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# Systemic inequities, dignity, and trust in the context of HIV care: a qualitative analysis

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## Abstract

Adherence and retention in care are key targets to achieve favorable health outcomes for people with HIV. Challenges with adherence and retention are pronounced for marginalized communities facing intersectional structural oppression. Community health worker delivery of Managed Problem Solving (MAPS+), an evidence-based behavioral intervention, has the potential to improve adherence and retention, yet understanding structural inequities affecting people with HIV is necessary to increase the likelihood of equitable implementation. The current study explores systemic inequities influencing HIV care adherence and retention, and approaches to address these challenges. We conducted semi-structured interviews with 13 clinics and 4 constituent groups: prescribing clinicians, non-prescribing clinical team members (e.g., medical case managers), clinic administrators, and policymakers. Through reflexive thematic analysis within a constructionist paradigm, we identified two key themes. The first elucidated experiences of systemic inequities such as access to resources, healthcare system navigation difficulties, power differentials, medical mistrust, intersectional stigma and potential patient burden associated with MAPS+. The second theme highlighted the ways in which staff and clinicians shoulder the burden of addressing inequities by approaching people with HIV with dignity and developing trusting relationships and how MAPS+ can bolster this approach by partnering with and centering patient needs. While these individual and organizational efforts are valuable, ending the HIV epidemic requires structural changes to address systemic inequities directly. This research underscores the complex interplay between structural oppression and HIV care, calling for comprehensive approaches to achieve health equity.

**Keywords** Implementation science, HIV care, Retention and adherence, Health equity

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The U.S. Department of Health and Human Services launched the Ending the HIV Epidemic (EHE) initiative in 2019 with the goal of reducing new HIV (Human Immunodeficiency Virus) diagnoses by 90% by 2030 [1]. Adherence to treatment and retention in care are essential for achieving viral suppression and reducing new diagnoses. Challenges with reaching viral suppression related to adherence and retention in care are particularly pronounced among individuals from marginalized and minoritized populations who experience inequities across the care continuum including linkage to care, treatment adherence, retention in care, and viral suppression [2, 3].

Forces of historical and ongoing structural oppression (e.g., racism, sexism, homophobia, transphobia, poverty, ableism) lead to downstream systemic inequities that inhibit successful treatment adherence and retention. Structural oppression operates through institutional (e.g., education, health care system, justice system, housing) and societal norms leading to inequities in the HIV care continuum [4, 5]. Importantly, many individuals with multiple minoritized identities experience intersectional structural oppression, that is the compounding effects of multiple intersecting systems of oppression [4, 6, 7, 8]. Indeed, within Black and Latine communities, LGBTQ+ (Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, and additional identities) identifying men and Black women within the US are disproportionately affected by inequities that impact HIV care [9]. For example, research has demonstrated how systemic inequities such as disproportionate incarceration, stigma related to social identity and neighborhood deprivation have been associated with decreased HIV testing, greater HIV risk, lower treatment utilization, and decreased viral suppression in Black LGBTQ+ identifying men [10, 11]. In addition, studies focused on Black women with HIV have found that experiences of discrimination, medical mistrust, community violence, and poor access to social services, transportation, and childcare are barriers to receiving and engaging in preventative HIV care [12, 13].

To address inequities in HIV care and to prevent new infections, researchers have focused on developing and testing interventions that optimize the benefits of care for PWH. Evidence-based treatments delivered in community-based settings have the potential to both address broader EHE goals and reduce inequities experienced by individuals with marginalized and minoritized identities, if they are designed to do so. One such example is Managed Problem Solving (MAPS) an evidence-based intervention to increase medication adherence and viral suppression in PWH. MAPS uses a collaborative problem-solving approach [14] to partner with the patient and support them in skill-building and identifying solutions for their individual needs, and empowering people to manage their own health. Efficacy research has

demonstrated that MAPS significantly increased medication adherence and viral suppression one year following intervention [15], and there is potential that MAPS can also be deployed, if adapted appropriately, to address care retention.

Harnessing the power of community health workers (CHWs) to deliver evidence-based interventions, such as MAPS, may increase feasibility of implementation and cultural responsiveness of the intervention itself, in addition to directly addressing structural factors. Specifically, CHW supported interventions have resulted in positive impacts on treatment adherence and subsequently viral load suppression in PWH within marginalized populations [15, 16, 17]. CHWs are often members of the communities where they work, selected by those communities, and work parallel to the health system [17]. These characteristics uniquely position CHWs both to understand the individual level experience of intersectional structural oppression and to help patients overcome structural barriers to care retention and treatment adherence through problem solving and advocacy. Supporting CHWs, who bridge gaps in communication between patients, communities, and the healthcare system, to deliver MAPS could be an effective approach for patients disproportionately impacted by health inequities [16].

In preparation for a hybrid type 2 effectiveness implementation trial, our team aimed to understand how to support CHW delivery of MAPS+ (an adapted version of MAPS that also focuses on care retention) by understanding determinants of implementation. Initial findings from our rapid qualitative analysis indicated key determinants of MAPS+ implementation across the implementation continuum from introducing MAPS+ to clinics (e.g., leadership and staff buy-in) to coordinating care between the CHW and the clinical team (e.g., clear communication of patient needs) [19]. Across the implementation continuum our results highlighted the importance of factors within the sociopolitical context (e.g., poverty, structural racism, structural stigma, norms of respect and dignity in HIV care).

To end the HIV epidemic, supporting treatment adherence and care retention within the larger context of structural oppression must be prioritized. Existing research has examined the systemic inequities faced by PWH that impact retention in care and treatment adherence especially for individuals who hold intersecting minoritized identities, such as socioeconomic stressors, stigma, discrimination, mistrust [3, 4, 7, 19, 20–22]. However, there remains a gap in understanding how these inequities manifest and how they are addressed across various systems and levels of care to reduce disparities in adherence and retention [20]. Our current study addresses this gap by centering the voices of a range of constituents

within the healthcare system to examine how intersectional structural oppression manifests across levels of context (e.g., within clinic policies, client experiences, the relationship between the client and clinicians). Additionally, we explore the ways in which individuals and systems navigate and mitigate these inequities and how they may interact with interventions, such as MAPS+, that are aimed at supporting adherence and retention. These results can inform the development of implementation strategies to improve the effectiveness of evidence-based intervention in communities facing structural inequities and highlight the ways in which interventions can mitigate disparities in adherence and retention in HIV care.

## Methods

### Study setting

The study took place in Philadelphia County, one of 48 counties in the United States prioritized through the EHE given high rates of new HIV diagnoses and low care retention [21].

We partnered with 13 Ryan White outpatient/ambulatory health service sites (O/AHS) funded through the Philadelphia Department of Public Health (PDPH) serving PWH in the eligible metropolitan area. Ryan White-funded clinics provide low-income individuals who are uninsured or underinsured with access to medical care. In addition, nearly 75% of patients served by Ryan White-funded O/AHS are from racial and ethnic minoritized backgrounds [22]. Each of the 13 O/AHS serve patient populations with a high prevalence of HIV.

### Participants

We recruited constituents to participate in pre-implementation interviews using purposive sampling across the Ryan White-funded clinics [24]. Constituent groups were collaboratively chosen in consultation with PDPH leadership and the study team and included prescribing clinicians, non-prescribing clinical team members (i.e., behavioral health consultants, medical case managers, outreach coordinators), clinic administrators, and policymakers from the Philadelphia Department of Public Health. We identified a sample size of approximately 30 participants with the expectation of achieving meaning saturation for a “richly textured understanding of issues” across constituent groups [25]. Participants were required to speak English fluently for interview participation.

### Procedures

We conducted semi-structured interviews from January 2021 to May 2021 to gather constituent perceptions of possible barriers and facilitators to equitable implementation of MAPS+ and adherence and retention more broadly (See Appendix A). Guided by the updated

Consolidated Framework for Implementation Research (CFIR), an implementation determinant framework, our interview guide queried around the following key domains: (1) innovation (i.e., MAPS characteristics); (2) outer setting (i.e., the economic, political, and social context within which an organization exists); (3) inner setting (i.e., the organizations in which MAPS+ will be implemented); and (4) characteristics of the individuals (i.e., patients, CHWs, clinicians, and other staff involved in implementation). We tailored the guides to each constituent group (See Appendix A for an example interview guide for prescribing clinicians).

Two research team members including the lead author piloted the interview guides and subsequent initial interviews. Two additional team members underwent comprehensive training to conduct the remaining interviews, in which they observed 2–4 interviews conducted by AS and then conducted at least one interview under observation to ensure quality. Interviews were conducted remotely (i.e., via Zoom secure or telephone) due to COVID-19 pandemic mitigation measures, audio-recorded, and lasted approximately one hour. No interviews ended prematurely. No participants engaged in follow-up interviews. All participants provided verbal informed consent and were compensated with a \$50 electronic gift card. The Institutional Review Boards of the University of Pennsylvania and City of Philadelphia approved this study. We adhered to Standards for Reporting Qualitative Research to ensure transparency and rigor in our reporting [26].

### Qualitative data analysis

Interviews were transcribed verbatim and imported into NVivo software for data management and analysis [27]. We sought to move beyond the initial identification of barriers and facilitators to MAPS+ implementation described in the primary research study [19] to more deeply understand the structures that influence adherence and retention for PWH to inform the equitable implementation of MAPS+. We conducted reflexive thematic analysis within a constructionist paradigm [28, 29]. We used both an inductive and deductive approach to analysis. Our team began by immersion in the transcripts to gain familiarity with the dataset. We then open coded eight transcripts to inductively identify key emergent constructs. Intersectionality theory [30, 31] and the CFIR provided theoretical scaffolding. Incorporating intersectionality allowed us to examine how systems and structures of power shape the context in which interventions are implemented. Use of the CFIR with attention to a priori attributes of interest (e.g., Outer Setting, Characteristics of the Intervention, Characteristics of the Individuals Involved) allowed us to clearly visualize the ways in which inequities manifest across levels of

context. In particular, CFIR’s description of Outer Setting determinants was enriched by intersectionality theory to describe how these determinants operate and generate downstream sequelae for PWH. Integration of inductive and deductive approaches allowed us to center participant-based meanings, while also organizing our themes within the CFIR [28]. While there are some limitations to using a combination of inductive and deductive approaches, such as difficulty merging inductive themes within a deductive framework, we found the CFIR provided useful structure.

We developed a codebook with both inductively and deductively derived codes, which functioned as interpretative labels. We then double-coded 5 transcripts to ensure conceptual concordance and made iterative codebook revisions. The team kept analytic memos as we coded to maintain awareness of our positionality and theoretical framework. These memos, which also provided an audit trail to enhance rigor, were utilized during weekly discussions about the relationships between codes and began identifying potential themes. After all of the relevant data were coded, we searched for themes to address the research question, identifying salient patterns and their relationships both within and across the codes. We then generated candidate themes, further refined these themes with team discussion and review of data extracts, and finalized both themes and subthemes [29].

The research team was comprised of physician scientists and researchers with expertise in implementation science, health equity, and HIV care. The lead author and coder of the qualitative data identifies as a Latina, cis-gender clinical psychologist with expertise in

community-engaged research and culturally responsive care and lived and professional experience with minoritized communities. The second author (CM) and coder identifies as a Black American, cis-gender scientist-practitioner in training, with lived and professional experience with marginalized communities. The third author (DC) and coder identifies as a Black American, cisgender woman and a clinical research scientist, with professional experience in studying environmental and social determinants of health. The three authors (AS, CM, DC) who conducted qualitative analyses engaged in ongoing self-reflection of our own positionality and biases via reflexive memos and group debriefing.

Results

Participant demographics

We enrolled a total of 31 constituents from four different groups (prescribing clinicians ( $n=6$ )), non-prescribing clinical team members (i.e., behavioral health consultants, medical case managers, outreach coordinators) ( $n=14$ ), clinic administrators ( $n=7$ ), and policymakers ( $n=4$ ). The non-prescribing clinical team members (i.e., behavioral health consultants, medical case managers, and outreach coordinators) were the most represented group (45%). The majority of the constituents (81%) identified as female and approximately half identified as non-Latine White, 30% as Black, and 20% as Latine. See Table 1 for additional identity and role related background information.

Our analysis generated two key themes. Our first theme, *Structures That Discriminate Create Systemic Inequities in HIV Care*, reflects the observable manifestations of structural oppression enacted across patients, staff, and clinics. Our second theme, *Dignity and Trust Serve To Ameliorate Systemic Inequities*, reflects the ways in which the constituents attempt to ameliorate inequities caused by structural oppression. We identified subthemes that will be described across CFIR domains: (See Table 2 for themes, subthemes, and illustrative quotes). They will be discussed in reference to adherence and retention in general and specifically to the theoretical MAPS+ implementation. Importantly, interactions between individuals (despite being indicated as potential determinants of equitable implementation) are not captured by the CFIR framework, however we have added the domain ‘clinical encounter’ to capture this construct [32]. See Fig. 1 for a visual of our themes and subthemes.

Theme 1: structures that discriminate create systemic inequities in HIV care

Constituents across groups identified systemic inequities as being the main drivers of poor adherence and care retention for PWH. Specifically, constituents commonly described aspects of intersectional structural oppression

Table 1 Constituent characteristics (N=31)

	n (%)
Constituent Group	
Prescribing clinicians	6 (19.3)
Non-prescribing clinical team members	14 (45.2)
Clinical administrators	7 (22.6)
Policymakers	4 (12.9)
Gender Identity	
Female	25 (80.7)
Male	6 (19.3)
Racial/Ethnic Identity	
Black/African American	9 (29.0)
Hispanic/Latine	4 (12.9)
White Hispanic/Latine	2 (6.5)
White non-Hispanic/Latine	15 (48.4)
Prefer not to disclose	1 (3.2)
	M (SD)
Age	44.9 (11.8)
Years in field	11.5 (8.3)

\*\*Other clinical team members” included team members who do not prescribe medications (i.e., behavioral health consultants, medical case managers, and outreach coordinators)

including racism, poverty, and homophobia as leading to inequities that affect the patients they serve. For example, one of the policy maker participants explained that “structures are designed and put in place to discriminate against People of Color” (Policy Maker, 1) and cause them to be disproportionately impacted by barriers to adherence and retention (e.g., living in under resourced neighborhoods, poverty, stigma).

The experience of systemic inequities that we observed in our data are characterized by six subthemes or manifestations of systemic inequities across multiple CFIR domains: (1) lack of access to resources and basic needs, (2) challenges navigating the healthcare system, (3) power differential within the medical setting, (4) medical mistrust, (5) intersectional stigma, and (6) undue patient burden. These manifestations of systemic inequities occur across levels of the CFIR. While all subthemes have the potential to influence MAPS+ implementation, any potential disadvantaged to MAPS were discussed within the context of patient burden, so a subtheme specific to MAPS+ will be presented.

#### **Outer setting: lack of access to resources and basic needs**

Constituents frequently highlighted concerns surrounding their patient’s lack of access to resources and basic needs, such as safety, food, stable housing, mental health care, internet, phones, and transportation which interferes with their ability to access and adhere to care: “All of the same lower wages, access to a safe school and a safe environment for themselves and for... their children prevents them from having the time and the money and the phone and the focus to get into appointments.” (Outreach Coordinator, 1) Constituents often shared that their unhoused patients experienced the most barriers to retention given difficulties with staying connected to care (i.e., lack of consistent phone numbers and addresses, lack of access to a computer or phone to access their chart).

Several constituents described the disproportionate impact of community violence on their patients, and the subsequent impact on care engagement: “In communities that are having a lot of violence and people are getting shot right outside our [patient]’s home, they may not want to come out of their house...they might not feel safe traveling.” (Behavioral Health Consultant, 1) Further, constituents described this disproportionate exposure to traumatic events (e.g., community violence, discrimination) and lack of access to timely and quality mental health supports as leading to unmet mental health needs for their patients.

Constituents shared that marginalization based on multiple aspects of patient’s identities compound to more severely affect adherence and retention: “We had to respond and name some of the ways...our Black-trans

women [patients] experience... health care, so it can’t just be, ‘They don’t come in because they don’t prioritize their healthcare’...They’re the larger portion of our [patient] that tend to be homeless, and to experience co-occurring issues, and tend to experience violence...—at the hand of the state.” (Clinical Administrator, 1).

Throughout the interviews, constituents emphasized that challenges with adherence to care were not due to patient’s lack of prioritizing their HIV care but rather a byproduct of systemic inequities that they encounter which require them to prioritize basic health and safety needs before engaging in and adhering to their HIV care: “If you’re struggling with... poverty... you’re gonna have more barriers because you have to jump through hoops to get resources which takes time and... physical and mental effort.” (Medical Case Manager, 1).

#### **Outer setting: challenges navigating the healthcare system**

The second subtheme surrounded inequities associated with navigating the healthcare system and included topics such as complexity of healthcare coverage, and inequities in health insurance coverage and health literacy increasing the navigation burdens.

Constituents discussed how navigating the healthcare system can be difficult and cumbersome for anyone, “navigating healthcare system... requires... a lot of organization skills,...I don’t think most people have organizational skills to navigate that well.” (Outreach Coordinator, 1) This complexity is exacerbated for PWH with multiple stressors and especially those who are uninsured or underinsured. One of the challenges described was the complexity of health insurance coverage and knowing what is and is not covered: “I think sometimes with insurance – that can be a difficult thing for our population to navigate... Either getting their medications or coming into the clinic cause they feel like – here we accept anybody regardless of insurance, but for specialist appointments that’s hard to navigate as well. If they don’t have that insurance cause it’s an out-of-pocket cost that they just don’t have right now.” (Medical Case Manager, 2)

Several constituents also noted added burden of navigating the healthcare system for many of their patients who have limited health literacy due to inequities in the education system: “If someone has a higher education, they maybe have better access or language around their healthcare than some of our [patients] do with less formal education.” (Clinical Administrator, 1) In sum, systemic inequities (e.g., lack of access to health insurance, limited health literacy) make an already complicated healthcare system even more challenging to navigate.

#### **Inner setting: power differentials within the medical setting**

Throughout our interviews, constituents shared how power differentials at multiple levels affect the quality of

**Table 2** Key quotes by theme and subtheme

<b>Structures That Discriminate Create Systemic Inequities in HIV Care</b>	
<b>"Structures are designed and put in place to discriminate against People of Color" (POLICY MAKER, 1),</b>	
Outer Setting: Lack of Access to Resources and Basic Needs	<p>"All of the same lower wages, access to a safe school and a safe environment for themselves and for... their children prevent them from having the time and the money and the phone and the focus to get into appointments." (Outreach Coordinator, 1)</p> <p>"In communities that are having a lot of violence and people are getting shot right outside our [patients]' home, they may not want to come out of their house... they might not feel safe traveling." (Behavioral Health Consultant, 1)</p> <p>"We had to respond and name some of the ways... our Black-trans women [patients] experience... health care, so it can't just be, 'They don't come in because they don't prioritize their healthcare... They're the larger portion of our [patient] that tend to be homeless, and to experience co-occurring issues, and tend to experience violence... —at the hand of the state.' (Clinical Administrator, 1)</p> <p>"If you're struggling with... poverty... you're gonna have more barriers because you have to jump through hoops to get resources which takes time and... physical and mental effort." (Medical Case Manager, 1)</p> <p>"We have people who are disconnected from care, sometimes those are folks who also have housing issues. And again, it's hard to have compliance whether it's taking meds or coming to appointments when the basic needs sometimes aren't met." (Behavioral Health Consultant, 1)</p> <p>"As far as retention, I would say our homeless population, because they tend to have, you know, phone numbers that are changing, no access to electronics to be able to access the MyChart, and maybe they'd save my phone number in their phone but then they lose service maybe have to get a new phone, like a burner phone, and transfer everything over. So, I think that's a big piece, big population is homeless or unstable housing." (Prescribing Clinician, 3)</p> <p>"And then of course, there's just the usual things that come up in life. Navigating healthcare system. That requires, I think, if you don't have any other problems, a lot of organization skills, lists, and calling back, and getting through the phone read, and leaving a message, and getting, calling the pharmacy- the pharmacy- the pharmacy card, the appointment card. I don't think most people have organizational skills to navigate that well. Appointments, if they have other problems. And have a difficult- life threatening diagnosis." (Outreach Coordinator, 1)</p> <p>"I think sometimes with insurance – that can be a difficult thing for our population to navigate... Either getting their medications or coming into the clinic cause they feel like – here we accept anybody regardless of insurance, but for specialist appointments that's hard to navigate as well. If they don't have that insurance cause it's an out-of-pocket cost that they just don't have right now." (Medical Case Manager, 2)</p> <p>"And also the disparities in the education system. If someone has a higher education, they maybe have better access or language around their healthcare than some of our [patients] do with less formal education." (Clinical Administrator, 1)</p>
Outer Setting: Challenges Navigating the Healthcare System	<p>"[patients] see case managers and medical providers... there's a power dynamic... they can withhold services and things like that a patient may need or want" (Clinical Administrator, 2)</p> <p>"In terms of medical providers, specifically physicians... there's often a hierarchy, pecking order... And a lot of it has to be with biases, the fact that 'I'm the doctor, I know best.' (Policy Maker, 1)</p> <p>"I think that there are sort of something built into the structures that we have established in terms of... the hierarchies within the medical communities that can make it appear to the patients as though the hierarchy of white [people] being the top and People of Color providing roles as medical assistants as nurses... And to them it appears like just another institution run by white people for white people." (Behavioral Health Consultant, 2)</p> <p>"In terms of medical providers, specifically physicians, I'll be honest, there's often a hierarchy, pecking order... And, I think that could potentially impair the ability of that person to be considered a trusted member of the team. And a lot of it has to be with biases, the fact that 'I'm the doctor, I know best.'" (Policy Maker, 1)</p> <p>"We don't really have that many providers of color on staff. And we don't... have many providers who identify as LGBTQIA... it creates this lack of cultural understanding for our [patients]... there's levels for things to be miscommunicated or also just unaddressed, because they're not bringing it up, because they may not feel like it's a safe space... there's a lack of trust there some level of insecurity or fear or shame." (Clinical Administrator, 3)</p> <p>"The clinic has... not been invested in, either like some of the suburban clinics have been invested in, where you have a higher commercial payer... it makes it hard to kind of get people in and out in an appropriate way. I would not go there for care." (Behavioral Health Consultant, 1)</p>
Inner Setting: Power Differential within the Medical Setting	



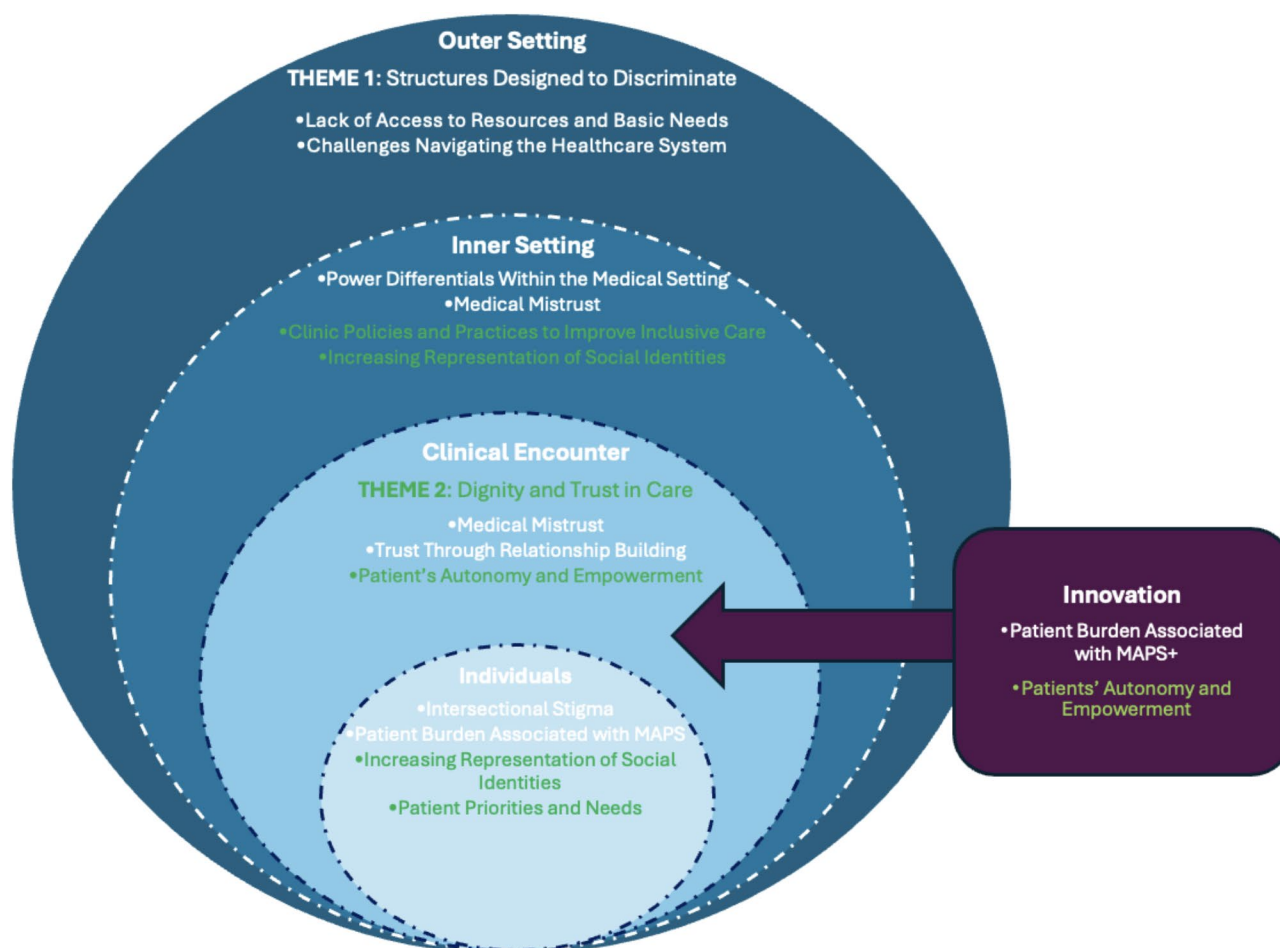
Table 2 (continued)

Structures That Discriminate Create Systemic Inequities in HIV Care “Structures are designed and put in place to discriminate against People of Color” (POLICY MAKER, 1).	
Inner Setting and Clinical Encounter:	“It’s implicit bias, if you gave them the same story, but one person was Black and one person was White, the outcome in terms of prescribing ART and the support that they’re going to be given and the messages are going to be different.” (Outreach Coordinator, 2)
Medical Mistrust	“I have had any number of conversations with patients over the years around, they believe that there is already a cure for HIV but the pharmaceutical companies are making so much money off of the drugs that they certainly don’t want to share that and that they are well aware that African-Americans are more impacted by HIV and so on so forth” (Behavioral Health Consultant, 2)
	“The trust is an issue, right? I think institutions, whether it’s our institution or others, with the institutional racism, we represent the institutional oppression. That’s not to say that we are the oppressor, but we represent that” (Behavioral Health Consultant, 3)
	“If they can’t see or relate themselves with the staff, they might think that’s another place that’s not going to be looking after my needs or is not going to be able to relate. . . . Because there would be that fear of are they going to be able to provide the service I need? Are they going to be discriminating against me or not?” (Outreach Coordinator, 2)
	“There are some patients who are untrusting. And they do feel that maybe there’s things that they could be . . . medicines that aren’t available just because of their color. I try, and we all try, to let them know that this is all there is out there. We don’t have a cure. Some patients feel there is a cure, you’re just not giving it. And we do our best to really encourage that they don’t feel that way. But it doesn’t always work.” (Prescribing Clinician, 1)
	“I have had any number of conversations with patients over the years around, they believe that there is already a cure for HIV but the pharmaceutical companies are making so much money off of the drugs that they certainly don’t want to share that and that they are well aware that African-Americans are more impacted by HIV and so on so forth” (Behavioral Health Consultant, 2).
Patient Characteristics: Intersectional Stigma	“Yeah, like I said, I think there’s an understandable mistrust of medical providers, especially like new treatments like “hey are they going to experiment on me?” (Medical Case Manager, 1) “I think in an urban environment, black communities, shame and stigma is very big. Countless times, patients will say that their family members, when they find out, are still taking away the dishes and making them use paper plates.” (Behavioral Health Consultant, 3) “I think shame and stigma for a young gay person who is still struggling and has some trauma about coming out to their family members and accepting their orientation. . . . there’s a whole different shame and stigma associated with that.” (Behavioral Health Consultant, 3) “It’s not that they forget their pills every day, it’s that the reminders of the pills spring up the trauma of their HIV diagnoses and ongoing, sort of, residual trauma and issues that have not been addressed from a mental health perspective.” (Prescribing Clinician, 2)
Patient Characteristics and Innovation Characteristics:	“MAPS is . . . geared towards the individual. . . . in terms of what barriers people are expressing. Are they systemic versus individual? . . . . We know the biggest concerns for clients, it’s not enough housing, people can’t afford to live in the places they do now.” (Policy Maker, 2)
Patient Burden	
Dignity And Trust Serve to Ameliorate Systemic Inequities	
“They need to be able to capture the client’s attention and trust within a very short amount of time. . . . And just be able to make those relationships. . . it’s half of the intervention.” (Clinical Administrator, 2)	
Inner Setting: Clinic	“I think the providers and the staff in our practice are aware that structural racism is an issue, implicit bias is an issue. They think of it in terms of race, and gender, and sexuality. I think that there is a lot of efforts for education at our practice and conversation around it. Some of the providers that I work most closely with and serve the patients the most, are very responsive to that and I would trust them with patients. . . that have trauma around their differences and how people have treated them because of that.” (Medical Case Manager, 2)
Policies and Provider Education To Improve Inclusive Care	“We also remind ourselves frequently . . . of the climate and the environment and how our patients might be impacted. . . even though it’s not in my backyard. And make sure that we’re reaching out to our patients that might be really impacted by those issues.” (Behavioral Health Consultant, 3)
	“We use pronouns for everybody. in our EPIC system once we have the information. . . the preferred name, comes up first. So that everybody knows to call the patient by their preferred name.” (Clinical Administrator, 2)

**Table 2** (continued)

<b>Structures That Discriminate Create Systemic Inequities in HIV Care</b> <b>"Structures are designed and put in place to discriminate against People of Color" (POLICY MAKER, 1).</b>	
Inner Setting and CHW Characteristics: Increasing Representation Of Social Identities	<p>"I appreciate they hired staff who were of color and that were bilingual.... I think that that's helpful, just so that the communities that we serve in our area, you know, you can go to a doctor that looks like you, grew up where you grew up, can culturally identify... I think that makes a difference with our communities." (Outreach Coordinator, 3)</p> <p>"I think if you have folks from the communities that we serve, all the better... Especially I think folks who deal with multiple levels of being marginalized.... you're probably more likely to gain some trust right from the time you walk in the door." (Medical Case Manager, 1)</p> <p>"You don't want another White social worker or person coming to tell this Black person, [or] this poor person.... that's something that they really have no idea what they're talking about. They've never been to this place, they haven't been down the street. It's not the type of sex that they have... our social workers and doctors are just giving advice that they read out of the book, where the CHW has lived experience and connectivity that they'll bring." (Clinical Administrator, 2)</p> <p>"Occasionally you run into the issue... if this person looks like someone from my neighborhood I don't want them to know. I think that's pretty rare I think more you will get increase in trust and increase in engagement because they can connect and they sort of provide a bridge for the trust." (Behavioral Health Consultant, 2)</p> <p>"One of the unique things is it really looks at a person holistically, understanding that it's not just about viral medical interventions, but you have to really look at these social determinants.... we have to try to mitigate some of that." (Policy Maker, 1)</p> <p>"I feel like we do a really good job just providing not just medical care but any type of care that the patient might need, such as case management help with insurance issues, problems with food insecurity, home insecurity, transportation helping us make policy decisions... whether it's somebody in our CQI meeting, for continuous quality improvement, making sure we have patient representation and patient representation in our safety and security discussions or just in general." (Behavioral Health Consultant, 3)</p> <p>"Our top priorities are to make sure that all of our patients have access to medications, to treatment, and to any other things we can offer: housing, food, and emotional support, treatment for drug addiction. We try to have everything they can possibly need at their reach." (Prescribing Clinician, 4)</p> <p>"We're family. We're not a white coat there. And our patients love that... So they like that feeling of family. They feel connected and cared for and looked after." (Outreach Coordinator, 3)</p> <p>"When I start off and I'm in there talking to the patient... I said listen this is a judgement free zone..... Just overall- that's the big piece is that whole big judgmental piece, taking yourself out of it because it's not about you. It's about what the patient needs." (Clinical Administrator, 3)</p> <p>"I think just having someone for the patient to pair with, that they feel like is assigned to them makes them feel more comfortable, I think, and more kind of watched-over. I think just especially with the new diagnosis." (Prescribing Clinician, 3)</p> <p>"Another concern of ours is having a better working relationship with behavioral health providers and even having a better referral or linkage pathway to behavioral health providers to be able to mainly assist newly diagnosed patients understand their illness and have an appreciation for their ability to have a control over their illness. So they feel more empowered and more equipped to be able to take medications daily." (Clinical Administrator, 4)</p> <p>"We talked to them in a language they understand. We teach them about when you come into the room, if you don't see us wash our hands, you say something. We teach them what to be expected, so that they're a part of their care. So they have say so. So, we empower them to say something. If they're not comfortable, say something." (Prescribing Clinician, 4)</p> <p>"There's no rocket science here... adherence is really all about delving into a person's life and trying to understand and get them to be able to think about what are the actual things getting in the way of their adherence, and MAPS really puts the patients at the center of that and says, "I'm not gonna tell you what you should do, you need to tell me what might work.... You're the expert in the room." (Clinical Administrator, 5)</p>
Patient Characteristics: Patient Priorities and Needs	
Clinical Encounter: Trust Through Relationship Building	
Clinical Encounter and Innovation Characteristics: Patient's Autonomy and Empowerment	





**Fig. 1** Themes and subthemes across levels of adapted CFIR

care people receive and the likelihood that they remain in care. Constituents often described the power differential in context of the power that clinicians have to withhold care, racial hierarchies, power imbalance between clinicians and staff, and material power or the withholding of resources.

Constituent described several ways in which clinicians hold power over patients, including knowledge and treatment. Specifically, one constituent share that given their positions within the medical system, clinical staff hold power over patients: “[patients] see case managers and medical providers... there’s a power dynamic....they can withhold services and things like that a patient may need or want.” (CLINICAL ADMINISTRATOR, 2) These power differentials were also discussed as occurring between clinicians and non-clinician staff. Several constituents shared that there was a medical hierarchy or “pecking order” such that the clinicians with a doctorate degree held more power than other staff in regard to respect and decision making: “In terms of medical providers, specifically physicians....there’s often a hierarchy, pecking order...

And a lot of it has to be with biases, the fact that “I’m the doctor, I know best.” (Policy Maker, 1)

Importantly, power differentials were often explicitly discussed as being a result of structural oppression in the form of entrenched racism and classism within the medical setting: “I think that there are sort of something built into the structures that we have established in terms of... the hierarchies within the medical communities that can make it appear to the patients as though the hierarchy of White [people] being the top and People of Color providing roles as medical assistants as nurses... And to them it appears like just another institution run by White people for White people.” (Behavioral Health Consultant, 2). Many constituents discussed how the lack of representation of staff who share similar lived experiences with patients contributes to power dynamics in which patients may feel uncomfortable or misunderstood: “We don’t really have that many providers Of Color on staff. And we don’t... have many providers who identify as LGBTQIA.... it creates this lack of cultural understanding for our [patients]...there’s levels for things to be miscommunicated or also just unaddressed, because they’re

*not bringing it up, because they may not feel like it's a safe space... there's a lack of trust there some level of insecurity or fear or shame."* (Clinical Administrator, 3) This lack of cultural understanding may drive power dynamics in which certain types of knowledge (e.g., medical terminology) are more valued than others (e.g., lived experience).

Participants also described how systems wield power over organizations through provision of funds. They frequently reported barriers associated with underfunding, like staff shortages, which forces staff to have to take over multiple roles, and the lack of physical space, which contributes to already extensive wait times. This material power differentially impacted clinics that serve under- and uninsured PWH. *"The clinic has... not been invested in, either like some of the suburban clinics have been invested in, where you have a higher commercial payer... it makes it hard to kind of, get people in and out in an appropriate way. I would not go there for care."* (Behavioral Health Consultant, 1)

#### **Inner setting and clinical encounter: medical mistrust**

The fourth subtheme represents ideas shared by constituents that patients' knowledge and experiences of historical and current mistreatment by medical professionals contributes to their mistrust of the medical system and challenges with adherence and retention in HIV care. Constituents discussed topics such as clinician bias, mistrust of clinician recommendations, and clinicians as representatives of oppressive structures.

Several non-prescribing staff reported clinician biases as leading to differential treatment for People of Color, such as prescribing clinicians are more likely to prescribe effective treatment to White patients: *"It's implicit bias, if you gave them the same story, but one person was Black and one person was White, the outcome in terms of prescribing ART and the support that they're going to be given and the messages are going to be different."* (Outreach Coordinator, 2) Constituents discussed clinician bias broadly and as an issue specific to their workplaces.

Constituents frequently shared that patients, especially Patients of Color, tend to experience mistrust towards clinicians and healthcare institutions. Several went further to explain that this mistrust is driven by the historical medical mistreatment of People of Color and the subsequent fear, within their communities, that clinicians have and will continue to mismanage their medical treatment. One constituent shared that patients believe they are being experimented upon, and that a cure exists but is being withheld: *"I have had any number of conversations with patients over the years around, they believe that there is already a cure for HIV but the pharmaceutical companies are making so much money off of the drugs that they certainly don't want to share that and that they are well aware that African-Americans are more*

*impacted by HIV and so on so forth."* (Behavioral Health Consultant, 2)

Further, some constituents shared their interpretations of patients' perspectives, specifically the belief that staff and clinicians represent the institutions that have harmed their communities: *"The trust is an issue, right? I think institutions, whether it's our institution or others, with the institutional racism, we represent the institutional oppression. That's not to say that we are the oppressor, but we represent that"* (Behavioral Health Consultant, 3) Constituents shared that mistrust is often exacerbated when patients are treated by staff and clinicians who do not understand their lived experiences. Constituents, especially staff in non-clinical roles, frequently noted that their patients are misunderstood by medical clinicians: *"If they can't see or relate themselves with the staff, they might think that's another place that's not going to be looking after my needs or is not going to be able to relate... Because there would be that fear of are they going to be able to provide the service I need? Are they going to be discriminating against me or not?"* (Outreach Coordinator, 2)

#### **Patient characteristics: intersectional stigma**

The fifth subtheme is related to intersectional stigma, or the convergence of multiple stigmatized identities and their joint effects on health and wellbeing. While this subtheme is being presented within the patient factor domain, it is important to emphasize that societal factors lead to the downstream experiences of interpersonal and self-stigma. Constituents discussed how interpersonal and self-stigma related to an HIV diagnosis and other stigmatized and marginalized identities influences adherence and retention in care.

Constituents communicated that PWH may have other aspects of their identities that are stigmatized in addition to their illness (e.g., gender identity or sexual orientation, socioeconomic status) and that these intersecting marginalized identities contributed to patient experience of stigma such that interpersonal stigma is exacerbated. For example, one constituent shared that interpersonal stigma related to HIV diagnosis is particularly prevalent in the Black community: *"I think in an urban environment, Black communities, shame and stigma is very big. Countless times, patients will say that their family members, when they find out, are still taking away the dishes and making them use paper plates"* (Behavioral Health Consultant, 3) Another constituent noted how many of their patients were dealing with compounded shame and stigma associated with their LGBTQ+ identity on top of their HIV diagnosis: *"I think shame and stigma for a young gay person who is still struggling and has some trauma about coming out to their family members and accepting their orientation... there's a whole*

*different shame and stigma associated with that” (Behavioral Health Consultant, 3)* Constituents described how the interpersonal stigma related to marginalized identities contributes to self-stigma and shame in which their patients at time internalize interpersonal and societal messages and become ashamed of their identities. For example, one constituent noted that medication adherence was more related to the reminder of being diagnosed with HIV than remembering to take the pill: *“It’s not that they forget their pills every day, it’s that the reminders of the pills spring up the trauma of their HIV diagnoses and ongoing, sort of, residual trauma and issues that have not been addressed from a mental health perspective” (Prescribing Clinician, 2)*

#### **Patient characteristics and innovation characteristics: potential patient burden and MAPS+**

When discussing potential barriers to MAPS+, we identified two major challenges compounded by ongoing structural inequities: (1) patients being over-burdened by medical appointment and challenges navigating medical system, and (2) the limitations of MAPS+ being an individual versus a systems level intervention. These subthemes occur across Patient Characteristics (e.g., burden experienced by the patient) and the Innovation Characteristics (MAPS+ as an individual intervention).

Constituents noted that MAPS+ could feel burdensome to already overwhelmed patients if they feel like the intervention is just another medical appointment. Navigating the medical system and medical appointment is already extremely burdensome; as such, constituents were hesitant to add another responsibility to patients. Importantly, constituents noted that framing MAPS+ as an intervention for the patient themselves may add misplaced blame on the patient when the drivers of nonadherence are often systemic and structural in nature. For example, a policymaker shared their concerns about MAPS+ being an individual intervention that works one on one with patients, rather than a structural intervention that addresses the underlying systemic inequities experienced by PHW: *“MAPS is...geared towards the individual.... in terms of what barriers people are expressing. Are they systemic versus individual?... We know the biggest concerns for clients, it’s not enough housing, people can’t afford to live in the places they do now.” (Policy Maker, 2)*

#### **Theme 2: dignity and trust serve to ameliorate systemic inequities**

The second theme, *dignity and trust in care*, refers to the expressed values of treating patients with dignity and prioritizing relationship building to develop trust: *“They need to be able to capture the client’s attention*

*and trust within a very short amount of time....And just be able to make those relationships. it’s half of the intervention.” (Clinical Administrator, 2)* This approach to care was often connected with a desire to ameliorate the previously mentioned structural inequities. Subthemes include: (1) Clinic policies and practices to improve inclusive care, (2) Increasing representation of social identities or lived experiences, (3) Centering patient priorities and needs, (4) Building trust through relationships, and (5) Encouraging patient’s autonomy and empowerment. Content related to MAPS+ is presented throughout the subthemes, as MAPS+ was commonly discussed in relation to subthemes in the context of potentially addressing systemic inequities.

#### **Inner setting: clinic policies and practices to improve inclusive care**

The first subtheme represents constituents’ perspectives of the importance of clinic policies and practices surrounding inclusive care and clinician education to reduce barriers experienced by PWH. Specifically, some constituents noted the need for all staff to be educated about of structural oppression and cultural responsiveness: *“I think the providers and the staff in our practice are aware that structural racism is an issue, implicit bias is an issue. They think of it in terms of race, and gender, and sexuality. I think that there is a lot of efforts for education at our practice and conversation around it.” (Medical Case Manager, 2)*

In addition, constituents shared clinic practices that aid in helping clinicians and staff understand the experiences of their patients (e.g., self-reflections, naming current societal issues): *“We also remind ourselves frequently... of the climate and the environment and how our patients might be impacted...even though it’s not in my backyard. And make sure that we’re reaching out to our patients that might be really impacted by those issues.” (Behavioral Health Consultant, 3)*

Standard clinic practices that support inclusivity and cultural responsiveness in their clinic were highlighted by constituents. They referred to the need for these practices given the diversity of patients they serve (e.g., legal status, nationality, gender identity, sexuality). For example, one constituent shared that their clinic makes an intentional effort to help patients feel included by displaying culturally representative artwork, doing outreach, and celebrating holidays representative of different religious and cultural traditions. In addition, they explained how they ensure patients’ preferred pronouns and names are utilized: *“We use pronouns for everybody,... in our EPIC system once we have the information... the preferred name, comes up first. So that everybody knows to call the patient by their preferred name.” (Clinical Administrator, 2)*

### **Inner setting and CHW characteristics: increasing representation of social identities**

The second subtheme focuses on constituent perspectives related to the importance of having staff with the same social identities or lived experiences of their patients for improving the care experience, trust and shared understanding.

We heard participants describe the importance of organizations intentionally hiring individuals who share lived experiences with their patients to build more trust in the organization. Many constituents shared that it is important to have clinicians and staff who look like their patients: *"I appreciate they hired staff who were of color and that were bilingual....I think that that's helpful, just so that the communities that we serve in our area, you know, you can go to a doctor that looks like you, grew up where you grew up, can culturally identify... I think that makes a difference with our communities."* (Outreach Coordinator, 3)

More specifically, when discussing what characteristics would be important for the CHWs providing MAPS+, many constituents referenced the CHW sharing lived experiences with the patients being a mechanism for building trust which then contributes to adherence and retention: *"I think if you have folks from the communities that we serve, all the better... Especially I think folks who deal with multiple levels of being marginalized... you're probably more likely to gain some trust right from the time you walk in the door."* (MEDICAL CASE MANAGER, 1) On the other hand, a couple constituents noted that while having CHWs from the communities of the patients they are serving may increase trust, it could also increase stigma: *"Occasionally you run into the issue... if this person looks like someone from my neighborhood I don't want them to know. I think that's pretty rare I think more you will get increase in trust and increase in engagement because they can connect and they sort of provide a bridge for the trust."* (Behavioral Health Consultant, 2)

Constituents also expressed how shared lived experience or aspects of social identity can contribute to a shared understanding and language: *"You don't want another White social worker or person coming to tell this Black person, [or] this poor person...that's something that they really have no idea what they're talking about. They've never been to this place, they haven't been down the street. It's not the type of sex that they have... our social workers and doctors are just giving advice that they read out of the book, where the CHW has lived experience and connectivity that they'll bring."* (Clinical Administrator, 2) This idea was discussed in relation to the clinician understanding the patient experiences, but also the clinician being able to speak in terminology that the patient understands.

### **Patient characteristics: patient priorities and needs**

This subtheme represents the idea that clinicians and systems must be responsive to patients' needs, even if they are not directly related to HIV care. Constituents discussed the need to address social determinants of health and incorporate patient voice in decision making.

Constituents discussed the importance of mitigating adverse social determinants of health by providing patients with resources such as cell phones for communication with clinicians and staff, bus passes to increase access to transportation, supporting patients to gain access to mental health and substance use treatment, and supporting with food and housing to ensure their basic physical needs are met: *"I feel like we do a really good job just providing not just medical care but any type of care that the patient might need, such as case management help with insurance issues, problems with food insecurity, home insecurity, transportation to appointments. [...] So it's not just taking care of their health but their overall wellness."* (Outreach Coordinator, 2)

An overarching shared value constituents discussed was seeing the patient as a whole person to best meet their needs: *"One of the unique things is it really looks at a person holistically, understanding that it's not just about viral medical interventions, but you have to really look at these social determinants...we have to try to mitigate some of that."* (Policy Maker, 1) In addition, constituents explained that to see the patient as a whole person is focus on their strengths and avoid seeing them through the lens of their diagnosis, in addition to making an effort to build relationships.

Constituents also discussed the desire to center patients' needs by incorporating patients' voices in decision making. *"We don't have enough patient representation helping us make policy decisions...whether it's somebody in our CQI meeting, for continuous quality improvement, making sure we have patient representation and patient representation in our safety and security discussions or just in general."* (Behavioral Health Consultant, 3)

### **Clinical encounter: trust through relationship building**

The fourth subtheme represents participants perceptions that building relationships with patients could increase trust thereby improving adherence and retention. Constituents discussed ways in which they intentionally build relationship such as treating patient as family, understanding the full person, and taking a non-judgmental approach. In addition, they discussed how MAPS+ has the potential to support relationship building.

Constituents shared the importance of creating a welcoming environment in which the patient feels at home at the clinic and with their staff. For example, one constituent noted, *"We're family. We're not a white coat there."*

*And our patients love that...So they like that feeling of family. They feel connected and cared for and looked after." (Outreach Coordinator, 3)* They noted that this is particularly important for individuals who experience high levels of interpersonal stigma or those that are unhoused, that may have strained or inconsistent relationships within their communities.

Given patients' often multiple stigmatized identities, constituents emphasized the role of openness and a non-judgmental approach in building a relationship in which patients feel comfortable and are more likely to return to care. *"When I start off and I'm in there talking to the patient... I said listen this is a judgement free zone..... Just overall- that's the big piece is that whole big judgmental piece, taking yourself out of it because it's not about you. It's about what the patient needs." (Clinical Administrator, 3)*

When trying to understand potential facilitator to MAPS+ use, constituents often expressed excitement about MAPS+ including a CHW to act as a partner to the patient. They saw this partnership as another way to build relationship with patients. *"I think just having someone for the patient to pair with, that they feel like is assigned to them makes them feel more comfortable, I think, and more kind of watched over. I think just especially with the new diagnosis." (Prescribing Clinician, 3)*

#### **Clinical encounter and innovation characteristics: patient's autonomy and empowerment**

The final subtheme represents constituents' discussion of fostering patient empowerment by supporting autonomy in decision-making in their own care. Specifically, constituents discussed empowering patients to have voice in their own treatment experience and the ways in which MAPS+ embodies autonomy and empowerment of patients.

Constituents described providing educational resources and support to empower their patients to be involved in their medical care. One constituent discussed coordinating with a behavioral health consultant to help *"patients understand their illness and have an appreciation for their ability to have a control over their illness. So they feel more empowered and more equipped to be able to take medications daily." (Clinical Administrator, 4)*

Constituents also shared the way in which they educate their patients about the medical process (e.g., what to expect, what is proper treatment): *"We talked to them in a language they understand. We teach them about when you come into the room, if you don't see us wash our hands, you say something. We teach them what to be expected, so that they're a part of their care. So they have say so. So, we empower them to say something. If they're not comfortable, say something." (Prescribing Clinician, 4)*

When discussing potential benefits of MAPS+, constituents shared the potential for MAPS+ to encourage autonomy and patient empowerment by seeing the patient as the expert of their lives and the director of their care. For example, one constituent shared, *"adherence is really all about delving into a person's life and trying to understand and get them to be able to think about what are the actual things getting in the way of their adherence, and MAPS really puts the patients at the center of that and says, 'I'm not gonna tell you what you should do, you need to tell me what might work...You're the expert in the room.'" (Clinical Administrator, 5)*

#### **Discussion**

We conducted reflexive thematic analysis within a constructionist paradigm to more deeply understand both the systemic inequities that influence adherence and retention to HIV care, and the approach that staff and organizations take to ameliorate those inequities. Our study was unique in that it included perspectives from four different constituent groups that serve high need populations with HIV, providing a multi-level perspective on HIV care inequities and the ways in which they manifest across levels of context within the healthcare system. Our study builds off of other work that has identified inequities in retention and adherence by further identifying the ways in which our constituents are navigating and addressing these inequities within the healthcare system. We also identified ways in which MAPS+ may exacerbate or diminish said inequities. Specifically, participants from four constituent groups (i.e., prescribing clinicians, non-prescribing clinical team members, administrators, and policymakers) described how PWH experience a multitude of systemic inequities that impact adherence and care retention. Consistent with previous research [8, 20, 22, 23, ], our constituents discussed inequities such as lack of access to resources and basic needs, challenges navigating the health care system due to educational and insurance inequities, power differentials, medical mistrust, and intersectional stigma disproportionately affecting PWH who often hold multiple marginalized identities. These findings are situated within the frame of intersectional structural oppression, such that the inequities experienced are due to upstream structures (e.g., racism, homophobia, transphobia, ableism) that work through systems (e.g., medical system, education, housing) to disempower and dehumanize individuals [33]. Our constituents made it clear that interventions aimed at supporting adherence and retention and ultimately the EHE will fall short if they are not examining and addressing structural issues. Researchers have increasingly called for the recognition of intersectional structural oppression and stigma as being critical to ending the HIV epidemic [34, 35]. Interventions for PWH treatment adherence and



care retention such as MAPS+ and others, while promising for empowering patients to identify barriers and potential solutions, must be situated within the frame of intersectional structural oppression, and require system level intervention to adequately influence ongoing inequities in adherence and care retention [36]. These findings have implications for research and policy initiatives focused on individual and systems level interventions aimed at Ending the HIV Epidemic.

Our findings suggest that clinicians and staff are taking on the burden to ameliorate these inequities within their clinical settings with little institutional and structural support. Our constituents were attuned to their patient's experiences and noticed the ways in which inequities manifested interpersonally. For example, they discussed trust as integral to successful adherence and retention for PWH with historical and current mistreatment of individuals with marginalized identities in the medical field leading to continued mistrust of clinicians. This entrenched mistrust can be attributed to a long history of mistreatment (e.g., the U.S. Public Health Service Untreated Syphilis Study at Tuskegee, in which a treatment was knowingly withheld from Black research participants) [37]. This finding is consistent with previous work demonstrating lower levels of trust are associated with poorer adherence, retention, and overall health outcomes [38, 39]. While structural oppression works to dehumanize individuals, clinicians and staff described working to create human connection. They noted the importance of relationship in building trust, especially with marginalized or minoritized patients. Research suggests these efforts are beneficial in that better quality relationships are associated with higher retention in HIV care [40].

Our participants also indicated the organizational responses to inequities such as mistrust and power dynamics. Specifically, shared concerns consistent with the literature that implicit racial bias is ongoing and contributes to inequitable treatment recommendation and outcomes [41]. Constituents emphasized the need to train current staff and clinicians as well as CHWs in the concepts of intersectional structural oppression to combat racial bias and improve quality of care [33, 42]. Structural competency, or the awareness of how issues within the clinic and patients are reflective of larger structural issues rather than the patient themselves, can allow clinicians to recognize ways that they have inadvertently perpetuated inequities and prevent bias [43]. Further, previous research has demonstrated a decrease in inequitable treatment recommendation and response with higher clinician cultural humility [44]. While there are important benefits of clinician training that improves the clinician-patient relationship and quality of care patients' receive, it is imperative that we acknowledge the

limitations of clinician level interventions when attempting to address system level issues [45].

In addition, constituents noted that lack of representation of staff and clinicians with lived experiences or social identities similar to their patients was a problem in many of their organizations. Limited representation of social identities may perpetuate power dynamics, misunderstanding, and mistrust of clinicians. When clinician's and staff do not understand the lived experiences of their patients those aspects of their experience may become invisible. Research supports the benefit of representation of individuals with similar lived experiences or social identities, in increasing trust [46]. Constituents shared that their organizations recognized this problem and were attempting to hire more individuals representative of their patient communities, but that individuals with intersecting minoritized identities (e.g., queer Latine individuals) are not visible in leadership positions within their organizations and instead are more likely to be in support roles. The importance of shared social identity was also discussed in the context of the role of CHWs in MAPS+. Consistent with research on the benefits of CHWs, constituents also mentioned that hiring CHWs with lived experience to deliver MAPS+ should be prioritized and would support equitable implementation. CHWs with lived experience have been shown to increase retention in care [47]. This might be explained by CHWs' ability to enhance dignity and quality of life of PWH, the very aspects of wellbeing that structural oppression often decreases.

Overall, our findings elucidated that while challenges influencing adherence and care retention for PWH were largely structural and systemic, the solutions have largely been individual or organizational. Staff and clinicians are taking it upon themselves to address the structural problems their patients face. They are shouldering the burden without the necessary structural support (e.g., funding, policies to address social determinants of health), leading staff and clinicians to become over-burdened themselves. Work by Jenkins [48] found that individual staff and clinicians are serving as "shock absorbers," absorbing the inequities experienced by patients and still generating quality care, at the expense of their own health. Similarly, while incorporating CHWs into care provision can be a tool for supporting health equity, economic and policy initiatives are needed to insure the equitable treatment and sustainability of this workforce [49]. This is because the structures that lead to HIV care inequities persist. We provide recommendations based on our findings to more fully address health inequities by moving beyond individual and organizational interventions.

We posit that principles proposed within the framework of intersectional stigma can be applied to inform the development of equity focused implementation of



interventions such as MAPS+. Intersectional stigma, a concept related to intersectional oppression that includes the compounded effects of holding multiple stigmatized identities on the opportunities and experiences of individuals (e.g., health stigma related to their HIV and sexual or gender minority stigma and structural inequities [22, 50]. Sievwright and colleagues [51] proposed four core principles of intersectional stigma interventions. We provide examples of how each principle can be applied in the context of interventions such as MAPS+ that aim to reduce inequities in adherence and retention of HIV care. First, identify the ways in which intersecting systems of oppression are being enacted and addressed within the intervention: Understand the historical mistreatment of People of Color in medicine and the lack of representation of individuals with minoritized identities among staff and clinicians, and address this by training clinicians and staff to understand structural causes of inequities and emphasizing relationship development. Second, mitigate current harms and target systems that are creating inequities: Collaborating with medical case managers to support patients in accessing housing vouchers in addition to enacting policies that support programs such as housing first to increase access to safe housing. In addition, recommendations for addressing structural oppression and stigma have highlighted the need for the use of material power, or distribution of funds to encourage tangible change [53, 54], which may include funding to hire and retain CHWs with lived experience. Relatedly, household economic strengthening or strategies that enhance household economic resilience (e.g., monthly food rations), improves the adherence and engagement [55]. Third, rectify oppressive power dynamics and improving the effectiveness of interventions, through including meaningful engagement and leadership of individuals with lived experience: Engage PWH and CHWs with lived experience in adaptation of the intervention. Fourth, support inherent power, and collective action among the communities themselves, rather than focusing just on inequities experienced: CHWs delivering MAPS+ could partner with patients to bolster protective factors such as social support and collective action.

The current study has several limitations. The first is that while we focus on inequities influencing patients, these were *staff, clinician, and policymaker* perspectives; neither patients nor CHWs were interviewed as part of this study. Importantly, although our constituents were not representative of the patient population, they seemed to be attuned to the needs and experiences of their patients. However, it is imperative that we not rely on staff and clinician voice only, and that the voices of PWH be centered in implementation efforts. Second, the results of this study are nuanced in that they are

specific to a large city and may not be representative of more rural settings. Third, data were collected during the height of the COVID pandemic and findings were likely influenced by experiences of COVID, especially given that PWH were communities disproportionately affected by COVID.

Despite these limitations, the current study provides insights into the ways in which clinicians, staff, and policymakers currently recognize and ameliorate inequities and how interventions such as MAPS+ can be leveraged to support equitable adherence and retention. In summary, our constituents elucidated experiences of systemic inequities such as access to resources, healthcare system navigation difficulties, power differentials, medical mistrust, intersectional stigma and potential patient burden associated with MAPS+. In addition, they highlighted ways in which staff and clinicians shoulder the burden of addressing inequities by approaching PWH with dignity and developing trusting relationships and how MAPS+ can bolster this approach by partnering with and centering patient needs. This research underscores the complex interplay between structural oppression and HIV care, calling for comprehensive approaches to achieve health equity. Alongside staff and clinician training and support, structural solutions comprised of policies that bring material power into the control of PWH, and that directly address systemic inequities (e.g., food and housing security, transportation, access to education, mistrust) and challenge systems of power are necessary to end the HIV epidemic [55].

### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12939-025-02481-8>.

Supplementary Material 1

### Author contributions

AS developed the interview guide, conducted interviews, analyzed data and wrote the manuscript. CM and DC engaged in data analysis and manuscript writing and review. KH contributed to the data analyses plan, interpretation of the data, and substantially reviewed and revised the manuscript. FM, RG, and KB all contributed to the conception of the study and review and revision of the manuscript. RB contributed to the overall conception of the study, the data analysis plan, interpretation of the data, and reviewed and edited multiple drafts of the manuscript.

### Funding

This publication was made possible in part through an Ending the HIV Epidemic Supplement from the Penn Center for AIDS Research (CFAR; P30 045088), the Penn CFAR ISPHRE Scientific Working Group, and the Penn Mental Health AIDS Research Center (P30 MH 097488).

### Data availability

The datasets generated and analyzed during the current study are not publicly available due to the potential of the interview data being identifying, but may be available from the corresponding author on reasonable request.

## Declarations

### Ethics approval and consent to participate

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by The Philadelphia Department of Public Health IRB (#2020-42.) Informed consent was obtained from all human subjects participating in this research.

### Consent for publication

N/A.

### Competing interests

Dr. Beidas is principal at Implementation Science & Practice, LLC. She is currently an appointed member of the National Advisory Mental Health Council and the NASEM study, "Blueprint for a national prevention infrastructure for behavioral health disorders," and serves on the scientific advisory board for AIM Youth Mental Health Foundation and the Klingenstein Third Generation Foundation. She has received consulting fees from United Behavioral Health and OptumLabs. She previously served on the scientific and advisory board for Optum Behavioral Health and has received royalties from Oxford University Press. Dr. Gross serves on the data and safety monitoring board for Pfizer Inc., unrelated to the current work. Drs. Sanchez and Hoskins supported by the National Institute of Mental Health Training Fellowship during the conduct of this work (T32 MH109433; Mandell/Beidas MPLs). For the remaining authors no disclosures were reported.

Received: 7 January 2025 / Accepted: 10 April 2025

Published online: 06 May 2025

## References

- ADDIN ZOTERO\_BIBL {uncited:[([http://zotero.org/groups/5203972/items/YP ESEJSB]),omitted:[([http://zotero.org/groups/5203972/items/JAXHNVt6]),cus tom:[]]} CSL\_BIBLIOGRAPHY Office of Infectious Disease and HIV/AIDS Policy. Ending the HIV epidemic: a plan for America. United States Department of Health and Human Services; 2023 [cited 2024 Apr 21]. Available from: <https://www.hrsa.gov/ending-hiv-epidemic>
- HIV Surveillance Report. 4. Centers for Disease Control and Prevention. 2021;(34).
- Rebeiro PF, McPherson TD, Goggins KM, Turner M, Bebawy SS, Rogers WB, et al. Health literacy and demographic disparities in HIV care continuum outcomes. *AIDS Behav*. 2018;22(8):2604–14.
- Bowleg L, Malekzadeh AN, Mbaba M, Boone CA. Ending the HIV epidemic for all, not just some: structural racism as a fundamental but overlooked social-structural determinant of the US HIV epidemic. *Curr Opin HIV AIDS*. 2022;17(2):40–5.
- Williams DR, Collins C. Racial residential segregation: A fundamental cause of Racial disparities in health. *Public Health Rep*. 2001;116(5):404–16.
- Homan P, Brown TH, King B. Structural intersectionality as a new direction for health disparities research. *J Health Soc Behav*. 2021;62(3):350–70.
- English D, Carter JA, Boone CA, Forbes N, Bowleg L, Malebranche DJ, et al. Intersecting structural oppression and black sexual minority Men's health. *Am J Prev Med*. 2021;60(6):781–91.
- Arrington-Sanders R, Hailey-Fair K, Wirtz AL, Morgan A, Brooks D, Castillo M, et al. Role of structural marginalization, HIV stigma, and mistrust on HIV prevention and treatment among young black Latinx men who have sex with men and transgender women: perspectives from youth service providers. *AIDS Patient Care STDs*. 2020;34(1):7–15.
- Estimated HIV incidence and prevalence in the United States, 2018–2022. Centers for Disease Control and Prevention. 2024. (HIV Surveillance Supplemental Report). Report No.: 29 (No.1). Available from: [https://www.cdc.gov/hiv-data/nhss/estimated-hiv-incidence-and-prevalence.html#cdc\\_survey\\_profile\\_related-using-this-data](https://www.cdc.gov/hiv-data/nhss/estimated-hiv-incidence-and-prevalence.html#cdc_survey_profile_related-using-this-data)
- Arnold EA, Rebchook GM, Kegeles SM. Triply cursed: racism, homophobia and HIV-related stigma are barriers to regular HIV testing, treatment adherence and disclosure among young black gay men. *Cult Health Sex*. 2014;16(5/6):710–22.
- English D, Carter JA, Bowleg L, Malebranche DJ, Talan AJ, Rendina HJ. Intersectional social control: the roles of incarceration and Police discrimination in psychological and HIV-related outcomes for black sexual minority men. *Soc Sci Med* 1982. 2020;258:113121.
- Irie WC, Mahone A, Johnson B, Marrazzo J, Van Der Mugavero MJ, et al. Just the stigma associated with PrEP makes you feel like it's HIV itself: exploring PrEP stigma, skepticism, and medical mistrust among black cisgender women in urban and rural counties in the U.S. Deep South. *Arch Sex Behav*. 2024;53(3):1187–95.
- Nydegger LA, Dickson-Gomez J, Ko TK. Structural and syndemic barriers to PrEP adoption among Black women at high risk for HIV: a qualitative exploration. *Cult Health Sex*. 2021;23(5):659–73.
- Nezu AM, Nezu CM, Perri MG. Problem-solving therapy for depression: Theory, research, and clinical guidelines. Oxford, England: John Wiley & Sons; (Problem-solving therapy for depression: Theory, research, and clinical guidelines.) 1989;xiv:274.
- Gross R, Bellamy SL, Chapman J, Han X, O'Duor J, Palmer SC, et al. Managed problem solving for antiretroviral therapy adherence: A randomized trial. *JAMA Intern Med*. 2013;173(4):300.
- Mwai GW, Mburu G, Torpey K, Frost P, Ford N, Seeley J. Role and outcomes of community health workers in HIV care in sub-Saharan Africa: a systematic review. *J Int AIDS Soc*. 2013;16(1):18586.
- Kenya S, Chida N, Symes S, Shor-Posner G. Can community health workers improve adherence to highly active antiretroviral therapy in the USA? A review of the literature. *HIV Med*. 2011;12(9):525–34.
- Kumbani LC, Jere DL, Banda CK, Chang C, Liu L, McCreary LL, et al. A peer group intervention implemented by community volunteers increased HIV prevention knowledge. *BMC Public Health*. 2023;23(1):301.
- Sanchez AL, Hoskins K, Pettit AR, Momplaisir F, Gross R, Brady KA, et al. Stakeholder perspectives on MAPS. *JAIDS J Acquir Immune Defic Syndr*. 2022;90(51):S190–6.
- Anderson AN, Higgins CM, Haardörfer R, Holstad MM, Nguyen MLT, Waldrop-Valverde D. Disparities in retention in care among adults living with HIV/AIDS: A systematic review. *AIDS Behav*. 2020;24(4):985–97.
- Filippone P, Serrano S, Campos S, Freeman R, Cluesman SR, Israel K, et al. Understanding why Racial/ethnic inequities along the HIV care continuum persist in the United States: a qualitative exploration of systemic barriers from the perspectives of African American/Black and Latino persons living with HIV. *Int J Equity Health*. 2023;22(1):168.
- Logie CH, James LI, Tharao W, Loutfy MR. HIV, gender, race, sexual orientation, and sex work: A qualitative study of intersectional stigma experienced by HIV-Positive women in Ontario, Canada. *PLoS Med*. 2011;8(11):e1001124.
- Randolph SD, Golin C, Welgus H, Lightfoot AF, Harding CJ, Riggins LF. How perceived structural racism and discrimination and medical mistrust in the health system influences participation in HIV health services for black women living in the United States South: A qualitative, descriptive study. *J Assoc Nurses AIDS Care JANAC*. 2020;31(5):598–605.
- Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Policy Ment Health Ment Health Serv Res*. 2015;42(5):533–44.
- Hennink MM, Kaiser BN, Marconi VC. Code saturation versus meaning saturation: how many interviews are enough? *Qual Health Res*. 2017;27(4):591–608.
- O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: A synthesis of recommendations. *Acad Med*. 2014;89(9):1245–51.
- Ltd QIP. NVivo qualitative data analysis software. QSR International Pty Ltd; 2014.
- Byrne D. A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Qual Quant*. 2022;56(3):1391–412.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101.
- Etherington C, Rodrigues IB, Giangregorio L, Graham ID, Hoens AM, Kasperavicius D, et al. Applying an intersectionality lens to the theoretical domains framework: a tool for thinking about how intersecting social identities and structures of power influence behaviour. *BMC Med Res Methodol*. 2020;20(1):169.
- Women of color at the center. Selections from the third National conference on women of color and the law: mapping the margins: intersectionality, identity politics, and violence against women of color. *Stanf Law Rev*. 1991;43(6):1241.
- Woodward EN, Singh RS, Ndebele-Ngwenya P, Melgar Castillo A, Dickson KS, Kirchner JE. A more practical guide to incorporating health equity domains in implementation determinant frameworks. *Implement Sci Commun*. 2021;2(1):61–61.

33. Watkins-Hayes C. Intersectionality and the sociology of HIV/AIDS: past, present, and future research directions. *Annu Rev Sociol.* 2014;40(1):431–57.
34. Turan B, Hatcher AM, Weiser SD, Johnson MO, Rice WS, Turan JM. Framing mechanisms linking HIV-Related stigma, adherence to treatment, and health outcomes. *Am J Public Health.* 2017;107(6):863–9.
35. Seyedroudbari S, Ghadimi F, Grady G, Uzosike O, Nkwihoreze H, Jemmott JB et al. Assessing Structural Racism and Discrimination Along the Pre-exposure Prophylaxis Continuum: A Systematic Review. *AIDS Behav.* 2024 Jun 8 [cited 2024 Aug 28]; Available from: <https://link.springer.com/https://doi.org/10.1007/s10461-024-04387-y>
36. Chater N, Loewenstein GF, the Individual-Level Solutions Has Led Behavioral Public Policy Astray. The i-Frame and the s-Frame: How Focusing on. *SSRN Electron J.* 2022 [cited 2024 Aug 28]; Available from: <https://www.ssrn.com/abstract=4046264>
37. Alsan M, Wanamaker M. Tuskegee and the health of black men\*\*. *Q J Econ.* 2018;133(1):407–55.
38. Graham JL, Shahani L, Grimes RM, Hartman C, Giordano TP. The influence of trust in physicians and trust in the healthcare system on linkage, retention, and adherence to HIV care. *AIDS Patient Care STDs.* 2015;29(12):661–7.
39. Pellowski JA, Price DM, Allen AM, Eaton LA, Kalichman SC. The differences between medical trust and mistrust and their respective influences on medication beliefs and ART adherence among African-Americans living with HIV. *Psychol Health.* 2017;32(9):1127–39.
40. Flickinger TE, Saha S, Moore RD, Beach MC. Higher quality communication and relationships are associated with improved patient engagement in HIV care. *JAIDS J Acquir Immune Defic Syndr.* 2013;63(3):362–6.
41. Calabrese SK, Earnshaw VA, Underhill K, Hansen NB, Dovidio JF. The impact of patient race on clinical decisions related to prescribing HIV Pre-Exposure prophylaxis (PrEP): assumptions about sexual risk compensation and implications for access. *AIDS Behav.* 2014;18(2):226–40.
42. Andrasik M, Broder G, Oseso L, Wallace S, Rentas F, Corey L. Stigma. Implicit bias, and Long-Lasting prevention interventions to end the domestic HIV/AIDS epidemic. *Am J Public Health.* 2020;110(1):67–8.
43. Hansen H, Metz JM. New medicine for the U.S. Health care system: training physicians for structural interventions. *Acad Med.* 2017;92(3):279–81.
44. Saha S, Korthuis PT, Cohn JA, Sharp VL, Moore RD, Beach MC. Primary care provider cultural competence and Racial disparities in HIV care and outcomes. *J Gen Intern Med.* 2013;28(5):622–9.
45. Burson RC, Familusi OO, Clapp JT. Imagining the 'structural' in medical education and practice in the united States: A curricular investigation. *Soc Sci Med.* 2022;300:114453.
46. Earl TR, Saha S, Lombe M, Korthuis PT, Sharp V, Cohn J, et al. Race, relationships, and trust in providers among black patients with HIV/AIDS. *Soc Work Res.* 2013;37(3):219–26.
47. Barnett ML, Klein CC, Gonzalez JC, Sanchez BE, Rosas YG, Corcoran F. How do Lay Health Worker Engage Caregivers? A Qualitative Study to Enhance Equity in Evidence-Based Parenting Programs. *Evid-Based Pract Child Adolesc Ment Health.* 2021/11/04 ed. 2023;8(2):221–35.
48. Jenkins TM. Physicians as shock absorbers: the system of structural factors driving burnout and dissatisfaction in medicine. *Soc Sci Med.* 2023;337:116311.
49. Schriger SH, Knowles M, Daglieri T, Kangovi S, Beidas RS. Barriers and facilitators to implementing an Evidence-Based community health worker model. *JAMA Health Forum.* 2024;5(3):e240034.
50. Sangaramoorthy T, Jamison AM, Dyer TV. HIV stigma, retention in care, and adherence among older black women living with HIV. *J Assoc Nurses AIDS Care.* 2017;28(4):518–31.
51. Sievwright KM, Stangl AL, Nyblade L, Lippman SA, Logie CH, Veras MADSM, et al. An expanded definition of intersectional stigma for public health research and praxis. *Am J Public Health.* 2022;112(54):S356–61.
52. Stanton MC, Ali SB, The Sustain Center Team. A typology of power in implementation: Building on the exploration, preparation, implementation, sustainment (EPIS) framework to advance mental health and HIV health equity. *Implement Res Pract.* 2022;3:263348952110642.
53. Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. *Am J Public Health.* 2013;103(5):813–21.
54. Swann M. Economic strengthening for retention in HIV care and adherence to antiretroviral therapy: a review of the evidence. *AIDS Care.* 2018;30(sup3):99–125.
55. Stangl AL, Atkins K, Leddy AM, Sievwright KM, Sevelius JM, Lippman SA, et al. What do we know about interventions to reduce intersectional stigma and discrimination in the context of HIV? A systematic review. *Stigma Health.* 2023;8(3):393–408.

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