

HIV Stigma in the MSM Community Today. What it Looks Like and Ways of Reducing It. A
Qualitative Study.

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Abstract

HIV Stigma in the MSM Community Today. What it Looks Like and Ways of Reducing It. A Focus Group Discussion.

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Poverty, stigma, and limited access to quality health care are drivers of the Human Immunodeficiency Virus (HIV) epidemic among marginalized populations, and these factors are disproportionately experienced by racial, ethnic, gender, and sexual minority groups. In the Focus Group Discussions (FGDs) with HIV seronegative men who have sex with men (MSM) and MSM living with HIV, participants described ways they were affected by HIV stigma they experienced within and outside the MSM community. They also provided ideas for interventions on stigma reduction based on their experience of past interventions and what they would like to see in their community. Most recommendations suggested were not isolated strategies but integrated and combined structural, institutional, community, interpersonal and individual levels of the socioecological models.

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INTRODUCTION

HIV and HIV Stigma in the MSM community

Human Immunodeficiency Virus (HIV) in the United States disproportionately affects poor and minority populations. Although Men who have Sex with Men (MSM) are estimated to represent 3.9% of the United States population (Grey et al., 2016), in 2017 they accounted for 70% (27,000) of new cases of HIV infections. Black/African American MSM (9,990) accounted for the largest number of new HIV cases, followed by Hispanic/Latinx MSM (7,830) and White MSM (7,560) (CDC, 2019). Poverty, stigma, and limited access to quality health care are drivers of the epidemic among these marginalized populations, and these factors are disproportionately experienced by racial, ethnic, gender, and sexual minority groups. Among MSM, men of color, specifically Black/African American and Hispanic/Latinx MSM are most impacted (CDC, 2018, 2019).

In the Pacific Northwest (PNW), gay and bisexual men carry the greatest burden of HIV. Although HIV has declined across the general population (CDC, 2018), incidence and prevalence remain high among MSM, and social stigma is a contributing factor (Lelutiū-Weinberger et al., 2019).

According to Goffman (1963, p. 3), stigma is “an attribute that is deeply discrediting.” Individuals are stigmatized when they are perceived to have an attribute that makes them different from others in a less than desirable way. Goffman emphasized that the essence of stigma is not in the attribute itself but in the language or construction of its relationships in a given context. In other words, particular attributes can be tainted, discounted and devalued within particular contexts because such attributes differ from the norm or traditional expectations. Earnshaw and Chaudior (2009), described HIV seropositivity as an “attribute that

is socially devalued” (p. 1162). HIV-related stigma manifests across cultures, and cadres of life all over the world, and this – stigma – may affect their behavioral, health and psychological outcomes (Li, Fung, Maticka-Tyndale, & Wong, 2018).

Stigma is thought to manifest through three mechanisms, enacted stigma, anticipated stigma, and internalized stigma and it is also experienced differently for MSM who are living with HIV and MSM whose HIV serostatus is negative (Marshall, Brewington, Allison, Haynes, & Zaller, 2017). Enacted stigma refers to the past experience of unfair treatment by others due to one’s seropositive status; anticipated stigma is the expected belief that prejudice, discrimination and stereotyping will be directed at the self from others in the future (Earnshaw & Chaudoir, 2009); internalized stigma is a subjective process, embedded in the sociocultural context, characterized by negative feelings (about the self), maladapted behavior, the transformation of identity or the application of stereotypes resulting from an individual’s experiences, perceptions or anticipation of negative social reactions on the basis of their mental illness (Szcześniak, Kobyłko, Wojciechowska, Kłapciński, & Rymaszewska, 2018). MSM encounter stigma from the general population, at the workplace, in hospitals or clinical settings from health care professionals, and from their friends and families, whether they are HIV seropositive or not. MSM also experience stigma in the utilization of PrEP for HIV prevention. This prevents disclosure of serostatus to current and potential partners, and also inhibits the utilization of medications that help prevent HIV (Koester et al., 2018).

Disproportionate impact on Black/Latinx MSM

Across all races, MSM are disproportionately affected by HIV. The sexual network is relatively small compared to the heterosexual population, while the HIV prevalence among MSM is high. This predisposes MSM to a higher risk of exposure to HIV. Among young men

aged 13 to 24 years, Black MSM are more than 14 times as likely to test positive for HIV than White MSM (CDC, 2015). This necessitates the need for interventions to target and engage MSM in their early lives with HIV prevention education and other tools they need to reduce the risk (Mayer et al., 2013; Andrasik et al., 2014; CDC, 2015) of HIV transmission.

Race also underpins other social drivers of HIV stigma in the MSM community. A combination of assortative mixing, a the tendency for a particular racial group to date others within their race, tight sexual networks and high viral loads within communities as a result of the negative impacts of stigma and discrimination on testing, access to care, ART adherence, and low rates of viral suppression (Fujimoto & Williams, 2015) account for the greater proportion, particularly true of African Americans in general and African American MSM.

In addition to race, gender and socioeconomic disparities as underlying factors of HIV transmission among the MSM community, age is also a factor with young MSM more at risk to be living with HIV (Hoenigl, Chaillon, Morris, & Little, 2016; Singh, 2017).

Importance of Intersectionality

Intersectionality is a concept used to characterize the convergence of multiple stigmatized identities within a person or group, and to address their joint effects on health and wellbeing (Turan et al., 2019). Stigma and homonegativity – an alternative term for homophobia that describes negative attitude towards homosexuality – against MSM interact with other forms of discrimination creating powerful forces that drive the HIV epidemic (Fabian et al., 2019). Race, ethnicity, and social economic status contribute to stigma and lead to mental and health disparities among MSM because they possess identities that are devalued (Pantelic, Sprague, & Stangl, 2019). In addition, internalized and enacted stigma around sexual minority orientation, homonegativity in the ethnic communities, fear of losing family and friends, and lack of support,

results in a low sense of self-worth and self-esteem and compel MSM to hide their HIV status, disengage with HIV services care such as ART uptake, medication adherence, delay in and/or avoidance of HIV testing, and prevents meaningful engagement with community-based HIV prevention efforts (Murray, Gaul, Sutton, & Nanin, 2018).

Structural intersectionality describes the interlocking interactions of structural conditions with social identities such as race, gender, sexual orientation, occupation, and class which complicate the lives of racial and other minority populations at an individual level (Collins, 2000; Crenshaw, 1991; Guenther, Pendaz, & Makene, 2011). i.e. MSM of color, living with HIV, and unable to gain access to HIV care due to lack financial support (paid job) that would allow have him affordable insurance. In my study's context, the use of intersectionality is deployed to understand the broad factors that not only impact the experiences of stigma among MSM but also how these factors impact other devalued identities like HIV seropositivity. Specifically, it illuminates the ways that racism, sexism, classism, homophobia, transphobia, xenophobia and socioeconomic power interact with broader structural forces to shape the experiences of MSM.

Using the socioecological model to understand the role of HIV Stigma in current HIV inequities.

To address and reduce HIV stigma among MSM, there is a need to appropriately conceptualize and clarify the concept of stigma, as not only an individual-level barrier but a multi-level barrier that is intertwined with racial, social, and economic forces. To better understand the role of stigma in current HIV inequities, I am using the socioecological model which has 5 levels – individual, interpersonal, community, institutional and structural (Kaufman, Cornish, Zimmerman, & Johnson, 2014). Stigma, including HIV-related stigma is also

perpetuated at three broad different levels with varying outcomes: structural or macro level, community or meso level, and individual or micro level (Kaufman et al., 2014; Li et al., 2018).

The drivers of HIV stigma at the structural or macro level include harmful cultural, social and gender norms; discriminatory health and occupational policies; and a poor legal environment that provides social protection for vulnerable populations (Stangl et al., 2019; Mayer et al., 2013). At this level, stigma against MSM works through unfriendly social and health policies, as well as religious and moral discourses that criminalize or label MSM as “perverts”, discriminate and marginalize their rights, and encourage social violence against MSM. These drivers create barriers to health access and treatment, facilitate risky social and health practices, and impede the abilities of MSM to engage in positive health-seeking behavior (Li et al., 2018; Rodríguez, Madera, & Díaz, 2013).

At the interpersonal and/or community level, social isolation, lack of social support and trust, especially from family, results in poor mental health among persons living with HIV (PLWH) (Whiteley, Brown, Swenson, Kapogiannis, & Harper, 2014), discrimination and violence towards PLWH and seronegative MSM, caused by HIV-related stigma thus puts all MSM at risk of reduced HIV testing, poor engagement in HIV care, sexual risk taking (between self and partners). The economic ramifications of stigma, (e.g. living below poverty level, unemployment) may also be experienced by MSM (Stangl et al., 2019). However, disparities persist within the MSM community in terms of how stigma and other co-occurring influences that drive HIV transmission rates are experienced (Halkitis, Wolitski & Millett, 2013).

According to Earnshaw et al. (2013), stigma is experienced differently between PLWH and MSM who are HIV seronegative.

Key individual level barriers include low socioeconomic status, poor health seeking behavior, lack of awareness of HIV infection, delays in testing which result in lower levels of ART use, issues with ART adherence, and lower rates of viral suppression. Income/Wealth disparities among minority populations create additional barriers to the successful acquisition of resources such as medical information and care, reducing the likelihood of obtaining quality health care (Halkitis, Wolitski, & Millett, 2013). The National Poverty Center (2017) stated that the rate of poverty is three times higher for Black/African American MSM compared to white MSM, and this is caused by socio-structural barriers such as low-income, low education, incarceration, unemployment (Maulsby et al., 2014; Reif, Safley, McAllaster, Wilson, & Whetten, 2017), and inaccessibility to HIV care and treatment.

According to Halkitis, Wolitski & Millett (2013), the drivers of HIV-related stigma among MSM in the United States regardless of race and ethnicity cannot be attributed solely to individual-level factors but also by a range of contextual factors that are deeply rooted in the cultural, historical, and political structures of the country. Social structures play a significant role in perpetuating or driving the HIV epidemic among MSM. Social structures and norms that underscore heteronormative identities, can foster homonegativity and discrimination against MSM and cause them to be isolated from their families, communities, and the general society that otherwise, would have formed a social support system for this group especially when they become HIV seropositive (Halkitis, Wolitski, Millett, 2013).

At the institutional level, HIV stigma works through unfriendly social environments that facilitate social rejection and exclusion of PLWH. Facility or healthcare-related stigma against MSM who seek health services from healthcare providers also result in negative health outcomes (Eaton et al., 2015). Hence several studies have argued that it is imperative to create an inclusive

health care system and one that encourages positive communication and the empowerment of MSM in order to reduce HIV stigma. (Batey et al., 2016; Davtyan, Olshansky, Brown, & Lakon, 2017; Heijnders & Van Der Meij, 2006; Shangani, Naanyu, Operario, & Genberg, 2018). HIV-related stigma perpetrated against PLWH by HIV seronegative MSM is also driven by the fear of contagion given the connections of morbidity and mortality to the disease (Brown, Macintyre, & Trujillo, 2003), as well as ignorance and lack of proper knowledge or understanding of the illness (Sengupta, Banks, Jonas, Miles, & Smith, 2011). Macro level and institutional factors include poverty, low income, unemployment, lack of insurance and connection to health care, as well as limitations in accessibility of HIV prevention efforts (Li et al., 2018; Magnus et al., 2010; Millett et al., 2012).

At the structural level, Wilson and Moore (2009) implicate the role of institutions as they may further reproduce the barriers to effective HIV response among the Black/African American MSM community. Their study showed that the lack or absence of culturally competent health providers and, the lack of transparency and open communication between health departments and community-based organizations (CBOs) are barriers to HIV stigma prevention efforts. Furthermore, the study found that existing interventions are not effectively tailored to the unique needs of Black/African American MSM, most especially in regard to their social and regional contexts.

The socioecological model helps to identify the intersection of factors that underpin and drive stigma, as well as the adverse outcomes of stigma for both HIV seropositive and HIV seronegative MSM. It disentangles all of the different dimensions of stigma, provides an understanding of how individuals, regardless of their sero-status, experience stigma, the mechanisms through which HIV stigma impacts individuals; the psychological, behavioral, and

health outcomes of stigma as well as reviews the measures of interventions that have been developed to reduce stigma in order to identify existing gaps. To understand this variation, and to also bridge the gap between the conceptualization and measurement of HIV stigma in the MSM community, a HIV Stigma Framework was proposed.

The framework essentially asks and addresses three key stigma questions: who is affected, how are they affected, and what are the outcomes (Earnshaw & Chaudoir, 2009).

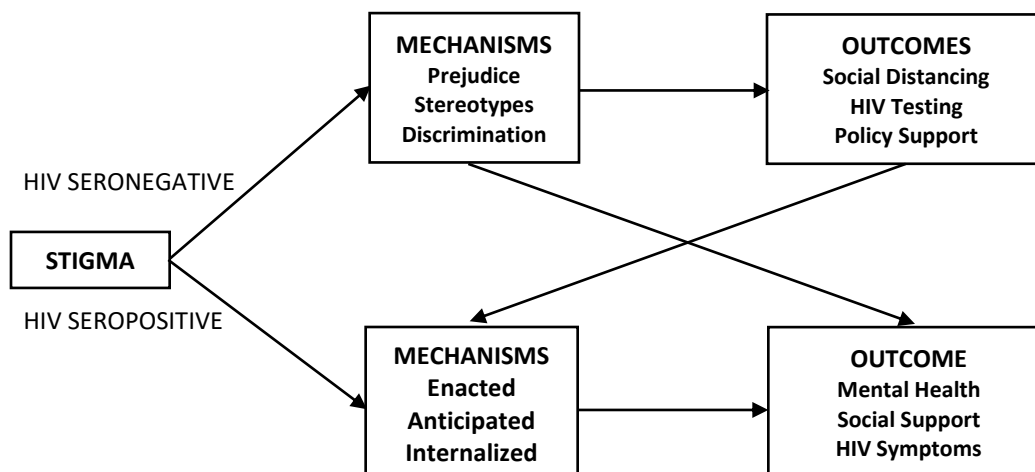
Using the HIV-Stigma framework to identify stigma interventions for MSM

This framework is thus deployed to explore the meaning of stigma, possible stigma reduction interventions, mechanisms and the resultant health outcomes experienced especially between PLWH and HIV seronegative respectively (Earnshaw & Chaudoir, 2009).

According to the HIV stigma framework (see figure 1) by Earnshaw and Chaudoir (2009), stigma is perpetuated among HIV seronegative individuals through three different mechanisms: prejudice, stereotyping, and discrimination. “Prejudice refers to the negative sentiments and feelings such as disgust, anger, resentment and fear” that HIV seronegative individuals may feel toward PLWH. Stereotypes are group-based beliefs about PLWH. “Discrimination refers to behavioral expressions of prejudice” by HIV seronegative individuals towards PLWH” (Earnshaw & Chaudoir, 2009, p. 1163). On the other hand, PLWH experience discrimination in the form of job loss, social rejection, and physical violence. When PLWH expect or anticipate the reoccurrence of these experiences, this is referred to as anticipated stigma. Anticipated stigma is the extent to which PLWH endorse whether knowingly or unknowingly, the negative stereotypes about themselves in relation to their seropositivity. Enacted, anticipated and internalized stigma among PLWH produce negative outcomes which include psychological and emotional distress, substance use, depression and other risky sexual

behaviors. These individuals are also less likely to disclose their status leading to higher transmission rates. In turn, stigma mechanisms also impact health outcomes among HIV uninfected individuals as negative stereotypes around the infection may prevent HIV testing and diagnosis; and can cause them to break social ties with people within their social and familial networks who are perceived to be seropositive.

Figure 1: Model of HIV stigma mechanisms and outcomes



Source: Earnshaw and Chaudior (2009).

Data have shown that comprehensive knowledge of how biological, psychosocial and economic factors interact to drive health-related stigma across the socioecological spectrum is important to effectively target interventions to help reduce HIV-stigma in communities (Nevin et al., 2018). Several studies (Batey et al., 2016; Nyblade et al., 2018, 2019) have explored the experiences of stigma and have put forward diverse methods and means to reduce health-related stigma in different communities and social contexts across the world. Yet, the issues of efficacy and appropriateness of stigma interventions in improving health outcomes still remain (Rao et al., 2019), especially for vulnerable groups like MSM. Additionally, there is a lack of

intersectional or holistic approaches to effectively address the multifaceted dimensions of HIV-stigma.

A randomized controlled trial conducted by Fabian et al. (2019), explored the effectiveness of an intervention to improve health outcomes among black women being treated for HIV. The intervention arm participated in group workshops designed to reduce HIV-related stigma, where peer facilitators lead group discussions, exercises on stigma and coping skills; and the control arm participated in a group workshops on breast cancer education, skill building and peer support/counselling. Although this study involved African American women, this can be tailored to the MSM communities. Fabian et al found that, tackling certain moderators including “stigma” when present at baseline of engagement in care by the women, resulted in greater improvement in health indices such as engagement and retention in care, an important chronic management of HIV.

A review by Brown et al. (2003) which assessed various HIV stigma-related interventions presented in several research studies also revealed the problem of ineffectiveness. This review showed that 14 of the 22 stigma reduction interventions “aimed to increase tolerance towards PLWH among different segments (or proxies) of the general population using a variety of intervention strategies with mixed success” (Brown et al., 2003, pp. 62–63). The results of their review also showed the need for evidence-based knowledge to inform effective HIV stigma-related interventions.

Similarly, the review conducted by Sengupta et al. (2011) assessed HIV stigma reduction interventions that used pre-assessment and post-assessment tests in a population that administered four stigma reduction strategies: information-based approaches, skill building attitudes, counselling approaches and contact/interaction with PLWH. The researchers

highlighted gaps in the knowledge of effectiveness in HIV stigma reduction interventions (Sengupta et al., 2011). Of the 19 studies reviewed, 14 studies recorded significant positive impact. The authors suggest that interventions might be more effective when a combination of strategies are deployed to reduce HIV stigma. However, none of the 19 studies reviewed showed a common measure for evaluating the efficacy of the interventions deployed. Furthermore, none of the 14 studies that documented significant positive impacts assessed the connection between HIV-stigma reduction and health behaviors and outcomes such as increases in HIV testing and improvements in mental health. In other words, knowledge of what constitutes holistic and effective interventions is limited.

Brown et al. (2003) found some limitations in HIV stigma interventions such as the lack of knowledge of the impact of successful and sustained interventions and few efforts that targeted health professionals. Similarly, Stangl et al. (2013) documented gaps in existing HIV stigma reduction strategies which included the lack of standardized stigma measures to assess the outcomes and effects of HIV-related stigma interventions, and the need for more meticulous and methodological research designs to describe the outcome of HIV-related stigma reduction efforts. There have been other interventions to reduce HIV stigma such as structural and biomedical approaches in preventing new acquisition or transmission of HIV and to form new strategies of reducing stigma (Stangl et al., 2013). The structural approach was to penalize discrimination in the workplace or hospital setting, therefore making sure that there is justice for PLWH if they are being discriminated against. The biomedical approach was to encourage the “normalization” of HIV through the availability of Antiretroviral Therapy (ART), used in the treatment of HIV, Pre-Exposure Prophylaxis (PrEP), Post-Exposure Prophylaxis (PEP), and access to HIV testing in reducing stigma in communities affected by HIV (Stangl et al., 2013).

Not disclosing HIV status because of fear of being harassed, embarrassed, victimized or incarcerated has been associated with increased HIV transmission (Rodriguez-Hart et al., 2018). Interventions that facilitate disclosure or that integrate a trauma-informed care approach with legal and mental health services have proven to be efficient in other study populations (National LGBT Health Education Center, n.d.). Training health care providers on knowledge, skills, tolerance for PLWH and their families has also facilitated reductions in HIV stigma. However, effective monitoring and provider perceptions of HIV stigma are needed to compare the outcomes of the HIV stigma reduction programs (Heijnders & Van Der Meij, 2006).

Several articles (Brown et al., 2003; Sengupta et al., 2011; Stangl et al., 2013) discussed the methods and means of reducing the stigma in different communities across the world. More research measuring the efficacy of HIV stigma interventions in improving health outcomes are needed amongst MSM. MSM encounter stigma from the general population, at the workplace, in the hospitals or clinical settings from health care professionals and even amongst their peers whether they are living with HIV or not.

Through a population of MSM in the Pacific Northwest, specifically in communities in the states of Washington and Oregon, this paper investigates: (1) the ways that HIV-related stigma is anticipated, internalized and experienced by MSM who are HIV seropositive; (2) the perceptions held by PLWH and HIV seronegative MSM especially in the context of HIV/AIDS; and (3) elicits suggestions from MSM living with HIV and MSM who are seropositive regarding effective intervention strategies to reduce HIV stigma that challenge HIV reduction efforts among this population.

To this end, this study will address the research question: what are the perceptions, attitudes and experiences of HIV stigma among MSM, perceptions of HIV stigma reduction

programs, and what strategies are perceived as effective in reducing stigma among this population.

STUDY AIMS

The study aims to understand the experiences of HIV-related stigma among MSM. It explores how stigma is experienced by PLWH and HIV seronegative MSM. This study also aims to utilize the stigma framework model to elucidate possible interventions that would be effective in reducing or eliminating HIV stigma in the MSM community.

METHODS

STUDY DESIGN SETTING

Between February 15th and May 31st, 2017, a total of 93 participants from 7 cities across the Pacific Northwest (PNW) of the United States along the I-5 corridor responded to an invitation/advertisement promoted by the UW/Fred Hutch CFAR Community Action Board – Stigma Working Group and Pierce County AIDS Foundation to participate in a series of 13 Focus Group Discussions (FGDs) in their respective areas. The investigators from UW/Fred Hutch CFAR Community Action Board – Stigma Working Group collaborated with community-based organizations (CBOs) throughout the PNW area to participate in this study. The cities included are Bellingham, Everett, Seattle, Tacoma, and Olympia, Washington, and Portland and Eugene, Oregon. All protocols for research with human subjects were approved by the Institution Review Board (IRB) of the University of Washington.

STUDY POPULATION

The study population was comprised of PLWH and HIV seronegative men, separated into two distinctive groups, who self-identified as gay, transgender and/or are men who have sex with

men (MSM) who resided in the seven cities mentioned above and were within the age range of 18 and 79.

SAMPLING METHOD/RECRUITMENT

Participants were organized into two major groups: MSM living with HIV and MSM who were HIV seronegative (including persons who were assigned male at birth and have a female gender identity – transgender women) at the time of the focus group. It is important to note that the focus groups for MSM who were living with HIV were independent of those for HIV seronegative MSM to preserve confidentiality and to create a safe space for participants to speak freely about their experiences with stigma and how it affects them. These two groups were further regrouped into smaller groups of 2 – 9 participants. A total of 13 focus group discussions (FGDs) for MSM were formed: seven groups for MSM living with HIV and six groups for HIV seronegative MSM. Each focus group discussed the questions listed in table 3 (see appendix).

The selection of study participants was informed by the community-based organizations in the cities mentioned above. The participants were recruited mainly through promotion of the FGDs by the community-based organizations listed in table 4 (see appendix) who were located in each of the 7 cities. The community-based organizations were able to engage members of the community by distributing recruitment flyers for the FGDs at community events. The flyer instructed interested parties to contact the study coordinator if they were interested in the study. The selected men were invited to answer qualifying questions by the study coordinator to determine if they met the eligibility criteria (18 years and above, identify as cisgender male, transgender woman, and reported having sex with men).

ELIGIBILITY/EXCLUSION

Eligibility criteria for the study participants were: cisgender men and transgender women who were at least 18 years, identified as gay, and/or reported sex with men, and willing to give informed consent. The exclusion criteria were cisgender women, cisgender men who identified as heterosexuals, transgender persons who were not having sex with men, minors who were under the age of 18 years, and those who were unable to provide informed consent. All participants received a \$50 gift card for their participation. Participants completed written informed consent. This study was approved by the University of Washington IRB (Institutional Review Board), protocol number 243.

DATA COLLECTION

The FGDs were facilitated by one interviewer who identified as MSM and a field assistant to take real time notes. The discussions were conducted in English and were audio recorded for accuracy and to ensure that all data from the FGD were captured. Verbal informed consent was obtained from all participants. All discussions were designed to take approximately 90 minutes to complete. The question guide included open-ended questions and probes. The development of the question guide was formulated by members of the community action board (CAB), stigma working group (SWG) and researchers from the Fred Hutch and the University of Washington (UW) who had previously conducted an extensive literature review on HIV stigma.

All participants signed a confidentiality agreement to preserve anonymity throughout the study. After recording of all sessions was completed and transcribed, all personal identifiers such as participant's names, organizations they were associated with, organizations or institutions they worked with as well as names of employers and certain areas, cities, states were de-identified. Once the transcription process was reviewed and finalized, all the audio files were destroyed.

The de-identified and transcribed data were accessible to the community based participatory research team members only.

DATA ANALYSIS

The CAB SWG identified members who wanted to learn how to analyze FGDs. A team of one community partner and one academic partner who had received training in community based participatory research conducted a half day training about coding and analyzing FGD using CBPR methods. The SWG formed teams of coders with a community and academic members. These groups co-developed codebook and independently co-coded each transcript, met in teams to discuss codes, and identify discrepancies until full consensus was reached on all of the final codes. Final codes from the first 3 FGDs were utilized to create an initial codebook.

I joined the CFAR CAB – SWG after the data collection had been completed. I familiarized myself with the data by reading the transcripts multiple times, took notes, attended monthly SWG meetings and collaborated with SWG members to orient myself with terms and language used in the transcripts. I modified the codebook with the assistance of my thesis committee. A second coder (graduate student) and I utilized the modified codebook to code the first three transcripts. We coded each transcript independently and then met to discuss our codes, identify discrepancies until consensus was reached for each code with the thesis committee. This process of ensuring intercoder agreement, invariably reduced the subjectivity inherent in coding (Bernard & Ryan, 2010). The updated codebook was used for the remaining transcripts. The codes were managed and organized using Microsoft Word documents and an Excel spreadsheet. During the coding process, codes were enumerated manually through an iterative process which included multiple meetings with coders and the thesis chair. Thematic content analysis was used to guide the identification of themes by tagging sets of texts with codes (in word document) that

are derived from theory or prior knowledge and then analyzing the distribution of codes statistically by counting the number of times the codes were applied in the data (Bernard & Ryan, 2010, pp. 287–288). The codes were considered a theme if it was endorsed by 6 or more people. The findings are presented with supporting quotes from the participants designated by their groups and participating cities.

RESULTS

A total of 93 individuals participated in the focus group discussions (FGDs) (see Table 1). The FGDs took place between February 15th and May 31st, 2017. Self-reported HIV serostatus indicated that 56 (60.2%) were persons living with HIV (PLWH), 33 (35.5%) were HIV seronegative, 2 participants (2.1%) were unaware of their HIV serostatus and 2 (2.1%) reported no prior testing for HIV.

Table 1: Participant Characteristics

Participant characteristics		N (%)
Age	18 – 29	14 (15.1)
	30 – 39	19 (20.4)
	40 – 49	16 (17.2)
	50 – 59	28 (30.1)
	60 – 69	12 (12.9)
	70 – 79	4 (4.3)
Race	White/Caucasian	62 (66.7)
	Black/African American	12 (12.9)
	Native American/Alaskan Native	5 (5.4)
	Asian	1 (1.1)
	Two or more races	8 (8.6)
	Other	3 (3.2)
	No answer	2 (2.2)
Gender	Cisgender Man	90 (96.8)
	Transgender Man/Transman	3 (3.2)

Sexual Orientation	Gay	76 (81.7)
	Bisexual	10 (10.8)
	Pansexual	2 (2.2)
	Asexual/Heterosexual/Other	3 (3.2)
	Prefer not to answer	2 (2.2)
Education	High school degree or less	19 (20.4)
	Some college degree	33 (35.5)
	College degree or more	38 (40.9)
	No answer	3 (3.2)

Participants described the ways they were affected by HIV-stigma they experienced within and outside the MSM community. This was a difficult and sensitive topic for most participants to discuss. Participants also discussed ideas for interventions on stigma reduction based on their experience of past interventions and what they would like to see in the community. (see Table 2).

Table 2: Theme and Subthemes Identified by Participants

Themes and Subthemes	Number of participants mentioning item [N=93 (%)]
Stigma	
<ul style="list-style-type: none"> • HIV-related • Sexual orientation • HIV-seronegative 	<p>64 (68.8)</p> <p>16 (17.2)</p> <p>6 (6.5)</p>
Suggested Interventions	
<ul style="list-style-type: none"> • Education <ul style="list-style-type: none"> ○ <i>Sex/Sexual education</i> ○ <i>Provider education</i> 	<p>89 (95.7)</p> <p>70 (75.3)</p> <p>19 (20.4)</p>
<ul style="list-style-type: none"> • Messaging 	50 (53.8)

<ul style="list-style-type: none"> • Media 	43 (46.2)
<ul style="list-style-type: none"> • Normalize 	26 (28)
<ul style="list-style-type: none"> • Increased widespread HIV testing 	20 (21.5)
<ul style="list-style-type: none"> • Improved access to preventive methods (PrEP, condoms) 	10 (10.8)
<ul style="list-style-type: none"> • Support <ul style="list-style-type: none"> ○ <i>Essential services</i> ○ <i>ASOs/FBOs</i> ○ <i>Community building</i> ○ <i>Family, friends</i> ○ <i>Mental health services/providers</i> ○ <i>Peer support/mentoring</i> 	20 (21.5) 19 (20.4) 18 (19.4) 17 (18.3) 16 (17.2) 10 (10.8)

Note: HIV – Human Immunodeficiency Virus; PrEP – Pre-Exposure Prophylaxis; ASOs – AIDS Services Organizations; FBOs – Faith Based Organizations

Types of stigma experienced

Participants described three subthemes (HIV-related, sexual orientation, and HIV-seronegative) pertaining to the different kinds of stigma experienced. These stigma experiences (HIV-related, sexual orientation and serodiscordant couples) were common to both seropositive and seronegative MSM groups. (See Table 2).

HIV-related stigma

HIV-related stigma – defined as the negative attitudes and beliefs about people living with HIV, especially when their serostatus is made known – was a key subtheme expressed by most participants (64/93) in the HIV seropositive (41/64) and HIV seronegative (23/64) MSM focus groups. HIV seropositive men revealed both anticipated and enacted forms of stigma, including fear of harm or danger, and social isolation upon disclosure of their seropositive status to family, and friends. Furthermore, MSM living with HIV who had not disclosed their status

anticipated the fear of negative treatment that they might receive from coworkers at their place of work or how they might be addressed when their serostatus is known.

Well, in the workplace, it's one of those situations. It's been a long time since that's been an issue. ...people that are HIV, oh, well, if they find out that you're HIV-positive, then they kind of set you off in a different group. You get isolated. *Participant living with HIV, Seattle*

...Oh, well, we can't talk to you anymore." And, people that are HIV, they're gonna go, "Oh, well, if they find out that you're HIV-positive, then they kind of set you off in a different group." You get isolated. *Participant living with HIV, Everett*

As a thought about people you've known for years and years suddenly turn around and hate you. You were great friends and all of a sudden, they learn this one fact about you [HIV seropositive status] and you're instantly hated. The turnaround is just crushing. *Participant living with HIV, Eugene*

HIV seronegative MSM reported the ways that they have seen HIV stigma perpetrated against MSM living with HIV. HIV seronegative MSM also reported their observations of how being HIV seropositive is perceived among the public especially during HIV-related intervention programs.

I used to help with HIV organizations. I don't have HIV, but it's like when I'm at the booth for AIDS Walk or at public events... people look at me like, oh, I don't have AIDS. I don't need to talk to you. And I'm like, it's not about that. We're just trying to educate you and talk to you. And they're like, oh no, I don't have AIDS, and they run away from my booth. But they wanted the condoms on the table, right? ... Thanks for disclosing... That whole stigma right there. They felt the need to now tell me, but I wasn't asking... *HIV-negative Participant, Tacoma*

I have friends who live in [name of city], and as long as you're not HIV-positive, as long as you're not out about being gay, it's a great place to be, but if those things happen, then it becomes a very challenging place to be, and it becomes very dangerous because you never know who's going to shoot [fire ammunitions] at your house. *HIV-negative Participant, Portland*

Sexual orientation

Among MSM who are HIV seronegative (13/16) and MSM living with HIV (3/16), the idea of disclosing their sexual orientation to certain groups was uncomfortable for some of the participants (16/93). Most participants felt excluded from social groups or felt unsafe because of

the threats of violence in their neighborhoods against MSM, this was particularly true in the Portland, OR area (5/16). Others were denied access to family members, limiting their ability to build relationships with their children. Sexual identity is thus, further complicated by seropositivity. This is an example of how the intersectionality of two devalued identities – HIV seropositive and homosexuality – interact to magnify the experiences of stigma.

I think it [identifying as being gay] also manifests in violence, both physical and verbal, depending where you are, especially in [name of state], in the rural areas. That's why I was hoping you guys would actually get in the rural areas and get some information there, because that's a voice that is not heard. It's a matter of life and death. That piece is kind of important. *HIV-negative Participant, Portland*

I get my healthcare through the Veterans' Administration, and sometimes, I think that they drag their feet on calling me back because, obviously, because I'm POZ, I must be gay, and I'm in a military environment. So, we've got a couple of stigmas going on there like I don't have to call this faggot back. *Participant living with HIV, Olympia*

I think... in our [gay] community, I feel it's pretty much the same. But I feel like in the straight community, if someone has HIV or AIDS, they automatically assume that person is gay. And because being gay has such a negative connotation associated with it, it's automatically even worse when you have HIV. It's like, not only does he have HIV, he's gay *HIV-negative Participant, Tacoma*

I inherently identify with the African Community and there is already so much stigma in being a black person, a gay person, and then top it off with being HIV-positive. I often joke with my friends. You can be black and gay. You can be black or gay. But you can't be black, gay, and HIV-positive. It's like a triple threat... You can't succeed. That's just too much for anybody in the community to handle, especially with family. Let's not even get started talking about church and all of those types of things. *Participant living with HIV, Portland*

HIV-seronegative

While HIV-seropositivity increases experiences of stigma, being HIV-seronegative especially within the MSM-HIV community, is not free from forms of discrimination and prejudice that tend to minimize the agency and validity of support services available to HIV seronegative MSM. This was not a major sub-theme; it was solely experienced by persons who

were HIV seronegative (6/33). Although this is also a form of HIV-related stigma, it is presented under this sub-theme as it is directly experienced from being HIV-seronegative.

Participants in the focus group discussions reported that there are several organizations that serve the HIV community that also require volunteers to participate in activities such as local community events and support group services. Thus, some volunteers from community-based organizations within the MSM community take time out to serve other LGBTQI members within the community. However, when HIV-seronegative MSM volunteer in these support groups, they are shunned, ignored, and they feel isolated because the MSM-HIV community feels that their seronegative status disqualifies them from being able to provide support or make important contributions to the group.

I think peer support is huge – peer support groups and even one-on-one counseling, with either HIV-positive or –when you’re with someone who’s like-minded or going through the same thing. I know it’s helped most of my friends who are in the HIV support group. I’ve met a few people that go to it and they’re lifelong friends... They’re kind of excluding me from their groups now because I’m not HIV-positive. I feel stigma. I feel stigma on me, as well. *HIV-negative Participant, Seattle*

Furthermore, HIV seronegative MSM who work in HIV support organizations also reported experiences of stereotypes and stigma assigned to HIV seropositivity based on the public’s assumption that they were seropositive because of their identification and work with HIV support groups.

...also, living in that isolation – even if you’re HIV-negative and you work in the field, the assumption is that you’re positive, so you’re treated that way, even though you’re negative. *HIV-negative Participant, Portland*

Interventions on stigma reduction

Participants discussed solutions or interventions that may help reduce or eliminate stigma within their communities. The subthemes were described between seropositive and seronegative groups across the I-5 corridor. Both groups agreed on majority of the interventions, however,

participants in the seronegative groups focused on interventions in regard to accessibility and availability of HIV testing sites and HIV prevention methods, while participants in the seropositive groups focused on interventions surrounding social support services that are not limited to AIDS Service Organizations and include other services like food and housing.

Education

The most often endorsed intervention focused on the importance of education (89/93). This subtheme was further subdivided into two categories. First, the most common form of interventions that was endorsed by both MSM living with HIV (40/70) and seronegative (30/70) groups was sex/sexual education (70/93). Sex and sexuality education was perceived as a way of educating members of the MSM communities about practicing safe sex and also educating and raising awareness among the general public about the diversity inherent in sexuality and sexual orientation. They recommended that sex and sexuality education be taught or introduced to kids early in life and continued through adolescence. Participants also suggested that having this information available in schools, workplace, and organizations would enhance existing HIV-stigma reduction efforts.

Well, I'm thinking, also, training in the schools. Whether you have one person, or a group of people – like a panel – people should be informed especially the kids. *Participant living with HIV, Seattle*

I would say education, because I feel like doing things on a one-to-one person basis, is how I try to affect people. Instead of just making a giant post somewhere, I'd rather talk to people one on one. And I try to do that with being a person of color, being queer, being an artist. I can be stigmatized sometimes, but I think as long as education and information proliferates, it will trickle down from people who are educated about it to people who need to know. *HIV-negative Participant, Eugene*

...The education part is the crux of the entire thing. Until we start educating the general public, until we start educating people on the real sides of these things, we're not going to get anywhere. The stigma is going to continue and it's probably going to get worse, especially in the climate we're in right now. *Participant living with HIV, Portland*

But I really do think that education [about sexuality] in schools would actually help a lot more because if you catch kids at a young enough age... when someone comes at them with ignorance and misinformation, they'll already know that it's not right... But I think if you can educate somebody early on in life, it's going to help destigmatize stuff that they would later possibly experience. *HIV-negative Participant, Tacoma*

...Everyone should be aware of these, and it should be in standard healthcare, through schools, through parents and everyone. So, everyone needs to be hit. *Participant living with HIV, Bellingham*

Second, participants expressed the importance of provider education (19/93) and ways to improve interaction by being culturally sensitive to PLWH and/or persons who identified as gay or transgender. Participants thought providers should be much more culturally sensitive around the delivery of quality care to MSM. This was echoed by both MSM living with HIV (8/19) and seronegative (11/19) groups and in the focus group discussions.

...the main thing would be the education for the providers and people dealing with us, so we can feel comfortable going to a place – at least have a sort of a safe place for us to go and feel comfortable, at least for an hour or 15 minutes, if you're in a doctor's office. But at least you can go and feel safe seeing that nobody's judging you. *Participant living with HIV, Everett*

Training their staff from the frontlines – people who answer the phones – when you're dealing with claims to figure out – to be culturally sensitive to LGBTQ communities. If a call center has not done that – A majority of providers, I would say, are not culturally sensitive towards LGTBQ communities, and have struggled for a long time to get their patients to actually self-identify so that they can provide the adequate care for them. *HIV-negative Participant, Seattle*

Messaging

This is the next major subtheme that was described by participants (50/93). MSM living with HIV (20/50) and seronegative (30/50) participants highlighted gaps in message delivery such as the use of stigmatizing words in advertising on social media apps. One of such terms is 'DDF', an acronym which means 'drug and disease free', this can be found on advertisements for rental properties or social media apps that provided dating services. This and other terms like 'clean' were perceived by participants as appalling or stigmatizing especially by participants who

reported using these services frequently. Participants living with HIV (5/20) and HIV seronegative MSM (6/30) supported HIV stigma reduction efforts that focus on the elimination of terminologies that convey negative associations with HIV seropositivity.

They want somebody who is not positive or almost like having anything to do with HIV at all. Part of me, part of my brain says it's understandable. Another part is just like, I hate when they use it. I hate when people use it because I look at it as a medical condition. That's my background, is I look at it as it's a medical thing. That's it. ...I even look at the personals [advertisements on social media and dating apps]. Yeah. They say, "looking for somebody clean." I know, just from my own experience, that they're not necessarily looking – if they say they're looking for somebody who's not dirty. That usually says to be they want somebody who's been showered. I want somebody who's drug-free and disease-free, clean. That kind of language. I know that is HIV-negative.
HIV-negative Participant, Olympia

The teaching of proper vocabulary when dealing with [persons living with HIV]. I think educating people and saying things like "clean," "DDF" are very insulting and degrading – "Clean," "you be clean, too –" Honey, I shower every day. I don't walk out of my house without wearing clean clothes and looking my best. That is vocabulary, and I do that [educate people] on Facebook. I am correcting people on vocabulary and how to talk... *Participant living with HIV, Tacoma*

The format of HIV-messaging was also emphasized by participants living with HIV (7/20) and seronegative groups (10/30). For example, the use of apps, catchy phrases, slogans or hashtags to deliver messages on HIV stigma reduction was discussed as especially important to target the younger segment of the public. However, the large majority of ideas on messaging, such as hashtags, were from participants in the younger, aged 18-39 demographic.

Making creative apps, yeah, is part of it. But the latest messaging that I've seen that I appreciate is the "undetectable equals uninfected" [also known as U=U] campaign.
Participant living with HIV, Eugene

Make a new hashtag. #something AIDSy. # HIV, and Me. *HIV-negative Participant, Tacoma*

I have an idea for a logo. It's the word "stigma", and it says, "Start To Initiate Greater Mass Awareness." *Participant living with HIV, Seattle*

Participants from both seronegative (14/30) and participants living with HIV (8/20) groups placed emphasis on “who” they would like to see deliver HIV-stigma reduction messages to the MSM community. Some participants suggested celebrities and/or social media influencers like Magic Johnson, Larry Kramer, Neil Harris, Ru Paul, Charlie Sheen.

Well, since we’re dreaming of ways to get the message out, someone should interview celebrities with HIV. Charlie Sheen, et cetera, et cetera. They hold a lot of sway. The public figures hold a lot of sway. So, if you can get the public figures. *Participant living with HIV, Eugene*

To play on that, what I was envisioning in my head is having, multiple spectrum of people based on race, ethnicities, and genders. “Hey, I’m a doctor. I’m a lawyer. I’m a judge. I’m a this. I’m a that. I’m a mom. I’m a dad. Then, again at the end, it’s just like, “And what do we have in common? We’re all positive.” ...Not too many people are really going to identify with Magic Johnson. Just because he’s kinda like that big person out there that a lot of folks know that’s positive *HIV-negative Participant, Olympia*

Media.

The third major subtheme participants (43/93) suggested regarding interventions on reducing HIV stigma in the community is the use of media to convey messages about the lived experiences of PLWH (20/43) and seronegative persons (23/43). All participants (both old and young) endorsing this theme agreed that media is a powerful tool and often plays a critical role in promoting positive HIV-messaging.

I agree with the role of media; it can be incredibly powerful. Usually, when you see a miniseries or a movie on TV, it highlights the beginnings of the pandemic. It is important... for people to understand the devastating impact that AIDS had 30-plus years ago. And it’s incredibly important to live healthy, thrive – in my case, a much healthier life despite the fact that I still smoke. *Participant living with HIV, Portland*

Participants living with HIV (9/20) and seronegative (12/23) groups described avenues through which these information or messages can be spread around the community and which can also be accessible to different age groups, such as word of mouth, posters, billboards, social media, use of apps, and internet.

I think it does need to happen, but for people that aren't online could probably be told, word of mouth, posters and stuff *HIV-negative Participant, Bellingham*

We need to see advertisement. We need to see billboards on the road that have maybe five people with one saying, "I'm HIV-positive," and one saying, "I'm gay," and one saying, "I'm straight," and we're all friends. *Participant living with HIV, Portland*

Participants living with HIV (8/20) and seronegative (7/23) groups also mentioned methods that can be used by the media for HIV seropositive message, and which they can also use to share past experiences such as mini-series, TV shows, reality TV, commercials and documentary series.

A reality television show would be really cool, if you're dreaming big. It would be really cool across the country, even internationally, to see the day-to-day lives of people who are living with HIV, and even a mixed relationship. That would be great to see behind – I just got that idea from that – to see behind the closed doors of a person living with the virus, and successfully living with the virus. *HIV-negative Participant, Seattle*

Regular people off the street doing a little like interviewing people and documentary series and something like that you know. It's nice to just talk to the public as opposed to someone who is a household name. Because, it's like they're paid to do that. They're just saying what's scripted. *HIV-negative Participant, Tacoma*

Participants living with HIV (3/20) and seronegative (4/23) groups placed emphasis on 'who' they would like to see deliver HIV-stigma reduction messages to the MSM community. Participants mentioned that the people who would play these roles should be represented by the population that is most affected by the stigma, and not models or actors. Participants suggested celebrities or social media influencers like Magic Johnson, Larry Kramer, Neil Harris, Ru Paul, and Charlie Sheen or regular people.

Well, since we're dreaming of ways to get the message out, someone should interview celebrities with HIV. Charlie Sheen, et cetera, et cetera. They hold a lot of sway. The public figures hold a lot of sway. So, if you can get the public figures. *Participant living with HIV, Eugene*

I actually really dig the commercial idea... I think that actually would help people. Just saying, "Hey, it's like, hi." Whether it's somebody who's famous [like] Magic Johnson, or not, and it's like, "Hey, I've been living with HIV for X number of years," ...having that [serostatus] as the last point in the commercial... "Here's my life. Here's my

husband. Here's my wife. Here's my kids. Here's all these things that I do. I'm healthy. Oh, and by the way, I'm HIV positive." Just that last little drop of that tagline. *HIV-negative Participant, Olympia*

Normalize.

The next subtheme discussed by participants (27/93) is normalizing HIV. This sub-theme was less common in the HIV seropositive groups (12/27) compared to the HIV seronegative groups (15/27). Participants emphasized that PLWH are to be portrayed as healthy human beings living with a chronic disease that can be managed when taking the appropriate medications. Normalization also meant the need to break down stereotypes of people who are HIV seropositive by showing that HIV-seropositivity cuts across all demographics regardless of race, sexual orientation and age. There is also a need to illustrate that members of this community are like "everyday people who perform everyday tasks".

Basically, going around, let people know what our community looks like, with, I guess, pamphlets, whatever. I think it's you that said it, about people working – showing people in everyday, working class...doing the same thing. In other words, we're just like everybody else. *Participant living with HIV, Seattle*

I'll say that, though. So, I feel like just putting faces to it and feeling like people are actually connecting the dots of HIV. I'm not sure if other people are doing that. *HIV-negative Participant, Bellingham*

Just showing the diversity of the HIV community. We are parents, we are husbands, we are wives, we date. It used to be where I was told that I shouldn't be dating, and we are who we are. We're normal folk. That's what it comes down to. We are just like everybody else. We're dads. We're whoever we are, and to say that we are supposed to be some depressed, sick individual who spends a lot of time alone in their room – yeah, that might be true for some of us, but that's an individual's issue. That has nothing to do with us as a community. *Participant living with HIV, Tacoma*

Widespread HIV testing.

Where HIV testing as a form of intervention didn't come up in the MSM living with HIV group, participants (20/33) in the seronegative focus groups recommended an intervention that they perceived would promote widespread HIV testing not just amongst partners, or within the MSM community, but with other sub-populations like people who inject drugs and general

population will help to promote widespread HIV-testing and also reduce HIV-stigma. For example, participants (3/20) felt that normalizing HIV testing so that partners would do it on their first date would be an ideal way forward.

...we got tested for HIV, for everything, Chlamydia, because I hadn't been tested. I hadn't been with anybody. and this person hadn't been tested recently, so we made a date out of it, and we came to {name of ASO} together and had testing... *HIV-negative Participant, Eugene*

I think it's good to have a variety of a diverse set of get tested as a group, because it makes it seem like a normal process to go through. More relatable, more regular, where it's not like just for the gay community, not just for people who do drugs, or for someone who is highly sexually active. *HIV-negative Participant, Tacoma*

Improved access to preventive methods.

Participants (10/33) in the seronegative group recommended improved access to preventive methods such as PrEP and condoms. These participants suggested that information about PrEP and condoms should be made available at the clinics, community events or in safe spaces where individuals can access information.

Yeah, PrEP I think the more and more people that get on that, the closer that brings them to being not HIV positive, but understanding the same thing, fighting the same thing. And I think that would bring people together. I never hear about it. *HIV-negative Participant, Bellingham*

They drink milk because they see the "Got Milk?" commercials, so – You rarely see anything – I've never seen PrEP on TV. That's one thing. *HIV-negative participant, Seattle*

Support.

The majority of participants in the Olympia HIV seropositive group (8/9) did not have access to any kind of current support services at the time of the focus group discussion.

However, participants living with HIV (64/93) and seronegative group (36/93) discussed the different types of support they would need or like to see more of as a component of the HIV-stigma reduction interventions. The need for HIV-support services and suggested types were

mentioned by all participants (93) who responded to this question. This shows the importance that participants assigned to direct service interventions needed to reduce stigma in their community.

The type of support services participants suggested from AIDS Service Organizations (ASOs) / Faith Based Organizations (FBOs) ranged from essential services like food and housing, community building, supportive family and friends, improved access to mental health care and providers who deliver these services, to peer support and/or mentoring. These support services were requested by participants in both seropositive and seronegative groups.

Participants living with HIV requested essential services (20/56) or other social services that would meet their daily needs, such as food, housing, financial aid/support, access to affordable insurance. Participants reported that they would feel supported if these services were available to them.

When I see others getting housing, I feel that I'm very supported, because there is hope that the things that I need are there, they are available. I don't know what tomorrow is going to be holding for me. I may not have housing, I may not have food, I may not have some of the needs, such as the very high cost of medication that may not be available. I advocate for lower cost, that becomes more available. *Participant living with HIV, Seattle*

Accessibility and affordability. You know, people being able to afford, if insurance companies aren't picking up, or if programs and places like the HIV don't pick them up, that there are – And also, just having that information, and, as I said, the accessibility. Those are two. *Participant living with HIV, Eugene*

Participants had mixed feeling about their ASOs/FBOs (19/93). Some were grateful for the support they received from the ASOs such as tests for sexually transmitted diseases and general support for PLWH from professional caseworkers. Participants felt that they could access services from these organizations as a group or individually and felt that they provided safe places. In general, participants living with HIV (11/19) and seronegative (8/19) groups who endorsed the need for these organizations, felt much more comfortable if they got support from

CBOs and FBOs. The kind of support these participants needed from the FBOs were ways that MSM could interact with the clergy without discrimination or stigma.

I also want to put in that [Name of ASO] is the go-to. I've been celibate for three and a half years, after a 28-year partnership. And so, when I did start to date again, we came to [name of ASO] together and had a testing date, where we got tested for HIV, for everything [STDs], Chlamydia, because I hadn't been tested. I hadn't been with anybody. And this person hadn't been tested recently, so we made a date out of it, and we came to [name of ASO] together and had testing. So [name of ASO] is the go-to for me here when I'm actually active. *Participant living with HIV, Eugene*

For me – as you said it, I was thinking about the group I met with... last night. It's really [about] finding culturally specific gatherings, and if not finding it, actually creating one. A group of us gay men of color specifically. We used to do it 20 years ago. We'd be able to talk about prevention message, what it means to be gay by however you identify as a person of color, and just create those gatherings again. *HIV-negative Participant, Portland*

Participants living with HIV (8/18) and HIV-negative MSM (10/18) discussed community building where they can work together and interact with members of the community through acts of service; others wanted outdoor activities such as camping and exploring new places; as well as community building through advocacy activities.

Actionable service from our political leaders. From local levels, national levels. I mean, I wanna see somebody like Jay Inslee actually go in, like, "Hey. Let me do some soup kitchen work." Or whatever it happens to be, just, even if it's only a one-hour photo opportunity. Do some damned work. That's the kind of stuff I wanna see. Not just, "Well, we're doing this." It's like yes, it sounds great. *HIV-negative Participant, Olympia*

...Show the community – we need to get more representatives to go out and explain a lot of stuff to people so they will understand the situation of what people with HIV and everything that people do not understand, and there's more representatives to go out and talk to them and explain, "This is what's happening in society all over..." *Participant living with HIV, Tacoma*

Support from family and friends such as acceptance, better communication towards PLWH and/or persons who identified as gay was also emphasized by participants living with HIV (13/17) and seronegative group (4/17). Participants proposed developing a skill-based intervention that would mitigate the stigma.

We've experienced an effort for us to connect with each other. That's pretty much been available for many years, but maybe there needs to be resources to connect with people [who] are not part of this community so that we can develop skills dealing with our perception with stigma and other people's fear or prejudice. I don't know how many of us have skills interacting with someone who has no experience with HIV. *Participant living with HIV, Eugene*

The supports I have is my friends and my family... but that's also tough because depending on [one's] circumstance, [would] they have their friends and family to support them? So, I don't know... These are hopefully your first support [systems], and for those who don't have it, just a proper organization that will help them. *HIV-negative Participant, Tacoma*

Participants (14/16) living with HIV and seronegative participants (2/16) also requested the availability and accessibility of mental healthcare services and providers to their communities.

I think it's important to have better mental healthcare. And that isn't really accessible unless you're going to a university where it's included in your tuition or your bills, or if you're paying out of pocket, because most insurances don't cover psychiatric or mental. *HIV-negative Participant, Bellingham*

So, it may seem lame and awfully right wing, but support also comes from within. And I think that having access to good, immediately accessible psychological care, just general counseling. I think anyone with a chronic condition needs access to whatever counseling they need for the whole term of it, not in crisis, because there's pill fatigue. There's disease fatigue. There are all of these things that you face as you progress through life with this... *Participant living with HIV, Olympia*

Participants living with HIV (8/10) and seronegative group (2/10), described the need for peer support/mentoring support groups for families dealing with recent diagnosis. They also wanted responsible individuals who have been through similar experience to be mentors to young individuals. Participants reported that they would feel supported if all of these needs were met.

If we have peer counseling for newly infected people, why can't there be – it would probably be the psychological piece – why can't there be peer families? Families who have moved through it and are in a good space. Here's a family newly dealing with it. Can there be a system set up such that families can talk to families? Dads can talk to dads, moms can talk to moms, so they know. I would like to think people are willing but

can't get their head around it. And there's too much emotional past or present or static whatever in a family dynamic... let's face it, this crisis is a platform from which anyone could use to heal or self-destruct. *Participant living with HIV, Olympia*

I find support in people that have been HIV positive as long as I have. Sharing with them, I get support from them. I know one friend of mine had – he was diagnosed in the late '70s. Been a long time with it. *Participant living with HIV, Eugene*

But if we had some sort of a mentor program, where people could come or go if they wanted to, not a one on one, I'll meet you at your house kind of thing, but a room like this that would be open and say there's going to be some mentors there, maybe HIV positive, maybe negative, they have information. These guys are going to be out there in the community, not afraid to be found out kind of stuff, but some sort of mentoring program. *HIV-negative participant, Eugene*

Other findings, although endorsed by some participants, did not emerge as major themes and as such were not included in the results. Stigma themes not included were serodiscordant couples (3/93) described as misconceptions that one has to be HIV seropositive to be sexually partnered with another HIV seropositive MSM. In other words, serodiscordant relationships were assumed to be impossible; and PrEP use (2/93) from non-PrEP users in the MSM community as having negative associations with PrEP use that are related to either sexual promiscuity or the use of a more expensive form of preventive method compared to condom use. Suggested intervention themes not included in the results included study participants desire for social support for all ages at community centers (4/93), crisis hotlines/chatlines (4/93) and services tailored to long term survivors (2/93).

DISCUSSION

This study investigated the ways that HIV stigma is anticipated, internalized and experienced daily by HIV seropositive MSM; perceptions of HIV stigma held by HIV seropositive and HIV seronegative MSM; and suggestions for effective intervention strategies to reduce HIV stigma and other types of stigma that challenge HIV mitigation efforts among this

population. The aim is to provide insights into a holistic and comprehensive approach to stigma reduction interventions for the MSM community.

To better organize stigma reported by the participants, these experiences have been categorized and discussed for HIV seropositive and HIV seronegative groups. In line with the literature, the associated mechanisms that perpetuate the reported stigma are also highlighted and discussed.

HIV-related stigma in the MSM community

The HIV Stigma Framework by Earnshaw and Chaudoir (2009) formed the main conceptual framework that was deployed to explore the issue of stigma among MSM. This framework addresses who is affected by stigma, how they are affected, and what the outcomes are. This discussion will address these questions. Although outcomes of stigma were not explicitly reported by the participants, the discussion will draw connections to possible outcomes from the literature based on participants reported experiences.

Stigmas described by MSM living with HIV were anticipated and enacted, and associated with intersecting devalued identities such as race, gender, sexual orientation and health condition. Stigma and resulting discrimination are driven by fear of infection, fear of economic ramifications due to the chronic nature of health condition (Stangl et al., 2019). Our data indicate that the majority of stigma attached to HIV seropositivity was manifested in the form of social isolation by family and friends from serostatus disclosure and anticipated from fear or harm or danger regarding their status, negative treatment on disclosure, and also violence against PLWH. According to Chambers et al. (2015), HIV stigma, produces poor health outcomes and negatively impacts all aspects of care. Stigma from sexual orientation manifested among both MSM living with HIV and seronegative MSM in the forms of social exclusion from churches and general

society, isolation from family and their children, as well as feelings of insecurity from threats of violence against MSM in their neighborhoods. Participants also felt that living with HIV further complicated their experiences of stigma as MSM. According to the Health Stigma and Discrimination framework, race, sexual orientation, occupation, and class-related stigma markers may interact with a health condition related-stigma to produce stigma practices such as stereotypes, prejudices, discriminatory behaviors, and stigmatizing behaviors as well as stigma experiences such as internalized, anticipated, and enacted stigma (Stangl et al., 2019).

Interestingly, HIV seronegative MSM reported experiences of prejudice, stereotype, and discrimination seen as isolation or distancing in a group activity as seen in this study, from MSM living with HIV within the community stating their experiences were not in any way comparable. This could be as a result of anticipated and internalized stigma experienced by participants living with HIV (Turan et al., 2017).

For both groups, these experiences occurred at the individual and community levels and were perpetuated through mechanisms associated with HIV-seropositivity and/or being MSM. According to the Health Stigma and Discrimination Framework, Figure 2 (see Appendix), the experience of stigma, discrimination and prejudice as well as their manifestations at the individual and/or community levels are products of broader factors that exist at a structural level (Stangl et al., 2019). In other words, although stigma experiences were reported at the individual and community level, the drivers and manifestations of stigma at the structural level must not be ignored.

This study thus underscores the importance of utilizing structural and intersectional approaches to understand the role of macro-level and institutional forces as they drive the

manifestations and outcomes of stigma. These approaches are critical to ensure that interventions to address or reduce stigma among the MSM population are effective (Rao et al., 2019).

Participants reported manifestations of stigma that were associated with HIV seropositivity and sexual orientation that are interwoven at the micro (interpersonal), meso (community) and macro (institutional, structural) levels. Social structures such as cultural and gender norms that underscore heteronormative identities can foster homonegativity and discrimination against MSM, and cause them to be isolated from their families, communities, and the general society that otherwise, would have formed a social support system for this group especially when they become HIV seropositive. The reported experiences of participants living with HIV and seronegative MSM corroborate the need for support at the different levels: interpersonal, community, institutional and structural. According to Halkitis et al (2012), social structures play a significant role in perpetuating the HIV epidemic among MSM. Social structures are influenced by structural and institutional level factors for example, legal, health and occupational policies that criminalize homosexuality, discriminate and marginalize the rights of MSM and individuals living with HIV, as well as religious laws which exclude the rights and participation of MSM (Stangl et al., 2019; Mayer et al., 2013; Rodríguez, Madera & Díaz, 2015).

HIV-related Stigma Reduction Interventions

There are documented gaps in HIV stigma reduction interventions such as the issues of efficacy and appropriateness of interventions, especially to improve health outcomes for different at-risk populations, and also the lack of holistic approaches to address the multifaceted dimensions of HIV-related stigma (Fabian et al., 2019). Similarly, a qualitative study by Wilson and Moore (2009) argued that interventions to reduce HIV stigma have been reductive because they do not effectively include the voices of those most affected. To address these gaps, this

study aimed to center the perspectives of MSM in illuminating interventions needed to address HIV-related stigma among MSM.

Participants identified several interventions they felt would be effective in reducing stigma. These interventions include education, appropriate messaging, the effective use of media, normalization of HIV, partner testing, improved access to preventive methods, funding, and support.

Education was the most recommended type of stigma reduction intervention and was endorsed as the best way to reduce stigma attached to MSM and HIV. Participants felt that education should have a positive focus on sex and sexuality education as well as healthcare provider education focusing on improving communication between health service providers who work with seronegative MSM and PLWH in the community. Healthcare and social services provider education must also focus on improving cultural sensitivity and responsiveness to both MSM and PLWH. The manifestation of negative attitudes toward MSM and PLWH among healthcare providers is common and is often an impediment to effective access to treatment (Singh, 2017). There are several studies (Geter, Herron, & Sutton, 2018; Marshall et al., 2017) that document HIV stigma among healthcare providers. The SPACES (stigma free spaces in medical scenarios) is an intervention that has been shown to reduce negative attitudes towards PLWH among health professionals in training (Varas-Díaz, Neilands, Rodríguez-Madera, & Padilla, 2016). According to Varas-Díaz et al., (2016), when applied to physicians in training, the SPACES intervention resulted in higher levels of HIV/AIDS knowledge, self-efficacy, and positive emotions with lower levels of subsequent stigma for participants. Although this intervention was created for heterosexual and gay Latinx population, it can also be tailored to and implemented in other communities.

Appropriate messaging about HIV seropositivity, was also proposed as an intervention. Strategies include the elimination of derogatory words from commercials, such as advertisements for rental properties, social and dating apps. Rather, communication and messaging around HIV should be positive and should also include the use of phrases or words that are able to effectively deliver messages on HIV stigma reduction such as hashtags, which especially can be used to target the younger subset of the population. The goal of this intervention, an interpersonal and community level of the socioecological model, is to promote communication around HIV and MSM who live with HIV. Several studies have argued that it is imperative to encourage positive communication in order to reduce HIV stigma, this approach also empowers PLWH, and helps to boost their emotional and mental well-being (Batey et al., 2016; Davtyan et al., 2017; Heijnders & Van Der Meij, 2006; Shangani et al., 2018).

Related to this, is the media by which messaging is conveyed. Participants emphasized the role that the media can play in promoting positive communication around HIV and also educating the public about the everyday lived experiences of HIV individuals. This can be done using avenues like word of mouth, posters, billboards, social media, apps, and the internet but participants suggested that individuals who rightly embody this message like celebrities or social media influencers who are living positively with HIV are better conveyors of positive HIV messaging. Methods such as mini-series, TV shows, reality TV, commercials, and documentary series were recommended as effective tools and platforms to convey positive HIV messages.

Social marketing using a variety of media channels has proven to be an effective strategy to reduce HIV stigma because it increases public exposure to positive information and messaging around the epidemic (National AIDS Trust, 2016). For example, National AIDS Trust, a charity organization based in the United Kingdom has successfully challenged and altered negative/and

or inaccurate media narratives about HIV through sustained media activities. Furthermore, the use of celebrities to communicate messages challenging stigma have also been shown to be effective all over the world. In the USA, the Stigma Project used a “range of eye-catching images for the Live HIV Neutral campaign.” These images used diverse subsets of the population including gay men and had messages that were meant to alter particular stereotypes and stigma attached to living with HIV. Similarly, between 2006 and 2009, France and Belgium worked with celebrities using media campaigns to challenge the negative opinions associated with HIV positivity (National AIDS Trust, 2016 p 4).

Normalization of HIV was especially recommended by HIV seropositive MSM and this refers to the need to portray people living with HIV as normal and healthy human beings who represent every demographic of the population and perform normal roles like other people, in order to break down existing stereotypes and stigma of HIV/AIDS morbidity and mortality. Normalization of HIV especially among the general public can include a range of strategies and education has been shown to be effective. Normalizing HIV through education should also involve families and friends of people living with HIV who have disclosed their status, in addition to the public. Educating them on the nuances of HIV, the ways it is spread, how treatment can help those who are living with HIV to manage the virus and live normal and healthy lives, as well as knowledge of strategies that help to show compassion to PLWH have been proven to be effective (Bogart et al., 2008; Pretorius, Greeff, Freeks, & Kruger, 2016).

Participants suggested that improved access to and availability of prevention methods such as widespread HIV testing, PrEP and condoms in clinics, community events, and safe spaces where individuals can readily access them, help to normalize acquisition of preventive methods and reduce stigma at the community, institutional, and structural levels. Studies (Mayer

et al., 2013; Stangl et al., 2013) have shown that biomedical approaches in combination with behavioral (e.g. sex education, counselling, community building) and structural (e.g. decriminalization of homosexuality, interventions to address inequality) interventions have been effective in the prevention of HIV transmission and adherence to ART at all levels of the socioecological model, there is still a paucity of data to show that this could be an effective HIV-stigma reduction intervention.

Finally, participants underscored the need for an array of support services for MSM and PLWH from families, friends, communities, and institutions. These services ranged from essential social services such as food, housing, financial/aid, and affordable insurance; to support from ASOs/FBOs. Services from FBOs need to ensure that MSM and PLWH are able to speak to religious figures or clergy men without feeling discriminated against. These organizations also need to provide community building activities through service acts, advocacy and social activities that increase interactions and connections between MSM and PLWH and the general community. Other services needed are: support and acceptance from family and friends; improved communication towards PLWH and MSM through skill-based interventions; peer support and/or mentoring services especially for families dealing with recent diagnosis (Stangl et al., 2019, 2013); availability and accessibility of mental health services; community centers as safe spaces for all ages to share and receive information; and availability of crisis hotlines/chat lines at social and health care facilities. These suggested interventions cut across all levels in the socioecological model and were suggested by both seropositive and seronegative groups.

High levels of social support whether from ASOs, FBOs, family, friends and local communities have been shown, in many settings, to promote healthy behaviors towards PLWH and MSM. For example, a comprehensive review of community-based HIV stigma reduction

interventions by Qiao, Li and Stanton (2014) explored factors that led to successful outcomes, across rural or urban regions of the US. Successful interventions deployed information-based approaches, skills building and increased contact with PLWH. At the individual and community levels, offering social support to MSM in serodiscordant relationships helped both partners and reduced HIV stigma within the community (Siegel, Meunier, & Lekas, 2018). Furthermore, increasing contact between PLWH and family members through community-based interventions has proven to be effective across multiple empirical studies suggesting that the interaction between these two groups in workshop styled interventions fosters understanding of HIV and the effects of stigma on PLWH. The outcomes of the interventions improved relationships and helped to reduce anticipated and enacted stigma (Chidrawi, Greeff, Temane, & Doak, 2016; Pretorius, Greeff, Freeks & Kruger 2016).

Interventions that integrate a trauma-informed care approach (e.g. using crisis hotlines and chat lines) with mental health/and general healthcare services have also been proven to be effective, according to the National LGBT Health Education Center. Training healthcare providers and social workers at both the individual and structural levels on knowledge, skills, tolerance for PLWH and their families has facilitated the reduction of HIV stigma and increased support towards affected populations (Nyblade et al., 2018, 2019). Similarly, Wilson and Moore (2009) recommend that effective HIV stigma reduction interventions must involve the meaningful engagement of culturally sensitive and competent frontline health workers in health departments and community-based organizations. These interventions should also be an integration of Community-Based Participatory Research (CBPR) approaches that include PLWH.

As suggested, engagement of the public and key community leaders such as religious leaders in HIV stigma reduction interventions is key to eliciting social support, improving positive communication and interaction, promoting acceptance of MSM and individuals living with HIV. Li et al. (2018) engaged PLWH and ethno-racial leaders from different service sectors (e.g., faith, media and social justice) to build community resilience and reduce HIV stigma utilizing two stigma reduction training programs: Acceptance Commitment Therapy Training (ACT) and Social Justice Capacity Building (SJCB). These interventions were implemented as part of a community-based HIV stigma reduction project known as Community Champions HIV/AIDS Advocates Mobilization Project (CHAMP). ACT used group discussion, mindfulness exercises and experiential group exercises, while the SJCB intervention used community leadership as a strategy to increase participants' understanding and readiness for community mobilization by developing advocacy towards positive social change. The combination of both interventions proved successful and decreased enacted and internalized stigma in the targeted community. These interventions can also be tailored to fit the MSM community by increasing the engagement of key community leaders and PLWH in HIV stigma reduction efforts as proposed by the study participants.

Also, common among participants' responses was that most recommendations were suggested not as isolated strategies but as integrated, and combined structural, institutional, community, interpersonal and individual levels of the socioecological models. This is backed by evidence in the literature that interventions to address stigma among PLWH and seronegative MSM are most effective when they combine structural-level and individual-level interventions compared to the use of either structural-level or individual-level interventions (Pantelic et al., 2019; Rao et al., 2019).

RECOMMENDATIONS

The discussion on HIV-stigma reduction interventions highlighted specific interventions to address stigma in the MSM community as suggested by the participants and it made connections to how participants' recommendations confirm or depart from existing interventions that have been proven effective by other studies. In addition, the following are additional broad recommendations to address HIV-related stigma as well as ways to implement effective interventions that will reduce stigma among MSM.

Effective interventions are those that include and engage the multiple identities of the target group whether based on their ethnicity, religion or socioeconomic background. These interventions must also be culturally tailored and should be augmented with strategies that have been shown to increase HIV testing and linkage to care, early initiation of treatment, and identification of transmission networks (Mayer et al., 2013).

Interventions must also include participatory approaches and meaningfully engage those in positions of power (e.g., policy makers, employers, landlords, frontline health workers), and include the participation of PLWH and affected groups such as advocates, families and friends (Wilson & Moore, 2009).

Most importantly, to ensure effectiveness, interventions must deploy multilevel approaches to address the behavioral, biomedical, psychological, cultural, and socioeconomic factors that operate at different levels to drive HIV stigma (Rao et al., 2019; Li et al., 2018; Reif et al., 2017; Pretorius et al., 2016). Socio-structural interventions must also include policies that penalize discrimination in the workplace or hospital setting and ensure social and legal protection for PLHW such that there is justice for them when they are discriminated against (Rodriguez-Hart et al., 2018).

LIMITATIONS

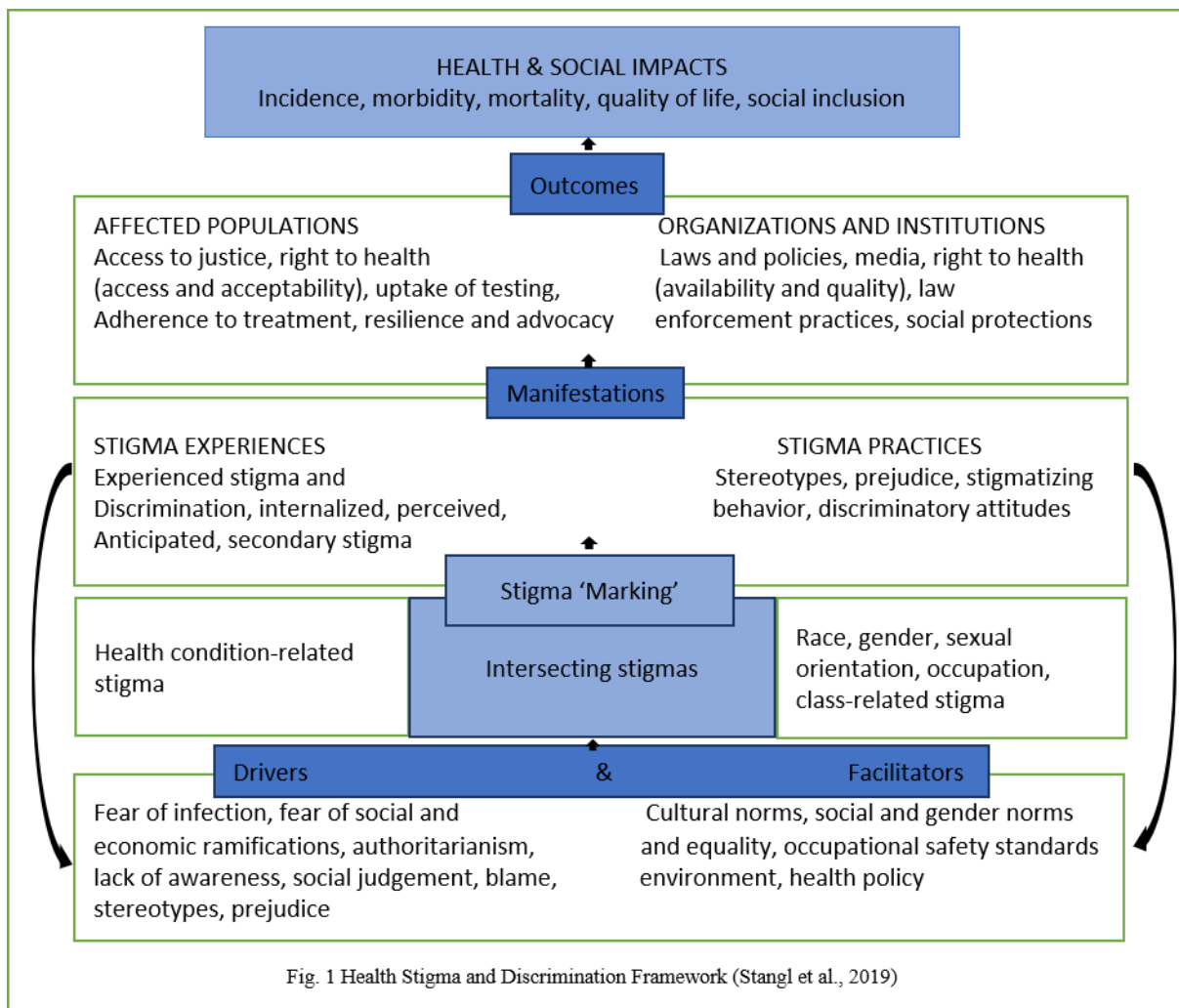
A limitation of this study was that the study population was specific to the MSM population in the states of Washington and Oregon and the attitudes, perceptions and opinions of this particular populations may not be generalizable to MSM populations in other parts of the country and the rest of the world. The participants were largely English-speaking Caucasian MSM under the age of 59. The findings revealed a lot of information on stigma experiences among Caucasian MSM living with HIV and HIV seronegative MSM. Hence, we lacked in-depth perspectives of minority ethnic groups, As such, the findings from this study cannot be generalized to a more diverse and wider ethno-racial population.

Furthermore, it is likely that during the FGDs, social desirability bias – defined as instances where some participants may have overshared and prevented others from expressing their thoughts and perceptions or were quiet – from the study participants may have been introduced. The FGD may not have captured all of the experiences that the study participants may have had, because they may not have felt comfortable. Interviewer effects – defined as different interviewer styles by the interviewer, during the focus group discussions may have impacted the quality of the data. A well-trained interviewer (as was the case in this study) is likely to mitigate the impact of social desirability bias and interviewer effects.

As a heterosexual cisgender woman of color, and the primary data analyst, I personally did not participate in the data collection and focus group discussions. I addressed this through literature reviews, enrolled in courses to learn more about the lesbian, gay, bisexual, transgender, two-spirit, queer, and questioning (LGBTQ) communities and public health, studied the transcripts multiple times, worked with key members of the MSM community through the CAB and SWG, and utilized a second coder to help reduce subjectivity.

Appendix

Figure 2: Health Stigma and Discrimination Framework



Source: Stangl et al. (2019)

Table 3: Focus Group Discussion Question Guide

Community
<p>How do you define YOUR community? How connected do you feel to communities that you identify with? Why? What makes you feel connected and/or disconnected with your community?</p>

Perception and Beliefs of Stigma
What is stigma? How do you define stigma? What does HIV/AIDS stigma look like? Is HIV/AIDS stigma a problem for: [the HIV positive community? Bi/Gay male community (MSM)? Transgender community? Same Gender Loving community? Kink Communities (Leather, BDSM, or others)? Communities of Color? Within different generations?] How about any other communities that we may not be mentioning? How have you or someone you know been impacted by HIV/AIDS stigma?
Disclosure and Support
What kinds of support would be helpful in addressing stigma and the impacts it has on your life? How about other members of your community? Where do you go for support? [for some of the topics we've discussed] Who has provided support? How often do you seek out support? What makes an individual or group supportive to be around? What makes an individual or group unsupportive to be around? Are there any types of support that you'd like to have but that are unavailable to you?
Past and Future Stigma Reduction
What stigma reduction efforts have taken place in your community? What types of challenges or problems have you experienced around HIV/AIDS stigma reduction efforts in the past? What types of <u>successful</u> HIV/AIDS stigma reduction efforts or components of programs have you seen that you'd like to see used again? What would you like future HIV/AIDS stigma reduction efforts to look like in your community? What would make you want to engage with HIV/AIDS stigma reduction? What do you think would work to reduce stigma for you? Thinking about your friends and community, what do you think would work to reduce stigma?
Messaging surrounding Stigma
What would effective HIV/AIDS stigma reduction messaging look like?

<p>Who should present this messaging? [ex: who would you like to see represented, types of images, who should this come from? etc.]</p> <p>Who should the target audience be?</p> <p>How could we create effective messaging that would be accessible to families?</p> <p>Who should present this messaging?</p> <p>How could we create effective messaging that would be accessible to people in the workplace?</p> <p>Who should present messaging?</p> <p>How might we create HIV/AIDS stigma reduction messaging that could be exchanged among friend/peer groups?</p> <p>Who should present messaging?</p> <p>What needs do you see for HIV/AIDS stigma reduction messaging in the broader community?</p> <p>What might that look like?</p> <p>Who should present messaging?</p> <p>Where do you get information from? (ex: billboards, posters, social media...)</p> <p>Are there any media outlets others within your community use that you might not use?</p> <p>What are your thoughts on using the following for carrying messages relating to HIV stigma?</p> <ul style="list-style-type: none"> • Mobile messaging • Posting in community spaces • Face to Face • Online • Social Media • Opinion/Thought Leaders • Television
<p>Additional Information and Wrap Up</p>
<p>Would anyone like to elaborate on anything that came up in the focus group today?</p> <p>We would like to do a member check in with you to share the data and findings that we are taking from these focus groups. What would be your preferred way to receive this information (Webinar, one-page information sheet, flyers, etc.)?</p> <p>Are there any final thoughts that you would like to share before our time comes to a close?</p>

Table 4: Community-based Organizations

<p>WA State Department of Health Lifelong Seattle, Everett, and Bellingham PCAF (Pierce County AIDS Foundation) Tacoma and Olympia CAP (Cascade AID Project) Vancouver, WA and Portland, Oregon HIV Alliance, Eugene CFAR Community Action Board UW/FredHutch</p>
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