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Original Articles

Associations with COVID-19 Symptoms, Prevention Interest, and Testing Among Sexual and Gender Minority Adults in a Diverse National Sample

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Abstract

Purpose: Sexual and gender minority (SGM) and racial/ethnic minority populations may differ in coronavirus disease 2019 (COVID-19) prevention, testing, and vaccine interest, although little research has explored these disparities. It is critical to understand the differential experiences within minoritized communities to ensure effective intervention and vaccine rollout.
Methods: In a national online survey of U.S. adult SGM individuals, conducted between April and August 2020, 932 participants responded about COVID-19 testing, symptoms, interest in vaccination, and interest in at-home testing. Bivariate associations between these outcomes and demographic factors, including sexual orientation, gender identity, endorsing intersex traits, gender modality, race/ethnicity, and HIV status were calculated.
Results: Despite 24% of the sample reporting COVID-19 symptoms, testing was relatively low at 13.3%. Transgender and bisexual/pansexual individuals were more likely to be interested in a COVID-19 vaccine and an at-home test compared with cisgender and gay/lesbian respondents, respectively. Compared with cisgender individuals, transgender individuals were nearly twice as likely to report COVID-19 symptoms. Latinx individuals were less likely to be interested in a future COVID-19 vaccination and Black individuals were less likely to be interested in an at-home COVID-19 test compared with White participants. Both respondents who endorsed intersex traits and people with HIV were less likely to be interested in an at-home test compared with those who did not endorse having intersex traits and people without HIV, respectively.
Conclusions: These results show critical disparities in COVID-19 symptomology and prevention interest within SGM populations that must be taken into account when designing or tailoring effective COVID-19 interventions.

Keywords: COVID-19, racial/ethnic minority, sexual and gender minority, testing, vaccine acceptability

Introduction

The coronavirus disease 2019 (COVID-19) pandemic has affected every facet of American life. As of March 12, 2021, there have been 29,052,862 cases and 527,726 deaths attributable to COVID-19 in the United States.[1] Pandemic mitigation strategies have led to widespread unemployment; the negative psychosocial impacts of prolonged stress and isolation are only just beginning to be understood.[2] Crucially, COVID-19 has not affected all communities equally. Minoritized communities—that is, populations burdened by socially and structurally facilitated discrimination and denied equal power due to forces, including racism, homo/biphobia, transphobia, or serophobia—have been the most impacted by COVID-19.[3–5] In addition to experiencing higher levels of COVID-19 morbidity and mortality, minoritized groups are vulnerable to downstream COVID-19 consequences because of multilevel manifestations of discrimination, including financial strain,[6,7] psychological stress,[8,9] and disruptions to daily life.[10,11]

As has been emphasized, historical and ongoing oppression has directly resulted in inequity in COVID-19 outcomes.[5,12] For example, sexual and gender minority (SGM) communities experience both individual- and structural-level discrimination that impacts health outcomes and the ability to access and receive treatment.[13,14]

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Compared with heterosexual and/or cisgender individuals, SGM individuals are more likely to live in poverty,[15–17] be unstably housed,[18] and experience victimization,[16,19,20] all symptoms of structural violence that impact health care engagement.[21] Given elevated rates of cigarette[22] and marijuana use,[23,24] overrepresentation in ''essential worker'' positions,[25] higher prevalence of asthma in sexual minority groups,[26] as well as diabetes in gay and bisexual men,[27] SGM individuals may also be at a higher risk for contracting COVID-19 and experiencing more serious complications.[4] Furthermore, SGM individuals may be less likely to access quality care due to high rates of uninsurance,[28,29] as well as experiences of discrimination and medical mistrust,[30] especially among transgender, gender nonbinary, and intersex individuals.[14,16,31] However, due to a lack of consistent SGM-related data capture in electronic medical records and national surveillance data, the exact disparities in COVID-19 outcomes experienced by SGM populations during the pandemic are unknown.

Black, indigenous, and other people of color (BIPOC) populations (e.g., Black, Native American/Indigenous, Latinx, Asian American, or other non-White individuals living in the United States) experience both individual and structural manifestations of racism and colonialism, and associated COVID-19-related risks and impacts.[5,12,32] As with SGM populations, BIPOC populations have a higher prevalence of numerous conditions: for example, Black and Latinx populations have higher rates of acute asthma,[33] cardiovascular diseases,[34,35] HIV,[36–38] and diabetes,[39] leading to higher COVID-19 morbidity and mortality. In addition, long histories of residential discrimination, including redlining, gentrification, and segregation, have made geography a key structural element of health inequity,[40] including in COVID-19 disparities.[41] Furthermore, the hypercriminalization of BIPOC populations also increases COVID-19 exposure risk, as COVID-19 has been shown to spread rapidly in carceral spaces.[42]

COVID-19 has further amplified existing health care disparities for BIPOC individuals; cost, medical mistrust, and discrimination at the point of care all impact the adequate and timely receipt of COVID-19 testing and treatment.[3,43] Although inequities in the impact of COVID-19 among Black and Latinx populations are better described, the majority of studies address racial disparities without considering the role of racism.[41]

In addition, people with HIV (PWH) remain vulnerable to higher COVID-19 exposure risk and elevated morbidity and mortality. PWH who are not virally suppressed may be at greater risk for contracting COVID-19 or experiencing severe illness.[44] PWH may experience lower rates of health care access overall due to stigma, poverty, and discrimination, leading to difficulty obtaining appropriate COVID-19-related care.[45]

Given the relative dearth of information regarding COVID-19 risks and preventive behaviors among minoritized populations and the volatile nature of the pandemic in the United States, there is a clear need to establish evidence that can be used to support equitable COVID-19 prevention, testing, and treatment. This study leverages a diverse national sample of SGM individuals to characterize prevalence of COVID-19 symptoms, testing, and vaccine and at-home test acceptability, as well as differences in these outcomes among minoritized individuals, including characterizing these patterns among understudied SGM populations.

Methods

Procedure

The COVID-19 Impacts Survey was conducted from April 13 to August 3, 2020. Study data were collected and managed using Research Electronic Data Capture (REDCap).[46,47] Eligibility criteria were: being at least 18 years of age, residing in the United States/U.S. territories, reporting a sexual or gender minority identity OR reporting living with HIV, and providing informed consent. We recruited participants through social media advertisements, direct outreach to organizations that served populations that were underrepresented in the sample, and recruitment within researchers' social networks. Participants who completed the study received a digital $10 VISA card. Study procedures were reviewed and deemed exempt by the Northwestern University Institutional Review Board, as we were not collecting identifiable data and there were no anticipated potential harms to the participant. Informed consent was obtained electronically before participants began the screener.

Sample

In total, 4082 participants provided informed consent and completed the screener. Data cleaning procedures were implemented to ensure that all individuals within the final analytic sample were unique responses (Fig. 1). Our initial round of cleaning eliminated responses that were ineligible in the screener, did not complete the survey, or failed at least one of the embedded attention checks. Our second round of cleaning eliminated responses that provided at least two inconsistent responses. Our final round of verification eliminated responses that provided invalid or duplicate email addresses, resulting in a sample of 952 (23.3%). For the purposes of this article, we only included individuals who reported a sexual or gender minority identity, for a final analytic sample of 932 (97.9%).

Measures

Demographics. Sex assigned at birth was determined by asking, ''What sex were you assigned at birth (i.e., on your birth certificate)?'' Response options included (1) Male, (2) Female, and (3) Prefer not to respond.

Sexual orientation was assessed by asking, ''Which of the following terms best describes your sexual orientation at this moment?'' Response options included (1) Gay or Lesbian, (2) Bisexual or Pansexual, (3) Questioning/Unsure, (4) Straight (Heterosexual), (5) Asexual, (6) Not listed, (7) Prefer not to respond, and (8) I'm not sure what this question is asking.

Gender identity was assessed by asking, ''Which of the following terms best describes your gender at this moment?'' Response options included (1) Woman, (2) Man, (3) Gender Nonbinary, (4) Questioning/Unsure, (5) Not listed, (6) Prefer not to respond, and (7) I'm not sure what this question is asking.

HIV status was determined by asking participants, ''Have you ever been diagnosed with HIV?'' Response options included (1) Yes, (2) No, and (3) Prefer not to respond.

Gender modality was assessed by asking, ''Some people use the term transgender to describe themselves when their gender does not align with the sex they were assigned at birth. Do you identify as transgender?'' Response options included (1) Yes, (2) No, (3) Prefer not to respond, (4) I'm not sure if I identify as transgender, and (5) I'm not sure what this question is asking.[48,49]

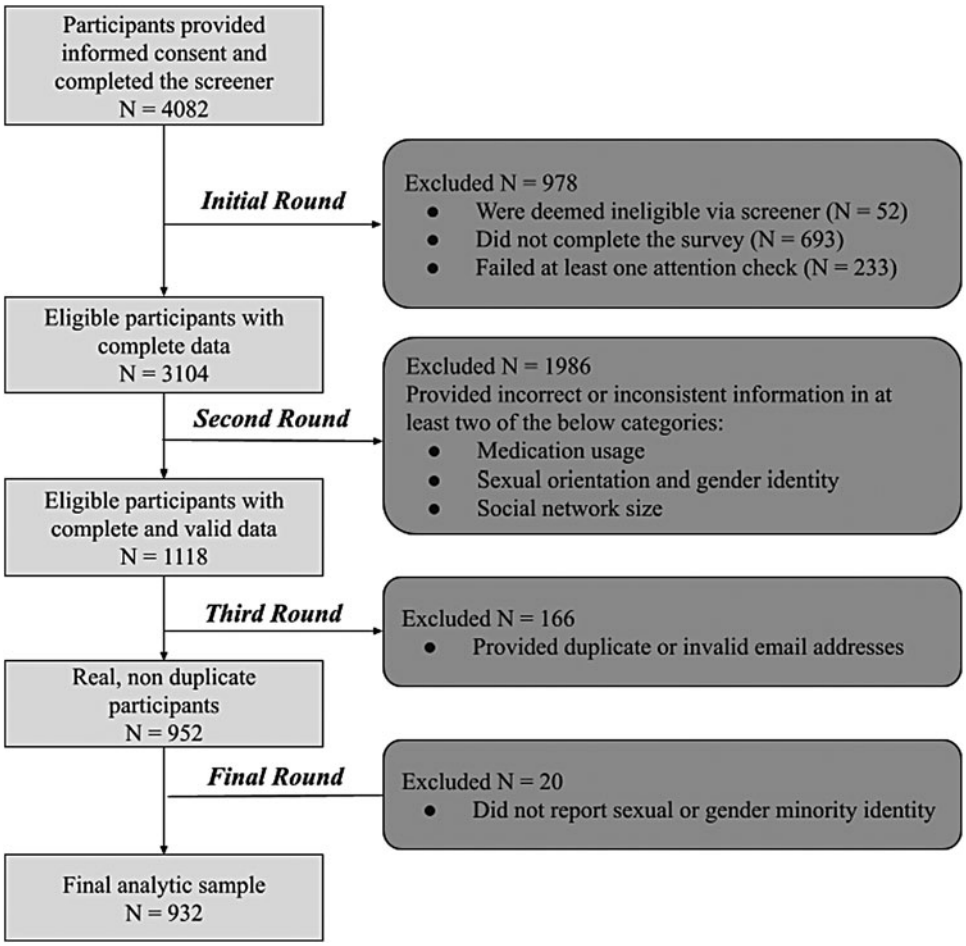

FIG. 1. Data cleaning flow chart.

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Having intersex traits was queried by asking, ''At birth, some people are assigned male or female, but their sexual anatomy, reproductive organs, and/or chromosomal patterns do not align with the typical definition of male or female. This physical condition is known as 'intersex.' Are you intersex?'' Response options included (1) Yes, (2) No, (3) Prefer not to respond, (4) I'm not sure if I am intersex, and (5) I'm not sure what this question is asking.[50]

Race/ethnicity was assessed by asking, ''How do you describe your race or ethnic background?'' Response options included (1) American Indian or Alaska Native, (2) Asian, (3) Black or African American, (4) Hispanic or Latino/a/x, (5) Native Hawaiian or Other Pacific Islander, (6) White, (7) Not listed. Participants who selected more than one option were categorized as (8) Multiracial. Due to the small sample size, Native Hawaiian or Other Pacific Islander participants were dropped in multivariable analyses.

COVID-19-related variables. Participants were asked, ''If a vaccine to prevent COVID-19 were to become available, would you consider getting this vaccine?'' and ''If there were an at-home test for respiratory viruses (like the novel coronavirus officially called SARS-CoV-2) that you could do on yourself and then mail in, would you consider taking this test?'' Response options included (1) Yes and (2) No.

COVID-19 symptoms were assessed by asking, ''In the past month, have you had any fever or 'cold and flu' symptoms, such as cough, shortness of breath, or the sudden onset of unexplained aches and pains?'' Response options included (1) Yes and (2) No. Recent testing rates were ascertained by asking, ''In the last month, have you been tested for COVID-19?'' Response options included (1) Yes, (2) No, and (3) Unsure.

Statistical analyses

Data cleaning and recoding was conducted in Microsoft Excel. Statistical analyses were conducted in Python.[51] Descriptive analyses were used to determine the prevalence of demographics. Associations of sexual orientation, gender identity, intersex traits, gender modality, race/ethnicity, and HIV status with four primary variables were tested: (1) COVID-19 symptoms; (2) Interest in COVID-19 vaccine; (3) Interest in at-home COVID-19 test; and (4) COVID-19 testing. Response options of ''Not Listed'' were excluded from all demographic variables. ''Straight'' was excluded from sexual orientation. Odds ratios (ORs) and 95% confidence intervals (CIs) were calculated for all bivariate associations.

Results

Demographics

The majority of participants identified as gay/lesbian (52.5%) or bisexual/pansexual (39.9%) (Table 1). More than one-fifth (20.2%) reported a transgender gender modality,

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Table 1. Demographics of the Survey Participants

	N	%
Sexual orientation ($n=931$)		
Gay/lesbian	489	52.52
Bisexual or pansexual	371	39.85
Asexual	18	1.93
Questioning/unsure	13	1.40
Straight	7	0.75
Not listed	33	3.54
Intersex ($n=921$)		
Yes	42	4.56
No	852	92.51
I'm not sure if I am intersex	27	2.93
Sex assigned at birth ($n=930$)		
Female	503	54.09
Male	427	45.91
Gender identity ($n=930$)		
Woman	328	35.27
Man	431	46.34
Gender nonbinary	135	14.52
Questioning/unsure	27	2.90
Not listed	9	0.97
Gender modality ($n=921$)		
Transgender	186	20.20
Not transgender	705	76.55
I'm not sure if I identify as transgender	30	3.26
Age, years (mean, standard deviation)	32.8	13.7
Diagnosed with HIV ($n=929$)		
Yes	150	16.15
No	779	83.85
Race/ethnicity ($n=932$)		
White	549	58.91
Hispanic or Latino/a/x	99	10.62
Black or African American	76	8.15
Asian	68	7.30
American Indian or Alaska Native	24	2.58
Native Hawaiian/Pacific Islander	4	0.43
Multiracial	101	10.84
Not listed	11	1.18
Would consider getting a COVID-19 vaccine ($n=928$)		
Yes	852	91.81
No	76	8.19
Would consider taking an at-home COVID-19 test ($n=928$)		
Yes	833	89.76
No	95	10.24
Had COVID-19 symptoms in the past month ($n=927$)		
Yes	222	23.95
No	705	76.05
Tested for COVID-19 in the last month ($n=928$)		
Yes	123	13.25
No	805	86.75

14.5% indicated a nonbinary gender identity, and 4.6% endorsed having intersex traits, notably higher than the estimated national prevalence.[52] More than one-half of the sample was White (58.9%), followed by Latinx (10.6%), multiracial (10.8%), Black (8.2%), and Asian participants (7.3%). Less than 5% of participants identified as American Indian/Alaska Native (2.6%), Native Hawaiian/Pacific Islander (0.4%), or a race/ethnicity that was not listed (1.2%).

COVID-19-related outcomes

A large majority of study participants expressed interest in receiving a future COVID-19 vaccine (91.8%) and an at-home test (89.8%) (Table 1). Nearly one-quarter of study participants reported having at least one symptom of COVID-19 (24.0%), but only 13.3% had been tested in the last month.

Bivariate associations

There were significant differences in COVID-19 experiences by sexual orientation. Namely, compared with gay/lesbian participants, bisexual/pansexual individuals were significantly more likely to report COVID-19 symptoms (OR = 1.38; 95% CI: 1.01–1.89), interest in a COVID-19 vaccine (OR = 1.69; 95% CI: 1.01–2.82), and interest in an at-home test (OR = 2.83; 95% CI: 1.71–4.70; Table 2).

Compared with those who did not endorse having intersex traits, those who did also had different COVID-19 experiences and prevention interests. Specifically, those who endorsed having intersex traits were significantly less likely to express interest in an at-home test (OR = 0.40; 95% CI: 0.19–0.87). Individuals who endorsed being unsure whether they had intersex traits were significantly more likely to report COVID-19 symptoms (OR = 2.64; 95% CI: 1.21–5.74).

Compared with men, gender nonbinary individuals were significantly more likely to be interested in vaccination (OR = 4.38; 95% CI: 1.33–14.4) and an at-home test (OR = 22.1; 95% CI: 3.03–16.1). However, the large CIs force caution in interpreting this statistic. The biggest differences were revealed when results were analyzed by gender modality. Transgender individuals were nearly twice as likely to report COVID-19 symptoms (OR = 1.91; 95% CI: 1.34–2.72) and an interest in a vaccine (OR = 2.30; 95% CI: 1.08–4.88) than their cisgender counterparts. In addition, transgender individuals were three times as likely to report willingness to use an at-home COVID-19 test (OR = 3.05; 95% CI: 1.45–6.42) compared with cisgender individuals (Table 2; frequencies and proportions are shown in Supplementary Table S1).

Latinx individuals were significantly less likely to be interested in a future COVID-19 vaccination (OR = 0.40; 95% CI: 0.21–0.74), and Black individuals were significantly less likely to be interested in an at-home COVID-19 test (OR = 0.46; 95% CI: 0.24–0.88) compared with White individuals. Conversely, multiracial individuals were significantly more likely than White participants to be interested in an at-home test, potentially due to their greater odds of displaying COVID-19 symptoms. Finally, participants with HIV were significantly less likely than their seronegative peers to be interested in either COVID-19 vaccination (OR = 0.40; 95% CI: 0.23–0.67) or at-home testing (OR = 0.27; 95% CI: 0.17–0.43).

Discussion

This is one of the first studies of COVID-19 testing, symptoms, and prevention interest with a diverse sample of SGM individuals, providing critical insights into the pandemic experiences of multiple under-researched populations. First, overall COVID-19 testing in our sample was low—although this could be reflective of the overall low national testing

Table 2. Associations Between Demographic Factors and Coronavirus Disease 2019 Prevention Interest, Symptoms, and Testing

	Vaccination		*At-home test*		*COVID-19 symptoms*		*Tested for COVID-19*	
	OR	*95% CI*	*OR*	*95% CI*	*OR*	*95% CI*	*OR*	*95% CI*
Sexual orientation ($n = 891$)								
Gay/lesbian	1.00	—	1.00	—	1.00	—	1.00	—
Bisexual or pansexual	**1.69**	**1.01–2.82**	**2.83**	**1.71–4.70**	**1.38**	**1.01–1.89**	1.11	0.74–1.65
Questioning/unsure	1.45	0.19–11.3	2.21	0.28–17.1	2.03	0.67–6.18	2.75	0.84–9.03
Asexual spectrum	2.56	0.34–19.4	—[a]	—	0.96	0.35–2.63	0.63	0.14–2.72
Intersex ($n = 921$)								
No	1.00	—	1.00	—	1.00	—	1.00	—
Yes	0.62	0.24–1.63	**0.40**	**0.19–0.87**	1.32	0.66–2.63	0.92	0.36–2.40
I'm not sure if I am intersex	1.05	0.24–4.53	—[a]	—	**2.64**	**1.21–5.74**	1.51	0.56–4.07
Gender identity ($n = 921$)								
Man	1.00	—	1.00	—	1.00	—	1.00	—
Woman	0.89	0.55–1.45	1.47	0.94–2.31	0.85	0.60–1.20	0.76	0.49–1.19
Gender nonbinary	**4.38**	**1.33–14.4**	**22.1**	**3.03–16.1**	1.42	0.93–2.17	1.36	0.81–2.29
Questioning/unsure	—[a]	—	—[a]	—	0.55	0.18–1.61	1.10	0.37–3.28
Gender modality ($n = 921$)								
Not transgender	1.00	—	1.00	—	1.00	—	1.00	—
Transgender	**2.30**	**1.08–4.88**	**3.05**	**1.45–6.42**	**1.91**	**1.34–2.72**	1.15	0.72–1.82
I'm not sure if I identify as transgender	2.99	0.40–22.3	—[a]	—	0.93	0.37–2.32	0.75	0.22–2.51
Race/ethnicity ($n = 917$)								
White	1.00	—	1.00	—	1.00	—	1.00	—
Black	0.57	0.26–1.23	**0.46**	**0.24–0.88**	1.04	0.58–1.85	1.38	0.64–2.98
Latinx	**0.40**	**0.21–0.74**	0.69	0.36–1.33	1.26	0.77–2.06	0.85	0.47–1.53
Asian	1.22	0.42–3.54	1.32	0.51–3.42	0.92	0.49–1.71	1.06	0.51–2.23
American Indian/Alaska Native	0.84	0.19–3.71	0.40	0.14–1.11	1.77	0.74–4.23	0.61	0.22–1.69
Multiracial	1.47	0.56–3.82	**3.42**	**1.05–11.2**	**1.72**	**1.08–2.73**	1.48	0.74–2.96
HIV status ($n = 929$)								
Negative	1.00	—	1.00	—	1.00	—	1.00	—
Positive	**0.40**	**0.23–0.67**	**0.27**	**0.17–0.43**	0.85	0.55–1.29	0.80	0.50–1.30

Boldface indicates statistical significance at $p < 0.05$.
[a]All individuals with this identity endorsed the behavior, preventing the calculation of ORs.
CI, confidence interval; OR, odds ratio.

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capacity, especially early in the pandemic. In fact, one national study of the general U.S. population conducted during the same time frame found that 22.7% of participants reported testing for COVID-19, which is markedly higher than the 13.3% testing rate we found.[53] Although that study asked about ever COVID-19 testing, it began in April 2020, approximately a month after the COVID-19 outbreak took hold in the United States; therefore, we consider the testing period to be comparable to the 1 month testing timespan used in the current study.

Notably, there were no significant demographic differences seen in rates of COVID-19 testing in our sample. This could be explained by the fact that our entire sample reported at least one minoritized identity and therefore all may be experiencing similar barriers to testing, reducing the likelihood of observing significant differences. Existing literature has shown that minoritized populations have poorer access to health care services in general due to structural barriers (i.e., lack of insurance, shortages in medical care in certain neighborhoods), a lack of cultural competency from providers, and medical mistrust.[14,45,54,55] Further qualitative work is essential to better understand barriers and facilitators to COVID-19 testing in minoritized groups.

There was high interest in both a vaccine and an at-home test for COVID-19 among our sample, although there were differences by demographics. For example, gender nonbinary individuals were significantly more likely than men to express interest in both vaccination and at-home testing, although large CIs indicate a potential instability of these estimates. As such, although this population could be seen as ''early adopters'' within the SGM community, these results should be interpreted with caution.

Bisexual/pansexual and transgender individuals were between two and three times as likely to be interested in a potential vaccine or an at-home test. This could be explained by the fact that both bisexual/pansexual and transgender individuals were significantly more likely to report COVID-19 symptoms than their gay/lesbian and cisgender peers, respectively. For these populations in particular, at-home testing may be seen as a way to receive health care without having to interact with medical institutions that perpetuate harm. This interpretation of our findings is consistent with extant literature highlighting the prevalence of medical discrimination against these populations in particular.[55,56] Similarly, multiracial individuals were more likely to report interest in an at-home test and were more likely to

report COVID-19 symptoms, although there was not a statistically significant difference in vaccination interest for this group.

Among certain populations known to experience greater levels of medical mistrust (notably intersex, Black, and Latinx populations, and PWH),[14,43,45] interest in vaccination or at-home testing was significantly lower compared with other individuals within our sample. As such, as COVID-19 vaccine rollout continues, significant community engagement will be needed to ensure that distribution strategies are equitable and culturally responsive. Partnering with SGM/BIPOC-serving and SGM/BIPOC-led organizations will be essential in ensuring that vital prevention options are equitably accessible. In particular, we recommend that health departments charged with overseeing vaccine rollout identify community-based organizations who provide direct services to SGM/BIPOC communities to serve as vaccination sites or engagement partners to spread awareness regarding vaccine safety and availability. In addition, we urge all institutions delivering vaccines to collect demographic data on race, ethnicity, sex, sexual orientation, and gender identity and modality, and use these data to evaluate and respond to issues of parity for minoritized communities during rollout.

Limitations

This study is not without limitations. This study was cross-sectional, meaning we cannot infer causality. Although we draw reasonable connections between our findings and extant evidence of factors impacting SGM health, we did not directly assess experiences such as exposure to structural discrimination. Qualitative work designed to help elucidate these causal pathways will be necessary moving forward. Future work should also emphasize an intersectional framework for the analysis of disparities; sample size precluded intersectional analyses on the basis of both SGM identity and racial/ethnic identity, but it is imperative to understand the unique experiences of multiple marginalized individuals to ensure an evidence-informed and equitable response to COVID-19.

Despite the rigorous guidelines used to clean the data, the final decision about whether to include a response was open to human error. Therefore, it was possible, although unlikely that we eliminated eligible participants who provided inconsistent information or included fictitious respondents. We used a convenience sample of SGM individuals recruited online. Although targeted advertising and recruiting was done to increase representation of certain groups, this is not a nationally representative sample and may not fully reflect the needs of SGM populations. However, the sample is likely biased toward decreased disparities, as the most marginalized members of populations experiencing the greatest health disparities may be less likely to take this survey, such as those without consistent internet access or who are unstably housed. As such, future work should aim to collect a larger and more nationally representative sample, with specific focus on groups not represented in typical online surveys. The proportion of individuals in our sample who endorsed having intersex traits was much higher than in the general population.[52] This could potentially indicate a degree of ''false positives''; this points to the need to validate measures to assess intersex identity/traits.

Conclusion

Epidemiological research into the distribution and impacts of COVID-19 within minoritized communities is an emerging, vital area of inquiry. Minoritized populations face known disparities because of historical and ongoing oppression that are likely to place them at greater risk for COVID-19 exposure, infection, and complications,[11,12,57] yet COVID-19's impacts on these populations remains understudied. The present study represents one of the first national surveys of symptoms, testing behaviors, and prevention interest for COVID-19 among SGM populations and understudied subpopulations. COVID-19 symptoms were common among our sample, yet testing was infrequent. Interest in future prevention options was high, although variation among some subgroups was noted. These results suggest that community-engaged work will be vital to the equitable distribution of any biomedical prevention strategies, and that transgender and BIPOC SGM individuals should receive particular emphasis in COVID-19 research and response. Ongoing study of the experiences of minoritized populations will be necessary to ensure an equitable COVID-19 response.

Authors' Contributions

G.P. conceptualized the article, crafted the analysis plan, and led drafting. J.X. and X.W. completed all analyses, M.M.R. and D.F. aided in drafting the article and critically revising it. D.C. helped with the literature review and data cleaning. E.E.G. and L.B.B. critically revised the article. All authors reviewed and approved the final article before submission.

Author Disclosure Statement

No competing financial interests exist.

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Supplementary Material

Supplementary Table S1

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