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SEARCH STRATEGY

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10 Years Ago

Anonymous

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FULL TEXT

Integration of Social Epidemiology and Community-Engaged Interventions to Improve Health Equity

Collaborations between social epidemiologists and community-engaged intervention researchers can enhance the contributions of both to reducing health inequities. Unlike their colleagues in other types of epidemiological research, social epidemiologists do not have clinical counterparts. Cardiovascular epidemiologists partner with cardiologists and nephrologists; cancer epidemiologists partner with oncologists. To acquire effective investigative approaches and the ability to translate results to actionable knowledge, social epidemiologists must forge partnerships with those who are targeting social determinants through health-enhancing policies, practices, and interventions. Similarly, this interaction enriches community-engaged intervention researchers' creation and modification of interventions, measurement of appropriate constructs, evaluation findings, and generation of new theories and strategies for change. Developing and translating data into real-world use with community players then becomes a more important role for both sets of researchers.

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Multilevel Intervention for Low-Income Maternal Smokers in the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC)

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ABSTRACT (ENGLISH)

Objectives. To test the efficacy of Babies Living Safe and Smokefree (BLiSS), a multilevel intervention initiated in a citywide safety net health system to improve low-income maternal smokers' abstinence and reduce child tobacco smoke exposure. **Methods.** This randomized controlled trial in Philadelphia, Pennsylvania (2015-2020), recruited low-income maternal smokers who received a brief smoking intervention (Ask, Advise, Refer [AAR]) from nutrition professionals in the Special Supplemental Nutrition Program for Women, Infants, and Children before randomization to (1) a multilevel intervention (AAR 1 multimodal behavioral intervention [MBI]; n 5 199) or (2) an attention control intervention (AAR 1 control; n = 197). **Results.** AAR 1 MBI mothers had significantly higher 12-month bioverified abstinence rates than did AAR 1 control mothers (odds ratio [OR] = 9.55; 95% confidence interval [CI] = 1.54, 59.30; P = .015). There were significant effects of time (b = -0.15; SE = 0.04; P <.001) and condition by time (b = -0.19; SE = 0.06; P <.001) on reported child exposure favoring AAR 1 MBI, but no group difference in child cotinine. Presence of other residential smokers was related to higher exposure. Higher baseline nicotine dependence was related to higher child exposure and lower abstinence likelihood at follow-up. **Conclusions.** The multilevel BLiSS intervention was acceptable and efficacious in a population that experiences elevated challenges with cessation.

FULL TEXT

Headnote

Objectives. To test the efficacy of Babies Living Safe and Smokefree (BLiSS), a multilevel intervention initiated in a citywide safety net health system to improve low-income maternal smokers' abstinence and reduce child tobacco smoke exposure. **Methods.** This randomized controlled trial in Philadelphia, Pennsylvania (2015-2020), recruited low-income maternal smokers who received a brief smoking intervention (Ask, Advise, Refer [AAR]) from nutrition professionals in the Special Supplemental Nutrition Program for Women, Infants, and Children before randomization to (1) a multilevel intervention (AAR 1 multimodal behavioral intervention [MBI]; n = 519) or (2) an attention control intervention (AAR 1 control; n = 197). **Results.** AAR 1 MBI mothers had significantly higher 12-month bioverified abstinence rates than did AAR 1 control mothers (odds ratio [OR] = 9.55; 95% confidence interval [CI] = 1.54, 59.30; P = .015). There were significant effects of time (b = -0.15; SE = 0.04; P < .001) and condition by time (b = -0.19; SE = 0.06; P < .001) on reported child exposure favoring AAR 1 MBI, but no group difference in child cotinine. Presence of other residential smokers was related to higher exposure. Higher baseline nicotine dependence was related to higher child exposure and lower abstinence likelihood at follow-up. **Conclusions.** The multilevel BLiSS intervention was acceptable and efficacious in a population that experiences elevated challenges with cessation.

Public Health Implications. BLiSS is a translatable intervention model that can successfully improve efforts to address the persistent tobacco-related burdens in low-income communities.

Trial Registration. Clinical Trials.gov identifier: NCT02602288.

Maternal smoking and child tobacco smoke exposure (TSE) remain leading causes of preventable disease and death.¹ In 2020, the World Health Organization estimated that tobacco kills more than 8 million people annually, including more than 1 million nonsmokers exposed to tobacco smoke.² Despite the decrease in global smoking prevalence since 2000, prevalence among females has decreased more slowly than prevalence among males, and an income disparity has emerged. Large disparities exist in the United States across disadvantaged groups,¹ with smoking prevalence in low-income groups nearly twice as high as prevalence in higher-income groups.³ Similar TSE disparities exist, with younger children from disadvantaged households bearing the greatest burden.⁴ Because of the serious consequences and growing disparities in maternal smoking and child TSE, effective interventions are needed in underresourced communities to address this public health priority.⁵

Low-income smokers respond well to evidence-based interventions.⁶ In practice, however, evidence-based interventions have limited reach to high-risk smokers, and poverty remains strongly linked to cessation challenges among maternal smokers.^{7,8} Public health researchers and practitioners have long recognized the potential population impact of addressing tobacco disparities by partnering with safety net community health organizations, such as the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). To date, however, approaches in these settings have had limited effectiveness, as they tend to emphasize brief advice without the more intensive skillstraining necessary to promote smoking behavior change.^{9,10} For example, standard WIC operations do not include routine tobacco screening and intervention, missing an opportunity to reach a high-risk population in which smoking rates exceed the general population. Also, systematic reviews of caregiver interventions designed to reduce child TSE and promote parental cessation reflect mixed results in trials to date as well as a void of multilevel interventions that could address a wider array of smoking determinants.¹¹⁻¹³ The Babies Living Safe and Smokefree (BLiSS) trial addressed these shortcomings by testing a multilevel intervention that targeted multiple determinants of smoking behavior change across levels of influence. The first treatment element was a WIC system intervention, translated from the American Academy of Pediatrics best practice guidelines for tobacco intervention (i.e., Ask, Advise, Refer [AAR], also known as 2As 1 R).¹⁴ Embedding it in routine client intake procedures, we designed this brief intervention to guide WIC nutrition counselors to encourage smokers to initiate behavior change and connect them to evidence-based resources. AAR was linked to a more intensive, multimodal behavioral intervention (MBI) grounded in telehealth counseling that was designed to address individual- and family-level determinants of cessation and child TSE. MBI elements included nicotine replacement and counseling integrated with a mobile app and multimedia health education and skills training

materials. Thus, BLiSS provided multiple sources of health information, advice, support and skills training, and repeated doses of intervention across multiple modalities and levels of influence.

A behavioral ecological model¹⁵ provided the conceptual framework. It suggests that systematic multilevel intervention elements delivered across levels of determinants can produce synergistic intervention effects that maximize the likelihood of behavior change. For example, integrated individual and family-level counseling components could augment WIC system-level messaging advocating smokefree homes and children's TSE protection. The interacting effects of advice, messaging, support, and accountability across levels of influence could enhance smokers' effort to reduce TSE compared with a single-level approach alone.^{16,17} We applied this logic in designing the multilevel BLiSS intervention (AAR 1 MBI). We hypothesized that integrating our WIC system-level intervention with the individual- and family-focused MBI elements would result in a more effective intervention than AAR plus an attention control intervention (AAR 1 control) in reducing bioverified child TSE (primary outcome) and promoting bioverified maternal smoking abstinence.

METHODS

We used a parallel 2-group randomized controlled design with assessments at baseline, 3-month end of treatment, and 12-month follow-up. In the trial, we implemented brief tobacco intervention in 10 Philadelphia, Pennsylvania, WIC clinics. After AAR, we based randomization on a permuted blocks design with stratification by site and presence of other smokers in the home (yes/no). The design was guided by CONSORT (Consolidated Standards of Reporting Trials) criteria.¹⁸ Eligible participants were English speaking, mothers or female guardians, smokers, and older than 17 years; owned a smartphone; and had a child younger than 6 years. Exclusion criteria included pregnancy and conditions that could interfere with the ability to provide informed consent or follow procedures (active psychosis, insufficient health literacy, and nonnicotine drug dependence). Figure 1 shows participant flow.

Procedures

Before enrolling participants, we conducted a formative analysis of WIC tobacco intervention practices to inform our translation of pediatric guidelines (AAR) to WIC operations.

We conducted eligibility and baseline assessments via telephone and then performed randomization and in-home treatment orientation, during which we collected children's baseline urine sample (to test for cotinine, a TSE biomarker). Both groups received information about cessation resources, nicotine replacement therapy (NRT), condition-specific written materials, mobile app, and 12-weeks of telephone counseling. Blinded research staff conducted 3- and 12-month structured telephone assessments followed by home visits to obtain child urine cotinine and bioverify participants' reported abstinence (with saliva cotinine and expired carbon monoxide).

WIC system intervention (both groups).

Nutrition professionals trained by investigators delivered AAR in routine paper-based client enrollment workflow. In the clinics, trial staff put up trial posters and set out pamphlets highlighting TSE dangers, benefits of smokefree homes and child TSE reduction, and AAR prompts to reflect smokefree norms in the WIC system and encourage WIC nutrition counselors' AAR delivery. During intake assessments, WIC counselors offered mothers information about TSE consequences and advice about TSE reduction and referral to the trial.

Attention control intervention (AAR + control). These participants received equivalent contact time as the AAR 1 MBI group that included AAR plus 12 weeks of nutrition counseling with parallel adjunctive treatment modalities.

Intervention included up to 5 sessions with intersession texts; the Fooducate app; and a multimedia tool kit from Sesame Street Workshop called Food for Thought: Eating Well on a Budget.

Multilevel multimodal behavioral intervention (AAR + MBI). Our published protocol¹⁶ details this 12-week intervention of evidence-based TSE-reduction and smoking cessation treatment elements delivered across 7 modalities:

1. Up to 5 telephone counseling sessions based on cognitive behavioral therapy for smoking intervention,¹⁹ evidence that smoking parents are motivated to modify smoking to protect children,²⁰⁻²² and our previous trials^{23,24} in which initial efforts with child TSE protection are shaped toward quitting as weeks progress;
2. The BLiSS mobile app-which was modified from the National Cancer Institute's QuitPal²⁵ and included features

- for real-time self-monitoring of smoking, child TSE, smoking urges, and progress-with an app-linked dashboard guided by counselor feedback;
3. Eight weeks of NRT (via gum, patch, or lozenge);
 4. Intersession text messaging with goal reminders and supportive advice;
 5. Ten animated video clips via text covering topics parallel to counseling content;
 6. A participant treatment binder with written information and worksheets; and
 7. A family-focused smokefree home guide that contained materials (e.g., no smoking signs) to facilitate smokefree home maintenance and child TSE protection.

Measures

We obtained outcome measures via structured timeline follow-back interviews and bioverification. We assessed child TSE as the reported number of daily cigarettes to which the child was exposed in the last 7 days, assaying urine cotinine using a validated high-performance liquid chromatography with tandem high-resolution mass spectrometry procedure (0.1 ng/mL limit of quantitation). We bioverified mothers who reported 7-day point prevalence smoking abstinence with saliva cotinine using NicAlert(Nymox Pharmaceutical Corporation, Hasbrouck Heights, NJ) or expired carbon monoxide (for participants actively using NRT).

We assessed baseline demographics, smoking history, and psychosocial variables, including variables planned as control variables in outcome analyses: nicotine dependence, other smokers at home, and depressive symptoms. We collected process measures to determine the level of participant adherence. We calculated MBI dosage by summing standardized variables representing treatment engagement: minutes of telephone counseling, number of BLiSS app page views, number of videos watched, weeks of NRT use at least 4 of 7 days, and frequency of referring to the participant binder and family guide (1 5 never to 6 = 8 or more times).

Statistical Analyses

We conducted statistical analyses using STATA version 15 (StataCorp, College Station, TX) and SAS 9.4 (Cary, NC). First, we examined data distributions. Child cotinine was not normally distributed and had extreme outliers. Therefore, we winsorized values at each time point that exceeded 3 SDs (20 values exceeding 466 ng/mL), and then we log-transformed data at each time point. In our inferential analyses, we used an intention-to-treat approach. We compared change scores using random effects linear regressions, with the randomization arm as a fixed effect and clinic as a random intercept to account for potential clustering. To investigate longitudinal trends in reported TSE and cotinine levels, we used multilevel random effects regressions with random effects to account for within-subject correlation over time and within-clinic correlation. In these models, we analyzed square roots of exposure variables to normalize them.

We coded time as an ordinal variable (i.e., 0,1,2). For abstinence analysis, we used logistic regressions with random intercepts for clinic and survey wave indicator variables. We assessed the balance of potential confounding variables between arms using linear or logistic regressions with random intercepts to account for within-clinic correlation. Because more AAR 1 MBI participants than AAR 1 control participants reported alcohol problems at baseline ($P = .028$), we added alcohol problems (1 5 yes, 0 5 no) to the list of a priori control variables (e.g., other smokers). No other baseline characteristics differed between randomization arms.

For missing data, we used the multiple imputation approach of Raghunathan et al.^{26,27} with 25 imputed data sets. Our primary inferential analyses reported results with multiple imputations. We used complete case analyses for dosage and adherence analyses. We bounded imputed values so that none would be outside possible ranges of variables (e.g., no negative cotinine values).

RESULTS

WIC professionals advised and referred 2846 maternal smokers, of whom we randomized 396 (Figure 1). The final 12-month attrition was 12.4%, and there was no between-group difference. Table 1 displays the baseline characteristics. For child TSE from maternal smoking, there was a significant effect of time ($b = -0.15$; $SE = 0.04$; $P < .001$) and condition by time ($b = -0.19$; $SE = 0.06$; $P < .001$). Both groups reported reduced exposure to mothers' cigarettes over time, with a greater reduction among AAR 1 MBI mothers (Figure 2, a). Baseline nicotine

dependence level ($b = 0.22$; $SE = 0.04$; $P < .001$) and number of other residential smokers ($b = 0.14$; $SE = 0.08$; $P < .046$) were significantly and positively associated with child TSE from mothers.

Change in TSE from all sources also showed significant effects of time ($b = -0.15$; $SE = 0.05$; $P = .002$) and condition by time ($b = -0.21$; $SE = 0.07$; $P = .002$; Figure 2, b) as well as significant positive associations with nicotine dependence ($b = 0.22$; $SE = 0.05$; $P < .001$) and residential smokers ($b = 0.59$; $SE = 0.10$; $P < .001$). Child cotinine results showed no effect of condition, time, or condition by time. Baseline nicotine dependence ($b = 0.12$; $SE = 0.03$; $P < .001$) and other residential smokers ($b = 0.21$; $SE = 0.05$; $P < .001$) were significantly and positively associated with cotinine. We obtained child cotinine samples from most participants who provided reported child TSE: at 3 months, we did not obtain samples from 6 AAR 1 control and 8 AAR 1 MBI participants reporting child TSE. At 12 months, we could not collect 1 AAR 1 control and 3 AAR 1 MBI samples.

There was a significant treatment effect on bioverified smoking abstinence favoring AAR 1 MBI (odds ratio [OR] 5 9.55; 95% confidence interval [CI] 5 1.54, 59.30; $P = .015$) but no effect of time or condition by time. The proportion of bioverified quitters was relatively higher in the AAR 1 MBI group than in the AAR 1 control group at 3 months (7.0% [14/199] vs 1.0% [2/197]) and 12 months (7.5% [15/199] vs 3.6% [7/197]). Bioverified abstinence was less likely for those with higher nicotine dependence (OR = 0.61; 95% CI = 0.38, 0.96; $P = .033$). Prebioverified, self-reported abstinence mirrored the pattern of bioverified results: more AAR 1 MBI than AAR 1 control participants reported abstinence at 3 months (8.0% [16/199] vs 1.0% [2/197]) and 12 months (9.5% [19/199] vs 5.1% [10/197]). Also, more AAR 1 MBI than AAR 1 control participants reported a quit attempt greater than 24 hours (69.2% vs 55.0%; $P < .01$), had more abstinent days during treatment (14.47 ± 22.02 vs 3.61 ± 9.85 days; $P = .001$), and had more days to relapse after quitting (25.53 ± 40.03 vs 14.23 ± 26.70 days; $P < .01$).

Process analysis showed that 61% of participants reported that their referring WIC counselor fully complied with the "advise" step of the clinic protocol. About 90% of participants in each group received at least some telephone intervention (Figure 1). MBI group telephone counselors maintained 90.0% or greater fidelity throughout the trial: the mean fidelity score on checklists of 121 random session recordings was 9.79 ± 0.49 among 10 items (1 = achieved and 0 = not achieved for each item). Table 2 shows that participants reported receiving the intended condition-specific treatment elements and that AAR 1 MBI participants, compared with AAR 1 control, reported greater effort in smoking treatment-related activities. The provision of NRT to AAR 1 MBI participants led to much higher NRT initiation rates in that group than in the AAR 1 control group. There were no group differences in use of cessation medications (e.g., varenicline) or additional counseling. For example, approximately 3% of participants in both groups reported cessation medication use; and 14.5% of AAR 1 control participants compared with 9.0% of AAR 1 MBI participants received additional treatment from the PA Free Quitline.

AAR 1 MBI participants completed an average of 3.10 ($SD = 1.66$) telephone counseling sessions, with 64.3% of participants completing more than 3 sessions. Mean app use was 16.48 ($SD = 17.52$) days, with most use occurring in the first week and tapering over time. Despite more than half of AAR 1 MBI participants initiating NRT, only 14.3% used NRT at least 4 days per week over 8 weeks. Approximately 68% referred to their participant written materials more than once (28.9% did so 4 or more times), and 50.9% used the family guide more than once (16.8% did so 4 or more times), whereas 91.5% watched at least 1 video (60.8% watched at least 4). Greater treatment dosage across all treatment modalities was associated with lower reported child TSE to maternal smoking ($r = -0.24$; $P = .038$) and all sources ($r = -0.26$; $P = .024$) at 3 months and more days abstinent during treatment ($r = 0.26$; $P = .02$). Dosage-outcome associations within modalities suggested that telephone counseling was the most integral mode of intervention. For example, completing more BLISS counseling sessions was related to the following outcomes: lower child cotinine at 3 ($r = -0.19$; $P = .016$) and 12 months ($r = -0.24$; $P = .002$), bioverified abstinence at 3 months ($r = 0.19$; $P = .01$), adoption of an indoor smoking ban at 3 ($r = 0.23$; $P = .001$) and 12 months ($r = 0.18$; $P = .013$), lower reported child TSE from maternal smoking ($r = -0.23$; $P = .003$) and all sources ($r = -0.24$; $P = .001$) at 3 months, and more days abstinent during treatment ($r = 0.34$; $P < .001$). By contrast, more weeks of NRT use and more app use did not relate to outcomes. Greater use of videos was associated with lower child cotinine at 3 months ($r = -0.16$; $P = .04$) and more abstinent days during treatment and follow-up ($P < .01$).

DISCUSSION

Our primary hypothesis that the AAR 1 MBI intervention would promote greater reductions in child TSE than the AAR 1 control intervention was supported by reported TSE results, consistent with results showing that AAR 1 MBI mothers were more likely to adopt residential smoking bans. However, there was no change in child cotinine in either group. Results did support our hypothesis that the AAR 1 MBI participants would demonstrate higher bioverified abstinence rates than the AAR 1 control group. AAR 1 MBI participants also had more days abstinent and days to relapse. Higher baseline nicotine dependence was associated with less success across all outcomes, and having more smokers living in the home was associated with greater child exposure.

The treatment effects on reported TSE reduction and adoption of residential smoking restrictions in this trial were consistent with previous studies.^{11,23,24} Our result showing no child cotinine reductions in either group is inconsistent with some previous findings.¹¹ For example, in some trials, child cotinine decreased equally in both experimental and control groups over time. We are aware of only 1 trial targeting low-income maternal smokers that demonstrated greater bioverified TSE reduction in experimental versus control groups.²³ However, compared with BLISS, that trial's experimental group had more counseling sessions over 16 weeks. This point has relevance, considering the AAR 1 MBI within-group analysis: greater counseling dosage was related to significantly lower child cotinine. Additionally, improving WIC counselor adherence to AAR could improve the impact of multiple channels delivering TSE-reduction messaging. Better provider adherence (> 80% of participants reporting pediatricians' full compliance to AAR procedures) occurred in our previous primary care-initiated multilevel intervention,²⁴ and child cotinine declined significantly in the entire study sample.

Plausible explanations for the null child cotinine results, despite reported reductions in child TSE, include limitations of reported versus observable measurement of TSE. For example, when reporting child TSE, participants are asked to recall days, times, locations, and sources of exposure. They may miss TSE occurring when their child is not in their direct care. Additionally, even though maternal smoking is a primary source of child TSE, cotinine levels can be affected by thirdhand smoke contamination, which tends to be elevated in low-income residential units even when parents report no indoor smoking.^{28,29} Residual tobacco contaminants and nicotine accumulation on indoor surfaces, walls, and furnishings are redispersed for months- even after smokefree home adoption or cessation. In 1 study,³⁰ child cotinine and residential tobacco contaminants were 5 to 7 times higher in homes of smokers who achieved indoor smoking bans than in nonsmokers' homes. Such evidence points to the importance of promoting household smoking bans and maternal smoking abstinence.

The abstinence results in this trial are notable, particularly because the sample of high-risk maternal smokers was not seeking smoking treatment at the WIC clinic encounter (AAR). Moreover, the outcome was bioverified and the treatment effect was observed using an attention control that included a clinic-based tobacco intervention. In a systematic review of trials targeting smoking parents, only 1 of 18 studies used a tobacco intervention control group and demonstrated the main effect of treatment on bioverified abstinence rates.³¹ Two more recent trials targeting smoking parents have demonstrated main effects of experimental treatment on bioverified abstinence rates compared with a standard care tobacco intervention control group.^{23,24} Another notable finding was the AAR 1 MBI group's high rate of NRT initiation, given the pervasively low uptake of NRT in low-income and racial minority communities. However, relatively few participants reported sustained NRT use, and greater use was not related to cessation. More individual-level counseling to guide proper NRT use or incentives to motivate sustained NRT use could facilitate a greater likelihood of cessation.

Although results suggest promising potential for the multilevel BLISS intervention for low-income maternal smokers, the null cotinine results and relatively low absolute quit rates warrant future modifications and enhancements. An ecological framework could guide the integration of enhancements targeting multiple determinants of smoking across levels of influence. For example, at the biological level, future trials could address the effects of elevated nicotine dependence on TSE and cessation outcomes and enhance NRT effects on cessation with combination NRT. At the clinic level, future trials could improve providers' AAR adherence by embedding decision aids in electronic health systems. Because the family-level treatment components in BLISS were minimal and the effect of

other smokers in the home undermined TSE protections, future trials could explore the utility of family counseling components. At the community and policy levels, health communication campaigns and tobacco legislation (including zoning that restricts proliferation of tobacco vendors in low-income neighborhoods) could amplify WIC agency efforts encouraging families to reduce child TSE.

Finally, BLiSS outcomes suggest that behavioral counseling grounded in social cognitive theory and cognitive behavioral therapy processes that target individual-level determinants could be the keystone in a multilevel intervention for smoking behavior change. Based on our evidence that higher dosage of telephone counseling was related to improved outcomes, future studies could explore ways to improve participants' treatment engagement. One evidence-based strategy is contingency management with financial incentives to facilitate session adherence and bioverified abstinence.^{32,33} The potential utility of financial incentives as an adjunct in the BLiSS model is compelling, particularly given the increasing enthusiasm for this method among key stakeholders, including public and private insurers.³⁴

Limitations

Limitations in this trial include incomplete information about AAR implementation. Our interpretation of results is also limited to the target population and inclusion criteria constraints on the sample. However, we assert that the BLiSS model is a pragmatic treatment model that could be translated to reach and engage broader populations of low-income smokers (an assertion a future dissemination and implementation trial could test). Similarly, a more pragmatic approach with fewer efficacy trial-related constraints would help inform future dissemination efforts.

Public Health Implications

Our findings suggest that a multilevel MBI package initiated in WIC was acceptable, feasible, and efficacious in promoting long-term smoking abstinence and reported child TSE reduction. Importantly, these results occurred in a population that experiences elevated barriers to initiating smoking treatment and achieving abstinence. Because we designed BLiSS as a pragmatic intervention (embedded in routine patient flow, based on standard care for clinic-based intervention, and modeled after quitline best practices), this approach could be readily adopted across state WIC systems or similar community-based safety net programs in partnership with state quitlines. Such implementation would be similar to existing medical system e-referral links to quitlines. Therefore, disseminating this approach would have a large impact on a persistent public health priority, reducing tobacco-related morbidity and mortality in low-income communities bearing the greatest burden.

Future iterations of the BLiSS approach could improve smoking treatment outcomes further by including strategies that use the growing evidence that treatment adherence and abstinence rates can be increased with contingency management—an intervention strategy gaining favor among public and private insurers.³⁴ To improve child TSE-reduction outcomes, future treatments could include programming to reduce thirdhand smoke (the residual environmental nicotine and tobacco contaminants that affect exposure and cotinine levels even after indoor smoking bans and cessation). Embedding future, novel intervention strategies in a behavioral ecological framework could amplify treatment effects on abstinence and child TSE outcomes through synergistic influences across levels of behavior change determinants. AJPH

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CONTRIBUTORS

B. N. Collins drafted the article, developed and oversaw the implementation of the telephone-based behavioral counseling intervention, and developed and supervised intervention training and fidelity monitoring of the smoking and nutrition interventions. B. N. Collins and S.J. Lepore developed the study concept and aims and the initial analytic plan, animated health education video clips, modified the QuitPal app that became the BLiSS research app used in the trial, operationalized and designed the WIC clinic intervention protocol, and implemented the WIC intervention training, fidelity monitoring, and fidelity feedback protocols. S.J. Lepore developed the telephone-based nutrition counseling intervention and developed the data quality assurance training and feedback protocols. B. Egleston finalized the analytic plan and allocation schedule, oversaw randomization procedures, and conducted data analyses. All authors interpreted the analytic results and contributed to and approved the final version of the article.

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The authors do not have any conflicts of interest to disclose.

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The Temple University institutional reviewboard approved this study (protocol 23188), and the participants' written informed consent was required for their participation in the study.

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Menstrual Health: Taking Action Against Period Poverty

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ABSTRACT (ENGLISH)

Period poverty is the lack of sufficient resources needed to manage menses, such as toilet, bathing, and laundering facilities; general menstrual education or information; and basic menstrual management supplies like tampons and pads.¹ Globally, period poverty and menstrual health and hygiene management have largely been examined in low- and middle-income countries.¹ However, this burden is also present in the United States. It is estimated that about one in four US menstruators will experience period poverty during her lifetime.^{2,3} Despite the prevalence, few understand, recognize, discuss, or study this issue domestically.³ In the United States, the limited existing literature on period poverty has largely noted that low-income and homeless populations in large urban cities, such as St. Louis, Missouri,³ and New York City,^{4,5} are among those most impacted by period poverty. However, period poverty is not limited to only those in "poverty" and can affect menstruators from any background at any time. The COVID-19 pandemic exacerbated period poverty. In the early months of the pandemic, there was fierce competition for resources (e.g., toilet paper, soap, wipes) and exorbitant gouging of these bathroom hygiene product prices.⁶ Compounded by increased job losses and unemployment because of the pandemic, fiscal barriers to accessing necessary menstrual products grew. The Coronavirus Aid, Relief, and Economic Security (CARES) Act, passed in March 2020, allowed employed menstruators with a health savings account or flexible savings account to purchase menstrual products with their respective coverage.⁷ But, given the bill's limited scope, it in fact furthered menstrual health disparities, as only 41% of private industry employees had access to a flexible health care spending account in 2019,⁸ and it lacked consideration for the skyrocketing unemployment rates of Americans—particularly among Black and Hispanic women.² Thus, conversations about menstrual products and hygiene needs among the majority of menstruators around the country were largely undiscussed. The overarching lack of attention to period poverty in society, research, medicine, and public wellness is attributable to deep-rooted menstrual stigma and shame. Many menstruators tend to conceal their menses out of fear or embarrassment, which yields conditioned self-silencing of their needs and further perpetuation of a generational and societal spiral of silence.⁹ This resounding stigma continually hinders both open discussion and policy engagement on menstrual experiences, management, and hygiene needs. Therefore, the purpose of this work is to combat this stigma by describing five actionable steps we can all take to begin addressing period poverty.

FULL TEXT

Period poverty is the lack of sufficient resources needed to manage menses, such as toilet, bathing, and laundering facilities; general menstrual education or information; and basic menstrual management supplies like tampons and pads.¹ Globally, period poverty and menstrual health and hygiene management have largely been examined in low- and middle-income countries.¹ However, this burden is also present in the United States. It is estimated that about one in four US menstruators will experience period poverty during her lifetime.^{2,3} Despite the prevalence, few understand, recognize, discuss, or study this issue domestically.³ In the United States, the limited existing literature on period poverty has largely noted that low-income and homeless populations in large urban cities, such as St. Louis, Missouri,³ and New York City,^{4,5} are among those most impacted by period poverty. However, period poverty is not limited to only those in "poverty" and can affect menstruators from any background at any time. The COVID-19 pandemic exacerbated period poverty. In the early months of the pandemic, there was fierce competition for resources (e.g., toilet paper, soap, wipes) and exorbitant gouging of these bathroom hygiene product prices.⁶ Compounded by increased job losses and unemployment because of the pandemic, fiscal barriers to accessing necessary menstrual products grew. The Coronavirus Aid, Relief, and Economic Security (CARES) Act, passed in March 2020, allowed employed menstruators with a health savings account or flexible savings account to purchase menstrual products with their respective coverage.⁷ But, given the bill's limited scope, it in fact furthered menstrual health disparities, as only 41% of private industry employees had access to a flexible health care spending account in 2019,⁸ and it lacked consideration for the skyrocketing unemployment rates of Americans—particularly among Black and Hispanic women.² Thus, conversations about menstrual products and hygiene needs among the majority of menstruators around the country were largely undiscussed. The overarching lack of attention to period poverty in society, research, medicine, and public wellness is attributable to deep-rooted menstrual stigma and shame. Many menstruators tend to conceal their menses out of fear or

embarrassment, which yields conditioned self-silencing of their needs and further perpetuation of a generational and societal spiral of silence.⁹ This resounding stigma continually hinders both open discussion and policy engagement on menstrual experiences, management, and hygiene needs. Therefore, the purpose of this work is to combat this stigma by describing five actionable steps we can all take to begin addressing period poverty.

TALK ABOUT PERIOD POVERTY

Period poverty is a devastating issue that we simply do not talk about enough. One of the first and most crucial steps toward minimizing period poverty is talking openly and honestly about what it is and who it affects, as we cannot start to address an issue without naming it. Compounded in menstrual stigma and shame, simply discussing any aspect of menstruation can be difficult-let alone resource needs or environmental limitations.⁹ Period poverty extends far beyond simply accessing products and includes having the privacy to change products, means of disposing materials, and a place to wash one's body. As such, anyone can be at risk for or experience period poverty. Many who learn of this real and concerning phenomenon are surprised. Thus, the definition of and concepts related to period poverty need to be openly discussed in public forums, such as town halls, city council meetings, and school board meetings-any place where social services and resource limitations are discussed. Local organizations can help spread awareness through media campaigns and community outreach efforts and begin to engage local government and policy-makers on the issue, to bring attention to the larger structural change needed to alleviate period poverty's burden.

The topic should also be discussed in academic settings. At the university level, student health centers, wellness offices, and other health care access points should provide menstrual products to students at free or reduced cost (as they do with other health products) and make their student body aware of this practice. Residence buildings could carry menstrual products on-hand for residents in need. In the United States, about 85% of colleges and universities provide free condoms to their students,¹⁰ and they ought to do the same with menstrual products. Medical and health professions trainees need to be taught about ways to identify and discuss period poverty with their patients in a culturally competent manner, as well as be in a position to intervene and provide patients with necessary products. This could lead to opportunities to discuss menstrual health more adeptly with patients, with improved attention to cycle characteristics and needs while normalizing menstrual conversations and combating stigma simultaneously. Clinicians and public health practitioners should be made aware of this consequential public health concern, as specific public health education on the topic of menstruation in any regard is currently lacking.¹¹ At the K-12 level, teachers and school administrators need to be aware of period poverty and its impacts on students' wellness and their education, in addition to having products available for menstruators in need.

UNDERSTAND MENSTRUAL INEQUITY

While beginning conversations about period poverty are crucial, they are pointless without full understanding and recognition of the menstrual inequities Black, Indigenous, and other persons of color (BIPOC) face in the United States. Previous research has noted that Black adolescents have, on average, a lower age of menarche than their White counterparts¹² and emphasized the BIPOC students and women tend to have gaps in practical menstrual knowledge¹³ and are left feeling unprepared for menarche,¹⁴ respectively. Overall, period poverty is not a singular concern; it is a multidisciplinary social construct impacted by multiple layers of oppression.

No More Secrets, a Philadelphia, Pennsylvania-based grassroots organization founded and operated by a Black mother-daughter team, is a sexuality awareness organization that has developed the only feminine hygiene bank and in-home delivery service in the Philadelphia region.¹⁵ In response to community needs, No More Secrets has opened a brick-and-mortar location called The SPOT Period, a menstrual hygiene and educational hub-the first of its kind in the nation.¹⁵ The SPOT comprehensively tackles period poverty, serving as a safe and comfortable place with proper waste management, functional toilets and washing facilities, free products, and resources, as well as menstrual hygiene awareness and uterine care educational workshops and programming. Tirelessly spreading awareness about period poverty and advocating for menstrual equity, they launched a new social action campaign, #BlackGirlsBleed. #BlackGirlsBleed seeks to address systemic racism and oppression in the menstrual health space by amplifying authentic voices of Black menstruators and experiences of BIPOC-owned and -lead organizations

addressing menstrual equity—an area historically dominated by White perspectives—to ultimately decrease generational silence and stigma surrounding menstruation in Black communities. BIPOC individuals consistently have their voices muted and ignored, and their own menstrual experiences nullified and rejected; thus, it is dire to acknowledge menstrual equity as an intersectional issue. So, follow, engage, read, and listen to BIPOC menstrual experiences, as true, equitable, menstrual justice cannot be achieved without racial justice.

DONATE MENSTRUAL PRODUCTS

A simple way to directly reduce one aspect of period poverty is to donate menstrual products to local libraries, food pantries, homeless shelters, schools, and churches and ensure physicians' offices and clinics have products on hand. When donating, consider a variety of product types, sizes, and absorbency levels to be as inclusive of the diversity of menstruators as possible. While donation is absolutely necessary, even more important is making the public aware of donation sites and places to receive donations to ensure that all menstruators have products when they need them. Increased public knowledge of menstrual product donation and access sites would bring a greater awareness to the issue of period poverty in general while simultaneously increasing the ease in which menstruators can access products and creating a resource network. It must be emphasized that donations alone will not address the enormous structural, and inherently discriminatory, problem of period poverty. In the same way that donating food to a pantry cannot alone solve food insecurity, menstrual donations can instead serve as assistance to individuals in need alongside other actions designed to address wider social and structural inequities.

CONDUCT RESEARCH AND ENGAGE WITH THE COMMUNITY

In-depth understanding and research on period poverty remain limited, and further research is needed to better conceptualize the full impact of period poverty in the community. Thus, application of collaborative community-based participatory research (CBPR) is necessary. CBPR is a research partnership approach between the community and the research organization. Ownership over investigation is shared, and the community and participants drive directives. CBPR places emphasis on community-researcher collaboration, which can uncover unique insights into the sociocultural composition of the community.⁹ This partnership-based approach can help to develop a more comprehensive understanding of public health concerns within a specific population, as well as potential solutions.⁹ CBPR may help facilitate and foster new evidence-based understanding of period poverty and can be used to ultimately address menstrual equity.

Moreover, varied research methodologies should be considered and explored. Mixed-methods and qualitative designs have been beneficial to capture the complexity of period poverty thus far. Specifically, qualitative approaches that encompass participatory methods (e.g., reflective writing and journaling, team-based activities), key informant interviewing, in-depth interviewing among adolescent girls,¹³ and assigned-female-at-birth transgender and nonbinary menstruators,¹⁶ while mixed approaches using in-depth interviewing, field-based audits of toilet facilities, and geospatial mapping have been used to capture the scope of menstrual management among menstruators who are homeless.⁴ Period poverty has multiple layers across the community continuum; thus, research development and engagement need to be done with the persons most impacted at its center and must employ varied strategies to fully understand the stories and lived experiences of persons impacted.

ADVOCATE MENSTRUAL EQUITY POLICY

To address period poverty, we need to eliminate menstrual inequities. E-mail, call, and write to your elected officials at the federal, state, and community levels. Advocate to make products more accessible. Inquire about why diapers are available and covered under the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), but tampons are not. Reach out to elected school board members. Ask them to ensure that all schools provide menstrual products in all bathrooms. It is possible to remove these policy-based barriers as several countries worldwide have already done it. Britain has eliminated the "tampon tax" by reclassifying menstrual products as essential.¹⁷ Scotland recently passed legislation mandating the provision of menstrual products to anyone who needs them.¹⁸ New Zealand has also extended an effort to provide menstrual products free of charge to all primary, intermediate, and secondary state schools, as well as kura, Maori-language immersion schools.¹⁷ This effort will continue throughout the 2021 school year and is an expansion of a pilot program that uncovered that

nearly 12% of New Zealand students aged 9 to 13 years who menstruate have trouble accessing necessary menstrual products and often miss school as a result.¹⁷

To date, only some US states and select cities have adopted menstrual equity policies, through eliminating taxation on products or reclassifying them. New York City; Los Angeles, California; and Chicago, Illinois have passed bills requiring city-funded homeless shelters to provide menstrual products to shelter residents.⁵ In addition to the aforementioned CARES Act, Grace Meng (D-NY) has made inroads toward legislation at the national level, bringing to the Congress floor the comprehensive Menstrual Equity for All Act.¹⁹ However, to reach the most menstruators, hygiene products need to be covered by government insurance and assistance programs.

Thus far, no proposed legislation has come close to filling the period poverty gap in its entirety, leaving many menstruators vulnerable. So, reach out to your legislators. Highlight this critical need. Ask them to join you in a comprehensive stand against period poverty. AJPH

CORRESPONDENCE

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CONFLICTS OF INTEREST

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DETAILS

Subject:	Students; Collaboration; Stigma; Donations; Savings accounts; Equity; COVID-19; Poverty; Hygiene; Oppression; Minority & ethnic groups; Menstruation; Homeless people; Pandemics; Public health; Toilet facilities; Unemployment; Coronaviruses; Education; Urban populations; Health care; Employee benefits; Health care industry; Expenditures; Security; Tampons; Homelessness; Toilet paper; Bathing; Income; Shame; Management; Bathrooms; Health disparities; Home delivery services; Research; Needs; Racial differences; Medicine; Health services; Health care expenditures; Urban poverty; Urban population; Low income groups; Personal hygiene; Savings
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11 Years Ago

Anonymous

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FULL TEXT

Health Equity and Public Health Leadership

Public health in general, and health equity in particular, promote themes of human interconnection, egalitarianism, and community. Fundamentally, we are all interdependent and interconnected, with "promises to keep." Building community involves invoking the theme of shared responsibility that can be made explicit by effective public health leaders. Achieving true health equity means that despite our differences and diversity, a revitalized community can arise that truly acknowledges the health aspirations of each individual. . . Leadership in health equity remains unfinished business for the 21 st century. A future free from health inequity will require renewed commitment to unite the forces of science, practice, and policy for positive social change. All sectors of society must heed the call and many can contribute.

From AJPH, Supplement 1 2010, pp. S10-S11 passim

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#TransLivesMatter: What We Owe to Transgender and Gender Diverse Youths

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[ProQuest document link](#)

ABSTRACT (ENGLISH)

As a nonbinary public health advocate, therapist, and researcher and as a parent of a trans girl, I am both moved and troubled by Rider et al.'s article in this issue of AJPH (p. 499). I want to thank and congratulate the authors for studying an extremely important yet underexamined topic in this put-at-risk population, and I thank AJPH for shedding light on this public health issue. As a sex work rights activist, it is important for me to clarify that sex trading among youths is psychologically, legally, and morally distinct from sex trading among adults. As such, trading sex as youths is, by nature, exploitative.

Trading sex is an extreme risk factor for mental health challenges, including suicide and self-harm among youths, and especially among transgender and gender diverse (TGD) youths. Approximately 6% of TGD 9th and 11th graders report having traded sex in their relatively short lifetimes. More than three quarters of TGD youths who traded sex attempted to end their lives by suicide. This is a public health catastrophe. Think about Layla, a 16-year-old Black trans girl, who trades sex to buy food and sleep in someone's place to spend the freezing winter nights indoors. Consider the multiple systems that actively pushed Layla to trade sex: the rejecting family; the overburdened school staff who do not understand why Layla is struggling academically; the lack of community support for TGD youths due to lack of funding by the city and state; and the transphobic laws and policies, along with pervasive negative attitudes toward TGD individuals in the United States.

Sex trading among youths is a result of the unjust lack of support, resources, and programs designed to empower youths, especially TGD youths. Put differently, sex trading among TGD youths is an indicator of failure at multiple levels, including the family, school, community, city, state, and federal systems. Clearly, there is a dire need for multilevel public health interventions and programs addressing sex trading among youths, especially among TGD

youths. In fact, we need interventions far earlier in the trajectory into sex trading. Tangible intervention recommendations to address sex trading among TGD youths, along with its antecedents and consequences across multiple levels are included (Box 1).

FULL TEXT

As a nonbinary public health advocate, therapist, and researcher and as a parent of a trans girl, I am both moved and troubled by Rider et al.'s article in this issue of AJPH (p. 499). I want to thank and congratulate the authors for studying an extremely important yet underexamined topic in this put-at-risk population, and I thank AJPH for shedding light on this public health issue. As a sex work rights activist, it is important for me to clarify that sex trading among youths is psychologically, legally, and morally distinct from sex trading among adults. As such, trading sex as youths is, by nature, exploitative.

Trading sex is an extreme risk factor for mental health challenges, including suicide and self-harm among youths, and especially among transgender and gender diverse (TGD) youths. Approximately 6% of TGD 9th and 11th graders report having traded sex in their relatively short lifetimes. More than three quarters of TGD youths who traded sex attempted to end their lives by suicide. This is a public health catastrophe.

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Sex trading among youths is a result of the unjust lack of support, resources, and programs designed to empower youths, especially TGD youths. Put differently, sex trading among TGD youths is an indicator of failure at multiple levels, including the family, school, community, city, state, and federal systems. Clearly, there is a dire need for multilevel public health interventions and programs addressing sex trading among youths, especially among TGD youths. In fact, we need interventions far earlier in the trajectory into sex trading. Tangible intervention recommendations to address sex trading among TGD youths, along with its antecedents and consequences across multiple levels are included (Box 1).

To continuously inform and refine multilevel intervention programs, further research on TGD youths who trade sex is warranted. First, investigating the individual, interpersonal, and institutional risk factors for sex trading is critical to further elucidate trajectories into sex trading and to identify more intervention targets to eliminate sex trading among TGD youths. Second, given the alarming rates of suicide attempts and self-harm among TGD youths who trade sex, examining familial, school, community, and other structural resilience factors is particularly needed. Third, applying syndemics theory to research about sex trading among TGD youths may prove beneficial because sex trading often coexists with other syndemic conditions, such as housing instability, polysubstance use, childhood trauma, and intimate partner violence.¹¹ Fourth, to protect TGD youths, future studies would benefit from inquiring with whom they traded sex and for what purposes.

Last, given that most TGD youths who traded sex identified as LGBTQ+ and of color, employing an intersectional framework in future research is essential to identifying the unique needs of TGD youths who trade sex.

I call on public health researchers, advocates, and policymakers to direct much-needed attention to TGD youths, especially those who trade sex, so that we can protect and allow them to lead thriving, fulfilling, and self-actualized lives. We owe it to them. #TransLivesMatter4jPU

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The author dedicates this editorial to their sister-in-law, Maleah Yates, who passed away too soon.

CONFLICTS OF INTEREST

The author has no conflicts of interest to disclose.

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DETAILS

Subject:	Domestic violence; Intervention; Transgender persons; Self destructive behavior; Trauma; Community support; Gays & lesbians; Public health; Mental health; Non-binary gender; Suicides & suicide attempts; Freezing; Family school relationship; Gender; Risk analysis; Food; Self-injury; Community involvement; Suicide; Adults; Sleep; Risk factors; Sex; Health risks; Prostitution; Families & family life; Law; At risk populations; Activism
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AJPH GLOBAL NEWS

Lewandowski, Stephen; Marziali, Megan E; Kalia, Vrinda; Abuawad, Ahlam K; Segura, Luis E

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FULL TEXT

Nurses' Perspectives on Primary Care Service Restructuring During the COVID-19 Pandemic

In response to the COVID-19 pandemic, health care organizations around the world were forced to restructure how they operate. A survey of nurses working in Western Cape, South Africa, showed that, although most nurses (75%) reported restructuring services in response to the pandemic, almost half (48%) raised concerns regarding long-term consequences of restructuring, such as lack of preventive services. Restructuring health care services was effective in treating patients with COVID-19 but may not be sustainable for the long-term care of patients with chronic conditions.

Citation. Crowley T, Kitshoff D, De Lange-Cloete F, et al. Reorganisation of primary care services during COVID-19 in the Western Cape, South Africa: perspectives of primary care nurses. *S Afr Fam Pract* (2004). 2021;63(1):e1-e10. <https://doi.org/10.4102/safp.v63i1.5358>

Impact of COVID-19 on a Male HIV and Sexually Transmitted Infections Clinic

Rick et al. questioned 838 male clients of a sexually transmitted infections and HIV clinic in Recife, Brazil, to understand how COVID-19 related mobility restrictions and overloaded health services affected this vulnerable population. For many, COVID-19 decreased income and increased HIV and sexually transmitted infection vulnerability. Access to testing and treatment services was less affected. This clinic made HIV self-tests available and implemented other mitigation efforts. The researchers unexpectedly found that nearly half of the participants reported not knowing what HIV pre-exposure prophylaxis was, despite its no-fee availability and recruitment drives.

Citation. Rick F, Ishigami BI, Figueiroa FJ, et al. Impact of COVID-19 on income, prevention attitudes, and access to healthcare among male clients in a sexually transmitted infections clinic. *Braz J Infect Dis*. 2021;25(5):101617. <https://doi.org/10.1016/j.bjid.2021.101617>

Patient Experiences of Telehealth During COVID-19

Use of telephone consultations for medical services increased during the COVID-19 pandemic in response to nationwide lockdowns. Curtis et al. explored patient perspectives regarding telephone consultations in the midst of a COVID-19 lockdown in an urban clinic in Dunedin, New Zealand, through a retrospective cross-sectional survey (March 24-April 24, 2020). Among the 108 participants who completed the survey, the median age was 54 years (range = 16-88 years). Most rated satisfaction with telephone consultations high (median = 9 of 10), with men less satisfied than women; all participants were likely to recommend telephone consultations to other patients.

Additionally, participants found telephone consultations to take less or a similar amount of time and to be more convenient or no different from in-person consultations. Telephone consultations appear to be a possible substitute for in-person visits, which has important implications for future pandemics and addressing disparities in access to health services.

Citation. Curtis M, Duncan R, Jing M, et al. "Not a perfect situation, but . . ." A single-practice survey of patient experience of phone consultations during COVID-19 alert level 4 in New Zealand. *N Z Med J*. 2021;134(1544):35-48.

Prevalence of HIV, Hepatitis C Virus, and Hepatitis B Virus in Central Asia and the Caucasus

Davlidova et al. conducted a systematic review of MEDLINE, Embase, and PsycINFO through October 2019 of the

prevalence of HIV, hepatitis C virus, and hepatitis B virus in Central Asia and the Caucasus, regions where these viruses pose a significant public health threat. The authors paid special attention to high-risk groups: people who inject drugs, female sex workers, men who have sex with men, incarcerated persons, and migrants. Wide ranges of prevalence were noted for all 3 viruses. The range was widest among people who inject drugs, among whom prevalence of HIV ranged from 0.0% to 30.1%, prevalence of hepatitis C virus ranged from 0.3% to 92.1%, and prevalence of hepatitis B virus ranged from 2.8% to 79.7%. The prevalences of HIV, hepatitis C virus, and hepatitis B virus are exceedingly high among high-risk groups in Central Asia and the Caucasus.

Citation. Davlidova S, Haley-Johnson Z, Nyhan K, Farooq A, Vermund SH, Ali S. Prevalence of HIV, HCV and HBV in Central Asia and the Caucasus: a systematic review. *Int J Infect Dis*. 2021;104:510-525.

<https://doi.org/10.1016/j.jiid.2020.12.068>

DETAILS

Subject:	Infections; Hepatitis B; Public health; COVID-19; Hepatitis C; Chronic conditions; Human immunodeficiency virus--HIV; Asian cultural groups; Health services; Long-term care; Risk groups; Nurses; Health care; Patients; Viruses; Pandemics; Hepatitis; Primary care; Coronaviruses; Systematic review; Health risks; Disease transmission
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Nurturing Innovation at the Roots: The Success of COVID-19 Vaccination in American Indian and Alaska Native Communities

Haroz, Emily E, PhD MA MHS ¹ ; Kemp, Christopher G, PhD MPH ¹ ; O'Keefe, Victoria M, PhD MS ¹ ; Pocock, Katherine, PA-C ² ; Wilson, David R, PhD ³ ; Christensen, Loretta, MD MBA MSJ FACS; Walls, Melissa, MA PhD; Barlow, Allison, PhD; Hammitt, Laura, MD ¹ Center for American Indian Health, Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore MD ² Whiteriver Indian Hospital, Whiteriver, AZ ³ Tribal Health Research Office, National Institutes of Health, Bethesda, MD

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ABSTRACT (ENGLISH)

American Indians and Alaska Natives (AI/ANs) experienced some of the highest rates of COVID-19 disease and death in the United States^{1,2}: an estimated 1 in 475 AI/ANs have died from COVID-19, in contrast to 1 in 825 White Americans.³ Infectious diseases have caused catastrophic losses among Indigenous populations since the first contact with Europeans; the distribution of smallpox-infected blankets by colonizers and federal officials is the earliest documentation of germ warfare and remains a devastating memory.^{4,5} The disproportionate impact of COVID-19 in AI/AN communities is a result of historically rooted systems of colonization, oppression, and marginalization.⁶ High rates of poverty, lack of running water, inadequate access to healthy food and transportation, poor indoor air quality, and overcrowded housing have all contributed to increased risk from COVID-19, especially on tribal reservations. Lack of electricity, Internet, and cell service, and inadequate infrastructure also created barriers to sharing prevention guidance, access to telemedicine, and health education. Chronic underfunding of the Indian Health Service resulted in insufficient resources and capacity to care for COVID-19 patients; many had to be transported off reservations to regional hospitals. High rates of underlying chronic health conditions, particularly those that contribute to more severe outcomes-including diabetes, heart disease, and lung disease, which are driven by these same social determinants-exacerbated the effects of COVID-19. Public health surveillance during COVID-19 has also failed at times to appropriately count and consider AI/ANs, an issue deemed "data genocide." Despite these challenges, the COVID-19 vaccination efforts in many AI/AN communities have been major successes; AI/ANs have the highest COVID-19 vaccination rate of any racial or ethnic group in the country (Figure 1). How can this success inform the ongoing implementation of vaccination efforts elsewhere? We draw from four decades of

work in partnership with tribes to outline several key lessons. Ultimately, we argue that the COVID-19 vaccination effort in AI/AN communities has been successful because it was nurtured at its roots by a deep well of community strength and by respect for tribal sovereignty.

FULL TEXT

American Indians and Alaska Natives (AI/ANs) experienced some of the highest rates of COVID-19 disease and death in the United States^{1,2}: an estimated 1 in 475 AI/ANs have died from COVID-19, in contrast to 1 in 825 White Americans.³ Infectious diseases have caused catastrophic losses among Indigenous populations since the first contact with Europeans; the distribution of smallpox-infected blankets by colonizers and federal officials is the earliest documentation of germ warfare and remains a devastating memory.^{4,5} The disproportionate impact of COVID-19 in AI/AN communities is a result of historically rooted systems of colonization, oppression, and marginalization.⁶ High rates of poverty, lack of running water, inadequate access to healthy food and transportation, poor indoor air quality, and overcrowded housing have all contributed to increased risk from COVID-19, especially on tribal reservations. Lack of electricity, Internet, and cell service, and inadequate infrastructure also created barriers to sharing prevention guidance, access to telemedicine, and health education. Chronic underfunding of the Indian Health Service resulted in insufficient resources and capacity to care for COVID-19 patients; many had to be transported off reservations to regional hospitals. High rates of underlying chronic health conditions, particularly those that contribute to more severe outcomes-including diabetes, heart disease, and lung disease, which are driven by these same social determinants-exacerbated the effects of COVID-19. Public health surveillance during COVID-19 has also failed at times to appropriately count and consider AI/ANs, an issue deemed "data genocide."⁷ Despite these challenges, the COVID-19 vaccination efforts in many AI/AN communities have been major successes; AI/ANs have the highest COVID-19 vaccination rate of any racial or ethnic group in the country (Figure 1). How can this success inform the ongoing implementation of vaccination efforts elsewhere? We draw from four decades of work in partnership with tribes to outline several key lessons. Ultimately, we argue that the COVID-19 vaccination effort in AI/AN communities has been successful because it was nurtured at its roots by a deep well of community strength and by respect for tribal sovereignty.

COMMUNITY ENGAGEMENT DURING TRIALS

Tribes have historically been hesitant about participating in clinical research because of past ethical violations. Egregious examples of unethical research include the ionized trials in Many Farms, Navajo Nation, and the misuse of Havasupai genetic materials.^{11,12} In response to these and other violations, many tribal governments have exercised their sovereignty by establishing independent ethical review processes to ensure that research is conducted in the best interests of its people. During the COVID-19 pandemic, several tribes chose to allow their citizens to participate in Phase 3 vaccine trials following extensive deliberations and layers of community approvals. Respect and engagement with tribal research processes of approvals helped to ensure that considerations were made for individuals, communities, and cultural contexts-ultimately contributing to improved understanding and acceptability of the vaccine itself. Simultaneously, in June 2020, the Food and Drug Administration released guidelines for vaccine developers¹³- encouraging, but not mandating, enrollment of subpopulations most affected by COVID-19. Guided by decades of advocacy by diversity, inclusivity, and antiracist movements, the COVID-19 Prevention Network and some vaccine developers invested time and money early on to work toward more representative study populations.¹⁴ Some tribes expressed interest in participating in COVID-19 vaccine clinical trials but lacked infrastructure and clinical trial expertise. Some companies worked with tribes and organizations with long-standing partnerships (e.g., Pfizer and Johns Hopkins Center for American Indian Health [JHCAIH]; Novavax and Black Hills Center for American Indian Health) or with specialized offices such as the Tribal Health Research Office at the National Institutes of Health (NIH), while other companies paused recruitment to ensure more adequate racial and ethnic representation.¹⁵ These efforts resulted in higher AI/AN participation for COVID-19 vaccine trials compared with 230 previous US-based vaccine trials¹⁶ (0.4% in previous trials vs 0.8% in the Moderna trial¹⁷; 1.0% and 1.6% of US participants in the Johnson and Johnson trial¹⁸ and Pfizer trial, respectively¹⁹; and 6.2% in the

Novavax COVID-19 trial [inclusive of Native Mexicans]).²⁰ More early and sustained community engagement throughout health innovation development and testing has the potential to contribute substantially to the eventual success of health programs. This kind of work, coupled with an investment in training for Indigenous and other underrepresented minority researchers, is urgently needed to foster inclusion, enhance impact for the communities most in need, and advance health equity.

EMBRACING CONTEXTUAL HETEROGENEITY

Inherent in the AI/AN vaccine rollout was an appreciation for the diversity of context. There are 9.7 million AI/ANs²¹ (and 574 federal-recognized and 63 state-recognized AI/AN tribes) speaking approximately 175 languages. From the beginning of distribution efforts, tribes could elect to work with the state vaccine implementation plans or design their own distribution and prioritization strategies. Many tribes elected to use their own plans. This self-determination and autonomy allowed for responsiveness to local communities, priorities, and contexts while working around structural constraints and benefiting from existing resources. Distribution efforts built on decades of experience in each setting. During vaccine rollout, some tribes included traditional healers or language speakers in the high-priority groups with earliest access to vaccines.²² In addition to offering vaccination at health care facilities, many tribes organized outreach events that were more accessible to rural residents. Other efforts included door-to-door vaccine outreach to medically fragile community members. In Alaska, vaccine distribution efforts leveraged existing systems (e.g., local pilots, sleds) to reach remote villages. Given the diversity of languages across AI/AN peoples, materials had to be developed in multiple languages. This tailored approach was rooted in trust and relationships and embraced heterogeneity in cultures and contexts. Moving forward, vaccine programs could deepen their appreciation of context as a critical potential precondition, moderator, and mediator of implementation success.²³

IMPORTANCE OF CULTURE

Indigenous cultural values played a critical role in the vaccine rollout. Broadly speaking, Indigenous knowledge systems value the connectedness of all beings and creation, whereby people and communities will "draw strength from the roots of their ancestors' vision, and take collective action to ensure the health and well-being of future generations."²⁴(p.55) COVID-19 vaccines were delivered against the backdrop of this collective approach. In a survey administered by the Urban Indian Health Institute that included responses from 1435 AI/ANs, the primary motivation to get vaccinated was "a strong sense of responsibility to protect the Native community and preserve cultural ways."²⁵ Vaccination communication strategies were structured around protecting others and the community, while also drawing on Indigenous knowledge and traditions to promote uptake (e.g., "For the Love of Our People"; <https://forourpeople.uihi.org>). Federal initiatives included the NIH's Community Engagement Alliance (<https://covid19community.nih.gov>). The JHCAIH established an advisory group spanning 14 tribal communities. This collaboration resulted in the rapid development and dissemination of culturally appropriate resources (<https://caih.jhu.edu/resource-library>). Elders have particular significance in many Indigenous belief systems as holders of cultural knowledge and traditions. In recognition of the importance of elders in supporting formal and informal education, partnerships with elders and traditional healers were key in demonstrating vaccine acceptability and promoting uptake. Although these examples are specific to Indigenous cultural values, every group has its own culture that plays a critical role in the successful implementation of health innovations. Acknowledgment and appreciation of cultural contexts will improve our understanding of implementation processes and will facilitate the delivery of COVID-19 vaccines, especially in communities with high hesitancy and mistrust.

FOCUS ON THE CONSUMER

The strategies and considerations listed in the previous sections not only focused on the health system but also aimed to drive consumer-level acceptability and adoption. Consumer preference was reflected in who delivered COVID-19 vaccine information-and how and where it was delivered. Many AI/AN communities have historically relied on paraprofessionals, such as community health representatives, to provide out-of-hospital services. For example, vaccine events, staffed by individuals from the community, became central to some tribes' efforts. These trusted groups increased the reach of vaccination and demonstrated the utility of a frugal and acceptable approach to vaccine delivery.

CONCLUSION

AI/AN communities were disproportionately affected by COVID-19 in a direct reflection of their experience of colonization, oppression, and marginalization. Nonetheless, they lead the country in the uptake of the COVID-19 vaccine. We examined age-adjusted COVID-19 mortality rates by race from January to August 2021 using data from the National Center for Health Statistics. We calculated monthly age-adjusted mortality rates based on US Census data from July 2019 and using direct age standardization (Figure 1). AI/AN people had the steepest decline in COVID-19 mortality rates of any racial group: their rates dropped to nearly the same levels as those of White and Asian populations earlier than the rates for other racial groups. As a result, hundreds of lives have been saved and a significant health disparity has been narrowed. Now, an estimated 57.4% of AI/AN people have received at least one dose of the vaccine, with some tribes reporting vaccination rates as high as 98%.²⁶ This vaccine success is a result of deep respect for and engagement with tribal sovereignty combined with the deep reservoir of strength and connectedness within AI/AN communities. The processes undertaken with AI/AN COVID-19 vaccination efforts show how these approaches can help advance health equity efforts and maximize public health impact. >4JPH

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E.E. Haroz contributed to conceptualization, data curation, formal analysis, and writing (original draft preparation). C.G. Kemp contributed to data curation, formal analysis, visualization, and writing (original draft preparation, reviewing, and editing). V.M. O'Keefe, K. Pocock, M. Walls, A. Barlow, and L. Hammitt contributed to conceptualization and writing (original draft preparation, reviewing, and editing). D.R. Wilson and L. Christensen contributed to writing (reviewing and editing).

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The authors have no conflicts of interest to report.

HUMAN PARTICIPANT PROTECTION

As a secondary data analysis of de-identified data, this work is not considered human participant research and is therefore exempt from institutional review board oversight per 45 CFR 46.101.

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DETAILS

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Residential Segregation and Cities' Responses in the Early Stage of the COVID-19 Pandemic: Preexisting Structural Factors and Health Care Access

Yang, Tse-Chuan, PhD ¹ ¹ Department of Preventive Medicine and Population Health, University of Texas Medical Branch, Galveston

[ProQuest document link](https://www.proquest.com/scholarly-journals/nurturing-innovation-at-roots-success-covid-19/docview/2638095370/se-2?accountid=211160)

ABSTRACT (ENGLISH)

In this issue of AJPH, Asabor et al. (p. 518) provide an investigation of whether residential segregation (hereafter "segregation") as a preexisting structural factor affected the spatial distribution of COVID-19 testing sites in the early stage of the pandemic and whether this relationship varied by racial/ethnic group. Segregation has a long history in the United States and is considered a manifestation of structural racism.¹ Segregation has been found to adversely affect racial/ethnic minorities' health outcomes even after taking individual differences into account.²

This line of research has been extended to COVID-19 infections and deaths.³ However, the relationship between segregation and access to health care services among communities of color during the pandemic has been underexplored. The analysis by Asabor et al. fills this gap and provides some important directions for future research. I summarize their study and key findings, discuss insights drawn from their study, and suggest future research directions.

FULL TEXT

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stage of the pandemic and whether this relationship varied by racial/ethnic group. Segregation has a long history in the United States and is considered a manifestation of structural racism.¹ Segregation has been found to adversely affect racial/ethnic minorities' health outcomes even after taking individual differences into account.²

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Measuring segregation with the Black-White dissimilarity index, an indicator of the evenness dimension of segregation, the authors first compiled a list of the 20 most segregated cities in the United States and then concentrated their analyses on the four most populous cities on the list: New York City; Los Angeles, California; Chicago, Illinois; and Houston, Texas. Applying Bayesian spatial Poisson regression to block group-level data as of June 2020 for each city, Asabor et al. found that racial/ethnic minority populations (i.e., non-Hispanic Blacks, Hispanics, and non-Hispanic American Indians) lived in places with fewer COVID-19 testing sites. Moreover, they documented heterogeneity in these relationships across cities. Specifically, except for Los Angeles, a 1 percentage point increase in the number of non-Hispanic Blacks was associated with a 1.06% to 3.05% decrease in the expected number of testing sites. The same increase in the number of Hispanics was related to a 1.69% to 5.64% decrease in the number of testing sites, but this relationship was not significant in New York City. By contrast, the percentage of the non-Hispanic American Indian population was not related to the number of testing sites in all cities, which can be attributed to the choice of cities studied.

This study advances the literature on segregation and health, especially COVID-19-related outcomes, in three ways. First, previous studies have investigated mainly how segregation affects racial/ethnic disparities in physical health, and little is known about whether segregation contributes to unequal access to health care services across racial/ethnic groups.² The majority of recent COVID-19 studies have focused on confirmed cases or deaths. From this perspective, the study by Asabor et al., which focuses on COVID-19 testing sites, is a valuable addition to the extant literature on segregation and the COVID-19 pandemic.^{3,4} This study is also one of the few to use advanced spatial analysis techniques to correct the potential bias associated with spatial autocorrelation embedded in ecological data. The authors' finding that the number of COVID-19 testing sites is lower in block groups with higher concentrations of non-Hispanic Blacks and Hispanics demonstrates that segregation has served as a barrier to access to COVID-19 testing sites, particularly for racial/ethnic minorities during the early stage of the pandemic. As the lack of screening may relax vigilance and thus facilitate the spread of COVID-19, this study offers a possible, yet untested, explanation for why non-Hispanic Blacks and Hispanics were severely affected by COVID-19 early in the pandemic.⁵

Second, a common approach to health equity is to address individual-level determinants that prohibit individuals from attaining their full health potential (<https://bit.ly/3oZnd89>). Beyond this individual-oriented perspective, the authors suggest that social-structural barriers that preceded the pandemic, such as segregation, should be considered in achieving health equity, especially in disaster situations. According to Asabor et al., people of color may have a high demand for tests given their characteristics of employment (e.g., they make up a large share of essential workers) and housing environments (e.g., they are often overcrowded) but testing sites are often located outside their neighborhoods. This finding highlights the issue of spatial mismatch, which creates unmet needs in a city's health care system and has important implications for other preventive health care behaviors, such as COVID-19 vaccination. This study corroborates the significance of places in shaping racial/ethnic health disparities.

Third, although some scholars have suggested that American Indians are disproportionately exposed to COVID-19,⁶ American Indians have received little attention in COVID-19 research compared with other minority groups. The lasting legacies of historical injustices (e.g., American Indians being forced to live on reservations) have led to segregation and a concentration of disadvantages for American Indian neighborhoods, which undermine American Indians' health.⁶ Asabor et al. go beyond the number of confirmed cases and deaths among American Indians and

are among the first to extend their research focus to the availability of COVID-19 testing sites for American Indian neighborhoods.

Despite the strengths and contributions of this study, some important questions remain. As the concept of segregation is multidimensional,¹ it is still unclear whether dimensions that Asabor et al. did not consider (e.g., exposure and clustering) are adversely associated with the distribution of COVID-19 testing sites. This is pertinent because the use of the dissimilarity index, as the authors acknowledged, may not fully reflect the segregation patterns in a city. Moreover, it is desirable to have a thorough understanding of how segregation affects not only access to but also utilization of health care services.

As segregation is a fundamental cause of racial/ethnic health disparities, the role of other factors, such as family structures, educational attainment, and built environment, in explaining the effect of segregation on COVID-19 testing sites should be clarified in future studies.⁷ Finally, previous research uses mainly census tract and zip code as the unit of analysis.^{4,7} Although Asabor et al. provide insight into the spatial distribution patterns of COVID-19 at a finer resolution with the census block group data, it remains important to examine what the appropriate spatial unit is for understanding the association between segregation and COVID-19-related outcomes.

These questions offer valuable research directions. For one, preexisting social-structural factors may alter one's susceptibility to infections either through substandard health care services in a neighborhood or by aggravating the risks associated with one's social position (e.g., poverty) or relationships. It is critical to thoroughly investigate how improving health care service delivery may offset the potential adverse effects of preexisting structural factors on infections. Similarly, identifying the appropriate spatial unit could help public health authorities to effectively assist marginalized populations during disaster situations.

In conclusion, Asabor et al. offer important evidence supporting the negative association of segregation with the number of COVID-19 testing sites and indicating that this relationship is heterogeneous across major US cities. Local governments' efforts to establish testing sites during the initial stage of the pandemic overlooked the preexisting structural inequalities that were precursors to the geographical and racial/ethnic health disparities. These structural inequalities should be addressed with structural and policy approaches.

When disasters such as COVID-19 strike, it is critical to develop public health programs that deliver essential health care resources to groups at the most marginalized intersections of race/ethnicity and socioeconomic conditions, such as mobile screening sites in segregated neighborhoods. Doing so ensures that the disadvantaged communities will receive equitable resources that privileged groups often enjoy. With such interventions, segregated communities and vulnerable individuals will have a better opportunity to mitigate the detrimental effects of preexisting structural inequalities on health during disasters. Åfpu

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Medical Crowdfunding and Disparities in Health Care Access in the United States, 2016-2020

Kenworthy, Nora, PhD; Igra, Mark, MA

[ProQuest document link](#)

ABSTRACT (ENGLISH)

Objectives. To assess whether medical crowdfunding use and outcomes are aligned with health financing needs in the United States. **Methods.** We collected data on 437 596 US medical GoFundMe campaigns between 2016 and 2020. In addition to summarizing trends in campaign initiation and earnings, we used state- and county-level data to assess whether crowdfunding usage and earnings were higher in areas with greater medical debt, uninsured populations, and poverty. **Results.** Campaigns raised more than \$2 billion from 21.7 million donations between 2016 and 2020. Returns were highly unequal, and success was low, especially in 2020: only 12% of campaigns met their goals, and 16% received no donations at all. Campaigns in 2020 raised substantially less money in areas with more medical debt, higher uninsurance rates, and lower incomes. **Conclusions.** Despite its popularity and portrayals as an ad-hoc safety net, medical crowdfunding is misaligned with key indicators of health financing needs in the United States. It is best positioned to help in populations that need it the least.

FULL TEXT

Headnote

Objectives. To assess whether medical crowdfunding use and outcomes are aligned with health financing needs in the United States.

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Conclusions. Despite its popularity and portrayals as an ad-hoc safety net, medical crowdfunding is misaligned with key indicators of health financing needs in the United States. It is best positioned to help in populations that need it the least. (Am J Public Health. 2022;112(3):491–498. <https://doi.org/10.2105/AJPH.2021.306617>)

Online crowdfunding is increasingly perceived as an ad-hoc social safety net in the United States. GoFundMe controls more than 90% of the US donation-based crowdfunding market, where more than one third of campaigns are for medical needs.^{1,2} More than 250 000 health-related campaigns are initiated yearly, raising more than \$650 million.¹ Patients and families typically use medical crowdfunding to solicit financial donations from social networks for individual health and medical expenses. The average campaign raises a modest amount of money—several thousand dollars—to provide financial help for needs ranging from emergency and chronic care costs to routine out-of-pocket costs and financial needs secondary to illness, such as lost wages.^{3,4} Medical crowdfunding has often been portrayed in the popular media as an ad-hoc safety net for patients in the United States, particularly in states where insurance coverage is low and medical debt and out-of-pocket costs are high. Many campaigners use crowdfunding to address health needs in the absence of more robust health coverage.^{3–5} But less attention has been paid to a key test of crowdfunding's efficacy as a "safety net": whether, and how well, it provides support to populations with the highest health financing needs.

More comprehensive research on the scope of US medical crowdfunding and its alignment with existing safety net systems is needed to inform health policy decisions amid significant financial and health precarity. To date, little research has captured large-scale data on medical crowdfunding campaigns in the United States. A recent research brief assessed the medical conditions addressed and association with statelevel charitable giving among nearly 300 000 medical crowdfunding campaigns.⁶ A large cross-sectional study of US cancer campaigns found that they raised less in areas with higher neighborhood deprivation, and those with existing socioeconomic advantage found more success.⁷ A similar study found that underinsured cancer campaigners "seek but do not receive higher donation amounts."⁸ Studies in the United Kingdom and Canada found substantial evidence that campaigns are being used to fill gaps in health coverage.^{3,5} Lee and Lehdonvirta complement these findings with a small but comprehensive study demonstrating that crowdfunding is used where formal and informal safety nets fail, but that success is harder to achieve in these areas.⁹

This is the first large study in the United States to examine crowdfunding's effectiveness as an ad-hoc safety net by assessing how its use, earnings, and outcomes align with populationlevel health financing needs. We gathered a cross-sectional data set of US medical crowdfunding campaigns from 2016 to 2020 to examine use, rates of success, and inequalities in returns. Given persistent concerns with crowdfunding inequalities, including its potential to be most successfully leveraged by people with already high levels of social, cultural, and economic capital,^{7,10–13} we utilized state- and county-level data to assess whether crowdfunding use and outcomes align with the areas of highest health financing and health coverage needs.

METHODS

Our cross-sectional study aimed to capture the largest possible set of publicly available US GoFundMe campaigns in recent years (2016–2020). Researchers have faced persistent difficulties in accessing platform-controlled data and generating representative samples of campaigns from available data. GoFundMe algorithms tend to prioritize more successful and geographically proximate campaigns in search results, which can bias samples. Many studies have relied on subsamples focused on specific medical conditions, using targeted keyword searches. Others have relied on convenience sampling strategies, pulling data from top search results or platform-curated discovery pages, which likely replicates algorithmic biases toward more successful and trending campaigns.^{9,14} Several recent studies have used GoFundMe's site index to generate lists of campaign pages⁷; however, we have found that the site index does not include all campaigns, especially those that are less successful.

To gather a more comprehensive set of campaigns, we created searches for each US zip code on GoFundMe in November 2020. GoFundMe search engines return results first for the searched zip code, and then nearby areas, up to 1000 individual campaigns. We found that 99.9% of zip code searches returned fewer than 1000 unique campaigns for that area, indicating that this is a strong strategy for generating a comprehensive set of available campaigns. Given evidence (discussed subsequently) that many low-performing campaigns are systematically removed from the GoFundMe Web site after 1 year, we performed our primary analysis on the subset of campaigns created in 2020. However, we summarized 5 years of data for comparison purposes. We identified 3 571 101 unique campaigns, of which 2360899 were US-based, with publicly accessible data; 504790 were in the "medical, illness, and healing" category. Our data set was limited to 447112 campaigns created after January 1, 2016. We excluded campaigns started less than a month before data collection (n = 5 9481), as these were more likely to have lower returns. In addition, we excluded 35 campaigns with average donations of \$25 000 or more from unverified "offline" donations: large "offline" donations, which are not monitored by GoFundMe, typically indicate joke or fraudulent activity.¹⁵ This left a sample of 437 596 US medical campaigns, 196 955 of them from 2020.

Data on campaign outcomes (goal, dollars raised, donations, shares), location (city and state), and date of campaign creation were automatically scraped from campaign pages. We first summarized key indicators of campaign performance by year. Analysis focused on 2 dependent variables: campaign prevalence, measured as the number of campaigns per 100 000 residents, and campaign earnings, typically measured as the amount of money raised. We measured correlations between state-level health financing needs, and campaign prevalence and earnings, by using data on proportions of state population with medical debt (from the 2018 National Financial Capability Survey)¹⁶ and percentage of population uninsured (from the 2018 US Census Small Area Health Insurance Estimates).¹⁷ Following earlier research indicating that cancer crowdfunding is less successful for marginalized populations in the United States⁷ and in areas with lower education and income in Canada,¹⁸ we assessed whether similar patterns exist in states with higher health financing needs. To test for further associations with economic inequities at a county level, we used a quintile analysis to assess crowdfunding use and earnings at different per-capita income quintiles, using 2018 US Census data.¹⁹

RESULTS

Of the campaigns in the "medical, illness, and healing" category on GoFundMe in 2016 to 2020, 437 596 met sampling criteria. These campaigns raised more than \$2 billion from 21.7 million donations, toward a collective goal of more than \$8.45 billion. As shown in Table 1, median campaign earnings were small, raising \$1970 toward a \$8000 goal, from 24 donors. Variation between successful and unsuccessful campaigns was vast: the top campaign raised \$2.4 million from more than 70 000 donors, while 16.1% of campaigns were entirely unfunded, raising \$0. Half of campaigns reached 25% of their goal; a third reached 50% of their goal; a fifth reached 75% of their goal; and less than 12% fully reached their goal.

Table 1 shows steady declines in median returns, goals, donations, and shares yearly, with steeper declines in 2020. This trend is likely attributable in part to the persistence of more successful campaigns overtime, whereas unsuccessful campaigns are more likely to be deleted. However, the growing popularity of GoFundMe may also be contributing to a more competitive environment. In 2020, we observed a much larger proportion of unfunded campaigns—33.8%—indicating that unfunded campaigns were removed by users or site moderators after a year. Tellingly, the 4.1 % of campaigns unfunded in 2019 were almost all from the last 2 months of the year, within a year of when we gathered our data. Notably, when we excluded unfunded campaigns in 2020, poorer campaign outcomes persisted on all indicators compared with earlier years. While 2020 data reflected the impacts of COVID-19, which may have increased campaign creation, we can also observe increased inequalities in returns. In 2020, the top campaign earned more than twice that of previous years, with 3 times the number of donations, while a large number of campaigns went unfunded. Competition and inequality among campaigns is very high, while likelihood of success is quite low, especially in 2020.

Because 2020 offered the most comprehensive data set, we analyzed 2020 data in subsequent tests while offering comparisons for other years in mental files. assess how medical crowdfunding aligned with health financing needs,

we tested the association between state-level campaign indicators and levels of medical debt and uninsurance. Figure 1 presents scatterplots of campaign prevalence (number of campaigns per 100 000 residents) and earnings (median \$ raised) alongside proportions of residents with medical debt and without insurance by state. There were positive associations between campaign prevalence and medical debt ($R^2 = 0.14$; $P < .01$) and between campaign prevalence and percentage of uninsured ($R^2 = 0.51$; $P < .001$), indicating that citizens in states with higher medical debt and uninsurance were turning more often to crowdfunding, as would be expected. In terms of campaign earnings, however, we observed a strong negative association between median campaign earnings and both medical debt ($R^2 = 0.25$; $P < .001$) and percentage of uninsured ($R^2 = 0.2$; $P < .001$; Figure 1). Thus, while medical crowdfunding is more common in states with lower insurance coverage and higher medical debt, campaigns in those states raised less money.

In Figures A through D (available as supplements to the online version of this article at <http://www.ajph.org>), we present similar analyses for other years-2016 to 2019-and 2020 excluding unfunded campaigns. Associations for campaign earnings remained similar and significant for all other years, indicating that crowdfunding earnings were consistently lower where needs were highest. There was a small but growing association between campaign prevalence and uninsurance over time, but this effect was particularly strong in 2020. For associations between prevalence and medical debt, 2020 was an outlier, and all other years showed no significant relationship. When we excluded unfunded campaigns for 2020, the relationship also all but disappeared, indicating that unfunded campaigns accounted for the association between campaign creation and medical debt. This may reflect the difficulties of leveraging crowdfunding to pay off medical debts rather than prevent them.²⁰

Given these state-level dynamics, we further explored how economic inequality might be associated with campaign prevalence and earnings at a smaller spatial level. Table 2 presents data on campaign prevalence, number of donations, and total amount raised by campaigns sorted by income quintile. Campaign location data were used to create equal population quintiles according to county median income. There were fewer campaigns in the high- and low-income quintiles and the greatest density of campaigns in the middle-income level. By contrast, both number of donations and overall amount raised by campaigns were lowest in low-income quintiles and increased noticeably in higher-income quintiles. This indicates that campaigns initiated in the highest-income areas of the United States will have the greatest likelihood of success. This effect remained similar for 2016 to 2019 as shown in Figure E (available as a supplement to the online version of this article at <http://www.ajph.org>).

DISCUSSION

This article provides one of the first large-scale assessments of medical crowdfunding in the United States, showing its use and outcomes are misaligned with key indicators of health financing needs. Medical crowdfunding is undeniably popular, but the \$2 billion raised by campaigns is small compared with the \$3.8 trillion spent on health care in the United States in 2019 alone.²¹ With more than 26 million individual donations, medical crowdfunding's impact on public attention and engagement far outpaces its contributions toward health expenditures. This finding is supported by survey data indicating that 20% of US households have contributed to a medical crowdfunding campaign.²² Despite growing popularity, rates of success were low, especially in 2020, with a large proportion of unfunded campaigns. These inequalities are compounded by state and local-level inequities. While increased financial needs can align with more campaigns, campaigns have the lowest earnings where needs are highest. Income is associated with campaign success, whereas campaign earnings are worst at the lowest income levels. These results align with recent research on cancer crowdfunding.^{7,18}

Several interwoven forces contribute to these effects. Because most crowdfunding campaigns rely on donations from social networks, and networked wealth can vary by socioeconomic status, campaigners from lower socioeconomic status groups have fewer networked resources on which to draw.¹³ Medical debt and uninsurance in communities leads to poorer overall health, higher care burdens, and higher income inequality, compounding inequalities in likelihood of crowdfunding success.^{23,24} And barriers to entry and success for crowdfunders correlate with these independent variables, such as literacy, education status, or technology access.⁴ Thus, medical crowdfunding can both fuel, and be fueled by, growing disparities in health care systems.²⁵

Is crowdfunding serving as an ad-hoc safety net? Lee and Lehdonvirta refer to crowdfunding as an "entrepreneurial safety net," noting that this competitive environment rewards the same "characteristics and endowments" as the broader market economy.^{9(p20)} Drawing on the cliff analogy for addressing social determinants of health,²⁶ we view safety nets as intended to equally catch those who fall off the cliff of good health. For a lucky and privileged few, crowdfunding offers not a net but a trampoline, launching them toward significant financial support. For the rest, the net is riddled with holes. There is an urgent need to understand crowdfunding as a driver of disparities in health care financing and access.

Digital platforms do not preserve data well, and users, who have a "right to be forgotten," can also delete their campaigns, removing crowdfunding data from the site.²⁷ We found a large proportion of unfunded campaigns in 2020 that was not apparent in earlier years, with indications that unfunded campaigns are being removed from the site. It is hard to discern whether removals are user- or platform-initiated. Like much retrospective online data, comparisons across years should be handled carefully because of this survival bias. We observed largely consistent trends across 2016 to 2020 in terms of misalignment with health financing needs, indicating that medical crowdfunding has consistently been least effective for those with the highest financial needs and, if anything, is worse than reported here because of selective deletion of unfunded campaigns.

Limitations

This study had several limitations. It was exploratory, and further research is needed to elaborate on these dynamics. By relying on zip code searches, a very small number (0.1%) of zip codes with very high population density may not have yielded comprehensive data. Data from 2020 likely included impacts of COVID-19 on crowdfunding, which other studies have noted increased overall campaign creation and lowered success because of growing competition and economic impacts of the pandemic.^{28,29} Here we found that associations in data were more pronounced, but not fundamentally different, between 2020 and previous years, with the exception of associations between medical debt and crowdfunding prevalence.

Public Health Implications

Crowdfunding is a disruptive technology that is reshaping how patients finance health care in the United States. While popular and frequently cited as an ad-hoc safety net, its protection is limited and inequitable. Campaigns raise a median of \$1970, which can certainly offer relief for some users from the cost burdens of care, but largely does so for those who need it least.²⁰ These minimal positive impacts come with steep social and health equity costs. Health policy researchers and policymakers must recognize this sector's impact on health care access and health and social inequities, particularly as a growing body of research demonstrates inequities in crowdfunding by race, gender, socioeconomic status, and, now, health care financing needs.^{7,10,13,18,29} Our preliminary analysis shows that crowdfunding's use and outcomes are misaligned with needs, making it neither an effective nor a fair means of filling safety net gaps. Further analyzing these trends requires public access to anonymized crowdfunding data, particularly for unfunded and deleted campaigns. Crowdfunding is symptomatic of broader financial toxicities and health inequities in the United States, conditions from which crowdfunding companies directly profit. Thus, crowdfunding is unlikely to effectively ameliorate these conditions and may well contribute to them.

Therefore, we offer 3 preliminary policy recommendations. First, there is an urgent need for more transparency in crowdfunding data: policymakers and researchers should call on companies like GoFundMe to publicly share data to enable better research and policymaking and support legislative efforts to mandate company disclosures of how user data are collected and sold. These data should be used to better inform policymakers and the public about the limited benefits-and significant inequities-of crowdfunding use for health coverage needs. Second, public health researchers should join calls for public transparency and accountability in company algorithms, which, in this case, may shape the visibility and success of campaigns, contributing to inequities. Finally, and most importantly, expanding more universal health coverage and social assistance would alleviate reliance on such inequitable and misaligned digital "safety nets."

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CONTRIBUTORS

N. Kenworthy led the conceptualization and writing. M. Igra collected the data and conducted the data analysis. Both authors contributed to revising and editing.

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CONFLICTS OF INTEREST

Neither author has any known conflicts of interest to declare.

HUMAN PARTICIPANT PROTECTION

This study was national in scope and used public secondary data as well as data collected from publicly available sources. The University of Washington Human Subjects Division determined that institutional review board approval was not required for this study because it used publicly available data and did not involve interactions or interventions.

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DETAILS

Subject:	Earnings; Cancer; Medical debt; Success; Poverty; Populations; Uninsured people; Health care access; Crowdfunding; Profits; Donations; Health; Money; Data collection; Funding; Health care; Financing; Cross-sectional studies; Postal codes; Public health
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Implications of Inequities in Health-Related Crowdfunding for the Business of Crowdfunding

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[ProQuest document link](#)

ABSTRACT (ENGLISH)

In an important new study of crowdfunding campaigns for health-related needs, Kenworthy and Igra (p. 491) detail findings from an analysis of nearly 437 596 US-based health-related crowdfunding campaigns on the GoFundMe crowdfunding platform. These campaigns stretch from 2016 through 2020, and nearly half were initiated in 2020. The campaigns Kenworthy and Igra analyzed raised more than \$2 billion, though this was well short of their overall goal of nearly \$8.5 billion. Their success in reaching their goals differed greatly, with 16.1% of campaigns raising no money (rising to more than one third of campaigns in 2020). Not surprisingly, Kenworthy and Igra found a positive correlation between campaign prevalence and local medical debt and uninsurance rates. However, campaigns in areas with higher medical debt and rates of uninsured people had less success in raising funding. Moreover, the number of donations and amount of money raised per campaign were lowest in low-income quintiles. In short, this research demonstrates that in the United States, medical crowdfunding is of limited use in meeting health-related needs and does the least to help those most in need of financial support.

FULL TEXT

In an important new study of crowdfunding campaigns for health-related needs, Kenworthy and Igra (p. 491) detail findings from an analysis of nearly 437 596 US-based health-related crowdfunding campaigns on the GoFundMe crowdfunding platform. These campaigns stretch from 2016 through 2020, and nearly half were initiated in 2020. The campaigns Kenworthy and Igra analyzed raised more than \$2 billion, though this was well short of their overall

goal of nearly \$8.5 billion. Their success in reaching their goals differed greatly, with 16.1% of campaigns raising no money (rising to more than one third of campaigns in 2020). Not surprisingly, Kenworthy and Igra found a positive correlation between campaign prevalence and local medical debt and uninsurance rates. However, campaigns in areas with higher medical debt and rates of uninsured people had less success in raising funding. Moreover, the number of donations and amount of money raised per campaign were lowest in low-income quintiles. In short, this research demonstrates that in the United States, medical crowdfunding is of limited use in meeting health-related needs and does the least to help those most in need of financial support.

GROWING EVIDENCE OF CROWDFUNDING'S INEQUITIES

These findings support and add important details to an existing body of work on the inequities found in health-related crowdfunding, much of which has been developed by Kenworthy, Igra, and their colleagues. Just as US-based health-related crowdfunding campaigns tend not to reach their fundraising goals, the same is true for China-based¹ and UK-based² crowdfunding campaigns. As Kenworthy and Igra show, campaigns in wealthier and better insured areas tend to benefit from social networks that are more able to donate to support their campaigns. Other studies have emphasized that higher rates of postsecondary education and home ownership are also positively correlated with campaign success.^{3,4}

How much money is donated to crowdfunding campaigns is shaped by a number of factors that further demonstrate the inequities of this practice. Evidence suggests that racialized minorities in the United States are less successful with crowdfunding, including Black, Asian, Native American, and Hawaiian residents.^{3,4} Among Canadians crowdfunding for support with access to health care and education, visible minorities are less likely to use crowdfunding and receive less financial support than White Canadians.⁵ There are significant inequities regarding who uses and takes on the labor of crowdfunding as well. Men and women in medical crowdfunding campaigns make up a similar proportion of recipients. However, women are greatly overrepresented among campaign organizers, including 80% of those campaigning on behalf of others in one study.⁴

The kind of need being supported shapes crowdfunding success as well, including in health-related campaigns. In a study on Canadians seeking help accessing addiction treatment services, only 1.6% of the amount requested was donated.⁶ Although it is hard to say with certainty in this case, the stigmatized nature of addiction may have contributed to the very low overall success of these campaigns. Many other factors are associated with campaign success that raise potential concerns regarding the fair distribution of health-related resources, including the campaigner's number of social media contacts, relationships with the news media, and facility with online technologies. Although not all disparities in crowdfunding outcomes are clearly unfair—for example, donors could disproportionately support needs related to severe diseases—the disparities identified by Kenworthy, Igra, and other researchers catalog a range of problematic inequities in crowdfunding.

GOFUNDME'S ROLE

Clearly describing the many inequities created by charitable crowdfunding is important for several reasons. First, GoFundMe in particular has a history of denying that this problem exists. The company's previous chief executive officer, Robert Solomon, called concerns that crowdfunding increases socioeconomic inequalities "hogwash" and dismissed research supporting this concern as based on "limited data sets."⁷ As Kenworthy and Igra note, however, crowdfunding campaigns that raise no funds are regularly deleted by users and, possibly, by the GoFundMe crowdfunding platform itself. Thus, if anything, studies looking at historical patterns in the distribution of crowdfunding resources may underestimate the number of campaigns raising no money and the inequities in crowdfunding as a practice. Perhaps GoFundMe and other crowdfunding platforms have access to proprietary data that support another conclusion. If so, they have an obligation to make these data public rather than dismissing contrary findings out of hand.

Second, GoFundMe is increasingly engaging in a public relations approach of shifting attention from the inadequacies of crowdfunding as an ad hoc social safety net to the failures of the US government, in particular, to provide adequate social supports. This push includes an editorial by the current GoFundMe chief executive officer, Tim Cadogan, in *USA Today* calling for a pandemic relief package from the US Congress, stating that "our platform

was never meant to be a source of support for basic needs, and it can never be a replacement for robust federal COVID-19 relief that is generous and targeted to help the millions of Americans who are struggling."⁸ Cadogan has also encouraged the US public to sign up for health insurance coverage on HealthCare.gov because "we don't view GoFundMe as a substitute for more comprehensive access to health care for everybody."⁹ These sentiments are absolutely correct-GoFundMe and other crowdfunding platforms are not a substitute for adequate social supports, including universal health care coverage. However, focusing on the government's shortcomings without also acknowledging and addressing the inequities found in crowdfunding serves to mask these platforms' own failings. Finally, GoFundMe has established a not-for-profit arm that pools donations for underserved needs, racialized minorities, and victims of discrimination through its charitable GoFundMe.org platform. It has done so with the explicit aim of addressing "the inequalities we see in our own community."¹⁰ This effort has the potential to address some of the inequities in charitable crowdfunding by not pitting recipients of donations against one another for the public's attention and elevating the visibility of causes benefiting underserved groups. However, the inequitable for-profit arm of GoFundMe remains much more visible than its nonprofit arm, and recipients of these pooled donations are often drawn from campaigns hosted on the for-profit entity. Furthermore, the philanthropic promotion of causes raises its own questions about equity regarding which individuals and causes benefit from these institutions. As GoFundMe moves into picking winners and losers through its philanthropic efforts, it produces another layer of opacity in its activities.

THE POVERTY OF CROWDFUNDING AS A SOLUTION TO NEED

Kenworthy and Igra's research makes the inequitable public health impact of charitable crowdfunding clear. It also demonstrates the need for more research on this topic. Continued research is needed on the geographic context of inequities in crowdfunding, including how different health systems, formal social safety nets, and socioeconomic disparities affect the distribution of funds raised through crowdfunding. Better understanding is needed on how different health-related needs, including stigmatized needs, impact the distribution of resources in online crowdfunding. Although health-related crowdfunding is the largest category of charitable crowdfunding, less is known about the distribution of crowdfunding resources for housing, legal representation, education, and other essential needs. Finally, these findings should drive continued research into how crowdfunding for health-related needs can be more equitable, including by promoting nonprofit platforms that pool donations with an aim toward health equity and both highlighting and seeking to address underlying institutional injustices.¹¹

That said, Kenworthy and Igra's research removes any doubt that crowdfunding is an inequitable and unacceptable surrogate for universal social supports for health-related needs. As they suggest, universal health coverage and other social supports are needed to make health-related crowdfunding less necessary. Crowdfunding platforms such as GoFundMe did not create the underlying social inequities around wealth, race, gender, and other factors that are reproduced by crowdfunding. Moreover, they are not the only stakeholders responsible for addressing these underlying inequities and the factors driving people to use crowdfunding for health-related needs. That said, where their business practices support and amplify inequities in crowdfunding outcomes, they have their own work to do in ameliorating these problems. ÅfPU

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DETAILS

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A Rapid Survey of State and Territorial Public Health Partnerships With Faith-Based Organizations to Promote COVID-19 Vaccination

ABSTRACT (ENGLISH)

During the COVID-19 pandemic, media accounts emerged describing faith-based organizations (FBOs) working alongside health departments to support the COVID-19 response. In May 2021, the Department of Health and Human Services, Centers for Disease Control and Prevention, and the Association of State and Territorial Health Officials (ASTHO) sent an electronic survey to the 59 ASTHO member jurisdictions and four major US cities to assess state and territorial engagement with FBOs. Findings suggest that public health officials in many jurisdictions were able to work effectively with FBOs during the COVID-19 pandemic to provide essential education and mitigation tools to diverse communities.

FULL TEXT

Headnote

During the COVID-19 pandemic, media accounts emerged describing faith-based organizations (FBOs) working alongside health departments to support the COVID-19 response. In May 2021, the Department of Health and Human Services, Centers for Disease Control and Prevention, and the Association of State and Territorial Health Officials (ASTHO) sent an electronic survey to the 59 ASTHO member jurisdictions and four major US cities to assess state and territorial engagement with FBOs. Findings suggest that public health officials in many jurisdictions were able to work effectively with FBOs during the COVID-19 pandemic to provide essential education and mitigation tools to diverse communities. (Am J Public Health. 2022;112(3):397-400.

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Vaccination is an important tool to help stop the COVID-19 pandemic. During the COVID-19 response, the Department of Health and Human Services (HHS) Center for Faith-Based and Neighborhood Partnerships, the Centers for Disease Control and Prevention (CDC), and the Association of State and Territorial Health Officials (ASTHO) encouraged health departments' engagement with faith-based organizations (FBOs) to help groups disproportionately affected.¹ We sought to assess the ability of health departments to work with FBOs to reach those in greatest need.

INTERVENTION

ASTHO developed a 13-question, mixed methods electronic survey with CDC and HHS to assess state and territorial engagement with FBOs to promote COVID-19 vaccination, other response efforts, and non-COVID-19 health collaboration.

PLACE AND TIME

From May 13 to 19, 2021, with support from the Robert Wood Johnson Foundation, ASTHO sent the survey to all 59 ASTHO jurisdictions and four major US cities.

PERSONS

Directors of public health preparedness were encouraged to enlist agency colleagues, such as immunization managers and minority or health equity directors, to complete the questionnaire.

PURPOSE

We sought to determine (1) the frequency of state and territorial health department partnerships with FBOs to promote COVID-19 vaccination and other response efforts and (2) factors supporting and hindering such partnerships.

IMPLEMENTATION

Twenty-six of 63 jurisdictions surveyed responded, for a response rate of 41%. We used descriptive epidemiology to

assess frequencies of responses and identified common themes and meaningful patterns in the data by repeated examination and sorting of answers and comments (i.e., a datadriven qualitative process).

EVALUATION

During the COVID-19 pandemic, 24 of 26 respondents (92%) reported that their department or agency engaged with FBOs to promote COVID-19 vaccination. Of the two that reported that FBOs had not been engaged, one shared that engaging FBOs was addressed at the local level. The other shared that lack of established relationships with FBOs, staff and resource limitations, and FBO distrust of government prevented FBO involvement.

Promotion of Health Equity

Of the 24 respondents whose health department or agency worked with FBOs, 100% viewed these partnerships as valuable for reaching racial and ethnic minority groups. In free text, a respondent explained that working with FBOs "was particularly valuable in outreach with racial and ethnic minority groups." Another described the "development of an equity plan, [establishment of] an equity task force to advance outreach, and [provision] of mobile vaccination specifically for partners, such as FBOs and NGOs, to take vaccines to the neighborhoods."

Inclusion of Diverse Religious Communities

Many respondents attempted to be inclusive in their faith-based outreach: 23 (96%) described working with churches, 18 (75%) with mosques, 14 (58%) with synagogues, and 14 (58%) with temples (Figure 1). In free text, respondents wrote of "reaching out to mosques prior to Ramadan," and "vaccine clinics at three mosques, which helped with vaccine rates in immigrant [groups]."

Serving as COVID-19 Vaccination Sites

Twenty-one of 24 jurisdictions said FBOs served as vaccination sites. Success stories included, "we [implemented a state-based vaccine initiative], which [puts] vaccination clinics at places of worship, [with the goal of] vaccinating 25,000 more people in these communities."

Health communication was key to COVID-19 vaccine promotion. Twentythree respondents said that FBOs served as trusted messengers, and 22 said FBOs disseminated communication materials. Communication challenges included "reliable and secure Internet connections-faith organizations [are] not always connected digitally."

Funding to Support Other COVID-19 Response

FBOs contributed to a variety of funded vaccination and other nonvaccination activities (Box 1). Fifteen respondents said FBOs supported vaccine registration and helped people in the community overcome other logistical issues related to getting a COVID-19 vaccine, and 11 provided transportation to vaccination sites.

Cultivation of Relationships

Findings suggest that both the health departments and FBOs were interested in collaboration. Most commonly, the department or agency reached out to FBOs for assistance with COVID-19 vaccination promotion efforts (21 of 24 respondents), but 16 respondents stated that FBOs had reached out to their health department. In free text, a respondent described how they had "built out a Community Engagement Branch in our incident command structure to integrate community and faith-based organizations into the COVID-19 response."

When asked about challenges in working with FBOs, four health departments described a need for stronger relationships with FBOs and greater knowledge about how they operate. Another described difficulty connecting "to smaller houses of worship that do not participate in coalitions or larger judicatory bodies." Two participants commented on communication challenges- for example, "We do all coordination with vaccine providers and community partnerships through e-mail. These FBOs prefer phone calls. That takes a lot of time." The role of FBOs continued to evolve over the COVID-19 response. One respondent noted:

Towards the beginning of the response, [we] had more FBOs interested in hosting a vaccination site than we had doses available. With vaccine available at many locations, there's less of a need for host sites, so working with FBOs now is more likely to focus on addressing vaccine hesitancy and providing credible information.

Partnership Benefits for Future Activities

Partnerships were seen by some respondents as potentially beneficial for future efforts. Respondents commented: "[We are] partnering with a leader in the faith sector to help houses of worship and faith-based organizations prepare

for emergencies," and "increased relationships should be a platform for future collaboration."

ADVERSE EFFECTS

Five respondents described vaccine hesitancy and government distrust within groups that have been marginalized. Participants noted, "the J&J pause had a [negative] effect on those communities, [as well as the] lack of vaccines early on [in the pandemic]." Others commented, "[There is] mixed support for vaccinations [in a] large number of churches in [our state]," and "some [houses of worship]/FBOs do not trust government or see that they have a role in emergency response."

While our findings suggest that belief systems can promote healthy behaviors, previous studies showed that some FBOs can be sources of misinformation, experience tensions over public health restrictions or guidance related to worship services, and, unfortunately, facilitate the transmission of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2).²⁻⁵

SUSTAINABILITY

Challenges included limited time and personnel to devote to maintaining relationships with FBOs. Understanding the value that FBOs add to preparedness and response efforts may help to justify the commitment and resources required to sustain such partnerships.

PUBLIC HEALTH SIGNIFICANCE

Our findings suggest that many jurisdictions were able to work effectively with FBOs during the COVID-19 pandemic. Furthermore, countless other congregations supported COVID-19 vaccination and other public health efforts without formal relationships with their health departments.^{6,7}

Our findings are subject to several limitations. Our survey was based on a small sample of respondents. However, respondents did represent eight of the 10 HHS regions. We do not know how the states or territories that did not complete the survey would have answered these questions. It is likely that respondents were those working with FBOs rather than those considering working with FBOs or facing challenges. Thus, findings should be interpreted as positive leaning. Our survey was limited to the domestic response in the United States. Future assessments might include public health partnerships with FBOs to respond to COVID-19 in international settings.⁸

During the COVID-19 pandemic, which has resulted in hundreds of thousands of deaths in the United States, one promising finding has been the ability of health departments to work with FBOs to reach those in greatest need. Health officials may consider ways to work with FBOs in future preparedness and response efforts.⁹ >4JPH

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Note. The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of CDC. Because information about COVID-19 can change rapidly, we encourage interested readers to visit [https:// www.cdc.gov](https://www.cdc.gov) for the most up-to-date information.

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CONTRIBUTORS

All authors conceptualized this article. A. Ottewell and P. Harper-Hardy led the analysis. S. Santibañez led the writing of the article with Input from all authors. All authors provided critical feedback and helped shape the writing. S. Santibañez and N. Smith supervised the project. All authors discussed the findings and contributed to writing the final article.

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CONFLICTS OF INTEREST

The authors do not have any potential or actual conflicts of Interest to disclose.

HUMAN PARTICIPANT PROTECTION

Consistent with applicable federal law and CDC policy, this activity was reviewed by CDC and was determined not to be research.

Sidebar

BOX 1- Vaccination and Other Non-Vaccination-Related COVID-19 Response Activities Conducted by Faith-Based Organizations (FBOs) Receiving Funding From State and Territorial Health Departments: United States, 2021

1. Community outreach and engagement: FBOs provided community coordinators and community health and outreach workers, supporting community education.
2. Personal hygiene: COVID-19 minigrants were used to support personal protective equipment, hand sanitizer, and cleaning supply distribution, and COVID-19 safety kits for food pantries or other distribution efforts.
3. COVID-19 testing: FBOs provided assistance to community members to access testing; health departments funded the development of COVID-19 testing materials for houses of worship, testing clinics, laboratory supplies, and analysis of test results.
4. Quarantine and isolation: FBOs provided assistance to community members accessing safe quarantine or isolation facilities.
5. Vaccine promotion: Health departments funded the development of COVID-19 vaccination materials for houses of worship and vaccination clinics.
6. Training: Health departments funded trainings for FBOs on responding to a pandemic respiratory emergency.
7. Health communications: FBOs amplified public health emergency messaging for houses of worship and assisted with translation of materials and public service announcements.

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DETAILS

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Database:	Public Health Database

Document 12 of 40

Socioeconomic Disparities of Low-Cost Air Quality Sensors in California, 2017-2020

Sun, Yi, MPH; Mousavi, Amirhosein, PhD; Masri, Shahir, PhD; Wu, Jun, PhD

[ProQuest document link](#)

ABSTRACT (ENGLISH)

Objectives. To (1) examine the disparity in availability of PurpleAir low-cost air quality sensors in California based on neighborhood socioeconomic status (SES) and exposure to fine particulate matter smaller than 2.5 micrometers (PM_{2.5}), (2) investigate the temporal trend of sensor distribution and operation, and (3) identify priority communities for future sensor distribution. **Methods.** We obtained census tract-level SES variables and PM_{2.5} concentrations from the CalEnviroScreen4.0 data set. We obtained real-time PurpleAir sensor data (July 2017-September 2020) to examine sensor distribution and operation. We conducted spatial and temporal analyses at the census tract level to investigate neighborhood SES and PM_{2.5} concentrations in relation to sensor distribution and operation. **Results.** The spatial coverage and the number of PurpleAir sensors increased significantly in California. Fewer sensors were distributed in census tracts with lower SES, higher PM_{2.5}, and higher proportions of racial/ethnic minority populations. Furthermore, a large proportion of existing sensors were not in operation at a given time, especially in disadvantaged communities. **Conclusions.** Disadvantaged communities should be given access to low-cost sensors to fill in spatial gaps of air quality monitoring and address environmental justice concerns. Sensor purchasing and deployment must be paired with regular maintenance to ensure their reliable performance.

FULL TEXT

Headnote

Objectives. To (1) examine the disparity in availability of PurpleAir low-cost air quality sensors in California based on

neighborhood socioeconomic status (SES) and exposure to fine particulate matter smaller than 2.5 micrometers (PM_{2.5}), (2) investigate the temporal trend of sensor distribution and operation, and (3) identify priority communities for future sensor distribution. **Methods.** We obtained census tract-level SES variables and PM_{2.5} concentrations from the CalEnviroScreen4.0 data set. We obtained real-time PurpleAir sensor data (July 2017–September 2020) to examine sensor distribution and operation. We conducted spatial and temporal analyses at the census tract level to investigate neighborhood SES and PM_{2.5} concentrations in relation to sensor distribution and operation. **Results.** The spatial coverage and the number of PurpleAir sensors increased significantly in California. Fewer sensors were distributed in census tracts with lower SES, higher PM_{2.5}, and higher proportions of racial/ethnic minority populations. Furthermore, a large proportion of existing sensors were not in operation at a given time, especially in disadvantaged communities. **Conclusions.** Disadvantaged communities should be given access to low-cost sensors to fill in spatial gaps of air quality monitoring and address environmental justice concerns. Sensor purchasing and deployment must be paired with regular maintenance to ensure their reliable performance.

The inequitable distribution of air pollution is one of the most pressing environmental justice issues.¹ Particulate matter with an aerodynamic diameter smaller than 2.5 micrometers (PM_{2.5}) is one of the most important pollutants in terms of adverse health impacts, and one that is exacerbating environmental racism.² Exposure to PM_{2.5} is known to increase the risk of a wide range of adverse health effects.³ Disproportionate exposure to PM_{2.5} is particularly concerning among lower socioeconomic status (SES) communities and communities of color^{1,4} because these subpopulations are already at greater risk for preventable diseases.⁵ Thus, there is growing interest in understanding the inequitable distribution of PM_{2.5} and its impact on vulnerable populations at a fine spatial scale. Traditional government-operated monitoring stations are usually unevenly and sparsely distributed, which limits their ability to measure PM_{2.5} variability at a local scale.⁶ With recent technology advances, low-cost air pollution sensors have been increasingly used to measure air quality at a high spatial and temporal resolution.^{7–9} In 2017, low-cost air quality sensors developed by the PurpleAir company began to be deployed to provide real-time PM_{2.5} data globally, with the majority being deployed in the United States.

A recent study comparing PurpleAir sensors with regulatory monitoring stations in California showed that PurpleAir data better represented PM_{2.5} spatially, enabling improved detection of air pollution hotspots.¹⁰ Moreover, such low-cost sensors are able to improve the accuracy of air quality index reporting during extreme air pollution episodes such as wildfires.¹¹ In addition to its high spatial resolution, the PurpleAir sensor network provides real-time particulate matter data at 10-minute intervals, making it suitable for investigating the air quality impacts of short-term pollution events. Through affordable prices, flexibility of deployment, and ease of maintenance, low-cost air pollution sensors can be owned and operated by governments, organizations, or individuals, which can enable broader awareness and finer-scale assessments of air pollution to promote more informed citizens and scientific research. As low-cost air pollution sensors continue to be deployed for various purposes, it is critical to understand sensor availability and operation conditions so as to equitably serve and represent communities of different income brackets and ethnic backgrounds.

A few studies have utilized low-cost air quality sensors to investigate the sufficiency of air quality monitoring and to characterize air pollution at the city or neighborhood scale.^{12–14} However, to our knowledge, there have been no prior studies that have examined the geographic distribution and operation of the rapidly expanding PurpleAir sensor network over a large geographic area. A better understanding is needed regarding the sensor distribution across areas of varying SES and disease burdens.

To better understand the spatial distribution and operation of low-cost sensors, we aimed to (1) examine the disparity in the availability of PurpleAir sensors in California based on neighborhood SES and PM_{2.5} exposure, (2) investigate the temporal trend of PurpleAir sensor distribution and operational status, and (3) identify priority communities for future sensor distribution.

METHODS

We examined population characteristics at the census tract level across the entire state of California. In total, we included 8035 (out of 8057) census tracts in this analysis based on the availability of population data in the

CalEnviroScreen database (CES draft 4.0 version, February 2021).¹⁵ Among states in the United States, California is an ideal region to investigate environmental justice issues related to air pollution because it is the most populous (> 39 million people) and most racially/ethnically diverse state, and has diverse air pollution emission sources (e.g., industry, agriculture, and traffic).

PurpleAir Sensor Data

We downloaded 10-minute-interval PurpleAir PM_{2.5} data (July 2017-September 2020) with sensor location coordinates and time stamps using the ThingSpeak's Application Programming Interface provided by the PurpleAir company. The latest PurpleAir sensor model (PA-II-SD) contains 2 PMS5003 instruments, which estimate particle mass concentrations by measuring the amount of light scattered at approximately 680 nm.¹⁶ We first applied a 75% data completeness criterion to daily data. If individual sensors were operating (turned on and reporting data) for less than 75% of a day, we considered these sensors to be "not fully operational" for that day. We calculated the sum of days labeled "fully operational" to define the operational status for a month and a year. Any sensor with readings meeting our completeness criteria (≥ 75%) was labeled "fully operational" for those periods.

Long-Term PM_{2.5} Concentrations

We obtained long-term PM_{2.5} concentration estimates from the CES data set,¹⁵ which was created by the California Environmental Protection Agency (EPA) to inform issues of environmental justice by screening socioeconomic conditions of disadvantaged communities in California. The latest CES includes statewide census tract-level average PM_{2.5} concentrations in 2015 through 2017, which were derived from outputs of a validated high-spatiotemporal resolution (1 km; daily) model that is based on ground-level PM_{2.5} measurements, satellite aerosol optical depth (from the Multi-Angle Implementation of Atmospheric Correction), land use, and meteorology.¹⁷ For PM_{2.5} predictions in 2016, the model showed reasonably high predictive power, with a cross-validation R² of 0.73 to 0.81. This continuous surface of high-resolution PM_{2.5} can be used to efficiently capture local and regional PM_{2.5} levels and identify high-risk areas.

Socioeconomic Factors

CES integrates both population characteristics and pollution burdens to produce a composite CES score (Figure A, available as a supplement to the online version of this article at <http://www.ajph.org>). We included 6 population characteristic indicators, including disease and SES factors (i.e., asthma [2015-2017], cardiovascular disease [2015-2017], educational attainment [2014-2018], poverty [2014-2018], unemployment [2014-2018], and housing burden [2012-2016]), 3 pollution burden indicators (i.e., diesel PM [particle phase of diesel exhaust emitted from diesel engines such as trucks, buses, and heavy-duty equipment, 2016], traffic impacts [2017], and PM_{2.5} concentrations [2015-2017] as described in "Long-Term PM_{2.5} Concentrations"), and 3 summary indicators (population characteristics score, pollution burden score, and overall CES score) at the census tract level. Pursuant to California Senate Bill 535, we defined disadvantaged communities (DACs) as the top 25% CES-scoring census tracts.¹⁸ We used CES to retrieve race/ethnicity and population density (total population/ km² per census tract) data from the 2018 American Community Survey.

Analysis

We examined the distribution of PurpleAir sensors in relation to PM_{2.5} concentrations, SES, and pollution burden metrics overtime and space. We examined the number of deployed sensors within each census tract across the state. Similarly, we examined both deployed and operational sensor count(s) in each census tract separately during each selected period. In the descriptive analysis, we grouped the number of sensors per census tract as "none," "1 or 2," and "3 or more." We further applied the Kruskal-Wallis Wilcoxon rank sum test to assess statistical significance relating to differences in the number of sensors and PM_{2.5} levels and SES factors.

To analyze predictors of the presence or absence (1/0 binary outcome) or the number of sensors (continuous outcome) in a census tract, we performed both a logistic regression and a generalized linear regression (analyses restricted to census tracts with ≥ 1 sensor) on race/ethnicity, socioeconomic factors, and PM_{2.5} concentrations from the CES data set. All models adjusted for population density and rural-urban status. We defined urban areas as those with a rural-urban commuting area code of 1.0, indicating a metropolitan area core with a primary flow of the

population within an urbanized area.¹⁹ We conducted all analyses with SAS version 9.4 (SAS Institute, Cary, NC). We used ArcMap 10.7 (ESRI, Redlands, CA) to visualize sensor distribution. We demonstrated the expansion of the sensor network over time by plotting the number of deployed sensors at 4 time periods during the study period: July to December 2017, January to December 2018, January to December 2019, and January to September 2020 (the end of study period). To assess the expansion of the sensor network over time, we examined monthly changes in the percentage of census tracts with deployed sensors and fully operational sensors in DACs (communities with the top 25% CES score) and non-DACs, respectively. To fully capture the differences of sensor development across non-DACs, we further divided census tracts ranked in the 0 to 75th percentile of CES score into 2 subgroups: 0% to 50% versus 50% to 75% CES score. In the temporal analysis, we calculated sensor density, defined as the number of sensors divided by census tract population density. Overall operational status, defined as the number of census tracts with fully operational sensor(s) divided by the total number of census tracts with deployed sensor(s), was also calculated overtime.

Furthermore, we identified census tracts without any sensor deployed by September 2020. To identify census tracts that should receive priority in terms of future sensor installation, we considered the following 2 metrics: (1) CES score (DAC: top 25% of score vs non-DAC: 0%-75% of score) and (2) PM_{2.5} concentrations (high: >12 µg/ m³ vs low: 0-12 µg/m³, US EPA's primary annual PM_{2.5} standard).²⁰ We combined these 2 metrics with an equal weight to create a map identifying future sensor installation priority regions.

RESULTS

Table 1 presents the distribution of PurpleAir sensors by population and pollution characteristics. Overall, 2211 (27.5%) of the 8035 census tracts in California had 1 or more deployed sensors, covering 27.9% of the population (10.9 million of 39.1 million). On average, more deployed and operational PurpleAir sensors were located in census tracts characterized by more affluence, lower disease rates, lower pollution burdens, and lower percentages of Hispanic and African American residents. For instance, the percentage of poverty (35.7%) among census tracts without deployed sensors was nearly double that of census tracts with 3 or more sensors (18.3%). The operational status of sensors showed similar patterns, suggesting that out-of-operation sensors were disproportionately distributed across socioeconomic lines. Results of the Kruskal-Wallis Wilcoxon rank sum test showed that the differences in the number of sensors for all selected CES indicators and race/ethnicity groups were statistically significant, except for the Asian American group.

Table 2 shows results from regression models. After we controlled for population density and urban-rural status, odds ratios were less than 1 for CES score, population characteristics score, SES indicators, proportions of African American or Hispanic residents, and PM_{2.5} concentrations; they were greater than 1 for proportions of nonHispanic White, Asian American, or other or multiple race/ethnicity populations. The results indicate a significantly lower likelihood of sensor presence in census tracts with higher SES vulnerability, CES scores, PM_{2.5} concentrations, and percentages of African American or Hispanic populations. In generalized linear regressions, the number of sensors in census tracts with deployed sensor(s) was significantly negatively ($B < 0$) associated with all selected SES indicators, African American or Hispanic residents, and PM_{2.5} concentrations, suggesting a smaller number of sensor deployment in census tracts with lower SES, higher PM_{2.5} concentrations, and higher proportions of African American or Hispanic residents in California.

The spatiotemporal development of the PurpleAir sensor network is presented in Figure B (available as a supplement to the online version of this article at <http://www.ajph.org>). Both the spatial coverage and number of sensors increased substantially from 2017 to 2020, as shown by the increased number of census tracts with deployed sensors (although not necessarily fully operational) as well as the increased number of sensors within certain census tracts over time. Statewide, the number of outdoor PurpleAir sensors grew roughly 20-fold, from 251 in December 2017 to 5180 in September 2020. Furthermore, only 238 census tracts had more than 1 sensor as of December 2018, compared with 1025 as of September 2020. However, 91% of the total number of outdoor sensors were deployed in non-DACs. Specifically, 12% of DACs (242 of 1983) and 33% of non-DACs (1981 of 6052) had PurpleAir sensors as of September 2020.

Figure 1a shows the temporal trend of sensor density for DACs and non-DACs from 2017 to mid-2020. All communities exhibited a steady increase in sensor density, followed by a decrease for DACs in mid-2020 but a sharp increase for non-DACs, especially within more advantaged non-DACs (0%-50% CES score). Interestingly, the sensor density for less advantaged non-DACs (50%-75% CES score) was even lower than for DACs. Figure 1 b shows the operational status of sensors. On average, the proportion of operating sensors among non-DACs was higher than among DACs. The operational status of sensors fluctuated substantially during the initial period of the PurpleAir sensor network, from 2017 to 2018. Afterward, the average proportion of census tracts with fully operational sensors increased from approximately 36% in 2018 to 88% in early 2020. Subsequently, as of March 2020, we observed extensive missing data (i.e., not fully operational). We observed a considerable decline in the proportion of operating sensors for both DACs and non-DACs until the end of the study period.

Figure 2 shows future deployment priority areas based on CES scores and PM2.5 concentrations. Among census tracts without any sensors, we considered those with top 25% CES scores and high PM2.5 levels to be in greatest need of sensor deployment to close the gap of environmental inequity. The high-risk regions (red), characterized by both a high socioeconomic disadvantage and high air pollution, were mainly located in the San Joaquin Valley and southern Los Angeles County and downwind areas.

DISCUSSION

To the best of our knowledge, this is the first study that examined the distribution and operation of low-cost sensors in relation to sociodemographic factors over multiple years across a large geographic region, and that identified priority areas for future sensor deployment. Our findings suggest that SES and race/ethnicity are related to sensor distribution, operation, and PM2.5 concentrations in California; specifically, census tracts with higher estimated PM2.5 concentrations, lower SES, and higher proportions of racial/ethnic minority populations had lower sensor availability. The gap between DACs and non-DACs tends to widen over time. This pattern runs counter to necessity since air pollution sensors are in the greatest need where air pollution is highest and where residents are more vulnerable to adverse health impacts from air pollution. These results underscore the need to prioritize such communities for future sensor distribution. In addition, although many PurpleAir sensors were deployed, concerns exist about the operational condition of the sensors, especially in DACs.

Understanding how SES and race/ethnicity are correlated with air pollution is crucial to addressing environmental injustice. Enhancing community-based air quality monitoring-and, in turn, promoting the use and sharing of air pollution data-could help to strengthen awareness, education, and action to reduce environmental injustice.²¹ A recent study (February 2020)²² examined patterns of PurpleAir sensor distribution as a snapshot in the United States as a whole as well as in California; it found a higher number of sensors in census tracts with higher income, higher education, and a greater proportion of White residents. Nationwide, more PurpleAir sensors were deployed in census tracts with higher PM2.5 concentrations, whereas the trend was opposite in California. We observed similar patterns between PurpleAir sensor distribution and SES, race/ ethnicity, and PM2.5 concentrations in California. Furthermore, we included more comprehensive socioeconomic factors, analyzed the sensor distribution longitudinally over time, and examined the operational status of sensors to develop a more comprehensive understanding of sensor distribution and operation.

We found it encouraging that PurpleAir sensors expanded rapidly in California. Of note, "deployment" in this analysis indicates sensors purchased and installed by both residents and government. In addition to sensors purchased and installed by communities or citizens, several government programs have promoted and contributed to the development of low-cost sensor networks. For example, 15 community-scale low-cost sensor networks have been deployed around the state as of 2020 under the California Air Protection Program, developed in response to Assembly Bill 617 and founded by the California Air Resources Board.²³ Approximately 400 PurpleAir sensors have been deployed in 14 California communities as of 2019 by the South Coast Air Quality Management District through a US EPA Science to Achieve Results (STAR) grant.²⁴ Previous studies also indicated that disadvantaged communities were given priority for sensor deployment through government programs.^{25,26} Nonetheless, disparities were still

evident for PurpleAir sensor monitoring. We also observed that many new sensors were installed in mid-2020, mostly among more advantaged communities (0%-50% CES score), which coincided with the widespread smoke that engulfed much of California during the record-breaking wildfire season in 2020. Future sensor deployment needs to give attention to the top 25% of DACs,¹⁸ as well as other communities that, although not fitting this definition, are still characterized by low SES, heavy pollution burdens, and high proportions of minority populations. We found that the PurpleAir sensor density among less advantaged non-DACs (50%-75% CES score) was consistently the lowest among all census tracts, which may partially be caused by a lack of both government support that usually focuses on DACs and investment of individual citizens who are unaware of air pollution and sensor technology because of lower education levels (or simply do not want to spend limited resources on sensor purchase). For example, the percentage of the population older than 25 years with less than a high school education in communities with a 50% to 75% CES score was much higher than that of communities with a 0% to 50% CES score (20% vs 8%), as well as the percentage of the population living below two times the federal poverty level (37% vs 21%).

Despite many PurpleAir sensors being installed, a substantial proportion did not continuously collect data, likely because of several external factors related to real-world conditions such as weather changes, poor Internet connections, and human behavior. Outdoor PurpleAir sensors are usually installed on the outside walls of buildings, powered by an outdoor electricity outlet, and require a local Wi-Fi network for data uploading. It is noteworthy that a vast number of sensors are purchased and deployed by individuals or volunteers instead of professionals (i.e., government authorities, scientists), which may result in inappropriate sensor maintenance (e.g., disrupted Wi-Fi connection or power supply), improper cleaning, or lack of regular checking on operational status.²⁷ In addition, many sensors were a result of project-based deployment and were not maintained after the termination of projects.²⁸ Furthermore, adverse events related to personal health and economics may affect human behavior (e.g., relocation, power or Wi-Fi being off) and sensor operation. The number of non-operational sensors has increased substantially since March 2020, likely because of the COVID-19 lockdowns and related hardship. People might also have voluntarily turned off devices if they were not concerned about air quality during the lockdown. To optimize sensor operation and data collection, targeted interventions from the PurpleAir company or relevant agencies can be developed in the future, such as sending messages to the sensor owners that encourage them to continuously monitor and conduct proper maintenance checks.

A primary strength of this study is the evaluation of the spatiotemporal distribution and operating status of PurpleAir sensors across sociodemographic factors as well as disease and pollution burdens. This is in contrast with other low-cost sensor studies focusing on technical feasibility and measurement accuracy^{26,29,30} but not considering SES contexts and operational status.³¹ Our findings help to facilitate further development of low-cost sensor networks to maximize their social and environmental health benefits.

The second strength is the focus on California, which has a diverse population, high air pollution levels, and dense PurpleAir sensor network. As of September 2020, the number of PurpleAir sensors in California accounted for approximately 60% of the global total, allowing us to characterize the air quality monitoring network at a fine spatial scale in a state where air pollution is a top concern. The third strength is that we examined multiple years of data to quantify the expansion of the PurpleAir sensor network and to identify potential factors that affect the operational status of the sensor network.

Several limitations should be noted when interpreting these study findings. First, there is a potential temporal mismatch given that the majority of population and pollution indicators, including PM_{2.5} estimates from the CES data set, were before 2018, whereas the PurpleAir distribution spanned 2017 to 2020. Second, our analysis was limited to the census tract level because of a lack of finer-scale data (e.g., block group or block). Additionally, although sensors on the edges of census tract boundaries may contribute to monitoring of surrounding areas, we did not take into account sensors in adjacent tracts. Furthermore, we solely used PM_{2.5} estimates from a spatial model. Despite the increasing coverage of the PurpleAir sensor network, 72% of census tracts in California still had no single sensor as of September 2020; the direct use of sensor data might introduce bias in exposure estimates in

areas and time periods with varying number of sensors.

That being said, future studies may use sensor-based measurements through statistical and machine learning models to improve PM_{2.5} estimates at a higher spatiotemporal resolution; these sensor data need to go through quality assurance and calibration to ensure that they are comparable to the measurements from federal reference or equivalent methods.³² Because aging may affect the performance of sensors over time, future work is needed to track the long-term distribution and performance of sensors, understand other factors that may influence sensor operation, and provide guidance for long-term data collection. Lastly, only the PurpleAir sensor network was examined in this analysis. To explore common assumptions about general sensor distribution and provide guidance for future sensor installation and maintenance, we selected the PurpleAir sensor network-the predominant low-cost sensor network currently in use-because of its wide use in government programs,²⁴ scientific research, and individual air monitoring as well as its robust performance,³³ high sensor density, and rapid and continued expansion. With the development of various low-cost air quality sensors, it would be valuable for future studies to investigate and compare other air pollutants from other low-cost sensor networks. AJPH

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CONTRIBUTORS

Y. Sun participated in methodology, software, data curation, formal analysis, and writing of the original draft. A. Mousavi participated in software, data curation, and writing, reviewing, and editing the article. S. Masri participated in methodology and writing, reviewing, and editing the article.

J. Wu participated through conceptualization, supervision, project administration, funding acquisition, methodology, data curation, and writing, reviewing, and editing the article.

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CONFLICTS OF INTEREST

The authors declare that they have no known conflict of interest that could have appeared to influence the work reported in this article.

HUMAN PARTICIPANT PROTECTION

This research involved only secondary data analysis using publicly available data and so was not subject to protocol approval.

Sidebar

Note. CES 5 CalEnviroScreen 4.0 version; n 5 the number of census tracts; PM_{2.5} 5 particulate matter with a diameter smaller than 2.5 µm; diesel PM 5 particle phase of diesel exhaust emitted from diesel engines. The total number of census tracts was n 5 8035. Deployed sensors: sensors located within a census tract as of September 2020; fully operational sensors: sensors with readings meeting our completeness criteria (≥ 75%) between January 2020 and September 2020; asthma rate: age-adjusted rate of emergency department visits for asthma per 10 000;

cardiovascular disease rate: age-adjusted rate of emergency department visits for heart attacks per 10 000; educational attainment: percentage of population older than 25 years with less than a high school education; poverty: percentage of population living below 2 times the federal poverty level; unemployment: percentage of the population aged >16 years that is unemployed and eligible for the labor force; housing burden: percentage of low-income households and households severely burdened by housing costs.

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DETAILS

Subject:	Socioeconomic status; Environmental justice; Spatial analysis; Socioeconomic factors; Censuses; Minority & ethnic groups; Datasets; Environmental equity; Sensors; Disease; Neighborhoods; Census; Air quality; Population density; Air pollution; Outdoor air quality; Ethnicity; Air monitoring; Community; Costs; Disadvantaged; Particulate matter; Low cost; Socioeconomics; Micrometers; Minority groups
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Mental Health and Protective Factors for Transgender and Gender-Diverse Youths Who Trade Sex: A Minnesota Statewide School-Based Study, 2019

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ABSTRACT (ENGLISH)

Objectives. To describe the prevalence of sex trading by gender and by associations with mental health concerns and protective factors. **Methods.** We used data from 9th and 11th graders who completed the 2019 Minnesota Student Survey. The analytic sample ($n = 67\,806$) included transgender and gender-diverse (TGD) youths and cisgender youths who reported trading sex. Data on 7 mental health measures and 4 school-related and health care-related protective factors were collected. **Results.** The prevalence of sex trading (5.9%) was 5 times higher among TGD students than cisgender students (1.2%). In addition, the prevalence of all mental health concerns was high among TGD students who traded sex (e.g., 75.9% reported a lifetime suicide attempt, as compared with 45.9% of cisgender students who traded sex). Fewer statistical differences were found across protective factors. When TGD students who traded sex were compared according to sex assigned at birth, no statistically significant differences were found. **Conclusions.** Our findings support strong calls for increased competence regarding gender and sex trading or exploitation in clinical and school-based settings to decrease health disparities among TGD youths. **Public Health Implications.** In this study, we have presented unique prevalence estimates of mental health disparities among TGD students in the United States who trade sex. Our results indicate that TGD students who trade sex are at risk for mental health symptoms and that sensitivity to both gender and sex trading or exploitation will be critical to meeting the needs of this group in clinical as well as school-based settings.

FULL TEXT

Headnote

Objectives. To describe the prevalence of sex trading by gender and by associations with mental health concerns and protective factors.

Methods. We used data from 9th and 11th graders who completed the 2019 Minnesota Student Survey. The analytic sample ($n = 67\,806$) included transgender and gender-diverse (TGD) youths and cisgender youths who reported trading sex. Data on 7 mental health measures and 4 school-related and health care-related protective factors were collected.

Results. The prevalence of sex trading (5.9%) was 5 times higher among TGD students than cisgender students (1.2%). In addition, the prevalence of all mental health concerns was high among TGD students who traded sex (e.g., 75.9% reported a lifetime suicide attempt, as compared with 45.9% of cisgender students who traded sex).

Fewer statistical differences were found across protective factors. When TGD students who traded sex were compared according to sex assigned at birth, no statistically significant differences were found.

Conclusions. Our findings support strong calls for increased competence regarding gender and sex trading or exploitation in clinical and school-based settings to decrease health disparities among TGD youths.

Public Health Implications. In this study, we have presented unique prevalence estimates of mental health disparities among TGD students in the United States who trade sex. Our results indicate that TGD students who trade sex are at risk for mental health symptoms and that sensitivity to both gender and sex trading or exploitation will be critical to meeting the needs of this group in clinical as well as schoolbased settings. (AmJ Public Health. 2022;112(3):499-508. <https://doi.org/10.2105/AJPH.2021.306623>)

Sex trading refers to the act of engaging in sexual services in exchange for something of value (e.g., money, food, drugs, alcohol, shelter). Sex trading is a neutral term that does not indicate how a young person might experience that behavior, which can include instances of survival sex, exploitation, violence, trafficking, and other experiences. In a pivotal population-based study of Minnesota high school students, 1.4% of participants (n 5 964) reported trading sex, and youth sex trading was associated with an increased risk of long-lasting negative health outcomes.¹ For example, rates of sex trading were elevated among students with long-term physical, mental, and behavioral health problems.¹

In the state of Minnesota, an individual younger than 25 years who trades sex for something of value is considered a victim of sexual exploitation. State legislators and institutions recognize the risks and harms associated with sex trading, exploitation, and trafficking and have enacted a piece of legislation titled the Safe Harbor Law. This policy removes criminal penalties for youths younger than 18 years who trade sex. State and federal funding supports a statewide program for young people up to the age of 24 years who trade sex, and the program includes regional navigators, service providers, and tribal governments that offer referrals to specialized, culturally responsive, youth-centered health care services as well as outreach programming, training, and protocol development.^{2,3}

Research focused on transgender and gender-diverse (TGD) youths who trade sex is limited. However, a few studies indicate that TGD youths are at risk for sex trading and exploitation as a result of factors such as homelessness, substance use, bullying at school, difficulty or lack of confidence with academics, and school disconnectedness or pushout.^{4,5} The gender minority stress and resilience model^{6,7} posits that the elevated risks for harassment and victimization experienced by TGD communities are associated with a higher likelihood of negative mental health outcomes (e.g., depressive symptoms, anxiety, self-harm, suicidal ideation, and suicide attempts). Structural factors such as stigma, unemployment, and lack of police protection further influence health outcomes and contexts that increase the likelihood of involvement in sex trading.³

Individual- and interpersonal-level factors, such as having future educational and career goals and school or teacher connectedness, may be protective against buying or selling sex⁸ and may be helpful in ending sex trading and increasing participation in substance use or mental health services.⁵ Previous research suggests that youths who trade sex do seek and access health care services⁹ but that they experience stigma and bias by providers or in health care settings, including within the mental health field.¹⁰ TGD young people also access services but at lower rates than their cisgender peers.¹¹ Given that TGD students visit the school nurse's office more often than their cisgender peers,¹¹ adults at school such as nurses, counselors, and youth workers may be additional sources of support and connection to provide education, resources, and advocacy to, for, and on behalf of TGD students. Because of the school-based methods used in the present study, we focused on school-related protective factors as a potential resource for youths in this highly vulnerable group.

Although there is only a small body of published literature and studies, it has been shown that TGD youths report experiencing concerns associated with sexual exploitation and sex trading.^{5,9,12-14} However, TGD youths who trade sex are often left out of relevant research, aggregated with other groups, or excluded owing to small sample sizes. Such exclusions contribute to their invisibility in critical discussions of prevention and intervention services,¹⁵ perpetuating risks for trajectories into trading sex. Furthermore, trading sex is highly stigmatized, often criminalized, and dangerous, making research participation difficult.¹⁶ Most research on sex trading focuses on cisgender girls

and women, although sex trading affects people of all genders. Studies with large, diverse samples of adolescents are needed for accurate comparisons between different gender groups who report trading sex. The purpose of this study was to describe prevalence rates of sex trading according to gender identity, associations with mental health concerns and school and health care-based factors, and differences by sex assigned at birth.

METHODS

Data for this study were derived from the Minnesota Student Survey (MSS), a triennial survey coordinated by the state departments of education, health, human services, and public safety. The MSS is offered as an online survey and is administered during a single class period to students in grades 5, 8, 9, and 11. In 2019, 81% of public school districts in the state participated, yielding data from 66% of 9th graders and 54% of 11th graders enrolled statewide (the question about sex trading was asked only of students in grades 9 and 11).

Survey Measures

Sex trading was assessed via the question "Have you ever traded sex or sexual activity to receive money, food, drugs, alcohol, a place to stay, or anything else?" (yes or no). Sex assigned at birth and gender were assessed with a series of questions adapted from validated approaches.¹⁷ Participants were first asked "What is your biological sex?" (male or female) and then were asked "Do you consider yourself transgender, genderqueer, or genderfluid?" (yes, no, I am not sure about my gender identity, or I am not sure what this question means). Students who reported that they were transgender, genderqueer, or genderfluid were then asked which of the following 4 responses described them: "male, trans male, trans man, or trans masculine"; "female, trans female, trans woman, or trans feminine"; "nonbinary, genderqueer, or genderfluid"; or "I prefer to describe my gender as something else."

Data on 7 measures of mental health were collected and are detailed in Table 1. Protective factors were 3 school-related measures and 1 health care-related experience. A 4-item scale adapted from the Student Engagement Inventory was used to assess school adult-student relationships; response options ranged from 1 (strongly disagree) to 4 (strongly agree; $\alpha = 0.84$).²⁰ The 4 scale items were (1) "Overall, adults at my school treat students fairly"; (2) "Adults at my school listen to students"; (3) "At my school, teachers care about students"; and (4) "Most teachers at my school are interested in me as a person."

Feeling safe at school was measured with a Likert-response item ("I feel safe at school") for which high scores indicated strong agreement. A dichotomous measure of help from an adult at school was created by combining affirmative responses to 2 questions asking whether an adult at school helped students "think about education options for after high school (college or other training program)" and "find career-focused field experiences (job shadowing, work-based learning, service learning, career camps, apprenticeships)." With regard to health care, we created a single dichotomous item assessing whether students had ever been treated for any long-term mental health, behavioral, or emotional problem.

Sociodemographic characteristics included grade (9th or 11th) and sexual orientation. Sexual orientation response options were as follows: "heterosexual (straight)," "bisexual," "gay or lesbian," "pansexual," "queer," "questioning/not sure," and "I don't describe myself in any of these ways." The "questioning/not sure" and "I don't describe myself in any of these ways" responses were combined into 1 group because of small sample sizes among youths trading sex.

Students selected all racial/ethnic categories that described them, and responses were combined to create a 6-category race/ethnicity variable denoting Native; Asian or Asian American; Black, African, or African American; Hispanic/Latinx; White; and multiple races. (The Native category is a combination of students who self-reported identifying as only American Indian or Alaska Native (AIAN), as only Native Hawaiian or other Pacific Islander (NHPI), as American Indian or Alaska Native and additional races and ethnicities, or as Native Hawaiian or other Pacific Islander and additional races and ethnicities, due to these groups' recognition as Indigenous peoples and experiences of colonialism.^{21,22})

An indicator of homelessness assessed whether students had experienced unstable housing during the preceding year (i.e., "lived in a shelter, somewhere not intended as a place to live, or someone else's home because you had no other place to stay"). School location was dichotomized as within or outside the Minneapolis/St. Paul metropolitan

area.

Data Analysis

Our analytic sample included participants who responded to the sex trading item and responded either yes or no as to whether they identified as transgender, genderqueer, or genderfluid ($n = 67\,806$). Participants were 1024 TGD students and 66782 cisgender students. Univariate statistics describing the sociodemographic characteristics of TGD and cisgender students who traded and never traded sex were calculated. Self-reported descriptions of gender identities (trans feminine, trans man, nonbinary, etc.) are presented but were not used to stratify the TGD sample owing to small subgroup sizes.

We used χ^2 tests to compare indicators of mental health and protective factors across 4 subgroups of students: TGD students who traded and never traded sex and cisgender students who traded and never traded sex. A second series of χ^2 tests focused only on TGD students and again compared 4 subgroups: TGD students assigned female at birth who traded and never traded sex and TGD students assigned male at birth who traded and never traded sex. Note that we have chosen these broad categories in an attempt to reflect the wording of the MSS survey items and the diversity of gender identities and experiences. We recognize that it is not possible to select terms that would be entirely inclusive owing to the Western conceptualization of gender in the MSS, the use of the English language, and many other considerations. Furthermore, although we acknowledge that sex assigned at birth may not reflect TGD participants' identities, we chose to stratify by this variable to maximize statistical power. To reduce type I error resulting from the large sample size and multiple group comparisons, we set the 2-sided significance level at .001.

RESULTS

Among 9th and 11th graders who completed the MSS, approximately 5.9% of TGD students, 1.3% of cisgender girls, and 1.2% of cisgender boys reported trading sex. Relative to their peers, TGD students who traded sex tended to be youths of color (e.g., 23.3% Nativei, 10.0% Black, African, or African American), to identify as LGBTQi (lesbian, gay, bisexual, queer or questioning; e.g., 26.7% pansexual, 25.0% bisexual), and to have experienced unstable housing (Table 2). Equal percentages of TGD and cisgender students who traded sex attended schools in metropolitan and nonmetropolitan locations.

Comparisons by Gender Identity and Sex Trading

We found statistically significant group differences for several mental health indicators, with greater mental health concerns among TGD youths and those who traded sex (Table 3). Fewer differences for protective factors were noted.

Mental health concerns. Across almost all indicators, the prevalence of mental health concerns was higher among TGD students who traded sex than among their peers. For example, 75.9% of TGD students who traded sex reported a lifetime suicide attempt, as compared with 45.9% of cisgender students who traded sex, 30.1% of TGD students who never traded sex, and 7.2% of cisgender students who never traded sex ($P < .001$ for each comparison). Similarly, nonsuicidal self-injury was highly prevalent among TGD students who traded sex (86.2%) and less common, yet still concerning, among cisgender students who traded sex (55.8%; $P < .001$).

Protective factors. In the case of protective factors, more similarities between groups were noted. For example, with the exception of TGD students who never traded sex and cisgender students who never traded sex, similarly high percentages of students reported having an adult at school who helped with educational and career options after high school. Likewise, comparisons between TGD and cisgender students who traded sex indicated no group differences except for feeling safe at school (50.0% vs 74.1%; $P < .001$).

Comparisons by Assigned Sex and Sex Trading

The many nonsignificant group differences between TGD students assigned female and assigned male at birth who traded sex suggest similarly high rates of mental health concerns (Table 4). Importantly, rates for most protective factors were also similar across groups.

Mental health concerns. Across all indicators of mental health concerns, rates were highest among TGD students assigned female at birth who traded sex and lowest among TGD students assigned male at birth who never traded sex. Comparisons between TGD students assigned female at birth and assigned male at birth who traded sex did

not reveal statistically significant differences, but rates were high. For example, both TGD students assigned female at birth and TGD students assigned male at birth who traded sex exhibited high rates of lifetime suicide attempts (82.4% vs 66.7%), lifetime suicidal ideation (94.1 % vs 70.8%) and positive screening for depressive symptoms (73.5% vs 62.5%).

Protective factors. Rates for all protective factors were similar among TGD students who traded sex, regardless of sex assigned at birth. No significant group differences were noted between TGD students assigned male at birth and TGD students assigned female at birth who traded sex with respect to feeling safe at school (51.6% vs 47.8%) or having an adult at school who helped with educational or career goals (62.9% vs 64.0%).

DISCUSSION

To our knowledge, this is the first largescale study to compare prevalence rates of mental health concerns and protective factors in a statewide, school-based sample of TGD and cisgender high school students who traded and never traded sex. Rates for all mental health concerns were alarmingly high among TGD students who traded sex, with more than three quarters reporting a lifetime suicide attempt. Rates were also high among TGD students who never traded sex and cisgender students who traded sex. These high rates did not differ significantly when TGD students who traded sex were stratified by sex assigned at birth. Such findings are critical in providing more comprehensive and nuanced understandings of opportunities for intervention and prevention, in addition to improving access to needed education and health care resources and challenging and discrediting misconceptions about sex trading.

Our findings indicated that, in comparison with their peers, greater numbers of Minnesota TGD students who traded sex identified as Native or Black, African, or African American. The majority of TGD students who traded sex reported their sexual orientation as something other than straight or heterosexual. Almost half of TGD youths who traded sex reported unstable housing, consistent with literature suggesting that exchanging sex to meet basic needs is common.^{15,23} Given this information, future research incorporating an intersectional approach is needed.

Our study, which disaggregated rates by sex assigned at birth when possible, adds specific data on TGD students to the field. Furthermore, it illuminates disparities in this particularly understudied population and identifies mental health and well-being as a critical area of needed support. The significance of the prevalence rates we calculated is that they were a determination not simply of risk levels but also of the multilevel power dynamics that contribute to risks. TGD identity in itself is not a risk factor for poorer health outcomes; the multiple minority stressors that TGD individuals face at all levels (individual, community, institutional) increase barriers to mental health and well-being.²⁴ Moreover, the intersectional stigma and discrimination faced by TGD youths contribute to fear and hesitancy in seeking critical resources to address their concerns (e.g., health care, housing). These barriers increase not only the potential for a trajectory into sex trading but also the risk of adverse health outcomes, including mental health concerns.

Given our findings that half of TGD students assigned female at birth and a third of TGD students assigned male at birth who trade sex reported a suicide attempt in the preceding year, our results call for policymakers, schools, and health care institutions to establish priorities and distribute resources to better support TGD students who trade sex, including youth initiatives and community-run intervention and prevention programs.

Importantly, young people who trade sex, regardless of gender, report protective factors related to school and health care services. Adults in school and clinical contexts, such as mental health and sexual health providers, can help both TGD and cisgender students who trade sex by using trauma-informed, healing-focused, and affirming approaches; having an understanding of sexual exploitation; responding in a nonjudgmental and nonpathologizing manner;²⁵ and deconstructing and challenging dominant narratives and expectations of gender and sexuality.

Approximately two thirds of TGD and cisgender students who traded sex reported that a school adult helped them think about educational and career options after high school, which has been noted as an important protective factor with respect to ending sex trading among youths.⁵ School adults such as nurses, counselors, social workers, and youth workers are in a unique position to talk with TGD students who trade sex about health risks and provide comprehensive and inclusive sexual education. They can also discuss the frequency of health-related visits for

preventive and therapeutic reasons, which can contribute to young people feeling empowered in their decision-making. Furthermore, they can engage with youths in attempts to change structural factors such as stigma, unemployment, and lack of police protection or housing.

Previous studies have demonstrated the importance of school protective factors in buffering against poorer mental health outcomes.^{26,27} The school setting and school adults may be particularly important avenues for bolstering such protective factors and support for not only TGD young people but all youths who trade sex and are attending school.

Strengths and Limitations

This large, statewide study provided adequate sample sizes for analyses across multiple mental health variables and protective factors. Also, the schoolbased sampling methodology increases the generalizability of our findings relative to studies with TGD young people in which convenience samples are used.

However, limitations exist, such as an inability to infer causality owing to the cross-sectional data used and the measurement problems inherent in secondary analyses. For example, only one broad question asked about sex trading, and no questions asked about reasons for trading sex, the role of coercive third parties (e.g., pimps or traffickers), or what youths wanted in terms of support and resources. We acknowledge the limitations of the terminology and recognize that the labels TGD students assigned male at birth and TGD students assigned female at birth may not reflect the heterogeneous labels, identities, and expressions of the TGD community.

Furthermore, the MSS failed to include "intersex" with the options of male and female when asking about sex. Response options for gender were also limited because the MSS grouped transgender, genderqueer, and genderfluid together and did not allow for multiple responses or a write-in category in which self-defined or culturally specific terms (e.g., Two-spirit) could be listed. Because of small cell sizes, even in this very large sample, we were unable to compare specific disaggregated gender identity groups. The large sample sizes for many comparisons resulted in multiple statistically significant findings. Small cells combined with a P value set at .001, however, may mask practical differences.

Finally, the rates we observed are likely underestimations as a result of missing data stemming from unresponsiveness, fear of answering, sociocultural stigma, lack of accessibility, or students not being surveyed owing to school absence, dropout, or pushout. Young people who trade sex and identify as TGD may feel shame; may worry about bias, mistreatment, or discrimination; or may not consider sex trading as exploitative or victimization, all of which can contribute to nondisclosure or school absence on the day of the survey.^{8,28}

Motivations behind sex trading among both TGD and cisgender youths are complex and highlight the need for future research, which should incorporate young people who trade sex as experts in their lived experiences.

Public Health Implications

In this study, we have presented unique census-style, school-based estimates of mental health disparities among TGD students who trade sex and informed intervention points and opportunities to prevent harm by identifying critical protective factors. Our results highlight that TGD students who trade sex are at particularly elevated risk and that sensitivity to both gender and sex trading will be critical in meeting the needs of this group in clinical and school-based settings. Disaggregating data and documenting the prevalence of sex trading and health disparities in marginalized communities are important for uprooting misconceptions about gender and sex trading, which may limit allocation of resources and access to services. AJPH

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CONTRIBUTORS

In addition to contributing equally as co-first authors, G. N. Rider and B.J. McMorris conceptualized the article, analyzed the data, and drafted and revised the article. C. Brown, M. E. Eisenberg, A. L. Gower, K. Johnston-Goodstar, M. Filoteo, E. Singerhouse, and L. Martin contributed to the interpretation of findings and critically reviewed and revised the article.

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CONFLICTS OF INTEREST

The authors report no conflicts of interest.

HUMAN PARTICIPANT PROTECTION

The University of Minnesota's institutional review board determined that this secondary analysis of existing anonymous data was exempt from review.

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DETAILS

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Mistrust, Empowerment, and Structural Change: Lessons We Should Be Learning From COVID-19

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ABSTRACT (ENGLISH)

Within the COVID-19 pandemic, public mistrust has been cast in the pivotal role of antagonist. From lack of acceptance of preventive measures, to online misinformation and disinformation, to low vaccination rates, "the epidemic of mistrust" has been characterized as a thwarter of public health mitigation efforts. However, among Black/African American individuals in the United States who remain twice as likely to die¹ yet significantly less likely to be vaccinated against COVID-19² versus White Americans, mistrust is not the primary etiology of racial and ethnic inequities. Instead, mistrust is a manifestation of the pervasive pathologies of structural racism and White supremacy.³ Historical awareness of and contemporary exposure to structural racism-the system of hierarchy, privilege, and power that largely benefits White individuals-has resulted in mistrust as a rational, adaptive response to an adversarial environment. Furthermore, White supremacy, the belief that White people are superior to people of other racial backgrounds, sustains structural racism and, thus, is a fundamental driver of mistrust among people of color.^{4,5}

A specific form of mistrust, medical mistrust, centers on the belief that health care providers, the health care system, the pharmaceutical industry, academic institutions, or the government as a steward of public health are acting against one's best interest or well-being.⁶ As a multidimensional belief system, medical mistrust likely exists on a spectrum from skepticism, to active suspicion, to belief in conspiracy theories or secret plots concerning perpetrators, motivations, and *modi operandi* that are not necessarily apocryphal.⁷ Typically, medical mistrust has been viewed through a deficit lens. This is unsurprising; negative characterizations of health beliefs espoused by people of color that diverge from those expressed by the dominant culture are a normative feature of race-based science. This is particularly true regarding mistrust beliefs. Individuals who express medical or research mistrust are frequently characterized as irrational, less well-educated, or possessing lower literacy.⁸ Among Black/African American individuals, medical mistrust has been associated with suboptimal health behaviors, such as nonadherence to antiretroviral therapy among people living with HIV, poor engagement in care, and decreased uptake of preventive behaviors, including vaccines.^{8,9} Unfortunately, a surfeit of attention within public discourse on combating the negative impacts of medical mistrust, particularly in regards to COVID-19 vaccine "hesitancy," has obscured the need to correct deficiencies and disparities in health care perpetuated by structural racism, White

supremacy, and inequitable power structures in the United States.

FULL TEXT

Within the COVID-19 pandemic, public mistrust has been cast in the pivotal role of antagonist. From lack of acceptance of preventive measures, to online misinformation and disinformation, to low vaccination rates, "the epidemic of mistrust" has been characterized as a thwarter of public health mitigation efforts. However, among Black/African American individuals in the United States who remain twice as likely to die¹ yet significantly less likely to be vaccinated against COVID-19² versus White Americans, mistrust is not the primary etiology of racial and ethnic inequities. Instead, mistrust is a manifestation of the pervasive pathologies of structural racism and White supremacy.³ Historical awareness of and contemporary exposure to structural racism—the system of hierarchy, privilege, and power that largely benefits White individuals—has resulted in mistrust as a rational, adaptive response to an adversarial environment. Furthermore, White supremacy, the belief that White people are superior to people of other racial backgrounds, sustains structural racism and, thus, is a fundamental driver of mistrust among people of color.^{4,5}

A specific form of mistrust, medical mistrust, centers on the belief that health care providers, the health care system, the pharmaceutical industry, academic institutions, or the government as a steward of public health are acting against one's best interest or well-being.⁶ As a multidimensional belief system, medical mistrust likely exists on a spectrum from skepticism, to active suspicion, to belief in conspiracy theories or secret plots concerning perpetrators, motivations, and *modi operandi* that are not necessarily apocryphal.⁷ Typically, medical mistrust has been viewed through a deficit lens. This is unsurprising; negative characterizations of health beliefs espoused by people of color that diverge from those expressed by the dominant culture are a normative feature of race-based science. This is particularly true regarding mistrust beliefs. Individuals who express medical or research mistrust are frequently characterized as irrational, less well-educated, or possessing lower literacy.⁸ Among Black/African American individuals, medical mistrust has been associated with suboptimal health behaviors, such as nonadherence to antiretroviral therapy among people living with HIV, poor engagement in care, and decreased uptake of preventive behaviors, including vaccines.^{8,9} Unfortunately, a surfeit of attention within public discourse on combating the negative impacts of medical mistrust, particularly in regards to COVID-19 vaccine "hesitancy," has obscured the need to correct deficiencies and disparities in health care perpetuated by structural racism, White supremacy, and inequitable power structures in the United States.

Specific historical and recent events have oftentimes been cited as the root cause of medical mistrust. As such, medical mistrust has been framed as a reaction to instances of medical, research, or public health malfeasance. For example, the Tuskegee Syphilis Study, during which Black men were enrolled without informed consent and observed for 40 years with no offer of treatment, is frequently cited as the exemplar of this unethical behavior.^{10,11} Another frequently cited example is compulsory and coercive sterilization dating back to the early 20th century, which disproportionately impacted Black/African American, Indigenous, and Latinx women.¹² Most recently, in 2020, unnecessary gynecological procedures were performed on women of color, many of whom were non-English speaking, held at Immigration and Customs Enforcement detention centers in the United States. Following an investigation, the Department of Homeland Security closed the facilities where the procedures were performed.¹³ These specific events are important to note. However, understood within a psychological and sociopolitical context, medical mistrust is an adaptive response to chronic, not episodic, inequity experienced by Black, Latinx, Indigenous, and some Asian American Pacific Islander communities. As an adaptive response to repeated exposures, medical mistrust can be protective and potentially promote resilience to discrimination and maltreatment experienced directly or indirectly within one's social network, family, or community.¹⁴ Given the persistence of COVID-19 inequities, a critical analysis of medical mistrust as an adaptive response that may promote individual-level resilience, community-level empowerment, and structural change is warranted.

UNDERSTANDING MISTRUST

Psychological literature, which is often deficient in racial diversity of both authorship and research participants, has

contributed to pathologized views of mistrust.¹⁵ A substantial portion of this research has focused on the more extreme end of the mistrust spectrum, exploring "conspiracy beliefs" as a reflection of individuals' psychological disposition. This research suggests that individuals who express "conspiracy beliefs" have low self-esteem, are paranoid, or are delusional.^{7,16} Individual-level perspectives such as these delegitimize rational belief systems and ignore the origins of mistrust among people of color.

Other research has contributed to a broader understanding of medical mistrust as a protective coping mechanism. An epistemic rationale for belief in conspiracy theories posits that they arise in the face of persistent threat. In such instances, conspiracy theories provide causal explanation and render order in the place of uncertainty and injustice.⁸ For example, racial and ethnic disparities in HIV incidence and mortality have been a persistent feature of the epidemic in the United States since its inception 40 years ago. In response, HIV-related conspiracy theories, such as HIV is a man-made virus or AIDS was created by the US government to control the Black population, have developed as common beliefs within the Black/African American community.¹⁷

Within health care settings, medical mistrust can develop as a response to inequitable or hostile situations. In a study to determine psychosocial factors associated with medical mistrust among Black/African American men, the author found that perceived racism in health care was the strongest correlate of mistrust and often resulted in lack of follow-up.¹⁸ Thus, when faced with antagonistic circumstances such as racism, individuals may develop mistrust and disengage from care to minimize psychological harm and restore a sense of control. As a protective response, medical mistrust may also manifest as caution or self-preservation in light of adverse exposures both within and external to the health care system.¹⁹ From a sociopolitical perspective, the interplay among physical, social, and political environments may contribute to stronger mistrust beliefs among individuals living in neighborhoods with higher concentrations of social vulnerability.^{8,20} Medical mistrust may also be a learned attitudinal response that is transmitted among members of the same group or community with shared identity and cultural experience.¹⁴

INTERVENTIONS TO ADDRESS MEDICAL MISTRUST

Following the approval of COVID-19 vaccines, there has been intense interest in "vaccine hesitancy," a manifestation of medical mistrust, particularly among Black individuals.⁹ Interventions to increase vaccine confidence include trusted messenger programs in which health care providers or community leaders communicate evidence-based data, debunk myths, and attempt to build trust in COVID-19 vaccines. While these programs may increase vaccine uptake, it is unlikely that short-term educational programming will have a sustainable impact on broader medical mistrust beliefs. Building trust in systems of care will necessitate structural change, authentic collaboration, and investment in community engagement.²¹

Interventions to mitigate medical mistrust at the patient and health care provider level have also been developed. However, to date, these interventions have been limited in scope, given how the concept has been oversimplified and undercontextualized. At the patient level, a few effective interventions using motivational interviewing and cognitive behavioral therapy have been implemented to increase awareness of the effects of medical mistrust on health outcomes.⁸ Of note, the goal of these interventions is not to reduce medical mistrust among participants. Instead, these interventions acknowledge mistrust as a rational response to racism and a protective survival mechanism as well as raise awareness about the effects of mistrust on health. A handful of health care provider-level interventions that aim to increase cultural competency and empathy for patients have also been developed. These interventions have generally not shown effects on increasing patient trust. In addition, interventions at the health care provider level to improve patient-centered communication and shared decision-making have been suggested.⁸ However, multilevel interventions that include structural components to abolish racist policies and practices are necessary to improve the trustworthiness of the health care system and related entities.⁸

RESILIENCE, EMPOWERMENT, AND STRUCTURAL CHANGE

Resilience has been characterized as a "dynamic process encompassing positive adaptation within the context of significant adversity."²²(p543) Within public health, resilience frameworks have often been applied to disaster preparedness to assess the ability of communities to recover and survive after an emergency. From a psychological perspective, resilience also involves growth and evolution. Melding the public health and psychological perspectives,

community resilience is the ability to withstand acute or chronic threats, to adapt, to survive, and to utilize the experience to catalyze change.²³

Thus, as a protective response that has the potential to promote resilience, mistrust may be an important or even necessary trait to catalyze community-level change.

Empowerment (e.g., self-reliance and self-sufficiency) is an essential component of community resilience. In addition, empowerment can also be conceptualized as an outcome. As a community adapts to and survives serious threat (such as pervasive racism), the change that occurs often necessitates a shift in power from external entities to the community itself. The shift usually requires advocacy, policy change, alteration of governance structure, and redistribution of resources. This process defines community empowerment.

Yet, can the adaptive, protective response of mistrust that promotes resilience also lead to individual-level and community empowerment? There are several HIV-related examples that suggest that it might. On the individual level, research determining barriers to uptake of key HIV-related interventions (e.g., preexposure prophylaxis [PrEP] and HIV testing) provide evidence of the positive association between HIV-specific medical mistrust (also known as HIV conspiracy beliefs) and intervention use. For example, higher HIV-specific mistrust was positively associated with willingness to use PrEP among Black women in the National Survey on HIV in the Black Community.¹⁷ Similarly, medical mistrust among racially and ethnically diverse individuals has been positively associated with greater HIV testing likelihood.⁸ Because mistrust may be an act of self-preservation against racist threats, engaging in self-protection behaviors, such as taking PrEP to prevent HIV infection, is a rational response if one believes that systems exist in opposition to one's own self-interest. Therefore, PrEP use and HIV testing may be acts of self-empowerment.

While similar evidence does not yet exist for COVID-19, similarities between the COVID-19 pandemic and the HIV epidemic within Black communities suggest that mistrust may contribute to the uptake of protective measures (e.g., greater testing or increased use of preventive measures such as masking).²⁴

On the community level, the COVID-19 pandemic has incited a groundswell of activism and empowerment. Coalitions comprising Black, Latinx, and Indigenous community members have arisen to provide services, education, and psychological support, and to advocate equitable access to testing, therapeutics, and vaccines. These efforts have been spurred by centuries of structural racism, marginalization, and rational mistrust that current systems of power will fill critical needs equitably. Newly developed racially and ethnically defined coalitions like the Black Boston COVID Coalition (BBCC) and the Latino Coalition Against COVID-19 have formed to build upon existing community resilience and ensure that their communities' needs are met. In addition, existing Indigenous and Asian American Pacific Islander organizations, such as the National Urban Indian Family Coalition and National Council of Asian Pacific Americans, have shifted focus to COVID-19 and social determinants of health, such as poverty and food insecurity.

Structural change is defined by a dramatic shift in the way a system operates. Bolstered by simultaneous social movements, these empowered community coalitions have advocated structural change in the form of postCOVID-19 business recovery, workforce diversity, immigration reform, universal access to health care, and fundamental shifts in resource distribution to achieve and sustain equity. For example, the BBCC has demanded that pandemic efforts not only stem the tide of COVID-19 but also leave "Black residents and Black businesses in a better place post-pandemic than we were before and during."²⁵ Through BBCC's advocacy efforts, Black- and Latinx-owned businesses have been contracted to expand COVID-19 vaccination access within diverse communities. After the pandemic, newly formed community coalitions should be strengthened and directly funded to address health inequities beyond COVID-19. Similarly, advocacy organizations that arose during the early HIV era have expanded their scope to include related infections, such as hepatitis C, as well as social justice issues (e.g., homophobia, transphobia, transactional sex work). Advocacy coalitions should also formally be engaged in partnerships with COVID-19 research networks to ensure that questions relevant to most-impacted communities are addressed and to mitigate medical and research mistrust.

CONCLUSION

Combating medical mistrust has been a central focus of efforts to address inequities, including those associated with both HIV and COVID-19. It is time to reconceptualize mistrust as a rational, adaptive response to structural racism. Leveraging this adaptive response and promoting resilience and empowerment require that we acknowledge the root cause of mistrust and support the development of community-led solutions that confront systemic inequity. Ultimately, empowerment realized at the community level will be an essential driver of structural change and lead to a more equitable future. ,4jPH

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CONFLICTS OF INTEREST

The authors report no conflicts of interest.

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DETAILS

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Refusal Rates to Sexual Orientation and Gender Identity Items in the Behavioral Risk Factor Surveillance System, 2014-2019

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[ProQuest document link](#)

ABSTRACT (ENGLISH)

Objectives. To explore trends in sexual orientation and gender Identity (SOGI) Item refusal In the Behavioral Risk Factor Surveillance System (BRFSS). **Methods.** We used annual data from 7 US states that implemented the SOGI module of the BRFSS from 2014 to 2019 to examine prevalence of sexual orientation (n = 373 332) and gender identity (n 5 373 336) item refusal. Analyses included the weighted Wald y2 test of association between refusal and year and logistic regressions predicting refusal by year. We weighted analyses to account for complex sampling design. **Results.** We found low SOGI item refusal rates, significant declines in these refusal rates overtime, and differences in refusal rates by age, sex, race, education, and language. We also found that Hispanic group membership did not explain SOGI item refusal when accounting for interview language; interview language was strongly associated with both sexual orientation and gender identity item refusal. **Conclusions.** Our results indicate acceptance of SOGI measurement and empirically support continuation of SOGI in health surveillance surveys. Findings indicate a need to further investigate the association between survey translation and item refusal.

FULL TEXT

Headnote

Objectives. To explore trends in sexual orientation and gender Identity (SOGI) Item refusal In the Behavioral Risk Factor Surveillance System (BRFSS).

Methods. We used annual data from 7 US states that implemented the SOGI module of the BRFSS from 2014 to 2019 to examine prevalence of sexual orientation (n = 373 332) and gender identity (n 5 373 336) item refusal. Analyses included the weighted Wald y2 test of association between refusal and year and logistic regressions predicting refusal by year. We weighted analyses to account for complex sampling design.

Results. We found low SOGI item refusal rates, significant declines in these refusal rates overtime, and differences in refusal rates by age, sex, race, education, and language. We also found that Hispanic group membership did not explain SOGI item refusal when accounting for interview language; interview language was strongly associated with both sexual orientation and gender identity item refusal.

Conclusions. Our results indicate acceptance of SOGI measurement and empirically support continuation of SOGI in health surveillance surveys. Findings indicate a need to further investigate the association between survey translation and item refusal. (Am J Public Health. 2022;112(3):443-452. <https://doi.org/10.2105/AJPH.2021.306625>) Despite a decade passing since the Institute of Medicine called for health surveillance for sexual and gender minority (SGM) populations¹ and more recent calls by the Biden administration,² National Academies of Science, Engineering, and Medicine,³ and Healthy People 2030,⁴ sexual orientation and gender identity (SOGI) data collection in US federal health surveys remains inconsistent. Federal health surveys are uniquely positioned to

routinely assess population health with probability-based samples across vast geographic units. Nationally representative results inform policy and advise public health initiatives. Thus, incomplete inclusion of SOGI questions stunts the progression of health equity research for SGM populations.

Sensitive questions in surveys, with income being a prime example,⁵ may result in various forms of item nonresponse (e.g., refusal to answer, answering "don't know"), contributing to missing data. Although nonresponse to sensitive questions has been attributed to respondent-level variation,^{5,6} research has identified differences in item acceptability over time and across groups.⁷⁻¹⁰ Whereas "don't know" responses may suggest item comprehension issues, refusals to answer may indicate that, despite comprehension, respondents find survey items unacceptable.

Unacceptability of SOGI items-specifically, concerns among survey administrators that participants could refuse to answer items or stop the interview if they consider items too personal to answer-has been cited as a potential reason for persistent gaps in SOGI item administration in federal surveys.^{7,11} Previous research has examined sexual orientation item comprehension and acceptability, including higher nonresponse by adults aged 65 years and older,⁸ Asian, Hispanic, and African American,⁹ and Spanish- and Asianlanguage respondents.¹⁰ Language, with authors suggesting translation and comprehension issues,¹² may explain higher rates of sexual orientation item nonresponse among Hispanic and Asian respondents.¹⁰ In sum, evidence indicates that, at least up until 2011, there were population differences in and generally declining nonresponse to sexual orientation items in various population health surveys.

However, these trends have been primarily assessed in individual US states and have not been replicated in the past decade, to our knowledge. Furthermore, only 1 article, using National Crime Victimization Survey data,¹³ has assessed nonresponse to gender identity items. Besides that assessment, a focus group study identified cisgender respondent discomfort with the gender identity item because of unfamiliarity with listed genders, the cisgender option being listed last, and disbelief in nonbinary identities.¹⁴ This gap in information about gender identity item nonresponse hampers efforts to understand item implementation in federal health surveys.

We explored trends in SOGI item refusal in the Behavioral Risk Factor Surveillance System (BRFSS) over a 6-year period. We considered group trends by sex, race and ethnicity, age, language, and education. To our knowledge, our study is unique in its inclusion of multiple US states, its focus on the acceptability of both SOGI items, and its ability to test trends across pooled independent cross sections over 6 years.

METHODS

The Centers for Disease Control and Prevention (CDC) conducts the BRFSS on a monthly and annual basis, producing one of the largest publicly available data sets in the United States. The survey comprises cross-sectional probability-based samples of adults aged 18 years and older from all US states and territories. Respondents complete computer-assisted telephone interviews on their demographics, health behaviors, and medical history. BRFSS sampling and survey administration include both landline and cellular telephones. The BRFSS includes a standardized core survey administered by all US states and territories, and the CDC offers optional modules. Since 2014, a SOGI optional module, officially created by the CDC, has been available for states and territories to administer with their core surveys. Although state-added questions about sexual orientation occurred before 2014, state-added data are not available in the CDC's public use BRFSS data set.¹⁵ Thus, 2014 was the first year in which SOGI data became available. We procured data for this study from the BRFSS Web site, which the CDC provides to the public.

Because we examined SOGI item refusal among BRFSS respondents between 2014 and 2019, we imposed 2 inclusion criteria. First, because of the voluntary status of the SOGI module, use varies among states and territories annually. To focus on trends in the SOGI module over time, we included only the 7 states (Delaware, Hawaii, Minnesota, New York, Ohio, Virginia, and Wisconsin) that consistently implemented the SOGI module from 2014 to 2019 (no US territory met this criteria). These criteria helped reduce potential bias associated with inconsistent implementation across geographic regions. Second, because ordering of the SOGI module in the larger survey is unclear, we included only complete case data. As we focused on item refusal, we needed certainty that respondents

had been administered the SOGI items.

The BRFSS reports response rates are based on American Association for Public Opinion Research response rate 4, which counts both complete and partial respondents in the numerator and estimates eligibility of cases of unknown eligibility in the denominator.^{16,17} Median response rates in the 7 states from 2014 to 2019 were approximately 45.7% (2014: median = 46.4% [range 5 33.0-54.4]; 2015: median = 45.0% [range = 34.5-57.6]; 2016: median = 43.0% [range = 36.3-55.2]; 2017: median = 44.6% [range = 32.9-51.7]; 2018: median = 46.6% [range 5 39.8-51.7]; 2019: median = 49.4% [range 5 37.3-73.1]).

Outcome Items

From 2014 to 2017, the sexual orientation item was worded as follows:

Do you consider yourself to be

- * straight,
- * lesbian or gay,
- * bisexual,
- * other (not read aloud),
- * don't know/not sure (not read aloud),
- * refused (not read aloud).

In the 2018 and 2019 surveys, this item changed to more closely resemble the National Health Interview Survey item.¹⁸ The changes included the following:

1. rewording the question to "Which of the following best represents how you think of yourself?";
2. showing male and female respondents the response options "gay" and "lesbian or gay," respectively;
3. replacing "straight" with "straight, that is, not gay," with "or lesbian" added for female respondents;
4. replacing "other" with "something else"; and
5. replacing "don't know/not sure" with "I don't know the answer."

The Spanish-language interview underwent analogous edits. For our study's purposes, we recoded the 2 male- and female-dependent sexual orientation variables into a single item to facilitate comparison across survey years.

The gender identity item in the BRFSS is a single question, by contrast with best practices recommended in the field,¹⁹ that assesses whether respondents are or are not transgender. The item is worded as follows:

Do you consider yourself to be transgender?

- * yes, transgender, male-to-female;
- * yes, transgender, female-to-male;
- * yes, transgender, gender nonconforming;
- * no;
- * don't know (not read aloud); and
- * refused (not read aloud).

We dichotomized each of the SOGI variables into item response versus item refusal (0/1). Item response included respondents who stated, "don't know/not sure," as these responses could convey that the respondent is questioning 1 of their identities or that they did not heed the Missing responses (not including refusal and responding "don't know") remained missing in analyses. Missingness for the SOGI items ranged between 0.01% and 0.19% and between 0.01% and 0.15%, respectively, across the 6 years. We excluded missing responses from analyses because missingness for these items is not explained by CDC documentation, and so we could not interpret missingness as refusals.

Covariates

We included sex, race and ethnicity, age, educational attainment, state, and interview language as covariates, given previous research indicating varying SOGI nonresponse by these characteristics.^{8,10} We included state because of variation across sociopolitical landscapes for SGM populations.²⁰ We designated New York as the reference state, as it typically had the highest prevalence of refusal for both SOGI items and had the largest total state subsample. All interviews were conducted in either English or Spanish in the 7 states in the sample.

We marked refusals to answer demographic questions as missing and did not include them in our analyses. Data missing on race and ethnicity and educational attainment were minimal (0.23%-1.87%). Sex included male and female responses only. The CDC recoded race/ethnicity into 5 groups: non-Hispanic White, non-Hispanic Black, non-Hispanic other (a composite of American Indian/Alaska Native, Asian, Native Hawaiian/other Pacific Islander, and other race), non-Hispanic multiracial, and Hispanic. The age variable included 6 categories: 18-24, 25-34, 35-44, 45-54, 55-64, and 65 years or older. We maintained these age categories for χ^2 testing; however, we treated the age variable continuously in logistic regression analyses to provide more interpretable odds ratios (ORs). Education level included the following: did not graduate from high school, graduated from high school, attended some college or technical school, and graduated from college or technical school (these last 2 options are abbreviated in the tables as "attended college" and "graduated from college").

Analyses

We used the weighted Wald χ^2 test to test associations between prevalence of item refusal and survey year for each state, race and ethnicity, sex, age, language, and education subgroup. Our goal with these χ^2 analyses was to assess whether trends in specific subgroups drove potential population declines in refusal. We used the Benjamini-Hochberg test²¹ with a false discovery rate of 0.05 to account for error inflation with repeated testing.

We then conducted logistic regressions to test whether item refusal declined overtime. We used 2 separate models to test associations between survey year and refusal for the sexual orientation item and for the gender identity item. We used the F-adjusted Hosmer-Lemeshow test to assess goodness of fit. Given changes to the sexual orientation item in 2018 to 2019, we conducted a post hoc sensitivity analysis omitting data from 2018 to 2019. We weighted all analyses to account for the complex sampling design and conducted all analyses using Stata/SE version 16.1 (StataCorp LP, College Station, TX).

RESULTS

The sexual orientation refusal analysis included 373 332 respondents, and the gender identity refusal analysis included 373 336 respondents. The largest proportions of respondents were female, non-Hispanic White, college or technical school graduates, and aged 65 years or older (Table 1).

Sexual Orientation

Wald χ^2 analyses (Figure 1, Table A, and Figure A show results [the latter two are available as a supplement to the online version of this article at <http://www.ajph.org>]) examining within-group associations between prevalence of refusal and time revealed significant associations for male ($P < .01$) and female ($P < .01$) respondents. We also found significant associations between prevalence of refusal and time among Hispanic respondents ($P < .01$), respondents who had not graduated from high school ($P < .01$), and respondents aged 25-34 ($P < .01$), 55-64 ($P < .01$), and 65 years or older ($P < .01$). We found significant associations for Spanish-language respondents ($P < .01$), but not for English-language respondents. Finally, we identified significant associations between refusal and time among New York respondents ($P < .01$). A final χ^2 for the full survey sample indicated an overall significant association between refusal and year ($P < .01$).

When we adjusted for state, race and ethnicity, sex, age, language, and education, we found that each increase in year was significantly associated with a 9% reduced odds of item refusal (adjusted odds ratio [AOR] = 0.91; 95% confidence interval [CI] = 0.89, 0.94; Table 2 presents adjusted results of all logistic regression analyses).

In the logistic regression on sexual orientation item refusal, female respondents were at increased odds of refusal (AOR = 1.35; 95% CI = 1.22, 1.51) compared with male respondents. Age was also a significant predictor of sexual orientation item refusal, with the odds of refusal increasing by 20% for each decade in age (AOR = 1.20; 95% CI = 1.16, 1.25). Compared with those who had attained less than a high school education, the odds of refusing to answer the sexual orientation question were greatly reduced for high school graduates (AOR 0.60; 95% CI = 0.51, 0.70), those with some college experience (AOR 0.39; 95% CI = 0.33, 0.43), and college graduates (AOR 0.36; 95% CI 0.30, 0.43). However, beyond all other variables in the analysis, Spanish-language response was the strongest predictor of refusal to answer the sexual orientation item, with Spanish-language respondents having 705% increased odds of refusal compared with English-language respondents (AOR 8.05; 95% CI 6.45, 10.04). Non-

Hispanic other race respondents were at greater odds for refusal (AOR 5 3.26; 95% CI 5 2.61,4.08) than were non-Hispanic White respondents, but there were no other significant differences between racial and ethnic groups in odds of refusal.

Given changes to the sexual orientation item in 2018, we conducted a post hoc analysis omitting the 2018 to 2019 data (Table C [available as a supplement to the online version of this article at <http://www.ajph.org>]) to test for change in prevalence of refusal to answer the sexual orientation item between only 2014 and 2017. This post hoc analysis revealed no significant change in prevalence of refusal over time (AOR 5 1.00; 95% CI 5 0.94,1.05), adjusting for all other covariates. Covariate results did not notably differ in the sensitivity analysis from the main model. Across all sexual orientation analyses, Hosmer-Lemeshow tests indicated problematic fit (i.e., $P < .05$), suggesting that model misspecification may be an issue. We probed interactions to examine whether model fit might improve, but the addition of interactions did not improve fit.

Gender Identity

Wald χ^2 analyses (Figure 2, Table B, and Figure A present the results [the latter two available as a supplement to the online version of this article at <http://www.ajph.org>]) examining within-group associations between prevalence of refusal and year revealed significant associations for male ($P < .01$) and female ($P < .01$) respondents. We also found significant associations among non-Hispanic White ($P < .01$), non-Hispanic Black ($P < .01$), and Hispanic respondents ($P < .01$), but not among non-Hispanic other and multiracial respondents. Prevalence of refusal was significantly associated with year for respondents with less than a high school diploma ($P < .01$) and a college degree ($P < .01$), and for respondents aged 55 to 64 ($P < .01$) and 65 years or older ($P < .01$). We found significant associations for both English- and Spanish-language respondents (both $P < .01$). Finally, we identified significant associations between refusal and time among respondents in Minnesota ($P < .01$), New York ($P < .01$), and Virginia ($P < .01$). A final χ^2 for the full survey sample indicated an overall significant association between refusal and year ($P < .01$). Logistic regression revealed that the odds of refusal to answer the gender identity item, adjusting for covariates, decreased by 16% annually (AOR 5 0.84; 95% CI 5 0.80, 0.88), indicating that decline in refusal to answer the gender identity item can be uniquely explained by the passage of time. Gender identity refusal was extremely low in general but, nonetheless, underwent significant declines.

In the logistic regression on gender identity item refusal, age was a significant predictor of refusal to answer the gender identity item, with the odds of refusal increasing by 20% for each decade in age (AOR = 1.20; 95% CI 5 1.13,1.28). Compared with those who had attained less than a high school education, the odds of refusing to answer the gender identity question were greatly reduced for high school graduates (AOR = 0.62; 95% CI = 0.47, 0.83), those with some college education (AOR 5 0.39; 95% CI = 0.29, 0.52), and college graduates (AOR 5 0.42; 95% CI 5 0.31,0.56). Although it was not to the same extent as the sexual orientation item, Spanish-language response was a strong predictor of refusal to answer the gender identity item, with Spanish-language respondents having 122% increased odds of refusal compared with English-language respondents (AOR = 2.22; 95% CI 5 1.49, 3.31). Non-Hispanic Black (AOR = 1.32; 95% CI = 1.01,1.74) and non-Hispanic other race (AOR 5 2.42; 95% CI = 1.63, 3.59) respondents had higher odds of refusal than did non-Hispanic White respondents. As with the sexual orientation analyses, Hosmer-Lemeshow tests indicated problematic fit (i.e., $P < .05$); probing interactions did not yield improvements in model fit.

DISCUSSION

Refusal to answer SOGI items was low and significantly declined from 2014 to 2019. In addition to declining refusal overtime generally, there were specific trends over time by demographic subgroups. The results suggest that SOGI items are increasingly acceptable to respondents in this federally sponsored health survey. More widespread adoption of these items would produce the critical mass of data needed to understand key health equity and disparities issues for SGM populations, fulfilling priorities set by the Biden administration,² a National Academies report,³ and key benchmarks set in Healthy People 2030.⁴

Although decline in refusal was observed across all covariates, specific areas may require further research. Previous research found that, compared with non-Hispanic White respondents, Hispanic respondents had been refusing to

answer sexual orientation items at higher rates.⁹ We, similarly, noted higher SOGI item refusal among Hispanic respondents compared with other racial groups from 2014 to 2017, although the disparity largely closed in 2018 to 2019. However, Hispanic respondents were not at higher odds of refusal in either of the regression analyses when controlling for interview language, indicating that this disparity in refusal may be because of the large proportion of Hispanic respondents (32.0%) who completed the survey in Spanish.

The BRFSS is not alone in this disparity in sexual orientation item refusal, given calls by a 2016 federal interagency working group to research and improve Spanish translation²² and noted issues in item translation for the National Survey of Family Growth.²³ The higher odds of gender identity item refusal in Spanish may indicate that translation and comprehension present similar issues for this item. Further research is needed to determine the causes of these disparate odds of refusal to answer SOGI items when asked in Spanish.

Although the reasons for declines in item refusal overtime were beyond the scope of this study, generally increasing acceptance of SGM individuals in the United States likely has some influence.²⁴⁻²⁶ The observation period for this study was marked by major accomplishments for LGBTQ (lesbian, gay, bisexual, transgender, queer or questioning) communities, including marriage equality and a continuing transgender rights movement. These movements may have shifted understanding of and reception to being asked about SOGI. Although we did not assess the reasons for such declines, factors such as knowing an SGM person and the effect of shifting social policies pertaining to the rights of SGM people may be contributing factors.

Although not an initial focus of the study, differences in prevalence of refusal between SOGI items emerged, with higher prevalence of refusal to answer the sexual orientation item than the gender identity item in each survey year. Given the lack of previous attention in the literature to gender identity item refusal, explanations for this difference in prevalence of refusal remain unexplored. One study that investigated sexual orientation nonresponse noted differences in interpretation and nonsalience of particular sexual orientations, for example, "straight."²³ Although further research needs to be done to understand gender identity item interpretation, it may be that the "yes, transgender..." and "no" responses are easier for respondents to understand and respond to.

Refusal to answer SOGI items in this period was low and declining, providing evidence to support SOGI items being added to standard demographic questions in the core BRFSS survey. These results add to previous findings that respondents are generally willing to answer SOGI items in public health surveys and corroborate evidence that SOGI survey item refusals are not as high as income, which ranged between 4.2% and 6.1% in the assessment of VanKim et al. of the New Mexico Adult Tobacco Survey and BRFSS.⁷ Although only 7 states met inclusion criteria for this study, more states and territories are implementing the module each year, with 29 states including the module in 2018 and 31 in 2019. Considering low and declining item refusal, increased uptake of the module, and the pressing public health need for population data on LGBTQ health, there is ample evidence and public health need to support integrating SOGI items into the BRFSS core survey for nationwide implementation.

Limitations

We note several study limitations. Limiting this study to 7 states, although geographically diverse, means results may not be nationally representative. Our use of complete case data may have underestimated refusal; we could not ascertain whether respondents broke off early without being asked the SOGI module because of its placement in the survey. Unfortunately, the BRFSS provides data on complete or partial interviews but not on when break off occurs or individual states' ordering of optional survey modules. Goodness-of-fit tests indicated potential poor model fit, which could be because of omitted variable bias. Item refusal is a complex phenomenon to predict solely from demographic characteristics, and data not collected in the BRFSS (e.g., political affiliation) may be more informative for item refusal. The binary sex variable, whereby respondents answered the question "Are you male or female?" could plausibly include respondents answering in terms of either their sex assigned at birth or gender identity. Changes to the sexual orientation item in 2018 to 2019 may have affected refusal, as suggested by the sensitivity analysis.

More consecutive years of data with the new wording are needed to further investigate trends. Future analyses should take into account that, overall, survey response rates have been declining overtime.^{6,27} Such analyses may

offer clear implications of the relationship between survey response rates and item refusal rates. Finally, the BRFSS strives for nationally representative samples of adults who are not living in institutional settings (e.g., military facilities, long-term care facilities, homeless shelters), so results may not generalize to these groups.

Public Health Implications

Our results refute concerns about sizeable proportions of respondents refusing to answer SOGI items in surveys. Health equity research about SGM populations has been hampered for decades by the general lack of SOGI data in federal surveys and was deemed "public health malpractice"¹¹ because of the languishing of a minority population's need for representation in data. In recent years, there has been much progress with additions not only to the BRFSS but also to other surveys, such as the National Survey of Drug Use and Health, the National Crime Victimization Survey, and the National Health Interview Survey.

Unfortunately, the progress of including SOGI data is not a settled matter in the United States. In 2018, the CDC had to issue clarification that the Trump administration was not attempting to omit the SOGI module from the BRFSS.²⁸ Similar speculation arose around the Trump administration's role in rescinding SOGI measures to be developed and implemented in the 2020 Census.²⁹ Thus, it is critical that researchers document evidence for scientifically informed decisions. Consequently, something as seemingly simple as illustrating response and refusal to survey items can speak volumes for the progression of health equity research.

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CONTRIBUTORS

R. P. O'Brien conducted the analyses and led the writing of the article with J. R. Blosnich's support and direction. J. R. Blosnich reviewed the analyses, supported the interpretation of findings, and contributed to editing the article. The authors conceptualized the study together.

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CONFLICTS OF INTEREST

The authors have no potential or actual conflicts of interest to disclose.

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This study was approved by the University of Southern California internal review board.

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DETAILS

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Pronouns Are a Public Health Issue

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[ProQuest document link](https://www.proquest.com/scholarly-journals/refusal-rates-sexual-orientation-gender-identity/docview/2638091810/se-2?accountid=211160)

ABSTRACT (ENGLISH)

In their study published in this issue of AJPH, Perales et al. (p. 482) drew from a 2020 Australian data set to demonstrate a significant association between the use of inclusive language in the workplace and a multidimensional measure of well-being at work in a sample of more than 400 trans- and gender-diverse (TGD) people (including transgender, nonbinary, agender, and other gender minority people) working for more than 100 unique employers. This study is notable both for its relatively large sample size (given the underresearched and often invisible nature of this population) and for its inclusion of workplace-level data (i.e., indicators of inclusive language use from both TGD and cisgender employees in each workplace setting). The resulting findings are the first, to our knowledge, to empirically establish the relationship between trans-inclusive language and mental well-being at work, and they offer important extensions to our knowledge of the contribution of employment-related discrimination to the health of TGD people.¹

Why is trans-inclusive language in the workplace (and beyond) a public health issue? Work and working conditions are widely accepted as important components of the social determinants of health (<https://bit.ly/3qsb6Qv>). Although less formally acknowledged, many scholars and advocates argue that gender identity, meaning one's internal experience and sense of gender, should also be considered a social determinant of health: TGD people experience profound health inequities, often associated with exposure to gender-related stigma and discrimination.² Indeed, these disparities are so stark that, in recent years, special sections have been devoted to TGD health in both AJPH and the Lancet.^{3,4}

These health inequities are linked to economic and other structural inequities. For example, highlighting the disproportionately high prevalence of HIV in TGD populations, Becasen et al. have noted the relevance of recognizing social and economic vulnerabilities systemically affecting this population as factors that likely increase HIV risk.⁵ Indeed, structural and interpersonal discrimination, experienced by TGD people as cisnormativity and transphobia, limit TGD people's access to the health benefits of work. A national US study identified that TGD people were more than twice as likely to be living in poverty (29%) as cisgender people; this is likely attributable to unemployment rates that are three times the national average, earning lower wages than their cisgender counterparts, and experiencing workplace discrimination and harassment that result in being fired, resigning, or being denied promotion. These patterns are compounded when intersectional marginalization is considered (<https://bit.ly/3z7nQjI>). Corroborating findings from Canada indicate that TGD people face higher rates of employment discrimination (2.2 times) and harassment (2.5 times) than do their cisgender peers, despite workplace protections.¹ Almost 30% of TGD people reported that they were, or thought they were, fired for being TGD, whereas 50% were, or thought they were, denied a job for being TGD (<https://bit.ly/32CvJBm>).

FULL TEXT

In their study published in this issue of AJPH, Perales et al. (p. 482) drew from a 2020 Australian data set to demonstrate a significant association between the use of inclusive language in the workplace and a multidimensional measure of well-being at work in a sample of more than 400 trans- and gender-diverse (TGD) people (including transgender, nonbinary, agender, and other gender minority people) working for more than 100 unique employers. This study is notable both for its relatively large sample size (given the underresearched and often invisible nature of this population) and for its inclusion of workplace-level data (i.e., indicators of inclusive language use from both TGD and cisgender employees in each workplace setting). The resulting findings are the first, to our knowledge, to empirically establish the relationship between trans-inclusive language and mental well-being at work, and they offer important extensions to our knowledge of the contribution of employment-related discrimination to the health of TGD people.¹

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These health inequities are linked to economic and other structural inequities. For example, highlighting the disproportionately high prevalence of HIV in TGD populations, Becasen et al. have noted the relevance of recognizing social and economic vulnerabilities systemically affecting this population as factors that likely increase HIV risk.⁵ Indeed, structural and interpersonal discrimination, experienced by TGD people as cisnormativity and transphobia, limit TGD people's access to the health benefits of work. A national US study identified that TGD people were more than twice as likely to be living in poverty (29%) as cisgender people; this is likely attributable to unemployment rates that are three times the national average, earning lower wages than their cisgender counterparts, and experiencing workplace discrimination and harassment that result in being fired, resigning, or being denied promotion. These patterns are compounded when intersectional marginalization is considered (<https://bit.ly/3z7nQjI>). Corroborating findings from Canada indicate that TGD people face higher rates of employment discrimination (2.2 times) and harassment (2.5 times) than do their cisgender peers, despite workplace protections.¹ Almost 30% of TGD people reported that they were, or thought they were, fired for being TGD, whereas 50% were, or thought they were, denied a job for being TGD (<https://bit.ly/32CvJBm>).

To understand the implications of the work of Perales et al., it is helpful to drill down into what was meant by inclusive language in their study. The key explanatory variables in the study centered on using correct pronouns and other associated gender markers (e.g., names). For example, TGD people were asked whether people made an effort to use their personal pronouns, and cisgender heterosexual people were asked if they would be comfortable using "they/ them/their" pronouns for a nonbinary person at work. We believe that transinclusive language includes any and all measures used to account for the identities of TGD people and that the indicators Perales et al. used are necessarily proxies of a broader concept. However, if we reframe the authors' findings in the simplest possible terms, we see that TGD people reported improved well-being in workplaces where their co-workers felt comfortable referring to them using the correct pronouns.

Use of trans-inclusive language- including the use of correct pronouns, affirming gendered terms such as honorifics (e.g., Ms., Mr., Mx.), and the promotion of gender-neutral language ("people" instead of "men" or "women") where appropriate- has a profound impact on the comfort and psychological safety of TGD people in the institutions with which they must interact; this includes, as demonstrated by Perales et al., the workplace. For many TGD people, being referred to by incorrect pronouns is experienced as a microaggression: a seemingly innocuous exchange that contains negative messaging about the group (in this case, the notion that a TGD person's gender identity does not merit recognition). Ample research has established a strong and negative relationship between exposure to microaggressions and TGD health.⁶ This is because use of transinclusive language, including correct pronoun use, is a fundamental component of gender affirmation, that is, the process whereby someone receives social recognition of their gender identity or expression, including via legal, social, or medical means.⁷ For example, Scheim et al. found that TGD people whose gender identity matched their legal documents (correct name and gender marker) had a 32% reduction in serious psychological distress and an approximately 25% reduction in suicidality than did those whose identification did not match their gender identity.⁸

Pronouns- single syllable words that roll off our tongues so many times in a single day- structure what is possible with respect to gender identity and can reinforce a gender binary with their use. This is likely why there is such resistance to using pronouns that do not neatly correspond to how an individual's gender is perceived or to using pronouns such as "they/them" that do not align with binary gender. Although they are simple words, using pronouns correctly for TGD people challenges the binary gender system that underpins so much of dominant Eurocentric, colonial social structures- the binary system that is necessary to uphold systems of patriarchy and misogyny. These tiny words do so much work and carry so much significance, not just for TGD people but for all who are affected by these systems of oppression. Through this lens, pronouns are truly a public health issue.

At the same time, it really is that simple. As Perales et al. demonstrate, an important step in creating trans-affirming workplaces is to ensure that all employees are able to respect and affirm TGD peoples' identities through the use of

correct pronouns and related gender markers. This could be accomplished through, for example, workplace training, including instruction in using trans-inclusive language and information about its role in addressing health and other inequities for TGD people; regular evaluations of organizational culture with respect to trans-inclusive language; and equity in hiring and promotion to ensure that TGD people are in positions in organizations that enable them to actively participate in these and other necessary interventions (the Appendix provides resources [available as a supplement to the online version of this article at <http://www.ajph.org>]). As a significant global workforce with an imperative to address health inequities, employers in the public health sector are well positioned to show leadership in this domain. We hope that through such action, the workplace can evolve to affirm the identities of TGD people and serve as a catalyst rather than an impediment to reduce social inequities and improve health in this population.

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Ending Homelessness and Advancing Health Equity: A Public Health of Consequence, March 2022

Kapadia, Farzana, PhD, MPH ¹ ¹ associate professor of epidemiology at the School of Global Public Health, New York University, New York, NY

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ABSTRACT (ENGLISH)

Widening sociostructural inequities, especially those arising from homelessness and housing insecurity, are drivers of the growing health inequities in the United States. Continued efforts to understand how homelessness will evolve over the course of the pandemic and beyond to impact adverse health outcomes in rural areas, in suburban communities, and in urban centers will be required. In parallel, pressing questions for public health advocates, policymakers, and community members seeking to end homelessness will include determining which populations to prioritize for intervention and what interventions will yield the most benefit to intervene on this critical driver of health inequity.

FULL TEXT

Widening sociostructural inequities, especially those arising from homelessness and housing insecurity, are drivers of the growing health inequities in the United States. Continued efforts to understand how homelessness will evolve over the course of the pandemic and beyond to impact adverse health outcomes in rural areas, in suburban communities, and in urban centers will be required. In parallel, pressing questions for public health advocates, policymakers, and community members seeking to end homelessness will include determining which populations to prioritize for intervention and what interventions will yield the most benefit to intervene on this critical driver of health inequity.

HOMELESSNESS INTERVENTIONS-WHO GETS PRIORITY?

Until there are sufficient resources to end homelessness in the United States, communities will struggle with how to allocate limited homeless services.

Thus begins the editorial by Shinn and Richard in this issue of AJPH (p. 378), describing, in the absence of necessary resources, which metrics communities can consider employing to determine how homeless services ought to be allocated. With the widely used tool to assess allocation of homelessness resources, the VI-SPDAT (Vulnerability Index - Service Prioritization Decision Assistance Tool), recognized as "invalid, unreliable and racially

biased," communities require guidance on processes to ensure appropriate and equitable allocation of homeless services. In an effort to account for the inadequacies of the VI-SPDAT and provide a more inclusive allocation framework, the authors offer a more nuanced approach that incorporates assessment of (1) which groups of individuals should be considered at risk, (2) which groups of individuals should be prioritized for intervention, and (3) which services or interventions are appropriate. Shinn and Richard also discuss challenges inherent in applying these risk assessment categories, particularly with respect to identifying priority groups for intervention. Given the discrepancy between needs and availability of resources, the choice of which group to prioritize (e.g., homeless veterans, unsheltered youth, etc.) for housing intervention and support will limit resource availability to other groups in need and likely extend racial inequities in service allocation.

People of color, Indigenous people, and particularly women of color and their families bear the disproportionate burden of homelessness and housing instability in the United States. As per the US Department of Housing and Urban Development's 2020 Annual Homeless Assessment Report to Congress ([https:// bit.ly/3e7olef](https://bit.ly/3e7olef)), 39% of all people experiencing homelessness and 53% of people experiencing homelessness as members of families with children were Black or African American people. In addition, Hispanic/Latino people represented 23% of all persons experiencing homelessness, and American Indian, Alaska Native, Pacific Islander, and Native Hawaiian persons represented 5%. Despite these clear racial and ethnic disparities in homelessness, prioritization of groups by risk status for intervention, as noted by Shinn and Roberts, can heighten racial disparities in homelessness by perpetuating inequitable and opaque systems for allocation of housing resources. Failure to apply a racial equity lens to allocation of homeless interventions will perpetuate structurally racist inequities in access to housing support systems and will continue to entrench people of color and Indigenous people in cycles of poverty.

HOMELESSNESS AND THE PANDEMIC

Layered on top of these existing inequities in homelessness intervention, the COVID-19 pandemic has profoundly exacerbated the homelessness crisis by fueling job loss, medical debt, job insecurity, reduction in homeless shelter capacity, and reduction in social services. Each of these underlying drivers of homelessness has been disproportionately shouldered by individuals and their families who earn lower incomes, have less job security, and are disproportionately people of color and Indigenous people.

Although federal, state, and local authorities galvanized a variety of resources to prevent homelessness, including direct financial support and eviction moratoriums, during the pandemic, these stopgap measures are likely to end or be significantly curtailed as the economy rebounds. However, people and families who experienced homelessness during this time will not rebound as easily. Between 2019 (<https://bit.ly/3J7fih2>) and 2020 (<https://bit.ly/3e7olef>), the number of persons experiencing homelessness increased nationwide, from 553,000 to 580,000. A 2021 report by the Economic Roundtable suggests that the recession caused by the pandemic could lead to an increase in homelessness by 49% over the next 4 years ([https://bit.ly/ 3yGUiZg](https://bit.ly/3yGUiZg)). Individuals who have a record of an eviction during this period, who had to forgo rent to cover unanticipated medical costs, who are unemployed because of the pandemic, who are employed in low-wage or part-time jobs that make it harder to save the funds needed to afford security deposits or encounter landlords unwilling to accept housing vouchers will face significant and often insurmountable hurdles in procuring affordable and stable housing.¹

ENDING HOMELESSNESS PRIORITIZING ALL

Shinn and Richard present a thoughtful discussion of the opportunities and pitfalls of applying different prioritization assessments to determine allocation of housing support for homeless individuals in the context of limited resources. This approach to allocation of resources may be more inclusive than prior mechanisms for identifying groups for homeless intervention. In addition, individuals who may not fall into the previously identified risk groups who are currently experiencing or likely to experience homelessness associated with the COVID-19 pandemic and pandemic recession should also be included.² Ignoring the needs of those who are newly homeless during this period will likely increase the rate of homelessness and hold back those already experiencing homelessness. Importantly, the absence of guidance on how to ensure that housing support is provided equitably for people of color and Indigenous people, who already shoulder the greatest burdens of sociostructural inequities during the pandemic, will likely lead

to growing racial and ethnic disparities in homelessness after the pandemic.

As summarized by Versey,³ the current patchwork of temporary assistance plans and categorizations of priority for housing support will likely be insufficient to meet the growing demand for support. Rather, a comprehensive federal housing policy that provides multilevel solutions to ensure long-term housing support is necessary to narrow the racial and sociostructural inequities in homelessness.³ Long-term and sustainable change requires overhauling local eviction laws in states that have highly punitive eviction policies, enacting rent control in urban neighborhoods where housing prices have increased dramatically and far outpaced low- and middle-income wages and increased tenant protections, and significantly expanding housing vouchers as well as greater investment in affordable housing stock to make housing available for individuals and families. In addition, eliminating background checks for prior evictions during the pandemic and for criminal records will further reduce inequities in homelessness. These are not unattainable goals. At this critical juncture, mobilizing the necessary resources and committing to a vision of affordable housing for all is necessary to achieve a healthier and more equitable society. >4JPH

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A Measure of Hope: New Questions for Postpandemic Rebuilding

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ABSTRACT (ENGLISH)

As the United States continues to grapple with the trauma COVID-19 has inflicted, how has the pandemic affected Americans' outlook on the future? Furthermore, with the nation at a critical juncture of social and economic recovery, how can public health address population-level hope and despair moving forward? In this issue of AJPH, Riley et al. (p. 509) begin to address these questions using a novel measure of the difference between anticipated life satisfaction (ALS) and current life satisfaction (CLS) to examine trends in hope across the nation and within US counties. This new way of tracking people's outlook on their lives may help with the development of programs and policies aimed at bolstering hope to support well-being. However, this novel measure also raises several questions about the public health implications of population-level hope. This population-level measure of hope contributes to the literature an aspect of the social environment not previously captured in the effort to theorize and test the associations between societal attitudes and health. Riley et al. aggregate individual responses to the Gallup National Health and Well-Being Index to summarize changes in hope at the county and national levels.

Although theories about how social environments and individuals interrelate have existed for decades, measuring the social environment based on aggregating individual attitudes is relatively rare in the literature. Most commonly, such measures have captured social capital: the resources that are rooted in social networks such as social connectedness, civic engagement, norms of reciprocity, and trust in others that facilitate cooperation for mutual benefit.¹ Recently, health scholars have aggregated individual responses to national survey data to capture area-level attitudes of anti-Black racism, xenophobia, and homophobia to examine their associations with mortality.²⁻⁴ Other studies have used aggregate individual data from Google searches and tweets as indicators of prejudicial social environments.

FULL TEXT

As the United States continues to grapple with the trauma COVID-19 has inflicted, how has the pandemic affected Americans' outlook on the future? Furthermore, with the nation at a critical juncture of social and economic recovery, how can public health address population-level hope and despair moving forward? In this issue of AJPH, Riley et al. (p. 509) begin to address these questions using a novel measure of the difference between anticipated life satisfaction (ALS) and current life satisfaction (CLS) to examine trends in hope across the nation and within US counties. This new way of tracking people's outlook on their lives may help with the development of programs and policies aimed at bolstering hope to support well-being. However, this novel measure also raises several questions about the public health implications of population-level hope.

This population-level measure of hope contributes to the literature an aspect of the social environment not previously captured in the effort to theorize and test the associations between societal attitudes and health. Riley et al. aggregate individual responses to the Gallup National Health and Well-Being Index to summarize changes in hope at the county and national levels.

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Questions remain about what a population-level measure of hope captures and how it should be applied in the future. How do other aspects of the social environment—such as income inequality, structural racism, and age distribution—influence and interact with population hope? Could aggregate measures of hope miss or underrepresent subpopulations who are marginalized in society? Do increases or decreases in hope predict future morbidity and mortality? Importantly, do all declines in hope warrant public health attention and resources equally? Answers to these questions will help to determine whether interventions to address declines in hope are warranted and, if so, in

which circumstances.

IMPLICATIONS FOR TRACKING HOPE

Riley et al. found that despite the remarkable hardships that people have endured during the COVID-19 pandemic, Americans remained optimistic about their futures. In fact, hope significantly increased in 2020. This finding highlights the ability of the nation's people to maintain a hopeful attitude about the future, even during a crisis never before experienced by anyone in this generation. This is a population strength that should be celebrated and activated as we rebuild US society. And yet, a maintenance in ALS drove this increase in hope, whereas CLS dropped considerably. What remains to be seen is whether ALS will continue to remain stable and whether CLS will improve with postpandemic recovery efforts.

According to Riley et al., even before the pandemic levels of hope varied across the country, with some parts of the country experiencing declines in hope. In the past few years, the phrase "deaths of despair" has been used to describe the declines in US life expectancy and increases in deaths from suicide, drug overdose, and alcohol use.⁷ Despair—the absence of hope—has been linked to numerous poor health outcomes and increased mortality. Therefore, tracking despair has emerged as a barometer of risk of poor mental health, unhealthy behaviors, and preventable mortality. The unique metric Riley et al. propose may help with forecasting increases in these public health problems for areas experiencing declines in hope.

However, conversations about despair have focused primarily on White Americans, and much less attention has been paid to Americans who experience long-standing marginalization, including Black, Indigenous, Filipinx, Latinx, and Pacific Islander communities and other communities of color, which have been hit hardest during the pandemic.^{8,9} Using a population-level measure of hope might hide or miss subpopulations experiencing despair because of their minoritized status in the United States at the intersections of poverty, race/ethnicity, immigration status, sexual orientation, gender identity, and disability. More work is needed to examine what changing hope means, especially for groups that have had reasons to despair long before the pandemic.

Not all increases and decreases in hope are equivalent or necessarily require public health intervention. For example, a decline in hope over time that is driven primarily by an increase in CLS with a simultaneous maintenance of ALS probably does not meet criteria necessary for intervention, especially when experienced by people already enjoying societal privilege. At the same time, an increase in hope that is driven by a decline in CLS and a maintenance of ALS may require our attention. Through an equity lens, interventions may be seen as more relevant when declines in CLS, ALS, or both are detected among populations who are already socially disadvantaged because of low education, poverty, sexism, heteronormativity, racism, xenophobia, segregation, disability, and more. These socially constructed factors are likely to influence and interact with levels of hope.

Furthermore, it is important to keep in mind that CLS and ALS are subjective measures based on individual responses. Although subjectivity is not inherently problematic, we must consider whether historically oppressed groups, especially communities of color, have been socially conditioned to accept lower objective standards of living. This may enable them to maintain life satisfaction and hope even when their socioeconomic status is comparatively lower. Maintenance or even increase in hope may be a sign of resilience, but it also does not address the underlying structural inequality that contributes to health inequities in these populations.

Although measures of the social context based on aggregated individual data may be extremely useful for research and policy, they must be applied carefully and with awareness of their limitations. Research finds that aggregate neighborhood indices may underrepresent the needs of those most vulnerable to experiencing health inequities in a geographic area ([https:// bit.ly/3oYf6sA](https://bit.ly/3oYf6sA); Morey et al.¹⁰). Future studies should consider who is represented (and underrepresented) in aggregate measures of hope and who stands to benefit most from interventions into societal hope. These issues highlight the complexity of examining changing hope over time and possible equity issues with using increases and decreases in hope as an indicator of a broader public health problem.

CONCLUSIONS

This measure of changes in hope that Riley et al. provide opens new doors for public health intervention and research. As knowledge emerges on how hope affects morbidity and mortality over time, major questions remain

about which segments of the population are likely to be affected and in which cases declines in hope warrant public health intervention. As the nation recovers from a pandemic, our attention should turn to how to build hope into the fabric of society. This will best be achieved by taking this opportunity that a pandemic has produced to build a more equitable society that will be more resilient and hopeful in the face of future national crises. AJPH

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DETAILS

Subject:	Population; Mortality; Intervention; Health disparities; Survival analysis; COVID-19; Racism; Xenophobia; Pandemics; Society; Public health; Morbidity; Attitudes; Coronaviruses; Aggregate data; Social networks; Social environment; Counties; Political participation; Data search; Trauma; Discrimination; Reciprocity; Norms; Search engines; International cooperation; Questions; Social organization; Social capital; Homophobia; Life satisfaction; Rehabilitation; Well being; Citizen participation; Health behavior; Drug overdose; Critical junctures
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We Keep Proving That SOGI Questions Work, but Have More to Learn

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ABSTRACT (ENGLISH)

In this issue of AJPH, O'Brien and Blosnich (p. 443) adeptly expand our growing knowledge base on sexual orientation and gender identity (SOGI) measurement. Methodologically speaking, the authors did everything right, including weighting their analyses to account for the sample design and reporting their outcome measures transparently (<https://bit.ly/aapor-tifaq>). If this article were appearing in a methodology journal, I might take issue with calling all item nonresponses "refusals" (vs the more general and accurate, if jargony, "item nonresponse"), but it's not. The major takehome is that much-needed data on sexual and gender minorities (SGMs) can be collected in large-scale general population surveys, furthering essential lesbian, gay, bisexual, transgender, questioning, and others (LGBTQ+) public health research. The article's geographically broadened scope, although not fully national, and assessment of both SO and GI measures overtime address major limitations of past research. Corroborating past results, they show that race/ethnicity and language are related to SOGI nonresponse and its decline over time. Generally speaking, non-Hispanic people of color are more likely not to answer SOGI items. Rather than recount their detailed findings, I comment on the state of our SOGI measurement knowledge and open questions in our practices.

FULL TEXT

In this issue of AJPH, O'Brien and Blosnich (p. 443) adeptly expand our growing knowledge base on sexual orientation and gender identity (SOGI) measurement. Methodologically speaking, the authors did everything right, including weighting their analyses to account for the sample design and reporting their outcome measures transparently (<https://bit.ly/aapor-tifaq>). If this article were appearing in a methodology journal, I might take issue with calling all item nonresponses "refusals" (vs the more general and accurate, if jargony, "item nonresponse"), but it's not. The major takehome is that much-needed data on sexual and gender minorities (SGMs) can be collected in large-scale general population surveys, furthering essential lesbian, gay, bisexual, transgender, questioning, and others (LGBTQ+) public health research. The article's geographically broadened scope, although not fully national, and assessment of both SO and GI measures overtime address major limitations of past research. Corroborating past results, they show that race/ethnicity and language are related to SOGI nonresponse and its decline over time. Generally speaking, non-Hispanic people of color are more likely not to answer SOGI items. Rather than recount their detailed findings, I comment on the state of our SOGI measurement knowledge and open questions in our

practices.

EXPANDING AND EVOLVING SOGI MEASURES

Most readers know that both SO and GI measurement in population-based health surveys (and surveys of other topics) have expanded rapidly in recent years,^{1,2} with the GI measure adoption curve being the steeper of the two. Efforts to establish SOGI questions in federal surveys will include numerous US Department of Health and Human Services surveys and will likely have a ripple effect on best practices for all surveys in the same way that the Office of Management and Budget's Directive 15 has influenced race and ethnicity reporting. These efforts will also address Healthy People 2030 goals related to SGM persons (<https://bit.ly/hp2030-lgbt>). Anecdotally, every survey I have worked on over the past few years has requested GI measures. This is probably because nearly all surveys historically included a sex/gender question (e.g., "Are you male or female?"), very few of which distinguished between so-called biological, chromosomal, anatomical, or legal sex (i.e., sex assigned at birth on one's birth certificate), and the social construct of gender. To say that "sex is biological" and "gender is social" is true from one perspective, and some GI measurement researchers have found that distinction useful for developing new questions.³ However, to me, the oversimplification of "biological sex" ignores the conceptual thorniness of the concept of "biological" (e.g., anatomical vs genetic vs hormonal vs other components that are part of one's biology). Personally, I see this dichotomy reflecting society's cisgender and binary gender biases. Even some modern GI measures can miss the mark regarding this subtlety. For example, the National Adult Tobacco Survey asks a two-step GI question (sex at birth and current GI). This is an approach I usually recommend. However, unlike other 2-step measures that ask about "sex assigned at birth," the National Adult Tobacco Survey asks, "What sex were you at birth?" (<https://bit.ly/3HohdMF>). The problem is the phrase "were you," asserting that if the respondent has a different GI now, they were some other sex before. Objectively speaking, medical staff assess a newborn (usually based on genitalia); declare, "It's a boy (or girl)!"; and record the baby's sex on his or her birth certificate. When genitalia are ambiguous, genetic testing may be done, which itself may or may not completely clarify which box to check. Intersex respondents would likely have problems with the phrase "were you," but so may gender nonconforming, nonbinary, and transgender people who feel they've always been the sex with which they currently identify, not the one to which they were misassigned at birth. Stepping back from the identity issue, evolving GI measures remind us about first principles of questionnaire design, such as writing questions that all respondents can answer easily.⁴ We should not blame individual survey designers for oversights such as this. GI measurement is an evolving practice in which few unambiguous best practices exist yet. I am encouraged that researchers have become sensitive to the SGM community even when they do not have specific LGBTQ+ analysis goals. This is an excellent example of how the often-stodgy (or at least passively conservative) practice of survey design can reflect positive societal progress and help further it.

FURTHERING SOGI MEASUREMENT RESEARCH

Despite the irrefutable evidence that SOGI questions can be asked in a way that is understandable and acceptable to both SGM and non-SGM respondents, there are still several promising avenues of research, forthcoming expansions, and areas where we need to know more to create comprehensive best practices:

1. What do "don't know" responses and refusals really mean? Survey methodology theory hypothesizes two general item nonresponse causes: sensitivity (i.e., refusal) and difficulty (i.e., "don't know").⁵ Some SOGI questions include detailed "don't know" responses (e.g., "Do you not know yet, or do you not know what this question means?"⁶) or follow-up "don't know" responses with clarification questions.³ Analyses of these responses by demographics, geography, English proficiency, interview language, and other important respondent or methodological factors should provide insights into why respondents do not answer SOGI questions.

2. The role of interviewers and mode. Most of the findings above come from interviewer-administered surveys. The relationship between mode, response accuracy and item nonresponse has been known for some time, particularly for sensitive questions.⁷ As more surveys switch from interviewer administration to self-administration,⁸ there are increasing opportunities to understand mode effects on SOGI measures. Researchers should watch the American Community Survey, the largest multimode survey in the world, for its SOGI evolution beyond the same-sex

household measure it currently includes (<https://bit.ly/acs2022>).

3. Relationships between unit nonresponse and item nonresponse. Without detracting from the finding that SOGI item nonresponse is decreasing over time, declining unit nonresponse rates (i.e., the inverse of response rates) are a potential confound. With declining response rates, all surveys include a smaller fraction of the eligible population than they used to. As a result, respondents today may be more agreeable than those of the past and thus may be more likely to answer questions on any topic.⁹ Ostensibly, weighting for unit nonresponse (in addition to sample design) should account for this decline, but, to my knowledge, the relationship has not been evaluated in the SOGI item nonresponse context. Furthermore, declining response rates mean that oversampling SGM persons or combining over years will often be required to have sufficient sample sizes for analysis. Alternative data sources can also be considered, and it is encouraging that electronic health records have started to include SOGI questions (<https://bit.ly/uscdi-v2>, <https://bit.ly/hl7standard>).

4. Speakers of Spanish and other languages. Difficulties translating SOGI questions into Spanish are widely documented.¹⁰ Language and culture are intimately tied, and researchers should use all data available to better understand how they moderate the relationship between other respondent characteristics and SOGI measurements.

5. Youth surveys and other issues with age and generation. Surveying youth about SOGI brings unique challenges. Identities may not be fully formed, and respondents will have much less sexual experience, on average. For SO, surveys should include measures of attraction to capture as much of the "nonstraight" population as possible. Similarly, asking gender expression along with identity will identify a wider range of gender nonconforming youth than asking about identity only¹¹ and also should provide important data on the social perception of gender and characteristics that put youth at risk for harm.¹² On the other end of the age and generational spectrum, although there has been anecdotal evidence that older respondents may have trouble answering SOGI questions accurately, this has not been systematically verified. Some surveys that previously limited SO questions to younger respondents (e.g., the California Health Interview Survey) no longer do this in an effort to advance SOGI measurement best practices and produce data on older SGM persons. Furthermore, understanding evolving SOGI terminology would be improved if surveys regularly asked SGM respondents what terms they use to describe themselves.

6. Establishment surveys. While surveys of people and households evolve, businesses and organizations are also evolving. Some are collecting SO and GI in their client, patient, and staff records providing new SOGI measures for business and establishment surveys. We should expect to see continued adoption of GI (and hopefully SO) measures in these surveys and the record systems that establishment respondents often use to answer them.

7. Asexuality. A relatively unmeasured dimension of sexuality and sexual identity is asexuality. People identifying as asexual would likely have trouble answering sexual identity or attraction questions that don't include an option for them to say they aren't sexually attracted to anyone. This group is completely invisible in most current SOGI measures and may be mixed into nonrespondents. How does someone who isn't attracted to anyone answer a question with response options about whether they are straight, lesbian, gay, or bisexual?

Public health and survey methodology are in a golden age of SOGI measurement. We know that SOGI measures can be asked in surveys without risk to overall data quality and representativeness, and we should advocate for them in as many contexts as possible. Furthering our knowledge base on how to ask them with wider groups of the general public will only improve our best practices. ÅfPU

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DETAILS

Subject:	Polls & surveys; Population; Transgender persons; Birth certificates; Ethnicity; Asexuality; Best practice; Sexuality; Gays & lesbians; Response rates; Public health; Design; Non-binary gender; Gender identity; Minority & ethnic groups; Overtime; Knowledge bases (artificial intelligence); Ethnic identity; Bisexuality; Sexual behavior; Weighting; Gender aspects; Questions; Gender; Health research
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Successful Strategies to Increase Cessation Rates Among Low-Income Maternal Smokers

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[ProQuest document link](#)

ABSTRACT (ENGLISH)

Collins et al. (p. 472) provide a valuable contribution to the tobacco cessation literature as they found that a "multilevel, MBI [multimodal behavioral intervention] package initiated in WIC [Special Supplemental Nutrition Program for Women, Infants, and Children] was acceptable, feasible, and efficacious in promoting long-term smoking abstinence and reported child TSE [tobacco smoke exposure] reduction" (p. 479). The findings are important as this approach, embedding tobacco cessation in community clinics, has potential to reduce tobacco-related morbidity and mortality in vulnerable populations. WIC serves low-income families in the United States. Low-income populations have a higher prevalence of smoking tobacco and initiate cessation assistance and treatment at lower rates, with greater challenges and less success compared with other populations. Tobacco cessation approaches that increase cessation rates in low-income populations can reduce these disparities. The study by Collins et al. designed and tested Babies Living Safe and Smokefree (BLISS), a WIC-embedded intervention that combined bestpractice guidelines for tobacco intervention (Ask, Advise, Refer [AAR]) with a more intensive multimodal behavioral intervention (MBI) grounded in telehealth counseling. The authors hypothesized primarily that AAR plus MBI would promote greater reductions in child tobacco smoke exposure than AAR plus controls. Interestingly, the hypothesis was supported by selfreported tobacco smoke exposure results, but there was no change in cotinine, a nicotine metabolite, in either group. The secondary hypothesis, focused on abstinence outcomes, was supported better by the findings of the study. Individuals in the AAR plus MBI group were more likely to report quit attempts, had more abstinent days, and had higher reported and bioverified abstinence rates.

FULL TEXT

Collins et al. (p. 472) provide a valuable contribution to the tobacco cessation literature as they found that a "multilevel, MBI [multimodal behavioral intervention] package initiated in WIC [Special Supplemental Nutrition Program for Women, Infants, and Children] was acceptable, feasible, and efficacious in promoting long-term smoking abstinence and reported child TSE [tobacco smoke exposure] reduction" (p. 479). The findings are important as this approach, embedding tobacco cessation in community clinics, has potential to reduce tobacco-related morbidity and mortality in vulnerable populations. WIC serves low-income families in the United States. Low-income populations have a higher prevalence of smoking tobacco and initiate cessation assistance and treatment at lower rates, with greater challenges and less success compared with other populations. Tobacco cessation approaches that increase cessation rates in low-income populations can reduce these disparities. The study by Collins et al. designed and tested Babies Living Safe and Smokefree (BLISS), a WIC-embedded intervention that combined bestpractice guidelines for tobacco intervention (Ask, Advise, Refer [AAR]) with a more intensive multimodal behavioral intervention (MBI) grounded in telehealth counseling. The authors hypothesized primarily that AAR plus MBI would promote greater reductions in child tobacco smoke exposure than AAR plus controls. Interestingly, the hypothesis was supported by selfreported tobacco smoke exposure results, but there was

no change in cotinine, a nicotine metabolite, in either group. The secondary hypothesis, focused on abstinence outcomes, was supported better by the findings of the study. Individuals in the AAR plus MBI group were more likely to report quit attempts, had more abstinent days, and had higher reported and bioverified abstinence rates. The intervention designed and tested by Collins et al. focused on mothers or female guardians who were smokers and had a child aged five years or younger. In addition to early parenthood, pregnancy and the first postpartum months are critical windows of opportunity for sustainable tobacco cessation. Many women quit tobacco as they plan for pregnancy or during pregnancy. Recent nationwide estimates indicate that close to one fourth of women who smoked before pregnancy quit and stayed abstinent through pregnancy.¹ However, most women who quit before or during pregnancy relapse within six months of birth.² It is essential that maternal smoking is screened and cessation support is offered as early as possible before pregnancy and during pregnancy and that cessation assistance programs continue to support women through the critical first postpartum months.

WIC is designed to serve low-income pregnant, postpartum, and breastfeeding women, and children up to age five years. For perspective, WIC served close to 12 million participants in 2018,³ of which approximately 1.2 million were pregnant women. In addition to WIC benefits, low-income maternal smokers have access to cessation support through prenatal and postnatal home visiting programs funded by the federal government (e.g., the Maternal, Infant, and Early Childhood Home Visiting Program) or by states via Medicaid. Home visiting programs are available in all US states to the most vulnerable families.⁴ For example, in 2020, approximately 70% of participating families had household incomes at or below the federal poverty level threshold, as determined by the US Department of Health and Human Services, and close to 80% relied on Medicaid or the Children's Health Insurance Program. Medicaid pays for close to half of the pregnancies and births in the United States. The prepregnancy and pregnancy tobacco smoking rates among Medicaid-insured women are approximately three times higher than among women with private insurance.

Home-visiting programs are available during pregnancy and, in general, the first year of the infant's life. Trained professionals (e.g., nurses, social workers, nutritionists) or community health workers meet regularly with pregnant women and parents of young children who want support. Home visitors evaluate families and provide services tailored to needs, including screening and providing brief interventions and referrals for tobacco cessation and overall care coordination. For example, the Maternal and Infant Health Program^{5,6} is available to all Medicaid-insured women during pregnancy and up to 12 months after delivery. Maternal and Infant Health Program home visitors use motivational interviewing techniques and best-practice guidelines⁷ (e.g., 5 R's, 5 A's) to encourage smokers to set a quit date and follow a quit plan, including referrals to the Michigan Quit Line Program and recommendations to use a cessation smartphone tool (e.g., QuitGuide app, SmokeFreeMOM text messages). In addition to WIC, embedding more intensive cessation interventions in home-visiting programs may further benefit maternal smokers and their families as home visiting begins during pregnancy and includes screening and care coordination during and after pregnancy, and providers are often trained in behavioral counseling.

Collins et al. highlight null cotinine results and relatively low absolute quit rates as the main limitations of the BLiSS intervention. Life partners, extended family, or peers smoking in the homes may have contributed to the null cotinine findings, despite BLiSS increasing maternal quit and abstinence rates. In addition, living with a partner who smokes or having family or peers who smoke reduces the likelihood of maternal tobacco cessation.⁸ At the same time, partner, family, or peer cessation support may be a promising approach to increase maternal tobacco cessation rates.⁹ Peer support smoking cessation programs emerge as effective and empowering and may be of great importance for vulnerable populations who have fewer opportunities to access cessation assistance programs.¹⁰ The existing evidence supports the idea that future tobacco cessation programs for vulnerable maternal smokers should consider family or peer support components.

The BLiSS intervention by Collins et al. included a smartphone mobile app component. The potential of mobile health, especially smartphone-based strategies, to increase the effectiveness and reach of tobacco cessation interventions in underserved populations, who access cessation assistance and treatment at lower rates, is great given the large and expanding smartphone ownership. Apps leverage the unique functionality of smartphones,

including artificial intelligence, to deliver messages and content deeply tailored using momentary assessments including cravings, stress, and need for support.

Embedding effective tobacco cessation interventions in WIC, home visiting, and other safety-net programs may be successful strategies to increase cessation rates among low-income maternal smokers. Such strategies have great potential to reduce tobacco disparities as low-income populations have a higher tobacco smoking prevalence and initiate cessation assistance and treatment at lower rates, with greater challenges and less success compared with other smokers. While brief embedded tobacco cessation interventions, which are the norm, showed some success, more intensive multilevel interventions including telehealth and mobile health components and consideration of family or peer support may be more effective. To maximize reach and effectiveness, efforts need to start early during pregnancy and continue after the birth and through infancy and childhood. States and communities should use the existing infrastructure, such as statewide prenatal and postpartum home-visiting programs and WIC, available to the majority of low-income pregnant women and mothers, to engage maternal smokers early in cessation assistance programs. Furthermore, to ensure the largest tobacco cessation impact and improve the long-term health of families, additional coordination is needed between federal (e.g., WIC) and state (e.g., Medicaid) programs, between clinical and community care, and during pregnancy, through the transition to postpartum care, and through the early years of childhood.

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CONFLICTS OF INTEREST

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DETAILS

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Trends and Variation in the Gap Between Current and Anticipated Life Satisfaction in the United States, 2008-2020

Riley, Carley, MD, MPP, MHS; Herrin, Jeph, PhD; Lam, Veronica, BA; Parsons, Allison A, PhD; Kaplan, George A, PhD; Liu, Diana, MS; Witters, Dan, MS; Krumholz, Harlan M, MD, SM; Roy, Brita, MD, MPH, MHS

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ABSTRACT (ENGLISH)

Objectives. To describe national- and county-level trends and variation in a novel measure of hope. **Methods.** Using data from the Gallup National Health and Well-Being Index ($n = 2\,766\,728$), we summarized the difference between anticipated life satisfaction (ALS) and current life satisfaction (CLS), measured by the Cantril Self-Anchoring Scale, for each year from 2008 to 2020 and by county over two 5-year periods in the United States. **Results.** Across all years, there was a significant positive trend in the difference between ALS and CLS for the nation ($P = .024$), which remained positive but not significant when we excluded 2020. Maintenance of ALS with a decrease in CLS drove the 2020 increase. From 2008-2012 to 2013-2017, 14.5% of counties with 300 or more responses ($n = 599$) experienced an increase in the difference of more than 1 SD, whereas 13.9% experienced a more than 1 SD decrease. Fifty-two counties experienced decreases in ALS and CLS. **Conclusions.** Responding to trends in the gap between ALS and CLS at national and local levels is essential for the collective well-being of our nation, especially as we navigate and emerge from crisis.

FULL TEXT

Headnote

Objectives. To describe national- and county-level trends and variation in a novel measure of hope.

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Results. Across all years, there was a significant positive trend in the difference between ALS and CLS for the nation ($P = .024$), which remained positive but not significant when we excluded 2020. Maintenance of ALS with a decrease in CLS drove the 2020 increase. From 2008-2012 to 2013-2017, 14.5% of counties with 300 or more responses ($n = 599$) experienced an increase in the difference of more than 1 SD, whereas 13.9% experienced a more than 1 SD decrease. Fifty-two counties experienced decreases in ALS and CLS.

Conclusions. Responding to trends in the gap between ALS and CLS at national and local levels is essential for the collective well-being of our nation, especially as we navigate and emerge from crisis. (*AmJ Public Health.* 2022;112(3):509-517. <https://doi.org/10.2105/AJPH.2021.306589>)

Hope—a positive mental state that enables people to persist and proceed toward their goals and on their life paths¹—is increasingly understood as vital to health and well-being.² At individual and population levels, greater levels of hope are correlated with better physical and mental health outcomes, health-related behaviors, emotional well-being, social relationships and support, life satisfaction, and quality of life.³⁻⁹ Even before the onset of the COVID-19 pandemic, the national discourse about hope and related constructs was elevated by evidence suggesting that increased mortality from suicide, drug overdose, and alcohol-related conditions—identified as deaths of despair—underlay unprecedented and sustained declines in life expectancy for the United States.^{10,11} The pandemic and its health, economic, and social consequences have further heightened concerns about hope, hope's role as a determinant of health and well-being, and potential consequences from population-level declines in hope.¹² Promoting hope requires knowledge of how it is changing over time and how it varies across the country. Although measures of hope exist,¹³ our nation currently lacks national data, trends, and benchmarks on hope overtime. We, therefore, used national data collected almost daily for the Gallup National Health and Well-Being Index (WBI) to describe the level and patterns of a newly constructed measure using data available for the US population from 2008 through 2020.¹⁴⁻¹⁶ This measure captures the common meaning of hope as the expectation that things will get better. We heard this sense of hope as an important and salient matter among communities we worked with aiming to improve their collective well-being. This definition also builds on the work of others who have used Gallup data in recent years to examine how variation in stress, optimism, and hope relates to population health outcomes in the United States.^{11,17} Accordingly, we defined hope as the difference between anticipated life satisfaction (ALS) 5 years hence and current life satisfaction (CLS) as reported at the time of the survey. We hypothesized that there would be geographic variation in this novel measure. We additionally hypothesized there would be a decrease in the gap between CLS and ALS for the nation as a whole in 2020.

METHODS

We used data from the WBI from January 2008 through September 2020. Of note, this index was named the "GallupHealthways Well-Being Index" from 2010 to 2016 and then the "GallupSharecare Well-Being Index" from 2017 to 2018. The sampling strategy, described in detail in the supplementary file (available at <http://www.ajph.org>), resulted in estimates projectable to 95% to 96% of the US adult population. The execution of this data collection methodology coupled with the national and county-level iterative proportionate weighting applied by Gallup resulted in sampling that was adequately randomized and estimates that were generalizable to the larger populations from which they are derived.

We used data from the Cantril Self-Anchoring Striving Scale, which was administered across all years. This 2-item scale was designed to assess people's attitudes toward their current and future life on a continuum from worst to best, anchored by their own identified values.¹⁸ We used the items of this scale to create the novel measure of hope in this study.

From 2008 through 2012, Gallup interviewed approximately 1000 US adults (aged 18 years) per day, for a total of approximately 353 000 US adults every year. From 2013 through 2016, Gallup interviewed approximately 500 US adults nearly every day, for a total of approximately 177 000 US adults every year. Near the end of 2017, Gallup moved to weekly sampling, completing more than 160 000 total interviews in 2017 and 115 929 in 2018. In 2018, the WBI moved to address-based sampling with a mail or Web mode of data collection and significantly reduced sample sizes compared with previous years. Smaller samples of 9645 and 2340 records were collected in 2019 and 2020, respectively. For more information about the sampling methods, see the online supplementary file.

Each respondent was assigned to a Federal Information Processing Standard area using their self-reported zip code. Each Federal Information Processing Standard code represents a US county or county equivalents (e.g., borough or parish). Zip codes that crossed county lines were mapped based on allocation to the county containing the majority of the population for that zip code. We used the most recently available demographic data from the US Census to characterize the populations of the counties.

Outcomes

We constructed our measure of hope using the components of the Cantril Self-Anchoring Striving Scale, which consists of the following prompt and 2 questions: Please imagine a ladder with steps numbered from 0 at the bottom to 10 at the top. The top of the ladder represents the best possible life for you and the bottom of the ladder represents the worst possible life for you. (1) On which step of the ladder would you say you personally feel you stand at this time? (2) On which step do you think you will stand about 5 years from now?

The first question measured CLS and the second measured ALS. To assess population hope for a region (US or county) in a given period, we subtracted the mean CLS from the mean ALS for that population for that period.¹⁹ A more positive difference between mean ALS and mean CLS indicated greater population hope. Our outcomes were population hope (high vs low, as described later) and change in population hope overtime. We also examined how CLS and ALS change over time.

Statistical Analysis

We summarized population hope nationally for the United States for each year from 2008 through 2020. We weighted item responses to correct for unequal selection probability, nonresponse, and double coverage of landline and cell phone users in the 2 sampling frames. We also weighted samples to match the US population according to gender, age, race, Hispanic ethnicity, education, region, population density, and telephone status (cell phone only, landline only, both, and cell phone mostly). The online supplementary file provides more information on weighting methods. For each annual sample, demographic weighting targets for the US were uniquely based on the most recently available Current Population Survey Annual Social and Economic Supplement figures for the US population aged 18 years or older, whereas phone status targets were based on the most recently available National Health Interview Survey. Population density targets were based on the most recent US Census. County-level weighting targets for 2008 through 2012 were based on 2011 Claritas demographic statistics, and weighting targets for 2013 through 2017 were based on 2017 Claritas demographic statistics. All reported margins of sampling error included computed design effects for weighting.

To examine national trends, we included all respondents each year. We performed a Cochran-Armitage nonparametric trend test²⁰ to assess trends over this 10-year period and graphed national trends overtime. We also examined trends in the components of the measure of hope: CLS and ALS.

To have adequate sample sizes for reporting county-level hope, we combined years 2008-2012 and 2013-2017. The last year with adequate numbers to make county-level estimates was 2017. The population size of 300 minimum threshold is a Gallup requirement for public reporting of large population samples that ensures stability of results and provides the weighting algorithm with sufficient records. We excluded counties with fewer than 300 respondents in either period. For each of the 2 periods and each retained county, we calculated the same outcomes previously described. Additionally, for each outcome, we classified each county according to whether it improved, remained unchanged, or worsened. Consistent with our previous work,²¹ we classified counties as having a meaningful change in hope if the change was 1 SD above or below the average county change; this threshold ensured that high

and low performers included a range of county characteristics. We report the number and percentage of counties in each of these categories.

To better understand whether changes in CLS or ALS drove change in hope, in each of the 3 larger groupings (i.e., above average, average, and below average change) we classified whether the changes in CLS and ALS were positive or negative. We plotted 2013 to 2017 scores against 2008 to 2012 scores to illustrate the distribution of changes in hope and its components between these 2 periods; we also plotted change in ALS against change in CLS. In addition, we report the 10 counties with the highest and lowest hope in 2013 to 2017, the 10 counties with the greatest improvement and greatest decline in hope between the 2 periods, and the corresponding ALS, CLS, and changes in ALS and CLS.

We performed all analyses using Stata version 16.1 (StataCorp LP, College Station, TX) and SPSS version 22.0 (SPSS, Armonk, NY). We used a critical value of α equal to 0.05 to assess statistical significance.

RESULTS

For national analyses, we included 2 766 728 respondents to the WBI from 2008 to 2020. For the county-level analysis, there were 599 counties with at least 300 respondents in each period, representing an estimated 78.1% of the total US population. Metropolitan counties were represented in the included sample disproportionately more than were nonmetropolitan counties, with 48.0% metropolitan counties included and 1.7% nonmetropolitan counties included. Counties included in the study had a younger age distribution, a lower percentage of White Americans (81.1% vs 86.8%) and Native Americans (1.7% vs 3.2%), higher percentages of Black Americans (12.1% vs 9.0%) and Asian Americans (4.1 % vs 0.9%), a higher percentage of Hispanic Americans (11.9% vs 7.5%), higher median household income distribution, and higher educational attainment than did counties that were not included (Table A [available as a supplement to the online version of this article at [http:// www.ajph.org](http://www.ajph.org)]).

National Trends and Variation in Hope

From 2008 to 2019, hope for the nation as a whole remained largely unchanged, ranging between +0.71 and +0.84, until it increased from +0.79 in 2019 to +0.92 in 2020 (Table 1). Across all years, there was a significant positive trend overall ($P = .024$); this trend was still positive but not significant when we excluded 2020. The increase in the difference between ALS and CLS in 2020 was driven by a decline in CLS (from 6.96 in 2019 to 6.84 in 2020; Table 1), whereas ALS remained unchanged (7.75 in 2019, 7.76 in 2020; Figure 1). These results are consistent with those found via the Gallup Panel22—a separate probability-based non-opt in panel of 120 000 panelists nationwide and one of the nation's few research panels that represent the entire US adult population—which saw a statistically significant decline in the percentage of respondents reporting a 7 or higher to CLS with little or no improvement to ALS over the course of the COVID-19 era.²³

County Trends and Variation in Hope

For the 2013 to 2017 period, counties in the top decile for hope had a mean difference between ALS and CLS of +1.1, with a range from +1.0 to +1.5.

Counties in the bottom decile for hope had a mean difference between ALS and CLS of +0.4, with a range from -0.2 to +0.5. The 10 counties with the highest and the 10 counties with the lowest hope in 2013 to 2017 are reported in Table B (available as a supplement to the online version of this article at [http:// www.ajph.org](http://www.ajph.org)).

From the first to the second period, 87 counties (14.5%) experienced an increase in hope greater in magnitude than 1 SD above the mean of the first period, and 83 (13.9%) experienced a decrease in hope greater in magnitude than 1 SD below the mean of the first period (Table C [available as a supplement to the online version of this article at [http:// www.ajph.org](http://www.ajph.org)]; Figure 2). Increase in hope resulted primarily from an increase in ALS

(Figure 3). Specifically, increased ALS led to increased hope with either a decrease in CLS ($n = 27$) or a lesser increase in CLS ($n = 48$), whereas a decrease in hope resulted primarily from an increase in CLS with either a decrease in ALS ($n = 45$) or a lesser increase in ALS ($n = 36$; Table D, available as a supplement to the online version of this article at <http://ajph.org>). Notably, 52 counties (8.9%) experienced decreases in both CLS and ALS from the first to second 5-year periods, although for 38 of these counties the difference between the 2 remained unchanged. The 10 counties with the greatest increases in hope and the 10 counties with the greatest decreases in

hope from 2008-2012 to 2013-2017 are reported in Table D (available as a supplement to the online version of this article at <http://www.ajph.org>).

DISCUSSION

Using the largest multiyear data set on life evaluation in the United States, this study provides the first, to our knowledge, comprehensive look at the gap between CLS and ALS. We found that this newly constructed measure remained largely unchanged at the national level year to year from 2008 through 2019, with a sharp increase in 2020, reflecting a distinct decline in CLS amid the COVID-19 pandemic, whereas ALS remained unchanged. Importantly, in the years before the pandemic, despite the relative stability in this measure at the national level, marked geographic variation existed across counties. Most notably and concerning, the difference between ALS and CLS declined in nearly 1 out of every 7 counties, whereas both CLS and ALS declined in nearly 1 out every 11 counties, even before the onset of the pandemic in late 2019. These findings suggest that declines in this novel measure of hope were concentrated in particular US counties.

During a year marked by a global pandemic and its economic and social consequences, the finding that US adults maintained their ALS despite the decrease in their CLS is remarkable. These findings suggest that, on average, adults in the United States retained a sense of hope for their future, despite significant decline in their current lives amid the pandemic. This pattern of change suggests that the change in CLS may be transient, that the maintained sense of hope for the future is potentially an asset to be used, and that the decline in CLS if maintained or worsened could portend further declines in the future—perhaps depending on whether conditions persist and what actions are taken. These results also underscore the responsiveness of these measures and suggest an increased likelihood that tracking and monitoring efforts to improve them would be useful.

The proportion of counties that experienced a decline in hope combined with the additional number of counties that experienced declines in both CLS and ALS before the onset of the pandemic is worrisome. This finding is concerning in part because of the anticipated negative downstream effects that may occur on the health and well-being of the people in those counties and for the US population as a whole. Although a positive future outlook is associated with good physical and mental health, engagement in healthy behaviors, and emotional and social well-being, a negative future outlook is a risk factor for poor physical health outcomes (e.g., increased mortality, unhealthy and risky behaviors, mental health disorders such as anxiety and depression).³⁻⁹

If experienced widely enough or perhaps in high enough concentrations in populations, the effects of hope on health may lead to shifts in population health. As an example, recent studies have shown how unprecedented declines in US life expectancy in the years before the onset of the pandemic were attributed to increasing mortality rates from drug overdoses, suicides, and alcohol-related conditions, which have become collectively referred to as deaths of despair.^{10,11} It has been suggested that the sustained negative effect on national life expectancy was a result of substantial declines in mental and physical health concentrated in particular US subpopulations. In their work studying hope and despair in the United States, Graham and Pinto¹¹ used measures of CLS and ALS, although not the difference between them, to examine the associations between hope and health inequities in US populations.^{24,25} They identified how "markers of ill-being," including lack of hope, were correlated with increasing rates of premature mortality among less-educated White persons.¹¹ As we discuss later, it appears that hope-and lack of hope-and associated health outcomes may concentrate in certain communities.^{11,26}

The concern about this trend in hope also arises, in part, from what it likely indicates about upstream factors at national and local levels. At the national level, the relative stability of hope for the decade before the pandemic followed by a nonintuitive increase in hope during the pandemic begs further examination of the conditions that contribute to national hope and the constructs that comprise this measure of hope. At the county level, the observed geographic variation in hope is not surprising, as place is a known contributor to the hope of a population.^{11,27} As an example, hopelessness has been shown to cluster at the neighborhood level, which is associated with local characteristics related to socioeconomic factors, opportunity, and the physical environment, including factors such as higher unemployment rate and greater perceived disorder.²⁶ The decline in hope in 1 of every 7 counties, along with the decline in both CLS and ALS in other counties, even before the pandemic may point to geographic populations

exposed to systemic or structural factors undermining hope. If modifiable local factors underlay observed trends, they may offer opportunities for intervention. It could also be that these first 100 counties serve as bellwether counties and signal the need for larger scale interventions beyond the local level.

Although our findings suggest a need to bolster hope for some people and places and rebuild hope for others, it is not yet evident how to accomplish this. Importantly, factors across multiple dimensions, including economic, social, and political, may contribute to population hope.^{13,26-29} Snyder et al. suggests that group-level hope is fostered by prosocial norms and institutions that encourage citizenship through factors such as civility, tolerance, nurturance, and altruism.¹³ Subsequently, Hirano et al. suggest that a sense of purpose and robust social networks are key factors to fostering hope in general urban populations in Japan.²⁸ More recently, a cross-national study of CLS identified 6 factors that explained nearly three quarters of the variation in national CLS: gross domestic product per capita, social support, healthy life expectancy, freedom to make life choices, generosity, and freedom from corruption.³⁰ Other studies have shown that factors across economic, social, cultural, environmental, and political domains influence population-level measures of well-being, although, to our knowledge, no researchers have studied hope directly or explicitly.³¹⁻³⁴ An extensive body of research has identified social factors, including social support, social trust, and generosity, as vital contributors to thriving, with complementary research suggesting their role in the production of hope in populations.^{26,29,35-43}

As a key determinant of health and well-being, hope is a public health matter. Consequently, it would be prudent for our nation to invest time, effort, and resources into investigating how best to improve hope, both nationally and locally. Even before the current public health crisis, stagnation, variation, and decline in population hope signaled the need for intervention. Recent research suggests that we may need to intervene in well-known population targets, such as economic vitality, as well as novel population targets like sense of purpose, civic engagement, and quality of social relationships.¹ If structural factors (e.g., lack of economic opportunity, physical disorder, racism) are contributing to stagnation, variation, and declines in hope, then progress will require systemic transformation.^{44,45} Moreover, the pandemic and recovery from it may be escalating this demand, making hope a necessary part of national and local strategies to navigate through and emerge from our current crisis. To drive improvement in population hope at national and county levels, it must be measured and tracked—something lacking in the United States outside the WBI—as well as prioritized and acted upon. In responding to CLS, ALS, and the difference between them for different populations and places, we must also learn the primary drivers for these measures and the most effective means for modifying them.

Immediate next steps could include comparing this novel measure with established measures of hope. The Cantril Self-Anchoring Scale, which provides the basis for this measure, has been tested among diverse populations for reliability and validity for its original purpose, whereas this newly constructed measure has not yet been validated.⁴⁶ Validation of this study's measure against existing measures of hope, such as the Adult Hope Scales,^{13,47,48} would be useful. Studies examining how the measure varies based on population sociodemographics, such as age, would also be helpful for interpreting results. Additionally, next steps should include conducting qualitative assessment of the measure and our findings, studying the actionable determinants of this novel measure of hope, and advancing the availability of timely data on hope at national and local levels.

Limitations

This study has limitations. First, nonresponse bias may have threatened the representativeness of the data. In collecting data for the largest data set on well-being in the United States, Gallup applied sampling and weighting methods to manage nonresponse bias and produce data representative of the populations included in the study. Of note, response rates³⁹ eroded over the 10-year measurement period from 15% to 10%, reflecting in part a methodologically requisite increase in the percentage of cell phone-based interviews each polling day from 15% in 2008 to 70% in 2017. As contact rates and cooperation rates were lower among cell phone users, the increase in the cell apportionment of the sampling frame contributed to deterioration in overall response rates relative to earlier years. Despite this erosion, state-level results for many shared metrics (e.g., obesity rates) were cross-validated with results from government-sponsored health surveys that have high response rates (e.g., the Centers for Disease

Control and Prevention's Behavioral Risk Factor Surveillance System [BRFSS]), with highly convergent results. These results affirm the weighting algorithms used with the WBI to overcome nonresponse bias and other related issues associated with data collected with lower response rates. For example, recent comparisons⁴⁹ of the WBI and BRFSS show that obesity estimates from the same measurement year (2017) yielded a correlation of 0.940, and state obesity ranks yielded a correlation of 0.947.

Second, county-level data were reported as 5-year aggregates only for counties with at least 300 respondents in 5 years; this report cannot demonstrate annual trends for counties in those 5-year time frames or provide insights into smaller and less densely populated counties with the vast majority of nonmetropolitan counties excluded from the county-level analysis. Still, the aggregate results provided reliable estimates within the confines of each reporting period, and the included counties are home to 78% of the US population, although they are skewed to counties with populations that are younger, are more educated, and have higher incomes. The included counties also have proportionately more Black, Asian, and Hispanic Americans and proportionately fewer White and Native Americans.

Conclusions

From 2008 through 2017, the gap between CLS and ALS remained stable nationally. During this period, this measure remained unchanged in many counties, increased in some, and decreased in 1 of every 7 counties, with declines in CLS and ALS in additional counties. Then in 2020, in the context of the COVID-19 pandemic, this novel measure of hope increased nationally as a result of maintenance in optimism about the future despite lower CLS. Public health action to foster and rebuild hope are essential for the health and well-being of our nation. Tracking and responding to hope with national and local strategies may be essential for our collective health and well-being as we navigate through and emerge from our current crisis. Åfpu

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CONTRIBUTORS

C. Riley and B. Roy conceptualized the study. C. Riley, J. Herrin, V. Lam, D. Liu, D. Witters, H. M. Krumholz, and B. Roy designed the study. J. Herrin, V. Lam, and D. Liu performed the analyses. All authors contributed to data interpretation, drafting and revising the article, and its final approval, and are guarantors.

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CONFLICTS OF INTEREST

C. Riley and B. Roy received funding from the Institute for Healthcare Improvement and Heluna Health to support

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HUMAN PARTICIPANT PROTECTION

The Yale University institutional review board exempted the study (protocol 1502015410) and informed consent was not required because the study was retrospective and used de-identified data.

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Erratum In: "Are We There Yet? The American Journey to Safer City Streets"

Anonymous

FULL TEXT

In: Staples JA, Yuan Y, Meddings L, BrubacherJR. Are we there yet? The American journey to safer city streets. Am J Public Health. 2021;111(9): 1586-1588. <https://doi.org/10.2105/AJPH.2021.306405>

The shape of the data points in a figure were incorrect. On page 1587, Figure 1 should be:

Note. Scatterplot depicting the number of pedestrian and cyclist fatalities for 1513 US cities with a population between 25 000 and 1 million residents. X-axis indicates the city population; y-axis indicates the number of traffic fatalities in 2019; dot size indicates the city population; circles indicate US cities outside of the Vision Zero Network; squares indicate US cities with in the Vision Zero Network; diamonds indicate Nordic cities. 4,6 American cities with fewer than 1 million residents account for 82% of all US urban vulnerable road user fatalities. An analogous figure including all cities with more than 25 000 residents can be found in the Appendix (available as a supplement to the online version of this article at <http://www.ajph.org>).

The data points were correct as published, and this correction does not affect the paper's conclusions.

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Achieving Health Equity

Landers, Stewart, JD, MCP; Bowleg, Lisa, PhD, MPH

[ProQuest document link](#)

ABSTRACT (ENGLISH)

In their essay "The Unfulfilled Promise of Public Health: It's Déjà Vu All Over Again," Fee and Brown write: We continue to mobilize episodically in response to particular threats and then let our interest lapse when the immediate crisis seems to be over. When will we learn to build and sustain the adequately supported institutions and personnel we need to protect the public's health in the long term? (<https://bit.ly/3G23dHx>; p. 41 -42) It certainly is déjà vu. Written almost 20 years ago, an era of defunding public health ensued that has undermined the efforts of public health practitioners to effect sustainable change. While many, perhaps even most, people working in public health agree that the path to health equity involves a significant change in how we do our work, the blueprint is still being designed. However, if we view health equity, and especially racial equity, as another transitory crisis, we cannot make the substantial changes needed to achieve equitable outcomes. Today, health equity or, rather, its converse-health inequity-is found almost everywhere in both the public health and health care sectors. The articles highlighted in this comment address institutional-level issues absent from many studies about the evidence base or efficacy of various interventions. Interventions do not happen in the absence of organizations that are needed to mobilize, coordinate, and implement them.

FULL TEXT

In their essay "The Unfulfilled Promise of Public Health: It's Déjà Vu All Over Again," Fee and Brown write: We continue to mobilize episodically in response to particular threats and then let our interest lapse when the immediate crisis seems to be over. When will we learn to build and sustain the adequately supported institutions and personnel we need to protect the public's health in the long term? (<https://bit.ly/3G23dHx>; p. 41 -42) It certainly is déjà vu. Written almost 20 years ago, an era of defunding public health ensued that has undermined the efforts of public health practitioners to effect sustainable change. While many, perhaps even most, people working in public health agree that the path to health equity involves a significant change in how we do our work, the

blueprint is still being designed. However, if we view health equity, and especially racial equity, as another transitory crisis, we cannot make the substantial changes needed to achieve equitable outcomes.

Today, health equity or, rather, its converse-health inequity-is found almost everywhere in both the public health and health care sectors. Whether it is a lack of access to clean water in US cities where most of the residents are people of color or the challenge of finding a health care provider knowledgeable about how to provide gender-affirming care to transgender people, we can see more clearly how our institutions fail to adequately protect and improve the health of all people. More specifically, they fail to address inequities in the health of people marginalized by social-structural factors such as poverty, stigma, discrimination, medical mistrust, underfunded school districts, and racially segregated and disinvested communities and neighborhoods.

The articles highlighted in this comment address institutional-level issues absent from many studies about the evidence base or efficacy of various interventions. Interventions do not happen in the absence of organizations that are needed to mobilize, coordinate, and implement them. Robillard et al. (p. 417) describe the "organizational ecology" challenges that determine which organizations survive, thrive, or fail because of threats including financial, organizational capacity, leadership and governance, and bias against smaller organizations. At the core of health equity, organizations built by communities that are "of the community" help people who have been marginalized feel cared for, something that larger and more "[financially] successful" organizations are often unable to do. Ojikutu et al. (p. 401) reframe medical mistrust as a resilient, adaptive response for people of color interacting with a network of health and public health organizations that are inequitable and often racist. The prescription is for community empowerment that includes leadership and community building by and for people of color. Both articles note how these structural challenges are present for both HIV and COVID-19 and, thus, how recommended solutions can have an impact on multiple health challenges.

Goldstein et al. (p. 408) use both HIV and COVID-19 surveillance data for Philadelphia, Pennsylvania, to compare and contrast how factors including occupational risk and income may or may not correlate with rates of both diseases by zip code area. Azucar et al. (p. 405) presents qualitative information on factors unique to LGBTQ people affecting COVID-19 vaccine hesitancy. Leadership by and for the community-again, a multi-issue strategy-was identified as an important focus to overcome that hesitancy.

Together, these articles further the knowledge base and suggest potential activities and supports to strengthen communities and organizations, and build the resilience of individuals and populations. Working diligently and cooperatively with communities historically marginalized by intersectional social- structural inequality-such as racism, sexism, heterosexism, classism, and cisgenderism-we can move toward a more transformative public health, one committed to dismantling inequitable approaches and rebuilding organizations that prioritize health equity, social justice, and equitable health outcomes for the communities they serve. ÅfPU

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AJPH Associate Editor

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Racial/Ethnic Segregation and Access to COVID-19 Testing: Spatial Distribution of COVID-19 Testing Sites in the Four Largest Highly Segregated Cities in the United States

ABSTRACT (ENGLISH)

Objectives. To quantify the relationship between the segregation of Black, Indigenous, and Latinx communities and COVID-19 testing sites in populous US cities. **Methods.** We mapped testing sites as of June 2020 in New York City; Chicago, Illinois; Los Angeles, California; and Houston, Texas; we applied Bayesian methods to estimate the association between testing site location and the proportion of the population that is Black, Latinx, or Indigenous per block group, the smallest unit for which the US Census collects sociodemographic data. **Results.** In New York City, Chicago, and Houston, the expected number of testing sites decreased by 1.29%, 3.05%, and 1.06%, respectively, for each percentage point increase in the Black population. In Chicago, Houston, and Los Angeles, testing sites decreased by 5.64%, 1.95%, and 1.69%, respectively, for each percentage point increase in the Latinx population. **Conclusions.** In the largest highly segregated US cities, neighborhoods with more Black and Latinx residents had fewer COVID-19 testing sites, likely limiting these communities' participation in the early response to COVID-19. **Public Health Implications.** In light of conversations on the ethics of racial vaccine prioritization, authorities should consider structural barriers to COVID-19 control efforts.

FULL TEXT

Headnote

Objectives. To quantify the relationship between the segregation of Black, Indigenous, and Latinx communities and COVID-19 testing sites in populous US cities.

Methods. We mapped testing sites as of June 2020 in New York City; Chicago, Illinois; Los Angeles, California; and Houston, Texas; we applied Bayesian methods to estimate the association between testing site location and the proportion of the population that is Black, Latinx, or Indigenous per block group, the smallest unit for which the US Census collects sociodemographic data.

Results. In New York City, Chicago, and Houston, the expected number of testing sites decreased by 1.29%, 3.05%, and 1.06%, respectively, for each percentage point increase in the Black population. In Chicago, Houston, and Los Angeles, testing sites decreased by 5.64%, 1.95%, and 1.69%, respectively, for each percentage point increase in the Latinx population.

Conclusions. In the largest highly segregated US cities, neighborhoods with more Black and Latinx residents had fewer COVID-19 testing sites, likely limiting these communities' participation in the early response to COVID-19.

Public Health Implications. In light of conversations on the ethics of racial vaccine prioritization, authorities should consider structural barriers to COVID-19 control efforts. (Am J Public Health. 2022;112(3):518-526.

<https://doi.org/10.2105/AJPH.2021.306558>)

Black, Indigenous, and Latinx communities in the United States have experienced disproportionate rates of COVID-19 infection, hospitalization, and mortality.¹ They will likely also take longer to recover as individuals and communities from the social and economic ramifications of the pandemic.² Observers outside public health predicted this epidemiological landscape in the absence of coordinated federal data collection. Lay Black people, Indigenous people, and other people of color (BIPOC) have identified structural racism—the historical, economic, political, and interpersonal factors resulting in poor outcomes for racial minorities—as the underlying mechanism for racial inequity during the pandemic.³ Structural racism precedes the health inequity observed during the pandemic through myriad pathways.⁴ Racial inequity in employment, housing, and wealth impede BIPOC communities' practice of social and physical distancing.^{5,6} Racial and ethnic discrimination in clinical settings and inequity in access to healthy food and clean air contribute to disproportionate rates of comorbidities that complicate COVID-19 among BIPOC.¹ We quantified the contribution of segregation, a geographic manifestation of structural racism, to

health inequity among Black, Indigenous, and Latinx communities during the COVID-19 pandemic.

There is limited academic work on the impact of structural racism on access to the early public health response to the pandemic, which largely consisted of the establishment of diagnostic testing sites. A previous study on access to testing in the United States focused on the relationship between testing locations and the percentage of counties that are "nonWhite" in addition to median income and the percentage uninsured.⁷ However, large geographic units (e.g., counties) may obscure the more local, neighborhood-level dynamics of structural racism.⁸ Furthermore, it is critical to be specific about the particular minority communities in question, as racism often manifests differently depending on the ethnoracial group.⁹

Racial segregation is the systematic geographic separation of racial and ethnic minorities from White neighborhoods through deliberate policies and practices and the resultant experience of social and economic marginality for separated racial and ethnic minorities.¹⁰ This geographic manifestation of structural racism long preceded the COVID-19 pandemic. In the United States, the most extreme patterns of segregation occur between Black and White Americans.¹¹ However, other groups, including Indigenous and Latinx communities, are also segregated from White communities.¹⁰ Although some literature points to the potential benefits of having neighbors of the same race, the process of segregation is distinct from the willful creation of enclaves for the preservation of ethnoracial vibrancy.¹²

Sociologist and legal scholar Monica Bell elucidates the complex, multilevel, and intentional process of segregation. Segregation consists of separation, concentration, subordination, and domination.⁸ First, there is uneven geographic distribution of racial or ethnic groups across a coherent geographic area (separation). Next, there is movement of marginalized ethnic groups into identifiable and stigmatized enclaves (concentration). Concentration highlights neighborhood effects- the influence of clusters of marginalized communities that leads to compounded deprivation. This process of concentration establishes and reproduces hegemonic racial hierarchy (subordination). Subordination goes beyond the observable consequences of concentration and articulates the subjective experience of segregation for racial minorities. The stigmatizing experience of subordination facilitates the social control and economic exploitation of disadvantaged groups by White people, who then hoard political opportunity and power (domination). Although the costs of domination are disproportionately experienced by marginalized people, domination also harms White people by hampering interracial social and political coalition building. Segregation is an intentional process that creates and rearticulates social order.

We characterize the spatial distribution of COVID-19 testing sites in the 4 most populous, highly segregated US cities using the dissimilarity index.^{13,14} We report on the relationship between the distribution of the early COVID-19 response and the segregation of Black, Indigenous, and Latinx communities.

METHODS

We used a complete list of testing sites made publicly available by GISCorps (Urban and Regional Information Systems Association, Des Plaines, IL) through June 2020. Testing sites included drive-through locations, preexisting hospital centers and clinics, commercial pharmacies, and pop-up testing sites. We then generated a list of the 20 most segregated US cities as measured by the dissimilarity index.¹⁵ The dissimilarity index is the most commonly used measure of segregation between 2 groups and reflects their relative distributions across neighborhoods in the same city.¹⁴ The index ranges between 0 and 100 and quantifies the percentage of 1 group that would have to move across neighborhoods to be distributed the same way as the second group. The higher the number, the more segregated the area.¹⁴ We then selected the 4 most populous cities on this list (i.e., New York City; Los Angeles, CA; Chicago, IL; and Houston, TX) to facilitate a focused analysis.¹⁶

Covariates

Our outcome was the number of testing sites in each census block group as of June 2020. Covariates of interest included the percentage of the population that was non-Hispanic Black or African American, the percentage of the population that was Hispanic or Latino, and the percentage of the population that was non-Hispanic American Indian or Alaska Native at the census block group level. With the exception of the Methods and Results sections, where we refer to covariates, we use the term "Black" interchangeably with the "Black or African American" census category,

"Indigenous" interchangeably with the "American Indian or Alaska Native" category, and "Latinx" interchangeably with the "Hispanic or Latino" category. We used 2020 ethnoracial estimates provided by SimplyAnalytics (New York, NY), a demographic analytics company. These 2020 estimates are generated using a combination of US Census Bureau data, including from the 2015 through 2019 5-year American Community Survey, the 2019 Public Use Microdata Sample, and the 2010 Decennial Census.

We used the percentage of a census block group that is non-Hispanic Black or African American, Hispanic or Latino, or non-Hispanic American Indian or Alaska Native to measure ethnoracial separation, as it is a critical component of segregation.⁸ Because segregation is structural and distinct from willful separation, these proportions capture the results of decades of racist policies and structures.¹⁷ Racial and ethnic separation serves as a marker of racially driven spatial discrimination and captures the impact of structural racism, as manifested by segregation. These particular ethnoracial groups were selected because of the COVID-19 inequities already demonstrated in the literature.^{1,10} The census block group is the smallest geographic unit for which the US Census Bureau publishes data on race and ethnicity. It is an administrative unit that is more detailed than a census tract and, therefore, more closely approximates neighborhood demographic dynamics than do aggregated tract-, county-, or state-level estimates.

Cartography

We performed geospatial analysis of the distribution of COVID-19 testing sites in Chicago, New York City, Houston, and Los Angeles. Because the dissimilarity index allows comparison of only 2 racial or ethnic groups at once, we chose Black-White separation. This dichotomy represents the most extreme segregation patterns in the United States.¹¹ We geocoded testing site addresses using a Google geocoding application programming interface (API) to arrive at latitude and longitude coordinates. We then generated corresponding census block group spatial identification numbers for testing site coordinates using a Census.gov geolocator API. Finally, we mapped the percentage of the city population that is non-Hispanic Black or African American and the percentage of the population that is non-Hispanic White using dot densities. We generated our maps in ArcGIS Pro version 2.6 (Esri, West Redlands, CA).

Statistical Model and Analysis

We performed a population-adjusted hierarchical Bayesian Poisson regression analysis using the `S.CAR` function in the `CARBayes` package.¹⁸ This model accounts for spatial correlation that may be present in the outcome by including block group-specific random effects that are correlated based on the geography of a city. Because we used the Leroux version of the conditional autoregressive model,¹⁹ random effects from neighboring block groups (i.e., those with a shared border) were more similar a priori. We allowed the data to determine the appropriate amount of spatial correlation and variability in the data by specifying weakly informative previous distributions on the model parameters. We included all ethnoracial groups in the same model but created separate models for each city. We tested zero-inflated Poisson models, but they were outperformed by our chosen model (see the supplemental tables for additional model fit details [available as a supplement to the online version of this article at <http://www.ajph.org>]).

Our model adjusted for population size using an offset term in the Poisson regression. We also performed a sensitivity analysis using population density as a covariate and present those results in the supplementary tables. Because income and race are along the causal pathway of racism, we did not adjust for employment, income, or other socioeconomic measures as covariates.²⁰ We made this choice to avoid adjusting away the economic or employment dimensions of structural racism and thereby underreporting the effect of racism on health care access.^{21,22} Because structural racism is an organizing system of oppression, structural racism includes the impact of income inequality, employment inequity, microaggressions, and internalized racism on racial minorities.⁴ Our use of racial covariates as proxies for structural racism, then, includes the impact of these and other unobservable mediators of structural racism on racial minorities. Our inclusion of race and ethnicity covariates does not presume there is an innate quality of the selected groups that can be separated or isolated from the economic, educational, and political context in which these groups live.²³ We report relative risks or incidence rate ratios, posterior SDs,

and 95% quantile-based credible intervals. We performed our analysis in R version 3.6.1 (R Foundation for Statistical Computing, Vienna, Austria).

RESULTS

Chicago has a dissimilarity index of 82.50 and is the most racially segregated city in the United States by this measure (Table 1). Chicago is also the third most populous city in the United States. There were 30 testing sites in Chicago as of June 2020 (Figure 1). With every percentage point increase in the proportion of the block group population that was non-Hispanic Black or African American, there was a 3.05% population-adjusted reduction in the expected number of testing sites in that block group (Table 2). With every percentage point increase in the proportion of the block group that was Hispanic or Latino, there was a 5.64% population-adjusted reduction in the expected number of testing sites in that block group. Results for the percentage of the block group that was non-Hispanic American Indian or Alaska Native were not significant in Chicago.

New York City has a dissimilarity index of 81.40 and is the second most racially segregated city in the United States by this measure (Table 1). New York is also the most populous city in the United States. There were 166 testing sites in New York City as of June 2020 (Figure 1). With every percentage point increase in the proportion of the block group population that was non-Hispanic Black or African American, there was a 1.29% population-adjusted reduction in the expected number of testing sites in that block group (Table 2). Results for the percentage of the block group that was either Hispanic or Latino or non-Hispanic American Indian or Alaska Native were not significant in New York.

Houston has a dissimilarity index of 68.60 and is the 14th most segregated city in the United States by this measure (Table 1). Houston is also the fourth most populous city in the United States. There were 80 testing sites in Houston as of June 2020 (Figure 1). With every percentage point increase in the proportion of the block group population that was non-Hispanic Black or African American, there was a 1.06% population-adjusted reduction in the expected number of testing sites in that block group (Table 2). With every percentage point increase in the proportion of the block group population that was Hispanic or Latino, there was a 1.95% population-adjusted decrease in the expected number of testing sites in that block group. Results for the percentage of the block group that was non-Hispanic American Indian or Alaska Native were not significant in Houston.

Los Angeles has a dissimilarity index of 66.90 and is the 18th most segregated city in the United States by this measure (Table 1). Los Angeles is also the second most populous city in the United States. There were 68 testing sites in Los Angeles as of June 2020 (Figure 1). With every percentage point increase in the proportion of the block group population that was Hispanic or Latino, there was a 1.69% population-adjusted decrease in the expected number of testing sites in that block group. Results for the percentage of the block group that was either non-Hispanic Black or African American or non-Hispanic American Indian or Alaska Native were not significant in Los Angeles.

DISCUSSION

By quantifying the association between the number of COVID-19 testing sites and the proportion of the population that is Black, Latinx, and Indigenous at the census block group level, we revealed the impact of historical and contemporary patterns of racial segregation on the public health response to the COVID-19 pandemic. Our primary findings are that even after adjusting for population, the expected number of testing sites decreases between 1.06% and 3.05% for each percentage point increase in the proportion of a census block group that is Black and between 1.69 and 5.64 for each percentage point increase in the proportion of a census block group that is Latinx. We demonstrate that the patterns of racial segregation that preceded the pandemic influenced the public health infrastructure established to address COVID-19 in the most populous US cities. Our study extends previous work by demonstrating racial and ethnic inequity at the neighborhood level, where residential segregation dynamics are manifest.⁸ Our suggestion of segregation as the specific instance of structural racism that underlies the demonstrated disparity uniquely contributes to the literature. Furthermore, our identification of the particular minority communities affected lends specificity to the literature in this area. Finally, this study is novel in accounting for spatial correlation in our statistical model.

There is a wealth of literature that elucidates how racial discrimination and geography lead to inequity in health and other social outcomes.²⁴ Redlining, for example, is a historical example of segregation with persistent health implications.¹⁷ Redlining occurred in cities across the United States, including Chicago, New York, Los Angeles, and Houston. This historical policy continues to have implications for contemporary public health in these cities. A 2019 Urban Institute study showed that contemporary access to capital in Chicago is directed more toward White neighborhoods than toward Black neighborhoods by a factor of 3 to 1. This disparate rate of investment already reflects adjustments made for mission-driven economic development initiatives that specifically target poor and minority communities for special investment.²⁵ Lack of commercial investment in marginalized communities has implications for health equity.

The early federal response to the pandemic was to establish testing centers via public-private partnership between the federal government, commercial pharmacies, and other businesses in addition to health centers. However, any partnership based on the preexisting distribution of businesses risks underserving BIPOC owing to historical and contemporary practices of investment on the basis of race and geography. For example, a community with fewer commercial pharmacies may not adequately benefit from a federal response predicated on partnerships with local businesses. The public health response to COVID-19 was superimposed on racist policy and structures. Thus, a race-blind approach to testing, coupled with preexisting health inequity, rendered BIPOC particularly vulnerable. Spatial discrimination and the way that structural racism mediates the differential geographic distribution of health system resources are critical to understanding the impact of structural racism on the response to the pandemic. Monica Bell's theory of segregation helps us recognize how segregation creates and reinforces racial inequities during the pandemic.⁸ The systematic separation of racial groups that long predated the pandemic has led to the concentration of ethnoracial minorities. The concentration of comorbidities that complicate COVID-19 in minority communities is a key example of a neighborhood effect. Concentration establishes and reproduces hegemonic racial hierarchy, which results in subordination. Subordination articulates the subjective dimensions of segregation for marginalized people. An example of subordination is the former US surgeon general's degrading call to Black "big mamas" and Latina "abuelas" to change their individual behaviors while ignoring the structural factors shaping increased COVID-19 risk in these communities. The stigmatizing experience of subordination facilitates the social control and economic exploitation of disadvantaged groups by White people, who then hoard political opportunity and power (domination).

Our results demonstrate domination in action: the sequestration of testing resources in White communities even as minority communities suffered so disproportionately.

The juxtaposition of disproportionately increased risk and disproportionately limited access to testing resources is not incidental. For example, in Chicago, more than 70% of early COVID-19 deaths were among Black people.²⁶ Latinx neighborhoods in the city were also among the hardest hit across Illinois.²⁶ This disease burden among BIPOC in Chicago was the combined result of preexisting health inequity as well as new challenges that arose during the pandemic. For both cultural reasons and economic inequality, 26% of Black Americans and 27% of Latinxs live in multigenerational households, compared with 16% of White Americans.²⁷ Additionally, because of employment inequity, BIPOC are more likely to have employment that does not accommodate remote work.^{5,28} These longstanding factors prevent hidden frontline and essential workers and their household members from social distancing. Furthermore, the incidence of homelessness and state detention are also increased in Black, Indigenous, and Latinx populations: research has demonstrated high rates of COVID19 in prisons and immigration detention centers.^{29,30} Residence and community in crowded, congregated settings confers an increased risk of respiratory disease and results in disease distribution along clear racial fault lines. Finally, the exclusion of undocumented immigrants and migrants, who are often Black and Latinx, from safety net health care protections renders them especially vulnerable to COVID-19.^{6,31}

Because of this, social determinants of health as articulated in Public Health 3.0 may not go far enough for Black, Latinx, and Indigenous communities. The present moment necessitates a shift to an appreciation of the "social-structural" determinants of health: Public Health 3.0x. The study of social determinants of health might suggest

individual or behavioral solutions to racial health inequity. A perspective that considers social determinants of health alone locates the burden of overcoming health inequity in supposedly "hard-to-reach" communities. However, investing in a shared language of structure accounts for histories and contemporary realities of oppression such as residential segregation. A shift to consideration of the "social-structural determinants of health" locates the burden of ameliorating health inequity in the health system rather than in minoritized individuals and communities. Race is not merely a unique social characteristic of communities that is associated with disease. Rather, the structural oppression faced by racially marginalized groups manifests as a shared experience of increased health vulnerability. A structural perspective suggests institutional solutions.

Limitations

Our study has several limitations. First, we focused on only the most populous racially segregated US cities. Second, the history of settler colonialism in the United States suggests that there may be associations between Indigenous populations and locations of COVID-19 testing sites similar to what we observed for Black and Latinx communities in our model; however, the relatively small proportion of the population comprising Indigenous peoples in the areas studied limited our ability to assess this effect. Results for the Indigenous population in New York and Houston were not significant, but they do suggest a possible inverse association between the location of testing centers and areas where Indigenous people live. The continued existence of reservations is a glaring example of the legacy of efforts to segregate the Indigenous population in the United States.³²

Third, we focused only on locations of testing sites, but the manner in which location relates to access may not be straightforward. For example, some sites may be located in overpoliced areas or otherwise unsafe locations, have inconvenient hours, or not be easily accessible to persons with a disability. Additionally, cross-jurisdictional travel to access testing is a possible attenuating factor. Consequently, our analysis does not directly show that such disparities in location necessarily lead to decreased testing access, but this effect is plausible and deserves further study. One illustration of this limitation is our inability to capture how the protests for racial justice in the summer of 2020 may have affected access to testing sites. Additionally, many academic centers, in particular, exist in proximity to minority communities that still face access issues despite proximity.³³

Lastly, numerical indices are a useful proxy for segregation by measuring separation. However, they are limited in that they do not necessarily capture the other dimensions of segregation (e.g., concentration, subordination, and domination). A strength of our approach is our articulation of proposed mechanisms for these other dimensions of segregation in the Discussion section.

Public Health Implications

We reveal the unique vulnerability of Black, Indigenous, and Latinx communities in the early response to COVID-19 and identify potential avenues to mitigate this vulnerability. In doing so, our work directly contributes to conversations about the ethics of a race-conscious approach to delivering the COVID-19 vaccine and distributing other health care resources.³⁴ Our data show that the largely race-blind patchwork testing strategy that did not explicitly account for race led to inequities in testing center placement. Thus, it is important to explicitly consider race in vaccine distribution. This is especially true considering how disproportionately BIPOC have been affected by COVID-19. Our work may also illuminate paths to meaningfully partnering with BIPOC communities in vaccine delivery and other public health efforts. We should consider nontraditional vaccine dispensation sites in neighborhoods that are primarily Black, Indigenous, or Latinx, including mobile units, barbershops, churches, and community centers.³⁵ However, vaccine prioritization on the basis of race absent genuine and long-term community partnership is unlikely to be successful. Local health departments may consider ways to cocreate an environment that is conducive to equitable and ethical BIPOC coleadership in COVID-19 control efforts and public health efforts beyond the pandemic. This might include the involvement of community partners in priority setting and the remuneration of local experts for their involvement in community-engaged programming. When we locate the challenge in the health care system rather than burdening members of vulnerable communities with bridging the participation gap based on individual behavioral factors, we make strides against the pandemic and toward health justice, fulfilling the promise of Public Health 3.0. ÂfPU

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CONTRIBUTORS

E. N. Asabor lead the conceptualization of the study, conducted the analysis, and drafted the article. J. L. Warren supervised the statistical analysis and critically revised the article. T. Cohen conceptualized the study and provided overall project supervision. All authors interpreted the results of the analysis.

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CONFLICTS OF INTEREST

Although unrelated to the current project, J. L. Warren discloses consulting fees from Revelar Inc. The authors otherwise have no conflicts of interest.

HUMAN PARTICIPANT PROTECTION

No protocol approval was necessary because no human participants were involved in this study and the data used were aggregated and are readily available to the public.

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DETAILS

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COVID-19-Related Discrimination Among Racial/Ethnic Minorities and Other Marginalized Communities in the United States

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[ProQuest document link](https://www.proquest.com/scholarly-journals/racial-ethnic-segregation-access-covid-19-testing/docview/2638090236/se-2?accountid=211160)

ABSTRACT (ENGLISH)

Objectives. To determine the prevalence of COVID-19-related discrimination among major US racial/ethnic groups and estimate associations between discrimination, race/ethnicity, and other sociodemographic characteristics.

Methods. We conducted a nationally representative online survey of 5500 American Indian/Alaska Native, Asian, Black/African American, Hawaiian/Pacific Islander, Latino (English and Spanish speaking), White, and multiracial adults from December 2020 to February 2021. Associations between sociodemographic characteristics and COVID-19-related discrimination were estimated via multinomial logistic regression.

Results. A total of 22.1% of the participants reported experiencing discriminatory behaviors, and 42.7% reported that people acted afraid of them. All racial/ethnic minorities were more likely than White adults to experience COVID-19-related discrimination, with Asian and American Indian/Alaska Native adults being most likely to experience such discrimination (discriminatory behaviors: adjusted odd ratio [AOR] 5 2.59; 95% confidence interval [CI] = 1.73, 3.89; and AOR = 2.67; 95% CI = 1.76, 4.04; people acting afraid: AOR = 1.54; 95% CI = 1.15, 2.07; and AOR = 1.84; 95% CI = 1.34, 2.51). Limited English proficiency, lower education, lower income, and residing in a big city or the East South Central census division also increased the prevalence of discrimination.

Conclusions. COVID-19-related discrimination is common, and it appears that the pandemic has exacerbated preexisting resentment against racial/ethnic minorities and marginalized communities. Efforts are needed to minimize and discredit racially driven language and discrimination around COVID-19 and future epidemics.

FULL TEXT

Headnote

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Conclusions. COVID-19-related discrimination is common, and it appears that the pandemic has exacerbated preexisting resentment against racial/ethnic minorities and marginalized communities. Efforts are needed to minimize and discredit racially driven language and discrimination around COVID-19 and future epidemics. (AmJ Public Health. 2022;112(3):453-466. <https://doi.org/10.2105/AJPH.2021.306594>)

Historically, infectious disease outbreaks have often been accompanied by discrimination, stigma, and xenophobia.^{1,2} How these diseases are named and discussed can have a major impact on subsequent discrimination. Because of this, both the World Health Organization and the Centers for Disease Control and Prevention have guidelines that recommend against attaching locations or ethnicity to a disease to minimize backlash against members (and perceived members) of the identified community.^{3,4} Despite these recommendations, some public officials in the United States repeatedly referred to COVID-19 as the "Chinese virus" or "Wuhan virus" instead of COVID-19,^{3,5} and reports of racist and xenophobic incidents directed toward those perceived to be Chinese or of Asian descent have increased.⁶⁻⁹ Because of the broad scope of systemic racism in the United States, we hypothesized that attributing blame for the pandemic could also extend to other minority and marginalized communities.

To date, 4 studies to our knowledge have attempted to measure the prevalence of COVID-19-related discrimination

in the United States. However, 2 focused on Asians only^{10,11}; 1 was restricted to Asian, Black, Latino, and White individuals¹²; and 1 combined several racial/ethnic minority groups into a single category ("other race").¹³ Thus, discrimination among other racial/ethnic minority groups (e.g., American Indian/Alaska Native) has yet to be assessed, and a comparison of all groups in one study is needed. Also, although other sociodemographic characteristics, such as age, household income, and immigration status, have been linked to a higher prevalence of discrimination,¹³ additional research is needed.

Thus, the goals of this study were to (1) estimate the prevalence of COVID-19-related discrimination among all major US racial/ethnic groups (as defined by the US Bureau of the Census), (2) estimate the association between COVID-19-related discrimination and race/ethnicity after adjusting for sociodemographic characteristics, and (3) identify other sociodemographic characteristics associated with COVID-19-related discrimination among a nationally representative and diverse sample of US adults.

METHODS

The COVID-19's Unequal Racial Burden (CURB) survey was administered by YouGov, a consumer research firm based in Palo Alto, California, that uses a proprietary, opt-in survey panel composed of more than 1.8 million US residents to conduct nationally representative online surveys. Panel members are recruited through a variety of methods to ensure diversity, including Web advertising, permission-based e-mail campaigns, partner-sponsored solicitations, telephone-to-Web recruitment, and mail-to-Web recruitment. Participants receive incentives through a loyalty program to complete individual surveys.

To obtain nationally representative estimates, YouGov randomly matches eligible panel members with matching demographic characteristics (matched sample) to a theoretical cohort (target sample) identified by sampling nationally representative data. The target sample for the CURB study was drawn from the 2018 American Community Survey 1-year sample and included 1000 Asian, 1000 Black/African American, 1000 Latino (including 500 Spanish-speaking), 1000 White, 500 American Indian/Alaska Native, 500 Hawaiian/Pacific Islander, and 500 multiracial adults 18 years or older (overall $n = 5500$). A proximity matching method was then used to match YouGov panel members (matched sample) to the target sample according to race/ethnicity, gender, age, education, and language preference (Latino sample only). YouGov invited matched panel members to participate via e-mail until sample quotas were met for each racial/ethnic group. Online surveys were completed between December 8, 2020, and February 17, 2021.

After survey completion, survey weights were calculated. Briefly, within each racial/ethnic group, the matched sample and American Community Survey 1-year data were combined and multivariable logistic regression adjusting for age, gender, education, and region was used to estimate probability for inclusion in the study. Probabilities were then grouped into deciles and poststratified on gender, age, education, and region to produce a final weight for each participant. Ultimately, this combination of matching and weighting allowed for the generation of national estimates.^{14,15} Weights generating nationally representative populations within each racial/ethnic group were used in this analysis (e.g., Asian participants represented all Asian adults in the United States). YouGov has been used previously to conduct nationally representative survey-based research.¹⁶⁻¹⁸

The CURB survey was designed to assess the social, behavioral, and economic effects of the COVID-19 pandemic among diverse populations, including experiences of discrimination. The survey was created in English, translated into Spanish by an American Translators Association certified translator, and finalized by 4 bilingual/bicultural researchers via team reconciliation¹⁹ and decentering methods.²⁰

Dependent Variable

Four items assessed experiences of COVID-19-related discrimination. Three were adapted from the Everyday Discrimination Scale: (1) people acting afraid of you, (2) being called names or insulted, and (3) being threatened or harassed.²¹ On the basis of news reports that people of Chinese descent were hearing racist comments from people thinking they were the cause of COVID-19, we created a new item that asked participants how often they heard racist comments because people thought they belonged to a group that contracts COVID-19 more often. For all 4 items, we asked how often participants had experienced the specific type of discrimination (e.g., people acting

afraid of you) "because they think you might have COVID-19" using a 4-level response scale (1 = never, 2 = rarely, 3 = sometimes, 4 = always). Complete data for all 4 items were available for 5494 participants (more than 99%). According to a multitrait scaling analysis,²² the people acting afraid of you item was not highly correlated with the other 3 items ($r = 0.49$). Thus, we developed 2 measures of COVID-19-related discrimination: a single-item measure (people acted afraid of you) and a 3-item scale (discriminatory behaviors). The discriminatory behaviors scale was scored as the mean of nonmissing values; the internal consistency reliability for the total sample was 0.88, with similar results in each racial/ethnic group. The continuous scale was then categorized according to the original response scale: never (score of 1), rarely (scores from above 1 to 2), sometimes (scores from above 2 to 3), and always (scores above 3). The people acted afraid of you measure ranged from 1 to 4 (original response scale). The 2 measures were then categorized into never, rarely, and sometimes/always; sometimes and always were combined into a single category owing to the small percentage of participants reporting "always" experiencing discrimination (4.2% and 1.7%, respectively). In sensitivity analyses, a composite "any" discrimination (sometimes/always or rarely) was also assessed. (For a full description of the survey questions and analysis metrics, see Table A, available as a supplement to the online version of this article at <http://www.ajph.org>.)

Independent Variables

All eligible panel members were asked "Which one of the following would you say best represents your race/ethnicity?" Response options were Latino/a/x or Hispanic, American Indian or Alaska Native, Asian, Black or African American, Pacific Islander, White, and multiracial. Among Asian participants, we included a question on national origin (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, or other Asian).

Self-reported sociodemographic characteristics included age (categorized as 18-34, 35-49, 50-64, 65 years or older), gender (male, female, transgender or nonbinary), immigration status (US-born citizen, foreign-born citizen or legal resident, undocumented), English speaking proficiency (limited vs not limited), highest education level (less than high school, high school, more than high school), employment status (employed vs not employed), family annual income (< \$20 000, \$20 000-\$59 999, \$60 000-\$99 999, \$100 000), census division, and urbanicity (big city, smaller city, suburban, small town, rural). Limited English proficiency was defined as being able to speak English "not at all," "poorly," or "fairly well." Amounts of missing data were minimal for all variables other than family annual income (659 [unweighted] participants selected "prefer not to say").

Statistical Analyses

Descriptive statistics were used to estimate the prevalence of COVID-19-related discrimination across racial/ethnic groups. Multinomial logistic regression was used to estimate the independent association between race/ethnicity, sociodemographic characteristics, and the prevalence (sometimes/always or rarely vs never) of discriminatory behaviors and people acting afraid of the participant. Models included race/ethnicity, age, gender, immigration status, limited English proficiency, educational attainment, employment status, family annual income, census division, and urbanicity.

We conducted a secondary analysis restricted to Asian respondents to assess whether demographic characteristics associated with COVID-19-related discrimination differed within Asian subpopulations. Multinomial logistic regression models included the same variables listed earlier, with national origin included instead of race/ethnicity. As a result of the large proportion of Asian participants with college degrees, education was recategorized as high school or less, some college/vocational degree, bachelor's degree, and postgraduate degree in this analysis. Census region was used instead of division to assess geographic differences.

As a sensitivity analysis, we used multivariable logistic regression to estimate the association between race/ethnicity and other social determinants and the odds of experiencing any discriminatory behaviors or people acting afraid (rarely/sometimes/always vs never).

We used SAS version 9.4 (SAS Inc, Cary, NC) for all of the analyses. All analyses were weighted to produce nationally representative estimates within each racial/ethnic group, and counts were rounded for interpretation.

RESULTS

There were 5804 online survey respondents (response rate: 20.0%) who were matched down to a sample of 5500 to

produce the final weighted data set. Demographic characteristics, stratified by race/ethnicity, are reported in Table B (available as a supplement to the online version of this article at <http://www.ajph.org>).

Prevalence and Frequency of Discrimination

Overall, 22.1% of participants reported experiencing discriminatory behaviors (sometimes/always: 12.4%; rarely: 9.7%), and 42.7% reported experiences of people acting afraid of them (sometimes/always: 22.6%; rarely: 20.1%). A full breakdown is included in Table C (available as a supplement to the online version of this article at <http://www.ajph.org>).

The prevalence of discriminatory behaviors was highest among Asian participants (sometimes/always: 12.6%; rarely: 17.4%; Figure 1 and Table D, available as a supplement to the online version of this article at <http://www.ajph.org>). More than one quarter of Latino (sometimes/always: 10.6%; rarely: 16.3%) and American Indian/ Alaska Native (sometimes/always: 16.8%; rarely: 9.4%) participants reported discriminatory behaviors, followed by Hawaiian/Pacific Islander (sometimes/always: 10.8%; rarely: 12.0%), Black/African American (sometimes/always: 9.1%; rarely: 11.4%), and multiracial (sometimes/always: 3.8%; rarely: 14.6%) adults; only 10% of White participants reported experiencing discriminatory behaviors (sometimes/always: 5.4%; rarely: 5.0%).

Similar trends were seen within the individual items in the discriminatory behaviors scale (Figure A, available as a supplement to the online version of this article at <http://www.ajph.org>). Reports of people acting afraid were common, with half of participants reporting that such discrimination occurred sometimes/always (Figure 1b). The prevalence of people acting afraid was highest among Hawaiian/Pacific Islander (sometimes/always: 27.7%; rarely: 21.2%), Latino (sometimes/always: 29.5%; rarely: 18.4%), and American Indian/Alaska Native (sometimes/always: 25.5%; rarely: 21.7%) adults, although the prevalence was similarly high among other racial/ethnic minority groups (Asian: sometimes/always: 22.5%; rarely: 21.5%; Black/African American: sometimes/always: 21.8%; rarely: 17.3%; multiracial: sometimes/always: 18.8%; rarely: 25.4%).

Race/Ethnicity and Discrimination

After adjustment, all racial/ethnic minority groups were substantially more likely to experience discriminatory behaviors (rarely vs none; adjusted odds ratios [AORs] 5 1.86-3.61), but only American Indian/Alaska Native and Asian participants were significantly more likely than White adults to report sometimes/always experiencing discriminatory behaviors (AOR = 2.67; 95% confidence interval [CI] = 1.76,4.04; and AOR = 2.59; 95% CI 5 1.73,3.89; Table 1).

Fewer racial/ethnic differences were seen across the people acted afraid of you item. Relative to White adults, only American Indian/Alaska Native (rarely: AOR 5 1.40; 95% CI = 1.03,1.91; times/always: AOR 5 95% CI 5 1.34, 2.51) and Hawaiian/Pacific Islander (rarely: AOR 5 1.42; 95% CI 5 1.02,1.97; sometimes/always: AOR 5 1.90; 95% CI 5 1.37, 2.64) adults were significantly more likely to report incidents in which people acted afraid of them across both frequency levels (Table 2). Asian adults appeared to also be more likely to report incidents of people acting afraid of them at both frequencies, but confidence intervals were wide (rarely: AOR 5 1.22; 95% CI 5 0.92,1.62; sometimes/always: OR 5 1.54; 95% CI 5 1.15, 2.07). Latino participants were more likely to report frequent (sometimes/always) incidents of people acting afraid of them (OR 5 1.45; 95% CI 5 1.08,1.96), and multiracial participants were more likely to report rare incidents of people acting afraid of them (AOR 5 1.44; 95% CI 5 1.07,1.95). No differences were seen between Black/African American and White adults.

Other Sociodemographic Characteristics

Among the sociodemographic variables, having limited English proficiency was most strongly associated with experiencing both discriminatory behaviors (rarely: AOR 5 2.14; 95% CI 5 1.59, 2.88; sometimes/always: AOR 5 4.06; 95% CI 5 3.02, 5.47) and people acting afraid (rarely: AOR 5 1.51; 95% CI 5 1.14, 1.99; sometimes/always: AOR 5 1.68; 95% CI 5 1.30,2.15; Tables 1 and 2). Being less than a high school graduate (relative to having more than a high school education) was also consistently associated with higher odds of experiencing discriminatory behaviors (rarely: AOR = 1.38; 95% CI = 1.01,1.89; sometimes/always: AOR = 1.77; 95% CI 5 1.26,2.49) and people acting afraid (rarely: AOR 5 1.37; 95% CI 5 1.03,1.83; sometimes/always: AOR 5 1.53; 95% CI 5 1.18,2.00). Lower annual income was associated with sometimes/always experiencing discriminatory behaviors (e.g., for <\$20

000 vs \$ \$100 000, discriminatory behaviors: AOR 5 2.02; 95% CI 5 1.35, 3.04; people acting afraid: AOR 5 1.98; 95% CI 5 1.50, 2.62). Adults living in the East South Central division (Alabama, Kentucky, Mississippi, and Tennessee) were most likely to experience discriminatory behaviors (rarely: AOR 5 1.99; 95% CI 5 1.28, 3.07; sometimes/always: AOR 5 2.43; 95% CI 5 1.50, 3.92) and sometimes/always experience people acting afraid of them (AOR 5 1.58; 95% CI 5 1.10, 2.26); minimal differences were seen across other census divisions.

Younger age (18-34 years), being male or transgender/nonbinary, and living in a city or rural area also appeared to be associated with higher odds of experiencing COVID-19-related discrimination (discriminatory behaviors or people acting afraid). Similar trends were seen when discrimination was modeled as any versus never (Table E, available as a supplement to the online version of this article at <http://www.ajph.org>).

Discrimination Against Asian Adults

When we restricted our analysis to Asian participants, Vietnamese adults reported higher levels of COVID19-related discrimination and Japanese adults reported the lowest levels (Figures B and C, available as supplements to the online version of this article at <http://www.ajph.org>). However, no substantial differences in COVID-19-related discrimination by national origin were seen either before or after adjustment, but confidence intervals were wide (Table 3).

Among Asians, limited English proficiency was strongly and consistently associated with experiencing discriminatory behaviors (rarely: AOR 5 2.04; 95% CI 5 1.09, 3.83; sometimes/always: AOR 5 2.60; 95% CI 5 1.40, 4.83) and people acting afraid (rarely: AOR 5 2.46; 95% CI 5 1.38, 4.39; sometimes/always: AOR 5 1.25; 95% CI 5 0.70, 2.24). Lower household income was also associated with experiencing discrimination sometimes/always (Table 3). Being employed and living in the South were associated with sometimes/always experiencing people acting afraid (AOR 5 1.54; 95% CI 5 1.03, 2.32; and AOR 5 2.05; 95% CI 5 1.30, 3.24, respectively). No differences in discrimination were seen across gender, educational level, or urbanicity.

DISCUSSION

In a nationally representative online survey conducted from December 2020 to February 2021 that included adults from the 6 major US racial/ethnic minority groups (as defined by the US Census Bureau) and White adults, we found that all racial/ethnic minorities experienced higher levels of COVID-19-related discrimination than White adults, with American Indian/Alaska Native, Asian, Hawaiian/Pacific Islander, and Latino adults having the highest prevalence. Despite news and social media reports on targeting of Chinese individuals, similar COVID-19-related discrimination trends were seen across all Asian adults regardless of national origin.

In comparison with White adults, all racial/ethnic minorities were more likely to report that people acted afraid of them because of suspected COVID-19 infection. Having limited English proficiency, less than a high school education, an annual income below \$60 000, and living in a big city, rural community, or Alabama, Kentucky, Mississippi, or Tennessee were also associated with experiencing increased discrimination. To the best of our knowledge, this is the largest, most racially diverse, and most recent assessment of COVID-19-related discrimination in the United States.

We found that experiencing COVID-19-related discrimination was common among Asian adults (discriminatory behaviors: 30%; people acting afraid: 44%) and that half of those experiencing discrimination reported that the discrimination occurred sometimes or always. These rates are substantially higher than estimates obtained earlier in the pandemic, suggesting that COVID-19-related discrimination has not improved overtime. In surveys conducted in March and April 2020, the prevalence of COVID-19-related discrimination was 18% and 22%, respectively, among Asian adults.¹³ Also, Liu et al. found that those who reported COVID-19-related discrimination in March were more likely to report such discrimination in April, supporting our finding that discrimination occurs repeatedly.¹³ In May and June 2020,¹³ of Bhutanese and Burmese refugees reported being threatened or harassed, and 28% reported feeling that others were afraid of them owing to COVID-19.¹¹ In a survey conducted from March to May 2020, Cheah et al. found that 50% of adults reported at least one incident of in-person COVID-19-related discrimination, but they adapted the Racial and Ethnic Microaggressions Scale, which includes less severe forms of discrimination (e.g., "people were unfriendly or unwelcoming").¹⁰ It has also been estimated that 42% of adults living

in the United States are extremely likely to engage in anti-Asian behaviors during the pandemic,²³ and more than 2800 incidences of anti-Asian hate were reported in 2020 alone.⁷ These estimates of the prevalence and frequency of COVID-19-related discrimination targeted at Asian individuals, including our own, represent a call for action. The prevalence of discriminatory behaviors was higher among all racial/ethnic minorities than among White adults, and most (American Indian/Alaska Native, Asian, Hawaiian/Pacific Islander, multiracial) were also more likely to report that people acted afraid of them. To the best of our knowledge, we are the first to report this substantial level of COVID-19-related discrimination toward American Indian/Alaska Native adults. In fact, American Indian/Alaska Native adults were just as likely to face frequent (sometimes/always) discriminatory behaviors as Asian adults (OR = 2.67 vs OR = 2.59) and were potentially more likely to report that people acted afraid of them (OR = 1.84 vs OR = 1.54). Hawaiian/Pacific Islanders were also at higher risk of reporting frequent incidents of people acting afraid of them (OR = 1.90).

Given these findings, it appears that the COVID-19 pandemic has exacerbated preexisting resentment against racial/ethnic minority groups in the United States. Future studies and public health efforts focused on COVID-19-related discrimination should explicitly include all major racial/ethnic groups, as most appear to be at equally high risk as Asian adults but have thus far been largely ignored in antidiscrimination efforts.

Both overall and among Asian participants, we found that limited English proficiency, lower household income, and lower education were the strongest predictors of reporting sometimes/always experiencing discriminatory behaviors and people acting afraid, even after adjustment for race/ethnicity. Liu et al. also assessed other predictors of discrimination during COVID-19.¹³ Although they did not include English proficiency as a predictor, they did find that immigrants (first or second generation vs nonimmigrant) were more likely to experience discrimination, as were those with lower household incomes. Interestingly, both our study and the Liu et al.¹³ investigation showed that older adults were less likely to experience COVID-19-related discrimination. Given the recent reporting of violence targeting older Asian adults,⁷ additional research is needed to assess whether older adults are truly less likely to experience COVID-19-related discrimination or they are less likely to report it.

Public health and media messaging must aim to reduce racism and xenophobia during COVID-19 and future pandemics. One recent study showed that COVID-19 messaging that focused on China or Chinese cultural practices as the origin of the pandemic (i.e., food markets) led to high levels of xenophobia and anti-Chinese sentiments, whereas information that did not mention China did not increase these negative beliefs.²⁴ In a recent analysis of Twitter data, half of the tweets that referred to COVID-19 as the "Chinese virus" had anti-Asian sentiments; moreover, anti-Asian sentiments associated with COVID-19 on Twitter increased by more than 700% after the first "Chinese virus" reference by former president Donald J. Trump in March 2020.³ A similar increase in implicit bias toward Asian Americans was seen in the United States after the first "Chinese virus" reference by the former president.²⁵ These findings provide further evidence that the language used by individuals in positions of influence (online and offline) can have a substantial impact on racism and xenophobia during public health emergencies.²⁶

Limitations

This study involved some limitations. First, the survey was administered online, and individuals with limited Internet access or familiarity with technology were less likely to be included. Although we did match and weight participants to obtain a nationally representative sample, it is possible that some selection bias existed. In our analysis, we found that both lower income levels and lower educational levels were associated with higher rates of discrimination, suggesting that we may be underestimating the burden of COVID-19-related discrimination in the United States. Second, the survey was administered only in English and Spanish (Latino participants only), and thus non-Latino individuals with limited English reading proficiency were more likely to be excluded. Limited English proficiency was the strongest predictor in our analysis, again suggesting that we may be underestimating the burden of COVID-19-related discrimination.

Third, although our survey was designed to be representative of the major US racial/ethnic groups, stratified results for Asians by national origin may not be representative, and sample sizes were small in some groups. Finally,

discrimination measures were based on individuals' perceptions of the motivation behind others' behaviors, and we did not ask about the perpetrators of discriminatory behaviors. Ethnographic approaches would enable a more nuanced understanding of these encounters. The extent to which our findings reflect actual discriminatory acts based on systemic racism, awareness or misperceptions of higher COVID-19 infection risks among certain racial/ethnic groups, a desire to protect oneself, and other factors needs to be investigated.

Public Health Implications

To our knowledge, this is the largest and most diverse survey on COVID-19-related discrimination in the United States to date, and it provides a critical update. Overall, in this nationally representative survey of US adults, we found that COVID-19-related discrimination was more prevalent than indicated in prior estimates and that all racial/ethnic minorities are at risk, with American Indian/Alaska Native, Asian, and Hawaiian/Pacific Islander adults experiencing the most discrimination. Limited English proficiency, lower education, and lower income were also significant predictors of discrimination. It appears that the COVID-19 pandemic has exacerbated preexisting resentment against racial/ethnic minorities, immigrants, and other marginalized communities. Moving forward, better efforts will be needed, especially from public officials, to minimize racially driven language around COVID-19 and future pandemics to stop targeted discrimination and xenophobia.

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CONTRIBUTORS

P. D. Strassle, A. L. Stewart, and A. M. Napoles designed the study. P. D. Strassle analyzed the data and wrote the first draft. All of the authors critically reviewed the article.

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

HUMAN PARTICIPANT PROTECTION

The institutional review board of the National Institutes of Health determined that this study did not qualify as human subjects research because data were deidentified.

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DETAILS

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Exposure to Inclusive Language and Well-Being atWork Among Transgender Employees in Australia, 2020

Perales, Francisco, PhD; Ablaza, Christine, PhD; Elkin, Nicki, MBA

[ProQuest document link](#)

ABSTRACT (ENGLISH)

Objectives. To provide empirical evidence of the positive effects of exposure to inclusive language on trans employees' well-being. **Methods.** We leveraged unique data from a large Australian national survey of workplace diversity and inclusion (2020 Australian Workplace Equality Index Employee Survey), focusing on a subset of trans respondents (n = 453). We derived self-reported and aggregate-level measures of exposure to transinclusive language and created a multidimensional index of employee well-being. We examined their relationships using fully adjusted random-intercept multilevel regression models. **Results.** We found strong, positive, and statistically

significant associations between different indicators of exposure to inclusive language at work and trans employees' well-being. These relationships were large in magnitude and emerged in the presence of an encompassing set of sociodemographic and workplace controls, including other markers of workplace diversity and inclusion (e.g., victimization experiences and identity disclosure). **Conclusions.** Our results provide robust evidence indicating that efforts to foster inclusive language at work can yield substantial, positive effects on trans people's feelings of belonging and inclusion, thereby contributing to their overall socioeconomic integration.

FULL TEXT

Headnote

Objectives. To provide empirical evidence of the positive effects of exposure to inclusive language on trans employees' well-being.

Methods. We leveraged unique data from a large Australian national survey of workplace diversity and inclusion (2020 Australian Workplace Equality Index Employee Survey), focusing on a subset of trans respondents ($n = 453$). We derived self-reported and aggregate-level measures of exposure to transinclusive language and created a multidimensional index of employee well-being. We examined their relationships using fully adjusted random-intercept multilevel regression models.

Results. We found strong, positive, and statistically significant associations between different indicators of exposure to inclusive language at work and trans employees' well-being. These relationships were large in magnitude and emerged in the presence of an encompassing set of sociodemographic and workplace controls, including other markers of workplace diversity and inclusion (e.g., victimization experiences and identity disclosure).

Conclusions. Our results provide robust evidence indicating that efforts to foster inclusive language at work can yield substantial, positive effects on trans people's feelings of belonging and inclusion, thereby contributing to their overall socioeconomic integration. (Am J Public Health. 2022;112(3):482-490. <https://doi.org/10.2105/AJPH.2021.306602>)

A wealth of research has documented that trans people- encompassing binary transgender men and women, nonbinary people, and agender people-are at comparatively greater risk of poverty and social exclusion, homelessness, and family estrangement^{1,2} and have a greater likelihood of developing mental health problems and disorders.^{3,4} The profound and multidimensional disadvantage experienced by trans people has been traced to the unique stressors facing this group, including stigma and discrimination stemming from deep-rooted heteroand cis-normative social structures, environments, and day-to-day practices.⁵⁻⁸

These stressors extend also to the domain of work, from which trans people are routinely excluded.⁹ For instance, the odds of unemployment are 3.2 times greater among trans individuals than cisgender individuals in the United States,¹⁰ and 43% of trans people in Germany reported experiences of work-related discrimination in a 2-year period.¹¹ In addition, studies have documented multiple barriers to career progression among trans people, discrimination in recruitment and promotion, high turnover, workplace bullying and ostracism, and low job satisfaction.¹²⁻¹⁴ The precarious situation of trans employees has fueled recent academic interest in the factors that contribute to better and worse work-related experiences among this group. One important factor, and the focus of this study, is exposure to inclusive language practices.

Language is a powerful vehicle not only for individuals to express their gender but also to validate or invalidate other people's genders. Gendered language is particularly salient to trans individuals' sense of self, given the discordance between their assigned and correct genders.¹⁵ As they affirm their gender, many trans people change their first names or choose to be referred to with personal pronouns that differ from those corresponding to their sex assigned at birth.¹⁶ For example, a trans woman may begin using feminine (i.e., she/her) or gender-neutral (e.g., they/them/their) pronouns.

Misgendering and mispronouncing are 2 important types of language-related microaggressions faced by trans individuals within the workplace and elsewhere. Misgendering occurs when people use gendered language that does not match how a trans person identifies (e.g., describing a trans man as a woman), whereas mispronouncing occurs when people use incorrect personal pronouns to refer to a trans person (e.g., using he/his/him pronouns to

refer to a binary trans woman).^{17,18} Research indicates that both misgendering and mispronouncing are relatively common, particularly within the workplace.^{1,17,19}

A small but growing body of research has pointed to the importance of exposure to inclusive language-across social settings and at different points over the life course-for the well-being of trans people. This research has proposed that misgendering and mispronouncing foster feelings of disrespect, invalidation, dismissiveness, alienation, and dysphoria among these individuals.²⁰ Some pioneering studies have begun to provide associated empirical evidence through the use of adolescent samples.^{21,22} For example, in their investigation of a US sample of 129 trans adolescents, Russell et al.²² found that depressive symptoms and suicidal behaviors decreased when these adolescents were allowed to use their chosen name in a greater number of settings (e.g., at home and at school). Studies focusing on trans adults are relatively scarce. Most rely on qualitative methodologies,²³⁻²⁵ precluding examination of generalizable patterns. A notable exception is McLemore's analysis of a US sample of transgender adults, which showed that frequency of misgendering was positively associated with psychological distress.^{26,27} In the workplace, more specifically, Huffman et al. analyzed survey data from a sample of 263 gender-diverse individuals in the United States.²⁰ Their findings indicated that coworkers' use of correct pronouns and titles contributed to trans employees' perceptions of workplace support, and this in turn increased their job and life satisfaction. Although these studies collectively suggest a link between inclusive language and well-being, the degree to which exposure to trans-inclusive language affects the well-being of trans employees remains an open question.

To date, investigating these relationships empirically has been challenging owing to a scarcity of suitable data. Trans people are a small population group,²⁸ and their numbers in population studies are usually insufficient for separate analysis. Furthermore, existing surveys often lack key information to identify trans respondents (e.g., sex assigned at birth and gender identity). In addition, few data sets collect information on both employees' use of trans-inclusive language and workplace well-being. This study overcomes these issues by leveraging unique data from an Australian survey on diversity and inclusion within the workplace: the Australian Workplace Equality Index (AWEI) Employee Survey. These data offer a rare opportunity to empirically examine how exposure to trans-inclusive language is associated with trans employees' well-being. On the basis of the reviewed theoretical and empirical literature, we expected to observe strong, positive associations between these 2 constructs.

METHODS

Data for the AWEI Employee Survey are collected by Pride in Diversity, a program that is part of ACON Health, Australia's largest not-for-profit lesbian, gay, bisexual, trans, and queer (LGBTQ) community health organization. The aim of this annual, repeated cross-sectional survey is to document the impact of LGBTQ inclusion initiatives on organizations and their employees.²⁹ Our study is based on data from the 2020 survey, which were collected through an online questionnaire issued to employees within organizations that were either members of Pride in Diversity or chose to participate. Participation of individual employees was voluntary.

The initial sample comprised more than 31 000 individuals from 149 organizations across a wide range of sectors and industries. Given the focus of this study, we analyzed data only from employees who identified as transgender, nonbinary, or agender (or as a member of another nondetermined gender minority group) and who had completed the survey modules on well-being and exposure to inclusive language. This yielded an analytic sample of 453 employees across 104 different employers.

Measures

Employee well-being. Our outcome variable was a composite index of employee well-being constructed by combining respondent-reported information on different domains of workplace inclusion and belongingness. Respondents who identified as gender or sexuality diverse were asked to rate their degree of agreement with 7 statements on a scale ranging from 1 (strongly disagree) to 5 (strongly agree). The statements were as follows: (1) "I feel mentally well at work," (2) "I feel safe and included within my immediate team," (3) "I feel accepted for who I am," (4) "I feel I can be myself at work," (5) "I feel productive at work," (6) "I feel engaged with the organization and my work," and (7) "I feel a sense of belonging here." More than 99.5% of respondents who reached this part of the

questionnaire pro deleted responses for each of the 7 statements.

The 7 scores were averaged into an index ranging from 1 to 5. For easier interpretation, the index was subsequently rescaled to range from 0 (worst possible employee well-being) to 100 (best possible employee well-being).

Rescaling was accomplished through the following linear transformation: $\text{new index} = (\text{original index} - 1) \times 25$. The resulting scale featured a remarkable degree of internal consistency (Cronbach $\alpha = 0.92$). In addition, results from a principal component analysis provided strong evidence of unidimensionality, with only a single factor having an eigenvalue above 1 (eigenvalue = 4.13). This factor 'Explained 69% of the variance, and all of the items were positively and strongly correlated with it ($r = 0.74\text{--}0.88$; for details, see the appendix, available as a supplement to the online version of this article at <http://www.ajph.org>). The scale's mean was 71.45, and its standard deviation was 23.13.

Exposure to trans-inclusive language. Our key explanatory variables were 1 measures of the degree to which trans employees were exposed to trans-inclusive language at work. The first 2 indicators were based on trans respondents' self-assessments. They were taken from survey items gauging trans employees' level of agreement with 2 statements pertaining to their experiences at work: "People make an effort to use my personal pronouns" and "I have been deliberately misgendered last year." Responses were made on a Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree); a "not applicable" option was also included. The 2 variables entered the base models as a set of dummy variables. "Strongly disagree" was arbitrarily designed as the reference category to which 'each of the 'other response categories was compared. In additional models, for parsimony, these variables were recast as continuous-level variables, with an additional dummy variable denoting whether respondents fell into the "not applicable" category to preserve linearity.

The third and fourth indicators approximated the cultural climate concerning language use in the organizations where trans employees worked. To derive these indicators, we exploited the multilevel structure of the AWEI Employee Survey data, with employees nested within organizations. Specifically, we aggregated responses to 2 survey items posed to all cisgender heterosexual individuals who worked within the same organizations as our focal trans respondents. The 2 items prompted these cisgender heterosexual individuals to rate their degree of agreement with the following statements: "I would be comfortable using they/their/them personal pronouns for a non-binary person at work" and "I would be comfortable referring to a colleague by a different name or personal pronouns if they were affirming their gender (transitioning) at work." Responses were made on a Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). These aggregated, organization-level measures entered the models as continuous-level variables.

Control variables. Several variables were used as model controls to minimize the risk of omitted-variable bias. All models included measures of respondents' gender identity (trans man, trans woman, nonbinary, agender, different identity, prefer not to say), age group (less than 24 years, 25-44 years, 45 years or older), educational level (degree, lower), culturally and linguistically diverse background (yes, no), Indigenous self-identification (yes, no), workplace location (urban, rural), job level (senior/executive, middle management, regular employee), employment sector (government, private sector, other), and organization size (less than 500 employees, 501-8000 employees, more than 8000 employees). Inclusion of more disaggregated measures of occupation and industry was not possible owing to small cell sizes. As is customary in research conducted in Australia, the culturally and linguistically diverse background and Indigenous measures were used to approximate race,"ethnicity.

The small amounts of missing data on age ($n = 4$), Indigeneity ($n = 5$), and culturally and linguistically diverse background ($n = 5$) were addressed through mode imputation. Missing data on organization size ($n = 63$) were more prevalent and dealt with through inclusion of a dummy variable denoting missing cases.

Some of our models were further adjusted for variables capturing workplace diversity and inclusion factors (beyond exposure to inclusive language) that could affect trans employees' well-being. These variables were based on items in which trans respondents rated their degree of agreement with several statements on a Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The statements were as follows: (1) "I have been the target of unwanted jokes due to my gender diversity last year," (2) "I have been the target of bullying/harassment due to my gender

diversity last year," (3) "I can freely use gendered toilets of choice without opposition here," (4) "Most people I work with are aware of my gender diversity," and (5) "There are people within the organization similar to me." All of these variables also included a "not applicable" category.

For parsimony, these variables entered the models as continuous-level variables, with an additional dummy variable identifying respondents who fell into the not applicable category. Table A (available as a supplement to the online version of this article at <http://www.ajph.org>) shows descriptive statistics for all analytic variables.

Analytic Approach

We used a series of multilevel (randomintercept) regression models to examine associations between our outcome variable capturing trans employees' well-being and our key explanatory variables capturing exposure to transinclusive language.³⁰ These models fully accounted for the hierarchical nature of the AWEI Employee Survey data, with employees (level 1) nested within organizations (level 2), generating appropriate parameter estimates and standard errors. The models can be formally expressed as follows:

(ProQuest: ... denotes formula omitted.)

where i and o represent individuals and organizations, W is an index of employee well-being, L is a given indicator of exposure to trans-inclusive language, C is a set of base control variables, D is a set of additional controls for workplace diversity and inclusion factors, a is a model intercept that is allowed to vary across organizations, e is an idiosyncratic error term, and β , g , and S are parameter estimates (i.e., model coefficients) to be estimated.

We initially estimated models including only the explanatory variables capturing exposure to trans-inclusive language- one at a time-and the base control variables (base models). We then estimated models including additional controls for workplace diversity and inclusion factors (augmented models). The 2 sets of estimates had advantages and disadvantages relative to each other. On the one hand, the base models were less likely to yield parameter estimates for the language variables that were downward biased owing to collinearity and overcontrolling because of the presence of the other workplace diversity and inclusion factors. On the other hand, the augmented models were less likely to suffer from omitted-variable bias caused by a failure to include important predictors of trans employee well-being.

RESULTS

In this section, we present the results of the random-intercept multilevel regression models. We first discuss the results of the base regression models and then the results of the augmented models.

Base Regression Models

Table 1 presents abridged results from our base regression models. Models 1 and 2 show the results for the explanatory variables capturing self-reported exposure to trans-inclusive language. Trans employees who perceived that their colleagues made an effort to use their personal pronouns reported greater levels of well-being (model 1). For example, on a scale from 0 to 100, there was a 43-unit difference in the well-being index between trans employees who strongly disagreed and those who strongly agreed with the relevant statement ($b = 43.25$; $P < .01$). Similarly, experiences of deliberate misgendering were negatively associated with trans employees' well-being (model 2). For instance, there was a 20-unit difference in the well-being index between trans employees who strongly disagreed and those who strongly agreed with the relevant statement ($b = -20.45$; $P < .01$). Results of analogous base regression models introducing the trans-inclusive language variables in a continuous metric are presented in Table C (available as a supplement to the online version of this article at <http://www.ajph.org>). Models 3 and 4 show the results for the explanatory variables capturing aggregate-level, derived measures of exposure to trans-inclusive language. Trans employees' well-being was higher when others in their organization reported being comfortable using they/ their/them pronouns (model 3: $b = 12.92$; $P = .04$) and when their colleagues reported being comfortable using a different name or pronouns for a person who transitioned at work (model 4: $b = 15.96$; $P = .04$).

The magnitude of these relationships can be better grasped by visual inspection of the different panels in Figures 1 and 2. These figures plot predicted means in employee well-being across categories or values of the inclusive language variables. All panels reveal monotonic, or nearly monotonic, increases in trans employee well-being as

exposure to trans-inclusive language increases. The magnitude of the effect appeared substantial.

The parameter estimates for the control variables are presented in Table B (available as a supplement to the online version of this article at <http://www.ajph.org>). Although these estimates are not of key interest to our research aims, they revealed that few other sociodemographic or employer variables significantly predicted trans employees' well-being. As an exception, we found a positive association between a culturally and linguistically diverse background and employee well-being.

Augmented Regression Models

Table 2 presents the results of augmented models that included additional variables capturing non-language-related workplace diversity and inclusion factors. For parsimony and comparability, all of the new variables as well as the selfreported language variables were introduced in the models in a continuous metric.

With the addition of the new variables, the parameter estimates for 3 of the 4 inclusive language variables remained statistically significant and in the expected direction. As an exception, the parameter estimate for the selfreported misgendering variable was no longer statistically significant in these models, which may have occurred because of misgendering being perceived as a form of bullying or harassment by trans people. Overall, this pattern of results suggests that the effect of exposure to inclusive language on trans employees' well-being was independent of the effect of other diversity and inclusion factors that characterize workplace culture.

The parameter estimates for the additional workplace diversity and inclusion variables were largely consistent with expectations. As can be seen in model 5, for example, trans employees reported significantly greater wellbeing at work if they had not been the target of jokes ($b = -5.09$; $P < .01$) or bullied or harassed ($b = -2.91$; $P < .01$), if they could use gendered toilets of their choice ($b = 2.27$; $P < .01$), if they were "out" to their coworkers ($b = 3.73$; $P < .01$), and if they had colleagues who were similar to them ($b = 4.76$; $P < .01$). These relationships are visually represented in Figure A (available as a supplement to the online version of this article at <http://www.ajph.org>), which plots predicted means in employee well-being across values of the different diversity and inclusion variables based on the results of model 5.

DISCUSSION

This study has provided novel empirical evidence of positive effects of exposure to inclusive language among trans employees. Using unique survey data from Australia, we found strong, positive, and statistically significant associations between multiple markers of exposure to trans-inclusive language and trans employees' well-being. These relationships emerged in the presence of an encompassing set of control variables and, in 3 of 4 cases, in models further adjusted for other workplace diversity and inclusion factors. Altogether, the results indicate that the positive effects of exposure to transinclusive language are not the product of confounding and operate independently of the effects of other workplace characteristics. Furthermore, these effects were more often statistically significant than those of the control variables (e.g., employee gender identity, ethnicity, or age and employer size, sector, or location) and were of a magnitude similar to that of other workplace diversity and inclusion variables with similar metrics (e.g., experiences of bullying and harassment).

Our findings are thus consistent with the results of a few earlier studies exploring relationships between inclusive language and trans people's wellbeing in samples of adolescents^{21,22} and adults.^{20,26,27} However, this study was the first to our knowledge to quantify the direct impact of inclusive language use on a multidimensional measure of trans well-being in the workplace context. In addition, it was among the first to empirically demonstrate the contributing role of other workplace diversity and inclusion factors in the well-being of trans employees, including being the victim of jokes or bullying, being able to use gendered toilets of choice, being "out" to coworkers, and recognizing similar others within the organization.²⁰

Strengths and Limitations

Our study featured several strengths stemming from the unique properties of the AWEI Employee Survey data. First, our analyses were based on the largest sample of trans people of all similar studies ($n = 453$). This sample size enabled us to examine the relationships of interest through complex multivariable regression models adjusted for a range of confounders within a multilevel framework. Second, we had access to 4 different measures of exposure to

trans-inclusive language at work, including measures based on trans respondents' self-reports and measures constructed out of aggregate reports from their colleagues. The fact that our results were consistent across all measures speaks of their mess. We constructed and used a nuanced, multidimensional indicator of employee well-being captured via information from 7 items tapping different facets of the concept (e.g., safety, acceptance, productivity).

There were, nevertheless, some limitations to our research. First, the AWEI Employee Survey is a voluntary, opt-in survey for both employees and employers that relies on a nonprobabilistic sampling approach. As a result, any measures of statistical inference used in this study need to be interpreted with a degree of caution. This limitation is shared with other studies in the field,^{20,26,27} highlighting the need for future research to corroborate our findings with probabilistic samples. The organizations that chose to participate in the AWEI Employee Survey may feature more "progressive" workplace cultures than those that did not participate. Therefore, it remains unclear whether our results can be extrapolated to other organizations.

Second, because of data unavailability or modest cell sizes, we were unable to adjust our models for employee income; separate ethnicity, language background, and migrant status indicators; or highly disaggregated measures of occupation and industry sector. Finally, although exhibiting favorable statistical properties, the survey measures used in our analyses, including the focal explanatory and outcome variables, have to our knowledge not been formally validated.

Public Health Implications

Work-related experiences and outcomes are important determinants of health.³¹ As such, our results point to levers that employers and policymakers can use to improve the health and wellbeing of trans individuals. They indicate that efforts to foster inclusive language in the workplace can yield substantial, positive effects on trans people's feelings of belonging and inclusion at work. Well-being at work is an important precursor of longer-term labor market outcomes such as employee retention and career progression, with potentially positive ramifications for outcomes in other domains of life.³² It follows that intervening to promote appropriate language use toward trans people at work may contribute to long-lasting positive effects on the lives of these individuals.

Current scholarship points to different interventions that can successfully change attitudes toward trans people and facilitate appropriate language use within the workplace. For example, increasing exposure to trans people reduces stigma and fosters appropriate workplace language practices.^{33,34} In addition to stronger antidiscrimination policies that boost employment rates among trans individuals, this goal can also be achieved through diversity and inclusion training that explicitly educates employees about the use of trans-inclusive language.³⁵ Recent research indicates that some employee groups are less comfortable than others using trans-inclusive language at work (e.g., male, older, and less educated employees and employees working in male-dominated industries, rural areas, or the public sector).¹⁷ Hence, targeted programs aimed at these employee groups may be particularly efficient and effective.

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CONTRIBUTORS

F. Perales led the study design and data analysis and wrote the initial draft of the article. C. Ablaza contributed to the study design, reviewed and summarized the existing literature, assisted with the data analysis, and critically reviewed the article. N. Elkin contributed to the study design, helped interpret the results, and critically reviewed the article.

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CONFLICTS OF INTEREST

Francisco Perales and Christine Ablaza report no conflicts of interest. Nicki Elkin would like to disclose working at ACON Health (a not-for-profit organization committed to diversity and inclusion in the workplace), which collected the Australian Workplace Equality Index Survey data used in this study.

HUMAN PARTICIPANT PROTECTION

This study was approved by the ethics committee of the University of Queensland. Because the study was based on analyses of secondary data from a survey designed for research purposes, informed consent was not necessary.

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DETAILS

Subject:	Indexes; Language; Regression analysis; Regression models; Diversity in the workplace; Equality; Transgender persons; Questionnaires; Workplace diversity; Victimization; Exposure; Statistical analysis; Work; Employees; Respondents; Variables; Multiculturalism & pluralism; Non-binary gender; Women; Gender identity; Teenagers; Polls & surveys; Eigenvalues
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The Tobacco Industry's Renewed Assault on Science: A Call for a United Public Health Response

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ABSTRACT (ENGLISH)

Corporate deception in public health is nothing new. From the fossil fuel industry hiding the environmental impact of fracking to the pharmaceutical industry misleading the medical community about the dangers of opioid use, for-profit industries have often misrepresented scientific findings to obscure negative evidence related to the public's health and well-being to protect their bottom line.

Among the worst offenders is the tobacco industry, who knowingly hid the truth about the impact of cigarette smoking for decades. Tobacco industry executives spun a narrative of doubt around the health risks of smoking, donated to politicians who would oppose greater regulations, and funded research designed to undercut objective scientific findings to protect profits.¹ Not until the landmark 1998 Master Settlement Agreement did such actions receive greater attention and tobacco companies were forbidden to engage in practices that conceal health risks. Unfortunately, history has begun to repeat itself. The tobacco industry is once again infiltrating scientific spaces and presenting a direct threat to the vital work of unbiased tobacco control scientists. With the popular introduction of e-cigarettes and other new nicotine products, the tobacco industry has remade itself into a self-proclaimed concerned corporate entity-and one that will go to great lengths to prop up their new products while opposing credible scientific findings. Both JUUL and Philip Morris have injected their narrative into scientific circles by publishing sponsored research in scientific journals. Other tactics include academic conference participation, where they introduce questionable findings, muddle earnest research efforts, and stifle honest debates among legitimate experts.

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Among the worst offenders is the tobacco industry, who knowingly hid the truth about the impact of cigarette smoking for decades. Tobacco industry executives spun a narrative of doubt around the health risks of smoking, donated to politicians who would oppose greater regulations, and funded research designed to undercut objective scientific findings to protect profits.¹ Not until the landmark 1998 Master Settlement Agreement did such actions receive greater attention and tobacco companies were forbidden to engage in practices that conceal health risks. Unfortunately, history has begun to repeat itself. The tobacco industry is once again infiltrating scientific spaces and presenting a direct threat to the vital work of unbiased tobacco control scientists. With the popular introduction of e-cigarettes and other new nicotine products, the tobacco industry has remade itself into a self-proclaimed concerned corporate entity-and one that will go to great lengths to prop up their new products while opposing credible scientific findings. Both JUUL and Philip Morris have injected their narrative into scientific circles by publishing sponsored research in scientific journals. Other tactics include academic conference participation, where they introduce questionable findings, muddle earnest research efforts, and stifle honest debates among legitimate experts. Although the Master Settlement Agreement ended tobacco industry-funded "research" groups such as the Tobacco Institute, which were designed to discredit the evidence between smoking and cancer, the Foundation for a Smoke-Free World (FSFW), founded in 2017 and funded by Philip Morris International, has worked to infiltrate scientific spaces and shape public discourse.² FSFW recently published articles in established journals, including the *International Journal of Environmental Research and Public Health* and *Drugs and Alcohol Today*, by evading conflict-of-interest documentation and policies or by obscuring their role in funding.²

Most egregiously, JUUL recently sponsored an entire special issue of the *American Journal of Health Behavior* to showcase its industry-funded research.³ JUUL's success in buying a complete issue was sufficiently concerning to garner a response from US Senators Elizabeth Warren and Richard Blumenthal, who called on acting Food and Drug Administration (FDA) Commissioner Janet Woodcock to more carefully examine industry-funded research, particularly with respect to conflict-of-interest documentation and the mechanisms through which the FDA evaluates the rigor of such studies.⁴

Scientific conferences are another venue where comprehensive policies must guard against industry influence. For example, the Society of Research on Nicotine and Tobacco (SRNT) previously allowed industry researchers to attend and present at their annual scientific conferences but recently banned tobacco industry employees from attending. SRNT made these changes in response to an outcry by many researchers who were disturbed by the overwhelming participation of industry researchers.

Allowing tobacco industry research in scientific publications and conferences has significant consequences. First, it lends the industry legitimacy and status-giving industry-sponsored research a false equivalence with independent, credible, public health research. Second, industry participation at academic conferences and other scientific arenas provides critical insight into tobacco control evidence and strategy, which the industry can then use to counter science-based policy initiatives. Third, legitimizing tobacco industry findings allows them to showcase their work to federal regulators. JUUL, for example, presented findings at the 2021 SRNT conference and then cited its own press release as evidence in their FDA Premarket Tobacco Product Application process.⁵ Lastly, younger researchers may not be aware of the tobacco industry's long history of dishonesty and therefore may be less likely to appreciate the consequences of industry participation in scientific forums. By appropriating the language of harm reduction, the tobacco industry cynically claims to care about users' health. But an industry whose financial success depends on the continuous generation of profits will never be in a position to authentically support the elimination of the disease and death caused by tobacco.

By participating in legitimate scientific activities, the tobacco industry gains the imprimatur of integrity-a veil that is

increasingly being taken at face value. Recent media appearances by Philip Morris International's former and current CEOs on CNBC and Bloomberg and in the Harvard Business Review as well as paid media placements in the Wall Street Journal and the Washington Post have given Philip Morris International platforms to stake claims of harm reduction to improve public health while continuing to sell deadly products. These efforts can all serve to shift public perceptions of the tobacco industry, subtly directing the general public into believing the industry's pretense that it can be part of the public health solution to end smoking. This may be particularly true among America's youth or those who have simply forgotten the industry's egregious reputation and their ongoing unethical practices.^{6,7} The consequences of allowing any corporate industry an equivalent seat at the table are obvious: for-profit entities have an inherent conflict with regulatory actions that should be informed by unbiased scientific findings. Unfortunately, some evidence indicates that the guardrails preventing industry influence have eroded.² To help thwart this insidious process, the scientific community must renew its commitment to strict implementation of conflict-of-interest policies and reject offers of paid placement in special journal editions. Specific recommendations for doing this have been proposed, including standardized reporting of conflicts of interests and funding in journals and the adoption of author databases of financial interests.² Tobacco researchers must also embrace policies to keep conferences free from industry participation and refuse to participate in forums with industry personnel. Finally, regulatory agencies must rely on independent, rather than industry-sponsored, study findings in assessing the population-level health impacts of novel tobacco products. If empirical findings support a population-level benefit, industry should follow established regulatory pathways for approvals prior to marketing. Lessons learned from decades of deception by the tobacco industry should not have to be repeated. Holding the tobacco industry accountable required more than 40 years of comprehensive, collaborative efforts. There is no indication that their motivations have changed—their goal remains the expansion of their market share for nicotine addiction regardless of the public health consequences. The public, the scientific community, the media, and decision-makers alike must maintain a skeptical view of any efforts by the tobacco industry that seek to influence scientific and regulatory efforts, particularly those that could serve to reduce their profits. We cannot afford to permit the makers of the world's deadliest products to distract us from a united, science-based effort to improve public health. Other corporations will doubtless seek to meddle in science; let's make sure our public health response is united, tested, and successful. Our future depends on it. ÁjPU

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

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Health Benefits of Strategies for Carbon Mitigation in US Transportation, 2017-2050

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ABSTRACT (ENGLISH)

Objectives. To quantify health benefits and carbon emissions of 2 transportation scenarios that contrast optimum levels of physical activity from active travel and minimal air pollution from electric cars. **Methods.** We used data on burden of disease, travel, and vehicle emissions in the US population and a health impact model to assess health benefits and harms of physical activity from transportation-related walking and cycling, fine particulate pollution from car emissions, and road traffic injuries. We compared baseline travel with walking and cycling a median of 150 weekly minutes for physical activity, and with electric cars that minimized carbon pollution and fine particulates. **Results.** In 2050, the target year for carbon neutrality, the active travel scenario avoided 167 000 deaths and gained 2.5 million disability-adjusted life years, monetized at \$1.6 trillion using the value of a statistical life. Carbon emissions were reduced by 24% from baseline. Electric cars avoided 1400 deaths and gained 16 400 disability-adjusted life years, monetized at \$13 billion. **Conclusions.** To achieve carbon neutrality in transportation and maximize health benefits, active travel should have a prominent role along with electric vehicles in national blueprints.

FULL TEXT

Headnote

Objectives. To quantify health benefits and carbon emissions of 2 transportation scenarios that contrast optimum levels of physical activity from active travel and minimal air pollution from electric cars. **Methods.** We used data on burden of disease, travel, and vehicle emissions in the US population and a health impact model to assess health benefits and harms of physical activity from transportation-related walking and cycling, fine particulate pollution from car emissions, and road traffic injuries. We compared baseline travel with walking and cycling a median of 150 weekly minutes for physical activity, and with electric cars that minimized carbon pollution and fine particulates. **Results.** In 2050, the target year for carbon neutrality, the active travel scenario avoided 167 000 deaths and gained 2.5 million disability-adjusted life years, monetized at \$1.6 trillion using the value of a statistical life. Carbon emissions were reduced by 24% from baseline. Electric cars avoided 1400 deaths and gained 16 400 disability-adjusted life years, monetized at \$13 billion. **Conclusions.** To achieve carbon neutrality in transportation and maximize health benefits, active travel should have a prominent role along with electric vehicles in national blueprints.

(ProQuest: ... denotes formulae omitted.)

Achieving carbon neutrality by 2050 is imperative to stem adverse health impacts of climate change.¹ In the United States, adoption of solar and wind power has put the energy sector on a trajectory to meet this goal. However, since 2017, carbon emissions in transportation have eclipsed other sectors and have trended upward.² Two strategies to reduce carbon emissions in transportation are (1) electrification of the vehicle fleet and (2) reduction of vehicle miles traveled (VMT). Both have significant health benefits through, respectively, air pollution reduction and increased physical activity associated with walking and cycling.

Although the strategies are complementary, the investments and policies to achieve them are very different. For example, electrification requires charging infrastructure and could include subsidies for electric vehicles or limitations on sales of new internal combustion engine vehicles. VMT reduction requires policies and investments to make land use and built environment changes that increase neighborhood access to the necessities of life and make transit affordable and convenient, automobile travel less attractive, and walking and cycling safer and more attractive. In considering options, quantification of the health benefits or harms of different strategies provides crucial information to decision-makers. Key questions include how to best optimize simultaneous health and climate benefits and to what extent health benefits potentially offset implementation costs.

To answer these questions, we contrasted idealized transportation scenarios that represent endpoints for health benefits and carbon mitigation: (1) electrification of US light-duty passenger vehicles (LDPVs) and (2) nonmotorized transport to achieve a national population median of up to 150 minutes per week of physical activity in adults—consistent with the guidelines of the 2018 Physical Activity Guidelines Committee.³ LDPVs include automobiles, light-duty pick-up trucks, passenger vans, and sports utility vehicles, and in 2017 accounted for 71% of greenhouse gas emissions (GHGEs) by US road vehicles.² Nonmotorized transport, or "active transport," is walking and cycling for nonrecreational purposes and travel to and from transit stops.

Previous research has identified 3 main health impact pathways in transportation: physical activity from active transport, fine particulate (particulate matter with a diameter of ≤ 2.5 μm ; PM_{2.5}) pollution from vehicle emissions, and road traffic injuries.⁴ US studies that integrated these pathways have focused on state, regional, or city impacts. Other studies, while national in scope, considered only PM_{2.5} pollution.⁵ To our knowledge, this is the first national health impact assessment that considers all 3 pathways and carbon dioxide (CO₂) emissions.

METHODS

The 2017 National Household Travel Survey⁶ describes baseline travel times for walking and cycling and baseline travel distances for walking, cycling, LDPVs, and bus and rail passengers.

We estimated truck VMT from Federal Highway Administration data,⁷ and we derived bus VMT from data on occupancy⁸ and bus personal miles traveled from the National Household Travel Survey.

We contrasted baseline travel with 4 alternative scenarios. The first (AT100%) represents ambitious expansion of

active travel so that half or more of US adults achieve 150 weekly minutes of moderate-intensity physical activity. We assumed total per-capita travel that is the same as baseline, reciprocal increases in active travel and decreases in LDPV travel, and a per-capita median of 75 minutes per week each for walking and cycling. Based on the US Environmental Protection Agency's Motor Vehicle Emissions Simulator (MOVES),⁹ this scenario assumes that national fuel economy standards¹⁰ for model year 2017 LDPVs are fully implemented by 2025 and extend through 2050. Carbon emissions per mile traveled fall from 405 grams CO₂ in 2015 to 226 grams CO₂ in 2050. MOVES also projects emissions of primary PM_{2.5}, tire and brake wear, and secondary constituents such as sulfur dioxide (SO₂) and oxides of nitrogen (NO_x) from 2015 to 2050. In the second scenario (AT25%), we estimated health benefits from active transport in which half or more of US adults attain 25% of the physical activity goal by walking and cycling, each for 18.5 minutes per week.

The third scenario is full electrification (EV100%) of LDPVs in which carbon emissions are reduced to zero by 2050, and primary and secondary constituents of PM_{2.5}, except for tire and brake wear, are reduced to zero. The fourth scenario (EV50%) is 50% electrification of LDPVs. The scenarios for electrification do not take into account carbon emissions or PM_{2.5} pollution from the generation of electricity that fuels electric LDPVs.

We assumed that all scenarios were implemented by 2050, the year we evaluated health impacts. Projections by the Federal Highway Administration indicate little change in per-capita VMT for light duty vehicles through 2047.¹¹ Similarly, 3 cycles of National Household Travel surveys (2001, 2009, and 2017) show marginal increases in active travel.¹² Barring significant changes in policy and investments, our baseline reasonably approximates "business as usual" in 2050.

The Integrated Transport and Health Impact Model

The Integrated Transport and Health Impact Model (ITHIM) implements comparative risk assessment for 3 health pathways. The methodology has been described previously⁴ and in supplemental materials (<https://ithim.org/> ithim). The method determines the change in the population burden of disease from the shift in the exposure distribution (or "dose") of physical activity, LDPV emissions, and collision risk. The reference exposure distribution is based on the current travel pattern ("baseline") or the current pattern projected at a future time ("business as usual"). The alternative distribution is given by a future scenario in which travel patterns are altered by policy, systems, and environmental change.

The change in the burden of disease (BD) is a function of the annual burden of disease, disease specific dose-response functions (DRF), and the change in "Dose." The latter 2 elements are expressed as the epidemiological population attributable fraction (PAF):

...(1)

The burden of disease is expressed as deaths and disability adjusted life years (DALYs) for specific diagnostic entities associated with physical activity, PM_{2.5}, and road traffic injuries. We downloaded data on age-, sex-, and cause-specific deaths and DALYs for the United States in 2015 from the Global Burden of Disease project.¹³ We estimated the 2050 US burden of disease from the projected US population¹⁴ in 2050 and the average annual percent changes in age-, sex-, and cause-specific mortality rates from 2015 to 2050.¹⁵

Physical Activity

The "dose" of physical activity was the population distribution of hours per week of walking and cycling for transport weighted by energetic intensity.¹⁶ We expressed energetic intensity as marginal metabolic equivalent task (mMET) hours per week (mMHWs) for physical activity beyond a resting state. We derived the distribution from the log-transformed per-capita mean weekly minutes of active travel and its standard deviation. We approximated the distribution in quintiles and stratified by sex and age (0-4, 5-14, 15-29, 30-44, 45-59, 60-69, 70-79, and ≥ 80 years). mMET weights for walking reflected age and sex variation from an average walking speed of 3 miles per hour (~3 mMETs) and we based those for cycling on an average speed of 12 miles per hour (5 mMETs). The change in dose (A) reflected changes in the distribution of mMET-weighted walking and cycling times from a baseline, b, to the alternative scenario, s.

The dose-response function was nonlinear,³ disease-specific, and, as incorporated into the PAF, has the form

...(2)

The PAF is calculated from an overall relative risk(RR), which incorporates relative risks of baseline (rrb) and scenario (rrs) at their respective mMHWs on the dose-response curve. Based on meta-analyses of Garcia et al.,¹⁷ the dose-response decreased linearly up to 10 mMHW. For higher levels, we set the relative risks to those of 10 mMHWs.

Dose-response gradients, eb (ARR per mMHW), were as follows: ischemic heart disease (0.9764), hypertensive heart disease (0.9764), stroke (0.9697), dementia (0.9666), diabetes (0.9666), depression (0.9695), colon cancer (0.9940), breast cancer (0.9813), and lung cancer (0.9771). We based the relative risk-physical activity gradient on active travel and leisure time. We estimated age- and sex-specific leisure physical activity times at quintiles of active transport times from National Health and Nutrition Examination Survey data that reported breakdowns of physical activity for leisure activities apart from walking and cycling for transport.¹⁸

Fine Particulate Matter

For comparative risk assessment, the dose-response function was

...(3)

For cardio-respiratory diseases, which include ischemic heart disease, hypertensive heart disease, stroke, asthma, chronic obstructive pulmonary disease, and respiratory tract infections, the RR/PM_{2.5} gradient, eb, was 1.0146 based on the meta-analysis of prospective cohort studies by Vodonos et al.¹⁹ For lung cancer, the RR/PM_{2.5} gradient was 1.0122.

We derived the change in national ambient PM_{2.5} concentration attributable to a change in VMT by LDPVs from changes in LDPV emissions of the baseline and the scenario. MOVES9 modeled the US vehicle fleet and generated primary and secondary constituents of PM_{2.5} in tons per year. LDPV emissions for PM_{2.5}, tire and brake wear, NO_x, and SO₂ were obtained between 2015 and 2050 in 5-year increments.

The US Environmental Protection Agency (USEPA) publishes coefficients, C, for US mortality per ton per year (TPY) of emissions of PM_{2.5}, NO_x, and SO₂ emissions for road vehicles.²⁰ Annual mortality is estimated by multiplying the coefficients by annual emissions for each precursor (i) and then summing. We derived ratios for each PM_{2.5} precursor relating change in ambient levels of PM_{2.5} to tons of emissions by equating annual deaths from the previously mentioned dose-response formula and USEPA's incidence per ton coefficients from 2015 to 2050.

...(4)

The change in ambient PM_{2.5} was given by multiplying the ratios by annual tons of PM_{2.5} precursors and summing.

...(5)

We assumed proportionality between emissions and VMT of LDPVs, yielding a change of -0.57 nanograms per cubic meter PM_{2.5} per percent reduction in VMT by LDPVs. For the EV100% scenario, we assumed 100% reduction in LDPV emissions of CO₂ and precursors of ambient PM_{2.5}, except for tire and brake wear.

Carbon Emissions

MOVES estimated carbon dioxide emitted per mile (emissions factor [EF]) by vehicle and fuel type. Aggregate emissions are given by

...(6)

CO₂ emission factors were VMT-weighted by fuel type (gas, diesel, and electric hybrid) of LDPVs at 5-year intervals from 2015 to 2050. Carbon emissions in the EV100% scenario were zero in 2050.

Road Traffic Injuries

Traffic collisions occur when a pedestrian, cyclist, or victim's vehicle is struck by another vehicle, and the risk of injury depends on both personal miles traveled (PMT) by the victim and VMT by the striking vehicle. The risk of injury is considered for every pairwise combination of victim mode (i) and striking vehicle (j) for baseline (B) and scenario (S) travel, where the modes are walking, cycling, LDPV, motorcycle, bus, and truck. Injury risk is nonlinear²¹ and has the functional form

...(7)

The risk function integrated into the expression for the PAF was

...(8)

where Bu is the number of baseline injuries for combinations of victim and striking vehicle.

We categorized injury severity as fatal or serious, and we stratified injuries by roadway type (highway, arterial, or local), which is a surrogate for traffic speed and volume. We downloaded data on fatal injuries for 2016 from the Fatality Analysis Reporting System²² and on serious injuries from the Crash Report Sampling System.²³

Monetization of Health Outcomes

The health benefits and harms attributable to the change in burden of disease and injury were monetized based on the value of a statistical life. We multiplied the change in the number of deaths by the 2019 value of a statistical life, \$9.8 million.²⁴

Modeling Platform and Analysis

ITHIM estimates health impacts' order of magnitude and direction. To avoid conveying undue precision, we rounded model estimates. We created an interactive Web site with decision-support and educational materials (<https://ithim.org/ithim>).

RESULTS

Per-capita median active travel time increased 10-fold in the AT100% scenario compared with baseline (Table 1). The AT100% scenario demonstrated large annual health benefits for physical activity and modest benefits for PM2.5 reduction, but increased deaths and decreased DALYs for road traffic injuries. EV100% did not change baseline levels of active transport and was associated with a modest reduction in annual deaths and gain in DALYs (1400 and 16 400, respectively) from PM2.5 reduction. The annual net benefit for AT100% was the avoidance of 167 000 deaths and the gain of 2.5 million DALYs. The annual monetized net benefits of AT100% greatly exceeded that of EV100%. In the AT100% scenario, carbon emissions were lowered by 150 million metric tons per year, 24%, from the 2050 baseline of 630 million metric tons per year. By design, the EV100% scenario had no carbon emissions. The less ambitious scenarios for AT25% and EV50% generated fewer health benefits and carbon reductions. However, the health benefits of meeting 25% of the AT goal greatly exceeded those of full electrification.

DISCUSSION

We found trade-offs in health benefits and carbon mitigation in idealized scenarios to achieve carbon neutrality in the transportation sector. Ambitious expansion of active travel had the potential for orders of magnitude greater health benefits than electrification of LDPVs. Benefits were attributable to increases in physical activity and reduction in PM2.5 pollution, which were moderated by increases in road traffic injuries, likely because of LDPVs striking pedestrians and cyclists.⁴ This is consistent with other health impact assessments.²⁵ However, because a large percentage of VMT by LDPVs in the United States (87%)⁶ occurs in trips exceeding 5 miles, which are less amenable to active travel, even large increases in active travel cannot achieve necessary transportation GHGE reductions. Strategies that complement electrification and support active transportation are also important. Land-use and housing changes to increase access to jobs and essential services within short distances, including in rural areas, and significant investments in high-quality electric transit (and its supporting walk and cycling infrastructure) can address longer trips while increasing physical activity and reducing traffic injuries, carbon emissions, and traffic congestion.

Light-duty fleet electrification had greater potential for carbon mitigation and generated health benefits from reduced PM2.5 pollution. Our estimates of avoided PM2.5-related mortality are similar to studies that accounted for geographic variation of air pollution and that included health impacts of other pollutants such as ozone.^{5,26} The greater health impact of

physical activity compared with PM2.5 pollution is similar to other studies in which active travel replaces conventional car travel.²⁵ The EV scenarios showed smaller benefits than some health impact studies of vehicle electrification. This may reflect differences in baseline year (e.g., 2015 vs 2050), defining health outcomes based on cause-specific mortality rather than all-causes mortality, and different health impact tools (HEAT,²⁷ BenMAP²⁸), which vary from ITHIM in age restrictions, dose-response functions, and methods for monetizing health outcomes.

Nonetheless, replacing fossil fuels with electricity does not change current car-centric transportation associated with long and sedentary commuting, noise, urban sprawl, community severance, and traffic injuries. Electrification will not entirely eliminate health risks because tire and brake wear will contribute to PM_{2.5}.

Both electrification and active travel scenarios pose significant implementation and policy challenges.²⁹ Technology for electric vehicles must be developed, deployed, and financed that addresses battery charging, vehicle range, and cost. Only 1.5% of new car sales were fully electric vehicles in 2019. Electrification is stimulated by voluntary pledges of vehicle manufacturers to phase out sales of gasoline-powered cars by 2050, rebates and tax incentives for electric car purchases, and the California gubernatorial executive order that bans sales of new gasoline-powered cars by 2035. By contrast, active travel does not require a change in technology, but significant financial investment in pedestrian, bicycle, and transit infrastructure and changes in land use that equilibrate future demand for housing and job growth. Several European countries with a broad portfolio of such investments have already exceeded the AT25% scenario goals for transport-related cycling (Netherlands) and walking (Switzerland), signaling that ambitious active travel is attainable.³⁰

California legislation in 2008 required regional transportation plans to reduce GHGEs, but a 2018 report found VMT still increasing and that a reduction of single-occupancy vehicle travel is necessary to achieve statewide GHGE reduction goals.³¹ This suggests that carbon neutrality in US transportation will not likely be achieved by 2050 without significant changes to how communities and transportation systems are planned, funded, and built. To promote additional housing, several US cities have upended traditional land use by abolishing single family zoning. These initial steps will have to be followed by larger systemic changes to elevate active travel to a dominant travel mode.

The 2 strategies highlight potentially divergent interests. For example, affordable housing or transit advocates may prioritize policies that reduce VMT, while some vehicle manufacturers prioritize policies that support electrification. The scenarios also contrast in that active travel investments (sidewalks, bike lanes, transit systems) are largely public, and electrification builds on private vehicle ownership. Recent national blueprints to achieve carbon neutrality clearly favor vehicle electrification and understate the role of active travel.²⁶ These documents do not question the hegemony of car-centric transportation or the impacts of their plans on the social determinants of health, and existing health and racial inequities.

Limitations

Our scenarios had important assumptions and limitations. We assumed that the 2015 baseline per-capita VMT and active travel would fairly represent travel patterns in 2050. We did not alter per-capita transit distances. An ambitious expansion of transit would add to active travel and be a source of additional health benefits. Our active travel scenarios accounted for safety in numbers in estimating the health burden of road traffic injuries, but we did not model walking and cycling infrastructure (e.g., separated lanes) that could significantly reduce collisions between active travelers and motorized vehicles.³²

Our LDPV electrification scenarios did not consider additional health benefits from electricity generated from renewable sources, which, in one study, was nearly double that of vehicle emissions.⁵ We did not assess the air pollution benefits of electrifying heavy-duty trucks, whose PM_{2.5} emissions substantially contribute to premature deaths. We did not incorporate potential changes in active travel or vehicle emissions associated with newer technologies such as ebikes, cargo bicycles, and autonomous vehicles.

We were not able to provide geographically resolved estimates of health impacts because statistically reliable calibration data on active travel were not available at the state or county level.⁶ For air pollution, we only modeled background levels and not those experienced by active travelers, whose exposure may be higher because of higher ventilation rates and proximity to busy roadways, warehouses, and truck depots. Systematic reviews of potential exposures of active travelers indicate that the benefits of physical activity far outweigh potential adverse outcomes from inhalation of PM_{2.5}.³³

We acknowledge uncertainties in ITHIM model parameters, which have been examined in Monte Carlo simulations³⁴ and sensitivity analyses iterating plausible but extreme values for individual parameters and

combinations.^{4,32} Although estimates varied, the health benefits of ambitious active travel scenarios exceed those of ambitious adoption of electric vehicles. Several recent publications^{19,35} suggest a range of values for the slope of the concentration response function for PM_{2.5}-related health outcomes. Our estimates of annual deaths are based on a slope in the middle of the range.

We did not apply a discount rate to our monetization; even after discounting, the monetized value of health benefits in the AT scenarios would be substantial. Monetizing the social cost of carbon generates even larger potential benefits for both the EV100% and AT100% scenarios—\$43 billion and \$10 billion in 2050 (assuming a cost of \$69 in 2007 dollars per ton of CO₂ and a discount rate of 3%).³⁴

We could not address racial and health equity because of gaps in calibration data and the lack of geographic resolution of our version of the ITHIM model. Researchers are developing versions of ITHIM that simulate travel patterns of individuals in synthetic populations so that health impacts can be aggregated over race/ethnicity, income, and other dimensions of equity and geospatial variation in air pollution.

We did not have the resources to model other transportation-health pathways, including emissions from ozone, elemental carbon, and nitrogen dioxide; noise; community severance; and access to goods and services, jobs, educational opportunities, health care, recreation, and social networks. We did not consider the health benefits of mitigating carbon emissions linked to heat waves, storms and sea level rise, and other climate disruption. We also did not address a post-COVID-19 transportation landscape, which has contradictory tendencies for active travel: increased bicycle ownership, closure of streets to cars, increased telecommuting, decreased retail destinations, and financially stressed transit systems with diminished ridership.

Public Health Implications

Although we presented the scenarios as contrasting visions, together they maximize carbon reductions and health benefits. To succeed together, policies and plans must substantially increase options to allow people to choose active transportation. This means the level of service to reach a wide array of destinations by walking, cycling, transit, and driving an electric car must be comparably time-efficient, affordable, and convenient. As we recover from a pandemic and venture out again, a heightened emphasis on active travel will also make major contributions to public health and carbon mitigation. Additional attention must be focused on safety and racial and health equity. The urgent imperative to rapidly reduce greenhouse gas emissions offers an opportunity to simultaneously and significantly reduce the burden of chronic disease and related health inequities and enormous health care costs.

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N. Maizlish was responsible for the concept, methodology, interpretation of the results, and drafting the article. L. Rudolph reviewed and edited the article. C. Jiang implemented the methodology and reviewed the article.

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The authors declare they have no actual or potential competing financial interests.

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The Challenges of Public Health Leadership

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ABSTRACT (ENGLISH)

My Quest for Health Equity: Notes on Learning While Leading By David Satcher 240 pp.;\$21.95 Baltimore, MD:Johns Hopkins University Press, 2020 (hardcover) ISBN: 9781421438313

FULL TEXT

My Quest for Health Equity: Notes on Learning While Leading By David Satcher 240 pp.;\$21.95 Baltimore, MD:Johns Hopkins University Press, 2020 (hardcover) ISBN: 9781421438313

Public health leadership is a challenging endeavor. Effective leaders must bridge science, public policy, and politics. At times, they must confront crises that garner massive amounts of public attention, such as the COVID-19 pandemic. More often, public health leaders grapple with issues such as vaccination and social determinants of health, including nutrition, exercise, housing, social structures, and the built environment. These factors shape health outcomes at the population level, cut across policy domains, and do not typically lend themselves to easy solutions.

The challenges and rewards of leadership in the realm of public health are at the heart of former surgeon general David Satcher's engaging new book *My Quest for Health Equity: Notes on Learning While Leading*. Written in a straightforward manner, the book explores public health leadership from a perspective shaped by deep experience with the challenges that often occur when public officials work to translate research into practice.

HEALTH DISPARITIES AND PUBLIC HEALTH LEADERSHIP

Across a varied and highly influential career, Dr. Satcher has emphasized the importance of health disparities and

sought out approaches to addressing them. After attending Morehouse College, Satcher completed medical training at Case Western and then a residency at the University of Rochester. From there, he moved on to Charles R. Drew Postgraduate School of Medicine and Martin Luther King, Jr. General Hospital, located in South Central Los Angeles. After a period working at Morehouse, Satcher became president of Meharry Medical College. There he led the merger of Meharry's Hubbard Hospital with the city of Nashville's public general hospital.¹ In 1993, after serving as an advisor during the development of President Bill Clinton's health plan, Satcher became the first African American to head the Centers for Disease Control and Prevention (CDC). In 1998, he became surgeon general of the United States Public Health Service.

Rather than detailing these events in a strictly chronological manner, Satcher centers *My Quest for Health Equity* around the concept of leadership. From his upbringing and from his experiences as an active participant in the civil rights movement, Satcher writes, he came to develop a distinct sense of what it means to be a leader.

The importance of clear communication of responsibilities and goals, Satcher reflects, was demonstrated to him by his parents. Throughout his childhood, they entrusted him with important tasks, ensured that he completed them, and encouraged him to pursue his education. The importance of an overarching mission was made clear to him by the civil rights movement and by the commitment of its leaders to the philosophy of nonviolence. Motivated by a commitment to something larger than oneself, leaders should acknowledge error and embrace opportunities to learn and to continue to grow. Self-aware and generous, they should focus on the achievement of a mission rather than on their own aggrandizement.

POLICY, INSTITUTIONS, AND CONTROVERSY

Satcher complements his discussion of leadership with chapters on obesity, reproductive health, and mental health. These chapters suggest the depth and breadth of the obstacles that public health leaders face. Crucial to the health of communities, public health is often easily overlooked in the popular discourse. Major public health successes such as the creation of a clean water supply, the elimination of malaria from the southern United States, and widespread vaccination against an array of diseases are routinely taken for granted. With time, these successes come to seem like features of the landscape rather than the products of human effort. In the case of vaccination, the absence of many once-common diseases has itself helped to fuel skepticism, indifference, and conspiracy theories. In the United States, these problems are compounded by fragmented institutions and by practices and priorities that have reproduced disparate outcomes across racial and ethnic groups overtime. As director of the CDC and as surgeon general, Satcher emphasized the importance of reaching out to underserved communities and addressing deeply rooted inequalities. Among other notable accomplishments, Satcher helped persuade President Clinton to offer a public apology for the Tuskegee Experiment, an acknowledgment of a historical wrong that plays an ongoing role in shaping vaccine hesitancy in Black communities.

Public health efforts often garner the most public attention during moments of controversy or as a result of emergent threats. In these instances, the political nature of public health leadership is unmistakable. Satcher was nominated to be surgeon general in the wake of the failed nomination of Henry Foster, who met opposition in the United States Senate because of his history of performing abortions. Satcher's predecessor as surgeon general, Joycelyn Elders, was forced to resign from the position after a controversy over public comments about masturbation and the prevention of HIV/AIDS.

Satcher's service at the CDC and as surgeon general was marked, almost inevitably, by politics. Just as he became head of the CDC, the agency was engulfed in a controversy about CDC-funded research on gun-related deaths. Published in the *New England Journal of Medicine*, the study showed that having a gun in the home was associated with a substantially higher risk of homicide by a family member or intimate partner.² Ultimately, Congress reduced funding for the CDC's injury prevention center and prohibited it from spending money to "advocate or promote gun control."³ During the administration of President George W. Bush, Satcher found himself out of favor after issuing a report on sexual health that criticized abstinence-only educational programs and acknowledged that safe sex could occur outside of a marriage.⁴

CONCLUSION

Satcher's book might have been made more powerful with a thorough discussion of the obstacles he faced during the 1990s and early 2000s, an era in which growing party polarization shaped the implementation of public health policies in important ways. Nonetheless, he offers a crisp distillation of his approach to leadership. His reflections on the challenges of leadership represent a needed addition to the public health literature and should be widely read by those who seek to understand and reflect on the intersections of health, policy, and politics. >4jPH

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Large-Scale Implementation of a Daily Rapid Antigen Testing Program in California for Detecting SARS-CoV-2

Ventura, Maria I, PhD; Delgado, Darci, PsyD; Velasquez, Susan, PhD; Foote, Eric, MD; Jacobson, Kathleen, MD; Arguello, Juan Carlos, DO; Warburton, Katherine, DO

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ABSTRACT (ENGLISH)

Objectives. To evaluate a daily antigen testing program for health care personnel. **Methods.** We examined antigen testing results between December 13, 2020, and April 30, 2021, from 5 forensic psychiatric inpatient hospitals throughout California. **Results.** Among 471 023 antigen tests administered, 449 positives (0.0036% false positives) were detected. **Conclusions.** Antigen tests had low false-positive rates, high positive predictive value, and high levels of acceptability, important characteristics when considering their application in the community. **Public Health Implications.** Daily antigen testing was feasible and should be considered to reduce COVID-19 transmission.

FULL TEXT

Headnote

Objectives. To evaluate a daily antigen testing program for health care personnel.

Methods. We examined antigen testing results between December 13, 2020, and April 30, 2021, from 5 forensic psychiatric inpatient hospitals throughout California.

Results. Among 471 023 antigen tests administered, 449 positives (0.0036% false positives) were detected.

Conclusions. Antigen tests had low false-positive rates, high positive predictive value, and high levels of acceptability, important characteristics when considering their application in the community.

Public Health Implications. Daily antigen testing was feasible and should be considered to reduce COVID-19 transmission. (Am J Public Health. 2022;112(3):467-471. <https://doi.org/10.2105/AJPH.2021.306588>)

The COVID-19 pandemic caused by severe acute respiratory syndrome coronavirus (SARS-CoV-2) has to date infected more than 171 million individuals worldwide, including 33 million in the United States.¹ Although vaccine efficacy is commended, those who cannot or choose not to be vaccinated remain at greatest risk for COVID-19. In this current pandemic phase, congregate settings such as nursing homes and schools rely on testing to reduce risk of infection in combination with masking, hand washing, physical distancing, and increased ventilation.² Viral antigen tests, although less sensitive for detecting COVID-19 than polymerase chain reaction (PCR) tests, have a turnaround time of 15 to 30 minutes and can be conducted on site at low cost, providing significant implementation advantages. A single negative antigen test cannot conclusively rule out SARS-CoV-2 infection³; however, use of repeated antigen testing has served as a response to practical and financial imperatives. PCR testing often has a turnaround time of 1 to 4 or more days, cannot be performed at the point of entry, and costs approximately 10 times more than antigen tests.²

Symptom screening at the point of entry has been used in an attempt to reduce transmission of SARS-CoV-2 within patient care settings by preventing infected workers from entering the building.⁴ However, symptom screening has been relatively ineffective in preventing workplace transmission. There is some evidence that asymptomatic or presymptomatic individuals account for at least 50% of transmission events.⁵ If health care professionals (HCPs) or teachers, for example, could be tested daily with results available before they interacted with patients or students, they could be prevented from unintentionally infecting others.^{6,7}

The California Department of State Hospitals has faced multiple outbreaks of COVID-19 since the beginning of the pandemic. The main goals of this study were to (1) describe our experience in implementing a daily rapid antigen testing program for all HCPs, (2) evaluate false-positive rates and the positive predictive value of antigen tests relative to PCR tests, and (3) assess the impact of daily testing on staff morale.

METHODS

The Department of State Hospitals maintains 5 forensic psychiatric inpatient hospitals throughout California employing approximately 10 000 HCPs, with the majority providing direct patient care. In consultation with the California Department of Public Health, the Department of State Hospitals implemented daily testing of all HCPs upon their arrival at the hospital with BinaxNOW rapid antigen tests⁸ to reduce new COVID-19 infections and outbreaks. A train-the-trainer framework was used in which an initial small group of staff members completed an in-

depth 2-hour training session on the BinaxNOW test kit, including didactics, video tutorials, and hands-on training. These trainers then served as subject matter experts and provided training to other HCPs to quickly allow for widespread, rapid implementation.

Broadly, 2 testing station layouts emerged: front entrance testing stations and on-unit testing stations. Front entrance stations were operated by 1 to 4 rapid antigen test screeners depending on timing of HCP arrivals throughout the day. Daily rapid antigen testing was mandatory for all directcare HCPs, and refusals, although rare, resulted in progressive discipline with the employee being sent home. Each HCP self-collected the anterior nares sample and followed the BinaxNOW package insert directions. On-unit stations were set up for hospitals that did not have grounds layouts or staffing resources conducive to large testing stations. In these facilities, 40 to 50 unit supervisors were responsible for conducting rapid antigen testing for their units at the beginnings of shifts at small screening stations. During the 15-minute test processing time, HCPs were instructed to begin shift duties but not engage with patients until their results were available.

If HCPs had a positive rapid antigen test result, they were instructed to complete a confirmatory PCR test within 48 hours of their positive antigen test. Positive predictive value was calculated by the number of positive antigen tests confirmed as positive via PCR by the total number of positive antigen tests with either a positive or a negative PCR.⁹ We conducted χ^2 analyses to compare the number of observed versus expected positive antigen results within specific job classifications. Three months into the daily rapid antigen testing program, all participating HCPs were invited to complete a voluntary, anonymous electronic survey that asked about their level of satisfaction with the program.

RESULTS

From December 13, 2020, through April 30, 2021, a total of 471 023 rapid antigen tests were administered to HCPs (Table 1). Approximately 24000 rapid antigen tests were conducted per week, averaging 500 to 800 tests per day with fluctuations dependent on several factors including, but not limited to, size of facility, day of the week, and holidays.

There were 486 positive rapid antigen tests, and 96% ($n = 466$) of individuals with a positive result completed a confirmatory PCR test within 48 hours. Of the 466 individuals with a confirmatory PCR, 449 were confirmed as being positive, representing 0.095% of all tests administered; only 17 false positives (0.0036%) were identified. Rapid antigen tests had an overall PCR positive predictive value of 96.4%.

Data on the presence of COVID-19 symptoms were captured for a subset of HCPs who tested positive ($n = 404$), among whom 77% reported being asymptomatic at the time of antigen testing. Vaccination of HCPs began on December 26, 2020. Antigen testing identified 4 instances of vaccine breakthrough. These individuals were confirmed as positive via PCR after being fully vaccinated or 14 days or more after the second dose of an mRNA vaccine.¹⁰

The distribution of observed COVID19 positive antigen tests among job classifications was found to be significantly different than what would be expected given the workforce compilation ($\chi^2 = 204.66$, $df = 6$; $P < .001$; Table 2). Janitorial and custodial staff, psychiatric technicians, and hospital police officers were 1.93, 1.77, and 1.51 times more likely, respectively, to contract COVID-19 on the basis of their workforce prevalence.

When surveyed about their experience, 78% of HCP respondents reported feeling satisfied with daily antigen testing, 65% felt safer overall with daily testing, 57% appreciated not having to wait for days to receive their PCR results, and 51% felt more comfortable working in close proximity to hospital coworkers. Daily antigen testing also appeared to affect employees' broader quality of life, as 71% reported feeling safer at home with daily testing. There were some drawbacks: 20% of respondents indicated that daily rapid antigen testing required too much time each day, 14% worried about privacy related to their test result, and 10% indicated that they would be embarrassed if they tested positive.

DISCUSSION

To our knowledge, our study represents the largest implementation of a daily antigen testing program in the United States to date, with 471 023 rapid antigen tests administered in a 4-month period. The antigen testing program

identified 449 individuals with COVID-19 who would have otherwise interacted with other people in the workplace, potentially infecting patients and coworkers.

Approximately 77% of those who tested positive via antigen testing were asymptomatic, and 4 asymptomatic vaccine breakthroughs were detected. Although we did not collect presymptom and postsymptom data on all HCPs with positive antigen test results, this high percentage still highlights the crucial role of asymptomatic testing in reducing the spread of COVID-19 within high-risk congregate settings. Self-reported symptom screening would have been insufficient to prevent these infected HCPs from going to work. Our findings add to a body of work demonstrating the utility of regular rapid antigen testing¹¹⁻¹³ in augmenting existing infection control practices to prevent infected individuals (in this case, the majority of whom were asymptomatic) from attending work and spreading COVID-19 to patients and other staff.

The low false-positive rate and high positive predictive value of antigen tests was invaluable because hospitals did not have to send home staff who were otherwise healthy. A higher falsepositive rate could have presented problems in maintaining staffing during the surge. For symptomatic individuals, the BinaxNOW antigen test has been shown to have 64.2% sensitivity, 100% specificity, 100% positive predictive value, and 91.2% negative predictive value; among asymptomatic individuals, the corresponding percentages are 35.8%, 99.8%, 91.7%, and 96.9%.¹⁴

We identified some pros and cons in terms of the different testing strategies implemented. With on-unit testing stations, test administrators became experts owing to the large quantities of rapid antigen tests they performed on a daily basis. However, because staff were tested on units, there was still potential unit exposure. Front entrance stations, by contrast, prevented staff from entering hospital grounds in the first place because they were tested at the point of entry. However, this testing set-up required staff to be pulled from their regular duties to operate the testing stations. In addition, the cost of daily rapid antigen tests is a consideration. Regardless of the testing station set-up, quick removal of HCPs from the workplace avoided extensive costly quarantine protocols.

We found little variation in false positives despite different implementation protocols across sites, highlighting the ease of use of rapid antigen tests with basic training. There was also evidence in our sample of a disproportionate prevalence of COVID-19 infections within certain job classifications, namely essential workers whose job duties precluded them from engaging in telework during the pandemic.

Our results show that widespread use of frequent testing can keep essential workers safe in the workplace. HCPs were overwhelmingly satisfied with the daily rapid antigen testing program, and the program improved feelings of safety for employees and their families. Our findings have significant implications for future interventions seeking to increase safety and boost morale among frontline HCPs during a pandemic.

PUBLIC HEALTH SIGNIFICANCE

A large-scale daily rapid antigen testing program was successfully implemented in which almost half a million tests were administered with low false-positive rates and high positive predictive value. The results of our study can inform future rapid antigen testing in multiple settings. Our work contributes to the growing body of literature supporting the use of rapid antigen tests as a preentry screen to reduce the number of mostly asymptomatic infected individuals entering the workplace while not falsely identifying healthy individuals as infected.⁹⁻¹¹

Many workplaces such as schools, prisons, jails, and hospital settings are currently struggling with a mixed group of vaccinated and unvaccinated staff. Although a stand-alone antigen test cannot be used to rule out a SARS-CoV-2, frequent rapid antigen testing has the potential to provide another layer of COVID-19 safety for essential workers such as teachers, law enforcement personnel, janitorial and food service workers, and health care professionals. We encourage policymakers and administrators in congregate settings to strongly consider using rapid antigen testing at the highest frequency possible (2-3 times per week or daily if resources allow) to screen large populations of individuals for SARS-CoV-2 as a means of preventing the introduction and spread of COVID-19, especially with increased transmission of the Delta and Omicron variants and rising case rates among unvaccinated and vaccinated individuals alike.

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This research was approved by the California Committee for the Protection of Human Subjects (project 2021-048). This project has an active institutional review board-approved waiver of informed consent. Obtaining informed consent was not possible. The project was initiated as part of an emergent public health response to the COVID-19 pandemic.

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When Not Implemented Communally, Citizen Science Efforts May Reflect, Reinforce, and Potentially Exacerbate Environmental Injustice

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ABSTRACT (ENGLISH)

Personal air sensors are increasingly being used to fill holes in governmental air-monitoring networks and provide users and their neighbors with accessible, accurate, and realtime information about air quality. These networks are needed given that governmental air monitors adequately cover only 19% of US counties.¹ But, as Sun et al. report in this issue (p.434), few studies have examined disparities in access to personal air sensors across space. This is critical because sensor access provides households with important health-protective information. Looking across the state of California, Sun et al. found that lower socioeconomic status, higher concentrations of fine inhalable particles with diameters 2.5 micrometers and smaller (PM_{2.5}), and greater racial/ethnic minority composition were associated

with fewer PurpleAir sensors per census tract in California. For example, poverty rates were double in tracts without any sensors, relative to those with three or more. This study, along with several others,^{2,3} is among the first to quantify socio-spatial disparities in access to personal air sensors. Importantly, Sun et al. teased out the spatial dynamics of nonoperational sensors, which are more common in socially disadvantaged tracts, and analyzed uneven growth in the PurpleAir sensor network through time. Over the four years under study, they found that California saw a 20-fold increase in the number of sensors, yet socially disadvantaged tracts had a lower rate of increase than more advantaged tracts. As PM_{2.5} is disproportionately concentrated in low-income, minority neighborhoods in California,⁴ Sun et al. and the other studies^{2,3} show the double burden experienced by residents as they also have reduced access to relevant air pollution exposure information.

FULL TEXT

Personal air sensors are increasingly being used to fill holes in governmental air-monitoring networks and provide users and their neighbors with accessible, accurate, and realtime information about air quality. These networks are needed given that governmental air monitors adequately cover only 19% of US counties.¹ But, as Sun et al. report in this issue (p.434), few studies have examined disparities in access to personal air sensors across space. This is critical because sensor access provides households with important health-protective information.

Looking across the state of California, Sun et al. found that lower socioeconomic status, higher concentrations of fine inhalable particles with diameters 2.5 micrometers and smaller (PM_{2.5}), and greater racial/ethnic minority composition were associated with fewer PurpleAir sensors per census tract in California. For example, poverty rates were double in tracts without any sensors, relative to those with three or more. This study, along with several others,^{2,3} is among the first to quantify sociospatial disparities in access to personal air sensors. Importantly, Sun et al. teased out the spatial dynamics of nonoperational sensors, which are more common in socially disadvantaged tracts, and analyzed uneven growth in the PurpleAir sensor network through time. Over the four years under study, they found that California saw a 20-fold increase in the number of sensors, yet socially disadvantaged tracts had a lower rate of increase than more advantaged tracts. As PM_{2.5} is disproportionately concentrated in low-income, minority neighborhoods in California,⁴ Sun et al. and the other studies^{2,3} show the double burden experienced by residents as they also have reduced access to relevant air pollution exposure information.

LIMITS TO MARKET-BASED CITIZEN SCIENCE

The social disparities in PurpleAir sensor locations documented in California may reflect broader limitations of market-based citizen science technologies for increasing the availability of air pollution information in an equitable manner. When not implemented communally, these citizen science efforts may reflect, reinforce, and potentially exacerbate environmental injustices. As Sun et al. found, Whiter and wealthier California communities had more sensors soon after PurpleAir started up, and then the gap in sensor access grew over time between disadvantaged and nondisadvantaged communities. These gaps converge with disparities in other air pollution protective behaviors, such as wearing air pollution masks and installing in-home air-filtration systems.⁵ The emergence of market-based approaches to monitoring air quality have shifted responsibility onto the individual consumer, and these approaches privilege those with enough affluence to buy sensors for their homes.

There are exceptions to this trend, as environmental justice communities (i.e., low income, minority communities beset by environmental challenges) have gained access to sensors and used them to monitor air quality in their communities. This is happening in the Glades region of Florida where journalists installed PurpleAir sensors so residents could track air pollution from sugar cane field burning. Residents used this information to build a legal case against the farmers for negligence in burning cane, which is now in federal court.⁶ Existing research on social disparities in access to sensors, coupled with cases of "fence-line" environmental justice communities using sensors to aid their cause, highlights how citizen science may both neglect and empower disadvantaged communities.

DEMOCRATIZING CITIZEN SCIENCE

We believe there is a role for universities, public health departments, environmental agencies, and nongovernmental organizations to democratize access to sensors by coordinating efforts to distribute sensors in socially

disadvantaged communities that lack them. There are examples of this happening that can serve as models for other communities. At the University of Utah, the AirU team brings sensors and an air quality curriculum to Salt Lake County middle and high schools.⁷ In an effort led by Mullen, we are currently working to install PurpleAir sensors in Salt Lake County environmental justice neighborhoods that are underserved by sensors. Collaborations between the City of Tacoma (Washington), Portland State University, and University of Washington have installed sensors in Tacoma and created a structure to ensure that they stay operational.⁸ Air quality agencies have also taken the lead in distributing sensors. The South Coast Air Quality District (SCAQD) in California distributed 400 sensors in environmental justice communities (Sun et al.). Puget Sound Clean Air Agency loans sensors temporarily to residents, educators, and community groups.⁹ Nongovernmental organizations are also active in increasing sensor access in communities with high need. In California, the Asian Pacific Islander Forward Movement distributed 50 sensors in northeast Los Angeles County with financial backing from the SCAQD.³ Citizens for Clean Air installed 24 sensors near Grand Junction, Colorado, to supplement the two state-run monitors to better understand how wildfire, truck traffic, and natural gas extraction are influencing local air quality.⁷

We recommend that these community leaders consider prioritizing locating sensors in community institutions, like schools, libraries, health care settings, and community centers, instead of at private homes (or in addition to private homes), for two reasons. First, these kinds of partnerships with community institutions can facilitate sensor access across a wide range of sociospatial contexts (e.g., at all schools in a district), as opposed to disproportionately at homes in affluent and White neighborhoods. Second, as Sun et al. report, it may decrease the numbers of sensors that become nonoperational over time as these institutions have reliable Internet access and electricity and are less likely to move than are private citizens. There are challenges to this approach, such as the need to install outdoor electrical outlets and troubleshoot public WiFi settings, which can be overcome with adequate lead time and committed people.

CITIZEN SCIENCE AND SOCIAL CHANGE

There are several different ways in which sensors can be used to achieve social change, some of which align more closely with the democratic ideals of citizen science than others. When approached with environmental justice as the goal, sensors are distributed in areas with the greatest need, which we argue should be characterized on the basis of high levels of PM_{2.5}, reduced access to sensors, and social disadvantage. Although environmental justice concerns may guide sensor placement in particular fence-line communities (e.g., Florida Glades⁶), such concerns are not the driving force. Instead, sensors tend to be purchased by individuals residing in relatively affluent neighborhoods (Sun et al. and other studies^{2,3}). When already privileged people have prime access to sensors, a real concern is that they may harness that information to fight local sources of pollution based on a NIMBY or not-in-my-backyard mentality. NIMBYism has the potential to intensify patterns of environmental injustice by shifting sources of pollution to already burdened communities with reduced access to information.¹⁰ Finally, there are applications that fully build on the democratic ideal of citizen science by using the public production of PM_{2.5} data as a catalyst for policy change.

In an ideal world, the information produced by an equitably distributed citizen science sensor network could be harnessed to better protect everyone's health—for example, by leveraging changes in US federal PM_{2.5} standards, which are sorely needed. A panel of esteemed scientists "unequivocally and unanimously concluded that the current PM_{2.5} standards do not adequately protect public health."¹¹(p681) In September 2021, the World Health Organization boldly cut its recommended annual average PM_{2.5} standard in half. Better monitoring and more PM_{2.5} data points, produced by engaged citizen scientists, could be instrumental in catalyzing bottom-up demands for US policy changes in PM_{2.5} standards. *AJPH*

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to report.

Sidebar

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DETAILS

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Disparities of COVID-19 and HIV Occurrence Based on Neighborhood Infection Incidence in Philadelphia, Pennsylvania

Goldstein, Neal D, PhD MBI; Webster, Jessica L, MPH; Robinson, Lucy F, PhD; Welles, Seth L, PhD ScD

[ProQuest document link](#)

ABSTRACT (ENGLISH)

Objectives. To evaluate the occurrence of HIV and COVID-19 infections in Philadelphia, Pennsylvania, through July 2020 and identify ecological correlates driving racial disparities in infection incidence. **Methods.** For each zip code tabulation area, we created citywide comparison Z-score measures of COVID-19 cases, new cases of HIV, and the difference between the scores. Choropleth maps were used to identify areas that were similar or dissimilar in terms of disease patterning, and weighted linear regression models helped identify independent ecological predictors of these patterns. **Results.** Relative to COVID-19, HIV represented a greater burden in Center City Philadelphia, whereas COVID-19 was more apparent in Northeast Philadelphia. Areas with a greater proportion of Black or African American residents were overrepresented in terms of both diseases. **Conclusions.** Although race is a shared nominal upstream factor that conveys increased risk for both infections, an understanding of separate structural, demographic, and economic risk factors that drive the overrepresentation of COVID-19 cases in racial/ethnic communities across Philadelphia is critical. **Public Health Implications.** Difference-based measures are useful in identifying areas that are underrepresented or overrepresented with respect to disease occurrence and may be able to elucidate effective or ineffective mitigation strategies.

FULL TEXT

Headnote

Objectives. To evaluate the occurrence of HIV and COVID-19 infections in Philadelphia, Pennsylvania, through July 2020 and identify ecological correlates driving racial disparities in infection incidence.

Methods. For each zip code tabulation area, we created citywide comparison Z-score measures of COVID-19 cases, new cases of HIV, and the difference between the scores. Choropleth maps were used to identify areas that were similar or dissimilar in terms of disease patterning, and weighted linear regression models helped identify independent ecological predictors of these patterns.

Results. Relative to COVID-19, HIV represented a greater burden in Center City Philadelphia, whereas COVID-19 was more apparent in Northeast Philadelphia. Areas with a greater proportion of Black or African American residents were overrepresented in terms of both diseases.

Conclusions. Although race is a shared nominal upstream factor that conveys increased risk for both infections, an understanding of separate structural, demographic, and economic risk factors that drive the overrepresentation of COVID-19 cases in racial/ethnic communities across Philadelphia is critical.

Public Health Implications. Difference-based measures are useful in identifying areas that are underrepresented or overrepresented with respect to disease occurrence and may be able to elucidate effective or ineffective mitigation strategies. (AmJ Public Health. 2022;112(3):408-416. <https://doi.org/10.2105/AJPH.2021.306538>)

The COVID-19 pandemic has highlighted how heightened rates of communicable diseases are often observed in marginalized and underserved communities. Indeed, both COVID-19 and HIV have disproportionately affected Black

and Latinx individuals across the United States.¹ Social and economic disparities associated with race and ethnicity are structural factors that could fuel both epidemics. In the case of HIV, disparities arise from exposure to institutional racism and stigma within health care settings, resulting in hesitancy to engage with the care continuum among racial and ethnic minority communities.² In addition, higher HIV rates may be related to lower incomes and lack of neighborhood access to HIV prevention services such as syringe exchange programs, resulting in the need to share injection drug paraphernalia.^{2,3}

In contrast, higher rates of COVID-19 among Black or Latinx communities are most certainly dependent on household crowding in conjunction with a greater likelihood of serving in high-risk occupations, as well as dependence on mass transit, which heightens the likelihood of increased contacts and acquisition of infection.⁴⁻⁸ Poverty may be a shared upstream determinant of each of these infections.⁹ In short, there are shared as well as unique ecological correlates driving individual risk for both infections. These specific risk factors, associated with racism, form the basis of our conceptual model leading to increased COVID-19 and HIV infections (Figure 1). Accordingly, when attempting to identify disparities in communities with an eye toward prevention and treatment, one needs a consistent metric for quantifying cases. For any given health outcome, Z-scores can be used to pinpoint areas that are substantially above or below the community average. These scores can then be correlated with various neighborhood-level risk factors to identify potential disparities. However, in an examination of the occurrence of a pair of health outcomes such as COVID-19 and HIV, comparisons of separate Z-scores would be cumbersome when identifying areas where the burden of one disease greatly outweighs the burden of another disease. Here we demonstrate the use of a difference-based approach to summarize and compare the occurrence of COVID-19 and HIV within neighborhoods. This measure may prove useful not only for revealing the heterogeneous distribution of multiple pathogens but also for describing the social milieu that give rise to disparities in the population.

We used COVID-19 and HIV surveillance data from Philadelphia, PA, a city that serves as a prototypical urban location with high rates of both infections. We hypothesized that variation in our difference-based measure would be driven by discordance of contextual social determinant risk factors that influence one's exposure and, thus, infection probability. We decided a priori to specifically highlight Center City Philadelphia (zip codes 19102, 19103, 19106, 19107, 19146, and 19147) because it is an affluent and heavily populated area with an established gay neighborhood (and thus, in all likelihood, a higher incidence of HIV) and accessible health care services.

METHODS

We designed a cross-sectional, ecological study of incident COVID-19 and HIV at the zip code tabulation area (ZCTA) level in Philadelphia, PA. Data on the geographic distribution of COVID-19 cases were obtained from the Philadelphia Department of Public Health and corresponded to the number of positive tests (deduplicated) in a given ZCTA through July 29, 2020, to capture the first wave of the pandemic in the city.¹⁰ Data on incident HIV cases in Philadelphia were obtained from AIDSVu and corresponded to the number of new cases of HIV in a given ZCTA between 2014 and 2018, the most recent year data were available,¹¹ although HIV incidence has remained stable of late.¹² The case counts in each ZCTA were divided by population size to create cumulative incidence rates per 100 000 people. Geocoding was done by residential address.

Outcome Measures

Z-scores were calculated for both COVID-19 and HIV cumulative incidences. The use of a relative, as opposed to an absolute, measure of disease frequency has the attractive property of being less influenced by the time frame of data collection; that is, COVID-19 cases had been accruing for only a few months relative to the 5 years for HIV case accrual in the AIDSVu data. Z-scores facilitated comparisons between ZCTA levels of the burden of infection for each virus and the citywide average cumulative incidence. Each unit change in the Z-scores for COVID-19 and HIV can be interpreted as an increase or decrease of 1 standard deviation in the rate of new cases relative to the citywide average incidence.

To derive the Z-score difference measure, we subtracted the HIV Z-score from the COVID-19 Z-score. A positive difference-based measure suggested that, relative to the citywide average, COVID-19 incidence was higher than HIV incidence for a given ZCTA, whereas a negative measure suggested that HIV incidence was higher than

COVID-19 incidence. A difference of approximately 0 suggested that both infections could be less than, equivalent to, or greater than the citywide averages by similar amounts; there was no clear evidence of dissimilar patterning of the infections in the given ZCTA. The choice of the order of subtractions was arbitrary and would influence only the sign of the final measure.

The creation of the Z-scores and the difference-based measure, our primary dependent variables, readily enabled cross-geographic comparisons and identification of associated risk factors.

Risk Factors

To demonstrate the use of our dependent measures to identify areas of substantial burden relative to the citywide average cumulative incidence, we posited that these ecological measures would be correlates of COVID-19 (percentage of workers employed in high-risk occupations and areas of population density^{4-7,13}), HIV (percentage of male-partnered households and number of drug overdose deaths¹⁴), or both infections (median household income, percentage of residents identifying as Black or African American, percentage of residents identifying as Hispanic or Latinx, and median age^{1,3,6,15}).

We obtained estimates of population density, occupation, male-partnered households, household income, age, and racial and ethnic composition from the 2018 American Community Survey 5-year estimates. Population density was calculated by dividing the population of each ZCTA by its area in square miles. High-risk occupation was operationalized as the percentage of residents in each ZCTA who worked as frontline workers and would be unlikely to work from home. Broadly, these occupations included those employed in service jobs (e.g., health care providers, food and beverage servers, emergency workers, child-care workers), construction and maintenance jobs, and production, transportation, and moving jobs. Male-partnered households within ZCTAs were calculated as the proportions of coupled households with primary respondents identifying as male and reporting the gender of partners as male as well. The number of unintentional drug overdose deaths was obtained from a 2019 Philadelphia Department of Public Health report¹⁶ and primarily reflected opioid deaths per ZCTA.

Statistical Analysis

We conducted descriptive analyses of Z-scores individually for COVID-19 and HIV, the Z-score difference-based measure, and the ecological risk factors, visualizing their spatial distributions via choropleth maps to assess the joint occurrence, or lack thereof, of the risk factors and the health outcomes. Correlation statistics and scatterplot matrices were used to identify bivariate associations among the risk factors and health outcomes. In addition, we used linear regression to construct 3 separate predictive models of the outcome variables: COVID-19 cumulative incidence rate, HIV cumulative incidence rate, and a joint model of COVID-19 conditional on HIV and other covariates statistically associated with each outcome (to identify possible correlates of similar and dissimilar disease patterning accounting for the ecological risk factors). Regression models were weighted by ZCTA population size to account for precision differences in incidence rates. The Wilcoxon rank-sum test was used to compare Center City and non-Center City ZCTAs in our descriptive analysis.

RESULTS

The population of Philadelphia was approximately 1.58 million people, ranging between 5000 and 75 000 residents across 47 populated ZCTAs. Case data are summarized in Table 1. A reference map identifying Philadelphia ZCTAs is available in Figure A (available as a supplement to the online version of this article at <http://www.ajph.org>).

Overall Outcome Measures

From the first reported case on March 10, 2020, through July 29, 2020, the Philadelphia ZCTA COVID-19 cumulative incidence ranged from a low of 691 to a high of 3587 cases per 100 000 people, with a mean of 1849 cases per 100 000 people (SD = 570 per 100 000; n = 5 85 057 total cases). The ZCTA HIV cumulative incidence for 2014 to 2018 ranged from a low of 28 to a high of 439 cases per 100 000 people, with a citywide mean of 198 cases per 100 000 people (SD = 112 per 100 000; n = 8508 total cases). COVID-19 incidence was lower in Center City ZCTAs (mean = 1325 cases per 100 000) than in non-Center City ZCTAs (mean = 1928 cases per 100 000; Wilcoxon rank-sum P = .01). HIV incidence was similar in Center City (mean = 221 cases per 100 000) and non-Center City (mean = 194 cases per 100 000) ZCTAs (Wilcoxon rank-sum P = .54 for difference).

Figure B (available as a supplement to the online version of this article at <http://www.ajph.org>) depicts the spatial distribution of COVID-19 and HIV Z-scores. Relative to the citywide mean, COVID-19 cumulative incidence rates were highest in West, North, and Northeast Philadelphia, with comparatively low rates in the Northwest and Center City areas. Meanwhile, relative to the citywide mean, HIV cumulative incidence rates were overrepresented in the Center City and North Central areas. Several revealing spatial patterns emerged from an examination of the difference-based measure of the 2 Z-scores (Figure 2). Twenty ZCTAs (47%) had burdens of disease similar to the citywide means; these areas tended to be located in North Central and Southwest Philadelphia. Center City and immediately west had a greater burden of HIV than COVID-19, whereas the reverse pattern was observed in the Northeast area.

To illustrate the utility of our Z-score indicators of COVID-19 and HIV, we focused on several ZCTAs with populations known to confer risk for each infection. ZCTA 19126 in North Philadelphia was 2.84 standard deviations greater than the citywide mean for COVID-19 (Z-score = 2.84) but comparable to the citywide mean for HIV (Z-score = -0.03); this ZCTA was the location of several nursing home outbreaks of COVID-19 (personal communication, Philadelphia Department of Public Health, May 2020). By contrast, ZCTA 19107 in Center City had a COVID-19 incidence rate that was approximately similar to the citywide mean (Z-score = 0.22) but exhibited an increase in HIV incidence of more than 2 standard deviations (Z-score = 2.09); this ZCTA is the heart of the city's gay neighborhood. In West Philadelphia, ZCTA 19142 had incidence rates in excess of 1 standard deviation above the citywide average for both COVID-19 (Z-score = 1.31) and HIV (Z-score = 1.68). This ZCTA has comparatively high proportions of residents in high-risk occupations and per capita overdose deaths. The difference-based measure of these Z-scores revealed areas of both similar disease patterning (ZCTA 19142 difference score = -0.37) and dissimilar disease patterning (ZCTA 19126 difference score = 2.87, ZCTA 19107 difference score = -1.86).

Associations With Risk Factors

The distribution of risk factors revealed distinct spatial patterning (Figure C, available as a supplement to the online version of this article at <http://www.ajph.org>). High-risk occupations were least frequent in Center City and the Northwest area and most frequent in the North and Northeast areas, with almost opposite geospatial patterning of median household income (Figure C). Accordingly, these 2 determinants were strongly inversely correlated ($r = -0.73$; $P < .01$) and related to higher COVID-19 Z-scores (Figure B). Population density was greatest in Center City and the West and North areas (Figure C).

The ZCTAs that proportionally had the most Black or African American residents were in West and North Philadelphia, and Hispanic and Latino residents tended to live in the North and Northwest areas (Figure C). Meanwhile, the highest proportions of male-partnered households were in Center City and immediately south and northeast (Figure C). Both population density and occupation followed expected patterns in the Center City area relative to neighborhoods outside of Center City: greater population density and fewer residents in high-risk occupations in Center City ($P < .01$ for each).

Increased proportion of high-risk occupations ($r = 0.44$; $P < .01$), decreased household income ($r = -0.44$; $P < .01$), and increased proportion of Black or African American residents ($r = 0.62$; $P < .01$) were all correlated with COVID-19 incidence. Meanwhile, increased overdose deaths ($r = 0.36$; $P < .01$), decreased household income ($r = -0.45$; $P < .01$), increased proportion of Black or African American residents ($r = 0.50$; $P < .01$), and lower median age ($r = -0.47$; $P < .01$) were correlated with HIV incidence. Scatterplot matrices (Figure D, available as a supplement to the online version of this article at <http://www.ajph.org>) indicated visual agreement with the spatial patterning depicted in Figure 2 and Figures B and C.

Table 2 presents the multiple linear regression estimates. Higher proportion of Black or African American residents ($b = 5.4$; 95% confidence interval [CI] = -0.4, 11.2) and higher median age ($b = 38.1$; 95% CI = 6.5, 69.8) were important predictors of COVID-19 incidence. Greater proportion of Black or African American residents was also an important predictor of an increase in HIV incidence ($b = 2.6$; 95% CI = 1.8, 3.4) along with an increased proportion of male-partnered households ($b = 183.6$; 95% CI = 113.0, 254.1), a higher proportion of Hispanic or Latinx residents ($b = 1.6$; 95% CI = -0.2, 3.1), and number of overdose deaths ($b = 36.2$; 95% CI = 7.4, 65.0). When COVID-19

incidence additionally accounted for HIV in the model, the proportion of Black or African American residents remained significant ($b = 7.0$; 95% CI 5 1.6,12.4), suggesting that race is a shared upstream factor in both infectious disease etiologies.

DISCUSSION

Our findings suggest the usefulness of a visual method to identify and quantify areas of greatly increased disease incidence that are often associated with racial and ethnic disparities, as is currently being observed with COVID-19 infection in Black and Latinx communities in the United States.¹ Not only does this proposed method offer immediate visualization and identification of areas of high disease incidence relative to citywide averages, but our results suggest that the use of disease incidence difference-based measures may identify putative demographic and income-based determinants of disease outcomes, explaining discordance or concordance of levels of multiple infections.

Moreover, we have presented analyses using ZCTA-specific infection data from Philadelphia as a demonstration of metropolitan area surveillance when identifying neighborhoods with infection or disease burden disparities. We emphasize that our difference-based measures must be interpreted in the context of individual Z-scores to identify the outcome driving the difference. As shown in Figure 2, there are multiple mechanisms by which a difference score could be equivalent (e.g., the difference between 2 elevated Z-scores could be the same as the difference between 1 elevated Z-score and 1 nonelevated Z-score), and although the measure is helpful in identifying heterogeneity it may not, in isolation, be able reveal the source.

As cautioned by others, it is important that we are explicit about our definition of race and ethnicity in our work.¹⁷ These are not proximal factors for COVID-19 or HIV infection; there is no biological basis for such a claim. Although COVID-19 and HIV share upstream nominal risk factors of race and ethnicity as determinants of increased rates of infection, with an increased incidence of both infections among people of color as *prima facie* evidence of downstream effects of discrimination or stigma,^{6,15} this is where the similarities in mechanisms end. One can hypothesize a causal cascade initiated by upstream racism and ethnic discrimination resulting in divergent pathways to increased COVID-19 and HIV transmission (Figure 1).

Specific to Philadelphia, our results indicate that, ecologically, the occurrence of COVID-19 and the occurrence of HIV do not follow obvious boundaries or share the same demographic parameters aside from race. The discordance of COVID-19 infection with HIV in Center City, as well as Northeast and Northwest Philadelphia, suggests that exposure patterns and risk factors differ by location and that any citywide public health intervention targeting a shared risk factor is unlikely to achieve homogeneous, effective results. This discordance is further supported by previous descriptive studies reporting relatively few cases of HIV infection among patients hospitalized for COVID-19.¹⁸

For example, HIV was more common (relative to citywide averages) in 2 distinct areas that are quite different in terms of socioeconomic status, Center City and immediately north of Center City, whereas COVID-19 was more common immediately north but not in Center City. Center City is the residential center for more affluent, professional individuals who choose to live in highrise buildings, as reflected in areas with the highest number of housing units, the highest population density, and the lowest average number of occupants per housing unit, and these individuals often do not work in professions that confer a higher risk of COVID-19. Immediately north of Center City, the north Broad Street area is characterized by high population density, low household income, greater injection drug use, and a greater proportion of residents who work in high-risk occupations.

Conversely, in areas with high rates of COVID-19 infection and a relatively low incidence of HIV, Philadelphia's Northeast area stands out in having a lower population density overall but also in having residents more likely to report occupations involving a high risk for COVID-19 exposure and infection, jobs that increase interactions with other people outside of their households and, thus, their chance of exposure to infection.¹³ Previous work has established that areas with lower deprivation are more likely to have access to COVID testing.¹⁹ Thus, the preponderance of COVID-19 cases in certain areas of the city, such as the Northeast, may relate to patterns of greater testing rather than reflecting a true community burden. Indeed, new cases of HIV were less likely to be found

in the Northeast and Northwest, 12 areas with some of the highest differences in Z-scores.

Our results agree with previous studies that considered residential and occupational contextual factors in efforts to explain racial and ethnic disparities concerning COVID-19 incidence.^{6,15} In these earlier reports, increased reliance on public transportation and involvement in a frontline occupation were drivers explaining a higher incidence of COVID-19 infection within communities of color. Thus, our findings support a model of population mixing as a major determinant of COVID-19 and argue against the shared risk profile view of HIV and COVID-19 put forth by others.⁹ Although both HIV and COVID-19 are communicable, the COVID-19 pandemic is fueled not through intimate behaviors but, rather, through reduced social distancing with others at high risk for infection as a result of various factors (e.g., occupation, reduced ability to work from home; Figure 1). Before extrapolating our results to other geographic areas, readers should consider the possibility of effect modifiers in the target population, such as differences between urban and rural locales.

Limitations and Strengths

We acknowledge 3 limitations. First, the ecological nature of this study precludes identifying causal mechanisms, and we caution against inferring individual-level associations. Second, the limited sample size may have obscured associations present in Philadelphia. For example, our regression estimates for age as an independent risk factor for COVID-19 suggested an association in the expected direction despite the confidence interval containing the null. Third, our reliance on reported case data did not take into account potential inaccuracies in surveillance. Despite the mandatory reporting requirement for a diagnosis of COVID-19 (or HIV), underreporting is likely. Previous work has suggested that underreporting may differ by ZCTA and is likely related to factors such as access to testing, occupation, and testing accuracy.^{20,21} Our use of these data served as a prototypical example of the proposed methods as opposed to construction of a causal model.

Finally, we need to emphasize that assessments of ZCTAs may not correctly identify where COVID-19 or HIV cases were acquired. Residents of ZCTAs with a high incidence of COVID-19 may have acquired infection at the workplace or traveling throughout the city for recreational activities. Similarly, given the long duration of HIV infection, HIV-positive residents of ZCTAs with a high incidence may have acquired infection in other parts of the city or in other geographic areas. Thus, neighborhoods themselves may not be mechanistically related to infection; rather, they may be residential centers for individuals who are at high risk of infection owing to demographic or occupational factors.

These limitations notwithstanding, our findings underscore the utility of employing comparisons of infection Z-scores to identify potential discordant sets of risk factors when using geospatial approaches to identify locations of greatest need for intervention. These methods can readily be applied to other diseases, such as ecological comparisons of syphilis and chlamydia rates among men who have sex with men in the search for drivers of the co-occurrence of these 2 sexually transmitted infections.

Public Health Implications

Public health intervention and prevention programs are driven by surveillance, in which decisions are made, as needed, at distinct points in time. It is important for health departments to identify areas that are underrepresented or overrepresented in terms of occurrence of disease, which can elucidate effective or ineffective mitigation strategies. We have demonstrated the application of a difference-based measure of COVID-19 and HIV incidence in Philadelphia in the search for ecological correlates of the 2 diseases, with a specific focus on explaining racial and ethnic disparities. Although it is possible that Black and Latinx individuals share nominal upstream factors that convey an increased risk for both infections, there are certainly other, non-HIV-related risk factors driving the overrepresentation of these individuals among COVID-19 patients. Other locations might consider operationalizing a difference-based disease Z-score measure for comparisons between geographic locations or infection occurrence at different points in time. ⁴PU

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CONTRIBUTORS

N. D. Goldstein and S. L. Welles were involved in the initial conceptualization of the work for this article. N. D. Goldstein and J. L. Webster conducted all of the analyses. N. D. Goldstein, J. L. Webster, and S. L. Welles developed the figures and tables. All of the authors were involved with the development of the analyses and contributed to the writing and editing of the article.

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

HUMAN PARTICIPANT PROTECTION

No protocol approval was needed for this study because publicly available data were used.

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DETAILS

Subject:	Infections; Public health; COVID-19; Regression analysis; Disease; Regression models; Neighborhoods; Risk factors; Human immunodeficiency virus--HIV; Population density; Viral diseases; Risk analysis; Ecological effects; African Americans; Race factors; Racism; Mitigation; Residents; Pandemics; Ethnic factors; Family income; Race; Coronaviruses; Households; Tabulation; Health risks; Racial differences; Economic factors; Ethnic groups; Ecological models; Drug overdose; Racial inequality
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Allocating Homeless Services After the Withdrawal of the Vulnerability Index-Service Prioritization Decision Assistance Tool

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[ProQuest document link](https://www.proquest.com/scholarly-journals/disparities-covid-19-hiv-occurrence-based-on/docview/2638088089/se-2?accountid=211160)

ABSTRACT (ENGLISH)

Until there are sufficient resources to end homelessness in the United States, communities will struggle with how to allocate limited homeless services. The Department of Housing and Urban Development (HUD) requires

communities to establish a coordinated assessment system using a standardized tool to prioritize services.¹ Until recently, the most widely used tool was the VI-SPDAT (Vulnerability Index-Service Prioritization Decision Assistance Tool) for single adults or a modification for youths and families.² The tool assesses individuals' level of vulnerability across their history of housing and homelessness, individual risk factors, socialization and daily functions, and wellness. It then prioritizes people with the highest scores for permanent supportive housing, those with intermediate scores for short-term, rapid-rehousing subsidies, and those with the lowest scores for minimal services. Typically, use of the VI-SPDAT conflates risk assessment with allocation of services, where only the vulnerability score is used to match people to housing and services. The tool has been criticized as invalid and unreliable³ and racially biased,⁴ but also defended as predicting returns to homelessness.⁵ There is little justification for the cutoffs between recommended housing options (although, frequently, communities lack sufficient resources to follow these recommendations). Ultimately, widespread concerns led the VI-SPDAT's creators to stop supporting its use.² This change requires communities to confront both empirical and ethical questions that the availability and near field-wide adoption of a tool, however flawed, allowed them to avoid. To aid communities as they confront these questions, we discuss three issues central to the design of a coordinated assessment processes: risk assessment (what should count as risk?), prioritization (who should get services first?), and matching (who should receive what?). In addition, we draw on bioethical frameworks for allocating scarce medical interventions to inform decisions.

FULL TEXT

Until there are sufficient resources to end homelessness in the United States, communities will struggle with how to allocate limited homeless services. The Department of Housing and Urban Development (HUD) requires communities to establish a coordinated assessment system using a standardized tool to prioritize services.¹ Until recently, the most widely used tool was the VI-SPDAT (Vulnerability Index-Service Prioritization Decision Assistance Tool) for single adults or a modification for youths and families.² The tool assesses individuals' level of vulnerability across their history of housing and homelessness, individual risk factors, socialization and daily functions, and wellness. It then prioritizes people with the highest scores for permanent supportive housing, those with intermediate scores for short-term, rapid-rehousing subsidies, and those with the lowest scores for minimal services. Typically, use of the VI-SPDAT conflates risk assessment with allocation of services, where only the vulnerability score is used to match people to housing and services. The tool has been criticized as invalid and unreliable³ and racially biased,⁴ but also defended as predicting returnsto homelessness.⁵ There is little justification for the cutoffs between recommended housing options (although, frequently, communities lack sufficient resources to follow these recommendations). Ultimately, widespread concerns led the VI-SPDAT's creators to stop supporting its use.² This change requires communities to confront both empirical and ethical questions that the availability and near field-wide adoption of a tool, however flawed, allowed them to avoid. To aid communities as they confront these questions, we discuss three issues central to the design of a coordinated assessment processes: risk assessment (what should count as risk?), prioritization (who should get services first?), and matching (who should receive what?). In addition, we draw on bioethical frameworks for allocating scarce medical interventions to inform decisions.

WHAT SHOULD COUNT AS RISK?

Most homeless service systems seek to assess risk and prioritize resources accordingly. But how should risk be defined? It is useful to contrast decisions about allocation of services to people who are currently homeless with the situation of homelessness prevention. In the case of prevention, the outcome of interest is clear: homelessness. Given a data set of predictors (say, questionnaire responses from applicants for services, or information about use of other services), it is not hard to build an empirical predictive model identifying people most likely to become homeless.⁶⁻⁸ One must still choose whether to offer scarce prevention services to those at highest risk or where they make the most difference. (If some people are likely to become homeless regardless of the help they receive, communities might want to adopt a triage model, serving those at moderate risk.) In the case of homelessness prevention, research shows that these decisions coincide: all types of services studied (whether cash for eviction prevention, casework to connect households to resources, or long-term housing vouchers) prevent the most homelessness when given to applicants at highest risk.^{7,9,10}

In the case of restoring currently homeless people to housing, it is less clear what sort of risk matters. Characteristics associated with becoming homeless in the first place? Risk for mortality on the streets? Physical or mental harms that may result from homelessness? These criteria are what the field typically calls vulnerability. However, evaluations of the VI-SPDAT have examined only returns to homelessness as a criterion, with mixed results. Brown et al. found no significant relationship between VI-SPDAT scores and returns to homelessness in one community,³ whereas Petry et al. did find a relationship in a multicomunity sample.⁵ Both found that type of housing assistance provided was a significant predictor. Allegheny County, Pennsylvania has recently developed a decision tool designed to measure need based on risk of harm using local administrative data rather than self-report. It combines three empirical predictive models for jail bookings, inpatient behavioral health stays, and frequent emergency room use, and is superior to the VI-SPDAT in predicting these outcomes.¹¹ Current data show that the new tool prioritizes more African American clients and men than the VI-SPDAT. However, most jurisdictions lack access to the integrated data systems that would allow this approach.

HUD describes the types of risk that communities can consider in assessments,¹² but local systems must decide the outcomes they deem most important, such as vulnerability to illness, victimization, risk of continued homelessness, or use of emergency services (and associated costs). Communities must also make two more decisions: how to prioritize those assessed, and which services to provide to which individuals and families.

WHO SHOULD GET SERVICES FIRST?

Should systems prioritize interventions to those at highest risk (however defined), determine where services make the most difference, or base allocation on some other value criterion? Although HUD states that homeless service systems should "prioritize people who are more likely to need some form of assistance to end their homelessness or who are more vulnerable to the effects of homelessness,"¹² other values often play in policy decisions. For example, as a nation, the United States has given priority to military veterans, with special resources made available by HUD, the Department of Veterans Affairs, and cities that participated in the Mayor's Challenge. Setting these priorities cut veteran homelessness nearly in half from 2010 to 2019,¹³ while rates of homelessness among other groups stagnated. Privileging veterans is a value proposition (people who serve their country should not be homeless) that is not one based on risk or maximizing program effects. But one could argue the ethics of prioritizing other populations. Following are a few of many possible examples:

- * Infants, to prevent consequences to early development.
- * African Americans and Native Americans, to advance racial justice and redress past harms and ongoing discrimination that put them at heightened risk of homelessness.
- * Youths, or perhaps young people aging out of foster care, to set their lives on a better trajectory.
- * People exiting incarceration whose risk of homelessness and recidivism are high without help.
- * People fleeing violence, to provide safety and security.
- * People with mental illnesses and other disabilities, who may be more likely to become chronically homeless.
- * People who have been homeless the longest, who have suffered the longest.
- * People who are not merely unhoused but also unsheltered (e.g., living on the streets), to protect them from the environmental hazards of living in places not meant for human habitation.

Advocates and policymakers might endorse many or all of these criteria. However, many conflict in both obvious ways (infants cannot be veterans) and more subtle ones. For example, because African Americans are more likely to use shelters than their White counterparts,¹³ a rule that prioritizes unsheltered people also favors White people.

WHO SHOULD GET WHAT?

Finally, communities must determine how to allocate different interventions. Many coordinated assessment systems, including typical use of the VI-SPDAT, assume that a single spectrum of service needs matches neatly onto tiered service intensity. The top tier is usually long-term housing assistance, with or without services. Randomized control trials have found that such assistance is most effective at ending homelessness. In the case of families, the 12-site Family Options randomized controlled trial showed that long-term subsidies that hold rental costs to 30% of income both end homelessness and have radiating benefits for other aspects of family life, without any dedicated services.

Neither short-term rapid-rehousing subsidies with modest services nor midterm transitional housing with extensive social services were much more effective for reducing homelessness or enhancing other aspects of well-being than usual care.¹⁴ In the case of individuals with serious mental illnesses and co-occurring substance use disorders, the five-site At Home Chez-Soi randomized controlled trial showed that permanent supportive housing following a Housing First approach with no prerequisites for entry, and with an emphasis on consumer choice, helped people get and stay housed better than programs that focused on changing behavior.^{15,16}

These studies showed average effects across all people studied. But does everyone need long-term interventions? Might some people flourish with more modest and less expensive services? If so, more people could be served. The Family Options study examined this question and found no evidence that interventions were differentially effective for families with more or fewer housing barriers, such as a history of eviction, or for families with more or fewer psychosocial challenges, such as substance abuse.¹⁴ One descriptive study of the VI-SPDAT found that returns to homelessness were higher for people with higher scores regardless of housing destination, but it did not test whether the associations differed depending on housing type.⁵ In general, the field lacks evidence about differential effects of interventions based on recipients' characteristics.

Cost savings, across all publicly funded systems, may also be less than supposed. In the Family Options study, offering families open-ended housing vouchers led to costs across all housing programs only 9% greater than for usual care over 37 months. Offering short-term rapid-rehousing subsidies cost 9% less than usual care.¹⁴ In the case of permanent supportive housing, a National

Academies report found the evidence of cost-benefit too weak to support any conclusion.¹⁷

Two approaches separate assessments from decisions about how to allocate interventions. The Canadian Homelessness Partnering Secretariat advocates two stages.¹⁸ The first stage assesses severity of need and risk of harm to self or others, along with patterns of homelessness and service use. The second involves planning for supportive services, including individual goals and preferences, strengths as well as problems, and past history of actions and responses. Community resources are an additional constraint. This procedure departs in critical ways from assigning resources based on an assessment score. Perhaps most importantly, once a person qualifies for services, individual choice matters. The Allegheny model similarly uses two phases.

Another possibility, known as progressive engagement, forgoes the assessment phase altogether and makes allocation decisions over time.¹⁹ It starts by offering minimal, inexpensive services to everyone. People who fail when given those minimal services get something more, with the most extensive and expensive services reserved for those who do not succeed at earlier stages. Starting with a "light touch" permits serving more people. Offering cheaper, less effective treatments to more people under conditions of scarcity may be justified ethically,²⁰ but has psychological costs. Mothers assigned to rapid rehousing following a progressive engagement model in the Family Options experiment found the uncertainty about the length of assistance "nerve-wracking," and that the program was "designed to keep you down, because the minute you make too much money they start taking everything away from you."²¹(p377)

INSIGHTS FROM BIOETHICS

To grapple with these questions, the homeless services field might benefit from literature in public health and bioethics concerned with allocating scarce medical interventions, where experts have named, debated, and tested principles for resource allocation. Seminal pieces argue that no criteria are value-free, and no single principle can allocate scarce interventions justly.²² Instead, the best processes are multiprinciple allocation systems to incorporate the complexity of our moral values. The most common principles used in medical resource allocation include treating people equally (lottery and first-come-first-served), favoring the worst off (or "prioritarianism"; e.g., sickest first or those who have had the least life), maximizing total benefits (or "utilitarianism"; e.g., benefiting the greatest number of people or maximizing the years of life saved), and, finally, rewarding social usefulness (e.g., past-oriented "reciprocity" or future-oriented "instrumental value" for essential workers or others seen to carry out important societal tasks).²²

Although most assessments and prioritization processes in the homelessness field have multiple ways to earn

"points," they may not integrate multiple principles. For example, the VI-SPDAT follows prioritarianism, favoring the most vulnerable first. Prioritizing veterans follows "reciprocity," rewarding social usefulness or societal values. Most public housing authorities use a mix of "treating people equally" and prioritarianism, using random lottery waiting lists and point-based eligibility to move up the list.

Other scholars have proposed using "categorized priority systems," or reserve systems, to divide resources across multiple categories of flexible size, and allow for the use of different priorities across them.^{23,24} Such systems have been used to manage school choice, allocate H-1B visas, assign marathon slots, and implement affirmative action policies. In the case of scarce medical resources, medical ethicists have promoted reserve categories for people with disabilities and essential personnel, based on different principles.²³ Such systems give everyone a chance but increase chances based on multiple, sometimes even incommensurable principles. For example, Allegheny County separates estimation of risk from a set of "business rules" that prioritize by risk, chronicity, and special eligibility categories (families, people fleeing domestic violence, and veterans).¹¹

Finally, recent work in public health in light of the COVID-19 pandemic can help the homeless service system integrate racial equity into decision frameworks. One study evaluated the efficacy, ethicality, and legality of different methods to reduce racial and ethnic disparities in COVID-19 treatments.²⁵ After reviewing decades of legal precedent, the article concluded that individual-level prioritization by race or ethnicity (excepting Native American tribal status) is likely to lead to legal challenges, but prioritizing factors associated with race, such as zip codes, and lowering age-based eligibility in disadvantaged neighborhoods (with lower life expectancy) can reduce racial disparities and meet legal scrutiny. Finally, it suggested that across frameworks, systems should be explicit about the value choices inherent in the allocation of scarce resources, rather than outsourcing decisions to an instrument.

CONCLUSION

Research has provided substantial evidence about how to prevent and end homelessness, if policymakers are willing to devote the resources to do so.⁹ As long as funding remains insufficient, departure from the VI-SPDAT requires communities to confront difficult questions regarding the allocation of scarce resources to end homelessness, from assessment of risk to prioritization and matching. Some questions, such as risk factors for mortality, chronicity, or returns to homelessness after housing, are empirical. But the most important questions involve values and system design. What outcomes does the community seek to avoid? Who should be prioritized against those outcomes? Persad et al. write, "Many allocation systems do not make their content explicit, nor do they justify their choices about inclusion, balancing, and specification. Elucidating, comparing, and evaluating allocation systems should be a research priority."²²(p426) These conclusions apply as well to homeless services as to the medical decisions Persad et al. describe.

In contexts of limited resources, we suggest that communities adopt trauma-informed assessment procedures that examine the risk of outcomes that collaborators with experience of homelessness seek to avoid. For prioritization, we suggest that communities use multiprinciple allocation decisions. Two groups that might receive categorical priority are families with children and individuals with disabilities. Additional categorical allocations might go where services are likely to make the most difference with respect to outcomes that communities have chosen. Groups at high risk of harm include people whose medical conditions are sensitive to housing,¹⁷ people exiting incarceration, or youths exiting foster care. For the large remaining group, prioritizing on length of homelessness would give everyone a chance, although realistically, scarce resources may make that chance small. Communities could choose differently. Throughout, communities should be vigilant that systems are equitable racially and counteract structural disadvantage. To determine service type, systems should incorporate consumer choice, case conferencing, and evidence of effectiveness. Although departure from the VI-SPDAT presents a challenge, it also presents an opportunity to design better systems. AJPH

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Worth Slowing Down for: Road Signs and Messages About the COVID-19 Pandemic

Mandelbaum, Jennifer, MPH

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ABSTRACT (ENGLISH)

There has been much discussion about the messaging on COVID-19, much of it focused on how the public interprets federal and state guidance on protective measures such as vaccinations and mask wearing. One overlooked strategy is private businesses using their road signage to support (or negate) public health practices related to the pandemic (Figures 1-4). Large signs outside businesses have the potential to reach a broader, more diverse audience than paper signs on doors advising patrons to follow Centers for Disease Control and Prevention guidelines. Whereas flyers about vaccination status and mask wearing on store entrances reach only the customers entering that business (and therefore may be viewed more often by a particular demographic), road signs can be seen by anyone passing by, regardless of intent to enter. Road signs raise several questions about the aim behind them. For example, what motivates businesses to shift their messaging away from weekly specials or new products and to public health? The economy and public health are inextricably linked; businesses, especially those that are service oriented, benefit from the general public practicing recommended preventive measures. The US pandemic response centers on the idea that restrictions (e.g., on occupancy) can be eased as the community spread of COVID-19 declines. More than the economic benefits of curtailing the pandemic, though, these messages may speak to something about collective action and reflect the public nature of pandemics. They are a reminder that few, if any, people have been spared the impacts of COVID-19.

Road signage could also be a means of tackling misinformation and making inroads with people who have hesitations about the COVID-19 vaccines. Private businesses may carry a type of cultural capital with the general public that experts (e.g., physicians and researchers on television and social media) do not. This capital may be used to engender greater trust in public health practices, policies, and institutions. Signage democratizes messaging about the pandemic, giving private citizens a voice to express their feelings about public health. Importantly, that also means that the content of road signs can steer the public away from sound public health practices or direct malice toward health departments and professionals. Rather than promoting public health, road signs could be used to cut deeper partisan divides into COVID-19 messaging.

FULL TEXT

There has been much discussion about the messaging on COVID-19, much of it focused on how the public interprets federal and state guidance on protective measures such as vaccinations and mask wearing. One overlooked strategy is private businesses using their road signage to support (or negate) public health practices related to the pandemic (Figures 1-4). Large signs outside businesses have the potential to reach a broader, more diverse audience than paper signs on doors advising patrons to follow Centers for Disease Control and Prevention guidelines. Whereas flyers about vaccination status and mask wearing on store entrances reach only the customers entering that business (and therefore may be viewed more often by a particular demographic), road signs can be seen by anyone passing by, regardless of intent to enter.

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The profusion of road signs addressing public health practices may reflect the unique, wide-reaching impact of the COVID-19 pandemic. Accurate, timely, and noticeable communication strategies are needed to combat challenges to effective health communication, including uncertainty, fear, and doubt. Private businesses, of their own volition, have used valuable advertising space to advocate (or contradict) practices that support public health. Road signs might be something to slow down for. -4JPU

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Structural Inequities, HIV Community-Based Organizations, and the End of the HIV Epidemic

Robillard, Alyssa G, PhD MCHES; Julious, Carmen H, MSW; Smallwood, Stacy W, PhD MPH; Douglas, Mark, MSW MEd; Gaddist, Bambi W, DrPH; Singleton, Tyler, MSW

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ABSTRACT (ENGLISH)

Community-based organizations (CBOs) are integral to achieving the goal of Ending the HIV epidemic (EHE). Their familiarity with and proximity to communities position them to effectively implement strategies necessary to address determinants of health through their formal and informal medical and social services. However, structural inequities have contributed to the demise of many organizations that were instrumental in early responses to the HIV epidemic. We define structural inequities for HIV CBOs as systems in which policies, institutional practices, organizational (mis)representations, and other norms work to produce and maintain inequities that affect CBOs' ability to survive and thrive. In this discussion, we describe the organizational threats to grassroots HIV CBOs and the risks to livelihood and longevity, including examples. The invaluable role of HIV CBOs in EHE and their role in responding to existing and novel infectious diseases like COVID-19 should not be overlooked. Recommendations to promote structural equity are offered.

FULL TEXT

Headnote

Community-based organizations (CBOs) are integral to achieving the goal of Ending the HIV epidemic (EHE). Their familiarity with and proximity to communities position them to effectively implement strategies necessary to address determinants of health through their formal and informal medical and social services. However, structural inequities have contributed to the demise of many organizations that were instrumental in early responses to the HIV epidemic. We define structural inequities for HIV CBOs as systems in which policies, institutional practices, organizational (mis)representations, and other norms work to produce and maintain inequities that affect CBOs' ability to survive and thrive. In this discussion, we describe the organizational threats to grassroots HIV CBOs and the risks to livelihood and longevity, including examples. The invaluable role of HIV CBOs in EHE and their role in responding to existing and novel infectious diseases like COVID-19 should not be overlooked. Recommendations to promote structural equity are offered.

Ending the HIV Epidemic (EHE) in the United States is an initiative of the US Department of Health and Human Services to reduce new HIV infections by 75% in the next 5 years, and by 90% in the next decade, by partnering with local and state health agencies to systematically test, expand access to medication (including pre-exposure prophylaxis), and respond quickly to potential outbreaks.¹ Successful strategies to achieve those goals include culturally appropriate and trauma-informed care, prevention and treatment of individuals at increased risk for acquiring HIV or falling out of care, development and distribution of an effective vaccine and universally accessible HIV cure, and outbreak monitoring and surveillance.² Social determinants that drive HIV-related disparities, including stigma, discrimination, poverty, unemployment, geography (regional and rural), and access to health care, also require targeted approaches.³

Ending the epidemic is multisectoral in nature.² The role of community-based organizations (CBOs) has historically been and continues to be integral in achieving that goal. Community-based nonprofit organizations serving highly vulnerable populations living with or at increased risk for acquiring HIV (subsequently referred to as HIV CBOs) are critical to achieve real-world impact.⁴ Their proximity to the communities they serve positions them to effectively implement strategies necessary to EHE, including efforts to address determinants of health through formal and informal medical and social services (e.g., linkages to care, housing, transportation, peer support).^{5,6} However, many organizations that were instrumental in responding to the US HIV epidemic have not survived in the changing landscape of prevention, care, and treatment as a result of structural inequities⁷⁻⁹—including Black, Indigenous, and people of color (BIPOC)—led CBOs that serve populations within and throughout their communities.

THE EVOLUTION OF GRASSROOTS HIV ORGANIZATIONS

Organizational ecology posits that the emergence and dissolution of organizations depend on selection and adaptation.¹⁰ Selection occurs when sociopolitical environments create space that optimizes some organizational characteristics over others. Adaptation occurs when organizations change their characteristics to align with evolving environmental conditions¹⁰ for the sake of their survival. HIV CBOs emerged within a sociopolitical climate that

warranted a critical response to a novel infectious disease observed initially among White gay men. As the epidemic progressed, it expanded to communities of color, including Black and Latinx communities that remain disproportionately affected and underserved today. Well before clinicians, researchers, or social service providers fully understood the virus or its pathology, local community groups were organizing activist efforts toward support, advocacy, calls for further research, and memorializing those lost within their communities. These local groups established grassroots CBOs that served hybrid purposes: activism and service.¹¹ They supported people living with HIV (PLWH) physically, socially, and emotionally, often with miniscule resources.

Organizational evolution is a theoretical variation of organizational ecology that highlights the role of contextual, environmental, and interorganizational factors that influence how organizations develop, change, and survive.¹² Studies of nongovernmental organizations have examined their ability to adapt in the interest of longevity, emphasizing their active agency in doing so.¹³⁻¹⁵ As the HIV epidemic evolved, many organizations expanded their focus from solely primary prevention to include secondary prevention strategies, such as case management and other support services for PLWH. CBOs focusing on HIV today offer services that include prevention education, HIV and sexually transmitted infection testing, harm reduction, behavioral health, substance use counseling and treatment, mental health services, patient navigation, case management, and medical care and treatment. These HIV organizations evolved because their adaptation was a necessary consequence of the changing landscape of HIV and the widening network of institutions involved in the response.¹⁶ This has kept organizational mortality at the forefront for many HIV CBOs, and caused the dissolution of many others. Grassroots organizations helped to shape early social and political responses to HIV.¹⁷ However, based on our collective observations, many have not survived.

STRUCTURAL INEQUITIES

Structural inequities are defined as the policies and practices embedded in systems that operate to produce inequitable distribution of the determinants of health.¹⁸ Borrowing from definitions of structural racism,^{19,20} we describe structural inequities as systems in which policies, institutional practices, organizational (mis)representations, and other norms work to produce and maintain inequities that affect CBOs' ability to survive and thrive. These inequities manifest economically, politically, socially, and culturally in ways that usurp autonomy and minimize CBOs' capacity by virtue of their proximity to the of ten-minoritized communities they serve. We see these inequities persist and manifest with the COVID-19 pandemic, during which, despite disproportionate burdens of risk and incidence among BIPOC populations, responses largely failed to consider the integral role of CBOs in reaching vulnerable groups.

CBOs must be centered and supported as we focus on ending the HIV epidemic. As representatives of and advocates for HIV CBOs, we offer this reflection to highlight the critical role of structural equity among grassroots organizations toward achieving EHE's goals. We describe the organizational mortality of HIV CBOs and threats to livelihood and longevity, including examples from our own collective experiences and observations. We then discuss the invaluable role of HIV CBOs in ending the epidemic, their role in responding to existing and novel infectious diseases like COVID-19, and recommendations to promote structural equity.

ORGANIZATIONAL MORTALITY: THREATS TO SURVIVAL

Advances in prevention and treatment paved the way for game-changing developments that reshaped the landscape of confronting the HIV epidemic.²¹ The advent of the Affordable Care Act (ACA) necessitated consideration of changes in funding streams. The National HIV/AIDS Strategy and the Centers for Disease Control and Prevention's (CDC's) High-Impact HIV Prevention interventions shifted attention and funding to key populations and select strategies in areas with a high burden of disease. The "treatment-as-prevention" approach demonstrated effectiveness in improving health outcomes for PLWH as well as interrupting transmission.²² Lastly, changes in the economy decreased access to government funding and private foundations for nonprofit organizations.²¹ A 2013 report examined the impact of changes in HIV prevention, funding, and treatment on the stability and sustainability of AIDS service organizations and CBOs, with emphasis on fiscal health, capacity to deliver and link to medical care, and leadership and governance.²¹ Many organizations reported

struggling financially. The report also indicated that organizations were concerned about the levels of knowledge and engagement of their administration and boards of directors and their ability to lead through a changing landscape. Such changes necessitated a fundamental restructuring of organizational business models not only to better serve clients, but also to remain viable.²³ We were unable to find a formal examination of the organizational mortality of HIV CBOs; therefore, it is difficult to know the number of organizations that have not survived. Recent findings from a national annual survey of HIV/ AIDS service organizations and CBOs indicate that stability and sustainability remain concerns.²⁴ Environmental and organizational challenges affect sustainability, broadly categorized as (1) financial threats, (2) organizational capacity and the ability to provide and link to medical care, (3) leadership and governance, and (4) organizational biases. We examine each through the lens of our collective professional leadership experiences.

Financial Threats

HIV CBOs depend on funding for stability and sustainability. Many were negatively affected by funding changes wrought by the changing HIV landscape, resulting in less funding for health departments and thus less funding for their local HIV CBOs, even as private funding for HIV CBOs also became scarce. Changes in federal mandates that no longer defined "minority organizations" as having executive directors of color and boards of directors at least 50% minority in makeup, shifted funding potential away from smaller minority-led CBOs, making it nearly impossible to compete with larger, more well-resourced organizations. These larger organizations were also able to pursue highly technical, high-magnitude funding opportunities with application turnaround time frames that could not realistically be met by smaller organizations with limited grant-writing resources. Recent decreases in funding for the Ryan White program²⁵ likely will most adversely affect smaller grassroots organizations. Furthermore, a lack of political champions willing to advocate for and challenge opposition to funding can also have adverse implications for the financial health of HIV CBOs.

Many HIV CBOs' efforts are hindered by circumstances such as disproportionately low funding compared with services provided, or unclear parameters for obtaining funding from state and local health departments. Being underresourced also has implications for being able to pay and retain staff. Delays in funding from health departments can be problematic for organizations that are experiencing financial difficulties as they attempt to bridge the gap between periods of limited funding. Systems of remuneration that require HIV CBOs to wait for reimbursements further jeopardize CBOs' ability to provide uninterrupted essential services to clients.

Anxiety about organizational survival is acute in contexts of high interorganizational competition, particularly for organizations that heavily depend on government funding.²⁶ When large, well-funded entities with clinical services are newly established in communities, they are better positioned to solicit additional funding, leaving less for organizations with longer, deeper histories of service within the local community. Large corporate-structured HIV-focused organizations, with financial profiles much different from those of CBOs, also threaten the stability and sustainability of local HIV CBOs by creating a competitive climate that can lean unfairly toward more well-funded entities.²⁷ Among local HIV CBOs, these entities have been likened to "big-box shops" that put "mom-and-pop shops" out of business.

With the advent of programs like 340B, a federal government discount drug program that provides reimbursements directly to organizations for patient pharmaceuticals, organizations are able to secure funding to support their programs and their organizations. This "franchisement of HIV" was a boon for organizations that were equipped to take advantage of it. For other organizations, however, stipulations for organizational enrollment into 340B programs were stringent, and interpretation of those requirements by gatekeepers like health departments and other entities either erroneously excluded them or hampered capacity-building efforts toward that end. The ACA and Ryan White program also created new possibilities for funding that larger corporate-structured or hospital-based entities and federally qualified health centers (FQHCs) were able to take advantage of quickly and with ease-building financial reserves that smaller organizations could not access. Some organizations, like FQHCs, are targeted for federal funding. However, intraorganizational differences within FQHCs can negatively affect CBOs. For example, where program staff of FQHCs may be amenable to partnerships with CBOs, FQHC administrators balk if partnerships

result in a loss of revenue. Furthermore, CBOs' capacity to expand and diversify themselves to integrate HIV into general and mainstream public health practices and services is dependent on their ability to sustain themselves financially to expand. Unfortunately, these varied financial threats were a death knell for some long-standing organizations that were either shuttered or co-opted.^{8,9}

Organizational Capacity

Despite their expertise, grassroots HIV CBOs in underserved communities often have limited access to the resources and services needed for them to thrive. Most nonprofit HIV CBOs were started by individuals with a passion to prevent HIV and support PLWH. However, this passion has not always been complemented by business acumen or fund-raising skills, stymieing sustainability. Many organizations had limited understanding of how to acquire and manage grant money or manage staff, including volunteers. Access to capacity-building assistance (CBA) was limited although the need was high.²⁸ Prior to a concerted effort from the CDC, no-cost CBA did not exist. Once available, it was incredibly beneficial, but has again become more difficult to access. Coordinated by health departments on behalf of all HIV-serving organizations, CBA can be delayed or inconsistent with the type of CBA that is most needed. CBA access is a persistent need for HIV CBOs, especially as prevention and treatment shifts indicate that CBA will become focused on organizational sunseting and sustainability as the HIV epidemic ends.

A critical asset of HIV CBOs is the ingenuity of staff who are committed to their clients and creative in their interactions with them, including those that may be myopically labeled "hard-to-reach."

Often, these staff have deep connections with the communities they serve, and many are themselves PLWH. Their effectiveness can make them targeted hires for better-resourced organizations that are able to pay staff significantly more. When these staff leave, or are pilfered, they take with them crucial institutional knowledge, upending capacity within their former organizations.

A shift to treatment-as-prevention as a high-impact intervention emphasized a medical model that many organizations were unprepared to offer and highlighted the need for capacity-building based on the biomedical model of care.²⁹ Organizations that were already clinic-based were more prepared for this shift, whereas others with no or limited capacity were marginalized, forcing some to close. Recognition of the effectiveness of a biomedical model also shifted funding toward this approach, while minimizing the role of social services (e.g., housing, employment assistance, food) necessary for patients to sustain medical gains.

Leadership and Governance

Organizational capacity is inextricably tied to organizational leadership. Nonprofit business acumen and tenacity of leadership can help guide organizations through difficult periods and position them for growth and success. A recent example is the response to local shutdowns due to the COVID pandemic and the pursuit of paycheck protection loans. The organizational angst many HIV CBOs experience is carried squarely on the shoulders of executive directors and CEOs who feel both a fiscal and social responsibility to clients and staff; this can be magnified for leadership of color with limited networks from which to draw support. In our experience, small CBOs with racial/ethnic leadership of color have been locked out of opportunities for growth that could sustain their organizations. Their designation as "little organizations" can be perceived as code for "the black or brown organizations," which places organizations led by people of color in a position to be professionally minimized and unsupported. Repeated instances of marginalization affects the mental and emotional health of such leaders, resulting in stress, worry, and anger-and few outlets to express such feelings. In localities where there are multiple organizations led by people of color, efforts to pit executive directors against one another can be divisive. Requests by leadership for capacity-building assistance can also be viewed as weaknesses in areas of support requested. Mistakes made by leadership of color can be amplified in attempts to nullify their capability.

HIV stigma, particularly in rural communities, can make it difficult to identify and recruit board members willing to openly serve as ambassadors. Because of factors such as increased social conservatism and lower levels of HIV awareness,³⁰ many vulnerable communities may experience a dearth of knowledgeable individuals who have the capacity to provide necessary insight for the sustainability of HIV CBOs; on the other hand, local contextual

knowledge of a community is critical to that same sustainability. The meaningful involvement of PLWH, community members, and consumers as board members is critical. Challenges to organizational growth include the selection of well-intentioned but inexperienced board members and difficulty recruiting diverse, heavily networked board members. Blurred lines between executive directors and CEOs and board member responsibilities introduce the potential for additional problems, as leaders' passion for the work may conflict with delineation of roles and responsibilities.

Organizational Biases

Inaccurate perceptions held by decision-making entities about the experience and capabilities of HIV CBOs can affect their access to opportunities for sustainability. Some organizations, seen by decision-makers as smaller less-equipped organizations, are tasked to do the difficult work of outreach to identify PLWH and then refer them to clinics for care; these clinic-based entities benefited financially from this setup. For years, smaller CBOs fed patients into clinics' 340B programs, helping to build income for these organizations, while smaller CBOs were unaware of 340B opportunities. In some instances, leadership from smaller CBOs were explicitly told they were ineligible for participation, and that these opportunities did not exist for them. This inaccurate translation of information denied smaller organizations the opportunity to build organizational capacity and financial infrastructure. Attempts were also made by larger entities to prevent access to 340B for smaller organizations once they were, in fact, determined to be eligible.

Health departments demonstrate biases toward working with larger, more established entities with greater resources rather than with smaller CBOs with fewer resources and a learning curve regarding organizational capacity. Funding practices by health departments and others that privilege larger clinic-based entities with significant funding, allowing them to decide whether to subcontract with HIV CBOs, construct a hierarchy that empowers them while placing the viability of smaller organizations at risk. Leadership who critique the system on its pointed biases can find themselves penalized—they receive less funding, ultimately resulting in critical voices and perspectives being reduced or eliminated. CBOs attempting to expand their services are regularly met with pushback, including the abrupt cancellation of contracts with larger clinic-based organizations. By expanding services to include access to medical professionals and medication, smaller CBOs are able to address the important biomedical aspects of prevention and treatment while also effectively responding to a variety of social service needs. CBOs are uniquely equipped to view clients through multiple lenses, and respond to the whole person, evidenced by referrals of "difficult" patients from larger entities back to smaller CBOs that can more effectively respond to clients' needs.

The mistaken belief that larger organizations are better equipped to provide community services because they are better resourced minimizes patients who prioritize not only quality health care but also personal care, especially patients labeled "difficult" or "hard-to-reach." In larger organizations, patients may have access to quality care but may not feel "cared for." Furthermore, patients can have adverse experiences with health care providers lacking cultural competence. Patient attitudes about historical medical and research abuses are relevant, but present-day experiences with health care matter for clients. No single organization is ideal for everyone, but CBO options should exist for patients to choose. HIV CBOs working on the frontlines herald innovative approaches that are sometimes ignored unless and until these ideas are promoted by larger, well-resourced organizations. Furthermore, these organizational biases extend into academic-community relationships where CBOs are often used and abused by researchers and universities as sites for participant recruitment without meaningful partnership, investment, and dissemination or translation of findings.³¹ Despite being viewed and treated as subordinate to larger organizations, there is much to be learned from HIV CBOs.

INVALUABLE ROLE OF HIV COMMUNITY-BASED ORGANIZATIONS

The collective achievements in reducing HIV incidence rates would not be possible without CBOs, which are community engaged by their very nature. HIV CBOs have been and continue to be critical in meeting the goals of the National HIV/AIDS Strategy. Because of both proximity and staff composition, grassroots HIV CBOs are a natural reflection of the communities they serve where they have deep, long-standing relationships. The epidemic in the United States has been aptly characterized as a "diverse set of microepidemics" across different settings around

the nation.^{32(p3078)} Extending that logic, communities represent even smaller units of unique epidemiological and structural characteristics that are deeply familiar to HIV CBOs. They use community-informed, community-engaged methods to serve their clients, and they can be better equipped to do so. Staff's personal and professional experiences with HIV in marginalized communities often reflect the contextual knowledge they have of the communities they serve, which also resonates with clients. Their ability to access social networks allows them to build authentic relationships with community members and develop trust.

Because of these sustained relationships, HIV CBOs have a footprint in communities where government and larger organizations may not. Community members and clients benefit from formal services and informal networks (e.g., peer groups) that help them feel seen, heard, welcome, and safe. Not only are HIV CBOs instrumental in treating and supporting PLWH, they are skilled in prevention, including testing and promoting uptake of pre-exposure prophylaxis. HIV CBOs can be instrumental in providing their clients and patients with a wide array of information and considerations necessary to help them make their own personal decisions, and thus CBOs will be essential toward promoting uptake of vaccines (e.g., HIV or COVID-19) and other novel strategies for future cures. HIV CBOs' investment in staff (some who began as clients) has also helped to enhance the overall HIV workforce, expanding their capacity to respond to new professional opportunities.

HIV CBOs are frontrunners of innovation and a source of information for what works. Often, HIV CBOs are already responding long before the completion of efforts to test and evaluate interventions. Access to evidence-based strategies allows them to use what is known and shift quickly in the best interest of their clients, especially for Southern or rural communities—where the failure to expand Medicaid, as made possible by the ACA, has jeopardized access to health care and services for clients. Furthermore, HIV CBOs are tasked with finding and reaching those labeled "hard-to-reach" with outreach strategies that are extensive, comprehensive, and informed by community relationships. HIV CBOs maintain a presence in places deemed untraditional or undesirable. They are equipped to meet those at risk exactly where they are because of trusted relationships that can aid in engagement and retention of care.⁵

In practice, HIV CBOs have flexibility to respond to community needs and are generally not constrained by bureaucracy; they can move quickly and creatively to tailor their approaches beyond the norm (e.g., flexible hours to facilitate "after-hour" services). HIV CBOs do the work that is hard, not the work that is convenient. With access to resources commensurate with their work, they can advance progress even faster. Reports of excellent treatment cascades are possible because of the labor of HIV CBOs. They should be acknowledged with equitable support (fiscal and otherwise) for their contributions toward ending the HIV epidemic.

Several similarities between HIV/AIDS and SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2, the causative agent of COVID-19)—including stark racial/ethnic disparities,^{33,34} social and structural drivers of transmission,³³ stigma,³⁴ and the role of human behavior in prevention,^{35,36}—highlight additional notable qualities of HIV CBOs. Strategies outlined in the National HIV/AIDS Strategy parallel those necessary to effectively address the COVID-19 pandemic,³⁷ thus also highlighting how HIV CBOs are uniquely positioned to respond to COVID-19. HIV CBOs are well suited for implementing daily testing and effective contact tracing. They can easily integrate activities to prevent COVID-19. There is still much that is unknown about COVID-19, although it is now established that PLWH who acquire SARSCoV-2 have greater adverse outcomes and that health inequities exacerbate them.³⁸ COVID has altered CBO outreach to existing clients and patients, and affected the availability of services. However, many HIV CBOs have adapted to meet the needs of their clients and patients while facing the dual pandemics of HIV and COVID-19, demonstrating leadership amid unprecedented challenges.³⁹

RECOMMENDATIONS

In a year marked by a growing acknowledgment of systemic racism, the United States is being pushed to confront its past in its pursuit of equity. If we are to take advantage of this inflection point, we must advance structural equity where it has lagged. HIV CBOs must be involved in meaningful ways if the EHE plan is to be achieved and sustained. We offer recommendations in Box 1 to protect and promote the sustainability and viability of HIV CBOs to meet this goal. These recommendations also serve to validate HIV CBOs (past and present) whose experiences

related to structural equity have been trivialized or doubted. Table 1 highlights barriers to structural equity and related recommendations.

CONCLUSION

Early in the epidemic, the concept of "ending" HIV was an idea that few, if any, could grasp. Both activist- and service-oriented grassroots organizations were early responders to the epidemic to protect the human rights of stigmatized groups. During that period, grassroots organizations were established by people for whom this work was personal; their passion was-and continues to translate into-a relentless commitment to ending the epidemic. Nonprofit HIV-focused CBOs have encountered numerous threats to survival. Over the past 2 decades, many (including those with long histories of service) have either shuttered their doors or been faced with the threat of ceasing operations. For each high-profile organizational closure, there are likely many others that quietly close down with little public acknowledgment of their years of service. When this happens, clients lose spaces for social support, and staff who are living with HIV lose not only their jobs but their sense of purpose.⁴⁰

Many of us have been actively responding to the HIV epidemic since its inception and have seen firsthand how it has ravaged communities and continues to disproportionately affect communities of color, especially Black communities. For HIV CBOs, ending the epidemic means "putting ourselves out of business"; this is our goal. However, we want to be "put out of the HIV business" or to "shift our missions" because the epidemic has ended, not because of structural inequities that privilege some and disadvantage others. We call for structural equity that supports the stability and sustainability of HIV CBOs across all efforts to end the epidemic. This is what we believe is necessary to get to zero and stay there. AJPH

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COVID-19 Vaccine Distribution in a Community With Large Numbers of Immigrants and Refugees

Malone, Brett, MD, MPH; Kim, Esther, MD; Jennings, Rachel, BA; Pacheco, Rainer A, BS; Kieu, Alex, MD

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ABSTRACT (ENGLISH)

Refugee and immigrant populations are extremely vulnerable to the consequences of the COVID-19 pandemic. COVID-19 vaccination is a critical tool in mitigating these consequences, but these same communities often lack access to COVID-19 vaccines. We describe the efforts of a community-based primary care clinic in Clarkston, Georgia to provide access to COVID-19 vaccines in a culturally sensitive manner to address this health disparity and vaccine hesitancy.

FULL TEXT

Headnote

Refugee and immigrant populations are extremely vulnerable to the consequences of the COVID-19 pandemic. COVID-19 vaccination is a critical tool in mitigating these consequences, but these same communities often lack access to COVID-19 vaccines. We describe the efforts of a community-based primary care clinic in Clarkston, Georgia to provide access to COVID-19 vaccines in a culturally sensitive manner to address this health disparity and vaccine hesitancy. (Am J Public Health. 2022;112(3):393-396. <https://doi.org/10.2105/AJPH.2021.306608>) Although the COVID-19 pandemic has affected everyone, certain populations are disproportionately burdened. African Americans are five times more likely to be hospitalized from a COVID-19 infection than White Americans,

and nearly twice as likely to die.¹ Although there are insufficient data on how the pandemic has affected refugees, several risk factors increase the likelihood of severe illness from COVID-19 among recently resettled refugees, including higher rates of comorbidities,² mental health concerns,^{3,4} health care access, language barriers,¹ low socioeconomic status,⁵⁻⁷ and social stressors.⁸

Clarkston, Georgia, is known as "the most diverse square mile in America" (<https://bit.ly/3JQfnpW>) as it has served as a refugee resettlement site for the past 30 years. Clarkston has welcomed immigrants seeking refuge from Bosnia, Kosovo, Liberia, Congo, Burundi, Sudan, Somalia, Ethiopia, Eritrea, Iraq, Syria, Bhutan, Burma, Afghanistan, and Pakistan.

Ethne Health was started in October 2018 as a primary care clinic in Clarkston. Ethne Health attempts to meet the diverse medical needs of the community in a culturally sensitive manner. In the past year, Ethne Health has provided COVID-19 testing and vaccinations for the community.

INTERVENTION

As vaccine hesitancy remains a barrier in the struggle to contain the COVID-19 pandemic, one recommended strategy is to directly engage communities through the utilization of community partners with trusted relationships.⁹ As a culturally sensitive neighbor-centered medical home located in the middle of a diverse community, Ethne Health is uniquely positioned to engage with those community partners to deliver COVID-19 vaccines.

PLACE AND TIME

Data from Ethne Health's vaccination campaign in Clarkston, Georgia (zip code 30021) were collected from January 6, 2021 through May 28, 2021.

PERSON

During the period of data collection, Ethne Health partially or fully vaccinated 3127 individuals with either the Pfizer or Moderna COVID-19 vaccine. Of these individuals, 2692 were fully vaccinated.

PURPOSE

Our main goal was to provide access to COVID-19 vaccines for the immigrant communities in and around Clarkston in a way that was culturally sensitive and accessible for all. Additionally, because of the scarcity of data on COVID-19 vaccination among refugees, we wanted our local vaccination campaign to serve as a model for future endeavors nationwide.

IMPLEMENTATION

For vaccine administration, four additional full-time staff (vaccine coordinator, nurse, registration coordinator, and community engagement coordinator) were hired, forming a COVID-19 vaccination team. They were buffered on vaccine distribution days by a large number of volunteers. Staff and volunteers came from a variety of racial/ethnic backgrounds with multiple languages represented. In situations where translation was needed and an in-person translator was not available, telephone translation services were used. Additionally, materials, including Emergency Use Authorization fact sheets, were printed in multiple languages and distributed appropriately.

EVALUATION

During the intervention period, Ethne Health partially or fully vaccinated 3127 individuals with either the Pfizer or Moderna COVID-19 vaccine. Demographic data were collected from 3090 individuals (98.9%). The racial and ethnic demographics of the overall group can be seen in Table 1. The percentages of those who identified as Black or African American, Asian, or White were 46.1%, 19.4%, and 34.1%, respectively. Overall, 3.4% identified as Hispanic/Latino.

Of the entire cohort who received at least one dose of either the Pfizer or Moderna vaccine from Ethne Health, 640 individuals (20.4%) had an address in the 30021 zip code. Demographic data were collected from 628 individuals (98.1%). As seen in Table 2, the percentages of those who identified as Black or African American, Asian, or White were 43.3%, 30.1%, and 26.3%, respectively. Those who identified as Hispanic/Latino made up 3.5% of the cohort, and 21 different languages were represented. The racial and ethnic demographics of our cohort vaccinated from the Clarkston zip code closely resembles those of the zip code at large.

In August 2021, the Prevention Research Center at Georgia State University stated that Clarkston has a "fully

vaccinated rate of nearly 42% ... outpacing neighboring communities that are similarly stressed, with low household income, low literacy and language ability, high density housing, and limited transportation."¹⁰ It highlights Ethne Health's vaccine distribution as one of the main reasons for success.

ADVERSE EFFECTS

Despite our progress thus far, many challenges still exist in vaccinating our community. Continued efforts need to be made to identify reasons why people remain unvaccinated and to address those concerns.

SUSTAINABILITY

Upon evaluation of the vaccination efforts, we believe that three main factors aided in our outreach to a diverse and sometimes vaccine hesitant population: (1) relationships of trust within the community, (2) multiple avenues of access, and (3) consistent vaccination location and time.

Trust

Psychological and social influences have been shown to have significant impacts on vaccination rates.¹¹ A community engagement coordinator can help utilize these factors to promote vaccination. With a decade of experience working in the Clarkston community with a refugee resettlement agency, our coordinator leveraged previously established relationships to engage trusted community partners. These trusted and well-respected community partners helped overcome the barriers of distrust and lack of access. Additionally, the coordinator's experience and relationship with community partners assisted us in developing a culturally sensitive approach to vaccine distribution.

Access

Individualized registration procedures were created that enabled community partners to schedule appointments for their community members without having to navigate registration forms or phone lines. Specifically, our community engagement coordinator worked directly with community partners to assist individuals and groups in registering for and transportation to vaccine appointments. Autonomous community members were able to preregister for vaccines through multiple avenues, including walk-ups and online registration. On vaccinations days, walk-ups were encouraged, and we accommodated accompanying family or friends who were not registered.

Consistency

We began in January and February 2021 with larger vaccine drives that required significant logistical planning and coordination. By the end of February 2021, we had switched to vaccinating smaller numbers outside of our clinic. This provided a more sustainable endeavor for our vaccine team and clinic, which helps avoid burnout. Additionally, it provided a consistent time and location for community members to find us and get vaccinated. They knew where to find us, when to find us, and that we would vaccinate them if they came.

PUBLIC HEALTH SIGNIFICANCE

Although immunization is not required for resettlement in the United States, overall, refugees are generally immunized. For example, in 2019, 94.6% of 28 478 age-eligible refugee arrivals from 88 countries had at least one documented measles-containing vaccine dose.¹² Achieving similar vaccination rates for COVID-19 may be difficult. As the COVID-19 pandemic continues, COVID-19 vaccine distribution is an utmost priority, especially among vulnerable refugee and immigrant populations. To accomplish this, we have learned that establishing trust, providing multiple avenues of access, and being consistent can minimize many obstacles. Trust can overcome vaccine hesitancy; reducing barriers to access and maintaining a consistent yet sustainable presence can help our community endure this formidable virus. Our vaccination campaign, though small in scale, can offer a model to provide access to COVID-19 vaccines in a way that is effective, sustainable, and culturally sensitive. >4JPU

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B. Malone, R. Jennings, and R.A. Pacheco contributed to data and statistics. B. Malone, E. Kim, and A. Kieu contributed to a review of the literature along with writing and editing.

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CONFLICTS OF INTEREST

All authors have no conflicts of interest to disclose.

HUMAN PARTICIPATION PROTECTION

Our team at Ethne Health is only analyzing completely de-identified data and is performing clinical services for a fee that are routinely done for nonresearch purposes.

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Adding Short-Term Social Pathways for COVID-19–Related Discrimination to Theoretical Frameworks and Structural Interventions

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ABSTRACT (ENGLISH)

In their article "COVID-19-Related Discrimination Among Racial/Ethnic Minorities and Other Marginalized Communities in the United States," Strassle et al. (p. 453) provide an excellent descriptive analysis of the prevalence of COVID-19-related discrimination by race/ethnicity in the United States between December 2020 and February 2021. The authors begin by acknowledging the increasing anti-Asian sentiment driven by references to COVID-19 as the "Chinese flu." However, in contrast to early reports of COVID-19-related discrimination that focused primarily on Asian Americans, Strassle et al. extend this work beyond Asian, Black, Latino, and multiracial groups to also include American Indian/Alaska Native and Native Hawaiian/Pacific Islander groups. The authors also examine Asian subpopulations, highlighting the potential heterogeneity within this population. Using a modified version of the Everyday Discrimination Scale explicitly designed to capture discrimination because of COVID-19, more than 22% of the sample reported exposure to discriminatory behaviors, and over 42% reported people being afraid of them. Unsurprisingly, every racial/ethnic group reported more discrimination experiences because of COVID-19 than White populations. Asian followed by Latino and American Indian/Alaska Native populations reported the highest prevalence of discrimination experiences. Although not significantly different from other Asian subpopulations, Vietnamese adults reported the most COVID-19-related discrimination, and Japanese adults reported the least COVID-19-related discrimination. Small sample sizes within Asian subpopulations may have precluded the ability to estimate statistically significant differences. However, the substantial variation in COVID-19-related discrimination reports should encourage future studies to disaggregate within racial/ethnic subgroups, when possible, for Asian populations, as well as other minoritized populations. In addition to race/ethnicity, other socially disadvantaged groups, namely those with lower levels of education, low income, nonnative English speakers, and individuals living in rural areas, were also significantly more likely to report COVID-19-related discrimination. Notably, these are all groups with higher levels of COVID-19-related morbidity and mortality. This article highlights the ubiquity of COVID-19-related discrimination and the salience of race/ethnicity among minoritized populations.¹ Therefore, this editorial aims to discuss how we can expand theory to fully understand the impacts of COVID-19-related discrimination and

make recommendations for reducing its negative impacts.

FULL TEXT

In their article "COVID-19-Related Discrimination Among Racial/Ethnic Minorities and Other Marginalized Communities in the United States," Strassle et al. (p. 453) provide an excellent descriptive analysis of the prevalence of COVID-19-related discrimination by race/ethnicity in the United States between December 2020 and February 2021. The authors begin by acknowledging the increasing anti-Asian sentiment driven by references to COVID-19 as the "Chinese flu." However, in contrast to early reports of COVID-19-related discrimination that focused primarily on Asian Americans, Strassle et al. extend this work beyond Asian, Black, Latino, and multiracial groups to also include American Indian/Alaska Native and Native Hawaiian/Pacific Islander groups. The authors also examine Asian subpopulations, highlighting the potential heterogeneity within this population. Using a modified version of the Everyday Discrimination Scale explicitly designed to capture discrimination because of COVID-19, more than 22% of the sample reported exposure to discriminatory behaviors, and over 42% reported people being afraid of them. Unsurprisingly, every racial/ethnic group reported more discrimination experiences because of COVID-19 than White populations. Asian followed by Latino and American Indian/Alaska Native populations reported the highest prevalence of discrimination experiences. Although not significantly different from other Asian subpopulations, Vietnamese adults reported the most COVID-19-related discrimination, and Japanese adults reported the least COVID-19-related discrimination. Small sample sizes within Asian subpopulations may have precluded the ability to estimate statistically significant differences. However, the substantial variation in COVID-19-related discrimination reports should encourage future studies to disaggregate within racial/ethnic subgroups, when possible, for Asian populations, as well as other minoritized populations. In addition to race/ethnicity, other socially disadvantaged groups, namely those with lower levels of education, low income, nonnative English speakers, and individuals living in rural areas, were also significantly more likely to report COVID-19-related discrimination. Notably, these are all groups with higher levels of COVID-19-related morbidity and mortality. This article highlights the ubiquity of COVID-19-related discrimination and the salience of race/ethnicity among minoritized populations.¹ Therefore, this editorial aims to discuss how we can expand theory to fully understand the impacts of COVID-19-related discrimination and make recommendations for reducing its negative impacts.

EXPANDING THEORY ON COVID-RELATED DISCRIMINATION

The most prominent discourse of discrimination in the literature has focused on discrimination against racial/ethnic minority groups, particularly Black Americans.^{2,3} However, Black Americans in this study did not report more COVID-19-related discrimination than other racial/ethnic minoritized or socially disadvantaged groups, despite the overwhelming media coverage of excess COVID-19 rates in this group. This could be attributable to Black Americans' experiencing discrimination from multiple sources and being less likely to attribute these experiences to COVID-19. Regardless of the underlying causes, these findings highlight the importance of COVID-19-related discrimination for many disadvantaged groups. Discrimination is defined as marginalization and differential treatment of a person who is a member of a stigmatized population.⁴ This treatment shapes risks and opportunities that have profound impacts on health. The empirical literature on discrimination and health has largely examined relationships between discrimination and chronic conditions,³ including heart disease,⁵ diabetes, and chronic kidney disease,⁶ via stress pathways that influence physiological processes resulting in poor health.^{2,3} Although COVID-19-related discrimination may have long-term effects on health via these pathways, the immediacy of experiences of discrimination because of COVID-19 affords us the opportunity to expand existing theoretical frameworks and enhance the discourse on the short-term health consequences of discrimination.

One of the most salient effects of discrimination is physical violence. Indeed, Strassle et al. highlight national trends of increasing physical violence toward older Asian adults, although their data do not show significantly higher reports of discrimination in this population. There are many other pathways that may link COVID-19-related discrimination

with shorter-term health outcomes directly through health behaviors or through social pathways. For example, discrimination attributed to being a member of a sexual minority group is directly related to substance use behaviors just 2 hours after the discriminatory encounter.⁷ It is possible that COVID-19-related discrimination also leads to negative coping behaviors, such as substance use, in the immediate aftermath of exposure to discriminatory treatment, and these relationships should be explored. Another pathway through which COVID-19-related discrimination may impact health, albeit indirectly, is through the restriction of health opportunities via relationships that are cut off because of fear of the person who might have COVID-19. Discrimination attributed to being a person who uses drugs or someone who has spent time in jail significantly shapes the level of HIV risk in their social network.⁸ So, the isolation that a person experiences because of COVID-19-related discrimination may inadvertently increase their risk of disease transmission because their opportunities for exposure to lower-risk groups is limited. This isolation may also negatively influence the employment and economic opportunities available to them and ultimately affect health because of lack of access to health insurance or ability to pay for care.^{2,3} The myriad ways that discrimination can immediately affect health directly and indirectly through upstream social determinants should be included in theoretical frameworks to further guide the literature.

STRUCTURAL INTERVENTIONS IMPACT DISCRIMINATION

Strassle et al. and countless other scholars have highlighted the frequency with which discrimination is reported, regardless of what discrimination is attributed to, particularly among populations of color. Identification of the scope of the problem begs us, as public health practitioners, to develop strategies to reduce discrimination and its negative effects on health. Strassle et al. suggest that one way to contend with racism and xenophobia related to pandemics is to enhance public health and media messaging. Structural interventions that promote culturally appropriate media messaging are powerful because they reach a broad group of people before and after they become exposed to discrimination.⁹ Current interventions have been limited to the individuals who experience discrimination or perpetrate discrimination. Thus, the reach of structural media messaging interventions could (1) reduce those who become exposed to discrimination by reshaping the ideas people have about racial/ethnic minoritized groups and (2) limit the need to develop individual-level interventions to prevent negative consequences among those who have been exposed to discrimination because media messages can continuously and simultaneously reach massive audiences.⁹ Public health practitioners should improve our ability to create and disseminate structural media messaging interventions across all media platforms and partner with health technology experts and media influencers who, if trained, could be highly effective in health education provision.¹⁰ In doing so, we can directly tackle media mis- and disinformation sources and challenge them when they spread discriminatory information. Effectively communicating with all groups of people and intercepting inaccurate health information is critical to reducing negative consequences resulting from COVID-19-related discrimination.

Other structural interventions that shape social policies to prevent discrimination and promote equitable health and economic resources should also be implemented to reduce discrimination and its negative effects. By acknowledging the extreme costs of discrimination on health, these policies could criminalize discriminatory behaviors and regulate accessibility of health resources for all populations. Quantifying the health-related savings if discrimination were nonexistent could encourage structural policy interventions.¹¹

CONCLUSION

Strassle et al. further a critically important understanding of COVID-19-related discrimination by racial/ethnic group. The theoretical frameworks guiding the examination of discrimination and health relationships should be expanded to explore short-term social pathways. To reduce discrimination and its negative health effects, structural interventions should be implemented. ÅfPU

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DETAILS

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Barriers to COVID-19 Vaccine Uptake in the LGBTQIA Community

Azucar, Danny, PhD, MPH; Slay, Lindsay, MSW; Valerio, Damaris Garcia; Kipke, Michele D, PhD

[ProQuest document link](#)

ABSTRACT (ENGLISH)

Objectives. To report findings from qualitative research that describe sources of hesitancy and barriers to vaccine uptake among lesbian, gay, bisexual, transgender, queer, intersex, and asexual (LGBTQIA) populations. **Methods.** In March 2021, we conducted focus groups with members of the Los Angeles, California LGBTQIA community to identify barriers to becoming vaccinated. Semistructured interviews were conducted with 32 individuals in 5 focus groups. Thematic analysis was conducted to identify themes. **Results.** Historical and ongoing medical trauma, including misgendering, and perceived emotional violence emerged as significant barriers to LGBTQIA individuals becoming vaccinated. Fear of violence was found to be a major barrier among transgender individuals, whereas fear of an unwelcoming vaccination site was a barrier for seniors. Finally, surviving was a higher priority than becoming vaccinated. **Conclusions.** Participants reported vaccine hesitancy and barriers that are unique to the life experiences of LGBTQIA individuals; these include medical trauma, violence, stigma, and discrimination. Our findings highlight the need to include LGBTQIA leaders and trusted individuals in the development of vaccination education and the delivery of vaccination services. (Am J Public Health. 2022;112(3):405407. <https://doi.org/10.2105/AJPH.2021.306599>)

FULL TEXT

Headnote

Objectives. To report findings from qualitative research that describe sources of hesitancy and barriers to vaccine uptake among lesbian, gay, bisexual, transgender, queer, intersex, and asexual (LGBTQIA) populations. **Methods.** In March 2021, we conducted focus groups with members of the Los Angeles, California LGBTQIA community to identify barriers to becoming vaccinated. Semistructured interviews were conducted with 32 individuals in 5 focus groups. Thematic analysis was conducted to identify themes. **Results.** Historical and ongoing medical trauma, including misgendering, and perceived emotional violence emerged as significant barriers to LGBTQIA individuals becoming vaccinated. Fear of violence was found to be a major barrier among transgender individuals, whereas fear of an unwelcoming vaccination site was a barrier for seniors. Finally, surviving was a higher priority than becoming vaccinated. **Conclusions.** Participants reported vaccine hesitancy and barriers that are unique to the life experiences of LGBTQIA individuals; these include medical trauma, violence, stigma, and discrimination. Our findings highlight the need to include LGBTQIA leaders and trusted individuals in the development of vaccination education and the delivery of vaccination services. (Am J Public Health. 2022;112(3):405407. <https://doi.org/10.2105/AJPH.2021.306599>)

In the race to vaccinate against COVID-19, 55.8% of people in the United States are fully vaccinated (as of October 3, 2021).¹ However, high levels of vaccine hesitancy and low vaccine uptake persist, especially in underserved, underrepresented populations,² including sexual and gender minorities and lesbian, gay, bisexual, transgender, queer, intersex, and asexual (LGBTQIA) people.³ Existing evidence suggests that since the pandemic began, the LGBTQIA community has been disproportionately affected by high infection rates and associated economic and

psychosocial burdens.^{4,5} LGBTQIA people of color are twice as likely as White non-LGBTQIA people to be diagnosed with COVID-19,⁶ and more likely than non-LGBTQIA people to have a preexisting condition (e.g., diabetes, obesity) and to suffer severe COVID19 outcomes.⁷ LGBTQIA people are more likely than non-LGBTQIA individuals to work in highly affected industries (e.g., restaurants), have lower incomes,⁸ and experience greater stigma and discrimination in health care settings.⁹

We conducted qualitative research in March 2021 with LGBTQIA service providers to understand sources of vaccine hesitancy and barriers to vaccine uptake in this population. We summarize the findings from this research and their public health implications.

METHODS

We conducted 5 focus groups with 32 individuals, the majority of whom were LGBTQIA; all of the groups included members of the LGBTQIA community or provided services to diverse segments of the LGBTQIA community (e.g., different racial/ethnic groups [especially African American and Latino/Hispanic], young adults, seniors, transgender and nonbinary people). We first worked with our LGBTQIA Community Advisory Board to identify participants for the study, then identified LGBTQIA health and social service agencies in Los Angeles, California and invited staff to participate in the study. None of these agencies offered vaccination services at the time of the study.

We conducted focus groups virtually (via HIPAAZoom) using a semistructured interview adapted from the COVID-19 Specific Vaccine Hesitancy and Acceptability in Multi-Ethnic Communities-Focus Group Guide.¹⁰ The interview guide included questions about the following topics: What are the greatest concerns or challenges that LGBTQIA individuals face when becoming vaccinated? When and where should vaccines be offered? Who should offer vaccines? What barriers are unique to LGBTQIA individuals? What or who influences LGBTQIA individuals to become or not become vaccinated? What resources are needed or missing? Each focus group included up to 11 participants and lasted approximately 2 hours. Participants were asked to share their own perspectives and experiences, and those of their clients. Participants were compensated \$75 for participating. We audio recorded, transcribed, de-identified, and analyzed the groups using a thematic analytic approach. This involved (1) developing inductive codes, (2) independently coding all transcripts, and (3) comparing emerging themes, including some not specified in the interview guide. After successive iterations, we merged codes and generated themes about vaccine hesitancy in LGBTQIA communities. Two team members analyzed and coded each transcript using ATLAS ti (Scientific Software Development; Berlin, Germany; 2020).

RESULTS

Several barriers to becoming vaccinated emerged, including lack of LGBTQIA "safe vaccine spaces" and lack of LGBTQIA representation with vaccination education and rollout efforts. We found that these barriers were particularly great for transgender, seniors, and individuals experiencing homelessness.

Historical and ongoing medical trauma, including misgendering and perceived emotional violence, emerged as a significant barrier to LGBTQIA individuals becoming vaccinated. One participant described how "You can't disconnect vaccine resistance from the communities folks live in. We've been historically discriminated against and/or abused by the medical system." Another participant said, "How can there be trust when [LGBTQIA] people are still living with HIV after 40 years, where's the vaccine for that?" Medical mistrust also depended on health providers' level of competency in respectfully addressing LGBTQIA people in clinical spaces, as shared by a transgender female participant who experienced misgendering: "Everybody at the vaccine site referred to me as 'sir.' Mind you, the medical form I filled out had asked those questions ... but was anybody actually paying attention to me as a person? No."

A common theme was the need for LGBTQIA leaders to have a "seat at the table" with vaccine planning and educational efforts. One participant noted, "Being seen and acknowledged at vaccine sites starts with ensuring there's LGBTQIA representation at every step along the vaccination process" and "creating the opportunity for LGBTQIA leaders to build trust between the vaccine and the community." Another participant said, "People sticking the needle in the arm, have they [even] been trained ... by LGBTQ organizations [or] people with lived experiences who are experts on the ground, who are also queer and trans people of color?" Another participant commented, "Let

us run our own communities. Stop coming in, telling us what to do and running our communities. Give us the opportunity to do that... or you're not going to get anywhere." This "by us for us" approach was supported by another participant: "When you can see someone [who looks like you], it brings out honesty, integrity, and sincerity-it allows you to really connect."

Fear of violence was found to be a major barrier to becoming vaccinated among transgender individuals. One participant stated, "Transwomen are afraid that they are going to be beat... [afraid] for their lives ... of being attacked ... to come out of their homes to get the vaccine." For aging LGBTQIA adults, lack of welcoming, openminded, and accepting resources emerged as a barrier in becoming vaccinated: "The programming and resources for trans and queer elders of color may not be the safest or affirming.... Queer older adults go [back into the closet] because they fear they're going to get mistreated ... when they're checking in to get the vaccine." For individuals experiencing homelessness, the priority is surviving, not becoming vaccinated: "When someone is unhoused, it's almost like survival trumps getting vaccinated."

DISCUSSION

With more dangerous and contagious variants of the virus now fueling the pandemic, it is critical that COVID-19 public health vaccination efforts be strategic, targeted, and, ideally, culturally tailored to increase vaccination uptake, especially in underserved, underrepresented populations. This article explores the barriers and opportunities to vaccine uptake among LGBTQIA communities. Although the interview guide did not directly address barriers related to intersectional identities, a clear finding was that people living at the intersection of multiple marginalized identities (i.e., transgender, seniors, and homeless) experience increased barriers when accessing the vaccine, and that mistrust persists between LGBTQIA communities and COVID-19 vaccine health providers given past and ongoing experiences of medical trauma.

Our findings suggest that educational campaigns need to include LGBTQIA and intersectional representation. Furthermore, vaccine services and resources need to be culturally tailored to create inclusive, welcoming, and safe spaces for members of the LGBTQIA community, paying particular attention to avoiding misgendering and stigma. Including LGBTQIA organizations in the development and delivery of vaccination services is an important step to ensuring that services are culturally tailored and relevant. Finally, it is important to recognize that LGBTQIA individuals' health needs and concerns are not limited to COVID-19. Vaccination services should ideally include other needed services, such as financial assistance, mental health and substance abuse treatment, HIV care and prevention, and primary care services.

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CONTRIBUTORS

D. Azucar analyzed and extracted insights from focus group transcripts, synthesized all research insights from the team, and led the authorship of the manuscript; he also served as corresponding author throughout the publication process. L. Slay coordinated the research group and administrative tasks involved with this research, analyzed and extracted insights from transcripts, and contributed to final authorship of the manuscript. D. Garcia Valerio analyzed

and extracted insights from focus group transcripts. M. D. Kipke served as the principal investigator of the study, authored the manuscript, and provided valuable insight throughout the conduct of the study, analysis of the data and interpretation of the findings, and the preparation and publication of this manuscript.

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CONFLICTS OF INTEREST

The authors have no conflicts of interests to declare.

HUMAN PARTICIPANT PROTECTION

This study was approved by the institutional review board of Children's Hospital Los Angeles Healthy Young Men's 2.0 Cohort Study (ID: CHLA14-00279).

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DETAILS

Subject:	Discrimination; COVID-19 vaccines; Public health; COVID-19; Public health education; Vaccines; Immunization; Trauma; Violence; Stigma; Transgender persons; Bisexuality; Fear; Older people; Asexuality; Aggression; Barriers; Human immunodeficiency virus--HIV; Minority & ethnic groups; Focus groups; Homeless people; Pandemics; Gays & lesbians; Non-binary gender; Vaccination; Qualitative research; Coronaviruses; Lesbianism; Medicine; Health services; LGBTQ people
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Collins, B. N., PhD., Lepore, S. J., PhD., & Egleston, B. L., PhD. (2022). Multilevel intervention for low-income maternal smokers in the special supplemental nutrition program for women, infants, and children (WIC). American Journal of Public Health, 112(3), 472-481. doi:<https://doi.org/10.2105/AJPH.2021.306601>

Objectives. To test the efficacy of Babies Living Safe and Smokefree (BLiSS), a multilevel intervention initiated in a citywide safety net health system to improve low-income maternal smokers' abstinence and reduce child tobacco smoke exposure. **Methods.** This randomized controlled trial in Philadelphia, Pennsylvania (2015-2020), recruited low-income maternal smokers who received a brief smoking intervention (Ask, Advise, Refer AARJ) from nutrition professionals in the Special Supplemental Nutrition Program for Women, Infants, and Children before randomization to (1) a multilevel intervention (AAR 1 multimodal behavioral intervention MBI; n = 199) or (2) an attention control intervention (AAR 1 control; n = 197). **Results.** AAR 1 MBI mothers had significantly higher 12-month bioverified abstinence rates than did AAR 1 control mothers (odds ratio OR] = 9.55; 95% confidence interval CI] = 1.54, 59.30; P = .015). There were significant effects of time (b = -0.15; SE = 0.04; P < .001) and condition by time (b = -0.19; SE = 0.06; P < .001) on reported child exposure favoring AAR 1 MBI, but no group difference in child cotinine. Presence of other residential smokers was related to higher exposure. Higher baseline nicotine dependence was related to higher child exposure and lower abstinence likelihood at follow-up. **Conclusions.** The multilevel BLiSS intervention was acceptable and efficacious in a population that experiences elevated challenges with cessation.

Casola, A. R., PhD.M.P.H.M.C.H.E.S., Luber, K., M.P.H., Riley, A. H., DrP.H.M.C.H.E.S., & Medley, L., M.Ed. (2022). Menstrual health: Taking action against period poverty. American Journal of Public Health, 112(3), 374-377. Retrieved from <https://www.proquest.com/scholarly-journals/menstrual-health-taking-action-against-period/docview/2638099490/se-2?accountid=211160>

Period poverty is the lack of sufficient resources needed to manage menses, such as toilet, bathing, and laundering facilities; general menstrual education or information; and basic menstrual management supplies like tampons and pads.¹ Globally, period poverty and menstrual health and hygiene management have largely been examined in low- and middle-income countries.¹ However, this burden is also present in the United States. It is estimated that about one in four US menstruators will experience period poverty during her lifetime.^{2,3} Despite the prevalence, few understand, recognize, discuss, or study this issue domestically.³ In the United States, the limited existing literature on period poverty has largely noted that low-income and homeless populations in large urban cities, such as St. Louis, Missouri,³ and New York City,^{4,5} are among those most impacted by period poverty. However, period poverty is not limited to only those in "poverty" and can affect menstruators from any background at any time. The COVID-19 pandemic exacerbated period poverty. In the early months of the pandemic, there was fierce competition for resources (e.g., toilet paper, soap, wipes) and exorbitant gouging of these bathroom hygiene product prices.⁶ Compounded by increased job losses and unemployment because of the pandemic, fiscal barriers to accessing necessary menstrual products grew. The Coronavirus Aid, Relief, and Economic Security (CARES) Act, passed in March 2020, allowed employed menstruators with a health savings account or flexible savings account to purchase menstrual products with their respective coverage.⁷ But, given the bill's limited scope, it in fact furthered menstrual health disparities, as only 41% of private industry employees had access to a flexible health care spending account in 2019,⁸ and it lacked consideration for the skyrocketing unemployment rates of Americans-particularly among Black and Hispanic women.² Thus, conversations about menstrual products and hygiene needs among the majority of menstruators around the country were largely undiscussed. The overarching lack of attention to period poverty in society, research, medicine, and public wellness is attributable to deep-rooted menstrual stigma and shame. Many menstruators tend to conceal their menses out of fear or embarrassment, which yields conditioned self-silencing of their needs and further perpetuation of a generational and societal spiral of silence.⁹ This resounding stigma continually hinders both open discussion and policy engagement on menstrual experiences, management, and

hygiene needs. Therefore, the purpose of this work is to combat this stigma by describing five actionable steps we can all take to begin addressing period poverty.

11 years ago. (2022). American Journal of Public Health, 112(3), 341. Retrieved from <https://www.proquest.com/scholarly-journals/11-years-ago/docview/2638099008/se-2?accountid=211160>

Antebi-Gruszka, N. (2022). #TransLivesMatter: What we owe to transgender and gender diverse youths. American Journal of Public Health, 112(3), 363-365. Retrieved from <https://www.proquest.com/scholarly-journals/translivesmatter-what-we-owe-transgender-gender/docview/2638097936/se-2?accountid=211160>

As a nonbinary public health advocate, therapist, and researcher and as a parent of a trans girl, I am both moved and troubled by Rider et al.'s article in this issue of AJPH (p. 499). I want to thank and congratulate the authors for studying an extremely important yet underexamined topic in this put-at-risk population, and I thank AJPH for shedding light on this public health issue. As a sex work rights activist, it is important for me to clarify that sex trading among youths is psychologically, legally, and morally distinct from sex trading among adults. As such, trading sex as youths is, by nature, exploitative. Trading sex is an extreme risk factor for mental health challenges, including suicide and self-harm among youths, and especially among transgender and gender diverse (TGD) youths. Approximately 6% of TGD 9th and 11th graders report having traded sex in their relatively short lifetimes. More than three quarters of TGD youths who traded sex attempted to end their lives by suicide. This is a public health catastrophe. Think about Layla, a 16-year-old Black trans girl, who trades sex to buy food and sleep in someone's place to spend the freezing winter nights indoors. Consider the multiple systems that actively pushed Layla to trade sex: the rejecting family; the overburdened school staff who do not understand why Layla is struggling academically; the lack of community support for TGD youths due to lack of funding by the city and state; and the transphobic laws and policies, along with pervasive negative attitudes toward TGD individuals in the United States. Sex trading among youths is a result of the unjust lack of support, resources, and programs designed to empower youths, especially TGD youths. Put differently, sex trading among TGD youths is an indicator of failure at multiple levels, including the family, school, community, city, state, and federal systems. Clearly, there is a dire need for multilevel public health interventions and programs addressing sex trading among youths, especially among TGD youths. In fact, we need interventions far earlier in the trajectory into sex trading. Tangible intervention recommendations to address sex trading among TGD youths, along with its antecedents and consequences across multiple levels are included (Box 1).

Lewandowski, S., Marziali, M. E., Kalia, V., Abuawad, A. K., & Segura, L. E. (2022). AJPH GLOBAL NEWS. American Journal of Public Health, 112(3), 342. doi:<https://doi.org/10.2105/AJPH.2021.306689>

Haroz, E. E., PhD.M.A.M.H.S., Kemp, C. G., PhD.M.P.H., O'Keefe, Victoria M, PhD,M.S., Pocock, K., P.A.-C., Wilson, D. R., PhD., Christensen, L.,M.D.M.B.A.M.S.J.F.A.C.S., . . . Hammitt, L., M.D. (2022). Nurturing innovation at the roots: The success of COVID-19 vaccination in american indian and alaska native communities. American Journal of Public Health, 112(3), 383-387. Retrieved from <https://www.proquest.com/scholarly-journals/nurturing-innovation-at-roots-success-covid-19/docview/2638095370/se-2?accountid=211160>

American Indians and Alaska Natives (AI/ANs) experienced some of the highest rates of COVID-19 disease and death in the United States^{1,2}: an estimated 1 in 475 AI/ANs have died from COVID-19, in contrast to 1 in 825 White Americans.³ Infectious diseases have caused catastrophic losses among Indigenous populations since the first contact with Europeans; the distribution of smallpox-infected blankets by colonizers and federal officials is the earliest documentation of germ warfare and remains a devastating memory.^{4,5} The disproportionate impact of COVID-19 in AI/AN communities is a result of historically rooted systems of colonization, oppression, and marginalization.⁶ High rates of poverty, lack of running water, inadequate access to healthy food and transportation, poor indoor air quality, and overcrowded housing have all contributed to increased risk from COVID-19, especially on tribal reservations. Lack of electricity, Internet, and cell service, and inadequate infrastructure also created barriers to sharing prevention guidance, access to telemedicine, and health education. Chronic underfunding of the Indian Health Service resulted in insufficient resources and capacity to care for COVID-19 patients; many had to be

transported off reservations to regional hospitals. High rates of underlying chronic health conditions, particularly those that contribute to more severe outcomes-including diabetes, heart disease, and lung disease, which are driven by these same social determinants-exacerbated the effects of COVID-19. Public health surveillance during COVID-19 has also failed at times to appropriately count and consider AI/ANs, an issue deemed "data genocide." Despite these challenges, the COVID-19 vaccination efforts in many AI/AN communities have been major successes; AI/ANs have the highest COVID-19 vaccination rate of any racial or ethnic group in the country (Figure 1). How can this success inform the ongoing implementation of vaccination efforts elsewhere? We draw from four decades of work in partnership with tribes to outline several key lessons. Ultimately, we argue that the COVID-19 vaccination effort in AI/AN communities has been successful because it was nurtured at its roots by a deep well of community strength and by respect for tribal sovereignty.

Yang, T., PhD. (2022). Residential segregation and cities' responses in the early stage of the COVID-19 pandemic: Preexisting structural factors and health care access. *American Journal of Public Health*, 112(3), 369-371. Retrieved from <https://www.proquest.com/scholarly-journals/residential-segregation-cities-responses-early/docview/2638095350/se-2?accountid=211160>

In this issue of *AJPH*, Asabor et al. (p. 518) provide an investigation of whether residential segregation (hereafter "segregation") as a preexisting structural factor affected the spatial distribution of COVID-19 testing sites in the early stage of the pandemic and whether this relationship varied by racial/ethnic group. Segregation has a long history in the United States and is considered a manifestation of structural racism.¹ Segregation has been found to adversely affect racial/ethnic minorities' health outcomes even after taking individual differences into account.² This line of research has been extended to COVID-19 infections and deaths.³ However, the relationship between segregation and access to health care services among communities of color during the pandemic has been underexplored. The analysis by Asabor et al. fills this gap and provides some important directions for future research. I summarize their study and key findings, discuss insights drawn from their study, and suggest future research directions.

Kenworthy, N., PhD., & Igra, M., M.A. (2022). Medical crowdfunding and disparities in health care access in the united states, 2016-2020. *American Journal of Public Health*, 112(3), 491-498. doi:<https://doi.org/10.2105/AJPH.2021.306617>

Objectives. To assess whether medical crowdfunding use and outcomes are aligned with health financing needs in the United States. **Methods.** We collected data on 437 596 US medical GoFundMe campaigns between 2016 and 2020. In addition to summarizing trends in campaign initiation and earnings, we used state- and county-level data to assess whether crowdfunding usage and earnings were higher in areas with greater medical debt, uninsured populations, and poverty. **Results.** Campaigns raised more than \$2 billion from 21.7 million donations between 2016 and 2020. Returns were highly unequal, and success was low, especially in 2020: only 12% of campaigns met their goals, and 16% received no donations at all. Campaigns in 2020 raised substantially less money in areas with more medical debt, higher uninsurance rates, and lower incomes. **Conclusions.** Despite its popularity and portrayals as an ad-hoc safety net, medical crowdfunding is misaligned with key indicators of health financing needs in the United States. It is best positioned to help in populations that need it the least.

Snyder, J., PhD. (2022). Implications of inequities in health-related crowdfunding for the business of crowdfunding. *American Journal of Public Health*, 112(3), 357-359. Retrieved from <https://www.proquest.com/scholarly-journals/implications-inequities-health-related/docview/2638094068/se-2?accountid=211160>

In an important new study of crowdfunding campaigns for health-related needs, Kenworthy and Igra (p. 491) detail findings from an analysis of nearly 437 596 US-based health-related crowdfunding campaigns on the GoFundMe crowdfunding platform. These campaigns stretch from 2016 through 2020, and nearly half were initiated in 2020. The campaigns Kenworthy and Igra analyzed raised more than \$2 billion, though this was well short of their overall goal of nearly \$8.5 billion. Their success in reaching their goals differed greatly, with 16.1% of campaigns raising no money (rising to more than one third of campaigns in 2020). Not surprisingly, Kenworthy and Igra found a positive correlation between campaign prevalence and local medical debt and uninsurance rates. However, campaigns in

areas with higher medical debt and rates of uninsured people had less success in raising funding. Moreover, the number of donations and amount of money raised per campaign were lowest in low-income quintiles. In short, this research demonstrates that in the United States, medical crowdfunding is of limited use in meeting health-related needs and does the least to help those most in need of financial support.

Santibanez, Scott, MD, D. Min, M.P.H.T.M., Ottewell, A., M.P.H., Harper-Hardy, P., Ryan, E., M.P.H., Christensen, H., M.T.S., & Smith, Nathaniel, MD, MABS, M.P.H., D.T.M.&H. (2022). A rapid survey of state and territorial public health partnerships with faith-based organizations to promote COVID-19 vaccination. *American Journal of Public Health*, 112(3), 397-400. doi:<https://doi.org/10.2105/AJPH.2021.306620>

During the COVID-19 pandemic, media accounts emerged describing faith-based organizations (FBOs) working alongside health departments to support the COVID-19 response. In May 2021, the Department of Health and Human Services, Centers for Disease Control and Prevention, and the Association of State and Territorial Health Officials (ASTHO) sent an electronic survey to the 59 ASTHO member jurisdictions and four major US cities to assess state and territorial engagement with FBOs. Findings suggest that public health officials in many jurisdictions were able to work effectively with FBOs during the COVID-19 pandemic to provide essential education and mitigation tools to diverse communities.

Sun, Y., M.P.H., Mousavi, A., PhD., Masri, S., PhD., & Wu, J., PhD. (2022). Socioeconomic disparities of low-cost air quality sensors in California, 2017-2020. *American Journal of Public Health*, 112(3), 434-442. doi:<https://doi.org/10.2105/AJPH.2021.306603>

Objectives. To (1) examine the disparity in availability of PurpleAir low-cost air quality sensors in California based on neighborhood socioeconomic status (SES) and exposure to fine particulate matter smaller than 2.5 micrometers (PM_{2.5}), (2) investigate the temporal trend of sensor distribution and operation, and (3) identify priority communities for future sensor distribution. **Methods.** We obtained census tract-level SES variables and PM_{2.5} concentrations from the CalEnviroScreen4.0 data set. We obtained real-time PurpleAir sensor data (July 2017-September 2020) to examine sensor distribution and operation. We conducted spatial and temporal analyses at the census tract level to investigate neighborhood SES and PM_{2.5} concentrations in relation to sensor distribution and operation. **Results.** The spatial coverage and the number of PurpleAir sensors increased significantly in California. Fewer sensors were distributed in census tracts with lower SES, higher PM_{2.5}, and higher proportions of racial/ethnic minority populations. Furthermore, a large proportion of existing sensors were not in operation at a given time, especially in disadvantaged communities. **Conclusions.** Disadvantaged communities should be given access to low-cost sensors to fill in spatial gaps of air quality monitoring and address environmental justice concerns. Sensor purchasing and deployment must be paired with regular maintenance to ensure their reliable performance.

Rider, G. N., McMorris, B. J., PhD., Brown, Camille, PhD., R.N., Eisenberg, Marla E, ScD., M.P.H., Gower, A. L., PhD., Johnston-Goodstar, K., . . . Martin, L., PhD. (2022). Mental health and protective factors for transgender and gender-diverse youths who trade sex: A Minnesota statewide school-based study, 2019. *American Journal of Public Health*, 112(3), 499-508. doi:<https://doi.org/10.2105/AJPH.2021.306623>

Objectives. To describe the prevalence of sex trading by gender and by associations with mental health concerns and protective factors. **Methods.** We used data from 9th and 11th graders who completed the 2019 Minnesota Student Survey. The analytic sample (n = 67 806) included transgender and gender-diverse (TGD) youths and cisgender youths who reported trading sex. Data on 7 mental health measures and 4 school-related and health care-related protective factors were collected. **Results.** The prevalence of sex trading (5.9%) was 5 times higher among TGD students than cisgender students (1.2%). In addition, the prevalence of all mental health concerns was high among TGD students who traded sex (e.g., 75.9% reported a lifetime suicide attempt, as compared with 45.9% of cisgender students who traded sex). Fewer statistical differences were found across protective factors. When TGD students who traded sex were compared according to sex assigned at birth, no statistically significant differences were found. **Conclusions.** Our findings support strong calls for increased competence regarding gender and sex trading or exploitation in clinical and school-based settings to decrease health disparities among TGD youths. Public

Health Implications. In this study, we have presented unique prevalence estimates of mental health disparities among TGD students in the United States who trade sex. Our results indicate that TGD students who trade sex are at risk for mental health symptoms and that sensitivity to both gender and sex trading or exploitation will be critical to meeting the needs of this group in clinical as well as school-based settings.

Ojikutu, Bisola O,M.D., M.P.H., Bogart, L. M., PhD., & Dong, L., PhD. (2022). Mistrust, empowerment, and structural change: Lessons we should be learning from COVID-19. *American Journal of Public Health*, 112(3), 401-404. Retrieved from <https://www.proquest.com/scholarly-journals/mistrust-empowerment-structural-change-lessons-we/docview/2638091821/se-2?accountid=211160>

Within the COVID-19 pandemic, public mistrust has been cast in the pivotal role of antagonist. From lack of acceptance of preventive measures, to online misinformation and disinformation, to low vaccination rates, "the epidemic of mistrust" has been characterized as a thwarter of public health mitigation efforts. However, among Black/African American individuals in the United States who remain twice as likely to die¹ yet significantly less likely to be vaccinated against COVID-19² versus White Americans, mistrust is not the primary etiology of racial and ethnic inequities. Instead, mistrust is a manifestation of the pervasive pathologies of structural racism and White supremacy.³ Historical awareness of and contemporary exposure to structural racism-the system of hierarchy, privilege, and power that largely benefits White individuals-has resulted in mistrust as a rational, adaptive response to an adversarial environment. Furthermore, White supremacy, the belief that White people are superior to people of other racial backgrounds, sustains structural racism and, thus, is a fundamental driver of mistrust among people of color.^{4,5} A specific form of mistrust, medical mistrust, centers on the belief that health care providers, the health care system, the pharmaceutical industry, academic institutions, or the government as a steward of public health are acting against one's best interest or well-being.⁶ As a multidimensional belief system, medical mistrust likely exists on a spectrum from skepticism, to active suspicion, to belief in conspiracy theories or secret plots concerning perpetrators, motivations, and *modi operandi* that are not necessarily apocryphal.⁷ Typically, medical mistrust has been viewed through a deficit lens. This is unsurprising; negative characterizations of health beliefs espoused by people of color that diverge from those expressed by the dominant culture are a normative feature of race-based science. This is particularly true regarding mistrust beliefs. Individuals who express medical or research mistrust are frequently characterized as irrational, less well-educated, or possessing lower literacy.⁸ Among Black/African American individuals, medical mistrust has been associated with suboptimal health behaviors, such as nonadherence to antiretroviral therapy among people living with HIV, poor engagement in care, and decreased uptake of preventive behaviors, including vaccines.^{8,9} Unfortunately, a surfeit of attention within public discourse on combating the negative impacts of medical mistrust, particularly in regards to COVID-19 vaccine "hesitancy," has obscured the need to correct deficiencies and disparities in health care perpetuated by structural racism, White supremacy, and inequitable power structures in the United States.

O'Brien, Rory P, MSW, MPH, & Bloisnich, John R, PhD., M.P.H. (2022). Refusal rates to sexual orientation and gender identity items in the behavioral risk factor surveillance system, 2014-2019. *American Journal of Public Health*, 112(3), 443-452. doi:<https://doi.org/10.2105/AJPH.2021.306625>

Objectives. To explore trends in sexual orientation and gender Identity (SOGI) Item refusal In the Behavioral Risk Factor Surveillance System (BRFSS). **Methods.** We used annual data from 7 US states that implemented the SOGI module of the BRFSS from 2014 to 2019 to examine prevalence of sexual orientation (n = 373 332) and gender identity (n 5 373 336) item refusal. Analyses included the weighted Wald χ^2 test of association between refusal and year and logistic regressions predicting refusal by year. We weighted analyses to account for complex sampling design. **Results.** We found low SOGI item refusal rates, significant declines in these refusal rates overtime, and differences in refusal rates by age, sex, race, education, and language. We also found that Hispanic group membership did not explain SOGI item refusal when accounting for interview language; interview language was strongly associated with both sexual orientation and gender identity item refusal. **Conclusions.** Our results indicate acceptance of SOGI measurement and empirically support continuation of SOGI in health surveillance surveys. Findings indicate a need to further investigate the association between survey translation and item refusal.

Ross, L. E., PhD., Kinitz, D. J., M.S.W., & Kia, H., PhD. (2022). Pronouns are a public health issue. *American Journal of Public Health*, 112(3), 360-362. Retrieved from <https://www.proquest.com/scholarly-journals/pronouns-are-public-health-issue/docview/2638091809/se-2?accountid=211160>

In their study published in this issue of *AJPH*, Perales et al. (p. 482) drew from a 2020 Australian data set to demonstrate a significant association between the use of inclusive language in the workplace and a multidimensional measure of well-being at work in a sample of more than 400 trans- and gender-diverse (TGD) people (including transgender, nonbinary, agender, and other gender minority people) working for more than 100 unique employers. This study is notable both for its relatively large sample size (given the underresearched and often invisible nature of this population) and for its inclusion of workplace-level data (i.e., indicators of inclusive language use from both TGD and cisgender employees in each workplace setting). The resulting findings are the first, to our knowledge, to empirically establish the relationship between trans-inclusive language and mental well-being at work, and they offer important extensions to our knowledge of the contribution of employment-related discrimination to the health of TGD people.¹ Why is trans-inclusive language in the workplace (and beyond) a public health issue? Work and working conditions are widely accepted as important components of the social determinants of health (<https://bit.ly/3qsb6Qv>). Although less formally acknowledged, many scholars and advocates argue that gender identity, meaning one's internal experience and sense of gender, should also be considered a social determinant of health: TGD people experience profound health inequities, often associated with exposure to gender-related stigma and discrimination.² Indeed, these disparities are so stark that, in recent years, special sections have been devoted to TGD health in both *AJPH* and the *Lancet*.^{3,4} These health inequities are linked to economic and other structural inequities. For example, highlighting the disproportionately high prevalence of HIV in TGD populations, Becasen et al. have noted the relevance of recognizing social and economic vulnerabilities systemically affecting this population as factors that likely increase HIV risk.⁵ Indeed, structural and interpersonal discrimination, experienced by TGD people as cisnormativity and transphobia, limit TGD people's access to the health benefits of work. A national US study identified that TGD people were more than twice as likely to be living in poverty (29%) as cisgender people; this is likely attributable to unemployment rates that are three times the national average, earning lower wages than their cisgender counterparts, and experiencing workplace discrimination and harassment that result in being fired, resigning, or being denied promotion. These patterns are compounded when intersectional marginalization is considered (<https://bit.ly/3z7nQjI>). Corroborating findings from Canada indicate that TGD people face higher rates of employment discrimination (2.2 times) and harassment (2.5 times) than do their cisgender peers, despite workplace protections.¹ Almost 30% of TGD people reported that they were, or thought they were, fired for being TGD, whereas 50% were, or thought they were, denied a job for being TGD (<https://bit.ly/32CvJBm>).

Kapadia, Farzana, PhD., M.P.H. (2022). Ending homelessness and advancing health equity: A public health of consequence, march 2022. *American Journal of Public Health*, 112(3), 372-373. Retrieved from <https://www.proquest.com/scholarly-journals/ending-homelessness-advancing-health-equity/docview/2638091324/se-2?accountid=211160>

Widening sociostructural inequities, especially those arising from homelessness and housing insecurity, are drivers of the growing health inequities in the United States. Continued efforts to understand how homelessness will evolve over the course of the pandemic and beyond to impact adverse health outcomes in rural areas, in suburban communities, and in urban centers will be required. In parallel, pressing questions for public health advocates, policymakers, and community members seeking to end homelessness will include determining which populations to prioritize for intervention and what interventions will yield the most benefit to intervene on this critical driver of health inequity.

Morey, B. N., PhD. M.P.H. (2022). A measure of hope: New questions for postpandemic rebuilding. *American Journal of Public Health*, 112(3), 345-347. Retrieved from <https://www.proquest.com/scholarly-journals/measure-hope-new-questions-postpandemic/docview/2638091294/se-2?accountid=211160>

As the United States continues to grapple with the trauma COVID-19 has inflicted, how has the pandemic affected Americans' outlook on the future? Furthermore, with the nation at a critical juncture of social and economic recovery,

how can public health address population-level hope and despair moving forward? In this issue of AJPH, Riley et al. (p. 509) begin to address these questions using a novel measure of the difference between anticipated life satisfaction (ALS) and current life satisfaction (CLS) to examine trends in hope across the nation and within US counties. This new way of tracking people's outlook on their lives may help with the development of programs and policies aimed at bolstering hope to support well-being. However, this novel measure also raises several questions about the public health implications of population-level hope. This population-level measure of hope contributes to the literature an aspect of the social environment not previously captured in the effort to theorize and test the associations between societal attitudes and health. Riley et al. aggregate individual responses to the Gallup National Health and Well-Being Index to summarize changes in hope at the county and national levels. Although theories about how social environments and individuals interrelate have existed for decades, measuring the social environment based on aggregating individual attitudes is relatively rare in the literature. Most commonly, such measures have captured social capital: the resources that are rooted in social networks such as social connectedness, civic engagement, norms of reciprocity, and trust in others that facilitate cooperation for mutual benefit.¹ Recently, health scholars have aggregated individual responses to national survey data to capture area-level attitudes of anti-Black racism, xenophobia, and homophobia to examine their associations with mortality.²⁻⁴ Other studies have used aggregate individual data from Google searches and tweets as indicators of prejudicial social environments.

Jans, M., PhD. (2022). We keep proving that SOGI questions work, but have more to learn. *American Journal of Public Health*, 112(3), 366-368. Retrieved from <https://www.proquest.com/scholarly-journals/we-keep-proving-that-sogi-questions-work-have/docview/2638091176/se-2?accountid=211160>

In this issue of AJPH, O'Brien and Blosnich (p. 443) adeptly expand our growing knowledge base on sexual orientation and gender identity (SOGI) measurement. Methodologically speaking, the authors did everything right, including weighting their analyses to account for the sample design and reporting their outcome measures transparently (<https://bit.ly/aapor-tifaq>). If this article were appearing in a methodology journal, I might take issue with calling all item nonresponses "refusals" (vs the more general and accurate, if jargony, "item nonresponse"), but it's not. The major takehome is that much-needed data on sexual and gender minorities (SGMs) can be collected in large-scale general population surveys, furthering essential lesbian, gay, bisexual, transgender, questioning, and others (LGBTQ+) public health research. The article's geographically broadened scope, although not fully national, and assessment of both SO and GI measures overtime address major limitations of past research. Corroborating past results, they show that race/ethnicity and language are related to SOGI nonresponse and its decline over time. Generally speaking, non-Hispanic people of color are more likely not to answer SOGI items. Rather than recount their detailed findings, I comment on the state of our SOGI measurement knowledge and open questions in our practices.

Meghea, C. I., PhD. (2022). Successful strategies to increase cessation rates among low-income maternal smokers. *American Journal of Public Health*, 112(3), 351-353. Retrieved from <https://www.proquest.com/scholarly-journals/successful-strategies-increase-cessation-rates/docview/2638090335/se-2?accountid=211160>

Collins et al. (p. 472) provide a valuable contribution to the tobacco cessation literature as they found that a "multilevel, MBI multimodal behavioral intervention] package initiated in WIC Special Supplemental Nutrition Program for Women, Infants, and Children] was acceptable, feasible, and efficacious in promoting long-term smoking abstinence and reported child TSE tobacco smoke exposure] reduction" (p. 479). The findings are important as this approach, embedding tobacco cessation in community clinics, has potential to reduce tobacco-related morbidity and mortality in vulnerable populations. WIC serves low-income families in the United States. Low-income populations have a higher prevalence of smoking tobacco and initiate cessation assistance and treatment at lower rates, with greater challenges and less success compared with other populations. Tobacco cessation approaches that increase cessation rates in low-income populations can reduce these disparities. The study by Collins et al. designed and tested Babies Living Safe and Smokefree (BLISS), a WIC-embedded intervention that combined best practice guidelines for tobacco intervention (Ask, Advise, Refer AARJ) with a more intensive multimodal behavioral intervention (MBI) grounded in telehealth counseling. The authors hypothesized primarily that

AAR plus MBI would promote greater reductions in child tobacco smoke exposure than AAR plus controls. Interestingly, the hypothesis was supported by self-reported tobacco smoke exposure results, but there was no change in cotinine, a nicotine metabolite, in either group. The secondary hypothesis, focused on abstinence outcomes, was supported better by the findings of the study. Individuals in the AAR plus MBI group were more likely to report quit attempts, had more abstinent days, and had higher reported and bioverified abstinence rates.

Riley, Carley, MD,M.P.P., M.H.S., Herrin, J., PhD., Lam, V., B.A., Parsons, A. A., PhD., Kaplan, G. A., PhD., Liu, D., M.S., . . . Roy, Brita, MD,M.P.H., M.H.S. (2022). Trends and variation in the gap between current and anticipated life satisfaction in the united states, 2008-2020. *American Journal of Public Health*, 112(3), 509-517.
doi:<https://doi.org/10.2105/AJPH.2021.306589>

Objectives. To describe national- and county-level trends and variation in a novel measure of hope. **Methods.** Using data from the Gallup National Health and Well-Being Index ($n = 2\,766\,728$), we summarized the difference between anticipated life satisfaction (ALS) and current life satisfaction (CLS), measured by the Cantril Self-Anchoring Scale, for each year from 2008 to 2020 and by county over two 5-year periods in the United States. **Results.** Across all years, there was a significant positive trend in the difference between ALS and CLS for the nation ($P = .024$), which remained positive but not significant when we excluded 2020. Maintenance of ALS with a decrease in CLS drove the 2020 increase. From 2008-2012 to 2013-2017, 14.5% of counties with 300 or more responses ($n = 599$) experienced an increase in the difference of more than 1 SD, whereas 13.9% experienced a more than 1 SD decrease. Fifty-two counties experienced decreases in ALS and CLS. **Conclusions.** Responding to trends in the gap between ALS and CLS at national and local levels is essential for the collective well-being of our nation, especially as we navigate and emerge from crisis.

Erratum in: "are we there yet? the american journey to safer city streets". (2022). *American Journal of Public Health*, 112(3) doi:<https://doi.org/10.2105/AJPH.2021.306405e>

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