

What shapes People Living With HIV's experiences of HIV stigma in Delaware?

A qualitative exploration of place and social position

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Abstract

Objectives: To understand how place and social position shape experiences of HIV stigma among people living with HIV (PLWH) in Delaware. HIV stigma impedes the health and wellbeing of PLWH. Yet, HIV stigma is often studied through psychosocial perspectives without considering social-structural conditions. Recent theorists have hypothesized that place and social position, two key social-structural conditions, fundamentally shape PLWH's experiences of stigma. Due to residential segregation of racial/ethnic and lesbian, gay, bisexual, transgender, and queer (LGBTQ) populations, place and social position are often inextricably intertwined within the U.S. **Methods:** Qualitative interviews were conducted with 42 PLWH and 14 care providers in 2017. Interviews were conducted with English- and Spanish-speaking PLWH in all three counties in Delaware, including: Wilmington in New Castle County, Smyrna in Kent County, and Georgetown in Sussex County. **Results:** Results suggest that PLWH's experiences of HIV stigma are shaped by place and social position. Although HIV stigma is still prevalent across Delaware, participants reported that HIV stigma is more pronounced in Kent and Sussex counties and in rural areas. Latinx and Haitian PLWH are at greater risk of experiencing HIV stigma than other racial/ethnic groups, with participants identifying misinformation within Latinx and Haitian communities as a key driver of HIV stigma. HIV stigma is further compounded by medical mistrust in the Haitian community. In contrast, participants noted that LGBTQ PLWH in Sussex County are somewhat buffered from HIV stigma by the LGBTQ community, which is reported to be more knowledgeable about HIV and accepting of PLWH. **Conclusions:** Multi-level interventions that address social-structural conditions in addition to individual-level factors are recommended to best address HIV stigma in Delaware. Interventions should target drivers of stigma, such as lack of knowledge, and consider how place and social position uniquely shape PLWH's experiences of stigma.

Introduction

Decades of research suggests that stigma, or social devaluation and discrediting, undermines outcomes and exacerbates inequities along the full HIV care continuum.^{1,2} The majority of HIV stigma research to date has focused on the individual level, and has demonstrated that individual people living with HIV (PLWH) who experience greater stigma have worse mental health, are less likely to be linked to care, are less adherent to antiretroviral therapy, and are less likely to achieve viral suppression.^{3,4} Yet, theorists working in structural stigma⁵ and intersectionality^{6,7} have called on HIV researchers to shift their focus beyond the individual level and attend to social and structural conditions to better understand experiences and outcomes of HIV stigma. Greater understanding of the social-structural conditions that shape HIV stigma is critical for tailoring intervention strategies to reduce and promote resilience to HIV stigma. The current study therefore explores two key interrelated social-structural conditions that shape experiences of stigma among PLWH throughout Delaware: place and social position.

Delaware is located in the South, the region with the highest rates of new HIV diagnoses in the U.S.^{8,9} Although Delaware is the second-smallest state in the U.S., its HIV incidence rate is ranked as the 16th highest in the nation (11.2 per 100,000 persons¹⁰). Delaware is comprised of three counties. New Castle is the northernmost and most populous county and is home to 73% of Delawareans living with HIV. Located in New Castle County, Wilmington is the largest city in Delaware and is home to over half (56%) of PLWH in New Castle and one-third (36%) of PLWH in Delaware. Kent and Sussex counties are south of New Castle, more rural, and are home to 12% and 15% of Delawareans living with HIV respectively. Routes of HIV transmission in New Castle and Kent counties are similar, with sexual contact among heterosexual individuals and men who have sex with men accounting for comparable HIV cases (i.e., 37% and 35% respectively in both counties). In Sussex County, rates of transmission are highest among men who have sex with men (59%). Health inequities persist in Delaware: 58% of Delawareans living with HIV are African American and 8% are Latinx.¹⁰

Social-Structural Conditions Shaping Experiences of HIV Stigma

Social-structural conditions may play key roles in shaping experiences of HIV stigma among PLWH. Hatzenbuehler's definition of structural stigma spans societal-level conditions, cultural norms, and policies that constrain the opportunities, resources, and wellbeing of stigmatized people.⁵ Structural stigma research has drawn attention to place-based variability in experiences and outcomes of stigma. Evidence generally suggests that stigmatized people living in places with greater structural stigma, indicated by aggregated attitudinal data and/or policy analysis, report greater individual-level experiences of stigma and have worse health outcomes than stigmatized people living in places with less structural stigma.⁵ Quantitative research on structural stigma often incorporates countries and states as the unit of analysis, and therefore much work on structural stigma to date has been conducted at macro levels (e.g., national, international). Yet there may be important variations in structural stigma at more local geographic levels, including within states. Evidence suggests that community members living in rural areas have less knowledge of HIV and contact with PLWH than community members in urban areas, in part due to differences in their social network structures.¹¹ Given that knowledge and contact are drivers of HIV stigma,¹ HIV stigma in rural areas may be greater than in urban areas. For example, a study conducted in Georgia suggests that PLWH in rural areas experience greater enacted stigma and internalized stigma than their counterparts who live in urban areas.¹²

In Delaware, Kent and Sussex counties are more rural than New Castle County, with populations per square mile one-quarter to one-fifth the size of New Castle.⁹

Social positions may play an additional role in shaping experiences of HIV stigma. Intersectionality theory draws attention to the multiple, interlocking systems of oppression and privilege that give rise to inequities in HIV and other health outcomes.^{6,7} These interlocking systems shape the ways in which individuals living at the intersections of multiple social positions experience HIV stigma. The concept of intersectional stigma was introduced by Berger to describe stigma experienced by Black women living with HIV at the intersections of sexism, racism, and HIV stigma.⁶ Since then, much research on intersectional stigma in the U.S. has focused on intersections of racism, homophobia, and HIV stigma given that Black gay and bisexual men are disproportionately affected by the HIV epidemic. Some of this work suggests Black gay men are “triply cursed”¹³ and that the stigmatization of homosexuality and HIV, along with racism, make it difficult for Black gay men living with HIV to seek support and HIV care.^{13,14} Although arguably less research to date has focused on the intersections of other social positions, some work suggests that features of Latinx culture shape experiences of stigma.¹⁵ Moreover, Haitian PLWH have historically faced pronounced stigma in the U.S.,^{5,6} the legacy of which may continue to shape their experiences today.

Importantly, place and social positions are intertwined due to residential segregation. Racial and ethnic residential segregation persists in Delaware. For example, although the Latinx population is generally equally distributed at the county-level (11.0% New Castle, 7.8% Kent, 9.8% Sussex),¹⁶ pockets of segregated communities persist at local levels. Similar to the rest of the U.S.,¹⁷ Latinx residential segregation in Delaware reflects economic inequality, employment segregation, and local population dynamics. Delaware is additionally home to a sizeable Haitian community in Kent and Sussex counties, where they constitute the majority of the workforce for the state’s poultry industry.¹⁸ Residential segregation of lesbian, gay, bisexual, transgender, and queer (LGBTQ) households also exists throughout the U.S. and in Delaware. Residential segregation of LGBTQ households may be driven, in part, by LGBTQ individuals leaving communities with greater LGBTQ stigma in favor of more LGBTQ-friendly communities.¹⁹ Rehoboth is a LGBTQ-friendly community in Sussex County.

Current Study

Although recent work on structural stigma and intersectionality underscores the importance of considering social-structural conditions when studying stigma, researchers to date have arguably understudied these conditions. Better understanding of the role of social-structural conditions in shaping the experiences of HIV stigma can inform tailored intervention strategies to address HIV stigma. The current study uses qualitative methods to explore how two interrelated social-structural conditions, including place and social position, shape the experiences of stigma among PLWH throughout the state of Delaware.

Method

Procedures and Participants

PLWH and providers were recruited in 2017 from an HIV care program within several locations in Delaware. Individuals were eligible to participate if they were age 18 or older, spoke English or Spanish, and received or provided care at one of three locations, including Wilmington in

New Castle County, Smyrna in Kent County, and Georgetown in Sussex County. Participants were recruited via flyers and word of mouth. Informed consent was obtained from interested individuals, and then interviews lasting up to an hour were conducted in private rooms. Interviews with Spanish-speaking participants were conducted with an interpreter. All interviews were conducted in person, digitally recorded, and later transcribed. Study procedures received institutional review board approval by the University of Delaware.

To develop a comprehensive understanding of HIV stigma, we interviewed both PLWH and providers, achieving data source triangulation.²⁰ Participants included 42 PLWH and 14 providers, with 24 participants from Wilmington, 13 from Smyrna and 19 from Georgetown. More interviews were conducted in Wilmington because there were more Spanish-speaking PLWH in Wilmington than at the other sites. Among PLWH, 30 participants spoke English and 12 spoke Spanish; 28 identified as men and 14 as women; 16 identified as Black, 13 as Latinx, 7 as White, and 5 as another race/ethnicity; and 20 identified as LGBTQ, 18 as heterosexual, and 4 as another sexual orientation. PLWH had been living with HIV for an average of 10.7 years.

Qualitative Protocol

The parent study was designed to compare barriers to HIV care throughout Delaware; therefore, a semi-structured qualitative protocol was developed to broadly explore barriers to HIV care. PLWH were asked questions about their experiences with HIV care (e.g., “Please tell me about your experiences with HIV care, including when you first started and how it’s gone so far.”) as well as barriers to and facilitators of HIV medical appointments (e.g., “What kinds of things make it challenging or difficult for you to come in for your appointments?”), HIV medication adherence (e.g., “What kinds of things make it easier for you to take your medication?”), and other healthcare (e.g., “Have you tried to see doctors or psychologists outside of the HIV program? If so, how has that gone?”). Because local stakeholders suggested that stigma was a barrier to HIV care, several interview questions focused on individuals’ experiences of stigma (e.g., “How much has the stigma of HIV been a problem for you? In other words, do you feel that people treat you differently or mistreat you because they know that you have HIV?”). Providers were asked questions about the same broad themes, with questions tailored to query about their perceptions of PLWH’s experiences (e.g., “Is stigma or discrimination a problem for your patients? In other words, do people treat your patients differently or mistreat them because they know that they’re living with HIV?”).

Analysis

All interviews were transcribed in English, and then analyzed using a grounded theory approach. Following standard qualitative data analysis methods,²¹ three members of the study team read the transcripts and identified recurring themes. They then created a codebook listing themes, detailed definitions of themes, inclusion/exclusion criteria, and example quotes. Themes included individual-, interpersonal-, and structural-level barriers as well as recommendations to address barriers. Using *Dedoose*, a qualitative data management program, two members of the team independently coded approximately 20% of transcribed text. An interrater reliability of Kappa=0.90 was achieved, and then team members coded the rest of the transcripts. Disagreements were resolved through discussion. The current paper focuses on a subset of themes related to stigma, including enacted and anticipated stigma at the interpersonal level, and community stigma and knowledge at the structural level. These themes overlapped with several

others, such as disclosure and concealment at the interpersonal level and experiences with care outside of the HIV program at the structural level.

Results

Place

Participants reported that HIV stigma is still prevalent in all three counties within Delaware. PLWH at every site reported that they had experienced enacted stigma from members of their community. As examples, a PLWH from Wilmington described social rejection and distancing: “They don’t wanna talk to you, get close to you... on the street where you live, everybody know. So everybody just go back inside like just breathing the same air is gonna get you sick.” A PLWH from Smyrna described judgment and gossip from others: “Once the wrong people know, then that’s when it turns into a disaster. Then everybody knows and then once everybody knows, everybody’s judging you.” A PLWH in Georgetown added that people “looked at people with HIV or AIDS as degenerates, whores, even pedophiles” in their community. A provider from Wilmington shared similar perspective, saying that “I’m seeing it (stigma) no different in 2017 than what I saw in the 80s. It’s just as prevalent.”

Lack of knowledge was identified as the primary driver of HIV stigma throughout the state. Participants perceived that community members continue to have misperceptions of HIV. For example, many PLWH and providers encountered community members who still thought HIV could be spread through hugging, touching, shaking hands and eating together. One PLWH in Smyrna commented: “those people are very ignorant, and rude, and just, just, illiterate to what’s really going on.” Participants also reported that community members continued to believe that HIV is a death sentence. Another PLWH in Smyrna reported that they had been called the “grim reaper.”

Although participants reported stigma throughout the state, PLWH and providers in Georgetown noted that stigma was more pronounced “down here” (i.e., in the Southern part of the state) than in the Northern part of the state. For example, a PLWH in Georgetown noted that “it’s just a very closed channel down here.” Participants in Georgetown described macroaggressions, or particularly harmful forms of stigma. For example, a PLWH in Georgetown described being fired from their job at a landscaping company after their HIV-status was revealed to their coworkers:

“I don’t know how they found out but they did. So they were cracking fag jokes and stuff about HIV... It got to the point where (my boss) found out that I was having a lot of issues with the guys and he said “I’m going to have to let you go because for your sake and for the morale of my people” and so I took him to court and you know, I got a small settlement but at least I hope it taught him that discrimination has no place.”

Participants noted that the lack of knowledge about HIV was particularly problematic in Georgetown, extending into healthcare settings outside of the HIV program. One PLWH observed that their primary care physician lacked essential knowledge about PrEP (i.e., an HIV prevention medication). They reported:

“(My primary care physician) didn’t even know about PrEP. And I had asked them about PrEP before. And he didn’t know. Like this was before I was diagnosed as HIV positive. I asked about it in 2013 when I found out about it and he was like “What is that?” And like this is my doctor.”

Providers in Georgetown additionally noted that that primary care physicians continue to stigmatize PLWH, despite advances in HIV knowledge within the medical field. One noted:

“I mean there’s certainly doctors that still get a patient with HIV and even though they know it’s a treatable disease they sort of shun away from it or have their own reservations about... how this patient got this disease and all that. And people come in here like “Well you sent me to this doctor for primary care but as soon as he saw me he put gloves on” this and that.”

Similarly, a provider in Smyrna highlighted that stigma from primary care providers undermined PLWH’s ability to access quality care for other chronic health conditions and co-morbidities:

“Providers not feeling comfortable treating them in terms of primary care even if their HIV is under control... We have great things for HIV care, but patients nowadays are not dying from HIV. They’re dying of heart failure, of diabetes, of depression, of MIs, cancer... I think stigma is playing a role.”

Social Positions

Several social positions emerged as particularly important in shaping individuals’ experiences of HIV stigma. Latinx PLWH described substantial HIV stigma within the Latinx community, which led many to anticipate stigma and conceal their HIV status. A Latinx PLWH in Georgetown reported that “the Hispanic culture is sometimes very judgmental and can discriminate for PLWH.” Another Latinx PLWH in Wilmington stated that “Hispanic culture is very tough when it comes to HIV and they might think bad about the disease and have negative perceptions about HIV.” Several participants identified lack of knowledge as a key driver of HIV stigma in the Latinx community. One Latinx PLWH in Wilmington noted:

“A lot of Hispanics think that you’re living with HIV and you come into my house and just because you give me a handshake or a hug that you’re going to transmit HIV, or that just because you’re eating with them or that you’re sharing utensils that somebody’s going to get infected but that’s not the case.”

Latinx participants expressed worrying about others learning about their HIV status and concealed their HIV. Whereas most White and Black PLWH described disclosing their HIV status to several other people, approximately half of Latinx PLWH noted that they had disclosed to one or no other people outside of their healthcare team.

Providers reported that Haitian PLWH also experienced substantial HIV stigma within the Haitian community. One provider in Smyrna noted that their Haitian patients “said they didn’t want to state what their diagnosis was because it was not something that their culture accepts readily, and that there would be further... problems for them if it were known.” Similar to HIV

stigma in the Latinx community, providers perceived that HIV stigma in the Haitian community was rooted in misinformation. A provider in Georgetown reported that “the Haitian population... believes that there is no HIV. HIV doesn’t really exist.” Different than the Latinx community, providers perceived that HIV stigma was compounded by pronounced medical mistrust, ultimately undermining healthcare engagement. A provider in Georgetown noted:

“We have also a large population of patients from Haiti... the main thing in access to care is trust. You know, these patients have to be seen again and again for complications before they actually buy into (medical care). But we still have patients that will travel back to their country to see a spiritual leader to, you know, offer them a potion so they can get rid of the disease, and I’ve had plenty of those patients that will be here for a while and then disappear and come in a hospital and we’ll have to deal with, you know, things all over again. So, there is a trust issue in that specific group and also a stigma within their own community.”

A provider from Smyrna identified stigma as a barrier to patient-provider communication, stating that “in Haitian cultures, if you have HIV, you are not a part of the community anymore and so we have patients that don’t want their names used with the translator service.” Another provider from Georgetown shared a story of a Haitian PLWH who concealed her HIV status due to pronounced anticipated stigma. She stopped taking her HIV medication because she was unable to hide the medication, which led to a severe infection and death.

In contrast to the experiences of Latinx and Haitian PLWH, PLWH and providers noted that gay men experienced less HIV stigma in the state. This was especially case in Georgetown, which is close to Rehoboth. One provider in Georgetown reported that “I think in today’s world (HIV is) still very taboo, still very stigmatized. But I think now certain populations, or especially our gay men, are way more open about it.” A PLWH in Georgetown noted that they experience more stigma from heterosexuals, whom they viewed as less knowledgeable about HIV:

“It’s more of a stigma when I deal with straight America. Like it’s wreaked havoc on the gay population so like a lot of ... you know when I talk to the gay population they’re a little more understanding and they get that it doesn’t define you and that it’s not a death sentence. when I deal with the straight population it’s just like they’re a little bit more uninformed. And it’s crazy because it’s like its being brought to their doorstep now because of IV drug use.”

Both PLWH and providers noted that many LGBTQ PLWH in Georgetown and Rehoboth experience positive health outcomes. One provider in Smyrna noted that LGBTQ PLWH tend to be more adherent to their medication because “all the gay men from the beach that are highly educated, smart, intelligent. They understand the regimen, they understand the vernacular and they come to their appointments.” However, not all LGBTQ PLWH have positive outcomes and experiences. Another provider described a PLWH patient who anticipated significant HIV and LGBTQ stigma from their family, and therefore concealed both their HIV-status and sexual orientation from them.

Discussion

The current study explores how social-structural conditions shape experiences of stigma among PLWH within Delaware. Results suggest that experiences of stigma among PLWH are shaped by their place and social position. Replicating previous findings identifying place-based differences in experiences of HIV stigma,¹² PLWH living in the Southern part of the state and in more rural areas described more pronounced HIV stigma than PLWH living in the Northern part of the state and in more urban areas. Concerning social positions, Latinx PLWH expressed significant concerns surrounding anticipated stigma and more Latinx PLWH concealed their HIV-status than PLWH in other social positions. Healthcare providers perceived that Haitian PLWH are at elevated risk of HIV stigma, and stigma within the Haitian community was attributed to perceived low levels of knowledge about HIV and compounded by medical mistrust. In contrast to the experiences of Latinx and Haitian PLWH, participants reported that PLWH generally experienced less stigma within the LGBTQ community. Although there have been recent upticks in LGBTQ stigma in the U.S., evidence suggests that LGBTQ stigma has generally decreased over the past two decades.²² LGBTQ individuals experiencing greater resilience and empowerment associated with their LGBTQ identities may also experience greater resilience and empowerment associated with other aspects of the self, including their HIV status.

Results additionally suggest that place and social positions intersect to shape experiences of stigma in Delaware, likely due to residential segregation of racial/ethnic minority and LGBTQ populations within the state. For example, experiences of stigma among Haitian PLWH were described by providers in Smyrna and Georgetown, but not Wilmington. In contrast, participants in Georgetown remarked that gay men experience less stigma in Georgetown and Rehoboth, perhaps because Rehoboth is a LGBTQ-friendly town.

Strengths and Limitations

Much previous work on HIV stigma focuses on the micro level by studying individuals living with HIV, resulting in a desocialized and decontextualized understanding of experiences of HIV stigma.²³ Researchers are beginning to focus on the macro level by studying structures, including how variation in structural stigma between states impacts experiences and outcomes of stigma.²⁴ The current study focuses on the mezzo level, exploring how social-structural conditions spanning one U.S. state shape PLWH's experiences of stigma. The study draws on a diverse sample in terms of race, ethnicity, and sexual orientation and incorporates perspectives of both PLWH and providers.

Several limitations of the study should be acknowledged. Findings surrounding HIV stigma experienced by Haitian PLWH are based on providers' perspectives. We were unable to recruit Haitian participants for a variety of reasons (e.g., mistrust of the medical and research community among patients). These results are reported given that the experiences of Haitians living with HIV in the U.S. have arguably been underreported in recent years, and are critical to understanding the landscape of HIV stigma in Delaware. Future studies should seek to explore experiences of stigma from the perspectives of Haitian PLWH. Additionally, comparisons of experiences of stigma were made with qualitative methods. Future quantitative studies can measure and compare levels of stigma between groups to identify statistically significant differences. Finally, this study was conducted in partnership with one HIV care program in Delaware. Although this program serves the largest number of PLWH in the state, results may not be generalizable to PLWH receiving care from other programs. Future work should be

conducted in partnership with more HIV care programs and in more locations to develop more generalizable and nuanced understanding of variations of experiences of HIV stigma within Delaware and elsewhere.

Public Health Implications

The current study suggests that social-structural conditions, including place and social positions, may fundamentally shape experiences of stigma among PLWH in Delaware. Theorists have argued for the importance of multi-level stigma interventions that include stigma reduction components at the structural, community, interpersonal, and individual levels.²⁵ Evidence suggests that there has been some progress: A recent review identified several stigma interventions that operated at more than one social-ecological level.²⁵ Interventionists should continue to develop and evaluate interventions that address stigma at multiple social-ecological levels. It may be particularly important to integrate empowerment-based components to combat intersectional stigma.²⁶ Moreover, results suggest that HIV stigma interventions may not be able to take a “one size fits all” approach, but instead may need to be tailored to specific places and social positions in Delaware.

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Author Notes

Justification of use of data from more than three years ago: Data for this project were collected in 2017, five years ago. Although we understand that DJPH typically prioritizes manuscripts with data collected within the past three years, we have no reason to believe that the results reported have changed since the data were collected. Stigma processes are very slow to change. As described in this paper, some participants noted that HIV stigma in Delaware was just as strong in 2017 as it was in the 1980s. We have no reason to believe that substantial changes in HIV stigma occurred between 2017 and 2022. Moreover, the epidemiologic profile of HIV has remained stable in Delaware. We therefore believe that our discussion of the roles of place and social position in shaping HIV stigma throughout Delaware remain relevant.

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