adapted Berger-aHSS quantitative surveys were completed. All analyses were performed using R statistical analysis software [24].

2.3.2 | *Qualitative analysis*

The recorded semi-structured interviews were transcribed in the language in which the interview was performed (Swahili, English or local dialect) by trained Kenyan research assistants, and translated into English when necessary. Framework analysis was implemented using the Health Stigma and Discrimination Framework, focused on the Stigma Experiences constructs [14, 25, 26]. A priori coding framework was developed, and the first 25% of transcripts were coded independently by two experienced qualitative analysts (DM and MG) of the research team, using both inductive and deductive methods to verify and ensure reliability of the coding process. Coding structures were iteratively compared, with any discrepancies resolved by consensus. A single coder then coded the remaining 66 transcripts using the master codebook, with additional generation of codes, memos and interview summaries. A total of 88 interview transcripts; 31 diagnosis and 57 treatment, were analysed. NVivo (Version 12) was used to facilitate analysis. Codes were then grouped into themes with respective quotes.

Each component of KS (HIV, cancer, and skin disease) was analysed for five different stigma constructs as follows: (1) anticipated: the anticipated fear of what would happen if others knew about the person's disease, (2) perceived: the stigma associated with each person's understanding of how others in their community feel about them and their disease, (3) experienced: the person's experience of discriminatory acts or behaviors, (4) internalized: the person absorbed and applied to themselves the negative messages or stereotypes about their illness and (5) secondary stigma: the stigma experienced by those close to the person.

2.3.3 | *Mixed methods; integration of qualitative and quantitative*

We triangulated the quantitative and qualitative results to understand convergence and divergence and developed joint displays. Secondary stigma was not captured by the Berger-aHSS nor the qualitative interviews and was therefore not included in the final analysis.

Table 1. Characteristics of participants living with HIV-associated KS diagnosed at AMPATH in western Kenya 2016–2019, with at least one stigma measurement during the study period

	Mean (SD), Median (Q1, Q3) or *N* (Percentage)	
Characteristic	**Participants with stigma measure (*N* = 117)**	**Participant without stigma measure (*N* = 97)**
Age	37.0 (31.0, 42.0)	36.0 (32.0, 43.3)
Male sex	78 (67.2%)	59 (61.5%)
CD4⁺ T cells, cells/μl at diagnosis	342.9 (264.0)	283.5 (290.7)
ACTG stage at diagnosis		
T1	102 (87.2%)	89 (92.7%)
T0	15 (12.8%)	7 (7.3%)

Abbreviations: ACTG, AIDS Clinical Trials Group; SD, standard deviation; Q1, quartile 1; Q3, quartile 3. "T" denotes ACTG tumor stage.

3 | RESULTS

3.1 | Quantitative

We enrolled 182 adults with newly diagnosed HIV-associated KS at AMPATH. A total of 64.3% (*N* = 117/182) of participants completed the adapted Berger-aHSS measuring *overall stigma* during at least one study visit. The median age of participants who completed at least one adapted Berger-aHSS measuring *overall stigma* was 37 years (IQR 31, 42), 67% (*N* = 78) were men (Table 1). Details of participant characteristics and loss to follow-up are included in Supplement A.

The median overall stigma score across all participants at all nine timepoints was 28.0 (IQR 28.0, 38.0). For overall stigma, the median sub-scores for the constructs measured by the Berger-aHSS were as follows (Table 2): internalized stigma was 6.00 (IQR 6.00, 9.00), perceived stigma was 4.00 (IQR 4.00, 7.00), anticipated stigma was 8.00 (IQR 7.00, 10.0), and experienced stigma was 10.0 (IQR 10.0, 13.0) (Figure 1) [16, 17].

Median stigma scores were similar for the three stigmas experienced by people with HIV-associated KS: HIV-related stigma was 28.00 (28.0, 34.0), cancer-related stigma was 28.0 (28.0, 34.8), and skin disease-related stigma was 28.0 (27.0, 34.0). The median overall stigma score was highest at baseline with a median of 34.0 (IQR 28.0, 58.0) and lowest at week 112 with a median of 28.0 (IQR 26.0, 31.0) (Figure 1). There was a statistically significant longitudinal decrease in overall stigma following KS diagnosis. Specifically, overall stigma score decreased by –0.15 +/– 0.028 points for each additional week following KS diagnosis after accounting for random intercepts by participant and fixed-affects for sex, age, KS stage at the time of diagnosis, death at the end of the study period

Table 2. Stigma and intersectional stigma across all time points in participants with HIV-associated Kaposi's sarcoma, as measured by adaptations of the Berger-aHSS scale

	Overall stigma (*N* = 421)	Cancer stigma (*N* = 368)	HIV stigma (*N* = 368)	Skin disease stigma (*N* = 368)
Stigma category				
Mild	336 (79.8%)	302 (82.1%)	313 (85.1%)	307 (83.4%)
Moderate	48 (11.4%)	29 (7.9%)	25 (6.8%)	24 (6.5%)
Severe	37 (8.8%)	37 (10.1%)	30 (8.2%)	37 (10.1%)
Overall score				
Mean (SD)	38.08 (19.07)	37.26 (19.37)	36.25 (17.97)	36.60 (19.04)
Median (Q1, Q3)	28.00 (28.00, 38.00)	28.00 (28.00, 36.00)	28.00 (28.00, 34.00)	28.00 (28.00, 34.00)
Self-stigma				
Mean (SD)	8.51 (4.61)	8.36 (4.68)	7.98 (4.36)	8.18 (4.57)
Median (Q1, Q3)	6.00 (6.00, 9.00)	6.00 (6.00, 8.00)	6.00 (6.00, 7.00)	6.00 (6.00, 7.25)
Perceived stigma				
Mean (SD)	6.11 (3.57)	5.99 (3.63)	5.57 (3.25)	5.82 (3.53)
Median (Q1, Q3)	4.00 (4.00, 7.00)	4.00 (4.00, 7.00)	4.00 (4.00, 5.00)	4.00 (4.00, 6.00)
Anticipated stigma				
Mean (SD)	9.09 (3.83)	8.74 (3.88)	9.39 (4.10)	8.71 (3.83)
Median (Q1, Q3)	8.00 (7.00, 10.00)	8.00 (5.00, 8.00)	8.00 (8.00, 12.00)	8.00 (5.00, 8.00)
Experienced stigma				
Mean (SD)	14.37 (8.61)	15.56 (9.51)	14.69 (8.83)	15.27 (9.40)
Median (Q1, Q3)	10.00 (10.00, 13.00)	11.00 (11.00, 13.00)	11.00 (11.00, 11.00)	11.00 (11.00, 11.00)

Abbreviations: SD, standard deviation; Q1, quartile 1; Q3, quartile 3.

and baseline CD4 count (95% CI: –0.21, –0.098; $p < 0.001$) (Supplement A, Table S1). Detailed regression analysis, including sensitivity analysis, is included in Supplement A.

3.2 | Qualitative results

Stigma was an important aspect of people with KS's lived experience, and among people with HIV-associated KS, the manifestations and degree of stigma varied among the three co-occurring stigmatized diseases (HIV, cancer and skin disease) (Figure 2). HIV-related stigma, specifically anticipated stigma around HIV-disclosure, was the most common type of stigma and the most concerning stigma among many participants. Cancer-related stigma was less commonly spontaneously expressed by participants; however, there were many stories of experienced cancer-related stigma, manifesting as social isolation and discrimination related to their cancer diagnosis.

Skin disease-related stigma was also a common theme, characterized by experienced stigma, which manifested as people staring and distancing themselves, and internalized stigma, manifesting with embarrassment and shame due to KS-related skin changes, drainage and odor.

3.3 | HIV stigma

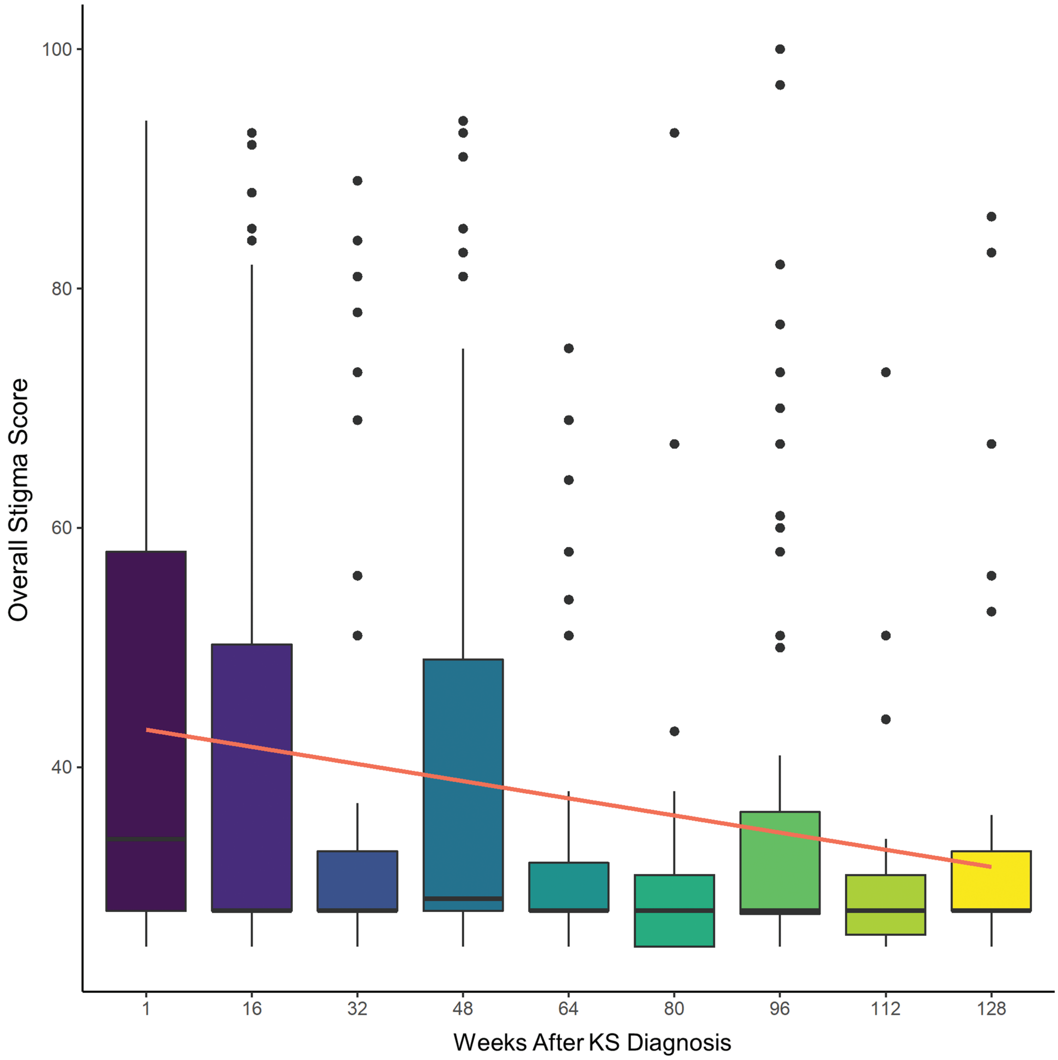
In semi-structured interviews, HIV-related stigma was the most common form of stigma expressed by people with KS. Many participants mentioned perceiving high levels of HIV stigma in the community. They were fearful of disclosing their HIV status to friends and family (anticipated stigma) and some recounted being left by their romantic partner after disclosing their status (experienced stigma).

3.3.1 | *Perceived HIV stigma*

People with KS were more concerned with the public perception of HIV than of cancer and even skin disease. In particular, participants identified HIV as having a "bad name" and being associated with perceived "promiscuous" behaviour. *"I was not afraid of cancer but HIV, it is still a strong name. Even now people see cancer as a normal thing, but HIV is a bit different…People take cancer as a normal thing… ."* (Participant 53, 34-year-old man, new HIV diagnosis) *"[F]or HIV it is regarded that one gets it due to promiscuity. So that brings a little fear. Yes. But that's not the case for cancer, yes. (Laughs)"* (Participant 76, 39-year-old woman, new HIV diagnosis)

3.3.2 | *Anticipated HIV stigma*

Participants expressed fear about HIV status disclosure, anticipating that friends would distance themselves and family members might leave because of their HIV status. *"Up to now I don't want them to know that I have… that I tested positive. I don't want them to know, but I don't mind them getting to know about cancer."* (Participant 76, 39-year-old woman, new HIV diagnosis).*"[I] was afraid of telling my wife because of—I tested positive [for HIV]."* (Participant 31, 28-year-old man, previous HIV diagnosis)



	1	16	32	48	64	80	96	112	128
Median (IQR)	34.0 (28.0, 58.0)	28.0 (28.0, 48.8)	28.0 (28.0, 33.3)	29.0 (28.0, 48.0)	28.0 (28.0, 31.8)	28.0 (25.3, 28.0)	28.0 (27.0, 37.0)	28.0 (26.0, 31.0)	28.0 (28.0, 33.0)
Mean (SD)	45.8 (22.6)	41.3 (22.0)	36.9 (19.1)	40.5 (20.2)	33.2 (12.6)	32.0 (13.5)	37.2 (19.1)	31.0 (9.9)	35.3 (16.9)

Figure 1. Longitudinal trend in overall stigma score among people with HIV-associated Kaposi's sarcoma. Boxplot and linear regression depicting overall stigma scores by week.
Note: The boxes represent the interquartile range (25th and 75th percentiles), and the median is depicted as a black horizontal line. The whiskers show the 0.35th and 99.65th percentiles. The outliers are depicted as black dots. The linear regression and 95% confidence intervals are depicted as the orange line and gray shadow, respectively. Abbreviations: IQR, interquartile range; KS, Kaposi's sarcoma; SD, standard deviation.

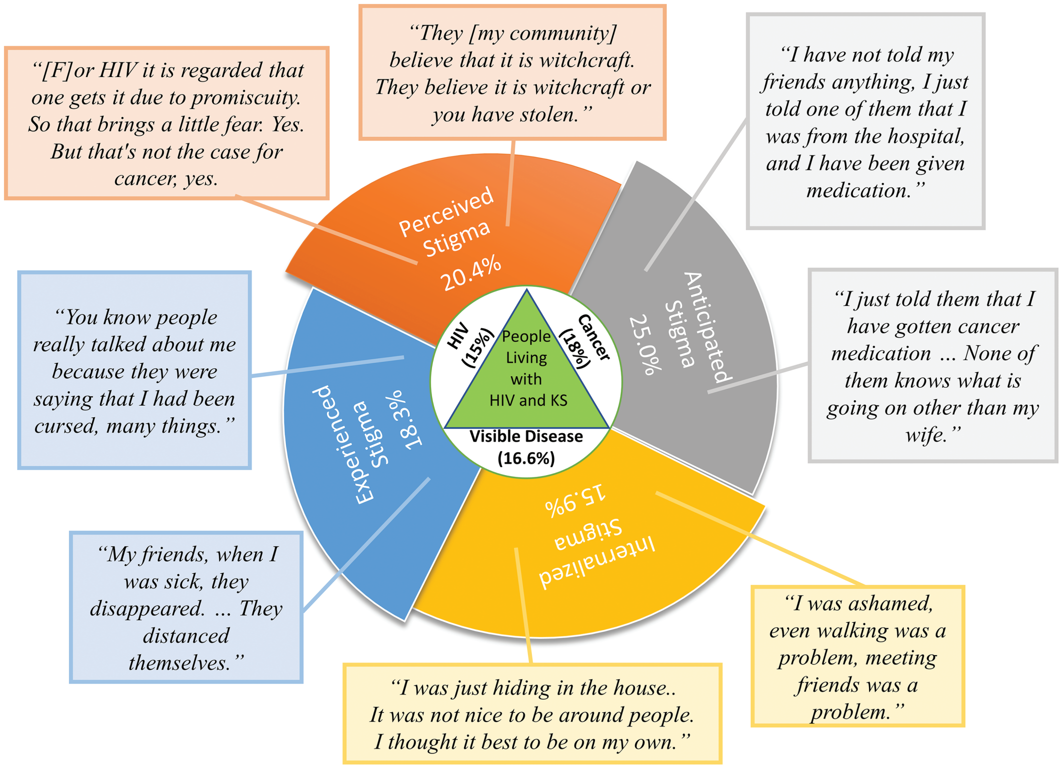
3.3.3 | Experienced HIV stigma

People with KS expressed fewer direct experiences of HIV-related stigma than for cancer-related and skin disease-related stigma, especially when their status was undisclosed. However, among participants who disclosed their status, friends and family would often distance themselves or leave:

> *[W]henever I went to take my medication, my wife would throw them away, so it got to a point where I got tired and decided to just quit taking them. When she saw the state that I was in she left, she left the children and went away.* (Participant 25, 29-year-old man, previous HIV diagnosis)

While rare, some individuals reported stigma from the healthcare workers involved in their care. One participant, who was pregnant, reported poor treatment from healthcare workers when her inability to take anti-retroviral medications caused an increase in her viral load:

> *…I was expecting [a child], that is what brought all the problem, the viral load started going up, taking the drugs was also a challenge, when I just tried to take them [ARVs]*



"[F]or HIV it is regarded that one gets it due to promiscuity. So that brings a little fear. Yes. But that's not the case for cancer, yes.

"They [my community] believe that it is witchcraft. They believe it is witchcraft or you have stolen."

"I have not told my friends anything, I just told one of them that I was from the hospital, and I have been given medication."

"I just told them that I have gotten cancer medication … None of them knows what is going on other than my wife."

"I was ashamed, even walking was a problem, meeting friends was a problem."

"I was just hiding in the house.. It was not nice to be around people. I thought it best to be on my own."

"My friends, when I was sick, they disappeared. … They distanced themselves."

"You know people really talked about me because they were saying that I had been cursed, many things."

Figure 2. Mixed-methods representation of stigma in HIV-associated Kaposi's sarcoma: manifestations and proportion experiencing moderate or severe overall stigma. Joint display of the manifestations of stigma described by the Health Stigma and Discrimination Framework, with each portion of the pinwheel representing one of the stigma constructs (perceived, anticipated, internalized and experiences) included in the analysis. The quantitative results are represented as the percentage of responses with moderate or severe stigma for each of the constructs. The call outs extending from each of the pinwheels include representative quotes for each construct.

> *I could vomit so I wasn't taking them as required.* (Participant 19, 39-year-old woman, previous HIV diagnosis)

When asked if the doctors spoke to her poorly, she responded *"Yes, they talked to me so badly, I had a really heavy heart, I tried removing it [the pregnancy], but I could not."* (Participant 19, 39-year-old woman, previous HIV diagnosis)

3.3.4 | *Internalized HIV stigma*

Fewer participants expressed internalized HIV-related stigma explicitly, though HIV diagnosis was associated with feelings of despair, devaluation of their life, and on occasion, suicidal thoughts.

> *For example, one patient said, "I was really scared because I thought…Where did I get it? How … could I have gotten it?' It really disturbed me I almost hanged myself." Subsequently, when asked if this fear made her lose hope about starting treatment, she acknowledged she had lost hope, "Yes, I thought it was best if I died."* (Participant 84, 30-year-old woman, previous HIV diagnosis)

3.4 | Cancer stigma

The manifestations of cancer-related stigma among people with KS were subtle and intertwined with a sense of fatalism and fear of death associated with their cancer diagnosis. Although most participants expressed HIV-related stigma overshadowing any cancer-related stigma, many participants experienced discrimination they associated with their cancer diagnosis.

3.4.1 | *Perceived cancer stigma*

There were mixed perceptions of cancer stigma in the community. Although there was a stigmatizing fear among some community members that cancer was contagious, some participants felt that because KS is a cancer specifically linked to HIV status, this precluded them from additional cancer-related stigma:

> *I was not stigmatized by the cancer because the Google stated to me clearly that this is a cancer related to HIV so it's not just a normal cancer I would have been stigmatized if this is a cancer which is not related with HIV, that is why I was very comfortable, this is a cancer related to HIV, then its fine, because I am HIV.* (Participant 23, 43-year-old man, previous HIV diagnosis)

3.4.2 | *Anticipated cancer stigma*

In contrast to anticipated HIV-related stigma, where fear of HIV status disclosure was common, no participants explicitly stated the notion of anticipated stigma related to their cancer diagnosis. *"When they told me that I had cancer I was open to our family. Even now everyone knows that I had cancer."* (Participant 58, 36-year-old woman, previous HIV diagnosis)

3.4.3 | *Experienced cancer stigma*

Participants only rarely described experienced stigma associated with their cancer diagnosis. However, many people noted that family and friends distanced themselves after learning about the cancer diagnosis, because of the need for money and other help with cancer treatment and beliefs that death from cancer was inevitable. *"[…] people kept away from me and like I said, the reason was because of the money needed for my treatment was a lot. […] not because I had cancer."* (Participant 54, 40-year-old man, new HIV diagnosis)

The relationship between cancer and death was a common theme and subtle component of the experiences of discrimination and distancing by family and friends. *"Cancer, you know cancer kills."* (Participant 76, 39-year-old woman, new HIV diagnosis)

3.4.4 | *Internalized cancer stigma*

Internalized cancer-related stigma was expressed by feelings of uselessness and hopelessness. Many participants expressed feeling their life was no longer worth living, and cancer was a death sentence. Participants also expressed feeling useless after their cancer diagnosis as their health worsened and they became dependent on others for financial and psychosocial support. *"Of course, I understood that my life is just useless, that means I am here for nothing, I cannot support my family, I cannot support myself, I saw that I was becoming useless."* (Participant 59, 44-year-old man, new HIV diagnosis)

3.5 | Skin-disease stigma

Skin changes are often the most prominent visible manifestations of KS, and stigma was more commonly associated with certain skin changes, such as swelling, weeping and odor than with the purple patches and skin nodules. Similar to the experience of cancer-related stigma, most participants did not express concerns about negative perceptions of skin disease by community members, but participants did hide their skin disease if possible (anticipated stigma), expressed embarrassment and shame because of skin changes (internalized stigma), and experienced staring and other subtle forms of stigmatization (experienced stigma).

3.5.1 | *Perceived skin-disease stigma*

Similar to cancer-related stigma, most participants did not express concerns about community members having negative perceptions of their skin disease, though some communicated fear over how others would react to their skin lesions. One person reported he worried about *"how they [others] would react"* to the *"spots."* (Participant 78, 35-year-old man, new HIV diagnosis)

3.5.2 | *Anticipated skin-disease stigma*

Participants primarily expressed anticipated skin disease-related stigma as it related to disclosure of their skin disease. Those who were able to cover and hide their skin disease did so, and those who could not, viewed the presence of skin lesions as automatic disclosure of their disease:

> *Even going outside…. at the estate, I would put on socks and cover up with a leso [cloth], but even with sock, someone can still tell that your legs are swollen. It was embarrassing.* (Participant 76, 39-year-old woman, new HIV diagnosis)

3.5.3 | *Experienced skin-disease stigma*

Many people with KS felt discriminated against because of their visible lesions, swellings or areas of discharge. Some participants were laughed at, asked to leave, abused or lost employment because of visible KS-related skin changes:

> *What I feared the most was how people were speaking to me, people didn't want me where they were because my leg was smelling, they would abuse me, that was my biggest fear.* (Participant 17, 32-year-old man, previous HIV diagnosis)

One participant specifically identified skin disease-related stigma as the reason for losing employment. *"Where I had been working, my boss fired me because of those wounds – so these wounds were bleeding so much."* (Participant 5, 34-year-old man, previous HIV diagnosis)

3.5.4 | *Internalized skin-disease stigma*

Many individuals expressed embarrassment of the changes in their skin and drainage associated with KS, this internalized stigma led them to avoid contact with other people:

> *I had some wounds which were discharging …I was stinking, the condition was ashaming me. Not that the friends were discriminating [against] me but I felt myself that it's not good to be where people are when you are not producing good smell.* (Participant 37, 40-year-old man, previous HIV diagnosis)

3.6 | Intersectionality in KS stigma

Among people with KS, the experiences of HIV, cancer and skin disease stigma are intertwined in everyday experience, making it challenging to analyse these as isolated disease-specific stigma experiences. The interviews reveal important manifestations of HIV-related, skin disease-related and cancer-related stigma, and some participants described the complexities of their intersectional relationship. While many participants said HIV-related stigma nullified other potential sources of stigma (e.g. cancer), others felt more stigmatized because they had HIV and cancer. Skin disease is stigmatizing in and of itself, and it is also a potentially identifiable visible manifestation of cancer and HIV. The experience of skin disease stigma thus shapes the experiences of HIV and cancer stigma. This is true for all three disease-specific aspects of stigma, which become interwoven to create the experience of KS stigma:

> *Since they have said it is just on the skin, my prayer is that I get well. Despite the fact that I have this other one [HIV] (laughs sarcastically), I hope to get well. This one [cancer] will disturb you! It does not please me, no (speaks in low tone)!* (Participant 82, 55-year-old woman, new HIV diagnosis)

> *I was afraid. I thought now the cancer in combination with the HIV virus will take me very fast [lead to death] (laughs).* (Participant 74, 29-year-old man, previous HIV diagnosis)

3.7 | Role of stigma in KS diagnosis and treatment

Many participants experienced an initial loss of hope, fear of telling others and shame upon diagnosis that began to fade as the patient recovered or others became familiar with their condition. For some patients, stigma led to the delay of both diagnosis and treatment of KS.

When asked about avoiding the hospital because of staring and negative attention, *"That even prevented me from just going to where they were, because of flies and the discharge, I mean it was affecting me, and it prevented me from going to the hospital or anywhere else…even that was the reason I couldn't walk around."* (Participant 17, 32-year-old man, previous HIV diagnosis)

In others, it was a motivating factor in seeking diagnosis and treatment to be cured more quickly.

> *"…my friends had started being shy of intermingling with my friends because I was stinking, the condition was ashaming me. […] infact it motivated me to look for a solution for the problem so that I go on with my normal life."* (Participant 37, 40-year-old man, previous HIV diagnosis)

3.8 | Role of treatment in reducing stigma

When asked what he is expecting to change once he starts treatment, one patient says, "You know when I get better, I will be free…I will be free to interact with people, they can even call me for a job, or I can … do my work for my life to move forward." (Participant 83, 32-year-old man, new HIV diagnosis)

One participant noted a significant change from initial diagnosis to time of illness improvement with treatment. Initially, no one cared for him, and many distanced themselves; however, when asked what people said when they saw him now, he responded *"I think they are just surprised to see me healed…they are just silent."* (Participant 49, 34-year-old man, previous HIV diagnosis)

4 | DISCUSSION

Our findings suggest that stigma is an important part of the lived experience of people with HIV-associated KS in Kenya. The finding that overall stigma is highest around the time of KS diagnosis and declines longitudinally is supported by the quantitative and qualitative portions of our analysis. People with HIV-associated KS have a unique experience because of the convergence of three co-occurring potentially stigmatizing diseases (HIV, cancer and skin disease), yet their stories of stigma are dominated by HIV-related stigma.

While longitudinal changes in stigma following cancer and skin disease diagnosis are not well studied, there is some prior work showing reductions of HIV stigma over time. A longitudinal study of the impact of stigma on quality of life among people living with HIV showed that HIV stigma was lower at 12 months than at baseline [27], though this was a secondary finding for which the reason was not fully explored. Here, we show that stigma among people with HIV-associated KS declined following KS diagnosis during longitudinal evaluation and may reflect recovery with treatment. During semi-structured interviews, people with HIV-associated KS described experiences of stigma decline associated with chemotherapy initiation, resolution of their KS skin lesions and improvement of their overall health. Despite the observation that HIV is perceived by people with KS as the most stigmatizing aspect of their experience, skin disease may be an important driver of stigmatization in the community, since it is the most visible marker of cancer and/or HIV. In this way, it is possible that people with KS become less visible in the community as their skin lesions resolve and they perceive less overall stigma.

When examining the intersectionality of HIV-related, cancer-related and skin disease-related stigma, people with KS identified HIV-related stigma as a central barrier to KS diagnosis and treatment. The HIV-related stigma impacted their lives more than both cancer-related and skin disease-related stigma. This is consistent with prior work in Kenya showing a higher proportion of women living with HIV reporting HIV stigma as compared to cervical cancer stigma [11]. Stories from this study corroborate this phenomenon, and participants articulated that stigma associated with their HIV diagnosis is stronger than their cancer or skin disease diagnosis. Interestingly, this relationship was not reflected in our quantitative evaluation, where the degree of HIV-related, cancer-related and skin disease-related stigma was similar. While using the same measure to assess different components of stigma is a common approach to measuring intersectional stigma [28], it is possible that this approach was not sensitive enough to allow participants to distinguish between HIV-related, cancer-related and skin disease-related stigma in the quantitative evaluation. This quantitative finding raises questions about whether this is the strongest instrument to quantitatively measure intersectional stigma in this setting, which warrants further investigation.

Among the stigma constructs from the Health Stigma and Discrimination Framework, anticipated HIV stigma related to HIV status disclosure was very common. This finding was consistent in the qualitative and quantitative analyses, where anticipated stigma was the highest sub-score on the Berger-aHSS scale for overall, cancer-related, skin disease-related, and HIV-related stigma. Prior studies have similarly found anticipated stigma to be the highest sub-score [29–31]. Anticipated stigma around HIV disclosure may be an important driver for stigma among people with HIV-associated KS and a key barrier to the diagnosis and treatment of HIV-associated KS. Anticipated HIV-related stigma is also an important factor in the HIV care continuum and is associated with lower eagerness to begin ART [32]. For people with HIV-associated malignancies, anticipated HIV-related stigma may be a barrier to the diagnosis and treatment of both HIV and cancer.

We acknowledge that definitive conclusions about longitudinal changes in stigma over time are limited due to attrition bias, as only people with KS who survived are represented at later time points. However, the overall trend towards decreasing stigma persisted after accounting for within subject changes in stigma over time and adjusting for AIDS Clinical Trials Group (ACTG) stage at diagnosis and death at the end of the study period.

KS is often visible, presenting with overt clues identifying a person as having HIV and cancer that may lead to stigma. Although in this way KS is different from other HIV-associated malignancies, the finding that HIV overshadows the intersectional nature of the stigma experience may be generalizable to other HIV-associated malignancies. Similarly, people with other HIV-associated malignancies may experience improvements in stigma following treatment and resolution of symptoms. One challenge to the generalizability is that stigma scores in this western Kenyan population were low relative to other populations. In our evaluation of stigma, the median overall stigma score was 28, indicating that most participants either strongly disagreed or disagreed with the statements about stigmatization in the Berger-aHSS. Using quantitative evaluation of stigma alone, without the mixed-methods approach used in this analysis, therefore, could potentially underestimate the burden of stigma in this context. Other studies quantitatively evaluating HIV stigma in the African context are mixed: some studies found universally high stigma for people living with HIV, while others found, similar to our study, low overall stigma [20, 33, 34]. Findings of overall low HIV stigma could be due to underreporting related to social desirability bias, cultural attitudes towards stigma in western Kenya or poor performance of adapted Berger-aHSS scales in our context [34].

5 | CONCLUSIONS

This mixed-methods evaluation highlights the importance of stigma in the lived experience of people with HIV-associated KS. While HIV-related stigma may dominate individuals' narratives about stigma, the intersectionality between skin, cancer and HIV still plays an important role in the experience of individuals living with a visible HIV-related cancer. By evaluating KS stigma through a convergent mixed-methods approach, our analysis underscores that experiences of stigma may be subtle, and quantitative evaluation of stigma may not adequately capture the experiences of intersectional stigma in certain contexts. Future research should focus on understanding whether stigma among people with HIV-associated KS leads to differences in cancer care utilization and clinical outcomes.

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COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHORS' CONTRIBUTIONS

EF, JM, IB, L Bogart and L Butler contributed to the conceptualization and design of the study. AS, HB, MLO, LC, TM, SK, EF and NB acquired the data. SC, RS, MG and DM analysed the data. SC, RS and EEF prepared the manuscript. EF, SC, RS, JM, L Bogart, L Butler, AS, HB, MLO, LC, TM, SK, NB, MG and DM reviewed and contributed to the final manuscript. All authors have read and approved the final version.

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DISCLAIMER

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author.

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SUPPORTING INFORMATION

Additional information may be found under the Supporting Information tab for this article:

Supplement A: Quantitative methods and results, supplemental

Supplement B: Semi-structured interview guides

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RESEARCH ARTICLE

The association between HIV stigma and HIV incidence in the context of universal testing and treatment: analysis of data from the HPTN 071 (PopART) trial in Zambia and South Africa

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Abstract

Introduction: To investigate the association between individual and community-level measures of HIV stigma and HIV incidence within the 21 communities participating in the HPTN (071) PopART trial in Zambia and South Africa.

Methods: Secondary analysis of data from a population-based cohort followed-up over 36 months between 2013 and 2018. The outcome was rate of incident HIV infection among individuals who were HIV negative at cohort entry. Individual-level exposures, measured in a random sample of all participants, were: (1) perception of stigma in the community, (2) perception of stigma in health settings and (3) fear and judgement towards people living with HIV. Individual-level analyses were conducted with adjusted, individual-level Poisson regression. Community-level HIV stigma exposures drew on data reported by people living with HIV, health workers and community members. We used linear regression to explore the association between HIV stigma and community-level HIV incidence.

Results: Among 8172 individuals who were HIV negative and answered individual-level stigma questions at enrolment to the cohort, there was no evidence of a statistically significant association between any domain of HIV stigma and risk of incident HIV infection. Among the full cohort of 26,110 individuals among whom HIV incidence was measured, there was no evidence that community-level HIV incidence was associated with any domain of HIV stigma.

Conclusions: HIV stigma is often cited as a barrier to the effectiveness of HIV prevention programming. However, in the setting for the HPTN 071 "PopART trial," measured stigma alone was not associated with the risk of HIV infection.

Keywords: HIV stigma; HIV incidence; cluster randomized trial; PLHIV; community members; health workers

Additional information may be found under the Supporting Information tab of this article.

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1 | INTRODUCTION

HIV stigma is widely acknowledged as an important barrier to the success of HIV control efforts. Stigma acts as a barrier to HIV testing uptake, and, for those people living with HIV (PLHIV), to linkage to care, treatment initiation and adherence to antiretroviral therapy (ART) [1–3]. While stigma is also often cited as a barrier to the success of HIV prevention [4, 5], there is limited literature on this association.

A variety of plausible mechanisms might link HIV stigma with risk of acquiring HIV infection. At the individual level, perceiving that HIV stigma is present in communities or health settings, or anticipating that seeking HIV testing or HIV prevention services might lead to stigmatization, may put people at risk of HIV infection [6, 7]. HIV testing is an important gateway to HIV prevention service access. Alternatively, those who hold stigmatizing attitudes towards PLHIV may perceive themselves to be at low risk and take fewer precautions to avoid HIV risk. At the community level, if HIV stigma limits access to testing or treatment for PLHIV, this might limit the preventive impact of ART [8, 9]. Finally, at the structural level, HIV stigma is closely linked to a range of other prejudices, notably in relation to sexual practice. Homophobia, and other forms of prejudice and discrimination against those who may be vulnerable to HIV infection, for example, female sex workers, or adolescent girls and young women, might affect safe sex choices and access to preventive health services for these groups [10, 11].

In pre-planned secondary analysis, we found that stigma has been gradually declining over time in Zambia and South Africa [12]. In this paper, we investigated the association between HIV stigma and risk of HIV infection among a large, representative population-based sample in the 21 communities participating in the HPTN 071 (PopART) trial in Zambia and South Africa. We assessed (1) whether those who reported perceived stigma, or fear and judgement towards PLHIV, were at greater risk of new HIV infection and (2) whether those who lived in communities with higher levels of stigma were at greater risk of new HIV infection during the trial.

2 | METHODS

2.1 | Setting

The HPTN 071 (PopART) trial was a three-arm cluster randomized trial conducted between 2013 and 2018 in 21 urban study communities (12 in Zambia and nine in Western Cape Province, South Africa) [13, 14]. We nested a mixed-method study within the PopART trial to assess the effect of HIV stigma on HIV outcomes. We have reported the results of the association between HIV stigma and viral suppression among HIV-positive participants [15]. In this paper, we present the results on HIV incidence among HIV-negative participants. Details of the main and sub-study designs have been described previously (Figure S1) [13, 16]. Briefly, study communities were arranged in seven triplets matched on geographical location and estimated HIV prevalence. Communities in each triplet were randomly allocated to three study arms. In the two treatment arms (A and B), a study-employed cadre of community-based health workers (HWs) known as Community HIV care Providers (CHiPs) delivered door-to-door HIV testing and referral services [17]. In Arm A, ART was offered to PLHIV regardless of CD4 count from the start of the trial; in Arms B and C, ART was offered according to national guidelines, which changed over the course of the trial and became regardless of CD4 count in 2016. HIV incidence was approximately 20% lower in Arms A and B combined than in the standard-of-care Arm C [14]. In all arms, health facility- and existing community-based HWs received training on the study aims but did not receive specific anti-stigma training. There was little evidence of a difference in stigma between arms at the end of the trial [12].

2.2 | Outcome study population

The study population for this analysis was community members at risk of HIV infection who were recruited to a population-based cohort (PC). In each community, one randomly selected adult aged 18–44 years was selected from a random sample of households. Enrolment mostly occurred between December 2013 and March 2015. Additional participants were enrolled in some study communities at 12 and 24 months, excluding households already sampled [14]. PC participants were surveyed at baseline (PC0) and at 12, 24 and 36 months (PC12/PC24/PC36). Laboratory-based HIV testing was performed for all participants at all visits.

We analysed outcomes among two populations. First, for individual-level analyses, questions on perceived stigma in community and health settings, and fear and judgement towards PLHIV, were asked of a 20% random sample of PC participants at each round. A new sample was drawn at each round. Participants entered the analysis cohort from the round at which they first answered questions about these three composite measures (domains) of stigma (Table S1), if at that round they were HIV negative and did not self-report being HIV positive. To be included, participants also needed to have at least one further HIV test following the first test and complete data on socio-demographic factors (age, sex, marital status and education) and HIV stigma measures in the round at which they joined. We refer to this group as the "individual-level analysis cohort" (Figure 1). In total, 8172 individuals were included, joining the cohort at PC0 (n = 3585), PC12 (n = 2293) and PC24 (n = 2294).

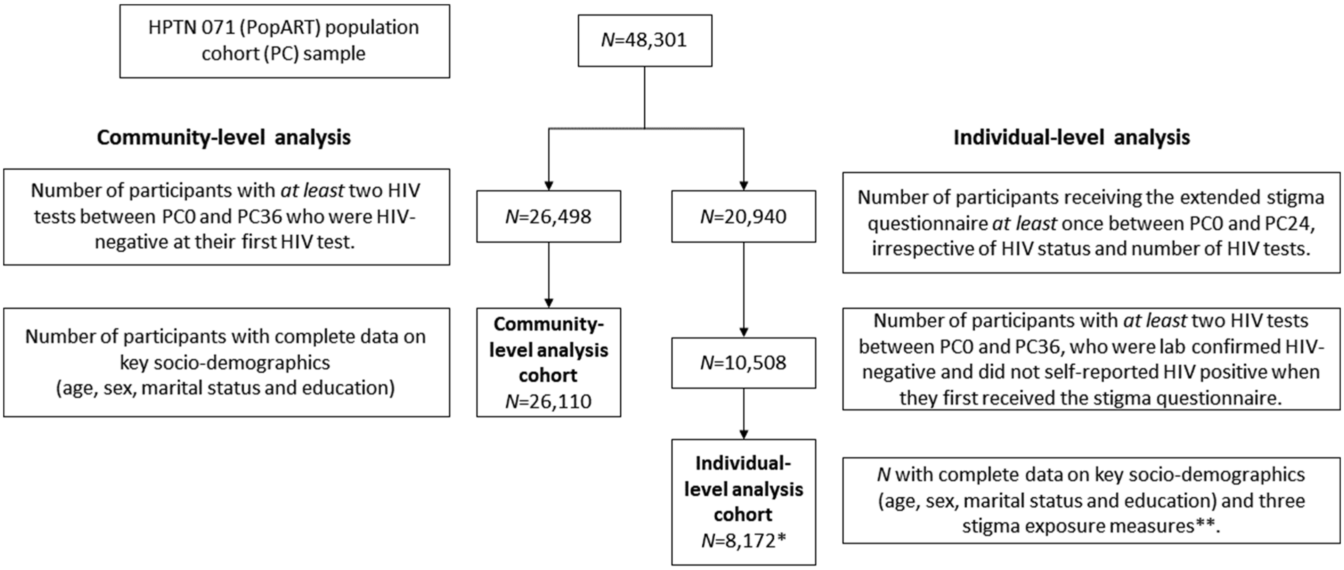
Second, for community-level analyses, we included all PC participants with at least two HIV tests who were HIV negative at their first HIV tests and had complete data on socio-demographic factors (n = 26,110). We refer to this group as the "community-level analysis cohort" (Figure 1). The individual-level analysis cohort sample is a subset of the community-level analysis cohort sample.

Blood samples were analysed in-country using a single fourth-generation assay (Architect HIV Ag/Ab Combo Assay, Abbott Diagnostics, Delkenheim, Germany). Further testing was performed at the HPTN Laboratory Center (HPTN LC, Johns Hopkins University, Baltimore, MD, USA). Samples that had reactive results in-country were tested with a second fourth-generation assay (GS HIV Combo Assay, Bio-Rad Laboratories, Redmond, WA, USA). If seroconversion was confirmed, testing was performed to determine whether the participant had acute infection at the previous visit. HIV incidence was measured among participants who were HIV negative at enrolment to the cohort. HIV infection was assumed to occur at the midpoint between the last HIV-negative sample and the first HIV-positive sample. Imputation methods were used when the time of infection was unclear because of missed visits. The methods used have been previously described in the main trial [13]. For this paper, we used one of the imputed datasets (selected at random) to undertake the analysis on the basis that the imputation was about the timing of sero-conversion, and not whether or not it occurred.

2.3 | Measurement of stigma exposures

We used previously validated individual and community-level composite stigma measures [18].

For individual-level stigma exposures, we used three composite measures reflecting (1) perceived stigma in communities (five items) (2) perceived stigma in healthcare settings (two items) and (3) fear and judgement towards PLHIV (three items) [17]. Stigma items were pre-coded using a 4-item



*There were 3,585, 2,293 and 2,294 participants receiving the stigma questionnaire for the first time and joining the cohort at PC0, PC12 and PC24, respectively.
**Perceived stigma in community, perceived stigma in healthcare settings, fear and judgement.
There were 967 new HIV infections in the community-level analysis cohort.
There were 234 new HIV infections in the individual-level analysis cohort.

Figure 1. Flowchart with (a) the cohort-level analysis cohort who had at least two HIV tests between PC0 and PC36 (*n* = 26,110) and (b) the individual-level analysis cohort who received the stigma questionnaire at least once between PC0 and PC24 and had at least two HIV tests between PC0 and PC36 (*n* = 8172).

Likert scale ("Strongly agree" (3), "agree" (2), "disagree" (1) and "strongly disagree" (0)). For the primary analysis, all stigma items were collapsed into binary variables coded as "disagree" versus "agree." This binary classification reflects whether participants agreed to any of the stigma items within each domain, compared to those who did not agree with any. In sensitivity analyses, we used the three composite stigma measures on a continuous scale, with values ranging from 0 to 3.

We developed community-level measures of stigma using data from the community-level analysis cohort above, and two further populations. At each round, we collected data from laboratory-confirmed HIV-positive PC participants who also self-reported they were HIV positive. We developed four stigma measures reflecting community-level stigma experienced by PLHIV in healthcare (three items) and community settings (five items), current internalized stigma (three items) and any stigma (combining the 11 items, Table S1). We used data collected at PC24 since this reflected the midpoint of the trial. We also collected data from HWs (excluding CHiPs) self-reporting not living with HIV in a separate cohort study, HWs which involved three rounds of data collection between July 2014 and February 2018; here, we used data from round 2 (R2) [15]. We developed three community-level stigma measures reflecting perceptions of stigma by co-workers in health facilities (four items), perceptions of stigma in the community (five items) and fear and judgement (five items, Table S1). Finally, we developed community-level summaries of responses of participants in the community-level analysis cohort to the individual-level questions on stigma detailed in the previous section.

To develop community-level summaries, for the data from PLHIV, each community was summarized with the % of PLHIV reporting each type of stigma. For the data from HWs and participants from the community-level analysis cohort, we developed community-level scores as the mean of the individual-level scores. The scores thus had a theoretical range from 0 to 3 such that, for example, a mean score of 1 indicated that people in that community on average responded "Disagree" to stigma items and a mean score of 2 indicated people that on average responded "Agree." Details of the item wording and other measurement details are reported elsewhere [18].

2.4 | Statistical analysis

We first described the individual-level analysis cohort comparing characteristics and stigma exposure measures between countries. We used chi square test to examine differences in the levels of stigma between those who were surveyed at baseline and those surveyed in later rounds (PC12 and PC24).

Participants' characteristics from the individual- and community-level analysis cohorts were similar (Table S2).

We then analysed the individual-level association between the three domains of HIV stigma and HIV incidence between 0 and 36 months. We report the number of new HIV infections, total person-years of observation, rate per 100 person-years and calculated incidence rate ratios using Poisson regression. We developed an unadjusted and two adjusted models; the first adjusted for age group and sex, and the second adjusted additionally for marital status and education. All models were adjusted using community as a fixed term. We used interaction tests to explore whether the strength of these associations differed by trial arm and age. We estimated the predictive margins of HIV seroconversion for each interaction and plotted the probability of seroconversion with 95% confidence intervals. In sensitivity analysis, we run the same models described above using (1) the scores of the three composite stigma measures (instead of the binary measures) and (2) the 11 individual stigma statements using the binary classification.

We then analysed associations between community-level stigma measures and HIV incidence between 0 and 36 months. We produced cluster-level scatter plots to illustrate the strength of association between community-level measures of stigma, expressed as scores (0–3) or percentages, and community-level HIV incidence between 0 and 36 months. We used linear regression adjusting for trial arm, weighted by the sample size in each community, and report the *p*-value for these associations.

2.5 | Ethical considerations

Ethical approval for all study procedures was obtained from the institutional review boards of the London School of Hygiene and Tropical Medicine, Stellenbosch University and the University of Zambia. All participants provided written informed consent prior to enrolment.

3 | RESULTS

The individual-level analysis cohort included 8172 individuals of whom 70.6% were female, 44.5% were under 25 years of age, 71.2% had completed secondary education and 51.3% were unmarried (Table 1). Participants in Zambia were younger and more frequently female, married and with lower levels of educational attainment compared to participants in South Africa.

At cohort entry, 58.5% of participants from the individual-level analysis cohort agreed or strongly agreed with at least one of five items reflecting perceived stigma in communities, 26.4% with at least one of two items reflecting perceived stigma in healthcare settings and 20.8% with at least one of three items reflecting fear and judgement towards PLHIV. Levels of perceived stigma and fear and judgement were higher in Zambia compared to South Africa. People recruited at later rounds were statistically significantly less likely to report any aspect of stigma, except fear and judgement in South Africa, than those recruited at earlier rounds (Table 1).

Participants were from communities with high HIV prevalence (range 3.0–35.6% at baseline) (Table 2). On average, 28.5% of PLHIV reported recent or current experience of at least one of 11 ways in which we measured stigma (range: 7.7–55.0%) (Table 2). Stigma in health settings was least commonly reported and varied least between communities. Community summaries of the responses of both community members and HWs not living with HIV on perceptions of stigma and fear and judgement towards PLHIV suggested that on average people “disagreed” with the statements provided, but with variation between individuals and communities.

There were 234 new HIV infections observed during 16,401 person-years (1.43 per 100 person-years) in the individual-level analysis cohort. There was no evidence of a statistically significant association between any of the three individual-level stigma domains and HIV incidence (Table 3). We found no evidence that associations differed by trial arm or age (Figures S2 and S3). Results were similar when using the continuous stigma exposure measures (Table 3), and we found no evidence of an association when we used the individual stigma statements (Table S3).

In the community-level analysis cohort of 26,110 individuals, a total of 967 new HIV infections were observed during 64,905 person-years of follow up (1.49 per 100 person-years). There was no evidence of a statistically significant association between any community-level measure of stigma and HIV incidence (Figure 2).

4 | DISCUSSION

In secondary analysis of data from a large cluster-randomized trial in 21 communities in Zambia and South Africa, we found that a substantial number of HIV-negative participants in the communities perceived stigma to be present in both the community and health settings, and, in some cases, held attitudes linked to fear and judgement of PLHIV. These individuals were not at greater risk of HIV infection compared to others in the community. In these same communities, a high proportion of PLHIV reported experiencing stigma (33.2% and 23.2% in Zambia and South Africa, respectively), while HWs, on average, “disagreed” with items on perception of stigma in communities and health settings. There was variation across communities, and differences between the two countries, in the level of reported stigma. However, we also found no evidence that the community-level HIV incidence rate was associated with these community-level measures of HIV stigma.

The literature on the association between HIV stigma and risk behaviour, access to prevention services and HIV incidence is much less developed [19] than that on PLHIV and access to diagnostic, care and treatment services. The HIV prevention cascade emphasizes three key components to support individuals from avoiding HIV acquisition: whether they are informed and motivated to adopt HIV prevention behaviours; whether they have readily accessible and available tools to them, such as condoms and pre-exposure prophylaxis; and whether they have the capacity to enact the relevant behaviours [20]. At the individual level, one could argue that holding stigmatizing attitudes might limit motivation to enact prevention behaviours, while perceiving stigma in the community and health settings might limit motivation to access prevention tools or seek advice. A study in Cape Town bars found that participants agreeing with statements indicating AIDS-related stigma reported higher levels of some risk behaviours [21]. In another study in Uganda, authors concluded that HIV risk was high among “boda boda” motorcyclists, was associated with HIV-related stigma and that “interventions aimed at reducing HIV-related stigma and alcohol use may potentially reduce the high rates of HIV transmission risk behavior” [22]. Data from Sierra Leone showed community-level HIV disclosure concerns among women to be a driver of risky sex and self-reported sexually transmitted infections [23]. Presumed HIV-negative or unknown status

Table 1. Summary characteristics of the individual-level analysis cohort (*n* = 8172), by country

	Zambia (*n* = 4766)		South Africa (*n* = 3406)		Total (*n* = 8172)	
	No.	%	No.	%	No.	%
Sex						
Male	1335	28.01	1064	31.24	2399	29.36
Female	3431	71.99	2342	68.76	5773	70.64
Age group (at PC0)						
16–24	2364	49.60	1271	37.32	3635	44.48
25–29	993	20.84	752	22.08	1745	21.35
30–34	665	13.95	555	16.29	1220	14.93
35–39	447	9.38	428	12.57	875	10.71
40+	297	6.23	400	11.74	697	8.53
Education (reported at first visit)						
Did not complete secondary	1400	29.37	426	12.51	1826	22.34
Completed secondary	3009	63.13	2813	82.59	5822	71.24
Further	357	7.49	167	4.90	524	6.41
Marital status (at enrolment)						
Married or living as married	2532	53.13	971	28.51	3503	42.87
Never married	1832	38.44	2361	69.32	4193	51.31
Divorced, separated or widowed	402	8.43	74	2.17	476	5.82
Any perceived stigma in the community[a]						
Agree, PC0 entry to cohort	1390/1917	72.51	841/1668	50.42	2231/3585	62.23
Agree, PC12 entry to cohort	890/1383	64.35	394/910	43.30	1284/2293	56.00
Agree, PC24 entry to cohort	910/1466	62.07	357/828	43.12	1267/2294	55.23
p value[b]				<0.01	<0.01	<0.01
Agree, all	3190/4766	66.93	1592/3406	46.74	4782/8172	58.52
Score (mean, SD)[c]	1.2	0.61	1.2	0.69	1.2	0.64
Any perceived stigma in healthcare settings[a]						
Agree, PC0 entry to cohort	543/1917	28.33	548/1668	32.85	1091/3585	30.43
Agree, PC12 entry to cohort	337/1383	24.37	226/910	24.84	563/2293	24.55
Agree, PC24 entry to cohort	301/1466	20.53	204/828	24.64	505/2294	22.01
p value[b]	<0.01	<0.01	<0.01			
Agree, all	1181/4766	24.78	978/3406	28.71	2159/8172	26.42
Score (mean, SD)[c]	0.9	0.66	1.1	0.69	1.0	0.67
Fear and judgement[a]						
Agree, PC0 entry to cohort	485/1917	25.30	304/1668	18.23	789/3585	22.01
Agree, PC12 entry to cohort	271/1383	19.60	188/910	20.66	459/2293	20.02
Agree, PC24 entry to cohort	296/1466	20.19	159/828	19.20	455/2294	19.83
p value[b]	<0.01	0.32	0.07			
Agree, all	1052/4766	22.07	651/3406	19.11	1703/8172	20.84
Score (mean, SD)[c]	0.8	0.58	0.9	0.58	0.9	0.58

Abbreviation: SD, standard deviation. PC0/PC12/PC24/PC36 population cohort at baseline, 12, 24 and 36 months.

[a] Entry to cohort indicates the first time the stigma questionnaire was given to participants.

[b] *p* value from chi square test looking at the differences in stigma measures over time by country and overall.

[c] All scores have a theoretical range from 0 (all answers of all individuals "Strongly Disagree") to 3 (all answers of all individuals "Strongly Agree"). A mean score of 1 indicates a person that, on average, responds "Disagree" to items within a score; a mean score of 2 indicates a person that on average responds "Agree."

individuals in China holding greater stigmatizing attitudes were more likely to be engaged in high-risk behaviour [24, 25]. The study we present here was much larger than these previous studies, and measured HIV incident infection as the outcome. However, we did not have direct data to test these associations, but the fact that we see no overall impact of HIV stigma on HIV incidence might indicate that these prevention behaviours were less relevant in our context.

At the community level, if HIV stigma affects the steps of care in the treatment cascade, then this might have

Table 2. HIV prevalence and community-level summaries of stigma, by country

	Zambia		**South Africa**		**Total**	
HIV prevalence[a]						
Baseline	21.0 (16.4–28.1)		21.2 (3.0–35.6)		21.1 (3.0–35.6)	
PC24	22.8 (16.5–30.9)		21.5 (3.6–36.1)		22.2 (3.6–36.1)	
Community-level summary of stigma, using data collected from:	**Community sample size (Arithmetic mean and range across communities)**	**Stigma prevalence*/score** (Geometric mean and range across communities)**	**Community sample size (Arithmetic mean and range across communities)**	**Stigma prevalence*/score** (Geometric mean and range across communities)**	**Community sample size (Arithmetic mean and range across communities)**	**Stigma prevalence*/score** (Geometric mean and range across communities)**
Community members living with HIV						
Experienced stigma (any), %	222 (106–353)	33.2% (18.9–55.0)*	170 (12–298)	23.2% (7.7–50.0)*	199 (12–353)	28.5% (7.7–55.0)*
Internalized stigma, mean score	226 (120–356)	0.9 (0.5–1.3)**	171 (12–300)	0.8 (0.6–1.0)**	202 (12–356)	0.8 (0.5–1.3)**
Experienced stigma in the community, %	224 (112–356)	23.6% (13.5–45.9)*	171 (12–300)	15.9% (3.6–41.7)*	202 (12–356)	19.9% (3.6–45.9)*
Experienced stigma in healthcare settings, %	225 (107–354)	4.3% (1.8–14.0)*	172 (12–299)	5.9% (1.3–16.7)*	202 (12–354)	4.9% (1.3–16.7)*
Community members not living with HIV						
Perceived stigma in the community, mean score	205 (125–266)	1.2 (0.8–1.5)**	181 (146–211)	1.2 (0.8–1.5)**	195 (125–266)	1.2 (0.8–1.5)**
Perceived stigma in healthcare settings, mean score	205 (122–273)	0.9 (0.6–1.3)**	181 (140–212)	1.1 (0.7–1.3)**	195 (122–273)	1.0 (0.6–1.3)**
Fear and judgement, mean score	195 (122–250)	0.9 (0.5–1.2)**	175 (140–208)	0.9 (0.6–1.1)**	186 (122–250)	0.9 (0.5–1.2)**
Health workers, self-reporting not living with HIV						
Perceived stigma among co-workers in healthcare settings, mean score	65 (24–128)	0.8 (0.6–1.1)**	30 (11–44)	0.8 (0.6–0.9)**	50 (11–128)	0.8 (0.6–1.1)**
Perceived stigma in the community, mean score	68 (41–126)	1.2 (0.9–1.4)**	27 (10–39)	1.5 (1.3–1.7)**	50 (10–126)	1.3 (0.9–1.7)**
Fear and judgement, mean score	68 (43–128)	0.7 (0.5–0.9)**	27 (11–42)	0.7 (0.6–0.9)**	50 (11–128)	0.7 (0.5–0.9)**

Note: In community-level analysis, measures of stigma were expressed as percentage/prevalence* or scores (0–3)** using the geometric mean. All scores have a theoretical range from 0 (all answers of all individuals “Strongly Disagree”) to 3 (all answers of all individuals “Strongly Agree”). A mean score of 1 indicates a person that, on average, responds “Disagree” to items within a score; a mean score of 2 indicates a person that on average responds “Agree.”

Abbreviations: HW, health workers; PC, population cohort; SR, self-report. PC24, population cohort at 24 months.

[a] Arithmetic mean and range in communities.

implications not only for PLHIV but also for those at risk of infection. In our previous work in this setting, we found limited evidence of an association between individual and community-level stigma measures and the prevalence of viral suppression among PLHIV. The only exception was for those who reported higher internalized stigma and who were less likely to be virally suppressed [15]. In this paper, our community-level analyses were intended to identify an association through the combined pathway of any effect of stigma on behaviour of those at risk of HIV infection as well as any impact on the likelihood that PLHIV may not be virally suppressed and/or having condomless sex. In the context of the literature, some may find the lack of any effect of HIV stigma on HIV incidence surprising. More large-scale studies

Table 3. Association between HIV stigma and HIV incidence (PC0–PC36) in the individual-level analysis cohort

Stigma measures	N/total person-yr (rate per 100 py)	Unadjusted IRR	Adjusted IRR[a]	Adjusted IRR[b]
Cohort-level analysis cohort (*n* = 26,110)	967/64,905 (1.49)			
Individual-level analysis cohort (*n* = 8172)	234/16,401 (1.43)			
Any perceived stigma in the community				
Don't agree	100/6570 (1.52)	1	1	1
Agree	134/9832 (1.36)	0.90 (0.67–1.20)	0.91 (0.68–1.21)	0.92 (0.69–1.23)
Any perceived stigma in healthcare settings				
Don't agree	168/11,776 (1.43)	1	1	1
Agree	66/4625 (1.43)	1.05 (0.78–1.41)	1.07 (0.79–1.44)	1.06 (0.79–1.42)
Fear and judgement				
Don't agree	193/12,898 (1.50)	1	1	1
Agree	41/3504 (1.17)	0.82 (0.58–1.17)	0.83 (0.59–1.17)	0.83 (0.59–1.17)
Score		0.92 (0.73–1.17)	0.92 (0.73–1.17)	0.92 (0.73–1.17)

Abbreviation: IRR, incidence rate ratio; PC, population cohort.
Note: All models were developed within a Poisson regression framework adjusted using community as a fixed term. Each circle represents one community. Size of the circles is proportional to the number of participants in each community. Dashed lines reflect linear regression slopes from cluster-level analyses of the associations and weighted by the size of the community in each cluster.
[a] Adjusted for sex and age group.
[b] Adjusted for sex, age group, marital status and education.

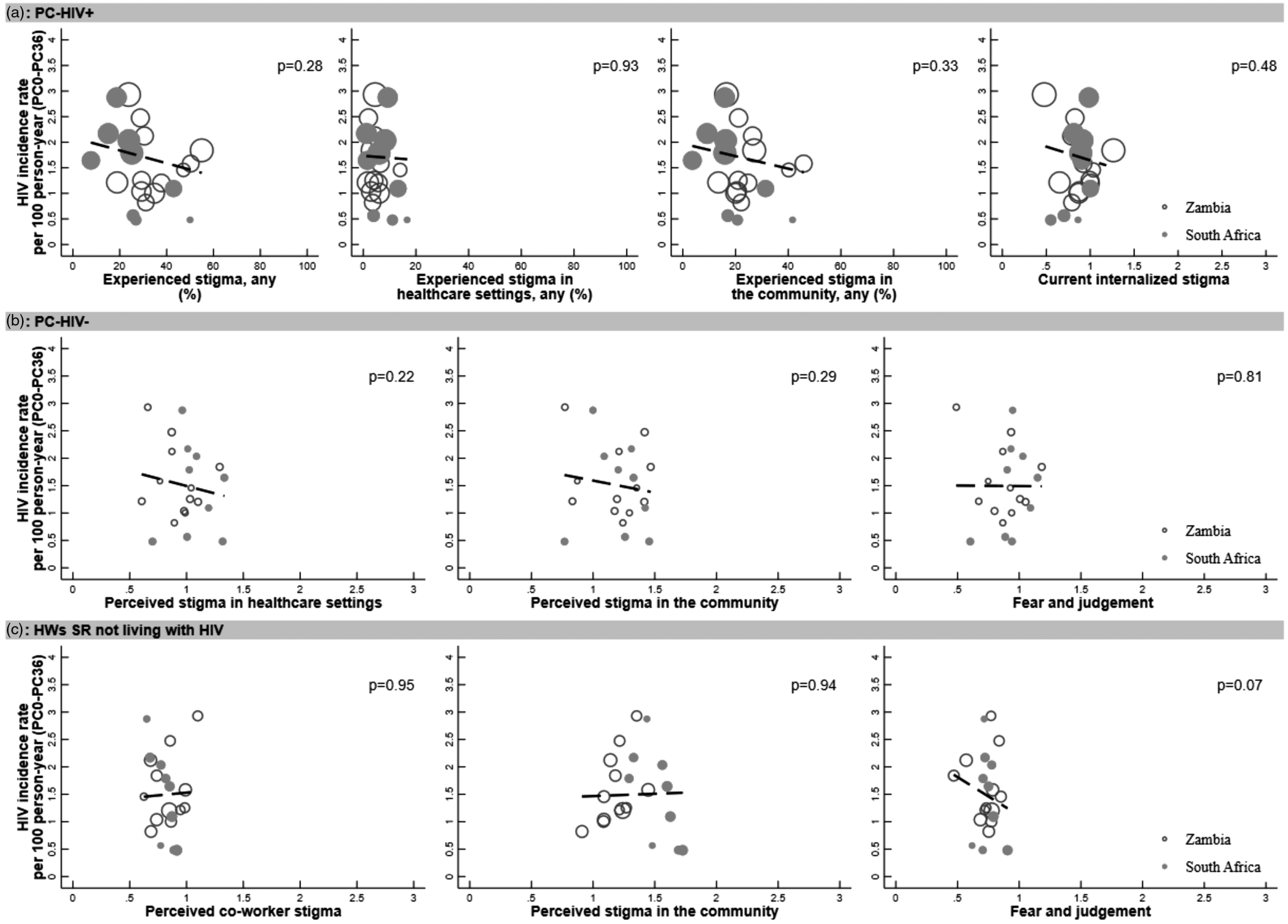
in other contexts would help deepen the research evidence base.

It is important to note that this analysis did not include items to measure the impacts of broader prejudice and discrimination experienced by a range of vulnerable and marginalized groups who in many settings may be at higher risk of HIV infection, including adolescent girls and young women, men who have sex with men, transgender people and female sex workers. We have published from our HW cohort on significant stigmatizing attitudes to some of these populations but did not include these items in this analysis because they were not asked of the participants [26]. These "key populations" experience overlapping, or intersectional, stigma and discrimination on the basis of their behaviour [27]. In some settings and for some populations, this also overlaps with socio-economic inequalities along gender and race/ethnicity lines. HIV prevention services and health promotion efforts require targeted efforts and sustained support if they are to reach and be most impactful among these groups.

Our study was conducted among a large, representative random sample of community members in 21 communities who were followed-up for up to 3 years to measure the risk of new HIV infection. We used theory-based, harmonized and validated measures of a range of domains of stigma across three different populations.

Nevertheless, our study had limitations. First, despite many years of research into measurement of stigma, and our use of best-practice measures, it remains a complex and evolving phenomenon, potentially subject to reporting biases. Therefore, the items we included to assess stigma may not have captured all the most important domains of stigma in our setting. Second, the communities we included were not randomly selected, or representative of the wide range of different types of community-level stigma that may be experienced. While there was a large amount of variation between communities in some aspects of stigma, there was less for others, limiting our capacity to explore associations. Third, these are secondary analyses of data collected for another purpose, and uncontrolled confounding may mask some true associations. Lastly, other intersecting stigmas that we did not measure, such as sexual behaviour stigma or key population stigma, may influence HIV incidence more strongly than HIV stigma.

What would be the policy implications if further research in other contexts confirmed no association between HIV stigma and risk of new HIV infection in other sub-Saharan African settings? This is good news in some ways—while stigma is a pernicious force that reduces the quality of life and health of PLHIV, its effects may not extend to heightening the risk of HIV infection. Efforts to eradicate HIV stigma are essential and must be redoubled for those already living with HIV and for those involved in HIV services, but these may not alone contribute to reducing the burden of new HIV infections. Societal enabling approaches to reduce HIV stigma and discrimination as well as remove legal barriers, reduce inequalities, improve gender equality and improve institutional and community structures will be needed to improve the effectiveness of HIV programmes and HIV outcomes [28]. Alternatively, further research in this area may help to identify which domains of stigma, under which conditions, do have a significant impact on HIV incidence, which would enable more optimized intervention design. For example, one area of growing importance is the emergence of reports of sigma related to a key HIV prevention tool, oral pre-exposure prophylaxis [29–32]. Community and clinic-based discussions, adherence clubs and



Each circle represents one community. Size of the circles are proportional to the number of participants in each community. Dashed lines reflect linear regression slopes from cluster-level analyses of the associations and weighted by the size of the community in each cluster.

Figure 2. The association between levels of HIV incidence between PC0 and PC36 and (a) internalized and experienced stigma reported by people living with HIV, (b) beliefs and perceptions of community members not living with HIV and (c) beliefs and perceptions of health workers self-reporting not living with HIV at PC24 and R2 in 21 communities in South Africa and Zambia.

activities normalizing sexual behaviour and HIV prevention are all critical components of the response.

5 | CONCLUSIONS

Our comprehensive analysis found no evidence of an association between HIV stigma and HIV incidence in the setting for the HPTN 071 "PopART" trial in Zambia and South Africa. Efforts to reduce new HIV infections and improve HIV prevention and treatment programmes considering HIV stigma in isolation may fail if not complemented by combination HIV prevention, with its biomedical, behavioural and structural components and person-centred, community-led approaches addressing all societal enablers of HIV, including stigma and discrimination. Continued scale up and strengthening of efforts to support the cascade of HIV prevention by increasing motivation to avoid HIV infection and use HIV prevention tools, removing barriers to access and empowering users to effectively use these tools over time are critical.

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COMPETING INTERESTS

There are no competing interests.

AUTHORS' CONTRIBUTIONS

JRH, GH, AS and VB conceptualized the manuscript. TP conducted the analysis with support from JRH and EW. TP, TM and CM-M oversaw in-country data collection of the health worker data set. NFB-M, EW, RD, ASc and DD managed the PC data sets. TP, CM-M and TM managed the health worker data sets. JH led the manuscript writing and conducted the literature review. RJH, SF, HA, PB and DD designed and led the cluster-randomized trial and population cohort study within which the study is nested. JS provided guidance and oversight to social science research within the trial. EP-M and YA oversaw the laboratory testing. GH and VB were responsible for the in-country management, including data collection, and with JRH and AS designed the questions on stigma included in this analysis and are co-investigators on the study protocol. All authors contributed to the writing of the article and have agreed the final draft for submission.

DISCLAIMER

The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIAID, NIMH, NIDA, PEPFAR, 3ie or the Bill & Melinda Gates Foundation.

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DATA AVAILABILITY STATEMENT

The data archive is held at Fred Hutch Cancer Center, Seattle, WA, USA. Requests can be sent to HPTN-Data-Access@scharp.org.

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SUPPORTING INFORMATION

Additional information may be found under the Supporting Information tab for this article:

Figure S1. Study timelines for the HPTN 071 (PopART) cluster randomized trial and the stigma ancillary study.

Figure S2. Probability of seroconversion between PC0 and PC36 by stigma measures and study arm among 8172 participants.

Figure S3. Probability of seroconversion between PC0 and PC36 by stigma measures and age groups among 8172 participants.

Table S1. Description of stigma exposure variables.

Table S2. Summary characteristics of the two study samples, by country.

Table S3. Association between individual HIV stigma statements and HIV incidence (PC0–PC36) in the individual-level analysis cohort (n = 8172).

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RESEARCH ARTICLE

Adaptation and psychometric evaluation of a scale to measure oral pre-exposure prophylaxis-related stigma among key and vulnerable populations in Kenya

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Abstract

Introduction: As oral pre-exposure prophylaxis (PrEP) services scale up throughout sub-Saharan Africa (SSA), clients continue to face challenges with sustained PrEP use. PrEP-related stigma has been shown to influence engagement throughout the HIV PrEP care continuum throughout SSA. Validated quantitative measures of PrEP-related stigma in SSA are of critical importance to better understand its impacts at each stage of the HIV PrEP care continuum. This study aimed to psychometrically evaluate a PrEP-related stigma scale for use among key and vulnerable populations in the context of a Kenya national PrEP programme.

Methods: As part of a larger prospective cohort study nested within Kenya's *Jilinde* programme, this study used baseline data collected from 1135 participants between September 2018 and April 2020. We used exploratory factor analysis to evaluate the factor structure of a PrEP-related stigma scale. We also assessed convergent construct validity of the PrEP-Related Stigma Scale by testing for expected correlations with depression and uptake of HIV services. Finally, we examined the relationship between PrEP-related stigma and key demographic, psychosocial and behavioural characteristics.

Results: We identified four dimensions of PrEP-related stigma: (1) interpersonal stigma, (2) PrEP norms, (3) negative self-image and (4) disclosure concerns. The scale demonstrated strong internal consistency ($\alpha = 0.84$), was positively correlated with depressive symptoms and negatively correlated with uptake of HIV services. Multivariable regression analysis demonstrated associations between PrEP-related stigma and sex worker identity.

Conclusions: The adapted and validated PrEP-Related Stigma Scale can enable programmes to quantify how PrEP-related stigma and its dimensions may differentially impact outcomes on the HIV PrEP care continuum, evaluate stigma interventions and tailor programmes accordingly. Opportunities exist to validate the scale in other populations and explore further dimensions of PrEP-related stigma.

Keywords: HIV care continuum; HIV prevention; key and vulnerable populations; PrEP; stigma

Additional information may be found under the Supporting Information tab of this article.

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1 | INTRODUCTION

Since the World Health Organization's 2015 recommendation of pre-exposure prophylaxis (PrEP) as an HIV prevention option for individuals at risk of HIV infection [1], countries throughout sub-Saharan Africa (SSA) have rapidly scaled oral PrEP service delivery [2]. While substantial progress has been made in oral PrEP awareness and initiation, research has shown that clients face individual, social and structural challenges with later phases of the HIV PrEP care continuum [3], including sustained PrEP use. One such challenge is PrEP-related stigma, which has been identified as a barrier for potential and current PrEP users throughout SSA [4–7]. Several studies have noted the important influence of stigma on decisions around PrEP disclosure and concealment [8–10], which has implications for support with and consistent use of PrEP.

PrEP-related stigma refers to stigma associated with the use of PrEP. In the literature, it has been linked to HIV stigma, given PrEP's association with HIV and common conflation of PrEP with HIV treatment. PrEP-related stigma also encompasses stigma related to sexual norms and behaviour and other perceived risks, rooted in cultural norms [11, 12]. The relationships between PrEP-related and sexual stigmas are particularly important among key and vulnerable populations (KVP), who have been the target of many PrEP programmes in SSA. For individuals using or considering PrEP, stigma experiences can include enacted stigma (stigmatizing behaviours from others because of PrEP use, including gossip or social exclusion), internalized stigma (shame or negative self-image related to PrEP use or consideration, based on societal beliefs about PrEP), perceived stigma (perceptions about how PrEP users are treated by others) or anticipated stigma (expectations that others will treat them differently because of PrEP) [13].

Despite emerging qualitative literature around PrEP-related stigma and its impacts [14–20], quantitative assessment of PrEP-related stigma remains sparse. This is particularly true in SSA, where PrEP implementation continues to scale up among diverse populations. Quantitative measures of PrEP-related stigma are critical to understand and intervene upon its impacts at each stage of the PrEP care continuum, and to evaluate PrEP-related stigma reduction programmes. This has implications for the broader HIV care continuum, given the potential for PrEP services to improve rates of HIV screening and diagnosis [21]. However, where PrEP-related stigma scales have been developed, they have only been validated among United States (U.S.) populations [17, 22–25]. Indeed, we identified only one study from SSA, which used a dedicated scale to measure PrEP-related stigma, which was adapted from scales developed for U.S. populations [26]. While this scale was found to be internally consistent among the study population, the authors did not report on its validity or other psychometric properties. To fill this critical measurement gap and improve understandings of PrEP-related stigma, we adapted and psychometrically evaluated a PrEP-related stigma scale for use among KVP in the context of a nationally scaled PrEP programme in Kenya.

2 | METHODS

2.1 | Study setting and sample

This study uses baseline survey data from a prospective cohort study within Kenya's *Jilinde* programme, which has been supporting oral PrEP services in 10 Kenyan counties since 2016 [27]. Through partnership with the Government of Kenya, *Jilinde* supported oral PrEP services for individuals most vulnerable to HIV infections, with a focus on men who have sex with men (MSM), female sex workers (FSW) and adolescent girls and young women (AGYW).

Participants were recruited into the study when accessing oral PrEP services (prescribing, counselling, risk assessment or eligibility determination) at a *Jilinde*-supported site. After the first clinical visit, PrEP providers briefly introduced the study to potential participants; those interested were referred to trained on-site data collectors for confirmation of eligibility and consent. Eligible clients had to be MSM, AGYW or FSW who initiated PrEP or were eligible to receive PrEP from a PrEP site. We excluded individuals who were ineligible for PrEP or were unwilling to participate. We did not exclude participants who declined PrEP.

2.2 | Data collection

Baseline data were collected between September 2018 and April 2020. Surveys were administered on the day of enrolment using an interviewer-administered questionnaire. Data collectors were experienced, trained quantitative interviewers with degrees or diplomas in health or social sciences. The questionnaire was administered in English, Kiswahili and Dholuo, based on the preferred language of each participant.

We collected data in REDCap using tablets, and uploaded data into a secure REDCap database for analysis [28].

2.3 | Measures

The baseline questionnaire assessed socio-demographic characteristics, prior PrEP use, recent sexual behaviour, uptake of HIV-related services, HIV risk perception, depressive symptoms and perceived PrEP-related stigma. We also asked participants whether they self-identified as MSM, AGYW or sex workers (regardless of gender). We offered the option to self-identify with multiple groups or with none, and categorized participants based on how they identified rather than on their presumed identity during study recruitment (i.e. if men did not self-identify as MSM, or if women did not identify as either FSW or AGYW, we did not impose these categories).

2.3.1 | *PrEP-related stigma*

The PrEP-Related Stigma Scale included 12 items with 4-point Likert response categories: strongly disagree, disagree, agree and strongly agree. At the time of study development (2017), no validated measures of PrEP-related stigma existed. We reviewed the literature and determined Reinius et al.'s 12-item adaptation of the Berger HIV Stigma Scale (HSS) [18, 29] to be most suitable based on language, content and framing of items. We adapted the items to be framed towards future PrEP use by replacing "because you have HIV" with "because you have thought about using PrEP" or "once you have started PrEP" (Table S1). Through consultation with clinicians and members of the KVP community, we made additional adaptations based on the study context and PrEP implementation experiences. For example, for an item which in the HSS asks about perceptions of people living with HIV as dirty, we replaced "dirty" with "immoral" to reflect PrEP use as a behaviour, rather than a condition.

2.3.2 | *Sexual behaviour*

We asked respondents their number of recent (within the past month) partners, condom use with recent (last month) partners (always/sometimes/never) and HIV status of recent partners. For sex workers, we asked about duration of sex work and whether they ever had condomless sex with clients (yes or no).

2.3.3 | *Uptake of services*

We asked if participants had ever accessed HIV-related services from an MSM-, sex worker- or AGYW-serving organization. For those who had, we calculated their total reported number of visits in the last 12 months to measure uptake of HIV-related services at KVP-serving organizations; those who had not ever accessed such services were assigned a value of 0 visits in the last 12 months. We also asked whether they had previously been offered PrEP (yes/no).

2.3.4 | HIV risk perception

We assessed HIV risk perception using a single question: "To what extent do you feel vulnerable to/at risk for HIV infection from any source?" Response options included high risk, medium risk, low risk or no risk.

2.3.5 | Depressive symptoms

We measured depressive symptoms using the Patient Health Questionnaire-9 (PHQ-9; Cronbach's alpha = 0.84) [30]. The PHQ-9 has been validated among adults living with HIV and community members in Kenya [31], and is increasingly used to evaluate psychological distress with vulnerable populations in SSA [32–35]. We used total PHQ-9 scores, which ranged from 0 to 27; consistent with previous research in the region [36], we classified individuals with scores of 10 or above as having symptoms suggestive of depression. Respondents who did not respond to all nine items (n = 22) were classified as missing.

2.4 | Statistical analysis

We calculated descriptive statistics for socio-demographic characteristics, partner HIV status, number of recent partners and primary partner's HIV status, history with PrEP, depression and uptake of HIV services from KVP-serving organizations.

2.5 | Evaluation of factor structure

To determine the number of factors to extract during exploratory factor analysis (EFA), we first examined the results of a principal component analysis (PCA) [37]. Given all items had 4-point Likert response categories, PCA was performed with a polychoric correlation matrix of item responses. Selection of number of factors for EFA was informed by examination of a scree plot, parallel analysis and the number of eigenvalues >1.0.

Based on an omnibus test revealing deviation from normality, we used iterative principal factor estimation for EFA, with oblique rotation to yield a final solution. Items with loadings on a single factor of at least 0.40 and uniqueness below 0.50 were retained.

2.6 | Assessment of internal consistency and construct validity

Based on the factor structure, we developed four subscales using simple mean scores. Each subscale had three items, with scores ranging from 0 to 3; a score of 3 indicated respondents "strongly agreed" with all items. We also generated a total PrEP-related stigma score by summing mean subscale scores, with total scores ranging from 0 to 12. As with subscale scores, higher total scores indicated higher levels of PrEP-related stigma. We used Cronbach's alpha and McDonald's omega to assess internal consistency of the overall scale and subscales. We also evaluated item-test and inter-item correlations.

We assessed convergent construct validity of the PrEP-Related Stigma Scale by testing for expected correlations between PrEP-related stigma (total score and subscale scores) and depressive symptoms (composite PHQ-9 score), as well as PrEP-related stigma and uptake of HIV services (total visits in the last 12 months). We hypothesized that PrEP-related stigma would have a positive correlation with depressive symptoms and a negative correlation with HIV services uptake.

2.7 | Factors associated with stigma

To examine how this scale could be used in research settings and to profile who may be more likely to experience PrEP-related stigma, we used linear regression to estimate associations between the outcome of PrEP-related stigma and socio-demographic characteristics hypothesized to be related to stigma. We first examined bivariate, unadjusted associations between total PrEP-related stigma scores and age, gender, HIV risk perception, partner HIV status, prior offers of PrEP and population group. Among FSW, we also examined associations with years in sex work. We then estimated four adjusted multivariable models: one with the full sample and one each with AGYW, FSW and MSM. Adjusted models included all variables found to be associated with PrEP-related stigma in unadjusted models based on a cut-off of p <0.25.

All analyses were conducted in Stata Version 15.

2.8 | Ethical considerations

Ethics approvals for the study were obtained from the Kenya Medical Research Institute Scientific Ethics Review Unit and the Johns Hopkins Bloomberg School of Public Health Institutional Review Board. All data collectors received training on human subject protections and gender and sexual diversity. Study protocols ensured that sensitive questions were only asked when participants had been informed about the questions and were ready to continue. All participants provided written informed consent, with the option to omit names from consent forms or use a thumbprint.

3 | RESULTS

In total, 1196 individuals were referred by providers and screened for study inclusion. Of 1181 eligible, 46 declined participation. Our final sample included 1135 participants who completed the baseline questionnaire (Table 1). Just over half (56.6%) identified as sex workers (55.2% FSW and 1.4% male sex workers). Less than one-tenth (9.3%) were MSM, and 26.7% were AGYW; 79 respondents (7.0%) did not identify as MSM, sex workers or AGYW.

The median age was 24 years (interquartile range [IQR]: 20–29); FSW were slightly older than others (median age 27, IQR 22–32). Most participants (88.6%) self-identified as women, and over half (59.3%) had completed primary school or less. The majority (81.2%) were unmarried, and 54.9% reported three or more recent (last month) sexual partners. A greater proportion of AGYW were married (34.8%) than

Table 1. Characteristics of participants at baseline

	Full sample (*n* = 1135)[a]	**AGYW (*n* = 303)**[c]	**FSW (*n* = 626)**[c]	**MSM (*n* = 105)**[c]
Age (median [IQR])	24 [20–29]	20 [18–22]	27 [22–32]	23 [21–25]
Self-reported gender identity				
Man	104 (9.2%)	0 (0.0%)	0 (0.0%)	81 (77.9%)
Woman	999 (88.6%)	302 (100.0%)	626 (100.0%)	0 (0%)
Other[b]	25 (2.2%)	0 (0.0%)	0 (0.0%)	23 (22.1%)
Geographic region				
Nairobi (Nairobi, Machakos and Kiambu Counties)	292 (25.8%)	6 (2.0%)	179 (28.6%)	84 (80.0%)
Lake (Kisumu, Migori and Kisii Counties)	434 (38.3%)	289 (95.4%)	108 (17.3%)	17 (16.2%)
Coast (Mombasa, Kilifi and Kwale Counties)	407 (35.9%)	8 (2.6%)	338 (54.1%)	4 (3.8%)
Education level				
Less than primary	118 (10.4%)	32 (10.6%)	66 (10.5%)	1 (1.0%)
Primary	554 (48.9%)	172 (56.8%)	327 (52.2%)	17 (16.2%)
Secondary	353 (31.2%)	74 (24.4%)	188 (30.0%)	60 (57.1%)
Tertiary	107 (9.5%)	25 (8.3%)	45 (7.2%)	27 (25.7%)
Employment status				
Unemployed/student	492 (43.5%)	239 (78.9%)	161 (25.8%)	59 (56.7%)
Self-employed	407 (36.0%)	36 (11.9%)	314 (50.2%)	18 (17.3%)
Regularly employed, part-time	80 (7.1%)	9 (3.0%)	50 (8.0%)	12 (11.5%)
Regularly employed, full-time	47 (4.2%)	12 (4.0%)	21 (3.4%)	7 (6.7%)
Seasonally employed	104 (9.2%)	7 (2.3%)	79 (12.6%)	8 (7.7%)
Gross monthly income, USD (median [IQR])	44 [1–131]	0 [0–1]	79 [35–153]	52 [1–131]
Marital status				
Unmarried	917 (81.1%)	191 (63.2%)	562 (89.8%)	93 (88.6%)
Married	156 (13.8%)	105 (34.8%)	28 (4.5%)	7 (6.7%)
Domestic partnership	57 (5.0%)	5 (1.7%)	36 (5.8%)	5 (4.8%)
Number of recent sex partners				
1	285 (26.6%)	197 (71.6%)	27 (4.4%)	26 (27%)
2	198 (18.5%)	55 (20.0%)	80 (13.0%)	28 (29%)
3 or more	587 (54.9%)	23 (8.4%)	509 (82.6%)	42 (44%)
Partner HIV status[d]				
Living with HIV	12 (5.7%)	4 (3.7%)	5 (8.0%)	0 (0%)
Not living with HIV	118 (55.7%)	64 (58.7%)	35 (55.0%)	11 (92.0%)
Unknown HIV status	82 (38.7%)	41 (37.6%)	24 (38.0%)	1 (8.0%)
Ever offered PrEP before				
Yes	75 (6.6%)	27 (8.9%)	35 (5.6%)	12 (11.4%)
No	1056 (93.4%)	275 (91.1%)	590 (94.4%)	93 (88.6%)
HIV risk perception				
No risk	50 (4.5%)	21 (7.1%)	17 (2.7%)	6 (5.7%)
Low risk	143 (12.8%)	52 (17.7%)	50 (8.0%)	26 (24.8%)
Medium risk	416 (37.3%)	143 (48.6%)	214 (34.3%)	45 (42.9%)
High risk	507 (45.4%)	78 (26.5%)	342 (54.9%)	28 (26.7%)
Depressive symptoms				
Not suggestive of depression	868 (78.0%)	264 (88.9%)	442 (71.2%)	89 (84.8%)
Suggestive of depression	245 (22.0%)	33 (11.1%)	179 (28.8%)	16 (15.2%)
Uptake of HIV services, last 12 months				
No visits	446 (43.2%)	74 (24.7%)	311 (50.1%)	51 (48.6%)
1–2 visits	315 (30.5%)	113 (37.7%)	166 (26.7%)	37 (35.2%)
3–6 visits	242 (23.4%)	105 (35.0%)	127 (20.5%)	13 (12.4%)
7 or more visits	29 (2.8%)	8 (2.7%)	17 (2.7%)	4 (3.8%)

[a] Missing values not shown.

[b] Includes transgender men (*n* = 4), transgender women (*n* = 18), intersex individuals (*n* = 2) and those with other, unknown or unreported gender identities (*n* = 5).

[c] Not mutually exclusive. Respondents could select all group identities that applied, though MSM and male sex worker categories were only presented to self-identified men and FSW/AGYW categories to self-identified women. No men reported multiple categories; 13 women respondents reported identifying as both AGYW and FSW. 16 men identified as male sex workers. 79 individuals reported not identifying as any risk group.

[d] Among those reporting being married or in domestic partnerships (*n* = 213).

Abbreviations: AGYW, adolescent girls and young women; FSW, female sex workers; IQR, interquartile range; MSM, men who have sex with men; PrEP, pre-exposure prophylaxis; USD, United States Dollar.

FSW (4.5%) or MSM (6.7%), and most AGYW (71.6%) had only one recent partner. Of those with primary partners, 38.7% reported not knowing their partner's HIV status. Most respondents (93.4%) had never been offered PrEP before the initial visit. Prior offers of PrEP were most common among MSM (11.4%).

In terms of HIV risk perception, 4.4% of respondents felt that they were not vulnerable to HIV infection, while 44.9% felt that they were at high risk. The majority of FSW (54.9%) reported feeling at high risk, compared with smaller percentages of AGYW (26.5%) and MSM (26.7%). Reports of visiting sex worker-, MSM- or AGYW-serving organizations for HIV services varied, with 43.2% of respondents saying they had not visited these sites in the last 12 months, 30.5% reporting one or two visits and 2.8% reporting seven or more visits. FSW (50.1%) and MSM (48.6%) more commonly reported not taking up HIV services than AGYW (24.7%). Finally, symptoms suggestive of depression were identified in 22.0% of respondents, with over one-quarter (28.8%) of FSW reporting depressive symptoms.

3.1 | PrEP-Related Stigma Scale factor structure

PCA of the 12 items produced four eigenvalues over one (range: 1.1–5.2) that together explained 80% of the variance. Examination of the scree plot and parallel analysis similarly favoured a four-factor model. Results from this factor analysis with oblique rotation are provided in Table 2. Factor loadings ranged from 0.70 to 0.94, with all items loading strongly onto at least one factor (loadings >0.40) and no items having uniqueness <0.50. As such, no items were dropped from the analysis.

We identified four factors (Table 2), which were named interpersonal stigma (factor 1), PrEP norms (factor 2), negative self-image (factor 3) and disclosure concerns (factor 4). In Table 2, we have indicated the type of stigma measured by each factor (internalized, perceived and anticipated).

Factor correlations were moderately positive, with the highest correlations observed between factors 1 and 2 (interpersonal stigma and PrEP norms; $r = 0.49$) and factors 2 and 3 (PrEP norms and negative self-image; $r = 0.51$). Factors 3 and 4 (negative self-image and disclosure concerns) had the weakest correlation ($r = 0.15$).

3.2 | Internal consistency and construct validation

For the internal consistency analysis of the full scale, the Cronbach's alpha and McDonald's omega were both 0.84. Cronbach's alpha (α) values for subscales ranged from 0.78 to 0.84 (interpersonal stigma $\alpha = 0.83$; PrEP norms $\alpha = 0.78$; negative self-image $\alpha = 0.84$; and disclosure concerns $\alpha = 0.80$). McDonald's omega (ω) values ranged from 0.79 to 0.84 (interpersonal stigma $\omega = 0.84$; PrEP norms $\omega = 0.79$; negative self-image $\omega = 0.84$; and disclosure concerns $\omega = 0.80$). The average inter-item correlation was 0.31, and all item-test correlations were >0.50.

Correlations between PrEP-related stigma scores with other constructs are presented in Table 3. Overall, PrEP-related stigma demonstrated a significantly small but positive correlation with depression, and small but negative correlation with uptake of HIV services. Subscales were significantly positively correlated with depression; only the factor 2 (PrEP norms) and factor 3 (negative self-image) subscales were significantly correlated with HIV services uptake.

3.3 | PrEP-related stigma prevalence and associated factors

Out of 12 possible points, the mean overall PrEP-related stigma score was 4.3 (SD 1.9). On subscales, scores were highest for the disclosure concerns subscale (mean 1.8, SD 0.8) and lowest for negative self-image (mean 0.5, SD 0.6). Scores averaged at 0.8 of 3 (SD 0.7) for interpersonal stigma and 1.1 of 3 (SD 0.7) for PrEP norms.

In subgroup analyses, overall PrEP-related stigma scores were higher among MSW (mean 4.6, SD 1.7) and FSW (mean 4.5, SD 1.7) compared to AGYW (mean 3.9, SD 2.2) or MSM (mean 4.3, SD 2.0). On subscales (Figure 1), MSM scored highest on the interpersonal stigma subscale (mean 0.9, SD 0.6), while FSW scored highest on the PrEP norms subscale (mean 1.2, SD 0.6) and MSW highest on the disclosure concerns subscale (mean 2.0, SD 0.7). Across groups, scores were highest on the disclosure concerns subscale and lowest on the negative self-image subscale.

In unadjusted models (Table 4), PrEP-related stigma was found to be associated with increased age ($\beta = 0.02$, $p < 0.01$), medium HIV risk perception ($\beta = 0.62$, $p = 0.03$), previous offers of PrEP ($\beta = -0.50$, $p = 0.03$) and identifying as a sex worker ($\beta = 0.46$, $p < 0.001$). In a multivariable model with the full sample (model 1), PrEP-related stigma was shown to be associated with identifying as a sex worker; adjusting for covariates, sex workers reported higher levels of PrEP-related stigma than others ($\beta = 0.49$, $p < 0.001$). In subgroup analyses with AGYW (model 2) and MSM (model 4), no variables were found to be associated with PrEP-related stigma. In the model with FSW (model 3), we found that FSW who reported low HIV risk perception had higher levels of PrEP-related stigma, adjusting for covariates ($\beta = 0.97$, $p = 0.04$).

4 | DISCUSSION

This is among the first studies to adapt and evaluate the psychometric properties of a scale to measure PrEP-related stigma in SSA. The final scale included 12 items. Factor analysis revealed a four-factor structure, corresponding to dimensions interpersonal stigma (factor 1), PrEP norms (factor 2), negative self-image (factor 3) and disclosure concerns (factor 4). The scale demonstrated strong internal consistency and appropriate convergent construct validity.

The four dimensions identified through this analysis align closely with those in the HSS from which our measure was adapted [29]. While this is to be expected given close alignment of the items (S1), our adaptation offers a validated measure to examine these dimensions as they relate to PrEP more specifically. While previously validated measures of PrEP-related stigma are limited to U.S. contexts, it is worth examining how our scale aligns with these existing measures. Similar to our scale, Siegler et al.'s 13-item measure of PrEP stigma [24] examined perceived, anticipated and internalized stigma; however, unlike our multidimensional scale, it was

Table 2. PrEP-Related Stigma Scale item means, factor loadings and factor correlations (*n* = 1135)

	Factor loadings[b]				
Items[a]	**Factor 1: Inter-personal stigma (anticipated)**	**Factor 2: PrEP norms (perceived)**	**Factor 3: Negative self-image (internalized)**	**Factor 4: Disclosure concerns (anticipated)**	**Uniqueness**
1. Are you afraid people you care about will stop calling after learning you have started or thought of using PrEP?	**0.84**	0.03	−0.01	−0.01	0.28
2. Are you afraid of losing friends if you tell them you have started or thought of using PrEP?	**0.94**	−0.03	−0.02	0.00	0.16
3. Some people might avoid touching you once they know you have started or thought of using PrEP.	**0.72**	0.04	0.09	0.01	0.37
4. You would work hard to keep your use of PrEP a secret.	0.07	−0.01	0.01	**0.83**	0.26
5. Telling someone you have thought of using PrEP is risky.	0.07	−0.07	0.02	**0.74**	0.45
6. You will be very careful who you tell that you have thought of using PrEP.	−0.11	0.08	−0.03	**0.85**	0.28
7. Most people you know believe a person who takes PrEP is immoral.	−0.01	**0.73**	−0.07	0.07	0.47
8. People you know who take PrEP are treated like outcasts.	−0.01	**0.87**	0.05	−0.02	0.23
9. Most people you know are uncomfortable around someone who takes PrEP.	0.08	**0.70**	0.11	0.01	0.35
10. You feel guilty because you have thought of using PrEP.	−0.02	0.05	**0.85**	0.00	0.25
11. People's attitudes about using PrEP make you feel worse about yourself.	0.04	0.07	**0.81**	0.00	0.25
12. You feel you are not as good a person as others because you have thought of using PrEP.	0.00	−0.05	**0.92**	0.00	0.19
	Internal consistency reliability coefficients				
Cronbach's alpha (α)	α = 0.83	α = 0.78	α = 0.84	α = 0.80	
McDonald's omega (ω)	ω = 0.84	ω = 0.79	ω = 0.84	ω = 0.80	

	Factor correlations			
	Factor 1	**Factor 2**	**Factor 3**	**Factor 4**
Factor 1: Interpersonal stigma	1			
Factor 2: PrEP norms	0.49	1		
Factor 3: Negative self-image	0.48	0.51	1	
Factor 4: Disclosure concerns	0.38	0.42	0.15	1

Abbreviation: PrEP, pre-exposure prophylaxis.

[a] All item responses were on a 4-point range from "strongly disagree" to "strongly agree." These items have been shortened; their exact wording is listed in the Supplementary File.

[b] The highest factor loading for each item is bolded.

Table 3. Correlation matrix of PrEP-related stigma, depression and engagement with PrEP services

	PrEP-related stigma: total score	Factor 1: Inter-personal stigma	Factor 2: PrEP norms	Factor 3: Negative self-image	Factor 4: Disclosure concerns	PHQ-9 total score	HIV services uptake
PrEP-related stigma (total score)	1.0						
Factor 1: Inter-personal stigma	0.73***	1.0					
Factor 2: PrEP norms	0.76***	0.41***	1.0				
Factor 3: Negative self-image	0.64***	0.39***	0.40***	1.0			
Factor 4: Disclosure concerns	0.69***	0.31***	0.35***	0.15***	1.0		
Depression (PHQ-9 total score)	0.20***	0.10*	0.20***	0.09**	0.15***	1.0	
HIV services uptake (visits last 12 months)	–0.07*	–0.02	–0.08*	–0.07*	–0.03	0.07*	1.0

$^{*}p$ <0.05.
$^{**}p$ <0.01.
$^{***}p$ <0.001.

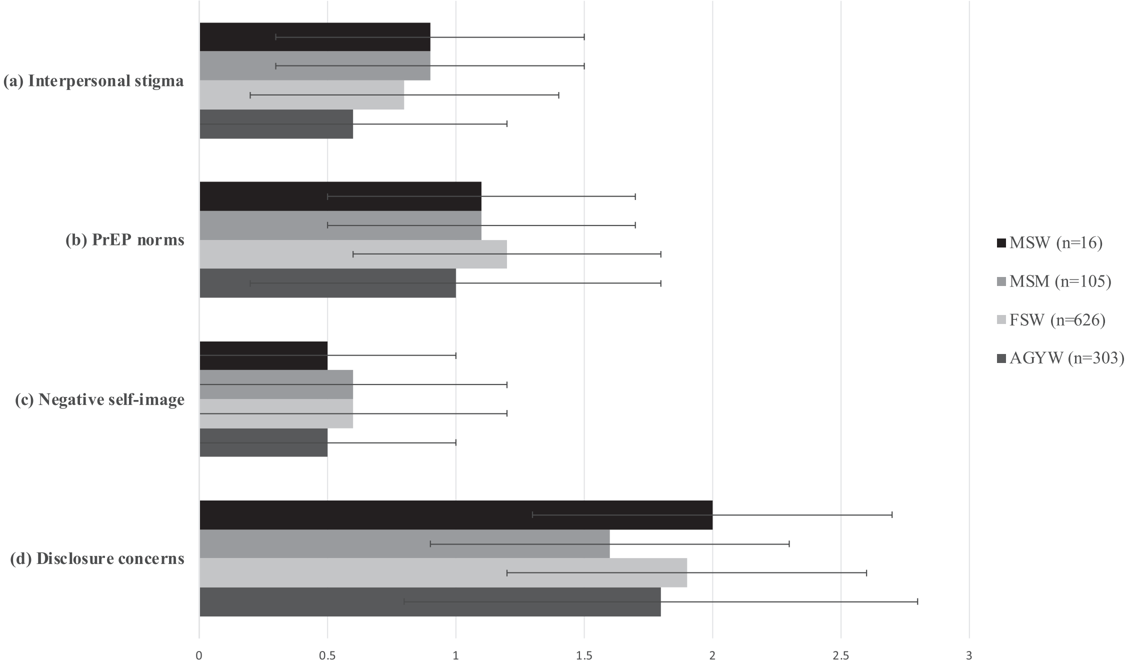

Figure 1. Means and standard deviations for PrEP-related stigma scores by subgroup (*n* = 1135). (a) Interpersonal stigma subscale; (b) PrEP norms subscale; (c) negative self-image subscale; and (d) disclosure concerns subscale. Shaded bars represent mean values for each scale per subgroup; error bars represent standard deviations from the mean. In each group (a–d), black (top) bars represent male sex workers (MSW, *n* = 16); medium grey (second from top) bars represent men who have sex with men (MSM, *n* = 105); light grey (third from top) bars represent female sex workers (FSW, *n* = 616); and dark grey (bottom) bars represent adolescent girls and young women (AGYW, *n* = 303). Possible scores ranged from 0 to 3 for each subscale (a–d). Abbreviations: PHC-9, Patient Health Questionnaire-9; PrEP, pre-exposure prophylaxis.

found to be unidimensional. Klein and Washington's shortened 11-item PrEP Stigma Scale [38] identified two high-performing dimensions of stigma, including a dimension of interpersonal concerns, which aligns with our interpersonal stigma dimension (factor 1). Our PrEP norms dimension aligns with several other measures, which have PrEP user stereotypes and community norms to be key dimensions of PrEP-related stigma [17, 22, 25]. Others have identified dimensions of PrEP stigma unmeasured in our study but important for future research. For example, Algarin et al.'s multidimensional Community PrEP-Related Stigma Scale [25] identified a dimension of positive community perceptions of PrEP.

We found that PrEP-related stigma was associated with sex worker identity, and that PrEP-related stigma was generally more prevalent among FSW than among MSM or AGYW. This sheds light on the ways in which PrEP-related stigma experiences may meaningfully vary based on the diverse identities and social positions of PrEP users. In our study, respondents identifying as sex workers (regardless of gender) reported higher levels of anticipated, perceived and internalized

Table 4. Linear regression of PrEP-related stigma on key characteristics

	Unadjusted associations		Model 1: Full sample (n = 1135)		Model 2: AGYW (n = 303)		Model 3: FSW (n = 626)		Model 4: MSM (n = 105)	
Characteristic	**β**	**SE**	**β**	**SE**	**β**	**SE**	**β**	**SE**	**β**	**SE**
Age	0.02[**]	0.01	0.13	0.09	0.02	0.04	0.01	0.01	0.03	0.04
Self-reported gender identity										
Woman	REF	REF	REF	REF	–	–	–	–	–	–
Man	0.14	0.20	0.39	0.21	–	–	–	–	–	–
Other	–0.44	0.39	–0.05	0.39	–	–	–	–	–	–
Perceived HIV risk										
No risk	REF	REF	REF	REF	REF	REF	REF	REF	REF	REF
Low risk	0.48	0.32	0.42	0.31	0.19	0.58	0.97[*]	0.47	–0.89	0.92
Medium risk	0.62[*]	0.29	0.53	0.29	0.63	0.52	0.73	0.42	–0.76	0.88
High risk	0.42	0.28	0.21	0.28	0.70	0.55	0.29	0.42	–0.88	0.91
Partner HIV status[a]										
Living with HIV	REF	REF	–	–	–	–	–	–	–	–
Not living with HIV	–0.59	0.62	–	–	–	–	–	–	–	–
Unknown HIV status	0.14	0.14	–	–	–	–	–	–	–	–
Previously offered PrEP										
No	REF	REF	REF	REF	REF	REF	REF	REF	REF	REF
Yes	–0.50[*]	0.23	–0.51[*]	0.23	–0.67	0.46	–0.74[*]	0.29	0.03	0.64
Identifies as MSM[a]										
No	REF	REF	–	–	–	–	–	–	–	–
Yes	0.40	0.20	–	–	–	–	–	–	–	–
Identifies as sex worker										
No	REF	REF	REF	REF	–	–	–	–	–	–
Yes	0.46[**]	0.12	0.49[**]	0.14	–	–	–	–	–	–
Years in sex work[b]										
Less than 1 year	REF	REF	–	–	–	–	REF	REF	–	–
1–2 years	0.34	0.33	–	–	–	–	0.26	0.33	–	–
3–5 years	0.34	0.33	–	–	–	–	0.31	0.33	–	–
6–9 years	0.57	0.38	–	–	–	–	0.44	0.39	–	–
10+ years	–0.07	0.41	–	–	–	–	–0.27	0.43	–	–

Abbreviations: AGYW, adolescent girls and young women; FSW, female sex workers; MSM, men who have sex with men; PrEP, pre-exposure prophylaxis.

[a] Variable excluded from multivariate models based on $p > 0.25$ during bivariate analysis.

[b] Among those reporting sex work.

[*] $p < 0.05$.

[**] $p < 0.01$.

PrEP-related stigma, suggesting PrEP-related stigma may be different among sex workers than others. While we did not measure sex work stigma directly, this relates to other literature describing intersecting PrEP and sex work stigmas [8, 11, 39]. Indeed, scholars have identified intersections between PrEP-related stigma and other forms of stigma and discrimination (including racial discrimination, transphobia, sexual stigma and others) in other populations [7, 17, 40, 41]. Further exploration of these intersections in SSA contexts is warranted through the use of parallel measures examining different identities and social positions [42].

Our PrEP-Related Stigma Scale makes an important contribution to the literature regarding stigma as a determinant of engagement with HIV services. Though much previous research regarding stigma and HIV services has focused on engagement in care and treatment for PLHIV [43, 44], this new scale enables more focused examination of stigma among individuals engaging with or considering an HIV prevention intervention. This valid and reliable instrument enables programmes to consider how PrEP-related stigma and its dimensions may differentially impact engagement with PrEP services, tailor programmes accordingly and evaluate the impacts of stigma reduction or mitigation programmes. For example, our finding that PrEP-related stigma was higher among those reporting sex work suggests a need for tailored stigma mitigation interventions among this population. Further, our finding that disclosure concerns were more common than negative self-image related to PrEP suggests a need for tailored support and safety planning to PrEP users who may conceal their PrEP use [45–47]. This scale also enables researchers to examine the impacts of PrEP-related stigma on other HIV care continuum outcomes, such as uptake of HIV testing during PrEP services, PrEP initiation, adherence and continuation or other patterns of PrEP use.

4.1 | Limitations

There are limitations to this research. First, the generalizability of our sample is limited, as our recruitment protocol which may have resulted in a sample highly motivated about PrEP. Further, we focused on three geographic regions in Kenya and the majority of our respondents were women and had partners who were either not living with HIV or had unknown HIV status. Second, while all participants in our study were new PrEP clients who had received counselling and education about PrEP through *Jilinde*, they may have had differing levels of prior exposure to PrEP, which may have influenced stigma. We were unable to thoroughly assess this prior exposure in our survey. Third, this was a cross-sectional analysis limited to baseline data, which limits the ability to draw causal inferences from our regression analysis. Longitudinal analysis was outside the scope of this study, but further analyses should examine the impacts of PrEP-related stigma at later stages of the HIV PrEP care continuum, including PrEP discontinuation and patterns of cycling PrEP use. Fourth, our study involved a close adaptation of an existing measure, which was designed to evaluate broader HIV stigma, rather than PrEP-related stigma specifically. While previous research has shown that PrEP-related stigma is highly related to HIV stigma, it is possible that there are additional dimensions of PrEP-related stigma not assessed with our adapted instrument. For example, previous work has found that PrEP is often associated with negative attitudes towards sexual practices and behaviour, such as sexual activity among AGYW, sex work or same-sex partnerships [7]. These relationships are context-dependent and warrant further investigation. Finally, we were not able to assess enacted PrEP-related stigma (e.g. “Has anyone ever gossiped about you because you use PrEP?”), as this was a baseline assessment among individuals who had not yet started PrEP. This may limit the generalizability of our scale to assess stigma experiences among current PrEP users.

5 | CONCLUSIONS

The PrEP-Related Stigma Scale has been shown as an appropriate scale for use among diverse communities in Kenya. This instrument, which was validated and found reliable in our study population, offers researchers a tool for quantifying experiences of anticipated, perceived and internalized PrEP-related stigma among diverse populations, to better understand its impacts on engagement with the HIV PrEP care continuum. Opportunities exist to validate the scale in other populations and to explore other dimensions of PrEP-related stigma, including those that may vary based on the unique identities and positions of PrEP users.

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COMPETING INTERESTS

The authors declare no competing interests.

AUTHORS’ CONTRIBUTIONS

DW, AM and JR conceptualized the study. KA and LK analysed the data, with supervision from DM. KA drafted the manuscript. LK, AM, JR, DW and DM provided critical review and feedback on the draft. All authors have read and approved the final manuscript.

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DISCLAIMER

The views expressed in this manuscript are those of the authors and do not necessarily represent the opinions of the project donors.

DATA AVAILABILITY STATEMENT

Jilinde Prospective Cohort Data are available online via prerelease at: https://clinepidb.org/ce/app/workspace/analyses/DS_9c28dda6c7.

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SUPPORTING INFORMATION

Additional information may be found under the Supporting Information tab for this article:
Table S1. Final PrEP Stigma Scale items.

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RESEARCH ARTICLE

"I was still very young": agency, stigma and HIV care strategies at school, baseline results of a qualitative study among youth in rural Kenya and Uganda

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Abstract

Introduction: Adolescents and young adults living with HIV (AYAH) have the lowest rates of retention in HIV care and antiretroviral therapy (ART) adherence, partly due to the demands of school associated with this life stage, to HIV-related stigma and to fears of serostatus disclosure. We explore the implications of school-based stigma and disclosure on the development of agency during a critical life stage in rural Kenya and Uganda.

Methods: We conducted a qualitative study in the baseline year of the *SEARCH Youth* study, a combination intervention using a life-stage approach among youth (15–24 years old) living with HIV in western Kenya and southwestern Uganda to improve viral load suppression and health outcomes. We conducted in-depth, semi-structured interviews in 2019 with three cohorts of purposively selected study participants (youth [$n = 83$], balanced for sex, life stage and HIV care status; recommended family members of youth [$n = 33$]; and providers [$n = 20$]). Inductive analysis exploring contextual factors affecting HIV care engagement revealed the high salience of schooling environments.

Results: Stigma within school settings, elicited by non-consensual serostatus disclosure, medication schedules and clinic appointments, exerts a constraining factor around which AYAH must navigate to identify and pursue opportunities available to them as young people. HIV status can affect cross-generational support and cohort formation, as AYAH differ from non-AYAH peers because of care-related demands affecting schooling, exams and graduation. However, adolescents demonstrate a capacity to overcome anticipated stigma and protect themselves by selectively disclosing HIV status to trusted peers and caregivers, as they develop a sense of agency concomitant with this life stage. Older adolescents showed greater ability to seek out supportive relationships than younger ones who relied on adult caregivers to facilitate this support.

Conclusions: School is a potential site of HIV stigma and also a setting for learning how to resist such stigma. School-going adolescents should be supported to identify helpful peers and selectively disclose serostatus as they master decision making about when and where to take medications, and who should know. Stigma is avoided by fewer visits to the clinic; providers should consider longer refills, discreet packaging and long-acting, injectable ART for students.

Keywords: adolescent; eastern Africa; highly active antiretroviral therapy; HIV; medication adherence; social stigma

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1 | INTRODUCTION

> *"It used to happen sometimes [seven years] back that I could forget about the appointment dates. I could even forget about where I keep my appointment card… I was still very young."* (male aged 18, day-scholar, Kenya)

Adolescents and young adults living with HIV (AYAH) face numerous challenges to engagement in the HIV care continuum: lower rates of retention in care and antiretroviral therapy (ART) adherence compared to adults [1, 2] and higher rates of virologic failure [3, 4]. The burden of HIV infections is disproportionately high among adolescents (between 10 and 19 years of age) and young adults (roughly between ages 18 and 24) living in low- and middle-income countries. In Kenya, more than 51% of new HIV diagnoses in 2017 occurred among youth aged 15–24 years [5]. In Uganda, adolescents aged between 13 and 19 years account for 50% of people living with HIV nationally [1], with a mean ART adherence rate of 61–64% [1, 2].

Both AYAH and adults experience medication-related burdens, such as drug side-effects, fears or discomfort with size of pills, pill burden [6, 7] and stigma. Vulnerability to stigma, however, is often heightened during adolescence and may combine with other barriers to care engagement in this population [8–13]. A study in Kenya reported that 57% of AYAH were lost to follow-up and long-term care efforts in part due to stigma in school settings [14]. In school settings, younger adolescents (aged 11–15) have limited agency over their living situations due to their dependence on caregivers [15]. In Uganda, AYAH may need to store and take medication under the supervision of school nurses, which can lead to involuntary disclosure [15]. Successful navigation of stigma and care engagement while in school has implications for later HIV care engagement. Transitioning out of school may further influence disengagement from care if not secured earlier in life [4, 16].

A minimalist reading of HIV stigma restricts it to "othering, blaming, and shaming," to distinguish it from other forms of HIV discrimination [8, 17–21]. Crenshaw's theory of intersectionality expanded stigma analysis to "capture … contextual dynamics of power" beyond the lens of single-axis analysis (e.g. gender alone and age alone) to include health status, disability, HIV status and age [21–26].

Life-course theory provides a useful framework for exploring how HIV stigma during adolescence operates as a constraining factor that can paradoxically promote the maturation of a sense of agency for AYAH during this life stage, as it necessitates the growth of skills for seeking HIV care opportunities in later life stages. Four principles structure life-course analysis: the individual's geo-historical context; the timing of transitions (e.g. from school to work-life and parenthood) within that context; the interdependence of "linked lives" (e.g. social network development during youth sets up expectations about one's life-course, relative to the life events of peers and prior generations); and human agency. Thus, life-course theory posits that historical context and the timing of critical periods in life influence developmental trajectories and health outcomes.

Human agency is expressed by altering the timing of life events and choosing the path one will follow. "Individuals construct their own life-course through the choices and actions they take within the opportunities and constraints of history and social circumstances" [9]. Agency is expressed within the synchronicity of life transitions in one's cohort of peers, as well as in the contingent opportunities, constraints and interlinked lives one is thrown into [27].

Using a life-course lens, we examine the implications of school as a setting wherein agency is developed in the context of stigma and the opportunities afforded by education and changing generational relationships. We distinguish between younger and older adolescents to suggest that within the institutional setting of school, youth develop their sense of agency around medication adherence through support-seeking and selective HIV disclosure (opportunity) and resistance to stigma (constraint). Agency in developing effective strategies to remain in care goes hand in hand with developing strategies to resist stigma. Both are learned in the school setting, and both entail making choices between opportunities and constraints [28–30].

The findings come from a longitudinal qualitative study examining the barriers and facilitators of HIV care engagement among youth enrolled in the "SEARCH Youth" study (Strategic Antiretroviral Therapy and HIV testing for Youth in Rural Africa, NCT03848728), a community cluster-randomized controlled trial in 28 rural communities in Kenya and Southwestern Uganda (14 communities per country). The study included a life-stage counselling component for youth, drawing on insights from life-course theory [9].

School-going AYAH experience amplified challenges to care engagement because school is a place of intense scrutiny from peers and adults where any difference is set in sharp relief [31]. During the transition from childhood to adulthood, young people tend to value acceptance and appreciation from their peers. In their absence, social marginalization occurs, which can be amplified by stigma [15]. HIV-related stigma in school environments can be increased by limited privacy, lack of family support and inadequate systems for supporting students living with HIV and their engagement in care [32–37]. For young people, disclosing one's HIV (positive) status can be associated with loss of friends, bullying, social exclusion and denied schooling [34, 38]. Yet, lack of disclosure has itself been associated with poorer health outcomes [18]. Understanding age-related constraints and opportunities, therefore, not only provides insight into how AYAH grapple with HIV-related stigma, but can also inform future interventions which address AYAH-identified barriers to adherence.

2 | METHODS

2.1 | Study context

"SEARCH Youth" is a combination-intervention study designed to address structural barriers and psychosocial needs through life-stage adapted counselling, technology-enabled provider mini-collaboratives, rapid viral load feedback and structured-choice clinic access, aimed at improving viral suppression among AYAH aged 15–24 years.

Through in-depth, semi-structured interviews, a qualitative component aims to identify barriers, facilitators and mechanisms of action of the study intervention at the patient, family, clinic and community (school and village) levels. This article presents findings from baseline data collected prior to intervention.

2.2 | Participants and procedures

The qualitative study used in-depth, semi-structured interviews with (1) a youth cohort of 83 participants of young people aged 15–24 years, purposively selected from 8 of the 28 communities in SEARCH-Youth study (balanced by study arm and region), with participant selection balanced by HIV care status (newly diagnosed; out of care for the past 6 months; and engaged in care), sex and age; (2) a cohort of 33 family members of the youth cohort, purposively selected upon recommendation from youth participants about which family member they trusted and was most involved in their HIV care; and (3) a provider cohort (n = 20) purposively selected from two intervention clinics per region to include clinical officers, nurses and peer educators. The three cohorts permitted triangulation of data on barriers and facilitators of HIV care. We did not interview school personnel who were not part of the formal clinical study. For this paper, we define younger adolescents as between 15 and 17 years, older adolescents as 18–20 years and those aged 21–24 as young adults.

2.3 | Data collection

A gender-balanced team (three men and three women) of trained qualitative researchers, native speakers of the local languages, administered the interviews at baseline between June and December 2019. Confidentiality was ensured by conducting interviews in private rooms in clinic facilities or community locations convenient for the participants. Audio recordings were transcribed and translated into English.

Interviews with AYAHs explored types and breadth of social support systems, experiences of HIV care and HIV status disclosure. Family member interviews explored perceived attitudes of schoolmates and others towards AYAHs, HIV care and treatment of AYAHs, and perceived burden of caregiving to AYAHs. Provider interview guides included perspectives on the needs and barriers to *care engagement* among AYAHs, and perceived challenges to *care delivery* to AYAH. The purpose of the qualitative interviews was not exclusively focused on school-based HIV stigma; rather, what emerged during our analysis was school as a site of stigma as well as support in resisting such stigma in order to engage in HIV care during a particular life stage. Reporting this emergent finding is useful for shaping future interventions in this demographic.

2.4 | Data analysis

A six-person team transcribed and coded data using Dedoose software (LO, AO, CA, FA, IM and JL]. An initial coding framework with broad codes was defined on the basis of topic areas from theory-informed interview guides developed by the project lead (CSC). The larger team (including MG and CSC) reviewed and discussed an initial set of transcripts and difficult coding segments, refined the broad codes with child codes and yielded a final coding framework reflective of both *a priori* concepts from theory and empirical research, and emergent codes reflecting phenomena and concepts derived from inductive coding of the data [39]. Codebook definitions and examples of code applications were reviewed throughout the analysis period. Our research question was: what are the barriers and facilitators to HIV care engagement common to youth in both Uganda and Kenya?

We used a thematic analysis on the resulting coded excerpts [40, 41]. Thematic analysis revealed the high salience of school settings as a context which alternately supports and undermines ART adherence for study participants currently or recently in school. We then undertook a deeper analysis of transcript excerpts via re-coding for terms related to the emergent theme of school contexts—principal, teacher(s), student(s), exam(s) and class(es). Subgroup analyses from this recoding were restricted to age, rather than gender and location, because of the limits of the data set we were using.

2.5 | Author(s) position statement(s)

The team-based analytical approach was enriched by the lived experience—"the knowledge gained by an individual through direct encounter with a phenomena" [42, 43]—of research team authors who had first-hand experience of school environments in the study setting (SL and others). Research team members who gathered data in Dholuo (LO and AO) and Runyankole (CA and FA) also engaged in data analysis and confirmed interpretations of the data to which additional team members contributed (JJP, MG and CSC). This ensured that the translation and interpretation of the data respectfully captured the nuances of participants' voices [44]. The researchers acknowledge that some may disagree with our interpretations on the basis of their differing experiences of the same environments.

2.6 | Ethical approval

The University of California San Francisco Committee on Human Research, the Ethical Review Committee of the Kenya Medical Research Institute, the Makerere University School of Medicine Research and Ethics Committee and the Uganda National Council of Science and Technology all approved this study as minimal risk for all participants, including minors. All study participants provided written informed consent to participate in the study.

3 | RESULTS

Participants in the youth cohort of the parent clinical study were aged 15–24 years and presented a mix of school-going (18%) and non-school-going (82%) individuals (including those who had recently left school). Youth in the qualitative sample reflected the composition of the SEARCH-Youth study population, achieving balance by region, treatment status and sex. The composition of the family member cohort, in contrast, was driven by youth cohort members' selection preferences, and was predominantly female (60%), with more partners (51.5%) than parents (24.2%) (Table 1).

School-going individuals included day-scholars and boarding school students. This paper focuses on them because tension between education and care engagement emerged as a key theme in our analysis. Stigma and disclosure decisions repeatedly emerged as affecting ART adherence and clinic attendance, and informed relationships with peers and older adults. Below, we present findings supported by excerpts from the transcripts and roughly aligned with the four principles of life-stage analysis: geo-historical context and timing of life-stage transitions; linked lives between peers and cross-generationally; and agency illustrated through choices within constraints and opportunities at school.

3.1 | Education in the context of community and life stage

Most participants lived with at least one parent, a sibling or another member of the family. Participants reported living within a 1-hour walking distance of their primary HIV care clinic. Overall, Ugandan participants were mostly

Table 1. Characteristics of study participants, by interview cohort

Cohort type	Characteristic	*n* (%)
Youth cohort	**Sex**	
	Female	54 (65.1%)
	Male	29 (34.9%)
	Age	
	15–17 (Younger adolescent)	16 (19.3%)
	18–20 (Older adolescent)	22 (26.5%)
	21–22 (Early young adult)	22 (26.5%)
	23–25 (Late young adult)	23 (27.7%)
	Care status (baseline)	
	New to care	34 (41.0%)
	Already in care	39 (47.0%)
	Re-engaging in care	10 (12.0%)
	Region	
	Uganda	38 (45.8%)
	Kenya	45 (54.2%)
Healthcare workers' cohort	Sex	
	Female	12 (60.0%)
	Male	8 (40.0%)
	Region	
	Uganda	12 (60.0%)
	Kenya	8 (40.0%)
Family cohort	Sex	
	Female	20 (60.6%)
	Male	13 (39.4%)
	Relationship	
	Partner	17 (51.5%)
	Parent/caregiver	8 (24.2%)
	Other	8 (24.2%)
	Region	
	Uganda	14 (42.4%)
	Kenya	19 (57.6%)

engaged in agriculture for subsistence or livelihood, while in Kenya, most male participants were engaged in fishing, and women in running small businesses. School-going youth may or may not end up in these occupations after schooling is completed. This vision of adulthood is a baseline expectation for the future, which schooling potentially expands beyond.

Both youth and caregivers recognized life-stage changes parallel attending and exiting school and that education facilitates opportunities. Thus, although school may be a site of stigma and ART adherence obstacles, the rewards of school merit facing these challenges. One Ugandan grandmother was adamant children in her care receive an education, while two older adolescents in Kenya mentioned plans to continue onto college to become social workers or teachers. The increased opportunities afforded by education are illustrated by one participant as she makes her transition out of adolescence and into early adulthood:

> *"As someone who has gone to school, I might get a job somewhere on a short notice …. As someone who has finished school, I tend to be very mobile."* (female aged 19, Kenya)

As she indicates, life-stage synchronization in later adolescence becomes more diversified as opportunities open up within historical and personal circumstances.

However, school opportunities are sometimes hindered by HIV care, setting AYAH students apart from their peers and normative expectations for schooling, exams and graduation. For younger adolescents, school schedules can work against medication and clinic times. As one participant observed going to clinic for refills on school days means missing parts of class *"that may have ended before you come back and … they can't rewind the already covered topic."* (male aged 18, Kenya, day-scholar). Choosing between class or medication remained particularly acute during exam periods and preparatory classes, which were explicitly cited as potential causes of medication interruption. Students were understandably unwilling to miss those particular classes.

Life-stage theory notes development and its attendant choices are shaped by the interdependence of lives across generations. Our data confirm that sometimes an adolescent's life-stage transition from school to work overlaps with a caregiver's own transition from work to retirement, which can impact both education and continuity in care:

> *I: "Are you concerned of any possible future barrier to his drugs adherence?"*
> *P: "I may not predict that. I am supposed to retire next year which may compromise his education because of the reduced income."* (Uncle of male aged 18, Kenya, day-scholar)

3.1.1 | *Linked lives, disclosure and social support via parents, teachers and pupils*

> *"I talked to the head teacher as well as his deputy …The deputy head teacher stays at school with the children. He told [my grandson], 'Don't you worry because even among us the teachers, there are some who are infected with HIV and we take our meds well because we want to have good health – so you should not be embarrassed about your situation.' So when I talked to the teachers, he understood his situation better. The teachers also understood his situation and they made sure that he takes his meds well. He is now doing fine."* (grandmother of a male aged 16, Uganda)

The older generation taking the lead for younger adolescents in navigating anticipated stigma also shows the interdependence of generations. Caretakers often brokered a supportive relationship with a school figure to help the student stay engaged in care—and in school. Several participants cited selective disclosure to at least one teacher who will always grant permission to visit the clinic as key in helping them stay engaged in care. In an interesting twist to students describing the importance of having teachers as allies and inspiration, a young teacher in the youth cohort was encouraged to stay adherent to ART on the day he tested positive when his cousin pointed out that he was not alone at school—even though he was a teacher:

> *"He talked to me at length over the phone, reminding me of even many other people including pupils and students of the same HIV status. So, it was about being faithful to the drugs as the only option."* (male aged 22, Kenya, new to care)

In this instance, the example of his students inspired a young-adult teacher to remain adherent; the younger generation provided an example to a slightly older youth. What is interesting here is the difference in timing between when HIV infection was acquired, with most of the pupils acquiring it perinatally, but the teacher in young adulthood.

3.1.2 | *Linked lives, otherness and belonging: peer groups*

Cross-generational links may help adolescents with institutional actors, but adolescents must demonstrate more agency when navigating peer-to-peer relationships. Here, *anticipated stigma* played a role in challenging care. Health education classes at school reportedly reduced enacted stigma, but not necessarily anticipated stigma. While one younger adolescent reported never experiencing stigma directly, and acknowledged that classmates educated about HIV would assist him during school classes when he fell ill, he "just feels it [enacted stigma] can happen" because he has seen other classmates stigmatized for HIV. In those cases, he observed, *"sometimes they [the perpetrators] are punished or suspended when the case reaches the administration."* In such instances, the anticipation of stigma may paradoxically reinforce social support-seeking behaviour.

Nevertheless, a sense of loneliness and self-othering can persist among some older adolescents:

> *"I really feel bad when I see people of my age living without the virus while I am the only one living with the virus."* (male aged 18, Kenya, day-scholar)

Joining a peer group with other AYAH, formally structured by a school or clinic, or informally when students unexpectedly see classmates at clinic and discover one another's status, facilitated care engagement. These networks reinforced commitment to medication schedules by ensuring students know they are not alone. A young male student (aged 15) observed of his AYAH peers, *"We usually motivate each other to adhere to the drugs well and also not to miss any appointments."* This sense of belonging applied both to younger participants and older ones:

> *"P: [The local clinic] is good, as I told you before; we do bookings for adolescents" day and low viral load day. When we meet as adolescents, we have a lot in common and we would not go gossiping about each other.*
> *I: What happens on adolescents' day?*
> *P: We play together and encourage one another to adhere well.*
> *I: Do you disclose your status to everyone who is in the adolescents' group?*
> *"P: Yes, we normally say that in this group we are all HIV positive and are all on HIV care and treatment as well. This makes them feel that it is a normal occurrence since even the providers are receiving HIV care and treatment."* (female aged 19, Kenya)

This participant noted that the adolescent day not only relieved her of the fear of gossip, but it also normalized her status as living with HIV, which created a safety network where the adolescents encouraged one another to stay in care. This synchronicity may carry over into longer-term support as the young people transition out of school.

3.1.3 | *Agency and ART as an agent of disclosure, leading to stigma at school*

> *"We have people who are envious within our community and you might disclose to them – then they will mock you with it, and that will demoralize or discourage you."* (female aged 19, Kenya)

Agency is shown within the constraints and opportunities of a historical context and social network. Stigma is one such social constraint for AYAH, especially when such stigma might end up discouraging ART adherence. Some participants mentioned experiencing stigma in the surrounding community in the form of gossip intended to tear others down. School does not necessarily negate community attitudes, since both students and teachers carry community attitudes with them. At school, students cannot easily avoid their peers.

Many participants expressed concern that taking medication during school hours could reveal their status and elicit a stigmatizing response. This fear was mentioned by providers, family and adolescents:

> *"She shared that she is supposed to take her drugs at 8pm and this forces her to carry drugs to class, which she is not comfortable doing. They are usually given a five-minute break and that is when she tries to fix her time with the drugs, which again is not working out so well because everybody shares the break and her friends do not equally want to leave her alone. She ends up missing doses because of that."* Provider (Non-facility based – Kenya)
>
> *"I went to his school and I talked to his teacher. He told me that [my grandson] was afraid of taking his meds because he did not want his schoolmates to know that he was infected with HIV – that if they ever get to know, they would start to make fun of him."* (grandmother of male aged 16, Uganda)

Anticipated stigma sometimes is not unfounded; participants also experienced enacted stigma. One student mentioned how his classmates make fun of his medication and the effect it had on him:

> *"The children at school always say that I take big pills like those they give pigs. … I started to hate myself."* (male aged 16, Uganda)

When such stigma is repeated, it runs the risk of discouraging students from continuing their medication schedules. In fact, taking medicine while at school involves several steps: getting the medicine into the school, finding a place to store it privately and take it soundlessly, excusing oneself to take it alone or to head to the nurse station and finding water or food to take with the medicine. One student reported using tap water that had not been boiled to take medicine while at school, so his classmates would not discover he was taking ART. Each of these points is an opportunity for one's status to be discovered by others; yet, identifying the available choices and pursuing some over others exhibits agency, and this agency develops as youth mature:

> *When I was in school I was free with a teacher and one of the workers. We used to be inspected when getting into school so I would hide my pill in my bag and I would choose that specific person. I later thought that that if it was only one person who knew about it I would have a problem when they were not around, so I decided to disclose to some of the teachers and the deputy principal; my dad helped me disclose to them. The deputy said that the infection was normal and if I wanted to continue with my studies then I should. Some of the students would leave their medication at the nurse's office, but I told them that I would just manage on my own.*
>
> *I: Do some of them give the school nurse their medication to keep for them?*
>
> *"P: Yes, but the nurses may also share out your status to others. I refused and decided to keep them in my box under lock and key and would use them at my own time."* (female aged 19, Kenya)

The above excerpt highlights how some students manage support from school faculty and staff, and the concern, clearly present but not shared by everyone, that nurses may be less trustworthy about student HIV status than faculty. Importantly, this participant was among the older adolescents, and was better able, with her father's help, to assert her own agency in taking the medication.

4 | DISCUSSION

This qualitative study conducted among adolescents and young adults living with HIV, their family members and care providers in eastern African communities, has elucidated actions AYAH undertake to resist forms of HIV-related stigma. The findings show how a refusal of stigma through selective disclosure to trusted allies, and inventing of ways to adhere to ART, leads to increased sense of agency and better health outcomes among AYAH during a key developmental life stage. This essential skill develops partly by resisting HIV stigma through selective disclosure to trusted teachers or staff, and through identifying and reaching out to helpful peers. Both older and younger adolescents stressed the importance of support systems at home and among staff at school, with older adolescents showing greater ability to direct these relationships and disclosures, and younger adolescents relying on parents or caregivers to pave the way. Earlier interventions to improve health outcomes for AYAH may have missed opportunities to leverage such life stage-based approaches, which have the potential for greater impact on adolescents [45].

Enacted stigma caused some youth to drop out of school (though not in every case), whereas anticipated stigma did not. Anticipated stigma did tempt younger adolescents to drop out of school, but was managed through speaking to teachers and adults, as the quote from the grandmother in Uganda demonstrated. In fact, the weight of our evidence suggests that navigating anticipated stigma permitted agency to mature for school-going youth, more than facing enacted stigma—perhaps because anticipated stigma permits extended reflection (often with trusted adults) and does not require immediate response. Adults could take the youth through a process of reflection on options for navigating around or coping with stigma, and tapping support systems. Being guided through such questions helps youth develop skills they will need later when confronting non-HIV-related challenges in life.

Stigma is, therefore, a rather immediate obstacle amenable to adolescent agency when other choices are still out of reach. For AYAH, taking ART paradoxically increases stigma (especially self-stigma) [46]. Yet, during a time of critical life-stage transitions and during the baseline year of an intervention study, youth were already engaged in finding ways to manage healthcare for themselves, while refusing to internalize stigma to become invested with greater responsibility for their own and their families' health [47–49].

4.1 | Limitations

Our cohort was a mix of boarding and day scholar informants, which may limit its generalizability to one or the other setting. However, baseline data do suggest our sample is fairly representative of AYAH in Kenyan and Ugandan schools, and similar to school-age cohorts throughout Anglophone Africa. Our findings agree with previous studies that despite the optimism brought by a sense of agency, school intensifies stigma triggers, with boarding schools especially ideal for such triggers to flourish and interrupt ART adherence [35, 50, 51].

We focused on school as a site of stigma without comparison to village-based stigma, partly because though challenging, school is a potential island of support. For this reason, we also did not focus on adolescents who exited school early. We did not interview school personnel as they are not part of the formal clinical study. Follow-up research should specifically triangulate with this group (admin, teachers, school nurses and security).

We did not use explicit probes for how adolescents developed a sense of agency over ART adherence, or how that agency developed differently among male and female participants; identifying this theme lays the groundwork for probes in follow-up interviews during this longitudinal study. Although we did not examine how adolescents identified trustworthy candidates for disclosure, we uncovered accounts of managing the process with caregiver assistance.

5 | CONCLUSIONS

Several recommendations follow from the implications our findings have for the HIV care continuum. Our participants mostly acquired HIV perinatally and were linked to care early. Their status was disclosed to them when they were old enough to understand. Introducing younger adolescents to a peer group of other AYAHs (especially including schoolmates) at the time of disclosure may create an initial support framework for resisting stigma by showing younger adolescents they are not alone [18]. This also creates the linkages between peers, which promotes synchronicity in life-course expectations and may help carry through adherence into adulthood, especially given that older adolescents expressed concern about managing their care once they graduated or found work away from family and school [29].

For older adolescents, their life stage is a key opportunity to establish successful engagement in care by appealing to their growing sense of (self-) responsibility, especially within a context where stigma is a reality. Through modelling opportunities for selective disclosure to teachers, staff and peers, providers can counsel adolescents on the key life skill of building supportive social and professional networks, while facilitating retention in care as the adolescent becomes an adult. Supported selective disclosure also confronts anticipated stigma directly by building confidence and discernment of others' character, as a concrete aspect of this skill. Securing at least one person from the administration or one teacher as an ally to easily excuse them from class with minimal additional explanation facilitated engagement in care.

The findings also highlight the importance of school settings as places where ART adherence is both challenged and supported. Stigma is avoided by fewer visits to the clinic, which means providers should consider longer refills and discreet packaging, or the rollout of long-acting ART to students as a key population. Appropriate food and potable water availability at schools is important for taking ART; and addressable by the school staff when possible. Keeping medication on site helped somewhat with adherence, except when on-site nurses are mistrusted because anticipated stigma raises confidentiality concerns. HIV education in school supported stigma reduction when teachers promptly responded to enacted stigma among students. Finally, teacher support for medication reminders or dorm room arrangements for boarders may also encourage adherence by decreasing opportunities for stigma to be enacted [51]. Interventions supporting agency around strategies AYAH already use to resist stigma and engage in care, in the context of care delivery cognizant of the constraints created by educational institutions, can support youth during this critical period of multiple life transitions.

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COMPETING INTERESTS

The authors declare they have no competing interests.

AUTHORS' CONTRIBUTIONS

JJP led analysis and wrote the manuscript, with contributions from CSC. SL drafted the background section. CA drafted the methods section. JA, FM, LO, FA, CA and AO as members of the core research team did initial analysis, data collection, curation and coding of the transcripts. MRK, TR and DVH conceived the parent study, revised critically and with CSC issued final approval. CSC conceived the original qualitative project, revised critically and issued final approval.

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DATA AVAILABILITY STATEMENT

Source data are transcribed and translated interview data, which require redaction prior to sharing to protect confidentiality, but are readily available upon request.

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SHORT REPORT

Does resource insecurity drive HIV-related stigma? Associations between food and housing insecurity with HIV-related stigma in cohort of women living with HIV in Canada

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Abstract

Introduction: Women living with HIV across global contexts are disproportionately impacted by food insecurity and housing insecurity. Food and housing insecurity are resource insecurities associated with poorer health outcomes among people living with HIV. Poverty, a deeply stigmatized phenomenon, is a contributing factor towards food and housing insecurity. HIV-related stigma—the devaluation, mistreatment and constrained access to power and opportunities experienced by people living with HIV—intersects with structural inequities. Few studies, however, have examined food and housing insecurity as drivers of HIV-related stigma. This study aimed to estimate the associations between food and housing insecurity with HIV-related stigma among women living with HIV in Canada.

Methods: This prospective cohort study of women living with HIV ($\geq$16 years old) in three provinces in Canada involved three waves of surveys collected at 18-month intervals between 2013 and 2018. To understand associations between food and housing security and HIV-related stigma, we conducted linear mixed effects regression models. We adjusted for socio-demographic characteristics associated with HIV-related stigma.

Results and discussion: Among participants (n = 1422), more than one-third (n = 509; 36%) reported baseline food insecurity and approximately one-tenth (n = 152, 11%) housing insecurity. Mean HIV-related stigma scores were consistent across waves 1 (mean [M] = 57.2, standard deviation [SD] = 20.0, N = 1401) and 2 (M = 57.4, SD = 19.0, N = 1227) but lower at wave 3 (M = 52.8, SD = 18.7, N = 918). On average, across time, food insecure participants reported HIV-related stigma scores that were 8.6 points higher (95% confidence interval [CI]: 6.4, 10.8) compared with food secure individuals. Similarly, participants reporting insecure housing at wave 1 tended to experience greater HIV-related stigma (6.2 points, 95% CI: 2.7, 9.6) over time compared to stably housed participants. There was an interaction between time and housing insecurity, whereby baseline housing insecurity was no longer associated with higher HIV-related stigma at the third wave.

Conclusions: Among women living with HIV in Canada, experiencing food and housing insecurity was associated with consistently higher levels of HIV-related stigma. In addition to the urgent need to tackle food and housing insecurity among people living with HIV to optimize wellbeing, getting to the heart of HIV-related stigma requires identifying and dismantling resource insecurity-related stigma drivers.

Keywords: food insecurity; housing insecurity; poverty; stigma; HIV stigma; women living with HIV

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1 | INTRODUCTION

A robust global evidence base reveals that food and housing insecurity disproportionately impact people living with HIV (PLHIV) [1–6]. Among PLHIV, food and housing insecurity are linked to poorer HIV outcomes, including unsuppressed viral load, lower CD4 count and poorer physical health [3, 6–10]. In Canada, out-of-pocket costs for publicly funded health services, including antiretroviral therapy (ART), vary by province [11]. This may result in PLHIV needing to apply for social assistance to access comprehensive ART coverage [11, 12]. Limited income from social assistance, low-wage employment and illness-related loss of income among employed PLHIV produce challenges acquiring and maintaining sufficient, reliable food and housing [3, 11–14]. This is not unique to Canada—socio-economic challenges, including food and housing insecurity, low income and unemployment, were also reported in a review of PLHIV in other high-income contexts, such as the United States, Australia and the United Kingdom [10]. In addition to being associated with poorer health outcomes [10], food and housing insecurity are resource insecurities linked with poverty, itself a deeply stigmatized phenomenon [15, 16].

Meta-analytic findings reveal associations between low income and higher HIV-related stigma [17], signalling the salience of exploring resource insecurity as a driver of HIV-related stigma. Few quantitative studies have explored this nexus of resource insecurity and HIV-related stigma [1–6, 10]. HIV-related stigma—the devaluation, mistreatment and constrained access to power among PLHIV—intersects with other socially marginalized identities [18–20], including low socio-economic status [21]. Among PLHIV experiencing homelessness and housing insecurity in the United States, being recently homeless was associated with increased internalized and perceived HIV-related stigma [22] and acquiring temporary housing was associated with reduced HIV-related stigma [23]. A cross-sectional study in Canada found that concurrent food and housing insecurity was associated with increased HIV-related stigma among women living with HIV (WLHIV) [24]. Food insecurity was also associated with increased internalized HIV-related stigma among WLHIV in the United States [7] and higher HIV-related stigma among PLHIV in Uganda [25, 26]. Together, these studies signal the need to better understand associations between food and housing insecurity with HIV-related stigma. This understanding could inform downstream interventions to mitigate experiences of intersecting stigma [18, 19], and upstream interventions to transform healthcare and social service environments to reduce stigma exposure [27, 28].

To address knowledge gaps regarding food and housing insecurity as drivers of HIV-related stigma, this study aimed to estimate the associations between food insecurity and housing insecurity with HIV-related stigma among a cohort of WLHIV in Canada.

2 | METHODS

2.1 | Study setting and population

Data for these analyses came from the Canadian HIV Women's Sexual & Reproductive Health Cohort Study (CHIWOS); methods are described elsewhere [29, 30]. This three-wave study was conducted in three Canadian provinces (Ontario, Quebec and British Columbia) between 2013 and 2018. Participants were 16 years or older who self-identified as women and HIV positive and agreed to complete a 2-hour interviewer-administered survey three times at 18-month intervals.

2.2 | Data collection

At each wave, participants completed a validated 10-item HIV Stigma Scale [31], which assesses personalized stigma, disclosure concerns, negative self-image and concern with public attitudes. Total scores were calculated as the sum of scores on each of the 10 items (rated on a 0 to 4 scale) multiplied by 2.5 such that total scores ranged from 0 to 100. The internal consistency of the scale in this study was 0.85.

At baseline, we assessed housing security by asking participants to describe their current place of residence. Individuals living in houses, apartments, self-contained rooms with amenities or group homes were considered to have secure housing. Individuals living in self-contained rooms without amenities, transition, halfway or safe houses, in their cars, couch-surfing or outdoors were considered to have insecure housing. Participants also answered three food security items from the Canadian Community Health Survey Household Food Security Survey (e.g. "in the past 12 months, you and other household members worried that food would run out before you got money to buy more") [32]. Response options were often (= 2), sometimes (= 1) or never true (= 0), and scores across the three items were summed and dichotomized, wherein a total score of 2 or greater indicated food insecurity. Surveys also included socio-demographic questions about age, gender identity, sexual orientation, educational attainment and racial/ethnic identity.

2.3 | Statistical analyses

First, we conducted bivariate tests (Pearson correlations, independent *t*-tests and two-way ANOVAs) to examine associations between HIV-related stigma, food and housing security, and socio-demographic and health characteristics. Then, we built mixed effects linear regression models with timepoints (level 1) clustered within individuals (level 2). In addition to having random intercepts for individuals, we also included a random coefficient for time to allow trajectories to vary between participants, using an unstructured covariance matrix to avoid imposing constraints on the residual covariances. To understand associations between resource insecurity and stigma over time, we included study wave, food or housing insecurity, and the interaction between wave and resource insecurity as the primary predictors in our models. To control for potential confounding variables, we also included socio-demographic characteristics that were significantly associated with HIV-related stigma in bivariate analyses. Missing data were handled using multiple imputation with all participants. All analyses were conducted in Stata v15 (College Station, TX).

2.4 | Ethical considerations

Informed consent was obtained from participants prior to each survey. Research ethics board (REB) approval was provided by Women's College Hospital, University of Toronto, Simon Fraser University and the University of British Columbia/Providence Health, and McGill University Health Centre. Study sites with independent REBs also obtained their own approval prior to commencing enrolment.

3 | RESULTS AND DISCUSSION

Sample characteristics at baseline are reported in Table 1. Among participants (n = 1422), at baseline more than one-third (n = 509; 36%) reported food insecurity and approximately one-tenth (n = 152, 11%) housing insecurity. Average HIV-related stigma scores were consistent across waves 1 (M = 57.2, SD = 20.0, N = 1401) and 2 (M = 57.4, SD = 19.0,

Table 1. Sample demographics among a cohort of women living with HIV in Canada (*N* = 1422)

	Mean (SD) or *N* (%)	Association with HIV stigma Pearson *r*, *t*- or *F*-statistic (*p*-value) Wave 1	Wave 2	Wave 3
Age at baseline	42.8 (10.6)	−0.12 (<0.001)	−0.13 (<0.001)	−0.13 (<0.001)
Months since HIV diagnosis	139.9 (84.6)	−0.13 (<0.001)	−0.18 (<0.001)	−0.10 (0.002)
Gender identity				
Transgender	54 (4%)	0.74 (0.46)	1.22 (0.22)	−0.11 (0.91)
Cisgender	1359 (96%)			
Sexual orientation				
LGBQ2S	180 (13%)	2.23 (0.03)	1.71 (0.09)	2.00 (0.05)
Heterosexual	1237 (87%)			
Educational attainment				
Less than high school	227 (16%)	0.08 (0.94)	−1.35 (0.18)	0.86 (0.39)
High school or greater	1188 (84%)			
Race/ethnicity				
White	584 (41%)	7.28 (<0.001)	11.23 (<0.001)	5.68 (<0.001)
African, Caribbean and Black	418 (29%)			
Indigenous	318 (22%)			
Other or mixed ethnicity	102 (8%)			
Food security				
Food insecure	509 (36%)	8.59 (<0.001)	8.45 (<0.001)	6.54 (<0.001)
Food secure	907 (64%)			
Housing stability				
Unstable housing	152 (11%)	4.23 (<0.001)	2.88 (<0.01)	0.83 (0.41)
Stable housing	1270 (89%)			

Abbreviations: LGBQ2S, lesbian, gay, bisexual, queer or Two-Spirit; SD, standard deviation.

Table 2. Longitudinal associations between HIV stigma and food/housing security among a cohort of women living with HIV in Canada (*N* = 1422)

	Food insecurity Est.	95% CI	*p*-value	Housing insecurity Est.	95% CI	*p*-value
Insecure	8.35	6.19, 10.51	<0.001	5.73	2.30, 9.15	0.001
Wave 2	0.34	−1.55, 2.22	0.72	0.56	−0.62, 1.73	0.35
Wave 3	−3.09	−5.19, −1.00	0.004	−3.51	−4.80, −2.21	<0.001
Insecure × Wave 2	−0.05	−2.36, 2.26	0.97	−2.31	−5.93, 1.32	0.21
Insecure × Wave 3	−1.54	−4.22, 1.13	0.26	−5.31	−10.37, −0.26	0.04

Note: Models adjusted for age, months since HIV diagnosis, sexual orientation and race/ethnicity.

N = 1227) but lower at wave 3 (*M* = 52.8, *SD* = 18.7, *N* = 918). Participants experiencing food insecurity at baseline were more likely to report significantly higher levels of HIV-related stigma at all three waves; unstable housing was also significantly associated with greater HIV-related stigma at the first two waves, but not third (Table 1).

Individuals who were younger, living with HIV for a shorter time period, identified as lesbian, gay, bisexual, queer or Two-Spirit (LGBQ2S) and from a racialized group (i.e. Black or Indigenous) also tended to experience greater HIV-related stigma across waves (Table 1). For example, at baseline, the mean HIV-related stigma score was 60.3 (*SD* = 19.5) for those who identified as LGBQ2S compared to 56.7 (*SD* = 20.0) for heterosexual participants, and was 60.7 (*SD* = 21.0) for participants who identified as Indigenous and 57.1 (*SD* = 19.0) for participants who identified as African, Caribbean or Black, compared to 54.8 (*SD* = 20.1) for participants identifying as white. As a result, age, months since HIV diagnosis, sexual orientation and race/ethnicity were included as covariates in multivariable analyses.

Results of multilevel regression models are reported in Table 2. Figure 1 presents adjusted scores by time and food insecurity and housing insecurity, along with 95% confidence intervals. At baseline, food insecure individuals reported

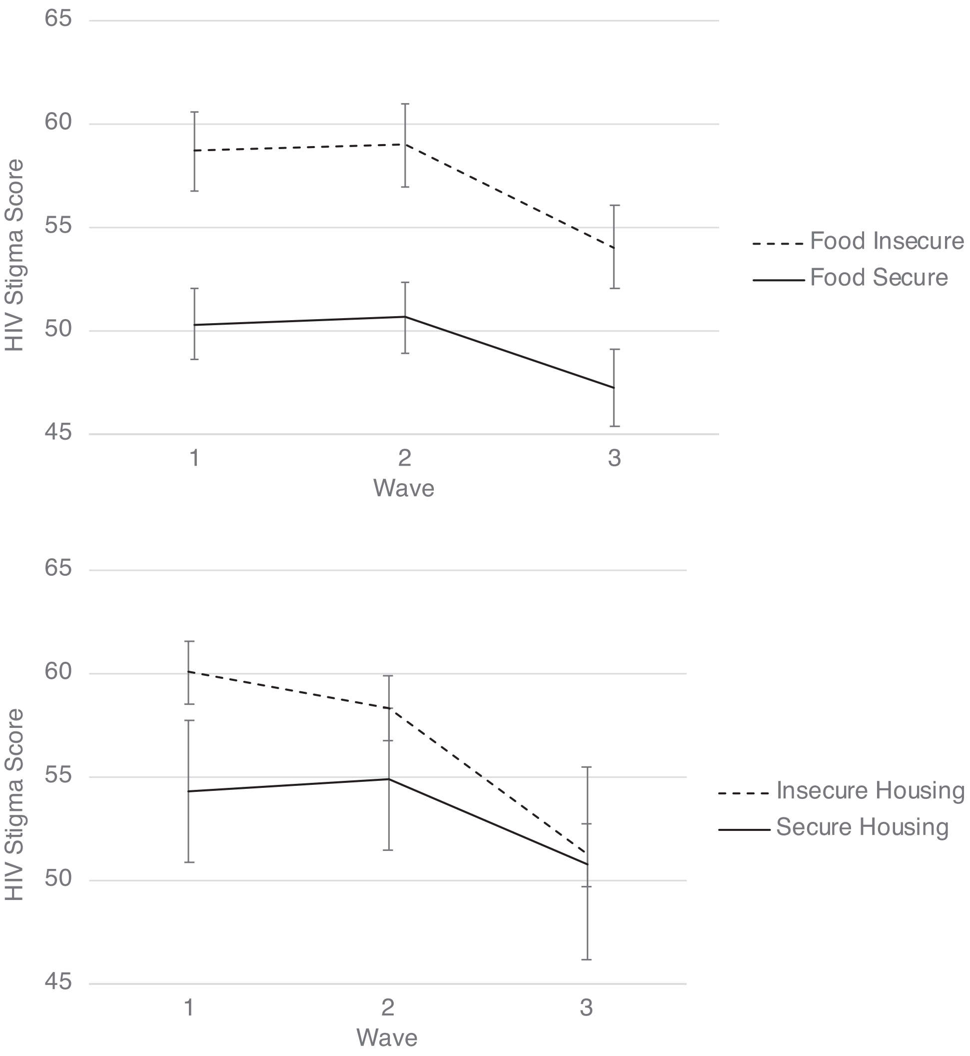

Figure 1. Trajectories of HIV stigma by food insecurity and housing security among a cohort of women living with HIV in Canada.
Note: Estimates are for average-aged, heterosexual, white participants with an average time since HIV diagnosis. Error bars represent 95% confidence intervals.

HIV-related stigma scores that were 8.35 points higher (95% CI: 6.19, 10.51) than food secure individuals. Similarly, housing insecure participants at wave 1 tended to experience greater HIV-related stigma (5.72 points, 95% CI: 2.30, 9.15) than those with secure housing. In both models, there was a significant effect of time, whereby stigma scores were significantly lower at wave 3. While those experiencing food insecurity at baseline consistently experienced higher stigma across all three waves, there was a significant interaction between time and housing insecurity, whereby housing insecurity at baseline was no longer associated with higher stigma by the third study wave.

In this study with WLHIV in Canada, we found that experiencing food or housing insecurity was associated with significantly higher levels of HIV-related stigma. This suggests that resource insecurity-related factors increase exposure to HIV-related stigma. These findings corroborate research on associations between HIV-related stigma and food insecurity in both high-income [2, 7, 33] and low- and middle-income contexts [25, 26], and between HIV-related stigma and housing insecurity in high-income contexts [22]. Despite calls to harness poverty alleviation to reduce HIV-related stigma in sub-Saharan Africa nearly a decade ago [34], there is limited research on poverty and resource scarcities as stigma drivers in sub-Saharan Africa, particularly with WLHIV who are most impacted by the pandemic.

Poverty contributes to food and housing insecurity [35, 36], and our findings build on the evidence base that poverty is associated with increased HIV-related stigma [7, 17, 22, 24]. Stigma towards poverty is rooted in social constructions that it symbolizes “failure,” “laziness” and “irresponsibility” [15, 37, 38]. Homelessness may be stigmatized more than poverty due to its visibility and perceived disruptiveness of public space [39]. Food insecurity can result in eating stigmatized foods and acquiring food through socially unacceptable means, resulting in blame, shame and social isolation [40, 41].

Our findings highlight the utility of applying a resource insecurity framework [41] to HIV-related stigma research.

Poverty is relational, involving social and institutional mistreatment, as well a core experience that involves disempowerment, suffering and struggle [42–44]. The "pathologization of poverty" (p. 78) [15], the ways in which people receiving disability-related benefits are stigmatized, is rooted in local moral economies where unemployment is socially devalued [15, 16, 45]. For instance, PLHIV who receive food assistance may experience social assistance services as uncompassionate and penalizing, while simultaneously feeling judged by society for being ill *and* for receiving social assistance [16]. It is plausible that these experiences heighten HIV-related stigma, itself rooted in moral judgement [46]. These findings on resource insecurity, alongside findings that lesbian, gay, bisexual and queer (LGBQ) and racialized participants experienced higher HIV-related stigma, reflect an intersectional experience of stigma [18–20], whereby social categories coalesce at the individual level of experience and expose interlocking systems of oppression [47].

HIV-related stigma reduced among participants over time, and stigma disparities by housing status also attenuated over time. Earnshaw et al. describe stigma as fluid and dynamic, situating stigma changes within historical context, developmental period and stigmatized status course [48]. For instance, our finding that younger participants reported higher HIV-related stigma could be understood from a developmental perspective, whereby younger persons undergo social transitions in education, employment and relationships that could present different stigma exposures [48]. Time since diagnosis was associated with reduced HIV-related stigma, aligning with the status course timescale, whereby persons can acquire stigma resilience, coping, self-esteem, self-efficacy and social support over time [48]. It is plausible that housing insecure participants at baseline were housed over time, as prior research documented that help-seeking self-efficacy and time living with HIV were associated with attaining stable housing over time [49]. Increased social support over time can also result in stigma reduction and assistance meeting housing needs [50].

3.1 | Strengths and limitations

There are three main limitations. First, we only collected housing and food insecurity data at baseline, and did not ask about duration of housing/food insecurity status. Thus, findings only tell us about how these indicators, assessed at one timepoint, affect later outcomes. Second, stigma is intersectional [19–21, 51], and we only examined HIV-related stigma. Third, we did not assess why HIV-related stigma reduced over time; historical contexts include social change movements, such as undetectable = untransmittable, that may reduce HIV-related stigma [48, 52, 53].

4 | CONCLUSIONS

Tackling resource insecurity is necessary to get to the heart of HIV-related stigma. HIV-related stigma and its relationships with resource insecurity require multi-faceted approaches. Structural interventions can address PLHIV's employment barriers, including workplace stigma, universal ART coverage and unpredictable periodic disability [54, 55]. Addressing housing insecurity could be integral to reducing HIV-related stigma [23]. As food and housing insecurity are associated with social isolation [3, 4, 56], strategies can leverage community solidarity and support [57]. Holistic approach to care can address poverty-related challenges [44], such as offering comprehensive and medically appropriate food support [58]. Advancing structural competency [59] and strengths-focused, client-centred clinical care [23] may produce social change for WLHIV.

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COMPETING INTERESTS

None to declare.

AUTHORS' CONTRIBUTIONS

CHL conceptualized paper and led writing. NS conducted analyses and contributed to writing. MK, SI, PK, ML, AK, AdP and ML provided edits and contributed to study design and implementation. All other CHIWOS Research Team^ members contributed to study design and supported data collection.

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All other CHIWOS Research Team Members who wish to remain anonymous.

DATA AVAILABILITY STATEMENT

Data are available from the Women's College Research Institute Women and HIV Research Program Data Access Coordinator for researchers and students who meet the research ethics board criteria for accessing confidential data. The current Data Access Coordinator is Jill Koebel and she can be reached at jill.koebel@wchospital.ca. The criteria for access to the confidential data include (1) being added as a CHIWOS researcher or student to the research ethics board (REB) application and (2) signing a CHIWOS Data Sharing and Collaboration Agreement. The de-identified data set cannot be publicly shared at this point as we do not have community or REB approval to do so. Co-authorship is a requirement for data access as per the CHIWOS authorship policy, which includes the requirement that the ICMJE authorship criteria be met by all authors.

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RESEARCH ARTICLE

A pretest-posttest design to assess the effectiveness of an intervention to reduce HIV-related stigma and discrimination in healthcare settings in Vietnam

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Abstract

Introduction: Stigma and discrimination are important barriers to HIV epidemic control. We implemented a multi-pronged facility-level intervention to reduce stigma and discrimination at health facilities across three high-burden provinces. Key components of the intervention included measurement of stigma, data review and use, participatory training of healthcare workers (HCWs), and engagement of people living with HIV and key populations in all stigma reduction activities.

Methods: From July 2018 to July 2019, we assessed HIV-related stigma and discrimination among patients and HCWs at 10 facilities at baseline and 9 months following an intervention. A repeated measures design was used to assess the change in stigma and discrimination among HCWs and a repeated cross-sectional design assessed the change in stigma and discrimination experienced by PLHIV. HCWs at target facilities were invited at random and PLHIV were recruited when presenting for care during the two assessment periods. McNemar's test was used to compare paired proportions among HCWs, and chi-square test was used to compare proportions among PLHIV. Mixed models were used to compare outcomes before and after the intervention.

Results: Semi-structured interviews were conducted with 649 and 652 PLHIV prior to and following the intervention, respectively. At baseline, over the previous 12 months, 21% reported experiencing discrimination, 16% reported self-stigma, 14% reported HIV disclosure without consent and 7% had received discriminatory reproductive health advice. Nine months after the intervention, there was a decrease in reported stigma and discrimination across all domains to 15%, 11%, 7% and 3.5%, respectively (all p-values <0.05). Among HCWs, 672 completed the pre- and post-intervention assessment. At baseline, 81% reported fear of HIV infection, 69% reported using unnecessary precautions when caring for PLHIV, 44% reported having observed other staff discriminate against PLHIV, 54% reported negative attitudes towards PLHIV and 41% felt uncomfortable working with colleagues living with HIV. The proportions decreased after the intervention to 52%, 34%, 32%, 35% and 24%, respectively (all p-values <0.05).

Conclusions: A multi-pronged facility-level intervention was successful at reducing healthcare-associated HIV-related stigma in Vietnam. The findings support the scale-up of this intervention in Vietnam and highlight key components potentially applicable in other settings.

Keywords: community engagement; HIV/AIDS; key populations; people living with HIV; stigma and discrimination; Vietnam

Additional information may be found under the Supporting Information tab of this article.

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1 | INTRODUCTION

Globally, stigma and discrimination are recognized as important barriers to ending AIDS by 2030 [1]. People living with HIV face stigma and discrimination in all aspects of their lives; within their families, communities, workplace and when seeking healthcare [2]. Stigma is often intersectional; in addition to HIV-related stigma, key populations (KPs) experience stigma related to substance use, sex work, gender identity and sexual orientation [3–6]. In the healthcare setting, HIV-related stigma affects access to and utilization of health services as well as the quality of care provided to people living with HIV [7]. Numerous studies have demonstrated the negative effects of stigma and discrimination on HIV testing, disclosure, linkage to care and adherence to antiretroviral therapy (ART) [8, 9]. The manifestations of HIV- and KP-related stigma in health facilities are well documented and include a refusal to provide care, providing poorer quality of care to patients living with HIV compared to other patients, disclosure of HIV status without consent, physical and verbal abuse, among others [10].

In healthcare settings, individual and institutional-level factors contribute to HIV-related stigma and discrimination [11]. Among healthcare workers (HCWs), HIV-related stigma is associated with a lack of knowledge about HIV transmission, concerns about occupational infection, prejudice towards KPs and certain risk behaviours, and lack of awareness about discrimination, its manifestations and consequences [11, 12]. At the institutional level, a lack of appropriate policies and protocols aimed to protect patients and HCWs and discourage discriminatory behaviours may contribute to an environment tolerant of stigma and discrimination. Interventions that focus on actionable drivers of stigma at the individual, environmental and policy levels have been shown to reduce HIV- and KP-related stigma in healthcare settings [10, 12]. Such interventions have not yet been implemented widely in a low-middle income country like Vietnam.

In Vietnam, there are an estimated 250,000 people living with HIV, a significant proportion of whom belong to KP groups, including people who inject drugs, men who have sex with men, transgender women and female sex workers [13]. In 2020, the country continued to make progress towards achieving the UNAIDS 95-95-95 target with 85% of people living with HIV knowing their HIV status, 78% of people who know their status on treatment and 96% of people on treatment with viral load less than 1000 copies/ml [14]. Challenges remain, however, particularly in case finding, linkage and retention, where HIV- and KP-associated stigma creates barriers for patients to engage and remain in care [15].

In 2017, the Vietnam Authority of HIV/AIDS Control of the Ministry of Health launched an effort to reduce stigma and discrimination in health facilities, where people living with HIV access treatment services. A multi-pronged facility-level intervention was developed to identify and address actionable drivers of stigma (Table 1). We evaluated the effect of the intervention on HIV-related stigma and discrimination among HCWs and patients receiving HIV care at healthcare facilities in three high burden provinces of Vietnam.

2 | METHODS

We assessed HIV-related stigma and discrimination among patients and HCWs at the targeted sites at baseline and 9 months following the start of the intervention. A repeated measures design was used to assess the change in stigma and discrimination among HCWs; the same HCWs were recruited for the baseline and the post-assessments. A repeated cross-sectional design was used to assess the change in stigma experienced by people living with HIV. An independent sample of people living with HIV was recruited for the baseline and post-assessment to represent the population at each period.

2.1 | Study site and population

The study was conducted at 10 health facilities in three provinces of Vietnam supported by the U.S. Centers for Disease Control and Prevention (CDC) under the U.S. President's Emergency Program For AIDS Relief. The provinces (Hanoi, Thai Nguyen and Binh Duong) were selected based on perceived need, commitment of provincial leaders and diversity of their settings. Facilities were selected by the following criteria: (1) providing ART services; (2) having at least 100 HIV-positive patients enrolled in care; (3) eligible for HIV service provision under social health insurance; and (4) newly started HIV clinical services. The latter represented greater perceived need for stigma reduction. The study population included adults, aged 18 years or older, receiving HIV care in the selected facilities for at least 6 months and HCWs at the selected facilities.

2.2 | Study subject selection

HCWs from all departments were grouped into three categories (physicians/physician assistants, nurses/midwifes and others [e.g. lab technicians, nurse assistants, receptionists, cleaners and security guards]) and were randomly selected by each facility's planning department to be invited to participate in the study. People living with HIV in both the pre- and post-assessments were invited to participate by clinic staff upon presenting for care during the assessment period. Eligible patients were recruited consecutively until the required sample size was reached.

2.3 | Sample size

The sample size was calculated to compare two related proportions for each domain measured among HCWs, and to compare proportions from two independent samples for each domain among people living with HIV. The sample size was then adjusted for clustering effect, finite population, non-response and staff turnover. The largest sample size among domains in each study group (622 HCWs and 496 patients) was selected, which provided adequate power to detect an intervention effect on all domains.

2.4 | Measures

We used questionnaires previously validated [16], used [17–20] and revised for appropriateness in the Vietnam context [21]. The HCW tool was originally developed as a programmatic tool for measuring stigma in diverse country settings [16]. In 2014, the tool was adapted for use in Thailand [17]. Simultaneously, Thailand developed a tool for measuring healthcare stigma among persons living with HIV. In 2016, the Thai tools were adapted for a pilot stigma reduction project in Vietnam [21]. In addition to demographic data, the questionnaires included four domains for people living with HIV, including (1) experienced discrimination,

Table 1. Components of intervention to reduce stigma and discrimination in health facilities in Vietnam

Activity	Description
Introductory meeting	Review project goals and activities, gain commitment from facility leadership, ensure all stakeholders understand roles and responsibility within the project
Pre-intervention assessment	Conduct survey on stigma and discrimination among patients and health workers from facility
Data review and activity planning workshop	Provide feedback on results of assessment to each facility, facilitate discussion of data among facility leaders, health workers, PLHIV and community leaders, perform root cause analysis and co-design interventions to address identified actionable drivers of stigma and discrimination
Participatory training	Conduct 2-day training of facility health workers on HIV- and KP-related stigma and discrimination with 11 modules: • Opening activities (expectations and objectives) • Naming stigma and discrimination through pictures • How stigma feels (reflection) • Naming stigma and discrimination in our health facility • Homework: true/false questions about key populations • Testimonies by key populations • The blame game • Value clarification (debate) • Fear-based stigma and discrimination and universal precautions • Analysing stigma and discrimination in our health facility • Action planning
Recognizing champions	Host ceremony with certificates provided to key opinion leaders, both HCWs and patients, within each facility who championed stigma reduction efforts
Review and revision of facility policies	Review, revision and dissemination of facility policies discouraging discrimination and reinforcing rights of PLHIV within health facilities
Information, education and communication activities	Use regular health worker staff meetings to disseminate policy updates, provide brief education sessions on universal precautions and risk of HIV transmission, and facilitate PLHIV testimonials. Sharing of information on social media pages and posters at facilities
PLHIV and KP engagement	Involve PLHIV and KP leaders in all aspects of the project, including data collection, training, workshops, intervention design, activity planning and policy revision
Post-intervention assessment	Conduct post-intervention survey among patients and health workers from facility with timely feedback of results for continuous improvement efforts

Abbreviations: HCWs, healthcare workers; KP, key population, PLHIV, people living with HIV.

(2) internalized stigma, (3) unwanted HIV disclosure and (4) discriminatory reproductive health advice. For HCWs, the tool contained six domains, including (1) fear of HIV infection, (2) unnecessary precautions, (3) observed enacted stigma, (4) negative attitudes towards people living with HIV, (5) working with colleagues living with HIV and (6) observed discrimination against KPs (Table 2 and File S1).

2.5 | Intervention

We used a multi-pronged facility-level intervention following key principles for stigma reduction defined by Nyblade et al., including addressing actionable drivers of stigma, creating partnerships between affected groups and opinion leaders, and putting affected groups at the centre of the response [1]. The core intervention was an HCW training, adapted for use in Vietnam, designed to address common fears and misconceptions about HIV, educate about HIV prevention in the healthcare setting and use participatory methods to create an open dialogue about HIV- and KP-related stigma (Table 1 and File S2).

2.6 | Data collection

Baseline data collection occurred between July and October 2018 and the post-assessment occurred between May and July 2019. Data were collected and managed using REDCap electronic data capture tools hosted at Beth Israel Deaconess Medical Center [22]. Patients were interviewed in a private room of the health facility by trained peers who used smart

Table 2. Description of study outcomes—composite domain indices

Domain	Numerator	Denominator
Healthcare workers		
1. Fear of HIV infection (three items)	Number of respondents who answered they would be "worried" (a little worried/worried/very worried) to any of the three items	Respondents who answered the items, excluding those who answered "non-applicable"
2. Unnecessary precautions and measures (two items)	Number of respondents who answered "YES" to any of the two items	
3. Observed enacted stigma (two items)	Number of respondents who answered "observed" (sometimes/often/most of the times) to any of the two items	All respondents
4. Expressed negative attitudes towards PLHIV (five items)	Number of respondents who answered "strongly agree or agree" with any of the statements/items 1–4, or "strongly disagree or disagree" with statement 5	
5. Uncomfortable working with PLHIV staff (one item)	Number of respondents who answered "uncomfortable" (a little uncomfortable, uncomfortable, very uncomfortable) to the item	
6. Observed discrimination against KP (one item/KP)	Number of respondents who answered "observed" (sometimes/often/most of the times) for each KP (MSM, FSW, MSW, PWID, TGW)	
People living with HIV		
1. Experienced discrimination (10 items)	Number of respondents who answered "YES" (in the past 12 months) to any of the 10 items	Respondents who answered at least one item within the domain, excluding those who answered "non-applicable"
2. Internalized stigma (two items)	Number of respondents who answered "YES" (in the past 12 months) to any of the two items	
3. Experienced disclosure of HIV status by health staff (two items)	Number of respondents who answered "YES" to any of the two items	
4. Experienced discriminatory reproductive health advice based on HIV status (four items)	Number of respondents who answered "YES, in the past 12 months" to any of the four items	

Abbreviations: FSW, female sex workers; KP, key population; MSM, men who have sex with men; MSW, male sex workers; PLHIV, people living with HIV; PWID, people who inject drugs; TGW, transgender women.

phones to access the online semi-structured questionnaire. HCWs gathered in a private room in groups of 5–10 with the data collector to complete the self-administered survey. HCWs accessed the survey through a web-link on their own devices and submitted their responses directly into REDCap.

2.7 | Ethical considerations

The study was approved by the Institutional Review Boards of Beth Israel Deaconess Medical Center (#2010P000334) in Boston, USA and Hanoi University of Public Health (#18-408/DD-YTCC) in Hanoi, Vietnam. The study protocol was reviewed and approved in accordance with the U.S. CDC human research protection procedures and was determined to be research, but CDC investigators did not interact with human subjects or have access to identifiable data or specimens for research purposes (#2018-092a). All subjects provided written informed consent prior to participation.

2.8 | Data analysis

The main outcomes were composite domain indices (Table 2). Proportions and 95% confidence intervals (CI) were calculated for categorical variables; and means and standard deviations (SD) for continuous variables. *T*-test was used to compare means. McNemar's test was used to compare paired proportions before and after the intervention among HCWs, and chi-square test was used to compare proportions before and after the intervention among people living with HIV. HCWs were included in the analysis only if they completed the

Table 3. Descriptive characteristics of participating PLHIV, *n* (%) or mean ± SD

	Before $N = 649$	After $N = 652$	*p*-value
Age (years)	39.6±8.4	39.7±8.9	0.825[a]
Gender			
Male	407 (63.1)	393 (60.3)	0.295[b]
Female	238 (36.9)	259 (39.7)	
Province			
Thai Nguyen	206 (31.7)	206 (31.6)	0.973[b]
Ha Noi	205 (31.6)	203 (31.1)	
Binh Duong	238 (36.7)	243 (37.3)	
Insurance			
Government insurance	594 (91.5)	604 (92.6)	0.001[b]
Private insurance	32 (4.9)	11 (1.7)	
No insurance	23 (3.6)	37 (5.7)	
Time from confirmed HIV (years)	8.5±4.9	7.9±5.2	0.031[a]
Disclosed HIV status			
No	100 (15.4)	122 (18.7)	0.113[b]
Yes	549 (84.6)	530 (81.3)	
Current ART			
Yes	648 (99.8)	649 (99.5)	0.624[c]
No	1 (0.2)	3 (0.5)	
Time on ART (years)	6.6±3.8	6.4±4.1	0.236[a]

Note: Four PLHIV did not report gender on the pre-intervention assessment.
Abbreviations: ART, antiretroviral therapy; PLHIV, people living with HIV; SD, standard deviation.
[a] *t*-test.
[b] chi-squared test.
[c] Fisher's exact test.

baseline assessment, attended the training intervention and completed the post-assessment. Logistic mixed models were used to compare outcomes before and after intervention, taking into account subject dependence for HCWs due to the repeated measure design, and clustering effect (healthcare facilities) for both HCWs and people living with HIV. Models were adjusted for demographic factors. Due to the high correlation between years since HIV diagnosis and years on ART, only the number of years on ART was included in the models. As there were only four patients not on ART, they were excluded from the analysis. We also examined interactions between gender or occupation of HCWs and the intervention effect. Analyses were performed using Stata/SE 14.2 (Stata Corporation, College Station, TX).

3 | RESULTS

3.1 | People living with HIV assessment

Overall, 649 and 652 people living with HIV participated in the pre- and post-intervention assessments, respectively. The groups were similar across age (mean age 40 years), gender (63% male), province of residence, time since HIV diagnosis, time on ART and HIV disclosure status. In the post-intervention group, there were slightly more patients on government health insurance or reporting no insurance (Table 3). Prior to the intervention, over the previous 12 months, 21% of people living with HIV reported experiencing discrimination, 16% reported self-stigma, 14% reported HIV disclosure without consent and 7% reported receiving discriminatory reproductive health advice. Nine months after the intervention, there was a decrease in reported stigma across all domains to 15%, 11%, 7% and 3.5%, respectively (all *p*-values <0.05) (Figure 1). After adjusting for age, gender, time on ART, insurance status, HIV disclosure and province of residence, the odds of reporting stigma and discrimination in the post-assessment was reduced across all domains with an adjusted OR (95% CI) of 0.64 (0.48–0.86) for experienced discrimination, 0.60 (0.43–0.84) for self-stigma, 0.49 (0.33–0.71) for disclosure of HIV status and 0.48 (0.28–0.82) for reproductive health (Table 4).

Women living with HIV were more likely to report self-stigma (OR = 1.85, 95% CI = 1.33–2.58), and HIV disclosure by an HCW without consent (OR = 1.60, 95% CI = 1.10–2.31) than their male counterparts. There was no significant difference between genders in the other two domains. People living with HIV who were on ART for 10 years or more were less likely to report self-stigma compared to those on ART for less than 5 years (OR = 0.58, 95% CI = 0.35–0.96). No differences based on time on ART were seen in the other three domains.

Some differences were seen across the three provinces. Compared to those in Binh Duong, patients in Thai Nguyen were less likely to report self-stigma (OR = 0.44, 95% CI = 0.11–0.60) and those in Thai Nguyen and Hanoi were less likely to report discrimination related to reproductive health (Thai Nguyen: OR = 0.25, 95% CI = 0.11–0.57; Hanoi: OR = 0.15, 95% CI = 0.06–0.39). There were no statistically significant associations between age or HIV disclosure and any of the four domains.

3.2 | HCW assessment

A total of 672 HCWs, who participated in the pre-assessment, intervention and post-assessment, were included in the analyses. Three-quarters were females and mean age was 35 years (Table 5). More than half (57%) were nurses or midwives, 20% were physicians or physician assistants and 23% were other HCWs.

Prior to the intervention, 81% of HCWs reported having some fear of HIV infection, 69% reported using unnecessary precautions when caring for people living with HIV, 44% reported having observed discrimination by other staff against people living with HIV, 54% reported negative attitudes towards people living with HIV and 41% reported feeling uncomfortable working with colleagues living with HIV. After the intervention, there was a significant decrease in reported stigma and discrimination across all five domains (Figure 2).

After adjusting for age, gender, occupation, years of working, contact with people living with HIV and province, the odds of reporting stigma and discrimination among HCWs in

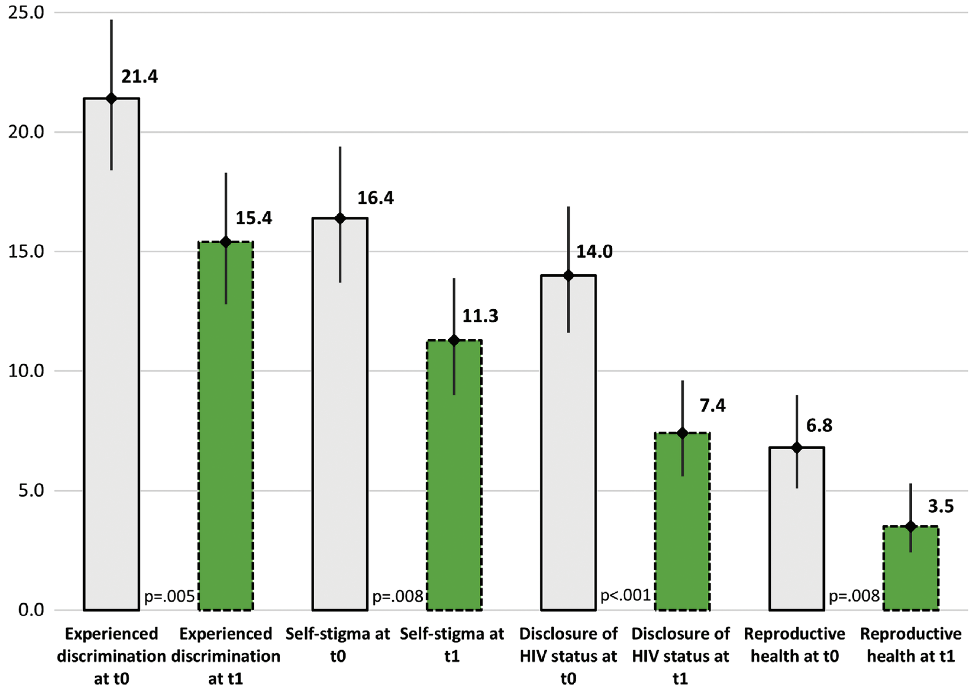

Figure 1. Four domains related to stigma and discrimination among people living with HIV before (t0) and after the intervention (t1), % (95% confidence interval). Note: Error bars represent 95% confidence intervals; *p*-value determined by chi-squared test; t0 represents the pre-intervention assessment and t1 represents the post-intervention assessment. This figure presents the percent of PLHIV participants who reported stigma and discrimination in each of four studied domains (experienced discrimination, internalized stigma, unwanted HIV disclosure and discriminatory reproductive health advice) at baseline and 9 months following the intervention. Abbreviation: PLHIV, people living with HIV.

the post-assessment reduced significantly across all domains (Table 6), including a 49% reduction in observed discrimination, 86% reduction in fear of infection and 87% reduction in the use of unnecessary precautions.

Table 7 and Figure 3 present observed discrimination against KPs among HCWs. Following the intervention, reported discrimination decreased between 40% and 57% across all KP groups.

4 | DISCUSSION

HIV- and KP-related stigma and discrimination are well-recognized barriers to HIV epidemic control [7, 8, 23, 24]. In Vietnam, nationwide data on stigma and discrimination in healthcare settings are generally lacking; however, available evidence suggests that stigma is pervasive across all aspects of the lives of people living with HIV. The 2014 People Living with HIV Stigma Index found that between 11% and 19% of people living with HIV avoided going to health facilities as a result of their HIV status [25]. A recent cross-sectional study in three high-prevalence provinces found that 86% of people living with HIV reported experiencing HIV-related stigma, from their community (63%), family (30%) and healthcare system (8%) [26]. Our study evaluated an intervention designed to reduce HIV-related stigma in health facilities. The results showed high rates of HIV- and KP-related stigma and discrimination at baseline across all measured domains, with one out of five people living with HIV reporting having experienced discrimination in the past 12 months. Following the intervention, there were significant reductions in all measured domains.

Our intervention employed evidence-based strategies, including engagement of facility leadership; inclusion of a broad range of health staff; use of tools and curricula adapted for local context; empowerment of key opinion leaders; and the use of participatory training methods designed to deepen HCW understanding about stigma and discrimination and its consequences, reduce fear and misconceptions about HIV transmission risk and gain commitment to act against stigma and discrimination within health facilities [11]. In addition, our approach focused on the immediate actionable drivers of stigma, and utilized quality improvement methods to empower facility leaders to use local data to tailor interventions [10, 27]. We emphasized engagement and co-creation with the HIV-positive and KP community, following the principle of placing communities and patients at the centre of the HIV response [28]. In addition to peer data collectors, people living with HIV and local community leaders were engaged in all aspects of the intervention, including the training, data feedback workshops and facility quality improvement teams.

It may be difficult to compare our results to other interventions previously reported as these had different approaches, timeline and measurements [29, 30]. A recent scoping review of stigma reduction interventions in healthcare settings in low- and middle-income countries found that, overall,

Table 4. Associations between the intervention and four domains of stigma and discrimination among people living with HIV, OR (95% CI)

	Experienced discrimination (*N* = 1284)		Self-stigma (*N* = 1281)		Disclosure of HIV status (*N* = 1285)		Reproductive health (*N* = 1285)	
	Unadjusted	**Adjusted**	**Unadjusted**	**Adjusted**	**Unadjusted**	**Adjusted**	**Unadjusted**	**Adjusted**
Intervention								
	1	1	1	1	1	1	1	1
Before	0.68 (0.51–0.90)	0.64 (0.48–0.86)	0.65 (0.47–0.90)	0.60 (0.43–0.84)	0.49 (0.34–0.71)	0.49 (0.33–0.71)	0.47 (0.28–0.80)	0.48 (0.28–0.82)
After	0.98 (0.96–1.00)	0.99 (0.97–1.00)	0.99 (0.97–1.01)	1.00 (0.98–1.02)	0.98 (0.96–1.00)	0.98 (0.95–1.00)	0.98 (0.95–1.01)	0.99 (0.96–1.02)
Age								
Gender								
Male	1	1	1	1	1	1	1	1
Female	1.11 (0.83–1.48)	1.13 (0.84–1.53)	1.77 (1.28–2.45)	1.85 (1.33–2.58)	1.64 (1.14–2.35)	1.60 (1.10–2.31)	0.77 (0.45–1.32)	0.81 (0.47–1.41)
Disclosed HIV status								
No	1	1	1	1	1	1	1	1
Yes	0.74 (0.52–1.05)	0.75 (0.52–1.07)	0.76 (0.51–1.14)	0.81 (0.53–1.22)	0.79 (0.50–1.25)	0.76 (0.48–1.21)	0.69 (0.38–1.25)	0.72 (0.39–1.33)
Years on ART								
<5 years	1	1	1	1	1	1	1	1
5 to <10 years	0.84 (0.61–1.16)	0.87 (0.62–1.24)	0.86 (0.60–1.25)	0.77 (0.53–1.13)	1.26 (0.84–1.89)	1.12 (0.72–1.73)	0.96 (0.54–1.70)	1.14 (0.62–2.12)
10+ years	0.79 (0.54–1.16)	0.93 (0.61–1.41)	0.55 (0.33–0.91)	0.58 (0.35–0.96)	0.96 (0.58–1.60)	1.03 (0.60–1.78)	0.92 (0.44–1.93)	1.08 (0.50–2.34)
Type of insurance								
Government insurance	1	1	1	1	1	1	1	1
Private insurance	0.74 (0.31–1.78)	0.56 (0.23–1.37)	1.62 (0.74–3.51)	1.27 (0.58–2.78)	1.15 (0.44–3.02)	0.93 (0.34–2.49)	1.47 (0.53–4.04)	1.05 (0.37–2.97)
No insurance	1.11 (0.58–2.13)	1.02 (0.53–1.98)	1.91 (1.00–3.65)	1.76 (0.91–3.41)	0.61 (0.22–1.72)	0.60 (0.21–1.72)	1.59 (0.60–4.24)	1.67 (0.61–4.57)
Province								
Binh Duong	1	1	1	1	1	1	1	1
Hanoi	0.96 (0.69–1.33)	1.03 (0.72–1.48)	0.81 (0.56–1.16)	0.88 (0.60–1.31)	1.20 (0.70–2.07)	1.28 (0.75–2.17)	0.14 (0.06–0.37)	0.15 (0.06–0.39)
Thai Nguyen	0.65 (0.45–0.93)	0.71 (0.48–1.04)	0.40 (0.26–0.62)	0.44 (0.11–0.60)	1.21 (0.70–2.08)	1.34 (0.78–2.29)	0.24 (0.11–0.53)	0.25 (0.11–0.57)

Abbreviations: 95% CI, 95% confidence interval; ART, antiretroviral therapy; OR, odds ratio.

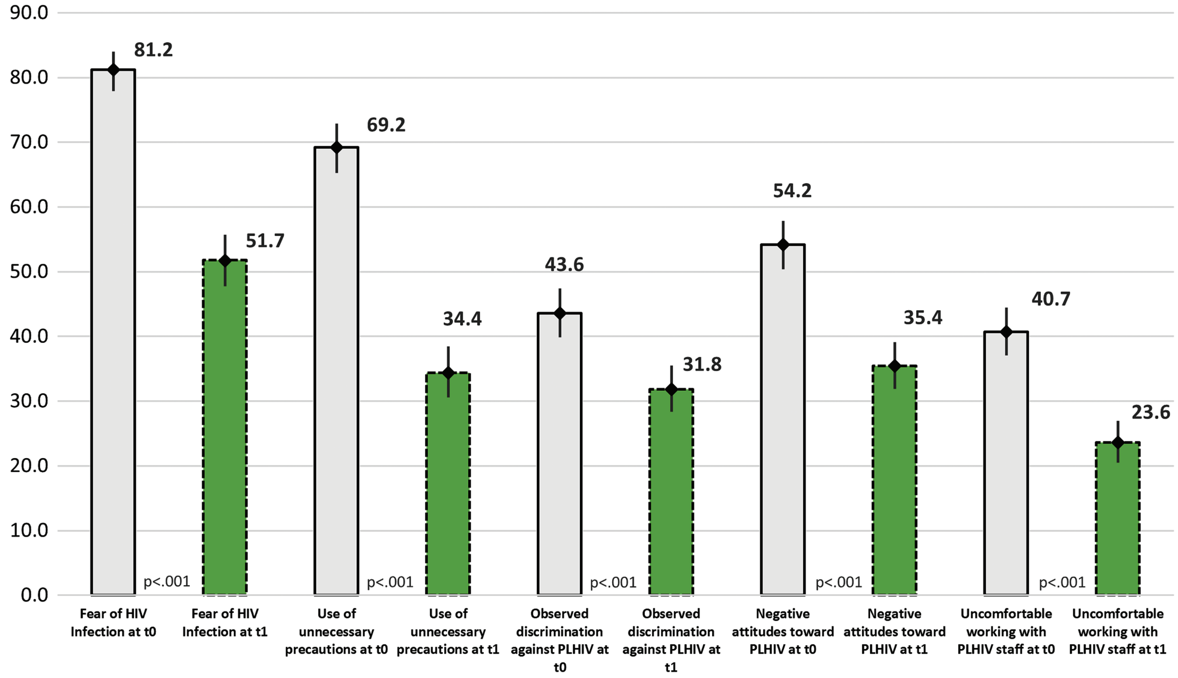

Figure 2. Five domains related to stigma and discrimination among healthcare workers before (t0) and after the intervention (t1), % (95% confidence interval). Note: Error bars represent 95% confidence intervals; *p*-value determined by McNemar's test; t0 represents the pre-intervention assessment and t1 represents the post-intervention assessment. This figure presents the percent of healthcare worker participants who reported stigma and discrimination in each of five studied domains (fear of HIV infection, unnecessary precautions, observed enacted stigma, negative attitudes towards people living with HIV and working with colleagues living with HIV) at baseline and 9 months following the intervention. Abbreviation: PLHIV, people living with HIV.

Table 5. Descriptive characteristics of participating health staff[a] at baseline, *n* (%) or mean ± SD

Age (years), *n* = 672	34.5±8.2
Gender, *n* = 671	
Male	167 (24.9%)
Female	504 (75.1%)
Province, *n* = 672	
Thai Nguyen	192 (28.6%)
Ha Noi	209 (31.1%)
Binh Duong	271 (40.3%)
Occupation, *n* = 672	
Physician/physician assistant	137 (20.4%)
Nurse/midwife	382 (56.8%)
Other	153 (22.8%)
Time working at the facility (years), *n* = 659	10.6±7.8
Care for or interact with people living with HIV, *n* = 672	
No	198 (29.5%)
Yes	474 (70.5%)
Time interacting with people living with HIV (years), *n* = 454	8.8±6.7

Abbreviations: SD, standard deviation.
[a] Baseline data, except for time working at the facility and time interacting with people living with HIV, which were not available in the baseline data.

interventions to reduce HIV-related stigma were effective in the areas they addressed and measured [31]. However, since stigma and discrimination were not defined and measured consistently, it is difficult to make meaningful comparisons across studies. Nonetheless, our study provides further evidence for the effectiveness of these strategies and highlights potential best practices to inform the design of stigma reduction programmes in other settings.

Despite finding significant reductions in all measured domains following the intervention, reported stigma and discrimination remained high in the post-assessment. After the intervention, the proportion of HCWs reporting stigma and discrimination was above 30% in four out of five domains (Figure 2). In addition, in the post-assessment, more than 15% of people living with HIV reported experiencing discrimination in the intervening 9-month period. As patients often receive healthcare from more than one healthcare provider and from multiple facilities, it is possible that ongoing discrimination may have occurred at facilities that were not participating in the intervention. These findings highlight the importance of employing ongoing efforts to measure, understand and reduce HIV-related stigma [27] and suggest that a system-wide response may be necessary to fully tackle stigma and discrimination in the healthcare setting [32].

Our results, that 15–21% of people living with HIV experienced healthcare-related discrimination, are comparable to those in other settings. In a pilot study of the Stigma Index 2.0, discrimination was reported by 13%, 38% and 43% of

Table 6. Adjusted associations between the intervention and five domains of stigma and discrimination among healthcare workers, OR (95% CI)

	Fear of infection (*N* = 613)	**Use of unnecessary precautions (*N* = 556)**	**Observed discrimination against people living with HIV (*N* = 658)**	**Negative attitudes towards people living with HIV (*N* = 658)**	**Uncomfortable working with people living with HIV staff (*N* = 656)**
Intervention					
Before	1	1	1	1	1
After	0.14 (0.09–0.20)	0.13 (0.09–0.20)	0.51 (0.39–0.67)	0.38 (0.29–0.49)	0.33 (0.25–0.45)
Age	0.95 (0.90–0.99)	1.02 (0.98–1.06)	0.96 (0.93–1.00)	1.02 (0.99–1.06)	0.93 (0.90–0.97)
Gender					
Male	1	1	1	1	1
Female	0.62 (0.36–1.04)	0.86 (0.54–1.37)	0.59 (0.39–0.89)	0.78 (0.53–1.15)	0.70 (0.45–1.09)
Occupation					
Physician/physician assistant	1	1	1	1	1
Nurse/midwife	1.39 (0.77–2.50)	2.55 (1.49–4.37)	0.51 (0.32–0.82)	1.26 (0.81–1.97)	0.64 (0.39–1.06)
Other	1.12 (0.59–2.13)	0.97 (0.53–1.76)	0.21 (0.12–0.36)	0.99 (0.61–1.59)	0.37 (0.21–0.65)
Years of working					
<5 years	1	1	1	1	1
5 to <10 years	1.16 (0.64–2.09)	1.28 (0.75–2.16)	1.28 (0.80–2.04)	0.87 (0.56–1.35)	1.16 (0.70–1.90)
10 to <20	1.08 (0.54–2.17)	1.66 (0.88–3.15)	1.66 (0.94–2.91)	0.92 (0.54–1.54)	1.39 (0.76–2.55)
20+ years	2.32 (0.71–7.52)	2.38 (0.81–7.04)	2.47 (0.96–6.35)	0.80 (0.33–1.91)	2.35 (0.84–6.54)
Contact with people living with HIV					
No	1	1	1	1	1
Yes	1.60 (1.00–2.55)	1.38 (0.88–2.17)	1.62 (1.11–2.36)	1.01 (0.72–1.43)	0.99 (0.66–1.47)
Province					
Binh Duong	1	1	1	1	1
Thai Nguyen	1.40 (0.82–2.41)	1.82 (0.65–5.09)	0.80 (0.42–1.53)	1.48 (0.87–2.50)	0.92 (0.58–1.48)
Hanoi	1.48 (0.86–2.55)	1.08 (0.38–3.03)	1.39 (0.73–2.64)	1.31 (0.77–2.24)	2.39 (1.49–3.84)

Abbreviations: 95% CI, 95% confidence interval; OR, odds ratio.

people living with HIV surveyed in Senegal, Uganda and Cameroon, respectively [33]. In contrast, in a study in South Africa and Zambia, only 7.3% reported experiencing healthcare stigma in the past year [34]. Such comparisons have limitations due to differences in measures, study population and country context, but nevertheless demonstrate the need for effective and scalable stigma reduction interventions.

Understanding HCW attitudes towards KPs and addressing intersectional stigma is crucial, particularly in a concentrated HIV epidemic as in Vietnam [4, 5, 35]. In our study, high rates of observed discrimination towards all KP groups were reported by HCWs, with particularly high rates for people who inject drugs even following the intervention. Individuals who acquired HIV through drug use suffer from intersectional stigma associated with fear of transmission as well as moral shaming of how HIV was acquired, which deters them from seeking healthcare services, disclosing their status, and contributes to unemployment, social isolation and marginalization [36]. This may be particularly true in Vietnam where HIV prevention campaigns in the early 2000s defined drug users and sex workers as "social evils" [37]. In Vietnam, stigma related to drug use has been shown to be negatively associated with access to care [38]. Likewise, men who have sex with men and transgender women in Vietnam have reported being stigmatized by the healthcare system and assert that a lack of KP-friendly care limits their access to HIV prevention services [39–41]. Even after the intervention, we found that women living with HIV were more likely to report self-stigma and unwanted disclosure of HIV status compared to their male counterparts after controlling for other factors. Higher rates of self-stigma among women living with HIV have been shown in other settings, but data in Vietnam are lacking [42, 43]. Further research exploring gender issues related to stigma is needed to better inform the development of interventions focused on addressing intersectional stigma and promote KP-friendly healthcare.

Our study may have important implications towards improving the continuum of care. Previous studies have demonstrated associations between internalized, anticipated, and experienced stigma and discrimination and outcomes along each stage of the HIV care continuum [44]. People living with HIV and members of KP groups may avoid

Table 7. Adjusted associations between the intervention and observed discrimination against key populations among healthcare workers, OR (95% CI)

	MSM (*N* = 655)	TGW (*N* = 655)	FSW (*N* = 654)	MSW (*N* = 653)	PWID (*N* = 656)
Intervention					
Before	1	1	1	1	1
After	0.60 (0.39–0.94)	0.59 (0.36–0.94)	0.45 (0.32–0.63)	0.56 (0.38–0.82)	0.43 (0.33–0.57)
Age	0.97 (0.91–1.03)	0.96 (0.91–1.02)	0.95 (0.90–0.99)	0.97 (0.92–1.02)	0.96 (0.92–1.00)
Gender					
Male	1	1	1	1	1
Female	0.55 (0.28–1.09)	0.73 (0.38–1.38)	0.93 (0.56–1.55)	1.58 (0.90–2.77)	0.70 (0.45–1.10)
Occupation					
Physician/physician assistant	1	1	1	1	1
Nurse/midwife	0.79 (0.36–1.74)	0.67 (0.32–1.40)	0.69 (0.39–1.22)	0.56 (0.31–1.03)	0.69 (0.42–1.13)
Other	0.48 (0.19–1.19)	0.55 (0.24–1.28)	0.34 (0.17–0.65)	0.35 (0.17–0.72)	0.28 (0.16–0.49)
Years of working					
<5 years	1	1	1	1	1
5 to <10 years	1.40 (0.62–3.17)	1.00 (0.47–2.16)	1.79 (1.01–3.19)	1.79 (0.97–3.29)	1.33 (0.81–2.19)
10 to <20	1.26 (0.46–3.41)	1.32 (0.53–3.32)	1.42 (0.70–2.90)	1.39 (0.65–2.99)	1.10 (0.61–2.00)
20+ years	1.41 (0.27–7.44)	1.59 (0.33–7.60)	2.42 (0.72–8.15)	1.10 (0.30–3.99)	2.21 (0.82–5.99)
Contact with people living with HIV					
No	1	1	1	1	1
Yes	1.93 (0.96–3.87)	1.44 (0.77–2.71)	2.01 (1.23–3.29)	1.58 (0.95–2.63)	1.17 (0.79–1.75)
Province					
Binh Duong	1	1	1	1	1
Thai Nguyen	0.26 (0.12–0.56)	0.42 (0.20–0.86)	0.97 (0.53–1.77)	0.34 (0.17–0.70)	1.12 (0.59–2.15)
Hanoi	0.51 (0.26–1.01)	0.92 (0.50–1.69)	2.28 (1.24–4.19)	1.72 (0.92–3.24)	2.26 (1.17–4.36)

Abbreviations: 95% CI, 95% confidence interval; FSW, female sex workers; MSM, men who have sex with men; MSW, male sex workers; OR, odds ratio; PWID, people who inject drugs; TGW, transgender women.

seeking HIV testing, prevention or treatment services, or may receive inadequate quality of care if they do seek services [2]. Although we are unable to extrapolate whether the reduction in our pilot intervention translated into positive health outcomes for people living with HIV in this setting, eliminating stigma in healthcare settings is likely to improve clients' willingness to engage in care, adherence to ART and to improve retention in care [1, 7–10]. This is an important area for ongoing research.

Our study has several limitations. First, with no control group, we cannot exclude that our results are due to secular trends. Second, social desirability bias may have contributed to the improved rates of reported stigma among HCWs. It is possible that, because of the intervention, HCWs better understood about stigma and, as a result, attempted to minimize it when completing the post-assessment. Additionally, providing the pre-assessment results to the facilities may have created pressure to report lower stigma on the post-assessment. However, this would not explain the concurrent decrease in stigma reported by people living with HIV in the study. Third, potential sampling bias may limit the generalizability of our results. For reasons of confidentiality and concerns about patient attrition, an independent sample of people living with HIV was enrolled for the pre- and post-assessments. Moreover, patients not engaged in care or not on ART were not included in our study and may have had different experiences, which were not captured by our data. Fourth, as we did not adequately collect data on gender identity, sexual practices or injection drug use, we could not categorize individuals by KP group. As a result, KP-related stigma was measured based on HCW observation rather than patient experience. Fifth, the post-assessment occurred at only one time point so we cannot comment on the durability of the change. To address this and the ongoing need, we are employing routine measurement of stigma among patients and HCWs every 6–12 months. Finally, we cannot exclude potential contributions to our findings from other concurrent efforts to reduce HIV- or KP-related stigma. However, given the intensity of our intervention at the participating facilities, it is unlikely that other efforts would have had a significant impact on our results.

5 | CONCLUSIONS

Reducing HIV-related stigma is an important part of Vietnam's effort to end the AIDS epidemic by 2030. In our study, a multi-pronged intervention was successful at reducing HIV-related stigma across 10 facilities in three provinces of Vietnam. Key components of the intervention included

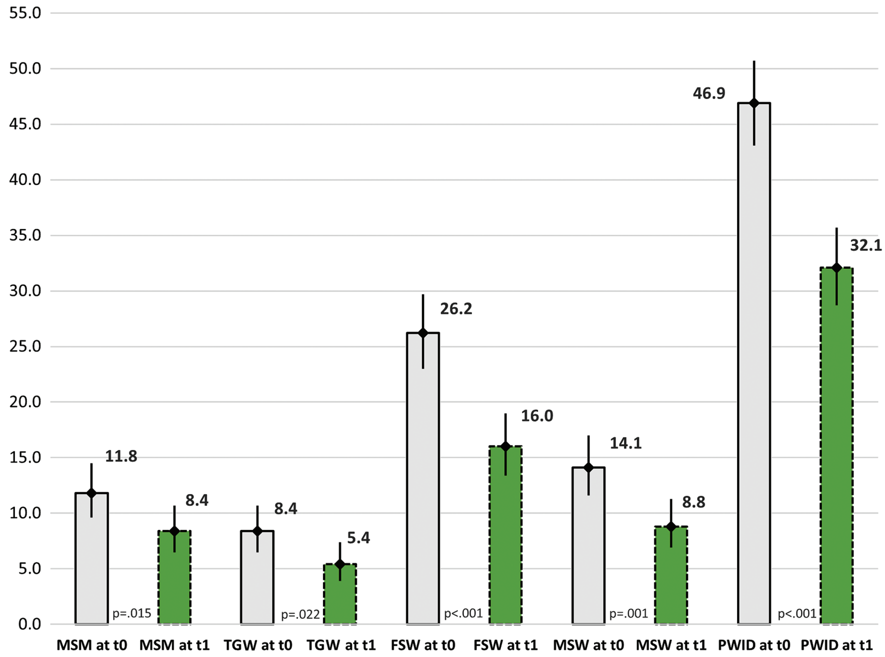

Figure 3. Observed discrimination against key populations among healthcare workers before (t0) and after the intervention (t1), % (95% confidence interval). Note: Error bars represent 95% confidence intervals; *p*-value determined by McNemar's test; t0 represents the pre-intervention assessment and t1 represents the post-intervention assessment. This figure presents the percent of healthcare worker participants who reported having observed discrimination against key populations at baseline and 9 months following the intervention. Abbreviations: FSW, female sex workers; MSM, men who have sex with men; MSW, male sex workers; PLHIV, people living with HIV; PWID, people who injects drugs; TGW, transgender women.

measurement of stigma and discrimination, data review and use, participatory training of HCWs, and meaningful engagement of people living with HIV and KP in the effort. Overall, our findings support the scale-up of this intervention in Vietnam and highlight important components potentially applicable to other country programmes and settings.

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COMPETING INTERESTS

All authors declare that they have no known competing interests related to the work reported in this paper.

AUTHORS' CONTRIBUTIONS

All authors have read and approved the final manuscript. TMP, AN, HDC and DHT conceived the study. TMP, DTH, DTNV and DTP designed the study and wrote the study protocol. NKU, VTL, NVT, LAKA and NTN facilitated and supervised data collection. DTNV, DTP and VTTN collected the data. DTH analysed the data. TMP and DTH wrote the paper. LAC revised and HDC approved the final version of the manuscript.

DISCLAIMER

The findings and conclusions in this report are those of the author(s) and do not necessarily represent the official position of the funding agencies.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author, TMP, upon reasonable request.

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SUPPORTING INFORMATION

Additional information may be found under the Supporting Information tab for this article:
File S1: Study questionnaires.
File S2: Description of the intervention.

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RESEARCH ARTICLE

Using a mixed-methods approach to adapt an HIV stigma reduction to address intersectional stigma faced by men who have sex with men in Ghana

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Abstract

Introduction: In Ghana, men who have sex with men (MSM) are estimated to be 11 times more likely to be living with HIV than the general population. Stigmas at the intersection of HIV, same-sex and gender non-conformity are potential key drivers behind this outsized HIV disease burden. Healthcare workers (HCWs) are essential to HIV prevention, care and treatment and can also be sources of stigma for people living with HIV and MSM. This article describes the process and results of adapting an evidence-based HIV stigma-reduction HCW training curriculum to address HIV, same-sex and gender non-conformity stigma among HCWs in the Greater Accra and Ashanti regions, Ghana.

Methods: Six steps were implemented from March 2020 to September 2021: formative research (in-depth interviews with stigma-reduction trainers [*n* = 8] and MSM living with HIV [*n* = 10], and focus group discussions with HCWs [*n* = 8] and MSM [*n* = 8]); rapid data analysis to inform a first-draft adapted curriculum; a stakeholder adaptation workshop; triangulation of adaptation with HCW baseline survey data (*N* = 200) and deeper analysis of formative data; iterative discussions with partner organizations for further refinement; external expert review; and final adaptation with the teams of HCWs and MSM being trained to deliver the curriculum.

Results: Key themes emerging under four immediately actionable drivers of health facility intersectional stigma (awareness, fear, attitudes and facility environment) informed the adaptation of the HIV training curriculum. Based on the findings, existing curriculum exercises were placed in one of four categories: (1) Expand—existing exercises that needed modifications to incorporate deeper MSM and gender non-conformity stigma content; (2) Generate—new exercises to fill gaps; (3) Maintain—exercises to keep with no modifications; and (4) Eliminate—exercises that could be dropped given training time constraints. New exercises were developed to address gender norms, the belief that being MSM is a mental illness and stigmatizing attitudes towards MSM.

Conclusions: Getting to the "heart of stigma" requires understanding and responding to both HIV and other intersecting stigma targeting sexual and gender diversity. Findings from this study can inform health facility stigma reduction programming not only for MSM, but also for other populations affected by HIV-related and intersectional stigma in Ghana and beyond.

Keywords: stigma; intervention; men who have sex with men; Africa; HIV care continuum; key and vulnerable populations

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1 | INTRODUCTION

Recognizing the role of stigma in the health and wellbeing of people living with, at risk of, or affected by HIV, the UN General Assembly political declaration on HIV and AIDS established the target of reducing stigma and discrimination to 10% by 2025 [1]. Efforts must now expand stigma-reduction programmes and build the evidence for effective implementation. "To get to the heart of stigma," these efforts must focus on key populations (KPs) affected by HIV and healthcare workers (HCWs) [2]. Their importance is underlined by specific 2025 global stigma sub-targets: less than 10% of HCWs will report stigmatizing attitudes towards KPs or people living with HIV (PLHIV) and less than 10% of KPs will experience stigma [2].

Ensuring KPs, including gay, bisexual and other men who have sex with men (MSM), have access to stigma-free HIV prevention and treatment services is a human rights imperative and key to ending AIDS by 2030 [3]. Between 2010 and 2019, MSM experienced a 25% increase in HIV infections [2]. Stigma at the intersection of HIV, same-sex and gender non-conformity has been identified as a potential key driver behind the outsized HIV disease burden among MSM [4–6]. Intersectional stigma occurs at the juncture of multiple stigmatized identities, arises from systems of oppression and may be synergistic in effect [7–10]. The stigma experienced by MSM is especially acute in countries where the legal, social and cultural milieu forces many MSM underground [11–15], making accessing health services, including HIV services, challenging [16, 17]. In many West African countries, including Ghana, stigma manifests through laws criminalizing homosexuality, impeding HIV prevention and treatment services for MSM [15, 18, 19]. While there is no specific Ghanaian law denouncing MSM, section 104 of the Criminal Code, "Unnatural carnal knowledge is sexual intercourse with a person in an unnatural manner or with an animal" is commonly interpreted to include same-sex behaviour [17, 20].

HCWs and healthcare facilities (HCFs) are essential to HIV prevention, care and treatment. They can also be sources of stigma for both PLHIV and KPs [21, 22], who have reported dismissive attitudes, coerced procedures and refusal to deliver treatment [2, 6, 23, 24]. In an HCF study in Ghana, 29% of HCWs indicated that if given the choice, they would prefer not to provide services to MSM [6]. The critical role of HCFs and HCWs in tackling stigma is emphasized by UN-led global HCF stigma-reduction initiatives [25–27]. Multiple HIV HCF stigma-reduction interventions are available [21, 22, 24, 28–32], and a few studies have developed interventions to address MSM stigma [33–35]. However, interventions to address intersectional (HIV, same-sex and gender non-conformity) stigma faced by MSM, particularly in West Africa, are limited [9, 23, 36].

In response, this article describes the process of adapting an evidence-based HIV stigma-reduction training curriculum, the Health Policy Plus (HP+) total facility approach [29], to address intersectional HCF stigma towards MSM in Ghana. This adaptation was conducted as an initial step in a study that is testing multi-level, intersectional stigma-reduction interventions to address HIV, same-sex and gender non-conformity stigma towards and among MSM in eight communities and HCFs in the Greater Accra and Ashanti regions, Ghana [37]. The latter region is more homogenous (most residents are Ashanti) and closely interconnected, whereas the former is more cosmopolitan and "anonymous," and the traditional setting of the Ga may be more accepting of non-conforming gender expression. However, within HCFs in both regions, HCWs come from across the country. Guided by the social ecological [38, 39] and ADAPT-ITT models [40], this study is adapting, integrating and testing evidence-based HIV stigma-reduction interventions at the organizational (HCF) [29], interpersonal (among MSM communities) [41] and intrapersonal (within the individual) [42] levels to address intersectional stigma towards and among MSM [Clinical Trials Registration #:NCT04108078]. This manuscript describes the adaptation process for the HCF-level intervention [43].

The HP+ HIV stigma-reduction "Total Facility" approach [29] targets the whole HCF, recognizing that stigma can occur in client interactions with both clinical and non-clinical HCWs and in HCF institutional processes and structures. It includes three phases—formative research, HCW and client capacity building through participatory training workshops and integration of stigma-reduction into HCF structures and processes. It targets four immediately actionable drivers of HIV stigma: (1) awareness and understanding of how stigma manifests in daily lives and interactions; (2) fear of HIV acquisition in routine contact with PLHIV; (3) attitudes which lead to shaming, blaming, judgement and stereotyping; and (4) institutional environment, structures, policies and practices that either sustain or reduce stigma [3]. HCWs and clients receive a 5-day training and a week of on-site coaching as they work as teams to jointly deliver participatory stigma-reduction training sessions in their facilities [43–45]. Each session includes a mix of up to 30 clinical and non-clinical staff across departments. Modular sessions accommodate differing hospital schedules. Depending on the setting and adaptation, the curriculum can range from a total of 6–14 hours delivered in 1–3 hour sessions [46, 47]. Stigma-reduction champions, which emerge organically from the trainings and are supported by HCF management, develop and implement additional stigma-reduction activities in their facilities. Such activities include onboarding new staff and incorporating stigma-reduction into existing practices, like rounds, staff recognition and complaint/compliment systems. In Ghana, the HP+ curriculum included one module focused on building understanding of sexual and gender diversity [44, 48].

2 | METHODS

The process of adapting the HP+ HIV stigma-reduction curriculum to address HCF intersectional MSM stigma included: formative research with rapid data analysis to inform a first-draft adapted curriculum; a stakeholder adaptation workshop; triangulation of adaptation with baseline HCW data and deeper analysis of formative data; iterative discussions with partner organizations providing services to MSM for further refinement; external expert review; and final adaptation with the teams of HCWs and community members being trained to deliver the curriculum (Figure 1). These activities were conducted from March 2020 to September 2021.

2.1 | Formative research

2.1.1 | Population and sampling

HCF Eight In-depth interviews (IDIs) were conducted with a convenience sample of HP+ HCF trainers invited to participate by telephone, with interviews conducted over Zoom. Sixteen Focus group discussions (FGDs) (six participants each) were conducted in person with convenience samples of clinical or non-clinical HCF staff employed at an HCF participating in the parent study. Interviewers worked with HCF management the day of the FGDs to identify separate groups of clinical and non-clinical staff and invite available staff to participate.

MSM Eight FGDs (6–10 participants each) were conducted through snowball sampling [49] of adult MSM (≥18 years) who were assigned male sex at birth, identified as

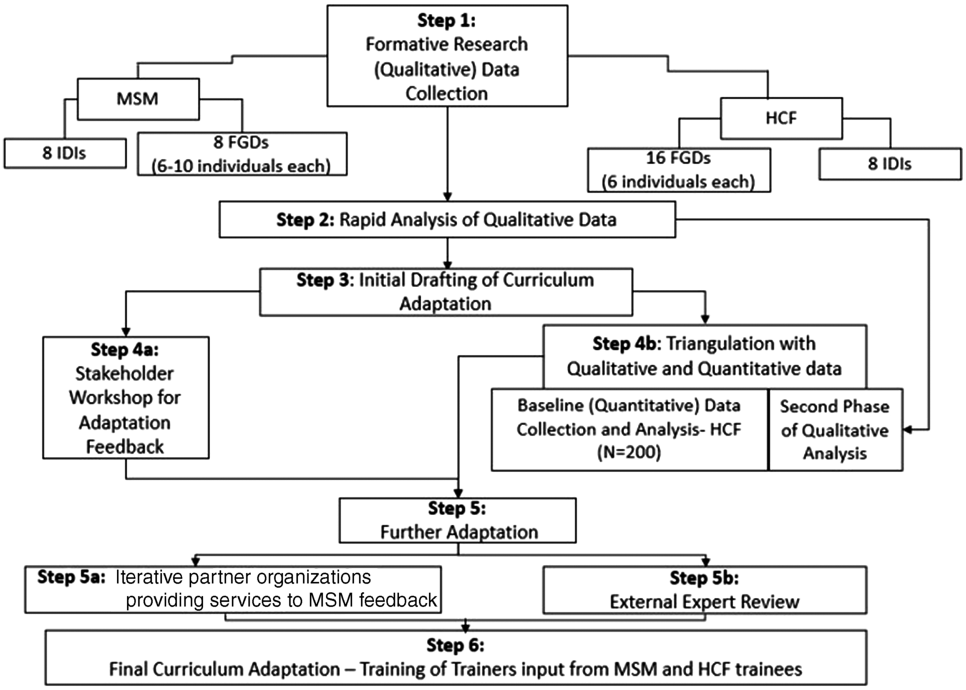


Figure 1. Curriculum adaptation methods and process. Abbreviations: FGDs, focus group discussions; HCF, health care facilities; IDIs, in-depth interviews; MSM, men who have sex with men.

cisgender men and reported sex with another man within the previous 6 months. MSM members of study partner organizations who offer MSM health and advocacy services identified eligible participants in their networks (either in-person or by telephone) and invited them to attend scheduled FGDs. No socio-demographic or health information was collected from FGD participants, and we did not endeavour to diversify the FGDs, limiting the generalizability to Ghana's entire MSM population. To protect confidentiality of HIV status, IDIs ($n = 8$) were conducted only with MSM who self-disclosed they were living with HIV and met the FGD eligibility criteria. To protect MSM respondents, no personal identifying information was collected, apart from signatures on consent forms kept in a locked cabinet. Keeping confidentiality was discussed with FGD participants who used pseudonyms in the FGDs. Interviews were held at the partner organization offices, which are known safe spaces in the MSM community but identified in the wider community only as community health organizations.

2.1.2 | Data collection

We trained research assistants experienced in HIV research to conduct the HCF IDIs and FGDs and MSM identified through the partner organizations to conduct the MSM IDIs and FGDs. These interviewers conducted the IDIs (1 hour) and FGDs (1.5–2 hours) using semi-structured guides in English or Twi, based on participants' preferences, and recorded, transcribed and translated as necessary. COVID precautions were implemented including masking, social distancing and hand sanitizing.

2.1.3 | Data analysis

Data analysis used an iterative process that began with a "rapid analysis" to immediately inform the intervention adaptation. The "rapid analysis" consisted of reviewing the transcripts and creating analytic summaries for each transcript [50]. The research team developed a summary template that captured: (1) MSM stigma drivers and manifestations; (2) HIV stigma drivers and manifestations; (3) intersectional stigma; (4) how stigma undermines HIV prevention and testing for MSM; (5) MSM-friendly services; (6) stigma reduction; and (7) the "Total-Facility" intervention. Seven team members reviewed the transcripts and used the template to take detailed notes on the emerging themes and record pertinent quotes. MS and GMRA collated these summaries into a singular "rapid-analysis" document, which informed the initial draft of the curriculum adaptation and intervention stakeholder adaptation workshop.

A more robust thematic analysis followed the "rapid-analysis." After reviewing every transcript, MS performed inductive "open" coding of at least one of each type of transcript [51, 52]. MS worked with the research team to develop a thematic codebook to capture drivers and manifestations of HIV and MSM stigmas and suggestions to improve the training. Additionally, deductive codes were created using the existing Health Stigma and Discrimination Framework [53], to help structure the exploration of intersectional stigma, and the Consolidated Framework for Implementation Science Research [54], to guide efforts preparing for intervention implementation. A team of five coders individually applied the codebook to the same four transcripts, meeting after each transcript to review the line-by-line coding, discuss discrepancies, make changes to the codebook and ultimately ensure consistency in coding application. The remaining transcripts were coded by one of these five individuals. Data were managed, coded and analysed using Dedoose 8.3. Upon completion of coding, the research team executed queries in Dedoose and reviewed coded data relevant to the intervention adaptation.

2.2 | Quantitative research

HCF baseline data were utilized to triangulate the formative findings to confirm and further refine the adaptation. The main study is ongoing, and future data collection rounds will allow for assessment of the full HCF intervention, including the training and additional stigma-reduction activities; this article focuses solely on the curriculum adaptation process.

2.2.1 | Population and sampling

Eligible HCF staff (*N* = 200) included both clinical and non-clinical staff employed at a hospital in the parent study [37]. Purposive sampling recruited staff likely to interact with MSM clients by selecting 60% of the sample from key departments (Antiretroviral therapy (ART) clinic, outpatient department, pharmacy and security/reception/management) and 40% from other departments. On data collection days, staff arriving first in the designated departments were invited to participate until sample targets were reached.

2.2.2 | Data collection and analysis

Data were collected using self-administered paper questionnaires, with interviewers present to assist as needed. All data were double-entered, and any discrepancies checked against the paper surveys. We present frequencies of key variables and summary statistics relevant to the four actionable drivers and the intervention adaptation process.

2.3 | Curriculum adaptation

Initial adaptation of the curriculum was done by two stigma-reduction master trainers (SC and MC) and one principal investigator (LN), all of whom tailored the HP+ "Total Facility" approach HIV stigma-reduction curriculum for Ghana [29, 44, 48]. The team reviewed the original HIV stigma-reduction curriculum considering findings from both study regions in the "rapid analysis." They identified the exercises that were: still relevant; relevant but needed additional intersectional stigma content; or irrelevant and could be dropped. As well, they noted where gaps existed that required new exercises. A participatory workshop with the full research team, which included MSM from partner organizations from each study region, was then held to discuss the "rapid analysis" findings and the initial curriculum adaptation. Based on these deliberations, the team adapted the existing exercises and created new ones, with support from both MSM partner organizations. An external stigma-reduction expert trainer then reviewed the adapted curriculum and further revisions ensued. Final adaptations occurred during the 5-day training-of-trainers of HCWs and MSM from both regions, who were to deliver the training in their respective facilities. HCF baseline data from both regions were utilized to triangulate and confirm the adaptation.

2.4 | Ethics

We obtained ethics approval from Yale University, Noguchi Memorial Institute for Medical Research, University of Toronto and Ghana Health Services. All respondents provided written informed consent after undergoing an informed consent process, which provided study information and stressed that participation was voluntary and would not impact their HCF employment or services relationship with the partner organization.

3 | RESULTS

The adaptation process led to existing curriculum exercises being placed in one of four categories: (1) Expand—modify existing exercises to incorporate or deepen MSM and gender non-conformity stigma content; (2) Generate—create new exercises; (3) Maintain—keep exercises with no modifications; and (4) Eliminate—drop exercises given time constraints. The original Ghana HP+ curriculum [44, 55] had 14 exercises. In the adapted curriculum, eight of the original exercises were kept (four with no changes and four with added intersectional stigma content), three new exercises were created and six original exercises were dropped. We describe key themes that informed the above categorization, organized by four key immediately actionable drivers [30], and highlight HCW survey data that triangulated the theme. Table 1 summarizes the findings by key driver, corresponding curriculum topic and specific exercises in the adapted curriculum.

3.1 | Immediately actionable drivers

3.1.1 | Driver 1: Awareness

Three themes emerged relevant to awareness: (1) lack of recognition of how MSM stigma manifests in health facilities, (2) limited understanding of how gender norms undergird intersectional stigma faced by MSM and (3) the belief that being MSM is a mental illness.

1) HCW appeared not to recognize how their own stigmatizing attitudes and beliefs may manifest in service delivery to MSM (even if unconsciously). This was evident in the HCW FGDs through a disconnect between clear descriptions of strongly held stigmatizing attitudes and beliefs about MSM and stigmatizing behaviours—such as bringing religion into the patient–provider encounter in a manner that judges MSM—and repeated statements from HCWs that services are delivered to MSM without stigma.

> *It depends on the whole situation. There are some people [MSM] you can easily convince them. For instance…I'll make sure I'm very close to you [MSM client]. I'll get to know what you really do. What really allowed you to be in there. I'll make sure I agree with you all the time. Then as time goes on, I try to convince you to come back… But there are some people it's very difficult to convince them.*

Table 1. Mixed-methods data informing curriculum adaptation, by curriculum topic and training exercise

Immediately actionable driver	Qualitative findings (MSM)	Qualitative findings (HCF and HP+ trainers)	Quantitative findings (HCF)	Curriculum topic	Workshop exercise
Awareness and knowledge	X	X	X	1. Building understanding and awareness of what stigma looks like in concrete terms with a focus on HIV, MSM and gender non-conforming stigma, gender norms and stigma, stigma, MSM and mental health	Naming stigma through pictures [EXPAND]
Attitudes	X	X	X	2. Building empathy and reducing distance	Values clarification [GENERATE]
					Outside the gender box [GENERATE] How myths about MSM and mental illness can lead to stigma [NEW] Identity soup [MAINTAIN] Gender and sexual diversity [EXPAND] Gender and sexual diversity terminologies [EXPAND] Listen to first-hand experiences of people experiencing stigma; discuss experiences in health facilities [MAINTAIN] Self-reflection [MAINTAIN]
Fear	N/A	X	X	Understanding and addressing fear of contracting HIV in the workplace	Fears about nonsexual transmission/quantity, quality and route of entry (QQR) [MAINTAIN]
Institutional environment	X		X	Understanding the importance of confidentiality and the link to stigma	Confidentiality and stigma [EXPAND]
			X	Building skills to address stigma and planning action to address stigma within health facilities	Challenge the stigma and be the change [EXPAND] Writing a code of practice and action plan [EXPAND]

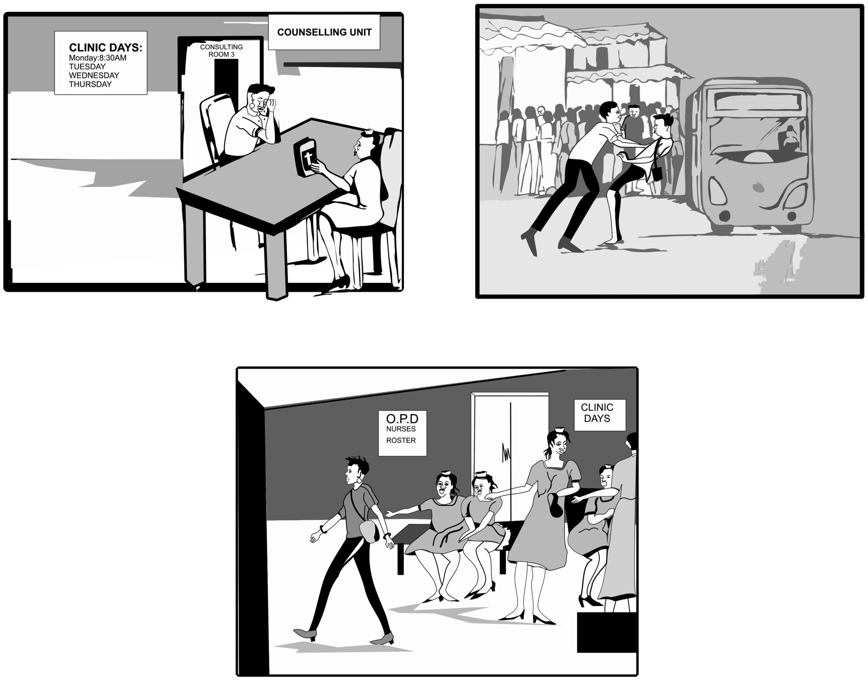
Abbreviations: HCF, health care facilities; HP+, health policy plus; MSM, men who have sex with men.

> *Very. You can read the bible from Genesis to Revelation, they don't hear. (FGD, Clinical HCW)*

Several of the original HP+ curriculum exercises respond to this driver by building understanding and awareness of stigma in general (e.g. *Self-Reflection* exercise). For the adaptation, the *stigma awareness* exercises were deepened by adding MSM and gender non-conformity content. For example, in the *Naming Stigma through Pictures* exercise (Figure 2), the team reviewed existing pictures and determined if they should be redrawn to be more contextually appropriate for the two study regions and where new pictures were required.

2) The second theme under the awareness driver is the strong gender norms around how "real and proper" Ghanaian men and women should look, dress, behave and uphold "traditional" marriage and childbearing and rearing norms. Men and women ostensibly "should" get married (to the opposite gender) and have children, with men as head of the household and responsible for taking care of the family financially, while women raise the children and manage domestic affairs. Both the HCW and MSM data demonstrate how MSM and gender non-conforming stigmas are shaped and driven by these strongly held traditional gender norms and a lack of awareness of the relationship between gender norms and MSM stigma:

> *R1: For a Ghanaian man you are supposed to be responsible, pay the bills in the house…take care of your wife.*
> *R2: Our culture makes us to understand that a man is a man. He should be in trousers, should walk masculine, have*



Participants look at pictures showing stigma and describe different forms of stigma in health facilities, with the objective to get health workers to identify what stigma looks like and discuss the causes of stigma.

Figure 2. Sample of redrawn pictures depicting stigma towards MSM for use in the “Naming Stigma Through Pictures” exercise.

Table 2. Agreement with gender norm statements related to MSM and gender non-conforming stigma among healthcare facility staff (*N* = 200)[a]

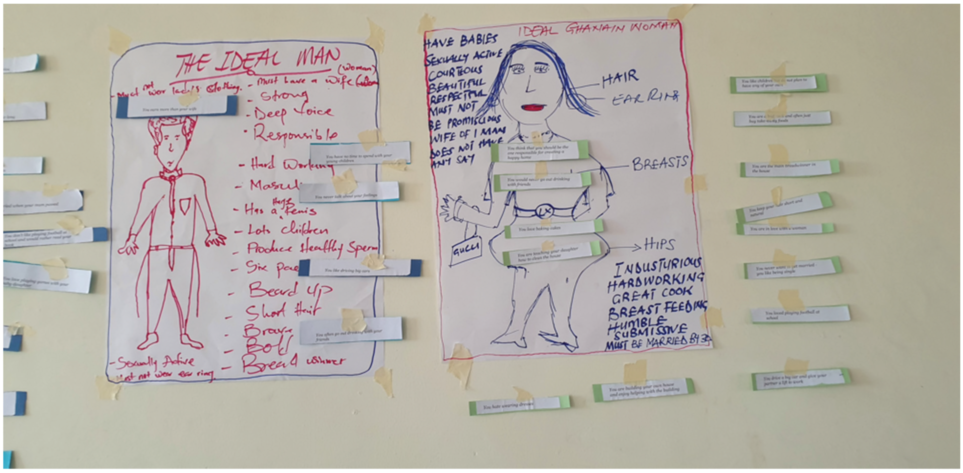
Do you strongly agree or disagree with the following statements?	Agree	Neither agree nor disagree	Disagree
A man should be able to dress like a woman, if he chooses.	8.2% (*N* = 195)	15.9% (*N* = 195)	75.9% (*N* = 195)
A woman should be able to present herself as a man in public, if she chooses.	11.6% (*N* = 198)	15.7% (*N* = 198)	72.7% (*N* = 198)
If a man has attraction/feelings for other men, they should do everything to overcome these feelings.	77.7% (*N* = 197)	13.2% (*N* = 197)	9.1% (*N* = 197)
If a person feels that they want to present their mannerisms, dress or practices in a different gender than the one they were born into (such as feminine presenting men), they should do everything to overcome these feelings.	62.6% (*N* = 198)	24.2% (*N* = 198)	13.1% (*N* = 198)

[a] *N*’s may vary due to non-response.
Abbreviation: MSM, men who have sex with men.

> *this masculine feature. He should behave like a boy, a man, that’s what our culture tells us. (FGD, Clinical HCW)*
>
> *My community is a bit hostile to Saso people [MSM], especially if you exhibit signs of femininity. They believe that as a man you have to behave like a man. I almost got killed because they think I am a curse or something to the community. They think I am not human and don’t deserve to live. (FGD, MSM)*

Responses to several gender norms statements from the HCW baseline data mirror the qualitative gender norms findings (Table 2).

In response, we deepened the gender content in the curriculum by adding a new exercise and expanding the existing sexual and gender diversity exercise. These two exercises, along with an in-person panel of MSM, work to create awareness of gender norms and how they relate to MSM stigma by building understanding of gender and sexual diversity and building empathy through in-person “contact” with MSM outside of a clinical setting. The exercises also promote self-reflection by trainees on how they express themselves, often on a daily basis, in ways that are outside of traditional gender norms or the gender role assigned to them



Examples from participants of "Ways we do not fit inside the gender box"

Women	Men
I like helping to build my own house	I went to Kasha market to buy foodstuffs to cook tilapia sauce
Keeping my hair short and natural	I wear my hair long in braids
I like watching football	Cooking / cleaning / showing emotions
I am building my own house	I cried at a sad movie
I drive a car	I cook, clean and do domestic work
I buy take away foods	I love playing with my baby daughter
I did higher education	I still cry when I remember my mum
	I cook for the family, do laundry, clean the house
	I keep my hair long, wear earrings
	Love my mom

Figure 3. Output from the gender box exercise.

at birth, and how that makes them feel. The new exercise on gender norms, *Outside the Gender Box*, was adapted from the *Keep the Best, Change the Rest* manual [56]. This exercise (Figure 3) was added to: explore societal gender norms and how they influence upbringing, attitudes and beliefs; examine the negative impact that gender norms can have on our lives and those who do not conform to gender norms; reflect on how we have stepped outside of gender norms in our own lives; and explore the link between gender norms and stigma, particularly towards gender non-conforming people. It is an interactive participatory exercise that ends with a debrief discussion.

3) The third theme emerging under the awareness driver is the belief that being a MSM is a symptom of mental illness. This belief manifests in thinking that MSM should be referred for services to address their "MSM mental illness." This belief appears to be reinforced by outdated medical training of same-sex attraction as a psychiatric diagnosis:

> *Such men [MSM], actually psychologically, they have a problem; if it is not addressed, okay psychologically they have a problem; they have to be looked at carefully or counseled to desist from that. (FGD, Clinical HCW)*

Quantitative data reinforced the importance of addressing the beliefs around MSM being a mental illness. Only a third (33.8%) of HCWs disagreed with the statement *Being MSM is a mental illness*, while over a third (37.4%) agreed and 28.7% neither agreed nor disagreed.

In response to this theme, a new exercise *How myths about MSM and mental illness can lead to stigma* was developed that combines a role play, short power point presentation and discussion. The objectives are to learn about research and beliefs around sexuality and mental disorders, discuss the myths that participants may have been taught and understand the link between stigma and mental health. A short presentation, developed by a senior Ghanaian psychiatrist and refined by a facility trainer, begins by first defining mental health and its relationship to physical, social and emotional wellbeing, in contrast to mental illness. Key myths and misconceptions are then named and debunked through facts. The consequences of these myths—such as how myths can drive stigma, rejection, social isolation and mental illness (e.g. depression)—are also explored. The session ends with discussion about how to change the situation.

3.1.2 | Driver 2: Fear

Fear as a driver of stigma was distinct for HIV and MSM stigmas. Given fear of acquiring HIV while providing care to PLHIV is already documented in Ghana as an important HIV stigma driver to address in health facilities [48], the qualitative guides did not focus on this issue. However, it is still surfaced

Table 3. Attitudes towards HIV and MSM among healthcare facility staff (*N* = 200)[a]

Attitude	Response	PLHIV	MSM
I would feel ashamed if someone in my family was…	Agree	15.3% (*N* = 196)	67.0% (*N* = 194)
	Neither agree nor disagree	6.6% (*N* = 196)	15.5% (*N* = 194)
	Disagree	78.1% (*N* = 196)	17.5% (*N* = 194)
I would feel that I had failed as a parent if I learned that my son was…	Agree	26.2% (*N* = 195)	74.2% (*N* = 194)
	Neither agree nor disagree	14.9% (*N* = 195)	13.9% (*N* = 194)
	Disagree	59.0% (*N* = 195)	11.9% (*N* = 194)
…threaten many of our basic social institutions	Agree	16.7% (*N* = 198)	58.6% (*N* = 198)
	Neither agree nor disagree	16.7% (*N* = 198)	17.7% (*N* = 198)
	Disagree	66.7% (*N* = 198)	23.7% (*N* = 198)
… persons are sinful	Agree	3.6% (*N* = 194)	85.2% (*N* = 196)
	Neither agree nor disagree	9.2% (*N* = 194)	11.2% (*N* = 196)
	Disagree	87.2% (*N* = 194)	3.6% (*N* = 196)
Total: % agreeing with at least one stigmatizing attitude		41.7% (*N* = 199)	92.5% (*N* = 199)

[a] *N*'s may vary due to non-response.
Abbreviations: MSM, men who have sex with men; PLHIV, people living with HIV.

in the qualitative discussions and the baseline survey confirmed that it remains an issue as 56.4% of HCWs expressed fear of HIV acquisition through at least one of four routine client care interactions, while 60.6% indicated they routinely use one of four unnecessary infection control measures when providing care for PLHIV. Further, 33.3% of HCWs thought their co-workers were hesitant to care for PLHIV and 21.1% reported they themselves were hesitant. In response, one of the two exercises that address fears of workplace HIV acquisition was retained as originally written. The other was dropped due to time considerations.

With respect to fear as a driver of MSM stigma, some discussion groups raised fear that providing services to MSM could lead to accusations of "promoting" or "encouraging" MSM:

> *R1: Honestly when any MSM walks to you, you are eager within to try to get the person out of it [Being MSM]. Though for the first time you will not tell the person, you don't tell it to their face…You are tempted to do that though it's not professional, you are tempted to do it so [otherwise] we become like you are encouraging them to come in and come in, that one it will [be on] our conscience. (FGD, Clinical HCW)*

Perhaps reflecting these fears, 35.1% of respondents reported that they thought their co-workers were hesitant to care for MSM, while 25.3% reported they themselves were. When asked whether, if they had a choice, they would prefer not to provide services to MSM, 14.1% reported they would prefer not to, whereas only 1.5% indicated they would prefer not to care for PLHIV.

Multiple exercises work in different ways to address these concerns by (1) helping HCWs understand that providing services to MSM does not "promote" MSM or encourage "more" same-sex behaviour and (2) building skills and confidence to challenge MSM stigma when it occurs, as well as respond to accusations that by providing stigma-free services or even for attending the workshop, HCWs are promoting MSM. This was done by adapting existing exercises to include new case studies (see confidentiality exercise) and role plays (Be the Change! exercise), as well as adding a new values clarification exercise (see attitudes section).

3.1.3 | Driver 3: Attitudes

While there were many stigmatizing attitudes expressed in the qualitative data and confirmed in the survey data (Table 3), two of the most common were: (1) The belief that MSM are "demonic," "evil," "morally and religiously wrong" and "sinful," and (2) The belief that MSM are wilfully "choosing" to engage in sexual behaviour that is "sinful" and "un-Ghanaian."

These attitudes manifested in a range of verbal and nonverbal behaviours described in both the HCW and MSM data, like scolding, asking medically unnecessary intrusive questions, bringing up religion to condemn MSM clients or other subtle yet punitive measures:

> *They treat you different. Like in my case, after telling her my situation and she [was] asking about my partner and I told her who my partner is, she brought out the Bible. I am a bold person, so when she brought the Bible out, I told her that I wanted to use the washroom. Then I went to another place, but what if I am like other people who are not as bold as I am and because they have had this encounter, decide not to go to any other health facility again? (FGD, MSM)*

The quantitative data reflect many of the stigmatizing attitudes present in the qualitative data (Table 3) and underscore how commonly these beliefs are held. Only 3.6% of HCWs disagreed with the statement that MSM are sinful, compared to 87.2% who disagreed that PLHIV are sinful. Only 16.3% disagreed with the statement that *Being MSM is a behavior that is chosen* (data now shown).

All curriculum exercises address the aspects of stigmatizing attitudes, whether through creating awareness of how stigmatizing attitudes can manifest unconsciously in service delivery (picture exercise) or tackling attitudes directly (new values clarification exercise), building knowledge and understanding

Table 4. Observed stigma by healthcare facility staff within their health facilities in the past 6 months (*N* = 200)[a]

In the past 6 months, how often have you observed health care workers, at least once…	PLHIV	MSM
Being unwilling to care for…	16.2% (*N* = 197)	11.1% (*N* = 199)
Providing poorer quality of care to…	13.7% (*N* = 197)	12.6% (*N* = 199)
Talking badly about…	29.5% (*N* = 197)	33.7% (*N* = 199)
Disclosing patient information without consent when not medically necessary	19.0% (*N* = 197)	9.0% (*N* = 199)

[a] *N*'s may vary due to non-response.
Abbreviations: MSM, men who have sex with men; PLHIV, people living with HIV.

of gender and sexual diversity, or through self-reflection. The panel discussion also allows HCWs to hear first-hand how stigmatizing attitudes and behaviours hurt and harm MSM clients and puts a "human" face to MSM, building bridges between MSM clients and HCWs.

3.1.4 | *Driver 4: Facility environment*

Breaches of confidentiality of HIV status or being MSM emerged as the one relevant theme under facility environment. Such breaches resulted from HCWs gossiping and not maintaining confidentiality, as well from the way services were structured and physical layout of the facility. Having MSM-specific services provided in a particular location or at a specific time can disclose that clients are MSM, while the HCF structure/architecture can cause involuntary HIV status disclosure if HIV treatment is provided only on specific days or a specific location:

> *People don't trust the confidentiality of the service providers. That's why most guys don't want to go to the facility. They always have the impression that people will gossip about them if they should visit the facility. (FGD, MSM)*
>
> *There was giggling from the time he took the folder and …, people were calling others to come and have a look at the person in question because it looks strange to all of us. So, we could tell that the person knew that we were giggling…though no one rudely spoke, but I think there was a bit of discomfort. (FGD, Clinical HCW)*

The quantitative data show that fears of breaches of confidentiality among PLHIV or MSM are not unfounded. Reporting on the past 6 months, 19% of HCW survey respondents reported observing an HCW disclosing a client's HIV status without their consent, while 9% reported observing disclosure that a client was MSM (Table 4). In response, we maintained and expanded the toolkit exercise on confidentiality by developing and incorporating case studies with MSM-specific scenarios based on the formative research.

The survey data provide more insights into potential areas under this driver to address, both through the curriculum and additional intervention activities (Table 5). While 78.5% of HCW respondents indicated they could list several ways to reduce stigma against PLHIV in their HCF, this dropped to 48.7% when asked about addressing MSM stigma. When asked if their facilities had policies to protect PLHIV from discrimination, 78.7% of HCWs agreed, but only 49.7% agreed they had policies to protect MSM.

The training ends with a set of exercises that focus on building skills to challenge stigma in the facility environment and plan for action to reduce stigma. For example, to build skills to challenge stigma, we expanded an assertiveness and role-playing exercise by adding role-plays focused on MSM stigma.

4 | DISCUSSION

Stigma-reduction interventions need to target the attitudes, beliefs, practices and policies that drive stigma as a means to support engagement across the HIV care continuum [30]. However, research on HCF stigma-reduction intervention development, adaptation and evaluation does not always explicitly provide this level of detail [22]. The original "Total Facility" curriculum did exactly that by (1) raising awareness on how HIV stigma manifests, (2) addressing fears of HIV transmission through education on routes of transmission, (3) providing a safe, non-judgemental space for participants to confront the judging, shaming, blaming and stereotyping involved in the stigmatization process and (4) focusing on policies and practices that encourage a stigma-free HCF environment. The process used in adapting this curriculum specifically sought to understand and document the drivers of intersectional stigma faced by MSM in Ghana in HCFs such that the exercises and activities could be tailored to target these specific drivers.

There is a dearth of interventions that address intersectional stigma, particularly for MSM in low-resource settings, and support HIV prevention and treatment [35]. The adapted curriculum is novel in that it addresses the intersection of HIV, same-sex and gender non-conformity stigmas. The need to recognize and understand an individual's membership in multiple stigmatized groups is a relatively recent phenomena in the field of stigma reduction [8, 57]. While global research highlights the deleterious impacts of stigma on health outcomes [53, 58–60], intersectional stigma research is just beginning to elucidate how multiple stigmatized conditions and identities are experienced and how their interlocking, compounding effects hamper healthcare access and worsen health outcomes [8]. The overlap of certain stigmatized health conditions and identities—particularly for MSM who shoulder a high burden of HIV—and the

Table 5. Health facility environment stigma factors among healthcare facility staff (*N* = 200)[a]

Statement	Response	PLHIV	MSM
I would feel comfortable working closely with a person who is…	Agree	74.7% (*N* = 194)	37.0% (*N* = 196)
	Neither agree nor disagree	10.3% (*N* = 194)	18.6% (*N* = 196)
	Disagree	14.9% (*N* = 194)	44.3% (*N* = 196)
I will get into trouble at work if I discriminate against …	Agree	77.4% (*N* = 199)	67.8% (*N* = 199)
	Neither agree nor disagree	5.0% (*N* = 199)	10.6% (*N* = 199)
	Disagree	17.6% (*N* = 199)	21.6% (*N* = 199)
My health facility has policies to protect … from discrimination	Agree	78.7% (*N* = 197)	49.7% (*N* = 197)
	Neither agree nor disagree	7.1% (*N* = 197)	23.9% (*N* = 197)
	Disagree	14.2% (*N* = 197)	26.4% (*N* = 197)
I can list several ways I could take action to reduce stigma and discrimination against … in my health facility	True	78.5% (*N* = 195)	48.7% (*N* = 195)
	False	6.7% (*N* = 195)	23.6% (*N* = 195)
	Don't know	14.9% (*N* = 195)	27.7% (*N* = 195)
I am confident that I can challenge stigma and discrimination against MSM in my health facility	True		44.9% (*N* = 198)
	False		29.3% (*N* = 198)
	Don't know		25.8% (*N* = 198)
I am aware of institutional barriers that may inhibit MSM from using health care services	True		27.9% (*N* = 197)
	False		36.5% (*N* = 197)
	Don't know		35.5% (*N* = 197)
I would feel unprepared talking with a MSM client about topics related to their sexuality	True		37.2% (*N* = 196)
	False		49.0% (*N* = 196)
	Don't know		13.8% (*N* = 196)
Health facility policies prevent me from providing quality care to MSM	True		6.1% (*N* = 197)
	False		84.3% (*N* = 197)
	Don't know		9.6% (*N* = 197)
National policies prevent me from providing quality care to MSM	True		7.7% (*N* = 196)
	False		77.0% (*N* = 196)
	Don't know		15.3% (*N* = 196)

[a] *N*'s may vary due to non-response.
Abbreviations: MSM, men who have sex with men; PLHIV, people living with HIV.

rootedness of stigma in larger systems of inequality and power are necessitating researchers and programme managers to consider novel ways to understand and address intersectional stigma [61]. Ultimately, as interventions often take a siloed approach to stigma reduction, addressing only one type of stigma at a single, socio-ecological level [58], future interventions will need to draw on an intersectional perspective to understand and address the co-experience of multiple stigmas, marginalization and resilience [8, 62].

Recent decades have witnessed the proliferation of evidence for how to reduce HIV stigma, particularly at the HCF level [22, 31, 32, 63, 64]. As such, there is a rich evidence base around stigma measurement and reduction that provides a solid foundation to apply an intersectional lens to existing evidence-based practices [30]. Our adaptation approach is an example of implementation research, sharing pragmatic insights around how to draw from an existing HIV stigma-reduction intervention to address intersectional stigma and promote access to HIV care. Researchers and programme managers should employ implementation science methods to guide and evaluate the adaptation and implementation of stigma-reduction interventions, particularly in low-resource settings [65]. To bridge the research-to-practice gap in the field of stigma-reduction, studies need to look beyond efficacy to also include a focus on implementation to identify critical barriers and facilitators to the scale-up of effective interventions.

5 | CONCLUSIONS

We adapted the HP+ HIV-focused HCF stigma-reduction training curriculum to address intersectional stigma faced by MSM in Ghana and ultimately support HIV prevention and treatment. The research team used a mixed-methods approach that drew on both formative qualitative data and baseline survey data to understand and document the drivers and manifestations of the intersecting stigma faced by MSM in HCFs—namely, HIV, same-sex and gender non-conformity stigmas. The research team used these data to expand or generate new exercises to ensure the curriculum adequately addressed the key drivers of intersectional stigma, including lack of awareness, fear, attitudes and the facility environment. A similar process could serve as a guide for other research and programming efforts seeking to expand existing evidence-based interventions to address intersectional stigma, particularly for KPs, in low-resource settings.

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COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHORS' CONTRIBUTIONS

LN, LEN and KT conceived of the parent study. LN and MAS drafted this article with input from KS, DD and GMRA. LN, SC, MC, EM, RV and EG adapted the training curriculum. EM, RV, EG and RA collected the baseline quantitative data. RV oversaw data entry, cleaning and analysis. MAS led qualitative data analysis. MAS, DT, GMRA, KS, SP and DD coded the qualitative data. KT, LN, LEN, EG, FB and PA oversaw the study activities.

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DATA AVAILABILITY STATEMENT

The datasets generated and analyzed during the current study are not publicly available due to the high risk of persecution and severe adverse social consequences related to the socio-political sensitivity of the topic of same-sex behaviors in Ghana; however, data are available from the corresponding author on reasonable request.

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VIEWPOINT

Community-led monitoring: a voice for key populations in Zimbabwe

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Community-led monitoring has the potential to be an effective mechanism for organized and systematic advocacy that is well appreciated by service providers. Engaging peers in service delivery is an effective strategy to reduce stigma among key populations. In this Viewpoint, we describe an example from Zimbabwe where a community treatment observatory model has been implemented to systematically provide services and track results for people living with HIV and key populations. It is a peer-based model that has been adopted by the Zimbabwe National Network of People living with HIV (ZNNP+).

With an HIV prevalence of 12.8%, which translates to 1.4 million people living with HIV, Zimbabwe remains one of the most HIV endemic countries in sub-Saharan Africa [1]. Recent data show that key populations, who include sex workers, men who have sex with men, transgender people, incarcerated people and various other groups, account for 62% of the new HIV infections [1]. Structural factors, such as pervasive stigma, discrimination, human rights violations, physical, emotional and sexual violence, are some of the challenges key populations face [2].

In Zimbabwe, the legal context marginalizes key populations by criminalizing same-sex relationships. The Zimbabwean penal code outlaws same-sex relations under the "sodomy" and "indecent act" clauses, and Section 81 prohibits the solicitation of sex work [3]. Further, the social environment in Zimbabwe engenders attitudes that impede key populations' access to healthcare; for instance, key populations in Zimbabwe believe that healthcare would be more accessible if they conformed to "sexual norms," and that the stigmatizing attitudes of healthcare workers towards key populations affect the quality of care offered [4]. Key populations, therefore, carry a disproportionate burden of HIV, tuberculosis, sexually transmitted infections, poor mental health and other health concerns [5].

Community-led monitoring has been an effective instrument for providing HIV prevention and care to key populations while ensuring services are stigma-free for all recipients. An example of a community-led monitoring system is the community treatment observatory. This observatory employs community members, such as people living with HIV or those representing key populations without HIV to collect data from their peers about the quantity and quality of HIV prevention, care and treatment services within communities [6]. The collected data are then analysed and used to inform community-driven healthcare services [6]. Such models have had success in Sierra Leone, where, within a year of implementing a community-led monitoring system, HIV testing increased by 85% among men who have sex with men, 100% among female sex workers, 96% among people who inject drugs and 90% among young people; while antiretroviral therapy uptake increased by 93% among people living with HIV [7].

Stigma and discrimination negatively impact the quality of life of people living with HIV in various ways, including detracting from mental health and inhibiting access to care [8–10]. ZNNP+ is a national umbrella body that supports the efforts to reduce stigma and discrimination against people living with HIV. To destigmatize care and improve health outcomes for people living with HIV, ZNNP+ utilizes a community treatment observatory model. The model is based on the principle of including often marginalized populations in the decision-making process around their healthcare. In doing so, healthcare systems can better ensure the rights of key populations and provide stigma-free care for all.

The community treatment observatory model at ZNNP+ involves recruiting and training self-disclosed community cadres living with HIV to collect data from their peers, coordinate community dialogues, and engage with community leaders and health facilities. The cadres include mentor mothers, community HIV and AIDS support agents and key population peer supporters who are sex workers and men who have sex with men. Mentor mothers are women living with HIV who have successfully delivered infants who are HIV negative through prevention of mother-to-child transmission and help their peers achieve the same. Community HIV and AIDS support agents are self-disclosed people living with HIV who help their peers access services that improve their quality of life. The community treatment observatory model aligns with recent calls to shift away from viral suppression-oriented care models towards more person-centred approaches that focus on ensuring the health of people living with HIV throughout their lives [11].

The community treatment observatory model plays two roles: ensuring data-driven evidence on issues affecting key populations and providing key populations with a platform to share their views confidentially. Community cadres are trained to do community-led monitoring using mobile data collection. Data collection consists of in-person qualitative and quantitative interviews using the customer satisfaction survey questionnaires that cover availability, affordability, accessibility, acceptability and appropriateness issues. This provides valuable insights into how key populations perceive the way they are being served at facilities. Community cadres collect data on satisfaction with time spent at health facilities, stigma and discrimination at facilities and in the community, privacy during consultations, and frequency and duration of antiretroviral treatment stock-outs.

In our experience, community-led monitoring has proved to be an effective mechanism for organized and systematic advocacy for the health and rights of key populations. Engaging peers in service delivery is an effective strategy to reduce stigma among key populations. Getting feedback from receivers of care could encourage healthcare workers to improve person-centred service and address issues, such as stigma, that cause low uptake of services and poor health outcomes. The example of ZNNP+ illustrates that, when properly resourced, communities can deliver crucial, destigmatized services to their peers. These services ultimately aim to ensure that health systems, governments and other stakeholders are accountable for meeting the needs and upholding the rights of key populations.

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COMPETING INTERESTS

All authors except KM are employees of ZNNP+.

AUTHORS' CONTRIBUTIONS

TM, CM and MM contributed to the conceptualization and writeup of the manuscript. GK contributed to the conceptualization, writeup and revision of the manuscript. KM contributed to the writeup and revision of the manuscript. TM, GK, CM, MM and KM all read and approved the final manuscript.

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REVIEW

Frameworks and measures for HIV-related internalized stigma, stigma and discrimination in healthcare and in laws and policies: a systematic review

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Abstract

Introduction: There is strong global commitment to eliminate HIV-related stigma, and work in this area continues to evolve. Wide variation exists in frameworks and measures used.

Methods: Building on the existing knowledge syntheses, we carried out a systematic review to identify frameworks and measures aiming to understand or assess internalized stigma, stigma and discrimination in healthcare, and in law and policy. The review addressed two questions: Which conceptual frameworks have been proposed to assess internalized stigma, stigma and discrimination experienced in healthcare settings, and stigma and discrimination entrenched in national laws and policies? Which measures of these different types of stigma and discrimination have been proposed and what are their descriptive properties? Searches, completed on 6 May 2021, cover publications from 2008 onwards. The review is registered in PROSPERO (CRD42021249348), the protocol incorporated stakeholder input, and the data are available in the Systematic Review Data Repository.

Results and discussion: Sixty-nine frameworks and 50 measures met the inclusion criteria. Critical appraisal figures and detailed evidence tables summarize these resources. We established a compendium of frameworks and a catalogue of measures of HIV-related stigma and discrimination. Seventeen frameworks and 10 measures addressed at least two of our focus domains, with least attention to stigma and discrimination in law and policy. The lack of common definitions and variability in scope and structure of HIV-related frameworks and measures creates challenges in understanding what is being addressed and measured, both in relation to stigma and efforts to mitigate or reduce its harmful effects. Having comparable data is essential for tracking change over time within and between interventions.

Conclusions: This systematic review provides an evidence base of current understandings of HIV-related stigma and discrimination and how further conceptual clarification and increased adaptation of existing tools might help overcome challenges across the HIV care continuum. With people living with HIV at the centre, experts from different stakeholder groups could usefully collaborate to guide a more streamlined approach for the field. This can help to achieve global targets and understand, measure and help mitigate the impact of different types of HIV-related stigma on people's health and quality of life.

Keywords: human rights; key and vulnerable populations; law and policy; quality of life; stigma; structural drivers

Additional information may be found under the Supporting Information tab of this article.

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1 | INTRODUCTION

HIV-related stigma and discrimination constitute significant barriers to HIV responses around the world. Fragmentation of efforts to address HIV-related stigma and discrimination has hampered progress to date. To strengthen the evidence base on HIV-related stigma and discrimination, it is urgent to analyse the different existing conceptualizations and measures to identify lessons that can inform more effective and efficient interventions moving forward.

Stigma can be described as a dynamic process of devaluation that significantly discredits an individual in the eyes of others, such as when certain attributes are seized upon within particular cultures or settings and defined as discreditable or unworthy. Much work around HIV-related stigma uses as its starting point Goffman's 1963 definition of stigma as "an attribute that is deeply discrediting" [1]. Socially constructed notions of difference, acceptability and fear drive evolving understandings of stigma, which now encompass notions of power and incorporate social psychological and socio-cultural approaches [2–4]. Yet, the diversity of co-existing definitions is important: it has spawned a multitude of conceptual frameworks around stigma and a lack of consensus on key aspects of what stigma actually is and how to measure it.

"Stigma" is often used in the literature to encompass both stigma and discrimination even as these are conceptually distinct. While stigma usually refers to an attitude or belief, discrimination is often seen as the behaviour or action that results from those attitudes or beliefs. Hence, when stigma is acted upon, the result can be discrimination. Discrimination may refer to any form of arbitrary distinction, exclusion or restriction affecting a person, usually (but not only) because of an inherent personal characteristic or perceived membership of a particular group [5].

Narrowing down to HIV-related stigma, this has been defined by the Joint United Nations Programme on HIV/AIDS (UNAIDS) as negative beliefs, feelings and attitudes towards people living with HIV, groups associated with people living with HIV (e.g. their families) and other key populations at higher risk of HIV infection, such as people who use drugs, sex workers, men who have sex with men and transgender people [6]. Different domains have been identified in attempts to categorize HIV-related stigma, including internalized, anticipated, perceived, enacted, externalized and structural stigma [7]. However, there is no universally agreed-upon list of types of HIV-related stigma and how each is defined. Working definitions adopted for this review are described in the analytical framework below.

The lack of consensus about HIV-related stigma domains creates challenges for consistent and comparable frameworks and measures for understanding them. Given that stigma is highly contextualized, including across these different domains, it is important that frameworks and measures be appropriate to local contexts, further complicating efforts to create comparable tools.

Discrimination, as defined under international human rights law, is any distinction, exclusion or restriction based indirectly or directly on grounds prohibited under international law, which has the effect or intent of nullifying the recognition, enjoyment or exercise on an equal basis of others of all human rights and fundamental freedoms, in the political, economic, social, cultural, civil or any other field [8]. HIV-related discrimination is, therefore, any distinction, exclusion or restriction (sometimes referred to as acts or omissions) based indirectly or directly on a person's real or perceived HIV status [9].

There is strong commitment to eliminate HIV-related stigma, starting with global political commitments and reflected in global and national strategies as well as many organizations and collaborations working to address stigma [10]. Yet, learning across interventions designed to mitigate against the experience and harmful impacts of stigma can be hindered, in part, by the multitude of frameworks and measures in use to assess its different dimensions.

Experiences of stigma for people living with and most affected by HIV can occur at many levels. This review systematically identifies and assesses frameworks and measures of HIV-related internalized stigma; stigma and discrimination within healthcare settings; and in laws and policies. These focus areas were selected as each requires a very different response, suggesting that, even as one might expect strong similarities within each of these domains, there might be substantial heterogeneity in frameworks and measures across them. Recognizing that to reduce stigma at scale, synergistic attention is required across all three domains, this is the first systematic review to look across them systematically.

The co-existence and potential interrelationship between HIV-related stigma and other devaluing attitudes related to drug use, sex work, sexual orientation and/or gender identity that affect populations disproportionately affected by HIV is critical, but beyond the scope of this review. The review focuses on conceptual frameworks and measures of HIV-related stigma itself, acknowledging as possible where additional types of stigma are addressed.

The systematic review was guided by two key questions:

1. Which conceptual frameworks have been proposed to assess internal stigma, stigma and discrimination experienced in healthcare settings, and stigma and discrimination entrenched in national laws and policies?
2. Which measures (e.g. assessment scales) of these different types of stigma and discrimination have been proposed and what are their descriptive properties?

2 | METHODS

The systematic review followed a detailed protocol (CRD42021249348) [11]. Part of a larger project undertaken by the IAS—International AIDS Society, this systematic review is accompanied by four national efforts exploring stigma and discrimination in Kenya, Malawi, South Africa and Zambia.

We searched multiple disciplinary and interdisciplinary sources. Citations and full-text publications were screened by independent literature reviewers, and eligibility decisions, including reasons for exclusions, were tracked in citation management software. Data abstraction and critical appraisal was conducted in online software designed for systematic reviews using detailed, pilot-tested forms. Given the complexity of the frameworks and measures, data were abstracted by one reviewer and checked by a second experienced systematic reviewer. The collected data are accessible in a review data repository [12].

2.1 | Analytic framework

Given the diversity of definitions in this interdisciplinary field, we established working definitions of the concepts of HIV-related "stigma," "internalized stigma" and "discrimination" grounded in existing literature for the purpose of this systematic review:

- Stigma refers to beliefs and/or attitudes about HIV.
- Internalized stigma refers to a person living with HIV internalizing negative attitudes associated with HIV and accepting these as applicable to themselves.
- Discrimination refers to the behaviours that result from attitudes or beliefs about HIV.
- Stigma and discrimination in healthcare refers to negative beliefs and behaviours based on perceived or actual HIV status experienced in healthcare delivery settings.
- Stigma and discrimination in laws and policies refers to distinctions, exclusion or restriction based on perceived HIV status or membership of a group that is vulnerable to HIV.

2.2 | Search strategy

To identify primary research studies, we searched PubMed, in particular to identify research on stigma experienced in healthcare settings, PsycINFO to identify psychological and social research on stigma, and the Web of Science to identify legal and policy analyses on stigma and discrimination. We identified government and non-governmental organization reports indexed in the Universal Human Rights Index, HeinOnline, Public Affairs Information Service (PAIS) and HIV Legal Network.

Additional grey literature searches targeted the websites of the IAS, UNAIDS, United Nations Development Programme, STRIVE (research consortium investigating the social norms and inequalities driving HIV acquisition), Health Policy Plus and Sage (resource-sharing community for Canadian HIV and hepatitis C service providers).

Systematic reviews were instrumental for reference-mining to ensure that all relevant material had been considered. Systematic reviews were identified through PubMed (biomedical literature) using the systematic review filter, through PsycINFO (psychosocial literature) and Web of Science (general science literature, including legal and policy analysis), as well as through the Cochrane Database of Systematic Reviews (focus on health) and the Campbell Collaboration (focus on social sciences). Furthermore, we searched the review registries PROSPERO and Open Science Framework to ensure that all relevant registered systematic reviews had been identified.

2.3 | Eligibility criteria

Detailed eligibility criteria are documented in the online Appendix. Briefly, publications addressing people living with or perceived to be living with HIV and people from groups who are disproportionately affected by HIV infection were eligible. Frameworks and measures had to address HIV-related internalized stigma, stigma and discrimination in healthcare or in laws and policies. Publications introducing frameworks were included regardless of the comparator or study design. Measure research had to describe the tool in sufficient detail to be included but needed no comparator. Framework publications were included regardless of any reported outcomes. Measure research had to report a description of the measure, the development process, or the evaluation or validation of the measure. Only publications from 2008 on were included, building on the first People Living with HIV Stigma Index published in 2008, which transformed thinking around HIV-related stigma measurement, fostering new levels of openness, nuance and confidence in stigma measures [13]. To maintain consistency in approaches to reviewing measures and frameworks, the same cut-off date was used for searches for frameworks. Searches were completed on 6 May 2021. The review was not restricted by setting but we restricted to English language for both frameworks and measures. Measures designed for other languages were included if the publication also presented an English translation.

2.4 | Data abstraction

For the frameworks, we abstracted the author group; publication year, scope, aim or purpose of the framework; terminology, domain of interest targeted, type, all stigma subtypes as reported by the authors, definition of the constructs stigma and/or discrimination; addressed targets; framework components; and a broad summary of the framework based on the authors' description.

For measures, we documented the author group; publication year; name of the tool; the stigma or discrimination subtype, the underlying framework, and definitions of stigma and discrimination; the targeted population; the surveyed population used to develop or assess the measure; the scale structure of the tool, number of items and answer mode; the documented reliability; and evidence of validity.

2.5 | Critical appraisal

For frameworks, we assessed the source (e.g. published by an individual author group or endorsement by a professional organization), stakeholder involvement (in the development of the framework), evidence base (components based on a systematic literature review or empirical data), defined population (framework target reported) and validity tested (e.g. goodness-of-fit assessed, applied in different contexts). For measures, we evaluated the demonstrated internal consistency, other reliability measures (temporal stability, rater agreement), content validity, structural validity, criterion validity, cross-cultural validity, responsiveness and interpretability by applying relevant COSMIN (COnsensus-based Standards for the selection of health Measurement Instruments) criteria [14]. Scoring information is provided in Figures 1 and 2.

2.6 | Synthesis

Recognizing that multiple types of stigma and discrimination may be concurrently experienced, our narrative synthesis focuses on frameworks and measures that address more than one of our three focus domains: internalized stigma, stigma and discrimination in healthcare, and in laws and policies. This can help us move towards a more complete understanding of different types of stigma and discrimination, and inform complex interventions moving forward.

3 | RESULTS AND DISCUSSION

The evidence review identified 69 frameworks and 50 measures. The initial searches identified 2199 citations, 1050 were obtained as full text. In total, 146 publications reported information on the included frameworks and measures. The literature flow is documented in the online Appendix (Figure S1).

3.1 | Frameworks

To address key question 1, the evidence table in the online Appendix (Table S1) provides a concise overview of the identified frameworks. The online Appendix also provides a compendium of the included frameworks to allow a meaningful overview. The evidence table provides a weblink to the original publication for all included frameworks.

Figure 1 summarizes the critical appraisal of the identified frameworks.

As the figure shows, for many domains, studies provided insufficient information or did not meet the prespecified criteria. Just over 10% of the identified frameworks were published by a well-known HIV-specific source, such as UNAIDS. Identified frameworks were usually developed to provide an analytic framework for a specific research question and purpose, such as the evaluation of an association. Only 6% of the frameworks reported stakeholder input into their development, with different "stakeholders" included, such as people living with HIV, health workers and administrators. Studies either did not report on the development process and any consensus finding results, or the model appeared to be derived from empirical data without in-depth conceptual considerations. Two thirds of the framework authors reported a literature review or referenced empirical literature to justify the framework or its components. A third of frameworks explicitly stated the population addressed. Many identified frameworks were broad and provided only minimal details on their scope. Finally, 39% of the frameworks reported a validity evaluation, by, for example, reporting on the model's goodness-of-fit to empirical data. Table S2 shows the number of criteria met for each identified framework.

Table 1 summarizes the 17 frameworks that address more than one stigma domain, for example both internalized stigma as well as stigma and discrimination in healthcare. The table includes information on each framework's scope, aim/purpose, other subtypes of stigma covered and a summary of the framework from the original authors' description.

Eight of these 17 frameworks encompass all three stigma domains examined. While they seek to highlight the complex web of factors affecting different types of stigma and their impacts, their reported scope varies tremendously. For example, Stangl's "Health Stigma and Discrimination Framework" is presented as global, while Woodgate's framework is specific

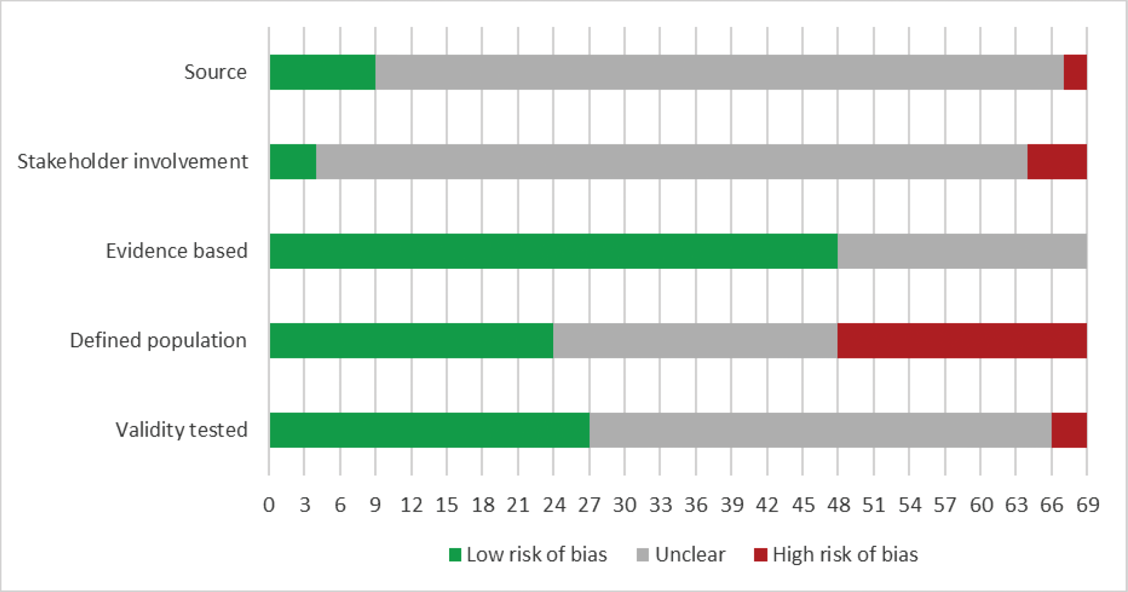

Figure 1. Critical appraisal summary: frameworks (*n* = 69).
Source: Assesses whether the framework was published or endorsed by a relevant organization; Stakeholder involvement: Assesses whether the framework was established with relevant stakeholder input; Evidence based: Assesses whether the components of the frameworks were based on a systematic literature review or empirical data; Defined population: Assesses whether the population the framework is designed to address is clearly reported; Validity tested: Assesses whether the validity of the framework was assessed (e.g., goodness of fit to empirical data assessed, framework applied in different contexts).
Low risk of bias: The potential source of bias is unlikely to distort the methodological quality of the measure; Unclear: There was insufficient detail reported to assess the potential source of bias; High risk of bias: There was evidence of bias.

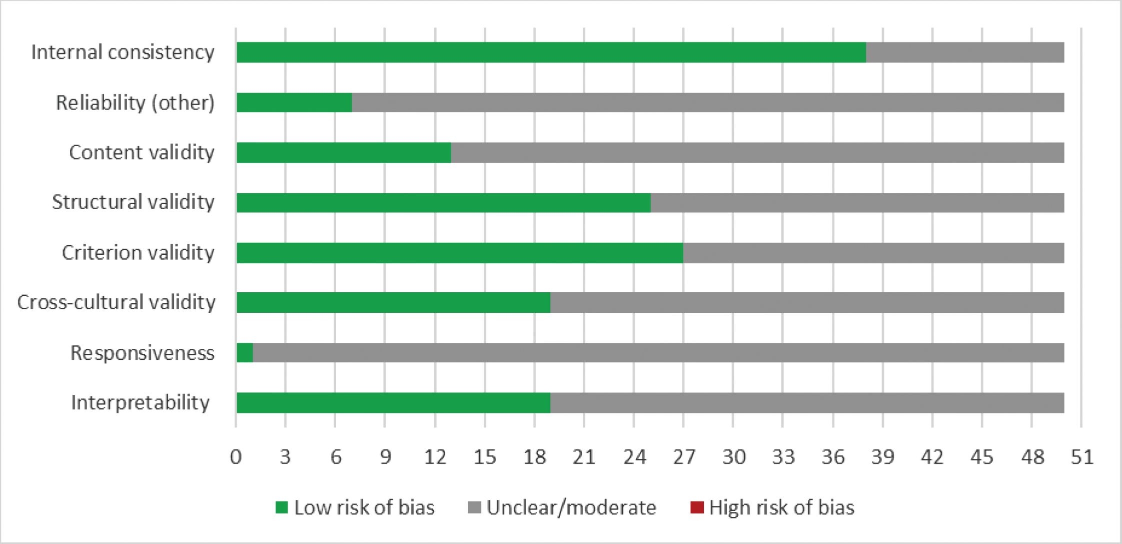

Figure 2. Critical appraisal: summary measures (*n* = 50).
Internal consistency: Assesses whether the internal consistency of the scale was reported and it was acceptable (e.g., Cronbach's alpha >0/70); Reliability (other): Assesses whether other measures of reliability were reported and results were acceptable (e.g., test-retest reliability, rater agreement); Content validity: Assesses whether the content of the measure was assessed for validity and the results were acceptable (e.g., face validity rated, expert review); Structural validity: Assesses whether the structural validity of the measure was assessed and the results were acceptable (e.g., through factor analysis); Criterion validity: Assesses whether convergent or discriminant validity to external criteria or other measures was determined and the results were acceptable; Cross-cultural validity: Assesses whether measures were taken to ensure cross-cultural validity (e.g., translation and back-translation of items; measure exists in multiple languages or was used in multiple geographic settings); Responsiveness: Assesses whether the measure demonstrated sensitivity to change (e.g., scores changed after an intervention as predicted); Interpretability: Assesses whether guidance is reported on the interpretation of scores (e.g., minimal clinical difference).
Low risk of bias: The potential source of bias is unlikely to distort the methodological quality of the measure; Unclear: There was insufficient detail reported to assess the potential source of bias; High risk of bias: There was evidence of bias.

to Indigenous people living with HIV in Canada, and Stevens' framework focuses on how HIV-related stigma affects rehabilitation [17, 22, 25].

Seven frameworks address internalized stigma and stigma and discrimination in healthcare, most of which have HIV-related clinical outcomes as their primary outcomes. Factors along the named pathways to these outcomes vary but frequently include depression, self-isolation and decreased social support.

Only Turan's framework addresses internalized stigma and stigma and discrimination in law [37]. In this framework, intersecting and structural stigmas operate through interpersonal factors, psychological resources, mental health (including internalized stigma) and stress processes to shape engagement in HIV care and HIV-related outcomes.

The UNAIDS framework examining gaps across the HIV prevention continuum encompasses stigma and discrimination in both healthcare and law, providing examples as to how these impede HIV prevention [24].

Overall, four frameworks explicitly considered intersecting stigmas [17, 27, 32, 37] (e.g. gender-related stigma or race-related stigma alongside HIV-related stigma) and four explicitly adopted a socio-ecological framework [17, 25, 26, 33].

3.2 | Measures

To address key question 2, we documented stigma measures in a comprehensive evidence table in the online Appendix (Table S3). It shows the type of identified stigma and discrimination measures, listing the measure details, reliability and validity. The table shows the main publication and supporting publications also reporting on the measure and contributing additional psychometric information.

Figure 2 summarizes the critical appraisal of all 50 identified measures.

Seventy-six percent of identified measures reported on internal consistency, such as Cronbach's alpha, and all publications that reported on reliability documented acceptable reliability for the measure's final version or across most subscales. Only seven studies reported on other reliability measures, mostly temporal stability assessed in test-retest administrations. A quarter of the measures reported on a formal analysis of content validity, for example through expert rating of the appropriateness and spectrum of items. Half of the identified measures reported structural validity, usually based on exploratory or confirmatory factor analysis. Similarly, half of the measures were able to document external validity through correlations with other measures, providing the evidence of convergent or discriminant validity. Of the

Table 1. Frameworks addressing multiple stigma domains (*n* = 17)

ID Framework name Domain Terminology Empirical/categorical	Scope and aim/purpose	Stigma subtype	Summary
Frameworks addressing internalized stigma, stigma and discrimination in healthcare and law			
Gilbert [15] Framework name: NA Domain: Internalized stigma, stigma or discrimination in healthcare settings, stigma or discrimination in law Terminology: Stigma Conceptual model	Scope: HIV-related stigma evidenced in South Africa Aim/purpose: To examine individual and social/structural components of HIV-related stigma in South Africa	Subtype: Internalized, enacted discrimination, by association, instrumental, symbolic	To provide a comprehensive framework that offers insights into the individual as well as the social/structural components of HIV-related stigma in a particular context.
Pescosolido and Martin [16] Framework name: Framework Integrating Normative Influences on Stigma (FINIS) Domain: Internalized stigma, stigma or discrimination in healthcare settings, stigma or discrimination in law Terminology: Stigma, discrimination Empirical model	Scope: A multilevel approach that can be tailored to stigmatized statuses Aim/purpose: To provide a theoretical architecture of concepts, proposing a stigma complex, a system of interrelated, heterogeneous parts bringing together insights across disciplines to provide a more realistic and complicated sense of the challenge facing research and change efforts	Subtype: Perceived, endorsed, anticipated, received, enacted, self-stigma, courtesy stigma, public stigma, prover-based stigma, structural stigma	In essence, the FINIS is a systems science approach. The rationale for FINIS lies in evidence, reviewed here, that stigma emanates from many societal and individual systems whose interconnections cannot be divorced from one another. They coexist in a dynamic relationship in which there is an interplay across, for example, the media, the community and the individual.
Stangl et al. [17] Stangl et al. [18]; ICRW [19]; Stangl and Barre [20]; Stangl et al. [21] Framework name: The Health Stigma and Discrimination Framework Domain: Internalized stigma, stigma or discrimination in healthcare settings, stigma or discrimination in law Terminology: Stigma, discrimination Conceptual model	Scope: Health-related stigmas Aim/purpose: To amplify our collective ability to respond effectively and at-scale to a major driver of poor health outcomes globally	Subtype: Internalized, perceived stigma, associated stigma, experienced discrimination	The Health Stigma and Discrimination Framework is a global, crosscutting framework based on theory, research and practice, which demonstrates its application to a range of health conditions, and discusses how stigma related to race, gender, sexual orientation, class and occupation intersects with health-related stigmas, and how the framework can be used to enhance research, programming and policy efforts.

(*Continued*)

Table 1. (Continued)

ID **Framework name** **Domain** **Terminology** **Empirical/categorical**	**Scope and aim/purpose**	**Stigma subtype**	**Summary**
Stevens et al. [22] Framework name: Rehabilitation framework Domain: Internalized stigma, stigma or discrimination in healthcare settings, stigma or discrimination in law Terminology: Stigma Conceptual model	Scope: Conceptualizing HIV in a rehabilitation framework Aim/purpose: To help rehabilitation professionals better understand the dynamic and nuanced forms of stigma and how they relate to rehabilitation	Subtype: Enacted, self and structural stigma	Three broad spheres of stigma are described: enacted, self and structural stigma. These three forms of stigma are then aligned in unique ways with three particular constructs of the International Classification of Functioning, Disability and Health: participation restrictions, environmental and personal contextual factors.
Thapa et al. [23] Framework name: NA Domain: Internalized stigma, stigma or discrimination in healthcare settings, stigma or discrimination in law Terminology: Stigma Empirical model	Scope: Effect of stigma-reduction intervention strategies on HIV test uptake Aim/purpose: A conceptual framework to illustrate mechanisms involved in reducing HIV stigma and increasing HIV test uptake	Subtype: NA	A conceptual framework to illustrate the mechanisms of the effect of stigma-reduction intervention strategies on HIV test uptake.
UNAIDS [24] Framework name: Effects of stigma and discrimination on health care access for prevention, testing and treatment Domain: Internalized stigma, stigma or discrimination in healthcare settings, stigma or discrimination in law Terminology: Stigma, discrimination Conceptual model	Scope: Stigma and discrimination as healthcare service barriers Aim/purpose: NA	Subtype: NA	Criminal laws, community attitudes, misinformation, prejudice and fear are all drivers of stigma and actual manifestations of discrimination affecting access to healthcare by people living with HIV and key populations.
UNAIDS [24] Framework name: Removing stigma and discrimination improves health care access for prevention, testing and treatment Domain: Internalized stigma, stigma or discrimination in healthcare settings, stigma or discrimination in law Terminology: Stigma, discrimination Conceptual model	Scope: Stigma and discrimination in healthcare access for prevention, testing and treatment. Confronting stigma to remove healthcare stigma barriers Aim/purpose: NA	Subtype: NA	By addressing drivers, removal of harmful laws, introduction of protective laws, education of rights holders and service providers and legal empowerment of communities to defend their rights, the gap between those who can access services and those who cannot can be closed, leading to better health for all.

(*Continued*)

Table 1. (Continued)

ID **Framework name** **Domain** **Terminology** **Empirical/categorical**	**Scope and aim/purpose**	**Stigma subtype**	**Summary**
Woodgate et al. [25] Framework name: Social ecological framework Domain: Internalized stigma, stigma or discrimination in healthcare settings, stigma or discrimination in law Terminology: Stigma, discrimination Conceptual model	Scope: Stigma and discrimination on the lives of Indigenous people who contracted HIV in their youth (i.e. 15–29 years of age) who are HIV positive within their various settings in Manitoba, Canada Aim/purpose: Developing a better structural understanding of the impacts of stigma and discrimination on the lives of Indigenous people who are HIV positive	Subtype: NA	Stigma and discrimination caused barriers for Indigenous people living with HIV through inhibiting their ease of access to supports, including family, peers, community and long- and short-term health services.
Frameworks addressing internalized stigma, stigma and discrimination in healthcare			
Darlington and Hutson [26] Framework name: Current state-of-science of HIV-related stigma among HIV + women in the Southern US Domain: Internalized stigma, stigma or discrimination in healthcare settings Terminology: Stigma Empirical model	Scope: HIV-related stigma among women living in the South Aim/purpose: Understanding HIV-related stigma among women in the Southern United States	Subtype: Perceived, experienced, internalized	A description of the current state-of-science of HIV-related stigma among HIV and women in the Southern United States
Earnshaw et al. [27] Earnshaw and Chaudoir [28]; Misir [29]; Goodin et al. [30]; Reinius et al. [31] Framework name: Hypothesized associations between HIV stigma mechanisms and health and well-being among people living with HIV Domain: Internalized stigma, stigma or discrimination in healthcare settings Terminology: Stigma Empirical model	Scope: HIV stigma mechanism and health and wellbeing Aim/purpose: To test the HIV stigma framework evaluating HIV stigma mechanisms and wellbeing	Subtype: Internalized, anticipated, enacted	Internalized stigma associates significantly with indicators of affective (i.e. helplessness regarding, acceptance of and perceived benefits of HIV) and behavioral (i.e. days in medical care gaps and ARV nonadherence) health and wellbeing. Enacted and anticipated stigma associate with indicators of physical health and wellbeing (i.e. CD4 count less than 200 and chronic illness comorbidity, respectively).

(*Continued*)

Table 1. (Continued)

ID **Framework name** **Domain** **Terminology** **Empirical/categorical**	**Scope and aim/purpose**	**Stigma subtype**	**Summary**
Logie et al. [32] Framework name: NA Domain: Internalized stigma, stigma or discrimination in healthcare settings Terminology: Stigma, discrimination Empirical model	Scope: Women living with HIV in Canada Aim/purpose: To integrate concepts from multiple frameworks and test pathways from intersectional stigma to HIV-related health outcomes via interpersonal, psychological, mental health and stress mechanisms among women living with HIV in Canada	Subtype: Intersectional	Integrating concepts from multiple frameworks to examine pathways from intersectional stigma to mental health via interpersonal and institutional support, and from mental health to care engagement and HIV-related health via coping strategies among women living with HIV.
Sen et al. [33] Framework name: Bronfenbrenner's ecological systems theory Domain: Internalized stigma, stigma or discrimination in healthcare settings Terminology: Stigma Conceptual model	Scope: Asian American and Pacific Islander men who have sex with men in the United States Aim/purpose: To explore the manifestation of HIV stigma at the micro, meso and macro levels and how these might impact on HIV testing and HIV service utilization	Subtype: Multilevel ecological framework of stigma	A model which is culturally grounded and bridges the individual, interpersonal and societal conceptualizations of stigma.
Thi et al. [34] Framework name: NA Domain: Internalized stigma, stigma or discrimination in healthcare settings Terminology: Stigma, discrimination Empirical model	Scope: Causes of HIV stigma and discrimination in Vietnam Aim/purpose: To provide a schematic diagram of stigma and discrimination against people living with HIV addressing causes, effects and relationships	Subtype: Internalized	Three main themes relating to stigma and discrimination emerged: (1) attitudes, misperceptions and negative media representations led to the stigmatization of people living with HIV; (2) acts of discrimination occurred within various sectors of Vietnamese society, including the family, community, healthcare sector and workplace; and (3) stigma and discrimination resulted in negative effects on people living with HIV.
Wardell et al. [35] Framework name: NA Domain: Internalized stigma, stigma or discrimination in healthcare settings Terminology: Stigma Empirical model	Scope: Associations among HIV-related stigma, coping and problem drinking Aim/purpose: Examining prospective bidirectional and mediated associations among HIV-related stigma, maladaptive coping and alcohol use severity in patients enrolled in the Ontario HIV Treatment Network Cohort study	Subtype: Enacted, internalized	Cross-lagged panel model of the prospective associations among HIV-related stigma, maladaptive coping strategies and alcohol use severity.

(*Continued*)

Table 1. (Continued)

ID **Framework name** **Domain** **Terminology** **Empirical/categorical**	**Scope and aim/purpose**	**Stigma subtype**	**Summary**
Watt et al. [36] Framework name: NA Domain: Internalized stigma, stigma or discrimination in healthcare settings Terminology: Stigma Conceptual model	Scope: Women and their partners attending a first antenatal care appointment in Tanzania Aim/purpose: Stigma visual used to discuss how issues of internalized, anticipated and enacted stigma might relate to their situation of living with HIV, and to try and reduce these as barriers of HIV care engagement	Subtype: Internalized, anticipated, enacted	Addressing HIV stigma at the first antenatal care visit can help individuals living with HIV to overcome stigma-related barriers to the initiation and maintenance of HIV care, and can reduce stigmatizing attitudes among those who test negative for HIV.
Frameworks addressing internalized stigma and stigma and discrimination in law			
Turan et al. [37] Framework name: Conceptual framework for HIV-related stigma, engagement in care, and health outcomes Domain: Internalized stigma, stigma or discrimination in law Terminology: Stigma Conceptual model	Scope: Adherence to treatment, health outcomes Aim/purpose: A conceptual framework for individual-level dimensions of stigma and potential individual and interpersonal mechanisms explaining how stigma affects HIV-related health	Subtype: Perceived community stigma, experienced stigma, internalized stigma, anticipated stigma, structural stigma, intersectional stigmas	In the context of intersectional and structural stigmas, individual-level dimensions of HIV-related stigma operate through interpersonal factors, mental health, psychological resources and biological stress pathways.
Frameworks addressing stigma and discrimination in healthcare and law			
UNAIDS [24] Framework name: Examples of stigma and discrimination that create gaps across the HIV prevention cascade Domain: Stigma or discrimination in healthcare settings, stigma or discrimination in law Terminology: Stigma, discrimination Conceptual model	Scope: Healthcare stigma and discrimination that create gaps across the HIV prevention cascade Aim/purpose: NA	Subtype: NA	The framework describes examples of stigma and discrimination that create gaps across the HIV prevention cascade

Abbreviations: NA, not applicable; US, United States.

identified measures, about 40% reported cross-cultural validity, demonstrated either as part of the measure construction using forward translations in translated measures or reporting the psychometric characteristics for different geographic contexts. Despite the frequency of application of measures, we only found one study explicitly addressing responsiveness, that is documenting the sensitivity of the measure of detecting change [38]. Of the identified measures, 39% reported information of the measure's interpretability, for example documenting the distribution of scores and helping future users of the measure understand what score ranges or cut-offs constitute a high stigma score.

Table 2 summarizes measures assessing at least two of our three domains of interest.

Some measures address all three types of stigma of interest, including the People Living with HIV Stigma Index (and its version 2.0). The website for this measure states that it has been used in many more countries and languages than we found through this review, and reports are available for many countries worldwide [13].

One other measure assessed all three types of stigma: a report of the findings of an HIV-related legal assessment in Zambia [42]. It encompassed legal and policy, survey and qualitative data, each presented separately but analysed jointly, providing an interesting model that might be adapted for use in other countries.

Five other measures were found that cover both internalized stigma and stigma and discrimination in healthcare. Each one is structured differently, capturing different elements of stigma. For example, within the Multiple Discrimination Scale, HIV-related stigma was assessed using Kalichman's Internal AIDS-Related Stigma Scale and the "experienced stigma" subscale from the People Living with HIV Stigma Index [45]. Alongside this, other pre-validated scales were included to assess stigma related to race/ethnicity and sexual orientation, with findings reported individually for each type of stigma as well as aggregated into an unweighted total.

Only the National Commitments and Policy Instrument focuses on stigma and discrimination in healthcare and in law and policy. It contains a range of relevant indicators on experiences of stigma and discrimination in healthcare, laws that might be discriminatory and laws that protect against HIV-related discrimination [49].

The scales that are most frequently adopted or adapted are those initially published by Berger (not shown in the table above as it focuses only on internalized stigma) and Earnshaw [27, 51].

The measure evidence table in the online Appendix (Table S4) documents the available measures in detail. Alongside the studies discussed above, it includes measures that assess a single stigma domain relevant to this review.

3.3 | Discussion

This review synthesizes a complex range of data covering frameworks and measures across the three identified domains of stigma. This evidence base helps identify opportunities and challenges, with a view to stimulating further discussion and advancing the field both conceptually and practically.

3.4 | Language of defining stigma and discrimination

There is much variation in how authors described/defined stigma. Language used included, in addition to internalized stigma, stigma and discrimination in healthcare settings and in law and policy, self-stigma, felt stigma, enacted stigma, anticipated stigma, perceived stigma, personal stigma and more. In addition, scale components were sometimes described using language that can be interpreted to be about stigma even when stigma is not explicitly named. With this range of language, inconsistently used, it can be difficult to ascertain, at face value what a framework or measure actually captures and how comparable it might be to others.

The understandable drive towards context- and construct-specific frameworks and measures has perhaps splintered the concept of stigma to such an extent that it hampers comparability, cross-setting learning and efforts to assess progress towards global targets. Our review aims to help address this by providing an overview and compendium of existing resources. Determining a standardized nomenclature for different types of stigma for use across frameworks and measures, that can be locally tailored, might be an important next step.

3.5 | Variety within frameworks and measures for internalized stigma

Within frameworks that address internalized stigma, this concept appears variably as the starting point of the framework, in the middle or as the outcome. The most common associations are between internalized stigma and mental health or HIV-related clinical outcomes.

Across both frameworks and tools, some measure HIV-related stigma broadly, with a sub-component/scale to capture internalized stigma, while others focus only on internalized stigma.

There is variety in terms of what the measures actually measure, with regard to both content and specificity of responses: the measures include different numbers of items, some are assessed dichotomously, while others use a Likert scale, and different time periods are covered. Thus, even where content is similar, assessments can look very different. No qualitative measures were identified.

The People Living with HIV Stigma Index 2.0, in its assessment of internalized stigma, also includes a "resilience scale" [43]. Capturing concepts, such as self-respect, self-confidence and the ability to feel love, this scale provides a positive framing within which resilience is seen as a counter measure to internalized stigma.

3.6 | Variety within frameworks and measures for stigma and discrimination in healthcare

Some frameworks focus exclusively on stigma and discrimination in healthcare, while others include this as component of a broader HIV-related stigma framework. The specificity of the framework determines the degree to which stigma and discrimination are explored, with focused frameworks providing more depth. Most of the frameworks capture triggers, manifestations and impacts within healthcare. Four frameworks are

Table 2. Measures addressing multiple stigma domains (*n* = 10)

ID Framework title and type Domain	Stigma/discrimination subtype Framework	Target population Surveyed participants	Scale structure Number of items Answer mode	Reported psychometric characteristics
Measures addressing internalized stigma, stigma and discrimination in healthcare and law				
Stigma Index [13] Chinouya et al. [39]; UNAIDS [40] Domain: Internalized stigma, stigma or discrimination in healthcare settings, stigma or discrimination in law Measure name: Stigma Index	Stigma subtype addressed: Experiences of stigma and discrimination and their causes; access to work and services; internal stigma; rights, laws and policies; effecting change; HIV testing; disclosure and confidentiality; treatment; having children; problems and challenges for people living with HIV Underlying framework: NA	Target population: People living with HIV Surveyed participants: Varies	Scale structure: 10 areas: Experiences of stigma and discrimination and their causes; access to work and services; internal stigma; rights, laws and policies; effecting change; HIV testing; disclosure and confidentiality; treatment; having children; problems and challenges for people living with HIV Number of items: NA Answer mode: Answer mode varies by item	Reliability: NA Validity: NA
Dos Santos et al. [41] Domain: Internalized stigma, stigma or discrimination in healthcare settings, stigma or discrimination in law Measure name: People Living with HIV Stigma Index (adaptation)	Stigma subtype addressed: Internalized Underlying framework: NA	Target population: People living with HIV/AIDS Surveyed participants: People living with HIV/AIDS in South Africa	Scale structure: three subdomains covering perceptions of self and internal stigma and examples of stigma or discrimination in different settings, such as the home, community, workplace, religious or healthcare settings; small adaptations were made to the Index, including the quantifying of all qualitative responses into nominal and ordinal scales and the inclusion of South Africa's best-known national law and policy guidelines as per the Index directives Number of items: NA Answer mode: Rating scale, Dichotomous scale, Answer mode varies by item	Reliability: NA Validity: NA

(*Continued*)

Table 2. (Continued)

ID Framework title and type Domain	Stigma/discrimination subtype Framework	Target population Surveyed participants	Scale structure Number of items Answer mode	Reported psychometric characteristics
Biemba et al. [42] Domain: Internalized stigma, stigma or discrimination in healthcare settings, stigma or discrimination in law Measure name: NA	Stigma subtype addressed: Internalized, perceived, enacted Underlying framework: NA	Target population: People living with HIV Surveyed participants: People living with HIV and health workers	Scale structure: Both quantitative and qualitative questions, narrower and modified form of legal environment assessment; questions separate for people living with HIV and health workers Number of items: NR Answer mode: Rating scale, Dichotomous scale, Free text, Answer mode varies by item	Reliability: NA Validity: NA
Friedland et al. [43] HIV Stigma Index 2.0 [44] Domain: Internalized stigma, stigma or discrimination in healthcare settings, stigma or discrimination in law Measure name: People Living with HIV Stigma Index 2.0	Stigma subtype addressed: Internalized Underlying framework: Adapted from the original People Living with HIV (PLHIV) Stigma Index	Target population: People living with HIV Surveyed participants: People living with HIV at least 18 years old who had known their status for at least 1 year	Scale structure: Sections consist of: disclosure, your experience of stigma and discrimination, internalized stigma and resilience, interactions with healthcare services, human rights and effecting change, stigma and discrimination experienced for reasons other than your HIV status, personal experience related to stigma/discrimination Number of items: six items Answer mode: Rating scale, Free text, Answer mode varies by item	Reliability: Good internal consistency (Cronbach's alphas for Cameroon, Senegal and Uganda were 0.70, 0.65 and 0.75, respectively) Validity: Cognitive interview respondents indicated that most questions were well understood and focus group participants said that the Stigma Index 2.0 addressed issues that were relevant to their lives, good construct validity

(*Continued*)

Table 2. (Continued)

ID Framework title and type Domain	Stigma/discrimination subtype Framework	Target population Surveyed participants	Scale structure Number of items Answer mode	Reported psychometric characteristics
Measures addressing internalized stigma and stigma and discrimination in healthcare				
Bogart et al. [45] Domain: Internalized stigma, stigma or discrimination in healthcare settings Measure name: Multiple Discrimination Scale	Stigma subtype addressed: Interpersonal discrimination, institutional discrimination, violent discrimination Underlying framework: NA	Target population: HIV-positive Black and Latino men who have sex with men Surveyed participants: HIV-positive Black and Latino men who have sex with men	Scale structure: three subdomains: discrimination events in the past year due to race/ethnicity (MDS-Race), sexual orientation (MDS-Gay) and HIV-serostatus (MDS-HIV) Number of items: 30 items total, 10 per subdomain Answer mode: Dichotomous scale	Reliability: Cronbach's alpha >0.80 for all three subscales; follow-up scores were used to assess test–retest reliability (> 0.60 for all subscales); the three MDS subscales were significantly correlated Validity: All three MDS subscales were significantly associated with validated stigma constructs from prior research, showing high convergent validity
Earnshaw et al. [27] Earnshaw and Chaudoir [28]; Misir [29]; Goodin et al. [30]; Reinius et al. [31] Domain: Internalized stigma, stigma or discrimination in healthcare settings Measure name: HIV Stigma Mechanism Measure	Stigma subtype addressed: Internalized, anticipated, enacted Underlying framework: HIV Stigma Framework (Earnshaw and Chaudoir)	Target population: People living with HIV Surveyed participants: People living with HIV recruited from an inner-city clinic in the Bronx, NY	Scale structure: three subdomains: internalized, anticipated and enacted Number of items: 24 items total, 6 internalized, 9 anticipated and 9 enacted Answer mode: Rating scale	Reliability: Cronbach's alpha internalized HIV stigma 0.89, anticipated HIV stigma 0.87 and enacted HIV stigma 0.87 Validity: The three scales were considered to be distinct with the majority of variability in each scale non-overlapping; internalized HIV stigma was uniquely associated with indicators of poorer affective health and wellbeing, including greater helplessness, lower acceptance and lower perceived benefits of having HIV

(*Continued*)

Table 2. (Continued)

ID **Framework title and type** **Domain**	**Stigma/discrimination subtype** **Framework**	**Target population** **Surveyed participants**	**Scale structure** **Number of items** **Answer mode**	**Reported psychometric characteristics**
Neuman et al. [46] Domain: Internalized stigma, stigma or discrimination in healthcare settings Measure name: NA	Stigma subtype addressed: Internalized stigma, interpersonal discrimination, discrimination experienced in healthcare facilities Underlying framework: NA	Target population: HIV-positive adults Surveyed participants: HIV-positive adults	Scale structure: three scales—interpersonal discrimination; discrimination experienced in healthcare facilities; and internalized stigma Number of items: 19 total Answer mode: Dichotomous scale	Reliability: Cronbach's alpha scores for both the interpersonal discrimination and healthcare discrimination measures were >0.8, the score for the internalized stigma score was 0.68 Validity: NA
Li et al. [47] Domain: Internalized stigma, stigma or discrimination in healthcare settings Measure name: NA	Stigma subtype addressed: Internalized, personal, occupational Underlying framework: Earnshaw and Chaudoir, 2009; Visser et al., 2008; Stein and Li, 2008	Target population: HIV-positive patients Surveyed participants: HIV-positive patients, non-HIV patients and healthcare providers	Scale structure: three scales; internalized (HIV + patients) and personal stigma (non-HIV+ patients) scale factors: guilt/blaming and being refused/refusing service; occupational stigma scale factors: blaming, professionalism and egalitarianism Number of items: 31 items across three scales Answer mode: Rating scale	Reliability: Internalized and personal stigma scales with reliability coefficients of 0.869 and 0.853; the occupational stigma scale had a three-factor structure with a reliability coefficient of 0.839 Validity: Confirmatory factor analysis confirmed that the factors identified from the development samples fit the validation sample; however, all *p*-values from the chi-squared goodness-of-fit tests were $p < 0.001$; among the three study groups, each of the subscales associated with measures of sample characteristics further validated the independence of each factor reflecting that they are representative of an independent sub-stigma mechanism

(*Continued*)

Table 2. (Continued)

ID Framework title and type Domain	Stigma/discrimination subtype Framework	Target population Surveyed participants	Scale structure Number of items Answer mode	Reported psychometric characteristics
Stangl et al. [48] Domain: Internalized stigma, stigma or discrimination in healthcare settings Measure name: NA	Stigma subtype addressed: Internalized, experienced, perceived Underlying framework: Health Stigma and Discrimination Framework (Stangl et al., 2019)	Target population: People living with HIV Surveyed participants: People living with HIV, community members and healthcare workers	Scale structure: seven scales and two experience measures (fear and judgement, internalized stigma, perceived stigma in community, experienced stigma in the community, perceived stigma in the healthcare setting, perceived co-worker stigma and experienced stigma in healthcare settings) Number of items: 35 questions in total Answer mode: Rating scale, Dichotomous scale	Reliability: Acceptable to very good internal consistency Validity: Subgroup factor analysis confirmed acceptable reliability for all three scales by country, sex and type of health worker
Measures addressing stigma and discrimination in healthcare and law				
UNAIDS [49] UNAIDS, WHO [50] Domain: Stigma or discrimination in healthcare settings, stigma or discrimination in law Measure name: National Commitments and Policy Instrument	Stigma subtype addressed: NA Underlying framework: NA	Target population: People living with HIV Surveyed participants: People living with HIV	Scale structure: two parts (Part A for national authorities and Part B for non-governmental partners) Number of items: 10 target areas Answer mode: Unclear	Reliability: NA Validity: NA

Abbreviations: NA, not applicable; NR, not reported; NY, New York.

designed to inform action to reduce stigma and discrimination in healthcare [52–55], while the UNAIDS frameworks identify how stigma and discrimination in healthcare impact the HIV prevention and care and treatment cascades, and how interventions might help address this.

Many measures capture beliefs and practices among health workers, some capture health worker and client perspectives through separate sub-scales and a few capture client experiences. Tested across diverse geographies and populations, these measures do not generally appear comparable. The UNAIDS indicators, included in the Global AIDS Monitoring framework, designed for use by all national governments reporting to UNAIDS, are the exception [49].

There is variety in the scope and specificity of measures: some measures of stigma and discrimination in healthcare are general, some capture something more specific, for example how stigma impacts decisions around childbearing among people living with HIV, and some also capture additional stigma.

3.7 | Variety within frameworks and measures for stigma and discrimination in law and policy

Where stigma and discrimination in law and policy are included in frameworks, this is usually generic with laws and policies mentioned as part of the macro-system or structural factors within a socio-ecological model. The UNAIDS models usefully point to specific laws that can be discriminatory and affect HIV-related outcomes, and Hagopian and colleagues provide a framework specific to how anti-homosexuality laws affect HIV-related stigma and outcomes [24, 56]. Stangl's framework draws attention to the existence of laws and policies as well as law enforcement practices and access to justice so as to capture information on implementation, which might also be discriminatory [17].

Three measures assessed stigma and discrimination in law and policy. The National Commitments and Policies Instrument and the Stigma Index, both of which are widely used, include quantitative measures of stigma and discrimination in law and policy, while Biemba and colleagues provide the only mixed-methods assessment [42, 43, 49].

Overall, there is a dearth of measures relating to HIV stigma and discrimination in law and policy. This may be due to the complexity and sensitivity of measuring these topics and the extensive investment that would be required to do this effectively at scale. Data are increasingly available about the existence of discriminatory laws and policies, but additional attention is needed to measure and evaluate their implementation to identify if, when or how these processes and structures have ramifications at the healthcare and personal levels.

3.8 | Looking across domains of stigma

Many of the frameworks that encompass different domains of stigma use variations of the socio-ecological framework to capture relevant factors from the individual to environmental levels. However, very few operate across all levels, and none sufficiently capture the three intertwined domains of stigma studied.

There are other domains of HIV-related stigma not included in this review as well as other types of stigma and discrimination that can intersect with HIV-related stigma, such as stigma and discrimination based on race/ethnicity, gender, sexual orientation or gender identity. Using any of these entry points, additional frameworks and measures might be identified that might help understand the domains of stigma studied here, particularly when these different types of stigma and discrimination are concurrently experienced.

3.9 | Looking across frameworks and measures

Focusing on those that seek to address more than one of our stigma domains of interest, frameworks are more encompassing than measures, bringing attention to the wide range of factors that influence experiences and outcomes. Understandably, no measure is sufficiently comprehensive to capture all of this. Across most of the frameworks, the components are very broad (e.g. mental health and culture), raising challenges for how each one might be measured. Further specificity and explicit definition might be required to ensure adequate measurement. This might be done as part of local adaptation, even as this may reduce comparability. Box 1 provides some guiding questions to help determine which framework and/or measures might be most useful in different situations.

3.10 | The challenge of comparability and context specificity

A plethora of measures exist, particularly for internalized stigma and stigma and discrimination experienced in healthcare, but their comparability is limited by their diversity. A recent review of interventions to address self-stigma did not include a formal meta-analysis due to the heterogeneity of measures used [57], and a 2015 UNAIDS report documented over 60 tools to assess and/or address stigma and discrimination just within healthcare [58]. While the need for local adaptation is evident, having a common starting point could help promote a balance of locally tailored yet internationally comparable data.

Although Stigma Index country reports are available online, data are rarely used in peer-reviewed literature. It would be helpful to see additional analyses of these data alongside their conceptual frameworks and information on sample sizes and sampling frames to help contextualize findings. Information on local adaptations might also help understand the comparability of findings.

3.11 | Implications for the HIV continuum of care

Many of the frameworks reviewed illustrate how stigma and discrimination are barriers to access across different points of the HIV care continuum. Recent modelling has estimated that reaching the UNAIDS societal enabler targets (which include "less than 10% of people living with HIV and key populations experience stigma and discrimination") will prevent 2.5 million new infections and 1.7 million AIDS-related deaths by 2030 [59]. Understanding how stigma and discrimination are being experienced, and being able to measure the impact of interventions to reduce them all along the continuum of care is critical to achieving global HIV targets, including the

Box 1: Considerations for selecting a framework and measure

This is not a stepwise process, simply guidance on issues to think through in trying to establish if existing HIV-related frameworks and measures might fit well with your planned work. Attention is also needed to ensure good fit between the chosen framework and measure(s).

Selecting a framework
-What type(s) of HIV-related stigma do you want to address? Is there an existing framework that matches this scope?
-What population(s) are you planning to work with and where? Have any frameworks been used in these contexts before?
-Where on the causal pathway does this stigma sit in your work: is it a predictor, intermediate or outcome variable? Which existing frameworks mirror this? And which ones also include other variables that you already think are important?
-Do you also want there to be attention to other, intersecting stigmas?
-What empirical or conceptual grounding underlying these frameworks aligns with your planned work?

Selecting measures

-Based on the scope of your work, is there an existing single measure that can cover everything you need or might you need to use multiple measures?
-Whose perspective(s)/experience(s) does each measure capture? Does that align with what you want to learn?
-For each measure, has it been validated? In your population, language and context of interest?
-In each case, has its reliability, interpretability and responsiveness been assessed?
-What time period does the measure cover (ever, last 30 days etc.)? Will this help you learn what you need in your work?
-How specific are response options (e.g. Y/N vs. Likert scale) and does that match your needs?

"95%-95%-95%" targets for HIV testing, treatment and viral suppression.

3.12 | Limitations

This review provides a comprehensive overview of existing frameworks and measures to advance the science of HIV-related stigma research. However, some limitations should be noted. The review was limited to newer work published since the publication of the original People Living with HIV Stigma Index [13]. We analysed only scientific articles or reports so that we could critically appraise the frameworks and measures, even as this may exclude the latest developments recently published in conference abstracts. The frameworks and measures reviewed are, to varying degrees, designed for the context within which they were developed; while some aspects might be universal, others may need to be refined for use in other social, cultural and economic contexts.

4 | CONCLUSIONS

Given the level of attention to addressing HIV-related stigma and discrimination, this review is particularly timely and can inform responses from global to local levels. The current Global AIDS Strategy and the 2021 Political Declaration on HIV and AIDS underscore the importance of addressing HIV-related stigma and discrimination in order to achieve global and national HIV targets. This will require rigorous measurement of stigma and discrimination across different spheres, including internalized stigma, and stigma and discrimination in healthcare and law and policy. The challenge remains how to do this with frameworks and measures that are both locally appropriate and globally comparable. Experts in the field from different stakeholder groups could usefully collaborate to guide a more streamlined approach for the field. People living with HIV must be at the centre of this work and support will be required from funders, international agencies and governments to ensure a process and outcomes that might gain broad traction.

Most importantly, the goal must be to understand, measure and help mitigate and alleviate the impact of different types of stigma. Frameworks and measures must be fit to help direct investment, prioritize appropriate actions and strengthen learning about effectiveness. This review provides a basis to seek consensus about appropriate concepts and measures to understand the experiences and drivers of stigma for different people in diverse contexts around the world. It is up to us all to ensure this consensus exercise takes place, and that ultimately the results translate into reducing stigma and enhancing the health, quality of life and human rights of all people.

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COMPETING INTERESTS

None of the authors have any competing interests.

AUTHORS' CONTRIBUTIONS

SH, LF and SG developed the systematic review. SH, AM, MB, SY, NF, NC and MR ran the searches and extracted the data. LF and SH wrote the first draft of the manuscript. All authors reviewed and revised the manuscript. All authors have read and approved the final manuscript. LF had final responsibility for the decision to submit for publication.

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The systematic review protocol was peer-reviewed by international content experts and a representative of the community of persons living with HIV to ensure that the review asks the right questions. Stakeholders were asked to review the draft review to ensure that all relevant frameworks, measures and intervention evaluations have been captured and that the review contributes meaningfully to the knowledge base and to ensure that the evidence review is as impactful as possible. The review is registered in PROSPERO and the data are available in the Systematic Review Data Repository [12]. We thank Brent Allan and members of the country teams for helpful comments.

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DATA AVAILABILITY STATEMENT

The authors confirm that the data supporting the findings of this study are available within the article.

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SUPPORTING INFORMATION

Additional information may be found under the Supporting Information tab for this article:

Figure S1. Literature flow diagram.
Table S1. Evidence table for frameworks.
Table S2. Critical appraisal frameworks.
Table S3. Critical appraisal for measures.
Table S4. Evidence table for measures.

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COMMENTARY

Recognizing and disrupting stigma in implementation of HIV prevention and care: a call to research and action

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Abstract

Introduction: There is robust evidence that stigma negatively impacts both people living with HIV and those who might benefit from HIV prevention interventions. Within healthcare settings, research on HIV stigma has focused on intra-personal processes (i.e. knowledge or internalization of community-level stigma that might limit clients' engagement in care) or interpersonal processes (i.e. stigmatized interactions with service providers). Intersectional approaches to stigma call us to examine the ways that intersecting systems of power and oppression produce stigma not only at the individual and interpersonal levels, but also within healthcare service delivery systems. This commentary argues for the importance of analysing and disrupting the way in which stigma may be (intentionally or unintentionally) enacted and sustained within HIV service implementation, that is the policies, protocols and strategies used to deliver HIV prevention and care. We contend that as HIV researchers and practitioners, we have failed to fully specify or examine the mechanisms through which HIV service implementation itself may reinforce stigma and perpetuate inequity.

Discussion: We apply Link and Phelan's five stigma components (labelling, stereotyping, separation, status loss and discrimination) as a framework for analysing the way in which stigma manifests in existing service implementation and for evaluating new HIV implementation strategies. We present three examples of common HIV service implementation strategies and consider their potential to activate stigma components, with particular attention to how our understanding of these dynamics can be enhanced and expanded by the application of intersectional perspectives. We then provide a set of sample questions that can be used to develop and test novel implementation strategies designed to mitigate against HIV-specific and intersectional stigma.

Conclusions: This commentary is a theory-informed call to action for the assessment of existing HIV service implementation, for the development of new stigma-reducing implementation strategies and for the explicit inclusion of stigma reduction as a core outcome in implementation research and evaluation. We argue that these strategies have the potential to make critical contributions to our ability to address many system-level form stigmas that undermine health and wellbeing for people living with HIV and those in need of HIV prevention services.

Keywords: stigma; health systems; intersectionality; HIV care continuum; HIV prevention

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1 | INTRODUCTION

HIV stigma negatively impacts both people living with HIV and those who might benefit from HIV prevention interventions [1–4]. The vast majority of research on HIV stigma in healthcare has focused on *intra-personal processes* (i.e. the ways in which the internalization of community-level stigma affects clients' engagement in care) or *inter-personal processes* (i.e. stigma in provider–client interactions) [4–7]. Limited research has examined the extent to which intra-personal and interpersonal processes are exacerbated by programmatic or systemic factors, including the way in which HIV prevention and care are delivered.

Public health researchers are increasingly recognizing the importance of intersectionality as a framework for understanding the ways in which healthcare systems create and sustain health inequities [8–11]. Intersectional approaches call us to examine not only individuals' experience of stigma at the intersections of systems of power and oppression, but also the policies, processes and protocols that create stigmatizing environments for clients [12, 13]. A central premise of stigma theory is that stigma occurs in situations in which power is exercised [14]. The implementation of healthcare involves an inherent power imbalance between client and provider/system because the client is entirely subject to rules about how, when, where and to whom care is provided or denied. These power dynamics intersect with social systems of power and oppression, such that those with power and control within healthcare systems are disproportionately privileged along lines of race, class and education [15], whereas clients in need of HIV services are disproportionately marginalized by those systems [16]. Intersectional and multi-level frameworks argue that health inequity is perpetuated through interactions between multiple sites and levels of power [12, 17] and that this power is exercised in the context of social institutions [8, 17–19]. HIV service implementation is one domain in which power is exercised in ways that perpetuate stigma at the intersection of social hierarchies.

This commentary argues for the importance of analysing and disrupting the way in which stigma may be enacted and sustained within HIV service implementation, by which we mean the policies, protocols and strategies used to deliver HIV prevention and care. HIV service implementation includes strategies that affect care delivery, including policies that determine how healthcare is organized, protocols that govern aspects of care delivery, such as treatment, testing and education, and procedures that define client–provider interactions. We contend that as HIV researchers and practitioners, we have failed to fully specify or examine the mechanisms through which HIV service implementation *itself* may reinforce stigma. This gap is a major limitation in our ability to address and rectify many system-level stigmas that undermine health and wellbeing for people living with HIV and those with prevention needs.

Link and Phelan's operationalization of five stigma components [14] provides a useful framework for analysing the way in which stigma may manifest in existing HIV service implementation and for evaluating new strategies as stigmatizing or stigma reducing. Below, we define these components and describe how they help identify the sources of intersectional stigma using three examples of HIV service implementation strategies—the use of risk-based algorithms to determine eligibility [20], the segregation of HIV services from other health services [21, 22] and the adoption of protocols that present logistical hurdles to receiving care [23]. We then provide guiding questions (Table 1) for use in the evaluation of new and existing HIV service implementation strategies in the context of intersectional stigma.

2 | DISCUSSION

Link and Phelan define stigma as the convergence of five inter-related components: labelling, stereotyping, separation, status loss and discrimination [14]. *Labelling* refers to the recognition of a particular condition or attribute as "different" and the assignment of a specific marker to communicate that difference in society. *Stereotyping* refers to a process in which these labelled differences are linked to negative or undesirable characteristics. Labelling and stereotyping operate together, but the recognition of labelling as a discrete stigma process underscores the fact that stigma results from the social construction of categories, rather than inherently valid distinctions. *Separation* refers to the process through which social labels and their stereotypes lead to a separation between "those people" and the rest of society. *Status loss* and *discrimination* refer to the ways in which labelling, stereotyping and separation lead to explicit actions that exclude and mistreat stigmatized groups. Status loss refers specifically to individuals' devalued placement in a social hierarchy, which often results in lower status individuals needing to expend additional effort and resources than higher status individuals to have their needs met. Status loss is a source of discrimination, but discrimination extends to other behaviours at the interpersonal, organizational or structural levels that disadvantage stigmatized populations.

In Table 1, we provide examples of how each component may manifest in HIV service implementation, along with specific questions corresponding to each component that can be used to assess the extent to which HIV service implementation strategies inadvertently activate stigma. For example, one common practice in HIV service provision is the use of "high-risk" screening algorithms to determine which clients are offered HIV testing, pre-exposure prophylaxis (PrEP) or other services [20, 24, 25]. This process places a negative *label* on specific behaviours (e.g. age of sexual debut, number of sexual partners, condomless anal sex and substance use) that may be fundamental to clients' identity, relationships or personal fulfilment. Individuals screened using these algorithms may feel that their behaviour is being judged, shamed or pathologized [26]. The concept of "high-risk" behaviours, individuals or populations evokes powerful *stereotypes*, which have consistently fuelled prejudice and discrimination within healthcare settings [27, 28]. As we (SAG) have written previously, risk-focused algorithms reinforce stereotypes and negative client perceptions among providers, which contribute to reluctance to offer prevention interventions to clients in need [29–31].

In column 4 of Table 1, we provide a series of questions for each stigma component to guide reflection on how HIV service implementation strategies may activate intersectional stigma and affect clients' care in different ways based on their social positioning within intersecting systems of power and oppression [32, 33]. An intersectional approach to HIV stigma begins by examining its interaction with other forms of societal stigma, for example sexism, heterosexism, racism and classism [12, 33, 34], and the ways these systems determine who is most vulnerable to and negatively impacted by HIV [16, 35, 36] and who is most able to benefit from existing HIV service implementation [37]. Additionally, HIV is frequently experienced in the context of other stigmatized health conditions and behaviours, such as substance use and sexual behaviour, which are themselves situated in intersecting power systems [12, 33].

Returning to our example of risk-based algorithms for determining HIV service eligibility, an intersectional lens helps us analyse why and for whom this practice might be stigmatizing. In the United States, negative sexual stereotypes about sexual minority men intersect with negative sexual stereotypes for Black and Latinx individuals in the context of heterosexist and racial marginalization [38–40]. Thus, sexual minority men of colour may be more likely to experience risk-focused assessments as stereotyping, contributing to harmful healthcare experiences. On the other hand, behaviour-based risk screens may fail to identify cisgender heterosexual women as in need of HIV-related services, because they neglect

Table 1. Questions for assessing HIV service implementation strategies for stigma

Stigma components	Examples of HIV service implementation strategies that might activate stigma components[a]	Questions for analysing and assessing existing HIV service implementation strategies	Questions for elevating an intersectional approach to combatting HIV service implementation stigma	Questions for developing and testing new HIV service implementation strategies
Labelling (i.e. classifying a particular condition or attribute as "different," and assigning a specific marker to communicate that difference in society)	Eligibility screens or protocols that label certain behaviours or people as "high-risk" Protocols that seek to identify certain clients as at risk for non-adherence Visual disclosure of client's HIV or medication status on charts or other paperwork Protocols that rely on provider discretion to offer HIV testing or other services	Does this strategy label certain behaviours or groups as relevant for HIV prevention and care and leave others out? Does it label those with HIV or those who need HIV prevention?	Do labelling practices within HIV prevention and care label certain groups more than others with respect to race, gender, sexuality, class, ability, immigration status and/or other intersecting dimensions of power and oppression?	Does this strategy decrease the need or opportunity to label clients in ways that may activate or reinforce stereotypes?
Stereotyping (i.e. linking labelled conditions or attributes to negative or undesirable characteristics)	Outreach efforts that "target" certain individuals or communities	Does this strategy reinforce stereotypes about who gets HIV or who is at risk for HIV? Does it rely on stereotypes about which types of clients are more/less likely to adhere to treatment or return for visits?	Does this programme, practice or policy reinforce stereotypes about people living with HIV or clients at risk for HIV at intersections of race, gender, sexuality, class, ability, immigration status and/or other intersecting dimensions of power and oppression?	Does this strategy reduce provider reliance on stereotypes to identify clients or make decisions about their care?
Separation (i.e. physical, linguistic or other segregation of labelled individuals from the rest of society)	Segregation of clinics, days/times, entrances or procedures for HIV treatment or prevention services Protocols that offer HIV-related services only to certain clients Failure to integrate HIV services into existing care (e.g. primary care or OBGYN) Creation of separate programmes for HIV prevention and care needs related to sexual health versus substance use	Does this strategy separate HIV services from other types of care? Does it separate people living with HIV or those with HIV prevention needs from other clients?	Do these separations create or reinforce segregation on the basis of race, gender, sexuality, class, ability, immigration status and/or other intersecting dimensions of power and oppression?	Does this strategy allow for greater integration of HIV services into mainstream or "normalized" care provision? If HIV-related services remain segregated, does the value of this segregation outweigh the potential cost? Have efforts been made to ensure that this separation is as de-stigmatizing as possible?

(*Continued*)

Table 1. Continued

Stigma components	Examples of HIV service implementation strategies that might activate stigma components[a]	Questions for analysing and assessing existing HIV service implementation strategies	Questions for elevating an intersectional approach to combatting HIV service implementation stigma	Questions for developing and testing new HIV service implementation strategies
Status loss (i.e. devalued placement in a social hierarchy that confers disadvantage)	Absence of policies against abuse or harassment of people living with HIV or clients seeking prevention Absence of policies that protect clients from disclosure of health information Absence of policies that promote gender-affirmation (e.g. name/pronoun checks and gender-neutral bathrooms)	Does this strategy place an undue burden on people living with HIV or other HIV service clients compared to others? Does it dehumanize or otherwise devalue certain clients?	Does this strategy reinforce existing patterns of inequity on the basis of race, gender, sexuality, class, ability, immigration status and/or other intersecting dimensions of power and oppression?	Does this strategy rectify or address existing barriers to care that have historically marginalized certain clients or populations?
Discrimination (i.e. explicit or implicit devaluation, rejection, exclusion or mistreatment)	Protocols that place logistical or financial burdens on patients to receive prescriptions Appointment times and visit structures that favour clients with flexible schedules and time/money for multiple visits Failure to provide adequate translation services	Does this strategy favour certain groups of clients over others?	Even if applied equally to all clients, are the outcomes of this strategy equitable on the basis of race, gender, sexuality, class, ability, immigration status and/or other intersecting dimensions of power and oppression?	Does this strategy proactively sanction discriminatory behaviour among providers and incentivize supporting and valuing clients?

[a] Examples may apply to multiple domains of stigma simultaneously.

structural, community and network factors that affect HIV acquisition [36, 41]. Because Black women comprise a disproportional percentage of new HIV diagnoses in the United States [16, 42], practices that neglect women perpetuate disparities at the intersection of racism, sexism and homophobia. Screening practices that emphasize labelling and stereotyping of "high-risk" individuals can contribute to discrimination and status loss for individuals with negatively stereotyped identity intersections and neglected identity intersections.

The final column of Table 1 provides questions for evaluating the extent to which new strategies mitigate against stigma to reduce health inequities. For example, as we develop strategies for increasing intervention uptake, it is important to consider the extent to which promulgation of stereotypes related to who "needs" HIV prevention and care may motivate individuals to underestimate their own need for these services to distance themselves from such stereotypes. Clients' risk perception is often unrelated to provider assessment of "objective" risk using screening tools, but is strongly negatively associated with perceived stigma [43, 44]. The stigmatizing nature of this method of screening may discourage clients from disclosing their relevant behaviours and identities to avoid being labelled or stereotyped and potentially discriminated against. While this has not specifically been tested, there is evidence that stigma can affect identity disclosure, which can impact HIV service provision [45]. Independent of behavioural eligibility, HIV stigma has been negatively associated with both testing behaviour and willingness to consider PrEP [27, 46, 47]. Questioning the extent to which an implementation strategy does or does not label clients or increase stereotyping may help create new stigma-mitigating strategies and promote increased access, uptake and sustainment of HIV services.

Another common HIV service implementation practice that may be unintentionally perpetuating stigma is the separation of HIV services from other service provision, including primary care, Obstetrics/Gynecology care or even sexually transmitted infection testing and treatment [21, 22]. There are several rationales for developing HIV-specific care programmes—protection of people living with HIV from HIV stigma in mainstream care settings, increasing community among clients living with HIV or ensuring that all providers in a care setting are experts in HIV care. However, the definition of separation as a core component of stigma requires us to consider the potential stigmatizing impacts of this implementation strategy. Applying Link and Phelan's framework [14], the continued *separation* of HIV services from other forms of healthcare *labels* HIV as fundamentally "different" from other healthcare needs and reinforces *stereotypes* that those in need of HIV-related services are qualitatively distinct from other clients. It also has the potential to confer *status loss*, by requiring people living with HIV or those needing HIV prevention services to expend additional time, effort and resources to access both these services and other needed healthcare services.

Applying an intersectional lens, this separation fails to acknowledge clients' complex health experiences and the interaction between HIV and other medical conditions that disproportionately impact those who are most marginalized in a particular socio-political context [12, 48, 49]. The burden of seeking separated care may be especially harmful considering that those with less access to HIV prevention services and HIV education, such as those in rural communities and burdened by class oppression, are disproportionately likely to have comorbid healthcare needs and more adverse HIV outcomes [50–52].

Taking HIV stigma mitigation seriously in the development of new HIV service implementation strategies requires us to reconsider the utility of limiting HIV services to separate healthcare sites, certain times/days or specialized personnel. Several studies conducted in sub-Saharan Africa have demonstrated that the integration of HIV care into primary healthcare, sometimes called decentralization, can improve clients' satisfaction with HIV education, increase willingness to accept HIV services, increase HIV care enrolment and increase client HIV care sustainment over time [53–57]. Comparatively, decentralization of HIV service provision may enable clients to navigate care without being labelled by people in their community as having HIV, which could lessen the experiences of discrimination and give people more control over disclosure [58].Therefore, when stigma in the forms of labelling, segregation and discrimination is reduced at the HIV services implementation level, it may in turn reduce labelling, segregation and discrimination at the interpersonal and community level for people living with HIV.

A third example of applying the five stigma components to analyse stigma in HIV service implementation is a consideration of the logistical barriers that clients must navigate in order to access care. While systems-level barriers are recognized as a critical issue, limited resources are devoted to changing clinic hours to increase accessibility, providing care in multiple languages or hiring client navigators who might help with transportation, childcare or other needs. Such systemic issues are often not considered explicitly stigma-related barriers to care, which is a missed opportunity for acknowledging the ways in which logistical barriers confer *status loss* for clients in need of care [59].

Relatedly, there had been increasing attention to the need for "immediate start" of anti-retroviral treatment or PrEP, in order to better support people recently diagnosed with HIV [59–63]. But in most settings, receipt of a prescription for HIV treatment or PrEP requires clients to attend multiple clinical visits, some of which are explicitly designed to assess whether they are likely to return for more clinical visits in the future [64]. Once clients are prescribed medication, refills may be restricted if they fail to return for testing and clinical visits at specific intervals [23, 65]. Additionally, there is often an emphasis on identifying clients who are likely to miss clinic visits and to consider placing additional restrictions on their access to medications [66]. Clients who are already marginalized on the basis of race, class or other experiences, such as substance use, are most likely to be labelled, stereotyped, denied services or blamed for their "failure" to sustain care, which can reinforce negative racial and class-based stereotypes [67–69].

Reframing implementation strategies that reduce logistical burdens and gatekeeping as stigma-reduction interventions may be particularly motivating for research and practice. For example, there is widespread recognition that frequent appointment requirements for HIV care and quarterly refill requirements for PrEP are extremely burdensome for clients [59, 70–72], but there has been little empirical assessment of whether allowing longer intervals between appointments and prescription refills would have any impacts on safety, efficacy or clinical outcomes. Reconsidering clinical protocols through the lens of stigma reducing, client-centred care may focus attention on innovative strategies that reduce medical gate-keeping and communicate to clients that facilitating their access to HIV prevention and care is valued. Importantly, the pathway to designing affirming, inclusive and stigma-reducing care necessitates listening to and centring the voices of those most affected by intersectional HIV stigma and committing to transforming the healthcare systems we have now to the healthcare systems marginalized people need. Further, these processes for evaluating and developing destigmatizing healthcare services are not only relevant for HIV prevention and care, but for all types of healthcare services, especially those designed for stigmatized health conditions.

3 | CONCLUSIONS

This commentary is intended to be a theory-informed call to action for the assessment of HIV service implementation, for the development of new stigma-reducing implementation strategies and for the explicit inclusion of stigma reduction as a core outcome in implementation research. We encourage researchers and practitioners to consider the insidious (and often unintentional) activation of stigma components in specific protocols, policies, programmes and service organization. We also encourage the application of intersectionality as a theoretical and methodological framework for greater understanding of the impact of HIV services implementation on the lives of people living with HIV and those in need of prevention in the context of intersecting systems of power and oppression. Using the questions in Table 1, we can begin to identify the ways that services implementation perpetuates stigma for those disproportionately burdened by the HIV epidemic and develop new strategies that transform healthcare systems in service of health equity.

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