Culturally Competent Sexual Healthcare as a Prerequisite for Obtaining Preexposure Prophylaxis: Findings from a Qualitative Study

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Abstract

Purpose: Men who have sex with men (MSM) experience stigma in healthcare settings, which impedes disclosure of sexual behavior, potentially limiting uptake of preexposure prophylaxis (PrEP). The purpose of this study was to describe the context of this limitation and explore geographical variability.

Methods: To understand how discomfort in healthcare settings affects PrEP utilization, we conducted two online focus groups with geographically diverse samples of MSM.

Results: Respondents identified primary care providers as preferred sources for PrEP, but potential uptake was limited by barriers to establishing nonjudgmental relationships with these providers.

Conclusion: Improved patient–provider communication about sexual behaviors might increase PrEP use among MSM.

Keywords: barriers to care, focus group, HIV/AIDS, MSM (men who have sex with men), prevention, qualitative methods

Introduction

G AY-IDENTIFIED AND other men who have sex with men (MSM) remain disproportionately burdened by the HIV epidemic in the United States, with an estimated 67% of new adult and adolescent infections in 2014 attributed to male-to-male sexual contact.¹ Daily oral preexposure prophylaxis (PrEP) reduced HIV incidence among MSM by 86%–99% in clinical trials when adherence was consistent,^{2–4} and provision of PrEP in clinical settings can be highly effective for MSM.⁵ The US Centers for Disease Control and Prevention has released guidelines for PrEP provision to MSM⁶ and estimates that one in four sexually active MSM are eligible for PrEP based on behavioral indications,⁷ but uptake in this population has been limited.⁸ Although PrEP use has increased recently among MSM,^{9–11} the proportion of MSM accessing PrEP remains far below levels that are necessary to impact HIV incidence substantially in this population.¹²

Several impediments to PrEP uptake exist, including barriers for potential consumers (e.g., awareness and interest) and providers (e.g., knowledge and willingness to prescribe), and structural-level barriers (e.g., affordability, stigma, and access to healthcare). These barriers have been organized into a Care Continuum Model that provides a theoretical framework to describe the progression from PrEP eligibility to accessing PrEP and achieving protection against HIV.¹³ This model posits that individual MSM must be aware of PrEP, have access to healthcare, be able to obtain prescriptions for PrEP, and adhere to PrEP medications to achieve maximal protective benefits. For PrEP to be prescribed, both patients and providers must be willing and prepared to discuss sexual health, HIV prevention, and PrEP.

However, studies of MSM have found that fewer than half disclose sexual orientation to primary care providers (PCPs),^{14,15} which can limit the uptake of preventive sexual health interventions, such as vaccination against hepatitis B virus and HIV/STI screening.^{16,17} A national survey of 4098 American MSM engaged in online sexual networking found that 45% of respondents were uncomfortable discussing male–male sexual behavior with PCPs and only 39% had ever discussed HIV prevention with these providers.¹⁸ This study found that knowledge of PrEP and prevalence

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of sexual health communication between MSM and PCPs varied by state, with less knowledge and poorer communication among MSM from states with greater levels of structural stigma (e.g., absence of legal rights and protections).¹⁸ These findings suggest that successful implementation of PrEP will require a deeper understanding of barriers to sexual health communication among MSM from diverse regions in the United States. Despite $\sim 18\%$ of HIV diagnoses occurring outside major metropolitan areas,¹ most qualitative research occurs in urban centers, where large research institutions are located and community infrastructure facilitates recruitment of study participants,^{19,20} which limits the understanding of this population and disconnects qualitative findings from populationrepresentative studies. Therefore, to explore factors influencing discussions about PrEP between MSM and their healthcare providers, we conducted online focus group (OFGs) discussions with MSM from numerous regions in the United States, using the same source population as Oldenburg et al.¹⁸

Methods

Focus groups

OFGs were designed to include MSM from diverse geographical regions in the United States. Discussions were hosted by a private company specializing in OFG research.²¹ OFGs were confidential and conducted on a secure website with a private, group chat room interface. Web cameras were not used (i.e., participants were not visible) and discussion was text based. A discussion guide, created by the study staff, included two major domains: knowledge of and interest in using PrEP, and preferences for and experiences with discussing sexual health with providers. A professional OFG moderator presented questions according to the discussion guide, with adaptation to the order and wording to facilitate conversation. The moderator was not a content expert; so, members of the study team observed the electronic discussions and sent questions or comments to the moderator that could be presented to participants in real time, to promote clarification or elaboration of discussion points. At the start of the OFGs, the moderator asked participants to read a consent statement, which explained the risks and benefits of participation. An opportunity to ask questions was provided and participants were required to acknowledge their consent in the text box before the OFG proceeded. OFGs were 90 minutes long and conducted in September 2013. Participants received \$75 incentives. The protocol was approved by the Fenway Health Institutional Review Board.

Subject selection

Participants were recruited from a large sexual networking website for MSM in the United States, through an ongoing collaboration with the parent company's research institute. Eligibility criteria included the following: being assigned male sex at birth; ≥ 18 years of age; HIV uninfected by self-report; and reporting condomless anal intercourse in the past 3 months with ≥ 1 casual male partner or with a main male sexual partner who is HIV infected. Website administrators distributed surveys assessing eligibility to randomly selected members who did not indicate they were HIV infected in their online profiles. Among 127 members who completed eligibility surveys, 88 met eligibility criteria and indicated interest in study participation. Members were sorted based on their reported availability and willingness to participate in each of the scheduled OFGs, and then purposively selected for invitation to promote geographic diversity (i.e., members from underrepresented geographic zones were prioritized for selection). Invitations were sent to 25 members for each OFG (50 total), with a goal of 10–12 participants per OFG. Members were sent email invitations to participate and received telephone reminders on the day of the OFG.

Data collection and analysis

Electronic transcripts of OFG discussions were downloaded after each OFG. Raw data were analyzed inductively using modified grounded theory.²² First, raw data were reviewed by two independent coders, and emergent concepts were assigned unique codes. Second, codes were arranged into categories. Members of the study team discussed concepts and categories and generated a list of higher order themes. Finally, categories and raw data were reviewed together to promote further elaboration of major themes.

Results

Participant characteristics

Twenty-four MSM participated in two OFGs (Table 1). Participants' median age was 48 (interquartile range [IQR], 40–52). Participants were from 16 states and the District of Columbia, representing all 9 US Census Divisions, and they lived in locations with a range of population sizes. Most participants identified as gay and single; two participants were bisexual and four had a main male sexual partner. Table 2 displays selected individual-level participant characteristics and illustrative quotations from the OFGs appear in Table 3.

Knowledge of PrEP

Few participants had heard of PrEP before the OFG, and knowledge was generally limited to a basic conceptual framework. However, some participants had a more nuanced understanding of PrEP, including issues related to adherence and side effects. Participants cited news articles and blog posts, especially sources dedicated to the Lesbian, Gay, Bisexual, and Transgender (LGBT) community, as their source of information about PrEP. One participant learned about PrEP while being enrolled in drug rehabilitation services. A theme across both OFGs was that participants with limited knowledge about PrEP identified healthcare providers as their preferred source for additional information. None of the participants had used PrEP and only participants who were currently or formerly in HIV-serodiscordant relationships indicated having interest in using PrEP before the OFG.

Discussing PrEP with PCPs

A common theme was participants' belief that PCPs would be ideal healthcare practitioners for discussions about HIV prevention and PrEP. However, only one participant had discussed PrEP with his healthcare provider. Among all participants, the perceived quality of prior sexual health discussions was variable and some were skeptical that their PCP would be knowledgeable about PrEP.

When participants were asked if they would feel comfortable discussing PrEP with their own PCPs, most indicated discomfort due to embarrassment or fears of being judged.

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 TABLE 1. PARTICIPANT CHARACTERISTICS

	$n = 24 (\%)^{a}$
Race	
White (not Hispanic or Latino)	21 (88)
Hispanic or Latino	3 (13)
Sexual orientation	
Gay or homosexual	22 (92)
Bisexual	2 (8)
Population of city	
≤5000	5 (21)
5001-50,000	4 (17)
50,001-250,000	4 (17)
250,001–1 million	7 (30)
>1 million	4 (17)
Income (USD)	
0–19,999	3 (13)
20,000-39,999	3 (13)
40,000–59,999	7 (30)
60,000–79,999	6 (25)
>80,000	5 (21)
Highest grade achieved	
Some college	7 (30)
College graduate	9 (38)
Some graduate school	2 (8)
Graduate/professional degree	6 (25)
Age, years; median (IQR)	48 (40–52)

Participants were distributed evenly with half (n=12) in each of the two focus groups.

^aTotal may exceed 100% due to rounding.

IQR, interquartile range.

Hesitation about discussing PrEP with PCPs was not universal and the experience of some participants suggested that establishing comfortable relationships with PCPs for discussing sexual health was possible.

Disclosure of sexual behaviors

A recurrent pattern in the data was a belief that sexual health is an important topic to discuss with PCPs, even for those participants who had not done so previously. Participants who had disclosed their sexual orientation to PCPs and who perceived their providers to be nonjudgmental indicated that they would be comfortable discussing PrEP during primary care. Conversely, participants who were not able to be open about their sexual orientation with PCPs viewed this limitation as a major barrier to discussing sexual health, HIV prevention, and PrEP. For some participants, nondisclosure of sexual behavior was a consequence of PCPs failing to take complete sexual health histories, whereas other participants directly avoided answering questions.

Pursuit of nonjudgmental sexual healthcare

One response to having experienced stigma in healthcare settings, or to having expectations of such stigma, was to select PCPs who openly identified as gay or who were perceived to be nonjudgmental. Having a gay provider was considered a potential facilitator to having informative discussions about PrEP. Attempts to identify openly gay or nonjudgmental PCPs were not always successful. Participants who felt discomfort or feared being judged by their PCP would prefer to discuss PrEP with other providers.

TABLE 2.	SELECTED	CHARACTERISTICS
of In	dividual P	ARTICIPANTS

	State	Community	Yearly
Age	of residence	size (people)	income (USD)
Focu	s group A		
50	Nevada	>1 million	>80,000
55	Minnesota	>1 million	40,000-59,999
30	Alaska	50,001-250,000	20,000-39,999
48	Texas	≤5000	20,000-39,999
50	District of	250,001-1 million	>80,000
	Columbia		
39	New York	>1 million	40,000-59,999
48	Connecticut	≤5000	0–19,999
40	Oregon	>1 million	40,000-59,999
50	Tennessee	50,001-250,000	60,000-79,999
59	New Mexico	≤5000	>80,000
36	Oklahoma	250,001-1 million	>80,000
56	Ohio	5001-50,000	20,000-39,999
Focu	s group B		
66	Rhode Island	5001-50,000	0-19,999
38	Florida	250,001-1 million	>80,000
31	Alaska	≤5000	40,000-59,999
41	Oregon	50,001-250,000	60,000-79,999
47	Tennessee	250,001-1 million	40,000-59,999
45	Rhode Island	5001-50,000	40,000-59,999
62	Utah	5001-50,000	60,000-79,999
51	District of	250,001-1 million	60,000-79,999
	Columbia		
42	Rhode Island	50,001-250,000	60,000-79,999
56	Iowa	250,001-1 million	40,000-59,999
29	Montana	≤5000	0-19,999
47	Texas	250,001-1 million	60,000–79,999

Discussion

This study sheds light on structural factors, including experienced and anticipated stigma in healthcare, which prevent MSM from seeking information or prescriptions for PrEP from their PCPs. Participants identified PCPs as the preferred source for information about PrEP. However, an emergent theme was the need for a nonjudgmental relationship with a PCP before disclosure of sexual orientation and discussions about sexual health, including HIV prevention and PrEP, could occur. Using the PrEP Care Continuum Model¹³ as a framework, this study provides a qualitative understanding of how structural stigma of MSM can result in poor patientprovider communication. Although Oldenburg et al.¹⁸ found state-level variability in communication and PrEP uptake, these findings suggest that stigma can affect MSM regardless of urbanicity or geographical region. However, MSM outside major metropolitan regions may have greater difficulty finding and establishing an acceptable relationship with a PCP and, consequentially, experience greater difficulty accessing sexual health interventions,^{16,17} including PrEP.

As PrEP awareness and interest are increasing among MSM,⁸ interventions are needed to train PCPs to conduct culturally competent discussions regarding sexual health and HIV prevention, identify PrEP candidates, and establish trusting relationships with patients that might facilitate disclosure of sexual orientation and HIV risk behaviors. Point-of-care tools for clinicians, such as culturally tailored HIV risk screeners,²³ could facilitate these conversations for PCPs

TABLE 3. ILLUSTRATIVE QUOTATIONS

	State of residence	Age
Knowledge of PrEP		
I know that it is a combination of a couple of recent HIV drugs that a person takes in order to reduce their risk of becoming HIV+ when they are currently HIV-	Montana	29
Discussing PrEP with PCP		
I have only discussed [sexual health] to see if he's heard of the newest and the greatest he never has.	New Mexico	59
A little uncomfortable; I think it clearly implies one may be engaging in known risky behavior	Nevada	50
Not really comfortabledoctors are so judgemental lol. I've been lectured many times for things that I've admitted	Oklahoma	36
I don't care for my present health care providerI feel he's homophobicI think. I don't know that for a fact!	Texas	47
Due to the size of the communityI would wonder how that person would view me in the future	Montana	29
I'd talk to minehe is straight but knows I'm gay.	Washington, District of Columbia	50
Disclosure of sexual behaviors		
I was reluctant to be open with sexuality with my primary doctor but I realized the importance and it was fine and am comfortable with it	Alaska	30
I try to talk to my doctor about anything relative to my health	Rhode Island	45
Although my PCP is not gay she is very open and tolerant.	Florida	38
My provider has never asked me about my sexual activity	Iowa	56
My medical provider does not know of my sexual preference I feel embarrassed to tell him anything personal about me	Texas	47
If a question was asked that was not related to the situation, and I didn't feel like I wanted to discuss it, I might lie or deflect just to move on.	Alaska	30
Pursuit of nonjudgmental sexual healthcare		
I asked my PCP [at an LGBT health center] about it (PrEP)I'm out to my PCP and my PCP is also out so it's very comfortable to talk to them.	Rhode Island	42
My pcp is gay, knows I'm gay. We've talked about sex practices before.	Washington, District of Columbia	51
It is critical to either have a gay provider or someone who is familiar and lacking in judgment concerning the details of gay sex providers who are not familiar with gay sex lack insight and familiarity concerning what transpires.	Texas	48
My partner is HIV+ and I do know his infectious disease doctor and have been tempted to speak with them about thisI have had a hard time identifying gay practitioners even working through friends as references	Nevada	50
I would try at my local gay and lesbian health clinic before my personal care physician.	Washington, District of Columbia	50
I live in a small community I would travel to a different doctor.	Montana	29
Mine questioned when I asked for HIV screening last month I guess I would ask [about PrEP] if I visited an [HIV/STI clinic] instead of general Dr. from now on.	Minnesota	55

LGBT, Lesbian, Gay, Bisexual, and Transgender; PCPs, primary care providers; PrEP, preexposure prophylaxis.

with less experience with MSM. Individual providers, health systems, professional organizations, and educational institutions each have a responsibility to improve sexual health communication and create environments where sexual minority patients can expect competent and nonjudgmental care. Training resources are available, such as www.lgbthealtheducation.org, which is a U.S. governmentfunded program, but providers need to be aware it exists and want to avail themselves of the training opportunities, if such sites, or other resources, are to have an impact on provider behavior. Until systemic changes in the actual and perceived quality of sexual healthcare for MSM occur, map-based location tools, such as www.PrEPlocator.org, which helps patients identify local PrEP providers, or www.AIDSvu .org, which shows variation in HIV prevalence and identifies HIV treatment and prevention resources, represent important resources.

This study design has limitations. Study themes may not be generalizable because our analyses are based on a limited number of OFGs; these discussions only included members of a partner-seeking website; and self-selection bias may exist. Importantly, the median age of participants was 48 years (range, 29-66) and only 13% were non-White, which reflects the sample characteristics of the source population,^{8,18} but limits extrapolation of our findings to young, minority MSM who may face unique barriers to accessing PrEP. To access this population, future research will require more targeted recruitment efforts. Generational and cultural differences in accessing and engaging in care may exist, but the phenomenon of stigma among a geographically diverse sample of MSM suggests this barrier may be prevalent in other populations of MSM. Additional research with young and racial/ethnic minority MSM is urgently needed, given disparities in HIV incidence²⁴ and PrEP use²⁵ in these populations.

Conclusion

OFGs with geographically diverse members of a partnerseeking website for MSM suggest that barriers to communicating about sexual health between MSM and providers may be limiting access to PrEP and could exacerbate inequities in PrEP uptake. Improved patient-provider communication about sexual orientation and sexual behaviors might increase PrEP use among MSM, particularly for MSM without access to LGBT-specialized providers.

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References

- Centers for Disease Control and Prevention: Diagnoses of HIV infection in the United States and dependent areas. HIV Surveillance Report, Volume 26. 2014. Available at www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hivsurveillance-report-us.pdf Accessed November 24, 2015.
- Grant RM, Lama JR, Anderson PL, et al.: Preexposure chemoprophylaxis for HIV prevention in men who have sex with men. N Engl J Med 2010;363:2587–2599.
- Anderson PL, Glidden DV, Liu A, et al.: Emtricitabinetenofovir concentrations and pre-exposure prophylaxis efficacy in men who have sex with men. Sci Transl Med 2012;4:151ra125.
- McCormack S, Dunn DT, Desai M, et al.: Pre-exposure prophylaxis to prevent the acquisition of HIV-1 infection (PROUD): Effectiveness results from the pilot phase of a pragmatic open-label randomised trial. Lancet 2016;387:53–60.
- Volk JE, Marcus JL, Phengrasamy T, et al.: No new HIV infections with increasing use of HIV preexposure prophylaxis in a clinical practice setting. Clin Infect Dis 2015;61:1601–1603.
- Centers for Disease Control and Prevention: US Public Health Service: Preexposure prophylaxis for the prevention of HIV infection in the United States—2014: A Clinical Practice Guideline. 2014. Available at www.cdc.gov/hiv/ pdf/prepguidelines2014.pdf Accessed May 31, 2016.
- Smith DK, Van Handel M, Wolitski RJ, et al.: Vital Signs: Estimated percentages and numbers of adults with indications for preexposure prophylaxis to prevent HIV acquisition—United States, 2015. MMWR Morb Mortal Wkly Rep 2015;64:1291–1295.
- Mayer KH, Oldenburg CE, Novak DS, et al.: Early adopters: Correlates of HIV chemoprophylaxis use in recent online samples of US men who have sex with men. AIDS Behav 2016;20:1489–1498.
- 9. Mayer KH, Levine K, Grasso C, et al.: Recent increases in PrEP utilization at a Boston Community Health Center among men who have sex with men, 2011–2014: Transition from research to clinical practice. Seattle, WA: International Antiviral Society-USA, 2015. Abstract number 972. Available at www.croiconference.org/sessions/recent-increases-prep-utilization-boston-community-health-center-among-men-who-have-sex-men Accessed November 24, 2015.

- Hood JE, Buskin SE, Dombrowski JC, et al.: Dramatic increase in preexposure prophylaxis use among MSM in King County, Washington. AIDS 2016;30:515–519.
- Mera R, McCallister S, Palmer B, et al.: Truvada for HIV preexposure prophylaxis (PrEP) utilization in the United States (2013–2015). Durban, South Africa: 21st International AIDS Conference, 2016. Abstract number TUAX0105LB. Available at http://programme.aids2016.org/Abstract/Abstract/10159 Accessed February 20, 2017.
- Sullivan PS, Carballo-Diéguez A, Coates T, et al.: Successes and challenges of HIV prevention in men who have sex with men. Lancet 2012;380:388–399.
- Kelley CF, Kahle E, Siegler A, et al.: Applying a PrEP continuum of care for men who have sex with men in Atlanta, Georgia. Clin Infect Dis 2015;61:1590–1597.
- Metcalfe R, Laird G, Nandwani R: Don't ask, sometimes tell. A survey of men who have sex with men sexual orientation disclosure in general practice. Int J STD AIDS 2015; 26:1028–1034.
- Eliason MJ, Schope R: Does "don't ask don't tell" apply to health care? Lesbian, gay, and bisexual people's disclosure to health care providers. J Gay Lesbian Med Assoc 2001; 5:125–134.
- 16. Ng BE, Moore D, Michelow W, et al.: Relationship between disclosure of same-sex sexual activity to providers, HIV diagnosis and sexual health services for men who have sex with men in Vancouver, Canada. Can J Public Health 2014;105:e186–e191.
- 17. Petroll AE, Mosack KE: Physician awareness of sexual orientation and preventive health recommendations to men who have sex with men. Sex Transm Dis 2011;38:63–67.
- Oldenburg CE, Perez-Brumer AG, Hatzenbuehler ML, et al.: State-level structural sexual stigma and HIV prevention in a national online sample of HIV-uninfected MSM in the United States. AIDS 2015;29:837–845.
- Preston DB, D'Augelli AR, Cain RE, et al.: Issues in the development of HIV-preventive interventions for men who have sex with men (MSM) in rural areas. J Prim Prev 2002;23:199–214.
- Bowen AM, Williams ML, Daniel CM, et al.: Internet based HIV prevention research targeting rural MSM: Feasibility, acceptability, and preliminary efficacy. J Behav Med 2008; 31:463–477.
- 21. InsideHeads: Online Marketing Research. Available at http://insideheads.com Accessed December 9, 2015.
- 22. Patton MQ: *Qualitative Research & Evaluation Methods, 3rd ed.* Thousand Oaks, CA: SAGE, 2002.
- 23. Smith DK, Pals SL, Herbst JH, et al.: Development of a clinical screening index predictive of incident HIV infection among men who have sex with men in the United States. J Acquir Immune Defic Syndr 2012;60:421–427.
- Sullivan PS, Peterson J, Rosenberg ES, et al.: Understanding racial HIV/STI disparities in black and white men who have sex with men: A multilevel approach. PLoS One 2014;9:e90514.
- 25. Eaton LA, Driffin DD, Bauermeister J, et al.: Minimal awareness and stalled uptake of pre-exposure prophylaxis (PrEP) among at risk, HIV-negative, black men who have sex with men. AIDS Patient Care STDS 2015;29:423–429.

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