

Submitted to

American Journal of
**PUBLIC
HEALTH**

A PUBLICATION OF
AMERICAN PUBLIC HEALTH ASSOCIATION

Racial Disparities in Cancer Care | Access to Care for
Transgender Veterans | Hepatitis C Among US Veterans |

Battling Tobacco Use at Home | HEALTH EQUITY | New Night

The Provision of Culturally Competent Services Be Enhanced for American Indian
and Alaska Native Veterans? | Improving Trends in Gender Disparities | Sociality
Among Hispanic and African American Veterans Following Surgery



AJPH

A PUBLICATION OF THE
AMERICAN PUBLIC HEALTH ASSOCIATION

COVER: On the eve of World AIDS Day In Kathmandu, Nepal, November 30, 2020, a woman lights candles forming a Red Ribbon (recognized symbol for AIDS awareness) as she prays for those who lost their lives due to HIV/AIDS, on the eve of World AIDS Day. World AIDS Day is marked worldwide annually on December 1 to raise awareness for those living with the virus.

Photo concept and selection by Aleisha Kropf. Photo by Sunil Pradhan / SOPA Images via APImages. Printed with permission.



Promoting public health research, policy, practice, and education is the *AJPH* mission. As we widen our scope to embrace global issues, we also sharpen our focus to support the needs of public health practitioners. We invite contributions of original unpublished research, opinion and commentary, and letters to the editor.

The *Journal* is printed on acid-free recycled paper.

AJPH July 2021, Vol 111, No. 7

EDITOR-IN-CHIEF

Alfredo Morabia, MD, PhD

SENIOR DEPUTY EDITOR

Michael C. Costanza, PhD

DEPUTY EDITOR

Farzana Kapadia, PhD

DEPUTY STATISTICAL EDITOR

Hua He, PhD

IMAGE EDITOR

Aleisha Kropf

ASSISTANT EDITOR

Shokhari Tate

STUDENT EDITOR

Michelle Sarah Livings, MPH

EDITORS

Luisa Borrell, DDS, PhD

Lisa Bowleg, PhD, MA

Theodore M. Brown, PhD

Nabarun Dasgupta, PhD, MPH

Paul C. Erwin, MD, DrPH

Daniel M. Fox, PhD

Colleen Grogan, PhD

Robert J. Kim-Farley, MD, MPH

Stewart J. Landers, JD, MCP

Denys T. Lau, PhD

Tanya Telfair LeBlanc, PhD

Jonathan I. Levy, ScD

Evan Mayo-Wilson, DPhil

Wendy Parmet, JD

Kenneth Rochel de Camargo Jr, MD, PhD

Daniel Tarantola, MD

Roger Vaughan, DrPH, MS

Eric R. Walsh-Buhi, PhD, MPH

Stella M. Yu, ScD, MPH

EDITORIAL BOARD

Heather M. Brandt, PhD (2023)

Maria DeJesus, PhD (2022)

Tee L. Guidotti, MD, DABT, MPH (2021)

Amy Hagopian, PhD, MHA (2021)

Hae-Ra Han, PhD, RN (2021), Chair

Sonja Hutchins, MD, DrPH, MPH (2021), Vice Chair

Amar Kanekar, PhD, MPH, MB (2023)

Yan Ma, PhD, MA, MS (2022)

A.G. Palladino, MPH, MJ, MS (2023)

Martha C. Romney, JD, BSN, MPH, MS (2022)

Laura Schwab Reese, PhD, MA (2023)

Gulzar H. Shah, PhD, MStat, MS (2022)

Mark A. Strand, PhD, MS

Ruth Charmaine White, PhD, MPH, MSW (2021)

Ashlee Van Schyndel (2021)

Cynthia Williams, PhD, MHA, PT (2022)

FORMER EDITORS-IN-CHIEF

Mary E. Northridge, PhD, MPH
(Editor Emerita)

Mervyn Susser

Michel Ibrahim

Alfred Yankauer

George Rosen

Abel Wolman

Charles-Edward A. Winslow

Harry S. Mustard

Mazjck Ravenel

STAFF

Georges C. Benjamin, MD

Executive Director/Publisher

Ashell Alston

Director of Publications

Brian Selzer

Deputy Director of Publications

Katie Poe

Journal Production Coordinator

Michael Henry

Associate Production Editor (Sr)

Morgan Richardson

Associate Production Editor

Phat Nguyen

Digital Publications Specialist

FREELANCE

Kelly Burch

Greg Edmondson

Aisha Jamil

Gary Norton

Michelle Quirk

Sarah Cook

Copyeditors

Aisha Jamil

Leona Selzer


Proofreaders

Vanessa Sifford

Graphic Designer

Reproduced with permission of copyright owner. Further reproduction prohibited
without permission.


EDITOR'S CHOICE

- 1175**  AIDS Versus COVID-19: Different Profiles, Common Causes, and Common Victims
A. Morabia

GLOBAL NEWS



- 1176** *AJPH* Global News

BOOKS & MEDIA

- 1177**  Preparing the Urban Public Health Workforce
N. Freudenberg

OPINIONS, IDEAS, & PRACTICE

EDITORIALS

- 1180**  1981-2021: HIV and Our World
S. Landers, F. Kapadia, and L. Bowleg
- 1183** Mind the Gap: Yet More Evidence for the Importance of Education for Children With Uncontrolled Asthma
N. Homaira and A. Jaffe
- 1186** Expanding Access to Medical Care Services to Undocumented New York City Residents Without Health Insurance: Reflections on the ActionHealthNYC Study
S. J. Haley
- 1189** The Case for Conceptualizing Youth–Police Contact as a Racialized Adverse Childhood Experience
D. B. Jackson
- 1192**  The Biggest Legal Obstacle to Gun Regulation: State Preemption Laws, Not the Second Amendment
J. Blocher
- 1194** Timely Overdose Death Reporting Is Challenging but We Must Do Better
M. D. Fliss, M. E. Cox, S. W. Dorris, and A. E. Austin
- 1197** Worker Health Inequities in Central America
C. E. Siqueira
- 1199** Public Health Insight From Excess Mortality During the COVID-19 Pandemic
C.-C. Ku
- 1202** The Unintended Health Consequences of Social Policies
S. Galea and R. Vaughan


PERSPECTIVES

- 1204** Support Pharmacy Infrastructure to Strengthen US COVID-19 Vaccination Efforts and Beyond
K. K. Marwitz, C. Haugtvedt, and A. B. Kostrzewa
- 1207** The Urgent Public Health Need to Develop “Crisis Standards of Housing”: Lessons From the COVID-19 Pandemic
J. A. Barocas and M. Earnest

COCHRANE SERIES

- 1210** Stakeholder Involvement in Systematic Reviews: Lessons From Cochrane’s Public Health and Health Systems Network
B. Merner, D. Lowe, L. Walsh, A. Synnot, J. Stratil, S. Lewin, C. Glenton, P. von Phillipsborn, L. Schonfeld, R. Ryan, D. O’Connor, J. L. Hoving, and S. Hill

POLICY

- 1216**  How Accountable to the Public Is Funding for Graduate Medical Education? The Case for State Medicaid GME Payments
T. M. Henderson

LAW & ETHICS

- 1220** The US Supreme Court and the Future of Sexual and Gender Minority Health
M. Liu, J. L. Turban, and K. H. Mayer

NOTES FROM THE FIELD

- 1223** Vaccination of the Elderly in Assisted Living by the Israeli Emergency Medical Services
E. Jaffe, K. Dopelt, N. Davidovitch, and Y. Bitan
- 1227** Rapid Creation of a Multiagency Alternate Care Site for COVID-19–Positive Individuals Experiencing Homelessness
C. Y. Wang, M. L. Palma, C. Haley, J. Watts, and K. Hinami

HIV/AIDS AND OUR WORLD: 1981–2021

- 1231** Forty Years of HIV: The Intersection of Laws, Stigma, and Sexual Behavior and Identity
D. W. Purcell



- 1234**  Beyond the Magic Bullet: What Will It Take to End the AIDS Epidemic?
W. M. El-Sadr
- 1237**   The Sankofa Paradox: Why Black Women Know the HIV Epidemic Ends With “WE”
D. D. Diallo
- 1240**   HIV Is a Story First Written on the Bodies of Gay and Bisexual Men
G. Ayala and A. Spieldecker
- 1243** Joseph Sonnabend and the AIDS Epidemic: Pioneering and Its Discontents
R. Boyer and G. M. Oppenheimer
- 1246**   Then and Now: Historical Landscape of HIV Prevention and Treatment Inequities Among Latinas
H. Amaro and G. Prado
- 1249** Forty Years of Fighting for Equitable Partnering in Research: We Are Not There Yet
M. V. Ellis
- 1252** Intersections of Treatment, Surveillance, and Criminal Law Responses to HIV and COVID-19
C. Hastings, A. McClelland, A. Guta, M. Owino, E. Manning, M. Orsini, R. Elliott, M. Gagnon, and S. Mollndrem
- 1255** Ending HIV in the United States Is Possible With the Proper Leadership and Sufficient and Targeted Resources
C. Schmid
- 1258** HIV’s Trajectory: Biomedical Triumph, Structural Failure
L. Beletsky, M. Thumath, D. F. Haley, G. Gonsalves, and A. Jordan
- 1261** The Importance of Social Movements: A Student Perspective on HIV/AIDS
C. N. Garcia-Wilde
- 1263** Reimagining Inclusivity in Health Care for Sexual Minorities to End the HIV Epidemic: A Student Perspective
B. D. Hanshaw
- 1265** Missed Opportunities for HIV Prevention in Puerto Rico: An Argument for Inclusivity and Community Coalitions
J. Lopez-Rios

RESEARCH & ANALYSIS




HISTORY

- 1267**  A Centenary Tale of Two Pandemics: The 1918 Influenza Pandemic and COVID-19, Part II
D. M. Morens, J. K. Taubenberger, and A. S. Fauci


POLICY

- 1273**   State Gun-Control, Gun-Rights, and Preemptive Firearm-Related Laws Across 50 US States for 2009–2018
J. L. Pomeranz, D. Silver, and S. A. Lief


SURVEILLANCE

- 1281**  Factors Associated With Calling 911 for an Overdose: An Ethnographic Decision Tree Modeling Approach
K. D. Wagner, B. Koch, J. M. Bowles, S. R. Verdugo, R. W. Harding, and P. J. Davidson
- 1284**  COVID-19 and the Drug Overdose Crisis: Uncovering the Deadliest Months in the United States, January–July 2020
J. Friedman and S. Akre
- 1292**  Homicide Epidemic in Cali, Colombia: A Surveillance System Data Analysis, 1993–2018
R. Guerrero-Velasco, V. H. Muñoz, A. Concha-Eastman, Á. J. Pretel-Meneses, M. I. Gutiérrez-Martínez, and J. Santaella-Tenorio

PERSPECTIVES FROM THE SOCIAL SCIENCES

- 1300**  Youth–Police Contact: Burdens and Inequities in an Adverse Childhood Experience, 2014–2017
A. Geller

METHODS



- 1309**  Stigma, Structural Vulnerability, and “What Matters Most” Among Women Living With HIV in Botswana, 2017
L. H. Yang, O. B. Poku, S. Misra, H. T. Mehta, S. Rampa, M. M. Eisenberg, L. S. Yang, T. X. D. Cao, L. I. Blank, T. D. Becker, B. G. Link, P. Entaile, P. R. Opondo, T. Arscott-Mills, A. R. Ho-Foster, and M. B. Blank

OPEN-THEMED RESEARCH







- 1318**  ActionHealthNYC: Effectiveness of a Health Care Access Program for the Uninsured, 2016–2017
R. K. Sood, J. Y. Bae, A. Sabety, P. Y. Chan, and C. Heindrichs
- 1328**  Community Health Worker Asthma Interventions for Children: Results From a Clinically Integrated Randomized Comparative Effectiveness Trial (2016–2019)
M. A. Martin, O. Pugach, G. Mosnaim, S. Weinstein, G. Rosales, A. Roy, A. A. Pappalardo, and S. Walton
- 1338**   Monitoring Self-Perceived Occupational Health Inequities in Central America, 2011 and 2018
M. Silva-Peñaherrera, D. Gimeno Ruiz de Porras, G. L. Delclos, M. R. Garbanzo, P. Merino-Salazar, M. Lopez-Ruiz, and F. G. Benavides
- 1348**  Digital Health Engagement in the US Population: Insights From the 2018 Health Information National Trends Survey
C. L. Ratcliff, M. Krakow, A. Greenberg-Worisek, and B. W. Hesse
- 1352**  Excess Mortality During the COVID-19 Pandemic
M. Todd, M. Pharis, S. P. Gulino, J. M. Robbins, and C. Bettigole

BACK MATTER

LETTERS & RESPONSES

- e1**  The Importance of Reporting Lag in Assessing Excess Deaths During the COVID-19 Pandemic
J. L. Salemi
- e3**  Excess Deaths Reveal the Substantial Impact of COVID-19 Pandemic on Mortality in the State of Florida
M. Tatar, A. Habibdoust, and F. A. Wilson

ERRATA

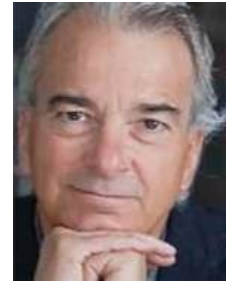
- e5**   ERRATUM In: Violent Victimization Among Lesbian, Gay, and Bisexual Populations in the United States: Findings From the National Crime Victimization Survey, 2017–2018
A. K. Bender and J. L. Lauritsen
- e6**   ERRATUM In: A Redesigned AJPH for the Times That Are “A-Changin’”
A. Morabia
- e7**   ERRATUM In: People-Centered Innovations in Data Collection: The Oregon Experience
S. Fiala and S. Landers

OTHER DEPARTMENTS

- 1358** Career Opportunities
- 1360** Subscription Form

Reproduced with permission of copyright owner. Further reproduction prohibited
without permission.

AIDS Versus COVID-19: Different Profiles, Common Causes, and Common Victims



In this issue, *AJPH* Deputy Editor Farzana Kapadia and Associate Editors Stewart Landers and Lisa Bowleg have assembled articles reviewing the record of the HIV/AIDS pandemic and emphasizing the urgent need to further control and then eradicate this persisting pandemic. See their editorial (p. 1180) summarizing the contents of the special section (pp. 1231–1266).

HIV/AIDS emerged 40 years ago. According to UNAIDS (Joint United Nations Programme on HIV and AIDS), to date, it has caused 33 million deaths and infected 76 million people; and it still infects approximately 1.7 million persons every year (<https://bit.ly/3217OD6>). HIV/AIDS belongs now to the short list of infectious diseases, such as tuberculosis, that have had a chronic, deadly presence for decades. Although SARS-CoV-2/COVID-19 has killed 3 million people in one year and infected 140 million, it will become a cyclic scourge infecting more than HIV but killing fewer.

Nevertheless, there is a key commonality between HIV/AIDS and SARS-CoV-2/COVID-19: both have thrived on the structural weaknesses of our global health care system. The most affected populations are the same. Locally, in the United States, people of color—especially those living in the Southern states that in 2021 had still not expanded Medicaid to provide affordable health insurance for the poor—suffer from the highest rates of new diagnoses (<https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics>). Today they are the most infected by and have a higher rate of mortality from SARS-CoV-2/COVID-19. Globally, low- and middle-income countries have struggled to get affordable AIDS treatments, then and now, and they are similarly struggling today to get access to the COVID-19 vaccines that have been developed at an extraordinary pace in the United States, Europe, China, and Russia.

Another fundamental and shameful commonality between the two pandemics are the attempts by conservative governments to stigmatize subgroups

of their populations. In the 1980s, the HIV/AIDS epidemic was first associated with gay and bisexual men even though hemophilic men and women, injectors of illegal drugs, and sex workers of both genders also developed the disease. In 2020, the former US president stigmatized the Asian population by describing COVID-19 as the “ChineseVirus” on social media and to journalists, unleashing waves of anti-Asian racism and xenophobia that have included violence. Listen to the May 2021 podcast of *AJPH*: “#ChineseVirus vs #COVID-19 Racism and Xenophobia on Social Media” (https://am.ajph.link/POD_May2021).

These commonalities between HIV/AIDS and COVID-19 call for analogous responses, such as (1) engaging the populations that have been made vulnerable by an inequitable system, because bringing all stakeholders to the decision table is indispensable for making and implementing effective public health policy; (2) collecting representative data and disaggregate them by gender, age, race/ethnicity, geography, sexual and gender minority status, and other key variables that are indispensable for focusing public health intervention; (3) thinking globally: it took too much time for most governments to understand that the HIV/AIDS pandemic, or any other pandemic, required a global response.

Most officials and organizations making policy for SARS-CoV-2/COVID-19 do not seem to have yet fully appreciated and applied these and related lessons from the HIV/AIDS epidemic. But at least the previous US administration, which denied the importance of science, marginalized the Centers for Disease Control and Prevention, and assigned leadership of the response to the pandemic to persons with inadequate expertise in public health, has now been replaced. **AJPH**

Alfredo Morabia, MD, PhD
Editor-in-Chief, *AJPH*
@AlfredoMorabia

DOI: <https://doi.org/10.2105/AJPH.2021.306362>

36 Years Ago

AIDS and Sexual Behavior Reported by Gay Men in San Francisco

[We] surveyed 655 gay men in San Francisco regarding their sexual practices during the previous month and the same month one year ago. The sample was selected to include men in situations that would lead to high risk of sexual activities related to AIDS... transmission (i.e., men frequenting bathhouses and gay bars) as well as men in low-risk situations (those going to neither place and men in primary relationships). The Bath group showed little change in frequency of bathhouse use and in number of sexual partners from that location. The other group showed substantial reductions in frequency of sexual contacts from bars, baths, . . . or parks. Men in monogamous relationships showed little change in sexual behavior within their relationship. Men in non-monogamous relationships and men not in relationships reported substantial reductions in high-risk sexual activity, but not a corresponding increase in low-risk sexual behavior.

From AJPH, May 1985, p. 493

38 Years Ago

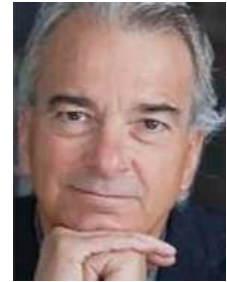
Similarities Between AIDS and Protein Calorie Malnutrition

The acquired immunodeficiency syndrome (AIDS) is characterized by a prodromal history of weight loss prior to diagnosis, and acute severe weight loss leading to cachexia is a general manifestation of the fully developed condition. This weight loss is a result of the infectious or neoplastic complications of AIDS, but it is also possible that nutritional deficiency may play a significant role in the clinical course of the immunodeficient state. There is a similarity between the immune deficiency, multiple infections, and severe weight loss seen in AIDS patients, and the association of protein calorie malnutrition (PCM) with reduced resistance to infection observed in malnourished children, particularly in the Third World. . . . The immunodeficiency in children with PCM can be reversed by nutritional rehabilitation, which suggests that restoration of the nutritional state may be a useful adjunct to therapy for AIDS patients.

From AJPH, November 1983, p. 1332

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

AIDS Versus COVID-19: Different Profiles, Common Causes, and Common Victims



In this issue, *AJPH* Deputy Editor Farzana Kapadia and Associate Editors Stewart Landers and Lisa Bowleg have assembled articles reviewing the record of the HIV/AIDS pandemic and emphasizing the urgent need to further control and then eradicate this persisting pandemic. See their editorial (p. 1180) summarizing the contents of the special section (pp. 1231–1266).

HIV/AIDS emerged 40 years ago. According to UNAIDS (Joint United Nations Programme on HIV and AIDS), to date, it has caused 33 million deaths and infected 76 million people; and it still infects approximately 1.7 million persons every year (<https://bit.ly/3217OD6>). HIV/AIDS belongs now to the short list of infectious diseases, such as tuberculosis, that have had a chronic, deadly presence for decades. Although SARS-CoV-2/COVID-19 has killed 3 million people in one year and infected 140 million, it will become a cyclic scourge infecting more than HIV but killing fewer.

Nevertheless, there is a key commonality between HIV/AIDS and SARS-CoV-2/COVID-19: both have thrived on the structural weaknesses of our global health care system. The most affected populations are the same. Locally, in the United States, people of color—especially those living in the Southern states that in 2021 had still not expanded Medicaid to provide affordable health insurance for the poor—suffer from the highest rates of new diagnoses (<https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics>). Today they are the most infected by and have a higher rate of mortality from SARS-CoV-2/COVID-19. Globally, low- and middle-income countries have struggled to get affordable AIDS treatments, then and now, and they are similarly struggling today to get access to the COVID-19 vaccines that have been developed at an extraordinary pace in the United States, Europe, China, and Russia.

Another fundamental and shameful commonality between the two pandemics are the attempts by conservative governments to stigmatize subgroups

of their populations. In the 1980s, the HIV/AIDS epidemic was first associated with gay and bisexual men even though hemophilic men and women, injectors of illegal drugs, and sex workers of both genders also developed the disease. In 2020, the former US president stigmatized the Asian population by describing COVID-19 as the “ChineseVirus” on social media and to journalists, unleashing waves of anti-Asian racism and xenophobia that have included violence. Listen to the May 2021 podcast of *AJPH*: “#ChineseVirus vs #COVID-19 Racism and Xenophobia on Social Media” (https://am.ajph.link/POD_May2021).

These commonalities between HIV/AIDS and COVID-19 call for analogous responses, such as (1) engaging the populations that have been made vulnerable by an inequitable system, because bringing all stakeholders to the decision table is indispensable for making and implementing effective public health policy; (2) collecting representative data and disaggregate them by gender, age, race/ethnicity, geography, sexual and gender minority status, and other key variables that are indispensable for focusing public health intervention; (3) thinking globally: it took too much time for most governments to understand that the HIV/AIDS pandemic, or any other pandemic, required a global response.

Most officials and organizations making policy for SARS-CoV-2/COVID-19 do not seem to have yet fully appreciated and applied these and related lessons from the HIV/AIDS epidemic. But at least the previous US administration, which denied the importance of science, marginalized the Centers for Disease Control and Prevention, and assigned leadership of the response to the pandemic to persons with inadequate expertise in public health, has now been replaced. **AJPH**

Alfredo Morabia, MD, PhD
Editor-in-Chief, *AJPH*
@AlfredoMorabia

DOI: <https://doi.org/10.2105/AJPH.2021.306362>

36 Years Ago

AIDS and Sexual Behavior Reported by Gay Men in San Francisco

[We] surveyed 655 gay men in San Francisco regarding their sexual practices during the previous month and the same month one year ago. The sample was selected to include men in situations that would lead to high risk of sexual activities related to AIDS... transmission (i.e., men frequenting bathhouses and gay bars) as well as men in low-risk situations (those going to neither place and men in primary relationships). The Bath group showed little change in frequency of bathhouse use and in number of sexual partners from that location. The other group showed substantial reductions in frequency of sexual contacts from bars, baths, . . . or parks. Men in monogamous relationships showed little change in sexual behavior within their relationship. Men in non-monogamous relationships and men not in relationships reported substantial reductions in high-risk sexual activity, but not a corresponding increase in low-risk sexual behavior.

From *AJPH*, May 1985, p. 493

38 Years Ago

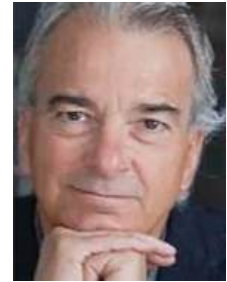
Similarities Between AIDS and Protein Calorie Malnutrition

The acquired immunodeficiency syndrome (AIDS) is characterized by a prodromal history of weight loss prior to diagnosis, and acute severe weight loss leading to cachexia is a general manifestation of the fully developed condition. This weight loss is a result of the infectious or neoplastic complications of AIDS, but it is also possible that nutritional deficiency may play a significant role in the clinical course of the immunodeficient state. There is a similarity between the immune deficiency, multiple infections, and severe weight loss seen in AIDS patients, and the association of protein calorie malnutrition (PCM) with reduced resistance to infection observed in malnourished children, particularly in the Third World. . . . The immunodeficiency in children with PCM can be reversed by nutritional rehabilitation, which suggests that restoration of the nutritional state may be a useful adjunct to therapy for AIDS patients.

From *AJPH*, November 1983, p. 1332

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

AIDS Versus COVID-19: Different Profiles, Common Causes, and Common Victims



In this issue, *AJPH* Deputy Editor Farzana Kapadia and Associate Editors Stewart Landers and Lisa Bowleg have assembled articles reviewing the record of the HIV/AIDS pandemic and emphasizing the urgent need to further control and then eradicate this persisting pandemic. See their editorial (p. 1180) summarizing the contents of the special section (pp. 1231–1266).

HIV/AIDS emerged 40 years ago. According to UNAIDS (Joint United Nations Programme on HIV and AIDS), to date, it has caused 33 million deaths and infected 76 million people; and it still infects approximately 1.7 million persons every year (<https://bit.ly/3217OD6>). HIV/AIDS belongs now to the short list of infectious diseases, such as tuberculosis, that have had a chronic, deadly presence for decades. Although SARS-CoV-2/COVID-19 has killed 3 million people in one year and infected 140 million, it will become a cyclic scourge infecting more than HIV but killing fewer.

Nevertheless, there is a key commonality between HIV/AIDS and SARS-CoV-2/COVID-19: both have thrived on the structural weaknesses of our global health care system. The most affected populations are the same. Locally, in the United States, people of color—especially those living in the Southern states that in 2021 had still not expanded Medicaid to provide affordable health insurance for the poor—suffer from the highest rates of new diagnoses (<https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics>). Today they are the most infected by and have a higher rate of mortality from SARS-CoV-2/COVID-19. Globally, low- and middle-income countries have struggled to get affordable AIDS treatments, then and now, and they are similarly struggling today to get access to the COVID-19 vaccines that have been developed at an extraordinary pace in the United States, Europe, China, and Russia.

Another fundamental and shameful commonality between the two pandemics are the attempts by conservative governments to stigmatize subgroups

of their populations. In the 1980s, the HIV/AIDS epidemic was first associated with gay and bisexual men even though hemophilic men and women, injectors of illegal drugs, and sex workers of both genders also developed the disease. In 2020, the former US president stigmatized the Asian population by describing COVID-19 as the “ChineseVirus” on social media and to journalists, unleashing waves of anti-Asian racism and xenophobia that have included violence. Listen to the May 2021 podcast of *AJPH*: “#ChineseVirus vs #COVID-19 Racism and Xenophobia on Social Media” (https://am.ajph.link/POD_May2021).

These commonalities between HIV/AIDS and COVID-19 call for analogous responses, such as (1) engaging the populations that have been made vulnerable by an inequitable system, because bringing all stakeholders to the decision table is indispensable for making and implementing effective public health policy; (2) collecting representative data and disaggregate them by gender, age, race/ethnicity, geography, sexual and gender minority status, and other key variables that are indispensable for focusing public health intervention; (3) thinking globally: it took too much time for most governments to understand that the HIV/AIDS pandemic, or any other pandemic, required a global response.

Most officials and organizations making policy for SARS-CoV-2/COVID-19 do not seem to have yet fully appreciated and applied these and related lessons from the HIV/AIDS epidemic. But at least the previous US administration, which denied the importance of science, marginalized the Centers for Disease Control and Prevention, and assigned leadership of the response to the pandemic to persons with inadequate expertise in public health, has now been replaced. **AJPH**

Alfredo Morabia, MD, PhD
Editor-in-Chief, *AJPH*
@AlfredoMorabia

DOI: <https://doi.org/10.2105/AJPH.2021.306362>

36 Years Ago

AIDS and Sexual Behavior Reported by Gay Men in San Francisco

[We] surveyed 655 gay men in San Francisco regarding their sexual practices during the previous month and the same month one year ago. The sample was selected to include men in situations that would lead to high risk of sexual activities related to AIDS... transmission (i.e., men frequenting bathhouses and gay bars) as well as men in low-risk situations (those going to neither place and men in primary relationships). The Bath group showed little change in frequency of bathhouse use and in number of sexual partners from that location. The other group showed substantial reductions in frequency of sexual contacts from bars, baths, . . . or parks. Men in monogamous relationships showed little change in sexual behavior within their relationship. Men in non-monogamous relationships and men not in relationships reported substantial reductions in high-risk sexual activity, but not a corresponding increase in low-risk sexual behavior.

From AJPH, May 1985, p. 493

38 Years Ago

Similarities Between AIDS and Protein Calorie Malnutrition

The acquired immunodeficiency syndrome (AIDS) is characterized by a prodromal history of weight loss prior to diagnosis, and acute severe weight loss leading to cachexia is a general manifestation of the fully developed condition. This weight loss is a result of the infectious or neoplastic complications of AIDS, but it is also possible that nutritional deficiency may play a significant role in the clinical course of the immunodeficient state. There is a similarity between the immune deficiency, multiple infections, and severe weight loss seen in AIDS patients, and the association of protein calorie malnutrition (PCM) with reduced resistance to infection observed in malnourished children, particularly in the Third World. . . . The immunodeficiency in children with PCM can be reversed by nutritional rehabilitation, which suggests that restoration of the nutritional state may be a useful adjunct to therapy for AIDS patients.

From AJPH, November 1983, p. 1332

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.



Hospitalization Rates Among Persons With HIV, Canada and the United States

Characterizing HIV Epidemic, Dnipropetrovsk, Ukraine

Misconceptions Regarding HIV/AIDS Among Pharmacists, Kelantan, Malaysia

Interventions for People Living With HIV With Depressive Symptoms, Botswana, Africa

Misconceptions Regarding HIV/AIDS Among Pharmacists in Malaysia

Pharmacists' negative attitudes can negatively affect patients' HIV/AIDS management. A survey of pharmacists residing in Kelantan, Malaysia, determined their HIV/AIDS knowledge, perceptions regarding treatment, and attitudes toward individuals living with HIV/AIDS. Of the 170 pharmacists surveyed, 67.1% viewed patients living with HIV/AIDS negatively. Despite high scores in disease-related knowledge, pharmacists had misconceptions regarding causes of, preventative measures for, and circumstances that require changes in treatment for HIV/AIDS.

Citation. Sidi Omar MM, Ab Wahab NAW, Ong AG, Mohamed Azam NI, Muhammad A, Ab Ghani SNA. Human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS): knowledge, perception, and attitude among pharmacists in Kelantan, Malaysia. *J Pharm.* 2021;1(1):8-18. <https://doi.org/10.31436/jop.v1i1.44>

Characterizing the HIV Epidemic in Ukraine

Shostakovych-Koretskaya et al. describe the ongoing HIV epidemic in the Dnipropetrovsk region of Ukraine using data from the Public Health Center of the Ministry of Health of Ukraine and the Dnipropetrovsk Regional Center for AIDS Prevention and Control from 2005 to 2017. HIV and AIDS cases increased by a factor of 1.9 and 3.0, respectively, over the study period. HIV and AIDS cases were greater in Dnipropetrovsk than nationally in Ukraine. Similarly, the incidence rate of HIV is 92.8 per 100 000 people in the Dnipropetrovsk region, which is significantly greater than the national estimate of 41.0 per 100 000 people. Estimates of prevalence and trends should be used in predicting the treatment needs of people living with HIV/AIDS in the Dnipropetrovsk region.

Citation. Shostakovych-Koretskaya LR, Lytvyn KY, Gubar IO, Chukhalova IV, Gudova MG, Lopatenko AA. [Main characteristics and prognosis of development of HIV epidemic in the Dnipropetrovsk region]. *Medicni perspektivi* [Medical Perspectives]. 2020;25(1):166-174. [Ukrainian] <https://doi.org/10.26641/2307-0404.2020.1.200417>

Hospitalization Rates Among Persons With HIV in Canada and the United States

Davy-Mendez et al. investigated how aging, HIV/AIDS comorbidities, and improvements in antiretroviral therapy for the management of HIV/AIDS have affected trends in all-cause and cause-specific hospitalization rates in persons with HIV between 2005 and 2015. Using data from 28 057 patients from 6 clinical cohorts (5 in the United States and 1 in Canada), Davy-Mendez et al. found that the unadjusted all-cause hospitalization rate decreased from 22.3 per 100 person-years (95% confidence interval [CI] = 20.6, 24.1) in 2005 to 13.0 in 2015 (95% CI = 12.2, 14.0).

The adjusted rates of hospitalization decreased for all-cause, cardiovascular, and AIDS-defining conditions but increased for non-AIDS-defining infections.

Citation. Davy-Mendez T, Napravnik S, Hogan BC, et al. Hospitalization rates and causes among persons with HIV in the US and Canada, 2005-2015. *J Infect Dis.* 2020; Epub ahead of print. <https://doi.org/10.1093/infdis/jiaa661>

Interventions for People Living With HIV With Depressive Symptoms in Botswana

Vavani et al. investigated depressive symptoms, self-reported intervention needs, and coping strategies among people living with HIV in Botswana through a survey completed by 291 mostly female respondents. More than 43% of respondents reported clinically significant depressive symptoms based on the Center for Epidemiologic Studies Depression scale, exceeding previous rate estimates in sub-Saharan Africa. Respondents strongly indicated a need for help with anxiety, depression, goal setting, and coping with HIV. Cognitive coping strategies, such as rumination, catastrophizing, and positive refocusing, appeared to influence depressive symptoms more than behavioral strategies. People living with HIV need integrated psychological programs with cognitive coping strategies.

Citation. Vavani B, Kraaij V, Spinhoven P, Amone-P'Olak K, Garnefski N. Intervention targets for people living with HIV and depressive symptoms in Botswana. *Afr J AIDS Res.* 2020;19(1):80-88. <https://doi.org/10.2989/16085906.2020.1727933>

Prepared by Stephen A. Lewandowski, Vrinda Kalia, Ahlam K. Abuawad, Megan E. Marziali, Columbia University, New York, NY. Correspondence should be sent to the AJPH Global News Team at les2196@cumc.columbia.edu

DOI: <https://doi.org/10.2105/AJPH.2021.306338>

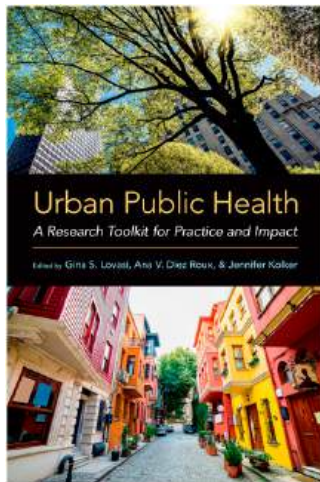
Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Preparing the Urban Public Health Workforce

Nicholas Freudenberg, DrPH

ABOUT THE AUTHOR

Nicholas Freudenberg is with the City University of New York Graduate School of Public Health and Health Policy, New York, NY.



Urban Public Health: A Research Toolkit for Practice and Impact
By Gina S. Lovasi, Ana V. Diez-Roux, and Jennifer Kolker, eds.

New York, NY: Oxford University Press; 2021
Hardcover: 361 pp; \$38.50
ISBN-10: 0190885300
ISBN-13: 978-0190885304

Urban Public Health: A Research Toolkit for Practice and Impact seeks to prepare public health and other professionals to understand, measure, and change urban settings to improve the well-being of people living in cities and shrink the wide gaps in health that now characterize most cities. Edited by Gina S. Lovasi, Ana V. Diez-Roux, and Jennifer Kolker, three leaders at the Dornsife School of Public Health at Drexel University, and including 51 authors, of whom 11 are based outside the United States, the book provides essential lessons for health professionals who work in cities.

Three main sections discuss core competencies for urban health professionals: identifying and collecting data for urban health research, choosing appropriate tools for working with urban health data, and selecting strategies to convert evidence into action to improve health. With examples from multiple cities, summaries of key issues for those mastering each competency, and useful references for readers who want more, the book makes a useful text for graduate-level students preparing for careers in urban health as well as for practicing professionals who want methodological updates and summaries of recent literature. Selected case studies bring real-world experience into the book and can help students apply lessons to their own practice.

I especially liked the chapter on urban health inequities, a key topic of concern in the face of the COVID-19 pandemic, Black Lives Matter, and a growing public health commitment to making the reduction of racial/ethnic, gender, and other health inequities a center of our work. In this chapter, Diez-Roux describes and defines urban health inequities; analyzes their causes, especially segregation; and reviews various approaches to reducing urban health inequities. Other chapters and authors take up methodological, programmatic, and policy dimensions of developing a public health practice that seeks to bring

about meaningful reductions in the wide inequities that now characterize cities in high-, middle-, and low-income countries.

No single book can provide urban health professionals with all they need to know, and as a challenge to these and other authors who teach about and study urban health, I identify some additional questions that I think our field needs to take up to fully prepare our students for their futures.

What is the role of power in improving or compromising urban health? This book is squarely located in the social determinants of health tradition,¹ now a leading paradigm in public health and one that challenges the biomedical and behavioral models of public health that dominated the last half of the twentieth century. But as others have noted, although social determinants of health takes on a wider range of determinants of health, it does not by itself identify who benefits from the current distribution of health and disease or who has the power to change the allocation of wealth and power that shape patterns of health agency.² By seeking answers to these questions, urban health researchers can make a significant contribution to identifying more effective strategies to reduce urban health inequities.

Similarly, urban health researchers and practitioners need to ask how modern capitalism³ and systemic racism,⁴ two intertwined systems, influence the health of urban populations. Capitalism is an economic and political system in which the search for profits by private actors drives the allocation of wealth and power. Systemic racism is a stratification system in which one group is given higher status and privilege based on their racial characteristics. Following in the path of Martin Luther King Jr, Malcom X, and others, Ibram X. Kendi

has called these two systems “evil conjoined twins.”⁵ How do these key determinants of urban ill health and inequities interact, support each other, or conflict?^{6–8}

As public health practitioners, scholars, and activists focus their attention on the most fundamental and modifiable causes of human and planetary well-being, how can they identify ways that cities, historically incubators of social change, can contribute to the transformation of capitalism and racism in ways that improve health? One way, suggested in this book, is to use systems science, the interdisciplinary field that studies the nature of systems, to analyze how the interactions between racism and capitalism create pathways to ill health. Both implementation science and, as Green has suggested, system science can be used to generate practice-based evidence,⁹ an approach that could enable researchers and policymakers to better learn from the public health policy and programmatic successes and failures that occur in cities every day.¹⁰

Urban health researchers have long grappled with the questions of scale.¹¹ How can we bring interventions to the level where they have a meaningful impact on population health? Which problems are best addressed at the neighborhood level and which at the municipal level? The book takes on these questions but often sidesteps the deeper questions about place-based research. How can researchers and practitioners avoid the local trap,¹² in which problems that manifest themselves at the local level are mistakenly assigned causation at that level, even when the real causes operate and need to be tackled at other higher levels? How can the lived experiences of those who experience problems at the local or

neighborhood level lead to insights that enable action on the municipal or national levels, where the power that shapes health often operates? There are no simple answers to these complex questions, but clearly effective public health researchers and practitioners will need strategies to make informed choices about what problems to study and at which levels.

As well as the need to develop the competencies to understand how power shapes the health of cities, aspiring urban health professionals need to find new ways to engage with partners who are essential for achieving urban health advances. Cities are incubators for social movements, long the motor force of public health advances.¹³ How do we enlist and support these movements in improving the health of cities? How do we provide them with the evidence they need to achieve their goals?

The book challenges readers to consider the full range of appropriate roles and skills for urban public health professionals. Yes, we need to know how to identify and collect data on the health of urban populations, choose appropriate tools for analyzing and interpreting urban health data, and select strategies for programs and policies that improve the health of urban populations. But public health professionals also need to know how to design, implement, and evaluate advocacy campaigns; frame messages for diverse constituencies; and assemble coalitions to advance their case. Future texts will need to assist students and faculty to develop these skills and to integrate them with the more technical skills described in this book.

Urban Public Health makes a strong case for the value of interdisciplinary teams that include geographers, epidemiologists, urban planners, and policy

researchers, among others. Also needed are historians, who can help us learn from past experiences; political economists, who can build the links between health, labor, tax, and other social policies; and social movement leaders, who can assist in linking social justice and public health campaigns.

Urban Public Health provides a useful starter toolkit for educating the public health professionals who can contribute to solving the most pressing health problems facing cities. May it inspire others to write its sequels, *Urban Public Health 2.0* and *3.0*, which will add the deeper social and political dimensions to this essential foundation. **AJPH**

CORRESPONDENCE

Correspondence should be sent to Nicholas Freudenberg, 55 West 125th St, New York, NY 10027 (e-mail: Nick.Freudenberg@sph.cuny.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

PUBLICATION INFORMATION

Full Citation: Freudenberg N. Preparing the urban public health workforce. *Am J Public Health*. 2021; 111(7):1177–1179.

Acceptance Date: April 7, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306327>

CONFLICTS OF INTEREST

The author has no conflicts of interest to declare.

REFERENCES

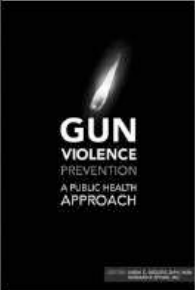
1. World Health Organization. Commission on Social Determinants of Health, 2005–2008. Available at: https://www.who.int/social_determinants/thecommission/en. Accessed April 22, 2021.
2. Dawes DE. *The Political Determinants of Health*. Baltimore, MD: Johns Hopkins University Press; 2020.
3. Sell SK, Williams OD. Health under capitalism: a global political economy of structural pathogenesis. *Rev Int Polit Econ*. 2020;27(1):1–25. <https://doi.org/10.1080/09692290.2019.1659842>
4. Schell CJ, Dyson K, Fuentes TL, et al. The ecological and evolutionary consequences of systemic racism in urban environments. *Science*. 2020;369(6510):eaay4497. <https://doi.org/10.1126/science.aay4497>
5. Kendi IX. *How to Be an Anti-Racist*. New York: One World; 2019.
6. Fernando JL. The Virocene epoch: the vulnerability nexus of viruses, capitalism and racism. *J Polit Ecol*.

2020;27(1):635–684. <https://doi.org/10.2458/v27i1.23748>


7. Virdee S. Racialized capitalism: an account of its contested origins and consolidation. *Sociol Rev.* 2019;67(1):3–27. <https://doi.org/10.1177/0038026118820293>
8. Rossi U. *Cities in Global Capitalism*. Hoboken, NJ: Wiley; 2017.
9. Green LW. Public health asks of systems science: to advance our evidence-based practice, can you help us get more practice-based evidence? *Am J Public Health.* 2006;96(3):406–409. <https://doi.org/10.2105/AJPH.2005.066035>
10. Gatzweiler FW, Reis S, Zhang Y, Jayasinghe S. Lessons from complexity science for urban health and well-being. *Cities Health.* 2017;1(2):210–223. <https://doi.org/10.1080/23748834.2018.1448551>
11. Pineo H, Glonti K, Rutter H, Zimmermann N, Wilkinson P, Davies M. Use of urban health indicator tools by built environment policy- and decision-makers: a systematic review and narrative synthesis. *J Urban Health.* 2020;97(3):418–435. [Erratum in: Pineo H, Glonti K, Rutter H, Zimmermann N, Wilkinson P, Davies M. *J Urban Health.* 2020;97(3):436–437. doi: 10.1007/s11524-019-00392-y]. <https://doi.org/10.1007/s11524-019-00378-w>
12. Born B, Purcell M. Food systems and the local trap. In: Inglis D, Gimlin D, ed. *The Globalization of Food*. Oxford: Berg; 2009:117–138.
13. Miller B, Nicholls W. Social movements in urban society: the city as a space of politicization. *Urban Geogr.* 2013;34(4):452–473. <https://doi.org/10.1080/02723638.2013.786904>

Gun Violence Prevention: A Public Health Approach


Edited By: Linda C. Degutis, DrPH, MSN, and Howard R. Spivak, MD



2021, SOFTCOVER
230 PP, 9780875533117

 APHABOOKSTORE.ORG

Gun Violence Prevention: A Public Health Approach acknowledges that guns are a part of the environment and culture. This book focuses on how to make society safer, not how to eliminate guns. Using the conceptual model for injury prevention, the book explores the factors contributing to gun violence and considers risk and protective factors in developing strategies to prevent gun violence and decrease its toll. It guides you with science and policy that make communities safer.



AN IMPRINT OF AMERICAN PUBLIC HEALTH ASSOCIATION

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

1981–2021: HIV and Our World

Stewart Landers, JD, MCP, Farzana Kapadia, PhD, MPH, and Lisa Bowleg, PhD, MA

ABOUT THE AUTHOR

Stewart Landers is with US Health Services, John Snow, Inc, Boston, MA, and is an associate editor of AJPH. Farzana Kapadia is with the School of Global Public Health and the Department of Population Health, New York University, New York, and is the deputy editor of AJPH. Lisa Bowleg is with the Department of Psychological and Brain Sciences, George Washington University, and is an associate editor of AJPH.

🔗 See also Morabia, p. 1175, and the HIV/AIDS and Our World: 1981–2021 section, pp. 1231–1266.

In January 1981, Ronald Reagan was inaugurated as president of the United States following the appointment of Margaret Thatcher as prime minister two years earlier in the United Kingdom. Globally, it was an era of widespread conservatism. In the United States, this was an era of reduced funding for major safety net programs, such as food stamps, Medicaid, environmental protections, education, and, of course, health care spending.¹ US federal policy on addiction was branded by the slogan “Just say no.” Civil rights and women’s rights were largely ignored. And the rights of lesbian, gay, and bisexual people, let alone those of transgender people, went unheard of and unmentioned. In short, the federal government had launched an all-out assault on poor and marginalized communities.

It was into this political reality that a cluster of five cases of *Pneumocystis* pneumonia were reported among young “active homosexuals” at three Los Angeles, California, hospitals.² The documented occurrence of AIDS among gay and bisexual men even resulted in a short-lived moniker for the illness: “Gay-Related Immune

Deficiency,” or “GRID.” The modern gay rights movement that was signaled by the Stonewall riots in New York City in 1969 had not yet reached the halls of medicine as the HIV epidemic unfolded across the United States.³ And as Ayala and Spieldenner show (p. 1240), the ongoing stigma, silence, and discrimination that gay men encountered in their daily lives was embedded in politics at the very time when these insidious characteristics could be even more destructive. In addition, Purcell (p. 1231) discusses how laws that criminalized the very existence of men who had sex with men contributed to the severity of the epidemic. Yet, he also explores the changes to the laws against same-sex sexual behavior and the rise of marriage equality and notes the creation and persistence of laws criminalizing HIV transmission.

THE ROLE OF INTERSECTIONALITY

During the 1980s and 1990s, and in rapid succession, new groups of people were added to the list of those affected by HIV: people who inject drugs;

hemophiliacs; immigrants; women, especially Black and Brown women; transgender women; and infants born to women with HIV. Together, these groups of people comprised a vast quilt of names and stories of people affected and infected by HIV. For these diverse groups of marginalized people, the level of organization in some to advocate for government action on HIV was weak or nonexistent (i.e., transgender women, people who inject drugs). Although often overlooked, Black women organized at the grassroots level, with groups like BEBASHI (Blacks Educating Blacks About Sexual Health Issues) in Philadelphia, Pennsylvania; WEATOC (We’re Educators—A Touch Of Class) in Boston, Massachusetts; and TWC (The Women’s Collective, part of TheWellProject) in Washington, DC, to educate and advocate for women and youths of color.

We have witnessed this over these past 40 years, and we now recognize and acknowledge that HIV is an intersectional disease that disproportionately affects women of color, gay and bisexual men of color, and people of color who inject drugs. Organizations such as SisterLove (as described by Diallo, p. 1237) have given Black women a voice and a platform in the HIV response and have fought for the recognition of women’s sexual and reproductive rights as well as health justice as intrinsic to reducing the inequities that drive HIV among women of color.

Equally important, Amaro and Prado (p. 1246) discuss how Latinas who have been affected by HIV, including those who inject drugs, have been ignored or sidelined in HIV prevention and intervention efforts and how only a small number of evidence-based

interventions for HIV prevention or successful engagement and retention in care exist to serve Latina women. It is clear across these articles, including that of Ellis (p. 1249), that the needs and lived realities of women of color will not be addressed until their voices are acknowledged and acted on. Until this happens, we will not improve access to HIV research, care, and prevention services to meet the needs of racially and ethnically diverse people with HIV.

EQUITABLE, INCLUSIVE STRATEGIES NEEDED

The early development and dissemination of a document known as “The Denver Principles”⁴ and the associated creed “Nothing about us without us” helped to lay the groundwork for the participation of people with HIV at all levels of community and organizational activity to address the HIV epidemic. However, a critical look at the lack of racial or ethnic diversity in the leadership of those working to develop power-sharing structures may have sown the seeds of the continuing challenges that we face today in ending the HIV epidemic.⁵ Consequently, Schmid (p. 1255) calls for targeting proper federal leadership and resources to the right jurisdictions—those most disproportionately affected—to meet the goals outlined in the federal Ending the HIV Epidemic plan. It is unproven whether the federal Ending the HIV Epidemic plan will support the interventions needed to reduce an annual US infection rate, which still hovers at approximately 37 000 new infections per year—the majority of which are among people of color.⁶ What we do know is that localities with the greatest success in reducing new cases, such as San Francisco, California;

New York City; and Massachusetts, have done so by reducing barriers to health care and improving racial equity in access to health care.⁷⁻⁹

In short, we know that it is necessary to remove barriers that prevent people from accessing HIV testing, linking to HIV care, and accessing and consistently using antiretroviral therapy. As we look back at the lessons learned over the past 40 years, moving forward we must demand that approaches to addressing HIV prioritize equitable solutions. As El-Sadr (p. 1234) points out, we cannot have a one-size-fits-all approach. Prevention efforts need to be attuned to the needs of the community, the needs of the place, the needs of the people, and their lived realities. We cannot expect HIV prevention policies to work by having people adapt to them; these policies must be adapted to meet the needs of the unique and diverse groups of people they seek to serve. Thus, a combination of behavioral and biomedical approaches is required—and each combination will need to be calibrated to each diverse community it seeks to serve. For example, Beletsky (p. 1258) points to the longstanding carceral punishments for drug use in the United States and elsewhere as obstacles to harm-reduction programs that could be implemented to mitigate the spread of HIV among people who inject drugs. These barriers are significant, as both the opioid and stimulant epidemics have led to increases in transmission through needle sharing or among sex partners using methamphetamines for recreational sex.

CHARTING A WAY FORWARD

As we begin the fifth decade of the HIV epidemic, let us reflect on and be

inspired by the mission of the #BlackLivesMatter movement to

build local power to intervene in violence inflicted on Black communities by the state and vigilantes. By combating and countering acts of violence, creating space for Black imagination and innovation, and centering Black joy, we are winning immediate improvements in our lives.¹⁰

Efforts to allocate resources, shape and reshape public policy, and create power-sharing structures must be made through a lens of racial equity. It is no longer acceptable to say, “We can’t find youths of color who want to be part of our advisory board.” Reflecting on this mission, and thinking about the next generation of rising HIV scholars and activists (Garcia-Wilde [p. 1261], Hanshaw [p. 1263], and Lopez-Rios [p. 1265]), we call for all people of good will who wish to make a contribution to ending the HIV epidemic to adopt an approach that is based on how those most affected lead their lives, pursue their passions, and seek to manage both their health and health care to build their resilience in the face of ongoing structural racism and threats of disease, discomfort, and danger. *AJPH*

CORRESPONDENCE

Correspondence should be sent to Stewart Landers, JSI, 44 Farnsworth St, Boston, MA 02210 (e-mail: landers@jsi.com). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

PUBLICATION INFORMATION

Full Citation: Landers S, Kapadia F, Bowleg L. 1981–2021: HIV and our world. *Am J Public Health*. 2021;111(7):1180–1182.

Acceptance Date: April 17, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306360>

CONTRIBUTORS

S. Landers and F. Kapadia drafted the editorial. All authors conceptualized and edited the

editorial, and invited authors and edited articles as part of the “HIV@40” commemorative dossier.

ACKNOWLEDGMENTS

We wish to acknowledge all people who have worked to prevent HIV infections and treated and cared for people with HIV as well as those who have died from HIV-related causes.

CONFLICTS OF INTEREST

None of the authors has any conflicts of interest to report.

REFERENCES

1. Phillips-Fein K. Conservatism: a state of the field. *J Am Hist*. 2011;98(3):723–743. <https://doi.org/10.1093/jahist/jar430>
2. Centers for Disease Control and Prevention. *Pneumocystis pneumonia*—Los Angeles. *MMWR Morb Mortal Wkly Rep*. 1981;30(21):1–3. Available at: https://www.cdc.gov/mmwr/preview/mmwrhtml/june_5.htm. Accessed May 2, 2021.
3. Landers S, Kapadia F. 50 Years after Stonewall, the LGBTQ health movement embodies empowerment, expertise, and energy. *Am J Public Health*. 2019;109(6):849–850. <https://doi.org/10.2105/AJPH.2019.305087>
4. Joint United Nations Programme on HIV and AIDS. The Denver Principles. 1983. Available at: https://data.unaids.org/pub/externaldocument/2007/gipa1983denverprinciples_en.pdf. Accessed April 24, 2021.
5. Kapadia F, Landers S. Ending the HIV epidemic: getting to zero AND staying at zero. *Am J Public Health*. 2020;110(1):15–16. <https://doi.org/10.2105/AJPH.2019.305462>
6. Centers for Disease Control and Prevention. HIV surveillance report, 2018 (updated); vol. 31. May 2020. Available at: <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Accessed April 1, 2021.
7. Cranston K, John B, Fukuda HD, et al. Sustained reduction in HIV diagnoses in Massachusetts, 2000–2014. *Am J Public Health*. 2017; 107(5):794–799. <https://doi.org/10.2105/AJPH.2017.303697>
8. San Francisco Department of Public Health, Population Health Division. HIV Epidemiology Annual Report. 2019. Available at: https://www.sfdph.org/dph/files/reports/RptsHIVAIDS/AnnualReport2019_Indigo_20200929_Web_fixed.pdf. Accessed April 6, 2021.
9. New York City Department of Health and Mental Hygiene. HIV surveillance annual report, 2018. Available at: <https://www1.nyc.gov/assets/doh/downloads/pdf/dires/hiv-surveillance-annualreport-2018.pdf>. Accessed April 6, 2021.
10. #BlackLivesMatter. About. Available at: <https://blacklivesmatter.com/about>. Accessed April 23, 2020.

is your organization an **APHA** member?



Nonprofits, government agencies and educational institutions play an important role in public health. But did you know they can also be members of APHA?

As an APHA agency member, you get discounts on ads in APHA publications and job postings on Public Health CareerMart.

And your employees receive registration discounts for APHA's Annual Meeting and Expo and savings of up to \$150 on individual APHA membership.

Become an APHA agency member today!

For details, call 202-777-3914
or visit www.apha.org/membership



Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Mind the Gap: Yet More Evidence for the Importance of Education for Children With Uncontrolled Asthma

Nusrat Homaira, PhD, and Adam Jaffe, MD

ABOUT THE AUTHORS

Nusrat Homaira and Adam Jaffe are with the Discipline of Paediatrics, School of Women's and Children's Health of University of New South Wales, Sydney, and Respiratory Department of Sydney Children's Hospital, Randwick, NSW, Australia.

See also Martin et al., p. 1328.

Despite significant advancements in effective treatments, asthma remains one of the most common causes of unscheduled hospital presentations in children.¹ The vast majority of asthma-related hospital presentations in children are preventable through ongoing simple interventions, which include the provision of asthma education to parents or carers of children with asthma, mediating home environmental triggers, ensuring that there is an asthma action plan in place, and ensuring that the family is aware of the appropriate use of prescribed medications and inhaler device technique.² As most of these interventions can be effectively provided outside the acute-care hospital setting, there is a growing interest in developing and implementing effective community-based approaches to improve asthma-related health outcomes in children and address the gap that exists between hospital and community care.

To help further inform asthma educational strategies, Martin et al. report a

study in this journal (p. 1328) in which they compare the effectiveness of clinically integrated community interventions on asthma control in mainly Hispanic children with uncontrolled asthma from low-income communities. Uncontrolled asthma in children can have significant negative impacts on quality of life and is associated with increased absenteeism from school.³ Knowledge of asthma self-management is one of the key components of asthma guidelines and is associated with reduced asthma hospital presentations.⁴ However, access to asthma education is often a barrier to self-management for asthma. Exploring different strategies to deliver asthma education beyond the clinic setting is key for successful asthma management.

In this trial, Martin et al. randomly assigned families to two groups: one group received up to 10 sessions over 12 months of asthma education provided within their homes by community health workers (CHWs), and the other group

was offered two one-hour in-clinic education sessions six months apart with a follow-up telephone call provided by an asthma educator. The primary outcome measure assessed in this study was asthma control measured by asthma control test or childhood asthma control test and self-reported activity limitation in the previous 14 days. Additional outcome measures assessed included the Asthma Control Questionnaire, asthma-related health care utilization, oral corticosteroid bursts, asthma medication (type, technique, and adherence), and home triggers.

The study demonstrated improvement in asthma control in both groups at 6 months following intervention, which continued through 12 months. While both groups performed similarly, the group randomized to receive asthma education from CHWs demonstrated greater change in asthma control compared with baseline. These findings are comparable to previous studies that have demonstrated that asthma education provided both in clinic settings led by asthma educators and in homes led by CHWs can improve asthma health outcomes in children.^{5,6} Even though both of the interventions were associated with asthma improvement in children, families in the asthma educator group found scheduling clinic visits and aligning their schedules to attend education sessions to be challenging; 49% received no intervention. This is not surprising given asthma education provided within clinic settings may not be the best approach for parents and carers of children with uncontrolled asthma given the burden of taking time off from work for repeat doctor visits,³ an issue that is likely further amplified in low-income families. Thus, from an implementation perspective, a CHW-led home-based approach to

provide asthma education for high-risk children might be a better option.

In addition, the study findings indicate that families receiving four to six and seven to nine visits showed a steady improvement at 12 months (5.0 points), which was maintained at 24 months, whereas families receiving one to three CHW visits improved a mean of 6.3 points at 12 months, followed by a slight decline (1.6 points) at 24 months. This is a particularly important finding as it provides a dose–response relationship of the intervention and may help optimize number of home visits in different settings. As the study population was largely Hispanic children from low-income families with limited access to health care services and at increased risk of morbidity associated with asthma,⁷ increased frequency of home visits may be necessary to achieve optimal benefits. However, in other countries with universal health coverage, a less intensified approach might achieve similar results and may also be sustainable and cost-effective. While the authors provide cost estimates for each mode of delivery of asthma education (\$135/session for asthma educator sessions and \$74/visit for CHWs) a full economic evaluation, including cost return on investment of the study, would have helped provide further evidence of cost-effectiveness of the programs.

The authors should be commended for designing comprehensive educational sessions for families covering information on key issues including asthma symptoms, control, triggers, action plans, medication technique, adherence, and caregiver and child concerns. However, home environment assessment and mediation of home environmental triggers were not included as part of the intervention in this study. It is well-documented that asthma exacerbations are linked to

indoor housing conditions and exposure to allergens such as inadequate ventilation, secondhand smoke, and pests.^{8,9} Home visitations provide an opportunity to assess and address potential environmental triggers, and inclusion of these could have added strength to the findings of the study.

One of the limitations of this study was that almost half of the participants in the group randomized to the asthma educator group received no intervention. Despite this high dropout rate, the asthma control achieved in children randomized to this group was comparable to the group that received more intensive education provided within homes by CHWs. This could be attributable to the quality of the education provided by asthma educators versus CHWs. Unlike the asthma educators, the CHWs did not have any formal certification. Further studies exploring carers' satisfaction with education received from asthma educators and CHWs will help determine the best mode of delivery of asthma education.

Also, from a public health perspective, the absence of a control group receiving standard care makes it difficult to tease out which is the best approach to provide asthma education to children with uncontrolled asthma. What is also intriguing is that those families who did not have an intervention but were contacted at regular intervals by a research assistant also demonstrated an improvement in asthma outcomes suggesting a Hawthorne effect.

Nevertheless, the study findings highlight that asthma education provided either in a clinic setting by asthma educators or within homes by CHWs will lead to improvement in asthma control and quality of life in children with uncontrolled asthma. It is worth highlighting that even though this study

demonstrated the effectiveness of face-to-face asthma education (either through clinic visits or home visits), given how the delivery of care during the COVID-19 pandemic has pivoted to virtual care, the effective delivery of asthma education using this technology deserves further study. The major challenge, as highlighted in this study, is to find a patient and family-centered approach that works best for individual families.

In conclusion, asthma education for families of children with asthma remains one of the cornerstones to effective asthma management. However, as asthma is a complex condition, a combination of interventions that address the social, behavioral, and physiological aspects of asthma through bridging the gap between hospital- and community-based services are necessary to achieve better health outcomes for children with asthma. Comprehensive asthma programs with multicomponent community-based interventions that include self-management education, home environment assessment, and integrated care coordination can have a significant impact on improving asthma-related quality of life in children¹⁰ and deserve future attention. **AJPH**

CORRESPONDENCE

Correspondence should be sent to Professor Adam Jaffe, Head, School of Women's and Children's Health, UNSW Sydney, Level-8 Bright Alliance, Corner of Avoca and High Streets, Randwick-2031, NSW, Australia (e-mail: a.jaffe@unsw.edu.au). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Homaira N, Jaffe A. Mind the gap: yet more evidence for the importance of education for children with uncontrolled asthma. *Am J Public Health*. 2021;111(7):1183–1185.

Acceptance Date: April 9, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306319>

CONTRIBUTORS

Both authors conceptualized the work. N. Homaira drafted the article and A. Jaffe provided technical and critical feedback with drafting the article.

ACKNOWLEDGMENTS

N. Homaira is supported through a research fellowship (APP115646) of the National Health and Medical Research Council of the Australian government.

CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

REFERENCES

1. Deloitte Access Economics. *The hidden cost of asthma*. Sydney, Australia: Asthma Australia and National Asthma Council Australia; 2015.
2. Clark NM. Community-based approaches to controlling childhood asthma. *Annu Rev Public Health*. 2012;33(1):193–208. <https://doi.org/10.1146/annurev-publhealth-031811-124532>
3. Trent CA, Zimbro KS, Rutledge CM. Barriers in asthma care for pediatric patients in primary care. *J Pediatr Health Care*. 2015;29(1):70–79. <https://doi.org/10.1016/j.pedhc.2014.07.002>
4. Global Initiative for Asthma. *Global Strategy for Asthma Management and Prevention*, 2019. 2019. Available at: <https://ginasthma.org>. Accessed April 27, 2021.
5. Campbell JD, Brooks M, Hosokawa P, Robinson J, Song L, Krieger J. Community health worker home visits for Medicaid-enrolled children with asthma: effects on asthma outcomes and costs. *Am J Public Health*. 2015;105(11):2366–2372. <https://doi.org/10.2105/AJPH.2015.302685>
6. Boulet L-P, Boulay M-È, Gauthier G, et al. Benefits of an asthma education program provided at primary care sites on asthma outcomes. *Respir Med*. 2015;109(8):991–1000. <https://doi.org/10.1016/j.rmed.2015.05.004>
7. Bloom B, Cohen RA, Freeman G. Summary health statistics for US children; National Health Interview Survey, 2010. *Vital Health Stat 10*. 2011;(250): 1–80.
8. Kanchongkittiphon W, Mendell MJ, Gaffin JM, Wang G, Phipatanakul W. Indoor environmental exposures and exacerbation of asthma: an update to the 2000 review by the Institute of Medicine. *Environ Health Perspect*. 2015;123(1):6–20. <https://doi.org/10.1289/ehp.1307922>
9. Bracken M, Fleming L, Hall P, et al. The importance of nurse-led home visits in the assessment of children with problematic asthma. *Arch Dis Child*. 2009;94(10):780–784. <https://doi.org/10.1136/adc.2008.152140>
10. Chan M, Gray M, Burns C, Owens L, Woolfenden S, Lingam R, et al. Community-based interventions for childhood asthma using comprehensive approaches: a systematic review and meta-analysis. *Allergy Asthma Clin Immunol*. 2021;17(1):19. <https://doi.org/10.1186/s13223-021-00522-9>

Advocacy for Public Health Policy Change: An Urgent Imperative



Harry M. Snyder, MD
Anthony B. Iton, MD, JD, MPH

Improving laws and policies start with advocacy and now more than ever this new book, *Advocacy for Public Health Policy Change: An Urgent Imperative* will be instrumental in training public health practitioners and students to turn their expertise into sound policies and laws. It will help these readers in these five key areas:

- Address the growing need to turn knowledge into better health policy.
- Offer a step-by-step planning and implementation framework for public health advocacy campaigns from start to finish.
- Expand professional development and satisfactions opportunities for the field.
- Improve service delivery.
- Improve health outcomes.

Place orders at aphabookstore.org. Email bookstoreservices@apha.org to request an exam copy for classroom use.

ISBN 978-0-87553-313-1 2020, SOFTCOVER, 250 PAGES

APHA PRESS
AN IMPRINT OF AMERICAN PUBLIC HEALTH ASSOCIATION

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Expanding Access to Medical Care Services to Undocumented New York City Residents Without Health Insurance: Reflections on the ActionHealthNYC Study

Sean J. Haley, PhD, MPH

ABOUT THE AUTHOR

Sean J. Haley is with the Department of Health Policy and Management, Graduate School of Public Health and Health Policy, City University of New York.

 See also Sood et al., p. 1318.

In “ActionHealthNYC: A Randomized Controlled Trial to Evaluate a Health Care Access Demonstration Program for the Uninsured,” Sood et al. (p. 1318) make a compelling argument that an intentional commitment to engage those who are both undocumented and uninsured can increase identification of a primary care provider and medical utilization.

The authors describe their 2016–2017 efforts to increase primary care access among those who were both undocumented and without health insurance. The ActionHealthNYC study randomized enrolled participants into either intervention or control groups, whereby intervention patients had appointments scheduled for them and were offered a standardized co-payment (patients did not have to negotiate payments themselves), a written

care plan was created, patients were provided an access handbook, reminders were sent for appointments, and follow-up calls were made for missed appointments. Patients with certain underlying conditions or at risk for homelessness were eligible for enhanced care coordination services. Services were delivered in the patients’ preferred language.

Study findings are consistent with improved access to care: intervention recipients were 1.2 times (58% vs 46%) more likely to report a primary care provider, 1.2 times (91% vs 77%) more likely to have seen a primary care provider in the last 9 months, and 1.5 times (4.1 vs 2.9 visits) as likely to have had more medical visits than control participants.

Importantly, study recruitment began during the 2016 presidential campaign,

when candidate Trump used anti-immigrant rhetoric to stoke economic and safety fears among the electorate. Within a week of his inauguration, President Trump issued executive orders that included provisions to hire 10 000 more immigration officers, withhold federal funding from sanctuary cities, build a southern border wall, and prohibit entry of residents from seven predominately Muslim nations. Anti-immigrant rhetoric, regulations, and executive orders continued throughout the study’s follow-up period and included changes to the Deferred Action for Childhood Arrivals (DACA) policy, removal of protected status for refugees who had fled natural disasters, and changes to rights for asylum seekers.¹ Medical providers across the country reported that those without documentation shunned health care services during the Trump administration.² If they sought treatment, many avoided bringing family members for fear that if the person seeking treatment were to be detained, family members might also be subjected to immigration proceedings.

Several ActionHealthNYC study features are worth highlighting. First, during this period of heightened national political scrutiny of undocumented residents, over 6000 potential participants responded to advertisements, and 2351 of those who responded completed an informed consent process and the first round of a 75-question assessment for what is largely perceived to be a New York City government-operated health care system. Second, nine to 12 months after they completed the initial assessment, nearly half (n = 1067) of the original participants completed a follow-up survey. Third, even as the intervention group significantly increased

engagement across all stated outcomes compared with controls, both groups documented considerable gains. For example, both the intervention and the control groups increased their primary care provider identification from approximately one quarter at baseline to 58% and 46%, respectively. In addition, at baseline approximately 60% of both groups had seen a primary care provider in the last 12 months; nine months later, participation in the intervention group increased to 91%, but participation in the control group also increased to a not-so-paltry 77%. Similar increases were seen for both groups regarding number of medical visits, attempts to make a medical appointment, and the ability to secure an appointment as soon as needed. One of the key takeaways from the study seems to be that if a trusted health care system engages vulnerable communities, even under hostile political conditions, patients will respond and engage.

Important as well are the questions that were not measured. For example, in a time of overt political threats, many of which came to fruition, why did so many people (approximately 6000) who were vulnerable to federal immigration actions respond? Why did nearly half of those who initially responded and were eligible to participate not complete the application? Why did more than half of the baseline participants who managed to complete the application and the initial assessment not complete the follow-up assessment nine months later? Why did so many vulnerable residents ($n = 1067$) complete the study (the incentive alone is an unsatisfying answer because a \$30 honorarium and an \$11 dollar metro card do not go far in New York City), and why did a considerable number of control participants engage

health care services more deeply nine months later without the intervention assistance? To be clear, the authors assessed differences between those who completed the first assessment but did not complete the follow-up questionnaire and those who did, and they explored differences between intervention and control groups to understand the strength of the results. However, given the intensity of the political climate, the questions related to participation and nonparticipation persist.

Results from this study and answers to the “why” questions remain important as states attempt to increase access to care by reducing the number of uninsured. With the help of the Affordable Care Act (ACA), New York made considerable gains. The uninsured rate in New York State declined from 10.7% in 2013 to 5.2% in 2019. However, in 2016 “noncitizens” were more likely to be uninsured than naturalized and native-born citizens (24.1% vs 5% and 3.8%, respectively).⁴ Importantly, undocumented residents are not eligible for Medicare or Medicaid (with the exception of “Emergency Medicaid”), and under the ACA are not allowed to purchase insurance in health insurance exchanges. However, those without documentation may be treated at Federally Qualified Health Centers.

There are additional unanswered study questions, including the extent of the out-of-pocket costs that participants experienced, since many tests, follow-up medical services, and medications for chronic conditions (e.g., hypertension, diabetes, asthma, depression) are not covered under Emergency Medicaid services. In all likelihood, financial support for the one-year study was drawn from the indigent care pool, as 70% of NYC Health + Hospitals’ adult population is insured by Medicaid

or has no insurance.⁵ Still, questions about the participants’ cost burden connect to other questions about the role of screening and the responsibility for ensuring access to (and payment for) ongoing medical treatment, management, and retention for vulnerable populations once patients have been engaged.

Finally, the article raises a fundamental question for those of us in public health: What is it that we owe those who live here? In 2017, at the time of the study, approximately six million of the 10.5 million undocumented immigrants residing in the United States still needed health insurance.⁶ In a high-income nation, I submit that there is an obligation to treat those who are already living here. I am not alone. At the second Democratic presidential debate in 2019, nearly every Democratic candidate (including President Biden) affirmed their support for extending health care coverage to undocumented immigrants.⁷

As much progress as New York has made to increase health care access, its health care costs remain considerably higher (attributed to price increases) than the national average.⁸ Considering anticipated COVID-19-related tax shortfalls, most states cannot consider supporting insurance expansions without federal support. Perhaps the Biden administration will remember the hand that the future president raised at the second Democratic presidential debate in favor of expanding health care coverage to those who were undocumented and will expand access to the health insurance exchanges, Medicaid, or Medicare. In the interim, given the myriad health conditions that may have worsened as those without documentation delayed needed medical visits, perhaps Congress could approve a supplemental appropriation for Federally Qualified

Health Centers to replicate key features of the ActionHealthNYC study, including intentional and targeted outreach, supportive scheduling and follow-up, language-appropriate services, and financial support for the delivery of a defined set of primary care services to allow Federally Qualified Health Centers to set a standard copayment or to waive sliding-scale fees, at least until economic conditions improve. **AJPH**

CORRESPONDENCE

Correspondence should be sent to Sean J. Haley, PhD, MPH, Assistant Professor, Department of Health Policy and Management, CUNY Graduate School of Public Health and Health Policy, 55 W 125th St, New York, NY 10027 (e-mail: sean.haley@sph.cuny.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

PUBLICATION INFORMATION

Full Citation: Haley SJ. Expanding access to medical care services to undocumented New York City residents without health insurance: reflections on the ActionHealthNYC study. *Am J Public Health*. 2021;111(7):1186–1188.

Acceptance Date: April 10, 2021

DOI: <https://doi.org/10.2105/AJPH.2021.306330>

CONFLICTS OF INTEREST

The author has no conflicts of interest to disclose.

REFERENCES

1. National Immigrant Justice Center. A timeline of the Trump administration’s efforts to end asylum. Heartland Alliance. 2019. Available at: https://immigrantjustice.org/sites/default/files/uploaded-files/no-content-type/2019-08/Asylum_Timeline_August2019.pdf. Accessed March 27, 2021.
2. Daley J. Trump’s nativist rhetoric scares immigrants away from seeking medical care. *Scientific American*. October 30, 2019. Available at: <https://www.scientificamerican.com/article/trumps-nativist-rhetoric-scares-immigrants-away-from-seeking-medical-care>. Accessed April 8, 2021.
3. Keisler-Starkey K, Bunch LN. Health insurance coverage in the United States: 2019. Current Population Reports. US Census Bureau. September 2020. Available at: <https://www.census.gov/content/dam/Census/library/publications/2020/demo/p60-271.pdf>. Accessed April 8, 2021.
4. New York State Health Foundation. Success in the Empire State: health insurance coverage trends: a closer look at the reduction of uninsured New Yorkers after the Affordable Care Act coverage expansions. 2017. Available at: <https://nyshealthfoundation.org/wp-content/uploads/2017/11/success-in-the-empire-state-health-insurance-trends-NY.pdf>. Accessed March 27, 2021.

5. Lau J, Knudsen J, Jackson H, et al. Staying connected in the COVID-19 pandemic: telehealth at the largest safety-net system in the United States. *Health Aff (Millwood)*. 2020;39(8):1437–1442. <https://doi.org/10.1377/hlthaff.2020.00903>
6. Krogstad JM, Passel JS, Cohn D. 5 facts about illegal immigration in the US. Pew Research Center. June 12, 2019. Available at: <https://pewrsr.ch/2WzWgY>. Accessed April 8, 2021.
7. Hoffman J. What would giving health care to undocumented immigrants mean. *New York Times*. July 3, 2019. Available at: <https://www.nytimes.com/2019/07/03/health/undocumented-immigrants-health-care.html>. Accessed April 8, 2021.
8. NYSHealth and the Health Care Cost Institute. Health care spending, prices, and utilization for employer-sponsored insurance in New York. New York State Health Foundation. 2019. Available at: <https://nyshealthfoundation.org/resource/health-care-spending-prices-and-utilization-for-employer-sponsored-insurance-in-new-york>. Accessed March 27, 2021.

AJPH July 2021, Vol 111, No. 7

Moving Life Course Theory Into Action: Making Change Happen
 Edited by Sarah Verbiest, DrPH, MSW, MPH

Over the past decade, practitioners in the field of maternal and child health have gained a general understanding of Life Course Theory and its potential application to practice. This book focuses on moving Life Course Theory into practice, thereby filling a need for practitioners across a variety of fields and providing them with valuable strategies on how to apply this approach.

Moving Life Course Theory Into Action is designed to fit into the busy lives of practitioners. With new ideas and strategies delivered in a compact handbook style format, each chapter includes key points that offer a quick summary of the main lessons advanced by the authors.

ISBN: 978-087553-2950, 496 pages, Softbound, 2018

APHABOOKSTORE.ORG

APHA
 AMERICAN PUBLIC HEALTH ASSOCIATION
FOR A BETTER AND HEALTHIER WORLD

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

The Case for Conceptualizing Youth–Police Contact as a Racialized Adverse Childhood Experience

Dylan B. Jackson, PhD

ABOUT THE AUTHOR

Dylan B. Jackson is with the Department of Population, Family, and Reproductive Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD.

 See also Geller, p. 1300.

In comparison with other age groups, youths are disproportionately subjected to increased surveillance by and involuntary contact with the police. Youths' overexposure to the police is partly attributable to their regular and extensive use of public spaces, the ongoing deployment of proactive policing tactics (i.e., strict enforcement of minor crimes to deter criminal behavior), and police presence in schools. In 2018, more than 10 million US youths and young adults (approximately one in four) experienced a police encounter, and approximately two thirds of these were police initiated.¹ Recent findings from national data indicate that such encounters can produce significant deleterious impacts to health and well-being.² Still, these seemingly ubiquitous police-initiated interactions with young people in the United States are not randomly distributed, but instead are more heavily concentrated in underresourced communities of color and serve as conduits for racial stratification in the criminal legal system. Specifically, abundant evidence indicates that Black youths—

particularly those in disadvantaged, marginalized communities—are disproportionately stopped by the police.³ Many questions remain, however, about police hypersurveillance of youths, including whether the distribution of specific interactional features of youth–police encounters is also racialized on a national scale.

In this issue of *AJPH*, Geller (p. 1300) illuminates this critical gap in our collective knowledge with her analysis of national data measuring youth–police contact in urban areas of the United States. Geller's analysis focuses on how race intersects with age, sex, and class to predict interactional features of youth–police encounters and, in doing so, expands on existing evidence linking aggressive policing to emotional distress, stigma, and posttraumatic stress among this sample of youths.²

She finds that nearly one in three youths reporting police-initiated contact was first stopped by the police when they were between 8 and 12 years of age. Furthermore, vicarious police contact was exceedingly common among

these youths, with 69% reporting indirect exposure to police stops through family, friends, neighbors, and associates. Although vicarious stops were largely unrelated to race in this sample, Geller's analysis revealed that Black boys in particular were most likely to experience direct police-initiated contact, and more than two thirds of those stopped reported officer aggression or intrusiveness during their most salient stop. By contrast, this was the case for only one in four White boys who were stopped. Experiences of officer intrusion were also concentrated among Black girls and virtually nonexistent among White girls. Exposure to aggressive policing was, therefore, heavily racialized among boys and girls. Still, these disparities were concentrated among low socioeconomic status youths. For boys, moreover, racial disparities were largest at higher levels of delinquency, despite persisting across youths' behavioral profiles.

Geller's work powerfully underscores the burdens of inequitable youth–police interactions and unequivocally reveals these experiences in the lives of Black youths for what they are—adverse childhood experiences, or “events that pose a serious threat to a child's physical or psychological well-being.”⁴ The descriptor of Black youths' exposures to aggressive policing as adverse childhood experiences, therefore, is not only apt, but completely harmonious with Geller's findings. But let me be perfectly clear—these youth–police encounters are not only adverse for Black youths but also traumatic, as they are experienced as “extremely frightening, harmful, or threatening”⁴ and have the capacity to trigger recurring negative emotions and physiological symptoms. The posttraumatic stress associated with these events is evidenced by recent population-based research,² studies

examining physiological stress biomarkers,⁵ and qualitative research grounded in youth voices.⁶⁻⁸ When Black youths describe the police, they describe them as dangerous, controlling, untrustworthy, and prejudiced, and their encounters (or anticipated encounters) with them as overwhelming, emotionally draining, and serving only to exacerbate and “compound everyday adversities.”⁶⁻⁸ One Black youth in Baltimore even referred to the police as his “number one fear in life.”⁶

Ultimately, what these youths convey in this work is that police-induced trauma is, in many respects, its own class of trauma; it is set apart as a uniquely potent historical, racialized, intergenerational form of trauma that is affixed to a collective experience of marginalization. It is, as Bryant-Davis and her colleagues put it, “racially motivated police brutality trauma”^{9(p854)} that demands interpretation through the appropriate sociocultural lens. We must acknowledge that, for Black youths, police-initiated microaggressions and violence—which are often inextricably tied to assumptions of Black criminality—are toxic, modern-day echoes of centuries of abuse and oppression, channeled through an institution that has been an instrument of structural racism for centuries. Such an acknowledgment also necessitates that we examine this form of adversity in context. Upon doing so, we can begin to unravel a profound paradox: although youths’ exposures to aggressive policing are certainly racialized adverse childhood experiences, they also defy categorization as isolated experiences or discrete events because of the crippling and seemingly unending weight of dread and hypervigilance in which these experiences are embedded. If events characterized by these features and producing

these intense reactions do not qualify as adverse, I am not sure what does.

Moving forward, explicit examinations of exposure to aggressive policing in the context of other adverse childhood experiences are needed, including closer attention to how racialized, aggressive policing may not be fully captured by current screening tools. For instance, despite the push to expand the concept of adverse childhood experiences in recent years, few existing tools that screen for adverse childhood experiences ask about police contact¹⁰ and may consequently overlook many affected youths in need of supports and services. Ultimately, we cannot ameliorate the health inequities associated with this form of state-perpetrated violence if we are not conducting proper screenings, and thus far, there has been no systematic effort in the United States to measure and study the aggressive policing of youths in the context of other adverse childhood experiences.

Given the present findings, it may be necessary to examine racialized, aggressive policing through a culturally informed adverse childhood experiences (or C-ACE) framework,¹¹ which acknowledges that, in the United States, certain racism-related adversities may be especially concentrated among Black youths. Considering that aggressive policing undermines adolescent well-being,² more research is also needed to fully disentangle exactly how both direct and vicarious exposure to violent and aggressive policing might contribute to inequities in adolescent mental and physical health via racial stratification. Finally, we must identify the policy and programmatic levers capable of mitigating the trauma of racialized police encounters, such as school personnel who can and should be trained to

facilitate nonstigmatizing, culturally competent conversations about these experiences in ways that provide support and prevent retraumatization.

In 2018, the American Public Health Association released a statement concerning the pressing need to address police violence against communities of color as a public health issue.¹² Ultimately, Geller’s results reaffirm that need while also beckoning us to confront the ongoing and particularly egregious crisis of over-policing Black youths in US communities and its countless harms, which we still do not fully comprehend. It is well past the time to curtail police hypersurveillance of youths and bolster community infrastructure to promote enhanced youth participation in the bastions of civic life and engagement, such as community centers, after-school programs, and youth empowerment programs. We must honor the humanity of and potential in all youths, centering our efforts on their strengths and trusting in and enabling their boundless promise. Youths have a voice and they have spoken. Will we listen? **AJPH**

CORRESPONDENCE

Correspondence should be sent to Dylan B. Jackson, Department of Population, Family, and Reproductive Health, Johns Hopkins Bloomberg School of Public Health, 615 N Wolfe St., Baltimore, MD 21205 (e-mail: dylan.jackson@jhu.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

PUBLICATION INFORMATION

Full Citation: Jackson DB. The case for conceptualizing youth-police contact as a racialized adverse childhood experience. *Am J Public Health*. 2021;111(7):1189–1191.

Acceptance Date: April 5, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306324>

ACKNOWLEDGMENTS


The author would like to thank Lisa Bowleg, PhD, for her comments on an earlier version of this editorial.

CONFLICTS OF INTEREST

The author has no conflicts of interest to declare.

REFERENCES

1. Harrel E, Davis E. Contacts between police and the public, 2018. December 2020. Available at: <https://www.bjs.gov/content/pub/pdf/cbpps18st.pdf>. Accessed April 21, 2021.
2. Jackson DB, Fahmy C, Vaughn MG, Testa A. Police stops among at-risk youth: repercussions for mental health. *J Adolesc Health*. 2019;65(5):627–632. <https://doi.org/10.1016/j.jadohealth.2019.05.027>
3. Epp CR, Maynard-Moody S, Haider-Markel DP. *Pulled Over: How Police Stops Define Race and Citizenship*. Chicago, IL: University of Chicago Press; 2014. <https://doi.org/10.7208/chicago/9780226114040.001.0001>
4. Bartlett JD, Sacks VA. Adverse childhood experiences are different than child trauma, and it's critical to understand why. April 10, 2019. Available at: <https://www.childtrends.org/blog/adverse-childhood-experiences-different-than-child-trauma-critical-to-understand-why>. Accessed April 21, 2021.
5. Browning CR, Tarrence J, LaPlant E, et al. Exposure to police-related deaths and physiological stress among urban Black youth. *Psychoneuroendocrinology*. 2021;125:104884. <https://doi.org/10.1016/j.psyneuen.2020.104884>
6. Smith Lee JR, Robinson MA. "That's my number one fear in life. It's the police": examining young Black men's exposures to trauma and loss resulting from police violence and police killings. *J Black Psychol*. 2019;45(3):143–184. <https://doi.org/10.1177/0095798419865152>
7. Nordberg A, Crawford MR, Praetorius RT, Hatcher SS. Exploring minority youths' police encounters: a qualitative interpretive meta-synthesis. *Child Adolesc Social Work J*. 2016;33(2):137–149. <https://doi.org/10.1007/s10560-015-0415-3>
8. Nordberg A, Twis MK, Stevens MA, Hatcher SS. Precarity and structural racism in Black youth encounters with police. *Child Adolesc Social Work J*. 2018;35(5):511–518. <https://doi.org/10.1007/s10560-018-0540-x>
9. Bryant-Davis T, Adams T, Alejandre A, Gray AA. The trauma lens of police violence against racial and ethnic minorities. *J Soc Issues*. 2017;73(4):852–871. <https://doi.org/10.1111/josi.12251>
10. Boyd RW, Ellison AM, Horn IB. Police, equity, and child health. *Pediatrics*. 2016;137(3):e20152711. <https://doi.org/10.1542/peds.2015-2711>
11. Bernard DL, Calhoun CD, Banks DE, Halliday CA, Hughes-Halbert C, Danielson CK. Making the "C-ACE" for a culturally-informed adverse childhood experiences framework to understand the pervasive mental health impact of racism on Black youth. *J Child Adolesc Trauma*. 2020;1–5. <https://doi.org/10.1007/s40653-020-00319-9>
12. American Public Health Association. Addressing law enforcement violence as a public health issue. November 13, 2018. Available at: <https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2019/01/29/law-enforcement-violence>. Accessed April 21, 2021.



**Oral Health in America:
Removing the Stain of Disparity**

*Edited by: Henrie M. Treadwell, PhD
and Caswell A. Evans, DDS, MPH*

Oral Health in America details inequities to an oral health care system that disproportionately affects the poor, those without insurance, underrepresented and underserved communities, the disabled, and senior citizens. This book addresses issues in workforce development including the use of dental therapists, the rationale for the development of racially/ethnically diverse providers, and the lack of public support through Medicaid, which would guarantee access and also provide a rationale for building a system, one that takes into account the impact of a lack of visionary and inclusive leadership on the nation's ability to insure health justice for all.

Place orders at aphabookstore.org. Email bookstoreservices@apha.org to request exam copy for classroom use.

ISBN: 978-087553-3056 2019, Softcover List Price: \$30 APHA Member Price: \$21

APHA PRESS
AN IMPRINT OF AMERICAN PUBLIC HEALTH ASSOCIATION

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

The Biggest Legal Obstacle to Gun Regulation: State Preemption Laws, Not the Second Amendment

Joseph Blocher, JD

ABOUT THE AUTHOR

Joseph Blocher is with the Center for Firearms Law, Duke University School of Law, Durham, NC.

🔗 See also Pomeranz et al., p. 1273.

Ten days before a 21-year-old man used an assault weapon to murder 10 people in a Boulder, Colorado, supermarket in March 2021, a judge struck down Boulder's local prohibition on such weapons. The judge's grounds for doing so were not, as one might expect, the Second Amendment to the US Constitution but rather Colorado's "preemption" law—one of roughly 40 such laws throughout the country that restrict the power of local governments to enact tailored solutions to gun violence.¹

Boulder joins a long list of US cities whose names will now forever be linked with mass shootings: Columbine, Colorado; Aurora, Colorado; Parkland, Florida; San Bernardino, California; and many others. Those cities—and most others—have something else in common as well. As Pomeranz et al. demonstrate in their article "State Gun-Control, Gun-Right, and Preemptive Firearm-Related Laws Across 50 US States for 2009–2018" (p. 1273), they are also subject to preemption laws limiting

their ability to regulate guns. Some "punitive" preemption laws go so far as to impose criminal or financial liability on local officials who fail to comply.

Although they are widespread today, firearm preemption laws are a relatively recent development. In 1979, just seven states fully or partially preempted local gun regulation.² But following a concerted campaign by the NRA (National Rifle Association of America) and other gun rights advocates, dozens of states adopted preemption laws relating to firearms throughout the ensuing decades, so that during the relevant study period—2009 through 2018—preemptive measures remained largely unchanged. Aside from becoming more punitive (which some did), there was little room to get any stricter.

The NRA argues that preemption laws are

vital as they prevent localities from enacting an incomprehensible patchwork of local ordinances. Without these measures unsuspecting gun owners would be forced to forego

the exercise of their Second Amendment rights or risk running afoul of convoluted and potentially inaccessible local rules.³

The judge in the Boulder case similarly found that "tourists may be dissuaded from visiting the area to avoid prosecution for otherwise lawful possession of a firearm."⁴

But the countervailing considerations should also be clear: some tourists might now be dissuaded from visiting the area for fear of gun violence, and some—perhaps most—residents feel less safe. And although it is true that, in the absence of preemption, local gun rules could vary, perhaps significantly, between urban and rural areas, gun harms also vary significantly from place to place. Gun homicide has long been a distinctly urban problem, so it is not hard to imagine why cities might choose to regulate guns more strictly. In rural areas, by contrast, police response times can be longer (arguably increasing the value of guns for self-defense), and opportunities for hunting and other recreational activities involving guns are more plentiful. A deregulatory approach might, therefore, be more popular and sensible.

There are undoubtedly some informational costs to this kind of local tailoring, as with any type of legal variation—people must learn and comply with different local laws, whether they be speed limits or insurance requirements or rules regarding drugs and alcohol. The NRA's emphasis on the costs of a "patchwork" is thus not irrational. But what Pomeranz et al.'s analysis shows is that the alleged patchworks have generally been replaced by a singular kind of uniformity: one favoring gun rights, rather than regulation. States, in other words, have generally not chosen to

replace local regulations with statewide gun-restrictive rules (which would resolve the patchwork concern) but rather to deregulate guns further, leaving a regulatory void.

It is difficult to know how different the world of gun regulation would look today were it not for the spread of preemption laws, but it seems likely that those laws have kept more gun laws off the books than the Second Amendment itself. Nearly 1500 Second Amendment cases have been filed since the Supreme Court announced, in 2008's *District of Columbia v. Heller*, that the right to keep and bear arms includes an "individual" right to do so for self-defense.⁵ But the vast majority of those challenges (more than 90%) have failed, meaning that for all the attention it receives in the gun debate, the Constitution has not played a transformative role in litigation outcomes.⁶

If a future study were able to estimate the number or nature of preempted local gun regulations, it would be an invaluable contribution. Historically speaking, an enormous amount of gun regulation has happened at the local level, including licensing requirements, public carry restrictions, place-based restrictions, and restrictions on certain classes of weapons.⁷ Those are precisely the kinds of laws that preemption statutes either wipe off the books or prevent from being passed.

A second major question from a policy perspective is what kinds of laws can effectively be enforced at the local level. A municipal restriction on manufacturing does not make much sense, because manufacturers will simply site themselves in the least-regulated jurisdictions, while their products travel across borders. But a public carry restriction—or, as in Boulder, a prohibition on carrying certain kinds of weapons—can be

enforced on the spot by local police regardless of what neighboring jurisdictions are doing. Efforts to evaluate the effectiveness of various local policies, therefore, also remain urgent.

Pomeranz et al.'s article is the first scholarly effort to connect state adoption of firearm preemption to state enactment (or not) of other firearm rules. One hopes that future work on firearms law and policy will continue to investigate the impact of these preemption laws, which, practically speaking, are a more important determinant of gun regulation than the Second Amendment itself. *AJPH*

ABOUT THE AUTHOR

Joseph Blocher is with the Center for Firearms Law, Duke University School of Law, Durham, NC.

CORRESPONDENCE

Correspondence should be sent to Joseph Blocher, Duke University School of Law, 210 Science Dr, Durham, NC 27708 (e-mail: blocher@law.duke.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Blocher J. The biggest legal obstacle to gun regulation: state preemption laws, not the Second Amendment. *Am J Public Health*. 2021;111(7):1192–1193.

Acceptance Date: April 5, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306325>

CONFLICTS OF INTEREST

The author has no conflicts of interest to declare.

REFERENCES

- Blocher J. American cities have always regulated guns. Now, most can't. *Washington Post*. March 25, 2021. Available at: https://www.washingtonpost.com/outlook/american-cities-have-always-regulated-guns-now-most-cant/2021/03/25/c346597c-8ce7-11eb-9423-04079921c915_story.html. Accessed April 21, 2021.
- Goss KA. Policy, politics, and paradox: the institutional origins of the great American gun war. *Fordham Law Rev*. 2004;73(2):681–714.
- National Rifle Association, Institute for Legislative Action. Strong firearms preemption laws are more important than ever. November 11, 2019. Available at: <https://www.nra.org/articles/20191111/strong-firearms-preemption-laws-are-more-important-than-ever>. Accessed April 21, 2021.
- Robert Lynn Chambers and James Michael Jones v. *The City of Boulder*. Case no. 18CV30581. District Court, Boulder County, State of Colorado (March 12, 2021). Available at: <https://www.courthousenews.com/wp-content/uploads/2021/03/assaultweapons.pdf>. Accessed April 21, 2021.
- District of Columbia v. Heller*, 554 US 570 (June 26, 2008).
- Ruben E, Blocher J. From theory to doctrine: an empirical analysis of the right to keep and bear arms after Heller. *Duke Law J*. 2018;67(7/3):1433–1509.
- Blocher J. Firearm localism. *Yale Law J*. 2013;123(1): 82–146.

Public Health CareerMart



job site for Public Health Professionals

- Career Coaching:** Work with one of our experienced and certified coaches to better manage, plan, and develop your career goals.
- Résumé Writing:** Take advantage of professional résumé writing for all professional levels.
- Résumé Critiques:** Our expert résumé writer provides helpful feedback.
- Career Tips:** Search by career stages or services you need using keywords or phrases.
- Salary and Benefits:** Negotiation techniques and salary analysis. Learn how to negotiate effectively and confidently for a job offer or raise!
- Reference Checking/Employment Verification:** Identify questionable references before they talk to prospective employers.
- Social Networking/Profile Development:** Make the right connections and open up job opportunities you never knew existed.
- You can find it all here:** careers.apha.org/jobseekers/resources/



Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Timely Overdose Death Reporting Is Challenging but We Must Do Better

Michael Dolan Fliss, PhD, MPS, MSW, Mary E. Cox, MPH, Samantha W. Dorris, MPH, and Anna E. Austin, PhD

ABOUT THE AUTHORS

Michael Dolan Fliss is with the University of North Carolina Injury Prevention Research Center, Chapel Hill, and the North Carolina Department of Health & Human Services, Division of Public Health, Injury & Violence Prevention Branch. Mary E. Cox is with the North Carolina Department of Health & Human Services, Division of Public Health, Injury & Violence Prevention Branch. Samantha W. Dorris and Anna E. Austin are with the University of North Carolina Injury Prevention Research Center.

 See also Friedman and Akre, p. 1284.

Cause of death determinations for overdoses can require months or, in some cases, more than a year.¹ Such delays impede timely surveillance and action. Rossen and colleagues^{1,2} have proposed using historical data to determine degrees of underreporting and then applying multiplication factors to upweight known deaths to estimated final counts. In this issue of *AJPH*, Friedman and Akre (p. 1284) used these provisional overdose death estimates to report monthly overdose deaths in 2020. They found that the greatest number of overdose deaths ever recorded in the United States occurred in mid-2020 during the COVID-19 pandemic.

We have long worked with provisional death records in North Carolina, with a focus on overdoses. Here we offer a context on the challenges of timely overdose death counting, corroborate the findings of Friedman and Akre, and share strategies to address data delays.

Readers may not know how a death record comes to be “provisional.” Details differ by state; we offer the following

summary for North Carolina. Both before and long after a death, data are generated and collected via medicolegal, public health, and community response systems and are used to assist in death categorization. The death certificate, once completed by the declaring physician, is submitted to centralized vital records. There it is coded into an electronic system housed at the North Carolina State Center for Health Statistics. Literal text fields are standardized to *International Classification of Diseases, 10th Revision (ICD-10)* codes, both manually and with software.³ Public health personnel use these data to understand disease burdens and to prevent future deaths.

Complex causes of death such as overdoses may require special investigations, autopsies, or substance and specimen testing. These deaths may be temporarily assigned an *ICD-10* code of R99 (ill-defined and unknown cause of mortality) to indicate that data are pending. It is these pending-data deaths, many later classified as overdoses, that delay timely death reporting.

LIMITATIONS

We agree with Friedman and Akre that the central limitation is that 2020 overdose death estimations are based on historical, prepandemic overdose death patterns. Reporting lags may have differed during the pandemic, leading to underestimated results. Although state data completeness was trending up nationwide,¹ pandemic challenges may have led to more incomplete data in 2020. It also is possible that the proportion of data-pending deaths anticipated to become overdose deaths changed during the pandemic. We do not yet have data on whether some deaths with R99 codes were newly related to COVID-19.

In addition, death information flows through multiple separated teams and data system silos, any of which may be down, upgrading, or changing. For example, the North Carolina State Center for Health Statistics is transitioning to an electronic death reporting system, and the state’s Office of the Chief Medical Examiner is simultaneously upgrading its centralized data system. Medicolegal and public health staff, essential workers already overburdened and under-resourced as a result of the overdose epidemic, have been doubly stretched by increases in COVID-19 deaths. These changes and challenges have caused delays in death record processing.

Even with these limitations, we have confidence in Friedman and Akre’s conclusions. In line with the confirmatory emergency medical service trends they share, we have seen similar spikes in overdoses in syndromic surveillance emergency department data⁴ that support their findings. Our team reviewing R99-coded deaths found similar spikes and longer lag times. Friedman and Akre

suggest that this may indicate their record-breaking counts are still underestimates.

TAKING ACTION FOR BETTER DATA

Timely counting of overdose deaths is critical. What can be done about these delays? We echo Friedman and Akre's call for both staff and infrastructure funding, and offer several approaches, as outlined subsequently.

Partnerships

Data partnerships with internal and external organizations have facilitated funding, research, timely reporting, action, and change across many sectors. Successful partnerships promote communication, transparency, understanding of others' scope of practice, and assistance in timely, conscious use of provisional data.

Faster Sources of Death Data

Other data can be used to circumvent delays. For example, states can add suspected overdose checkboxes to death certificates,⁵ and medical examiners can flag suspected overdoses at first contact (i.e., within days of death). Literal text from timely emergency medical service and law enforcement reports, patient electronic medical records, and medical examiner investigation reports can provide additional details on the substances involved.

Faster Sources of Overdose Data

Overdose-related indicators exist across dozens of data sources, including

substance abuse treatment visits, calls requesting treatment resources, prescription and dispensing data, overdose reversal reports, and social service data. Data lags vary, but near-real-time emergency department syndromic surveillance systems can identify accelerating trends in overdoses within days. Data dashboards such as that in North Carolina⁶ can aggregate indicators and local programs, providing more timely awareness than offered through death counts alone.

Flow Diagrams

Building Unified Modeling Language activity diagrams⁷ can help map the interrelated flow of data and teamwork after an overdose death. The process of building an accurate activity diagram invariably requires collaboration and interviews to identify delay points caused by overwork, underfunding, or antiquated systems. This collaboration and mapping catalyzes change.

Infrastructure and Informatics Approaches

We echo Friedman and Akre's call for investments in public health infrastructure. Public health has called for a modernization of our many antiquated systems with the "Data: Elemental to Health" campaign.⁸ Infrastructure improvements are not constrained to back-end databases and front-end visualization tools, but also include robust connections between systems and "bench science" lab machines to prepare and test samples quickly. Machine learning approaches can play a role; we have found that incorporating demographic data helps predict the percentage of pending-data deaths that will become overdoses.

Interoperability and Accessibility

We agree with Friedman and Akre that granular data to detect sharp overdose spikes are needed. Public Health 3.0⁹ calls for interoperable access to timely, granular, and actionable data, including novel data sources such as modeled estimates. The Centers for Disease Control and Prevention could provide these modeled monthly and rolling estimates on its Web site, where many data sources are already provided in easily accessible formats. However, we have also experienced hesitancy in integrating and communicating modeled data. Those already challenged with differentiating quality, lag, and biases among data sources may be further challenged in combining "true" and modeled data. However, the line between modeled and unmodeled data is often gray; integrating modeled estimates may promote increased data literacy.

CONCLUSIONS

We share Friedman and Akre's call to increase the response to the ongoing overdose epidemic in the United States, even during the COVID-19 pandemic. They aptly endorse both downstream harm reduction and upstream structural responses; we concur.

Moreover, the overdose epidemic in the United States and the COVID-19 pandemic are not simply unrelated, simultaneous events. They may be "syndemics,"¹⁰ co-occurring at higher frequencies in underresourced communities with mutually deleterious effects. They share respiratory system suppression as a mechanism of death, and COVID-19 survivors may experience chronic pain that can lead to overdose. Increases in unemployment, financial

burdens, overworked front-line workers, and long-term COVID-19-associated illnesses have likely had a negative impact on the overdose epidemic, compounding decreased access to mental, social, and medical services.

Retrospective funding later in an epidemic helps, but this approach leaves public health perpetually playing catch up. Public health funding, staffing, and informatics infrastructure must be sufficiently and proactively supported to attain and maintain the data timeliness needed for response as epidemics develop. *AJPH*

CORRESPONDENCE

Correspondence should be sent to Michael Dolan Fliss, PhD, MPS, MSW, UNC Injury Prevention Research Center, CB# 7505, 725 Martin Luther King Jr. Blvd, Chapel Hill, NC 27599-7505 (e-mail: mike.dolan.fliss@unc.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Fliss MD, Cox ME, Dorris SW, Austin AE. Timely overdose death reporting is challenging but we must do better. *Am J Public Health*. 2021;111(7):1194-1196.

Acceptance Date: April 9, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306332>

CONTRIBUTORS

All of the authors contributed to the content of the editorial by discussing aspects of provisional death estimation. M. D. Fliss authored the initial draft. M. E. Cox, S. W. Dorris, and A. E. Austin provided critical feedback and suggested directions to the draft. All of the authors co-edited the final version.

ACKNOWLEDGMENTS

We thank the countless individuals and dozens of teams on the front lines of public health who have maintained timely, accurate data amidst the COVID-19 pandemic. We specifically thank all of our data partners for their collaboration and transparency; without them we would never have been able to piece together the flow of data on overdose deaths. We celebrate our partnership with the North Carolina Office of the Chief Medical Examiner and thank the North Carolina State Center for Health Statistics for its steadfast vital records and informatics support. We praise the North Carolina Violent Death Reporting System, the State Unintentional Drug Overdose Reporting System, and the Rapid Overdose Death Detection system, which provided detailed data on violent

and overdose deaths. Finally, we acknowledge the lives lost and the loved ones and communities left behind. We encourage everyone working with overdose data to make innovative efforts to maximize the use of those data to end the overdose epidemic.

Note. Although we are indebted to our institutional data partners for their work, innovation, and education, this work represents only the views of the authors; it does not represent the position of any institution.

CONFLICTS OF INTEREST

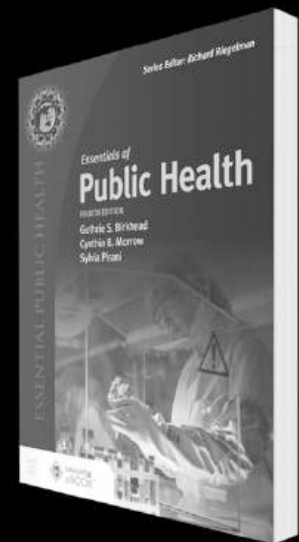
The authors have no conflicts of interest to disclose.

REFERENCES

- Ahmad F, Rossen L, Sutton P. Provisional drug overdose death counts. Available at: <https://www.cdc.gov/nchs/nvss/vsrr/drug-overdose-data.htm>. Accessed March 28, 2021.
- Rossen LM, Ahmad FB, Spencer MR, Warner M, Sutton P. Methods to adjust provisional counts of drug overdose deaths for underreporting. Available at: <https://www.cdc.gov/nchs/data/vsrr/report006.pdf>. Accessed March 28, 2021.
- Lu TH. Using ACME (Automatic Classification of Medical Entry) software to monitor and improve the quality of cause of death statistics. *J Epidemiol Community Health*. 2003;57(6):470-471. <https://doi.org/10.1136/jech.57.6.470>
- Harmon KJ, Fliss MD, Marshall SW, Peticolas K, Proescholdbell SK, Waller AE. The impact of the COVID-19 pandemic on the utilization of emergency department services for the treatment of injuries. *Am J Emerg Med*. 2021;47:187-191. <https://doi.org/10.1016/j.ajem.2021.04.019>
- Rockett IRH, Caine ED, Connery HS, Nolte KB. Overcoming the limitations of "accident" as a manner of death for drug overdose mortality: case for a death certificate checkbox. *Inj Prev*. 2020; Epub ahead of print. <https://doi.org/10.1136/injuryprev-2020-043830>
- North Carolina Division of Public Health, Injury & Violence Prevention Branch. North Carolina Opioid Action Plan data dashboard. Available at: <https://www.ncdhhs.gov/about/departments/initiatives/opioid-epidemic/opioid-action-plan-data-dashboard>. Accessed April 3, 2021.
- Miles R, Hamilton K. *Learning UML 2.0*. Boston, MA: O'Reilly; 2006.
- Council of State & Territorial Epidemiologists. Data: elemental to health. Available at: <https://www.cste.org/page/DM-2021>. Accessed April 3, 2021.
- Wang YC, DeSalvo K. Timely, granular, and actionable: informatics in the Public Health 3.0 era. *Am J Public Health*. 2018;108(7):930-934. <https://doi.org/10.2105/AJPH.2018.304406>
- Tsai AC, Venkataramani AS. Syndemics and health disparities: a methodological note. *AIDS Behav*. 2016;20(2):423-430. <https://doi.org/10.1007/s10461-015-1260-2>

Introduce and Inspire Your Students in the Field of Public Health

This thorough introduction to public health and the U.S. public health system also explores the wide range of career opportunities available in the field.



Instructor exam copies available at: go.jblearning.com/Birkhead4

APHA PRESS
AN IMPRINT OF AMERICAN PUBLIC HEALTH ASSOCIATION



Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Worker Health Inequities in Central America

C. Eduardo Siqueira, MD, ScD, MPH

ABOUT THE AUTHOR

The author is with the Department of Urban Planning and Community Health, School for the Environment, University of Massachusetts Boston, and the Graduate Entry Medical School, University of Limerick, Limerick, Ireland.

 See also Silva-Peñaherrera et al., p. 1338.

The lack of availability of reliable data to describe and compare worker health inequities in Central American countries has been a weakness that the Silva-Peñaherrera et al. study in this issue (p. 1338) helps to overcome. Landsbergis et al.¹ have emphasized the need for such periodical surveys in the United States to track the progress of working conditions and their impact on worker health inequities.

This study appears to be the Central American component of the larger study by Silva-Peñaherrera et al.² in which national survey data on working conditions and health collected from 15 Latin American and Caribbean countries were used to analyze poor self-perceived general health. Although the study was limited in that the authors used cross-sectional and self-reported data and did not control for potential explanatory factors (e.g., differential exposures to hazards), the large and representative sample and the originality of the methods chosen to compare self-perceived general health indicators support the finding of a concerning trend in worker health in Central America. In addition to confirming the significant role of employment conditions in improving self-perceived general health during the period under consideration, the study

shows that occupation, gender, age, and education gaps among Central American countries increased and remained wide. In other words, most countries in the region made little progress in reducing those gaps between 2011 and 2018.

The authors suggest potential explanations for country-specific differences in health patterns, for example reductions in the prevalence of poor self-perceived general health at the country level combined with increases at the regional level. They argue that the improvements at the country level could be a result of better health status among workers in Guatemala, where almost 40% of the region's population resides. In addition, marked improvements in the health conditions of indigenous Guatemalans, who account for 60% of the country's population, might have contributed to the lower prevalence of poor self-perceived general health.

The patterns found are not surprising, however. According to the Economic Commission for Latin America and the Caribbean,³ there is a proneness to external financial shocks in Central America along with a lack of economies of scale in production, a limited transport and communications infrastructure, and high levels of emigration of

skilled individuals to North America and Europe. Also, development in the region is unequal, levels of socioeconomic inequality and poverty are high, working conditions are often precarious, and several countries have experienced political instability and undemocratic regimes. As an example of between-country differences, Costa Rica, which is considered the most stable and democratic nation in the region, has consistently shown better health and socioeconomic indicators than Nicaragua or Honduras.⁴

The observed gender differences in poor self-perceived health status are likely associated with the region's unequal distributions of manual and nonmanual jobs and skilled and unskilled jobs. Approximately 60% of men worked in manual skilled jobs in both study years, whereas about 33% of women worked in such jobs in 2018 (up from 22% in 2011). By contrast, about 45% of women worked in nonmanual unskilled jobs in 2018, as compared with 17% of men (26% of men worked in such jobs in 2011). According to the authors, approximately 51% of men and 18% of women reporting poor self-perceived general health in 2018 would have reported better health if their working and employment conditions had been similar to those of nonmanual skilled workers, and approximately 45% of men and 28% of women would have reported better health if all workers in Central America had a high level of education.

These findings replicate those of other studies indicating that skilled workers usually are employed in less hazardous jobs and have higher levels of education, more job control and autonomy, and better working conditions than unskilled workers.⁵

From a public health policy perspective, the implications of monitoring

worker health inequities in Central America should point to solutions and recommendations beyond better routine worker health monitoring by government agencies. We should also study what needs to be done, explore how we can reduce workplace health inequities, and identify the actors who can make workplace changes happen. Research on such issues needs to be strengthened to move the needle toward policies that aim at reducing exposures to workplace hazards and protecting the workplace rights of all workers, in addition to promoting universal employment and better working conditions for women, young people, indigenous communities, and migrants in Central America.

In 2014, I led a comprehensive review of the literature on the effects of social, economic, and labor policies on occupational health disparities in the United States. The conclusion of the review was that “[t]here is a need to build coalitions and collaborations to command the resources necessary to identify, and then reduce and eliminate occupational disparities by establishing healthy, safe, and just work for all.”⁶(p572)

Even considering the many differences between the United States and Central America, I argue that a similar effort may be needed in the latter, where there certainly are country-specific and regional contexts that shape fundamental social determinants of health, which in turn may explain most findings of the Silva-Peñaherrera et al. article. As the pandemic made explicit once again in Latin America over the past year, reducing workplace health inequities in the Americas will require major structural socioeconomic reforms that replace neoliberal racial capitalism with democratic, progressive alternatives such as the Green New Deal in the United States.⁷ *AJPH*

CORRESPONDENCE

Correspondence should be sent to C. Eduardo Siqueira, MD, ScD, MPH, 100 Morrissey Blvd, Boston, MA 02125 (e-mail: carlos.siqueira@umb.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

PUBLICATION INFORMATION

Full Citation: Siqueira CE. Worker health inequities in Central America. *Am J Public Health*. 2021;111(7):1197–1198.

Acceptance Date: April 15, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306337>

CONFLICTS OF INTEREST

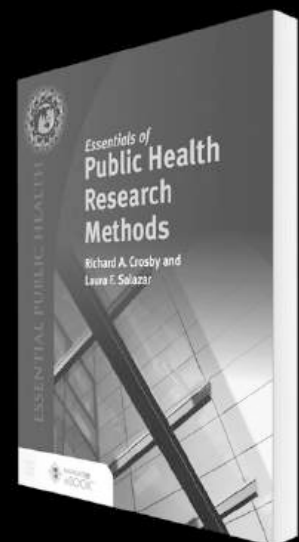
The author declares no conflicts of interest.

REFERENCES

1. Landsbergis PA, Choi B, Dobson M, et al. The key role of work in population health inequities. *Am J Public Health*. 2018;108(3):296–297. <https://doi.org/10.2105/AJPH.2017.304288>
2. Silva-Peñaherrera M, Lopez-Ruiz M, Merino-Salazar P, et al. Health inequity in workers of Latin America and the Caribbean. *Int J Equity Health*. 2020;19(1):109. <https://doi.org/10.1186/s12939-020-01228-x>
3. Economic Commission for Latin America and the Caribbean. The Caribbean outlook, 2018. Available at: <https://www.cepal.org/en/publications/43581-caribbean-outlook>. Accessed April 4, 2021.
4. Herrera CA, Di Paolantonio G, Plaza Reneses T. Health at a glance: Latin America and the Caribbean, 2020. Available at: <http://documents.worldbank.org/curated/en/450921608631647181/Health-at-a-Glance-Latin-America-and-the-Caribbean-2020>. Accessed April 4, 2021.
5. Borrell C, Muntaner C, Benach J, Artazoz L. Social class and self-reported health status among men and women: what is the role of work organisation, household material standards and household labour? *Soc Sci Med*. 2004;58(10):1869–1887. [https://doi.org/10.1016/S0277-9536\(03\)00408-8](https://doi.org/10.1016/S0277-9536(03)00408-8)
6. Siqueira CE, Gaydos M, Monforton E, et al. Effects of social, economic, and labor policies on occupational health disparities. *Am J Ind Med*. 2014;57(5):557–572. <https://doi.org/10.1002/ajim.22186>
7. Galvin R, Healy N. The Green New Deal in the United States: what it is and how to pay for it. *Energy Res Soc Sci*. 2020;67:101529. <https://doi.org/10.1016/j.erss.2020.101529>

Give Your Public Health Students an Underlying Foundation for Evidence-Based Practice

Teach students about important public health issues, while they learn how to select and apply various research methodologies.



Instructor exam copies available at:
go.jblearning.com/
Crosby

APHA PRESS
AN IMPRINT OF AMERICAN PUBLIC HEALTH ASSOCIATION

**JONES & BARTLETT
LEARNING**
An Ascend Learning Company

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Public Health Insight From Excess Mortality During the COVID-19 Pandemic

Chu-Chang Ku, PhD

ABOUT THE AUTHOR

Chu-Chang Ku is with the School of Health and Related Research, University of Sheffield, Sheffield, UK.

 See also Todd et al., p. 1352.

Since early 2020, COVID-19 has spread over the world and has caused a dramatic loss of lives and economic productivity. Mortality from COVID-19 is one of the basic indices used in assessing and monitoring the losses the pandemic has caused. Excess mortality is determined by comparing the observed mortality to the expected mortality in a scenario without COVID-19. Knowing the amount of excess mortality allows researchers to assess COVID-19's impact with a broader scope and thus makes it important for policy-making at the population level.

ESTIMATION OF EXCESS MORTALITY

A high-quality estimate of excess mortality is not simply comparing the deaths during the pandemic to the expected deaths but involves certain complexities. First, the calculation of expected mortality relies on routinely collected data from a well-established death registration system. Also, events that have significant impacts on population dynamics over the past few years, such as regional

conflicts and natural disasters, might largely affect the baseline population and require additional adjustment before being used for comparison. Furthermore, even if a well-established death registration system existed, a large number of unexpected deaths at the beginning of an outbreak may collapse the system because of a lack of resources for examination and certification. Further efforts are required to estimate the number of missing deaths during the early phase of an outbreak.

In this issue of *AJPH*, Todd et al. (p. 1352) analyze excess deaths by age, sex, and ethnicity to investigate public health threats during the COVID-19 pandemic. The authors compared the difference between the observed mortality in 2020 and the expected mortality, which was built on routinely collected mortality data of the past five years with a time-series model adjusted for seasonality. Although Todd et al. did not explore the detailed causes and trends of excess mortality because of data limitations, the overview provided in their study presents the niches for further research

on health inequality during the COVID-19 pandemic. For instance, the link between excess mortality and socioeconomic status and the changes in the distribution of causes for non-COVID-19 deaths can be further addressed.

VULNERABLE POPULATIONS

Vulnerable groups are people who are at high risk for contracting COVID-19 and less resilient to the negative impacts of the disease. The stratification of excess mortality by risk factors indicates which populations have been affected more by the COVID-19 pandemic. The difference in the level of impact can be regarded as a roadmap to identify vulnerable groups with an urgent need to be protected. Todd et al. describe excess mortality by age, sex, and ethnicity, revealing higher rates of excess death among older adults and non-White populations. Health vulnerability is also commonly addressed by socioeconomic status, which is affected by income level and standard of living. For example, Decoster et al.¹ found that a lower household income and Strang et al.² found that living in areas with lower socioeconomic status were associated with higher rates of excess mortality; both of these studies also highlighted higher excess mortality among older adults in nursing homes compared with noninstitutionalized adults at a similar age.

In addition, vulnerability can result from health status. Patients with underlying conditions and diseases may reduce their visits to health care facilities to avoid the risk of COVID-19 infection. As a result, the delayed care seeking for non-COVID-19 diseases and conditions may reduce the opportunity for timely diagnosis and treatment and thus increase the risk of poor outcomes,

including death. This indirect impact through the health care pathway has been seen in experiences of other diseases and is evident in patients with respiratory diseases that have similar symptoms to those of COVID-19.^{3,4}

From the perspective of mental health, financial hardship and feelings of isolation have been common factors associated with excess mortality during the COVID-19 pandemic. The risk of suicide and mental illness, therefore, gained public attention in the implementation of lockdown and social-distancing restrictions during the pandemic.⁵ So far, in developed countries during the COVID-19 pandemic, suicide rates have been seen to not increase or to decrease slightly, suggesting that social safety nets and preventive measures may have attenuated the negative impact of the pandemic on mental health. However, there are still concerns that suicide rates may increase in the long run as the social safety nets run out of financial support.^{6,7}

Which groups are vulnerable can change as the pandemic evolves, and policymakers should be aware of this change to prevent further consequences to social stability. The excess mortality stratified by risk factors has the potential to show health disparities during the pandemic and to be an indicator of the functionality of social safety nets. Moreover, time-series analyses of excess mortality stratified by risk factors will enable us to distinguish and quantify COVID-19's impact on different vulnerable groups over time.

DISTINGUISHING CAUSES OF EXCESS DEATHS

Todd et al. report that 23% of excess mortality in Philadelphia, Pennsylvania, is not directly attributed to COVID-19,

but they did not conduct a detailed analysis of the cause of these non-COVID-19 deaths. In fact, the excess mortality for a particular cause during the COVID-19 pandemic is not always positive. There is high variation in the cause distribution of excess deaths over time, reflecting the societal and behavioral changes influenced by COVID-19.^{4,8,9} Understanding the causes of non-COVID-19 excess deaths can be useful in allocating resources for tackling specific challenges.

Among the causes of death not directly related to COVID-19, accidental deaths have shown a noticeable change following the implementation of COVID-19 control measures. Most of the early interventions for COVID-19 aimed to prevent COVID-19 transmission by limiting social contact through lockdown and travel restrictions. These restrictions led to a decrease in accidental deaths in settings such as Peru,¹⁰ whereas higher rates of traffic accidents were observed in California.¹¹ The contrasting trends of accidental deaths may be associated with the heterogeneity in transportation systems as well as road behavior, which reflects the role of contextual factors in understanding the changes in excess deaths.

The contrasting effects on excess deaths can also occur in the same setting. For example, control measures for COVID-19, such as restricting social contact and wearing face masks, can help prevent other communicable diseases. Conversely, COVID-19-related interruptions in health care systems and vaccination programs can lead to an increase in excess deaths.^{9,12}

Despite improved estimations for excess deaths from COVID-19, the composition of excess deaths by non-COVID-19 causes remains unclear in many settings. In addition to high-

quality estimates of excess deaths from COVID-19, research on the causes and trends of non-COVID-19 deaths during the pandemic is needed. A more thorough understanding of excess deaths can offer public health insight on strategies for resource allocation and maintenance of social stability during the COVID-19 pandemic. **AJPH**

CORRESPONDENCE

Correspondence should be sent to Chu-Chang Ku, 30 Regent St, Sheffield City Centre, Sheffield S1 4DA, UK (e-mail: c.ku@sheffield.ac.uk). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Ku C-C. Public health insight from excess mortality during the COVID-19 pandemic. *Am J Public Health*. 2021;111(7):1199–1201.

Acceptance Date: April 15, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306350>

ACKNOWLEDGMENTS

The author would like to thank Han Fu, PhD, for her expert insight.

CONFLICTS OF INTEREST

The author has no conflicts of interest to declare.

REFERENCES

- Decoster A, Minten T, Spinnewijn J. The income gradient in mortality during the COVID-19 crisis: evidence from Belgium. October 23, 2020. Available at: https://personal.lse.ac.uk/spinnewijn/DMS_draft.pdf. Accessed April 30, 2021.
- Strang P, Fürst P, Schultz T. Excess deaths from COVID-19 correlate with age and socio-economic status. A database study in the Stockholm region. *Ups J Med Sci*. 2020;125(4):297–304. <https://doi.org/10.1080/03009734.2020.1828513>
- Centers for Disease Control and Prevention. Delay or avoidance of medical care because of COVID-19–related concerns—United States, June 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(36):1250–1257. <https://doi.org/10.15585/mmwr.mm6936a4>
- Centers for Disease Control and Prevention. Tuberculosis—United States, 2020. *MMWR Morb Mortal Wkly Rep*. 2021;70(12):409–414. <https://doi.org/10.15585/mmwr.mm7012a1>
- John A, Pirkis J, Gunnell D, Appleby L, Morrissey J. Trends in suicide during the COVID-19 pandemic. *BMJ*. 2020;371:m4352. <https://doi.org/10.1136/bmj.m4352>
- Appleby L. What has been the effect of COVID-19 on suicide rates? *BMJ*. 2021;372:n834. <https://doi.org/10.1136/bmj.n834>

7. Stubbs T, Kring W, Laskaridis C, Kentikelenis A, Gallagher K. Whatever it takes? The global financial safety net, COVID-19, and developing countries. *World Dev.* 2021;137:105171. <https://doi.org/10.1016/j.worlddev.2020.105171>
8. Santi L, Golinelli D, Tampieri A, et al. Non-COVID-19 patients in times of pandemic: emergency department visits, hospitalizations and cause-specific mortality in Northern Italy. *PLoS One.* 2021; 16(3):e0248995. <https://doi.org/10.1371/journal.pone.0248995>
9. Rutter MD, Brookes M, Lee TJ, Rogers P, Sharp L. Impact of the COVID-19 pandemic on UK endoscopic activity and cancer detection: a National Endoscopy Database analysis. *Gut.* 2021;70(3): 537–543. <https://doi.org/10.1136/gutjnl-2020-322179>
10. Calderon-Anyosa RJC, Kaufman JS. Impact of COVID-19 lockdown policy on homicide, suicide, and motor vehicle deaths in Peru. *Prev Med.* 2021; 143:106331. <https://doi.org/10.1016/j.ypmed.2020.106331>
11. A dark conundrum: Americans are driving less, but more are dying in accidents. *Economist.* April 3, 2021. Available at: <https://www.economist.com/graphic-detail/2021/04/03/americans-are-driving-less-but-more-are-dying-in-accidents>. Accessed April 30, 2021.
12. Abbas K, Procter SR, van Zandvoort K, et al. Routine childhood immunisation during the COVID-19 pandemic in Africa: a benefit-risk analysis of health benefits versus excess risk of SARS-CoV-2 infection. *Lancet Glob Health.* 2020;8(10):e1264–e1272. [https://doi.org/10.1016/S2214-109X\(20\)30308-9](https://doi.org/10.1016/S2214-109X(20)30308-9)

Read
AJPH
A PUBLICATION OF THE
AMERICAN PUBLIC HEALTH ASSOCIATION

Earn Continuing Education credits while you learn

Thanks to APHA's program with the *American Journal of Public Health*, earning continuing education credits is easy.

By reading select articles from *AJPH*, you can get credits for **CHES®**, **CME**, **CNE**, and **CPH**.

SIGN UP TODAY!

Introductory rate:
 APHA members: \$10 per credit
 Non-members: \$20 per credit

ce
Online Continuing Education Program

[APHA.org/continuing-education](https://www.apha.org/continuing-education)



Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

The Unintended Health Consequences of Social Policies

Sandro Galea, MD, DrPH, and Roger Vaughan, DrPH, MS

ABOUT THE AUTHORS

Sandro Galea is with the School of Public Health, Boston University, Boston, MA. Roger Vaughan is an AJPH associate editor and is with the Department of Biostatistics, The Rockefeller University, New York, NY.

🔗 See also Geller, p. 1300, and Yang et al., p. 1309.

It is a short step from understanding that health is a product of the forces around us—of the conditions of where we live, work, and play—to a call to generate social policy that changes conditions that create health in populations. Social policies can, by design, change elements of the world around us, ranging, for example, from taxation policies that can provide resources to governments to invest in better parks and opportunities for recreation to policies that alter transportation routes or make health care resources available to more people. It is therefore reasonable that public health increasingly sees the implementation of healthy social policy as part of its goal, consistent with the aspirations of a muscular public health.¹

There are two principal barriers to the consistent implementation of healthy social policy. The first is political. Policy-making definitionally involves the shifting of resources. Taxation, for example, takes money from individuals, sectors, or groups and allocates it to funding public goods. The implementation of particular health programs must involve the commitment of assets that could have been used for other purposes, which groups who do not benefit from

the programs would perhaps prefer. Therefore, the implementation of social policy for health must navigate these political challenges and be seen by the public and policymakers alike as a priority for action and investment of public funds. It is with this in mind that we have often advocated public health telling the story of health² as a means of making the case for the importance of particular policies to elevate their visibility and importance amid other potential policies that do not have health at their core.

The second barrier to the implementation of healthy social policy, however, is quite different. A core challenge to the implementation of healthy social policy is that identifying the best way to structure social policies that will benefit as many people as possible—and not create health gaps—is quite difficult. Fundamentally, human populations are complex systems,³ and complex systems are shaped by a range of forces, including system dynamics and emergent population effects that result from the unforeseen impact of changing small but critical elements—in particular, population systems. Therefore, the implementation of large-scale social policies requires the wisdom to

anticipate their potential consequences, to the end of thinking through the best approach to achieve desired, prosocial ends.

OPTIMIZING SOCIAL POLICY IMPACT

One approach to understanding how to optimize social policies for health is by studying, and understanding, the unintended consequences of existing policies, to educate our thinking about how to do better with future social policies. Three articles in the past two issues of *AJPH* allow us to do just that.

In this issue, Yang et al. (p. 1309) explore the consequences of free HIV testing during antenatal care in Botswana. This testing was designed to detect HIV in pregnant women, creating opportunities for treatment and to prevent maternal–fetal transmission of HIV. However, as Yang et al. show, this policy can also result in women being blamed and stigmatized for being HIV positive. They suggest that in the context of a culture that has pervasive gender inequalities, this antenatal care testing approach perpetuates structural vulnerabilities, stigmatizing women and clearly having long-tail unintended consequences.

Moving to a very different context, articles by Putnam-Hornstein et al.⁴ and by Geller (p. 1300 in this issue) consider two different sets of policies in the United States. Putnam-Hornstein et al.⁴ document rates of child protection involvement and termination of parental rights in the United States. They find, consistent with previous work using different methodology, that about a quarter of children are investigated for maltreatment during childhood and that this is dramatically different by race/ethnicity, with one in two Black or Native

American children being so investigated—twice the proportion for White children. Accepting that the intent of child protection policies is positive—an effort to ensure that all children are safe and protected from abuse or neglect—this high prevalence of investigation, so dramatically different by racial/ethnic group, suggests an imposition of structural bias that likely pervades child protection systems and that threatens the long-term well-being of children, particularly those who are then affected by termination of parental rights.

Perhaps more concerning, the work of Geller documents racial differences in police contact as assessed through the Fragile Families and Child Wellbeing Study. Geller finds that exposure to policing is unevenly distributed, with Black boys in particular reporting more, and more aggressive, police contact than their White counterparts. Geller's findings suggest that police contact often acts as an early adverse childhood experience that can then go on to have implications for health and behavior for non-White youths for decades to come. Both these articles show how social policies that may be designed to promote a better society—making antenatal testing care available, protecting children from abuse, policing to protect communities—have unintended consequences that can go on to harm health in the long-term.

LESSONS LEARNED

There is much to learn from these articles. Three observations emerge that we think are worth reflecting on. First, there is nothing simple ever about policies that are implemented and affect large populations. This may seem trite but is often, in our estimation, forgotten in our reflexive desire to put in place

approaches that extend promising scientific observations. The evident positive, for example, that emerges from widely available antenatal HIV testing needs to be understood together with the harms that emerge from its implementation. This does not mean that we should not be implementing antenatal HIV testing but rather that we need to recognize the full set of its consequences to be able to best tailor the policy to be effective, with an eye to maximizing positive intent.

Second, the full set of consequences of broad-ranging social policies requires vigilance to document both positives and negatives, and the humility to recognize that policies need to be modified as needed to maximize the former and minimize the latter. Systems to ensure that we have adequate child protection, for example, undoubtedly are responsible for substantial good, but that good must be weighed against the negatives of overinvolvement of child protection systems, particularly when the systems are racially or socioeconomically patterned, imposing a disproportionate burden of surveillance and potential termination of parental rights on particular groups. We should be willing to do the thought experiment to identify possible collateral consequences before program implementation and monitor not only the intended results of programs and policies but the downstream unintended consequences and be prepared to pivot and revise as necessary.

Third, all social policies are implemented in our broader cultural context, and that context shapes the implementation—and the impact—of social policies. Hence, widely available antenatal HIV testing may be a particular problem for HIV-positive women in cultures that are characterized by deep gender inequities. Similarly, efforts at community policing simply cannot be divorced

from deep-seated racial bias that results in particular minority youths bearing the brunt of policing efforts. Social policies must be designed to promote health equity, and that needs to account for the preexisting uneven playing field that characterizes our world. It takes the implementation of policies that are explicitly antiracist, for example, to overcome a context that too readily leads to Black Americans bearing the brunt of efforts at imposing social good, no matter how well intentioned. The articles are an important—and sobering—reminder. **AJPH**

CORRESPONDENCE

Correspondence should be sent to Roger Vaughan, The Rockefeller University, 1230 York Ave, New York, NY 10065 (e-mail: roger.vaughan@rockefeller.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Galea S, Vaughan R. The unintended health consequences of social policies. *Am J Public Health*. 2021;111(7):1202–1203.

Acceptance Date: April 7, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306328>

CONTRIBUTORS

The authors contributed equally to this editorial.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

REFERENCES

- Galea S, Vaughan R. On choosing the right starting question: a public health of consequence, August 2019. *Am J Public Health*. 2019;109(8):1075–1076. <https://doi.org/10.2105/AJPH.2019.305173>
- Galea S, Vaughan R. Embedding prevention at the heart of the US health conversation. *Am J Public Health*. 2021;111(1):17–19. <https://doi.org/10.2105/AJPH.2020.306009>
- Galea S, Riddle M, Kaplan GA. Causal thinking and complex system approaches in epidemiology. *Int J Epidemiol*. 2010;39(1):97–106. <https://doi.org/10.1093/ije/dyp296>
- Putnam-Hornstein et al. Cumulative rates of child protection involvement and terminations of parental rights in a California birth cohort, 1999–2017. *Am J Public Health*. 2021;111(6):1157–1163.

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Support Pharmacy Infrastructure to Strengthen US COVID-19 Vaccination Efforts and Beyond

Kathryn K. Marwitz, PharmD, MPH, Candace Haugtvedt, PhD, MS, RPh, and Audrey B. Kostrzewa, PharmD, MPH

ABOUT THE AUTHORS

Kathryn K. Marwitz is with the College of Pharmacy, Natural and Health Sciences, Manchester University, Fort Wayne, IN. Candace Haugtvedt is with the Department of Healthcare Administration, St. Mary of the Woods College and the Chicago School of Professional Psychology, Westerville, OH. Audrey B. Kostrzewa is with the School of Pharmacy, Concordia University Wisconsin, Mequon, WI.

Recently, the Biden administration announced the Centers for Disease Control and Prevention (CDC) Federal Retail Pharmacy Program for COVID-19 vaccination to increase COVID-19 vaccine accessibility to local communities. Although pharmacies and pharmacists have already administered COVID-19 vaccines through state-initiated programs, this program sends COVID-19 vaccine supply directly to community pharmacies.¹ The CDC states that as vaccine supply increases, the federal government plans to expand this program to include 40 000 pharmacies across the United States.¹ Nine of 10 people live within five miles of a pharmacy, making pharmacies a natural and accessible point for vaccine administration.² Providing COVID-19 vaccination at local community pharmacies can increase vaccine accessibility, especially in underserved areas, where health care clinics and hospitals are limited. Pharmacists and pharmacy staff have stood on the frontlines of the COVID-19

pandemic, carrying out vital medication-related services while performing COVID-19 testing, offering telehealth services, and vaccinating the public against the flu and other vaccine-preventable diseases. They are ready, willing, and able to protect public health by administering COVID-19 vaccinations.

PUBLIC HEALTH PRACTITIONERS

In 2006, the American Public Health Association (APHA) published a policy statement describing the role of pharmacists in public health.³ This statement identified pharmacists as practitioners who provide high-quality patient care by counseling patients about their medications and health conditions, providing advice on over-the-counter medications, calling insurance companies to resolve medication cost problems, and administering routine vaccines.³ APHA has continued to recognize pharmacists'

role in public health and established an official APHA Pharmacy Section in 2018 containing a broad membership of pharmacists, pharmacy technicians, researchers, drug information experts, and other disciplines.

Since the publication of the 2006 policy, pharmacists have also gained prescribing rights for oral contraceptives in several states, strengthened collaborative practice for tobacco cessation and disease-state management with prescribers, and increased availability of naloxone at the pharmacy counter among many other public health activities.⁴ Embedded within communities, community pharmacists are a trusted and accessible source of health information. Several studies demonstrate that with the involvement of pharmacists, medication use and health outcomes improve, and health care utilization, such as emergency department visits, decrease.⁵

PRIORITIZING MEDICATION SAFETY

As the federal government and state and local communities look to community pharmacists to carry out these important COVID-19 vaccination efforts through the Federal Retail Pharmacy Program, we must ensure that safe medication practices are maintained. Before the pandemic, a series of events shed light on the stresses experienced by understaffed and overburdened community pharmacists and technicians who are routinely asked to manage several competing responsibilities with little staffing and operational support.

To initiate a plan to address these workplace concerns, a collaboration conference with diverse pharmacy stakeholders was held in July 2019 titled Enhancing Well-being and Resilience Among the Pharmacist Workforce. The

goal of this conference was to develop actionable recommendations to address issues and concerns associated with burnout, stress, work overload, and moral injury.⁶ Among their 50 recommendations for improvement was that

employers must prioritize patient safety, quality of care, and pharmacist well-being when setting workload expectations and ensure the pharmacy workforce is adequately staffed, trained, and utilized to complete the expected work volume.⁶

In January 2020, a series of articles by the *New York Times* further illustrated the urgency of these pharmacy workplace and staffing issues.⁷ A recent study by Beal et al. confirmed these reports by surveying more than 1200 community pharmacists. This study found that pharmacists working in national chain and grocery store pharmacies continue to have workplace concerns in several ways and are in favor of addressing prescription volume-based metrics as one contributor of moral injury.⁸

Addressing prescription volume metrics and understaffed work environments remains a complex issue, as pharmacy payment models still favor payment focused on prescription volume over payment for patient care provided by pharmacists. A multilevel approach addressing systems changes at the national and state levels through laws and policies as well as at the employer-employee level through policies and procedures will be necessary. At present, the pandemic has only reinforced these pharmacy workplace concerns through increases in responsibilities including COVID-19 testing and vaccination services without addressing the underlying issues. Recent news coverage has highlighted the impact of the

pandemic on these continued workplace concerns in pharmacies as well as other health care settings.⁹

The Institute of Medicine published *To Err is Human: Building a Safer Health System* over twenty years ago which described the impact of poorly designed medical systems on patient safety in the clinical hospital setting with applicable information for outpatient consideration.¹⁰ This highly cited report describes the significant financial and emotional toll that medical and medication errors have on communities.¹⁰ Recognizing that unintentional medication errors are a result of poorly designed medical systems and not the individual health care provider, this report also advocated the design of systems that prioritize safety and human factors considerations. Ensuring appropriate staffing ratios, reducing workplace distractions, developing and maintaining reasonable work hours and break time, and examining medication use processes and procedures are ways the pharmacy profession and associated employers can protect patient safety by design.

Research pertaining to the rate of medication errors in the community pharmacy is limited, but pharmacists performing multiple verification steps in conjunction with medication barcode scanning and patient counseling assures patients that their safety is being prioritized.¹¹ As pharmacists are tasked with additional responsibilities to vaccinate the population against COVID-19, it is good practice to reassess the components of the medication system, including staffing and prescription volume in community pharmacies to ensure that safety and well-being for patients and pharmacy personnel remains at the center.

SUPPORT AND SUSTAIN INFRASTRUCTURE

Numerous community pharmacy businesses have publicized plans to hire more pharmacists, technicians, and support staff to administer COVID-19 vaccinations, but whether adequate staffing levels can be achieved is not yet known. To meet the vaccine demand while preserving a pharmacy's high standards for medication safety, pharmacies must ensure that pharmacy staffing and operations are prioritized. Pharmacists need support through adequate staffing levels and technical and operational assistance to store, reconstitute, and administer COVID-19 vaccines and continue typical medication dispensing and counseling processes. Pharmacists and pharmacy staff also work closely with patients to provide vaccinations and patient counseling and need personal protective equipment to protect themselves against COVID-19 exposure. These supplies should be readily available.

In addition, messaging about COVID-19 vaccine eligibility by state officials must be made clear so pharmacists are not caught between patient demands for vaccination and state guidance limiting eligibility. Public health and state officials should work directly with pharmacists to provide information to patients seeking COVID-19 vaccination. Because pharmacies traditionally adopt a walk-in vaccination model, clear communication about the need for patient appointments, based on vaccine eligibility, is imperative.¹²

Finally, the CDC must collect data from pharmacists, technicians, patients, and pharmacy corporations to study the Federal Retail Pharmacy Program for COVID-19 vaccinations and its impact on

COVID-19 vaccination access and system-mediated medication safety. These data can be used to inform the effectiveness and safety of using community pharmacists to address large-scale public health emergencies and help the United States prepare for future public health needs.

SUPPORT COVID-19 VACCINATION

As we collectively call on pharmacists as vital public health practitioners during the COVID-19 pandemic, let's go one step further by investing in pharmacists and pharmacy infrastructure to ensure that they have the resources they need to safely care for and vaccinate the public during the COVID-19 pandemic and beyond. **AJPH**

CORRESPONDENCE

Correspondence should be sent to Kathryn K. Marwitz, 10627 Diebold Rd, Fort Wayne, IN 46845 (e-mail: kkmarwitz@manchester.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Marwitz KK, Haugtvedt C, Kostrzewa AB. Support pharmacy infrastructure to strengthen US COVID-19 vaccination efforts and beyond. *Am J Public Health*. 2021;111(7):1204-1206.

Acceptance Date: March 28, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306314>

CONTRIBUTORS

K. K. Marwitz led the drafting of the editorial. All authors conceptualized, revised, edited, and prepared the editorial.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

REFERENCES

- Centers for Disease Control and Prevention. Understanding the federal retail pharmacy program for COVID-19 vaccination. 2021. Available at: <https://www.cdc.gov/vaccines/covid-19/retail-pharmacy-program/index.html>. Accessed March 19, 2021.
- National Association of Chain Drug Stores. Face-to-face with community pharmacies. Available at:

<https://www.nacds.org/pdfs/about/rximpact-leavebehind.pdf>. Accessed March 19, 2021.

- American Public Health Association. The role of the pharmacist in public health. *APHA Policy* 200614. Available at: <https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/07/13/05/the-role-of-the-pharmacist-in-public-health>. Accessed March 19, 2021.
- Adams AJ, Weaver KK. The continuum of pharmacist prescriptive authority. *Ann Pharmacother*. 2016;50(9):778-784. <https://doi.org/10.1177/1060028016653608>
- Murphy EM, Rodis JL, Mann HJ. Three ways to advocate for the economic value of the pharmacist in health care. *J Am Pharm Assoc*. 2020;60(6):e116-e124. <https://doi.org/10.1016/j.japh.2020.08.006>
- American Pharmacists Association. Enhancing well-being and resilience among the pharmacist workforce: a National Consensus Conference. Available at: https://www.pharmacist.com/sites/default/files/audience/APhA_Well_Being_Resilience_Report_%200719.pdf. Accessed March 19, 2021.
- Gabler E. How chaos at chain pharmacies is putting patients at risk. Available at: <https://www.nytimes.com/2020/01/31/health/pharmacists-medication-errors.htm>. Accessed March 18, 2021.
- Beal JL, Clabaugh M, Illingworth Plake KS. Policy solutions to address community pharmacy working conditions. *J Am Pharm Assoc*. 2021;S1544-S3191. <https://doi.org/10.1016/j.japh.2021.02.011>
- NBC News. Overworked, understaffed: pharmacists say industry in crisis puts patient safety at risk. March 16, 2021. Available at: <https://www.nbcnews.com/health/health-care/overworked-understaffed-pharmacists-say-industry-crisis-puts-patient-safety-risk-n1261151>. Accessed March 18, 2021.
- Kohn LT, Corrigan JM, Donaldson MS, eds. *To Err Is Human: Building a Safer Health System*. Washington, DC: National Academies Press; 1999.
- Hong K, Hong YD, Cooke CE. Medication errors in community pharmacies: the need for commitment, transparency, and research. *Res Social Adm Pharm*. 2019;15(7):823-826. <https://doi.org/10.1016/j.sapharm.2018.11.014>
- Bach AT, Goad JA. The role of community pharmacy-based vaccination in the USA: current practice and future directions. *Integr Pharm Res Pract*. 2015;4:67-77. <https://doi.org/10.2147/IPRP.S63822>



Racism: Science & Tools for the Public Health Professional

Edited by
Chandra L. Ford, PhD
Derek M. Griffith, PhD
Marino A. Bruce, PhD
and Keon L. Gilbert, DrPH

ISBN: 978-0-87553-303-2
2019, Softcover
List Price: \$69
APHA Member Price: \$48.30

This important publication builds on the racial health equity work that public health advocates and others have been doing for decades. They have documented the existence of health inequities and have combatted health inequities stemming from racism. This book, which targets racism directly and includes the word squarely in its title, marks an important shift in the field's antiracism struggle for racial health equity. It is intended for use in a wide range of settings including health departments, schools, and in the private, public, and nonprofit sectors where public health professionals work.

ORDER TODAY AT
aphabookstore.org

FOR REVIEW COPIES CONTACT
david.hartogs@apha.org

APHA PRESS
AN IMPRINT OF AMERICAN PUBLIC HEALTH ASSOCIATION

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

The Urgent Public Health Need to Develop “Crisis Standards of Housing”: Lessons From the COVID-19 Pandemic

Joshua A. Barocas, MD, and Mark Earnest, MD, PhD

ABOUT THE AUTHORS

Joshua A. Barocas is with the Section of Infectious Diseases, Boston Medical Center, and the Department of Medicine, Boston University School of Medicine, Boston, MA. Mark Earnest is with the Division of General Internal Medicine, University of Colorado Anschutz Medical Campus, Aurora.

From the beginning of the coronavirus (COVID-19) pandemic, a crisis of space overwhelmed hospitals across the United States. As coronavirus cases surged, hospitals filled beyond their capacity. Spaces that under normal circumstances would have been considered inadequate for patient care were seized for that purpose. Hospital hallways and conference rooms filled with beds and patients.

Those space limitations forced health care providers to confront how they would provide care under the direst circumstances. Across the United States, health care leaders codified “crisis standards of care” because they recognized that exceeding the standard capacity of existing resources does not remove the responsibility to provide the best possible care given the circumstances.¹ Those “crisis standards of care” were accompanied by additional funding, workforce development, and relaxation of policies dictating where care might be delivered.

While hospitals swelled beyond capacity, a related crisis of space played

out across the United States. One of the more profound side effects of the pandemic in the United States has been its impact on people experiencing homelessness (PEH). As coronavirus numbers have grown and the economy has stagnated, a growing number of people are at risk for or experiencing housing instability or homelessness. In early 2020, an estimated 568 000 people experienced homelessness.² Despite policies intended to stave off evictions, that number grew steadily over the year. It is estimated that homelessness will increase by 45% by the end of 2021.³ There is much to learn from the process of developing “crisis standards of care” that can be readily applied to the homelessness crisis. As such, we propose a “crisis standards of housing.”

The dramatic increase in the number of people living on the streets represents the confluence of trends. The pandemic’s economic impact on lower-income Americans has been devastating; half have experienced either job loss or have a household member who has.⁴ Compared with middle- and upper-

income adults who lost a job during the pandemic, low-income individuals are 33% more likely to remain unemployed—with women, immigrants, Hispanic persons, and those with lower education levels being the hardest hit.⁴ Black and Brown persons, women, and immigrants are at the highest risk of losing housing.⁵

As the need for emergency housing has soared, the available supply of shelter beds has decreased. Before the pandemic, the number of PEH outnumbered the number of available shelter beds by more than double.² Given the need for increased distance between clients, many shelters reduced their available beds—in some cases by more than half.⁶ Although some states increased capacity by creating new shelter spaces or leasing rooms in hotels, such efforts were exceptional. As such, a growing number of PEH have been left without a shelter option.

In the absence of available beds, people seeking shelter gravitated toward the safest, most hospitable places they could find: the well-lit, centrally located parks that the public had left behind. Consequently, policymakers and everyday Americans have been forced to confront one of our greatest collective failures: our society’s inability to ensure stable housing for all.

Just as emergency measures such as invoking the Defense Production Act have been taken to fight the pandemic, emergency steps must also be taken to prevent more Americans from experiencing homelessness. Approximately 20% of the 13.8 million adults in rental housing report being behind in rent.⁷ To mitigate this risk, the Centers for Disease Control and Prevention took the necessary step of extending the federal eviction moratorium,⁸ but the mandate must be extended into the fall

if not winter. The \$45 billion in rental assistance included in President Biden's American Rescue Plan will help prevent evictions, but only if people in need are able to access the funds. Local and state health departments, hospitals, and federally qualified health centers should temporarily assign case managers and social workers to ensure receipt of rental assistance for anyone who is eligible.

Temporary measures must be coupled with longer-term commitments to ending homelessness. The Housing First model is an effective solution to homelessness, with upwards of 75% of people remaining stably housed after one year.⁹ But the growing homelessness crisis caused by the pandemic requires additional solutions and capacity building. One potential solution is to develop and train a public health workforce of people with lived experience with homelessness. Peer-support models have been implemented among PEH and shown to reduce harms from substance use, increase adherence to treatment of tuberculosis, and even improve housing stability—particularly when couched within programs such as Housing First.^{10,11} Applying a peer-educator model for the development of a public health workforce for PEH could serve dual functions. First, it would provide meaningful employment to those providing the support, lifting people out of the cycle of poverty and housing instability. Second, as has been noted in peer-support studies for this population, education and counseling from someone with first-hand experience have the potential to improve health-related outcomes for those receiving the support.^{10,11} Peer-educator models are effective in part because they produce much higher levels of trust than traditional intervention models.^{10,11} Federal investments in innovations such as peer-

educator models coupled with Housing First initiatives, in addition to improved access to jobs and low-income housing and rent relief, would signal a true commitment to ending homelessness.

In addition, we must end the criminalization of homelessness. Each time a person is punished for attempting to survive—by panhandling for money, sleeping on a park bench, or setting up an encampment—the cycle of incarceration and homelessness becomes more difficult to escape. Many cities deploy “sweeps” of encampments in which personal belongings are discarded and people are either displaced or incarcerated. Such practices are expensive and counterproductive—Los Angeles, California spent \$30 million in 2019 on sweeps.¹² Forcing people to relocate compounds the stigma of homelessness and does nothing to disrupt the underlying conditions that cause it.

Providing resources to those experiencing homelessness is a more humane and potentially cost-effective solution than sweeps. One study demonstrated that providing direct financial support to PEH dramatically improved their lives and decreased unhealthy behaviors in both the short and long term.¹³ Participants who were given \$7500 (Canadian) found stable housing and were able to attain food security faster than those who received no cash. The cash recipients decreased their spending on alcohol, cigarettes, and other drugs by 39%. Decriminalizing homelessness would also require decriminalization of substance use, mental illness, and sex work—all of which are common for various reasons among PEH—and decriminalization would reduce barriers to care for substance use, and mental illness in particular.

Decriminalizing homelessness could allow people a place to exist through

sanctioned encampments while stable housing options are being established. Just as hospitals filled beyond capacity opened spaces not traditionally used for patient care, we must provide safe, legal spaces for people to exist given the overwhelmed and underresourced status of shelters. Opponents of sanctioned encampments have long argued that they are costly and encourage drug use and vagrancy. In reality, sanctioned encampments are less costly to a city than shelters and sweeps, afford individuals a sense of community, and can lead to improved health outcomes.¹⁴ Legal encampments also force society to confront its failure to ensure stable housing for everyone. As researcher Rebecca Finkes noted, “The visibility of the permitted encampments brings the issue of homelessness to light, and invites the greater community to lend a helping hand.”^{14(p20)} The sanctioned encampment in Seattle, Washington that she was referencing helped mobilize city officials and nonprofit organizations to work together to develop low-income housing and provide resources and skills training. Such a move should not be interpreted as giving up, but rather recognized as a communal awakening that society must do better while simultaneously admitting that we have yet to do so.

Businesses can also play a critical role in ending homelessness, just as they have in the pandemic. The Defense Production Act mobilized the rapid manufacturing of ventilators, personal protective equipment, testing supplies, vaccines, and other necessary tools to fight the pandemic.¹⁵ The same authorization could be used to award contracts to hotels, construction companies, and other manufacturers to requisition unused bed capacity in hotels and dormitories for temporary

housing, jump-start the manufacturing of linens and hygiene products, and enable the construction of emergency low-income housing developments. If we are to end homelessness, the business sector needs to be a partner.

Crisis standards are critical to mitigating emergencies like the coronavirus pandemic. The urgency of this moment should not obscure the fact that homelessness has been a smoldering epidemic for years; the pandemic has merely exposed its enormity and society's inaction. Nevertheless, the pandemic has also demonstrated our collective ability to innovate. A nation that can produce multiple vaccines against a novel virus in less than a year can do much more for PEH than provide a couple of nights in quarantine or a few allowable encampments. This should be the moment that we finally end homelessness in the United States. A nation as wealthy as ours just needs to apply the same ingenuity, commitment, and innovative spirit that we are using to combat the coronavirus. *AJPH*

ABOUT THE AUTHORS

Joshua A. Barocas is with the Section of Infectious Diseases, Boston Medical Center, and the Department of Medicine, Boston University School of Medicine, Boston, MA. Mark Earnest is with the Division of General Internal Medicine, University of Colorado Anschutz Medical Campus, Aurora.

CORRESPONDENCE

Correspondence should be sent to Joshua A. Barocas, MD, Boston University Medical Campus, 801 Massachusetts Ave, 2nd Floor, Boston, MA 02131 (e-mail: Joshua.Barocas@CUAnschutz.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Barocas JA, Earnest M. The urgent public health need to develop "crisis standards of housing": lessons from the COVID-19 pandemic. *Am J Public Health*. 2021;111(7):1207–1209. Acceptance Date: April 9, 2021. DOI: <https://doi.org/10.2105/AJPH.2021.306333>

CONTRIBUTORS

Both authors conceived of the idea, drafted the first and revised versions of the manuscript, and contributed equally to the manuscript.

CONFLICTS OF INTEREST

The authors have no conflicts of interest.

REFERENCES

1. Technical Resources Assistance Center and Information Exchange (TRACIE). State level crisis standards of care. Department of Health and Human Services, assistant secretary for preparedness and response. Available at: <https://asprtracie.hhs.gov/technical-resources/63/crisis-standards-of-care/0>. Accessed April 25, 2021.
2. National Alliance to End Homelessness. State of homelessness: 2020 edition. Available at: <https://endhomelessness.org/homelessness-in-america/homelessness-statistics/state-of-homelessness-report>. Accessed April 8, 2021.
3. Community Solutions. Analysis on unemployment projects 40–45% increase in homelessness this year. 2020. Available at: <https://community.solutions/analysis-on-unemployment-projects-40-45-increase-in-homelessness-this-year>. Accessed April 25, 2021.
4. Pew Research Center. Economic fallout from COVID-19 continues to hit lower-income Americans the hardest. September 24, 2020. Available at: <https://www.pewresearch.org/social-trends/2020/09/24/economic-fallout-from-covid-19-continues-to-hit-lower-income-americans-the-hardest>. Accessed April 25, 2021.
5. Kochhar R. Hispanic women, immigrants, young adults, those with less education hit hardest by COVID-19 job losses. Pew Research Center. June 9, 2020. Available at: <https://www.pewresearch.org/fact-tank/2020/06/09/hispanic-women-immigrants-young-adults-those-with-less-education-hit-hardest-by-covid-19-job-losses>. Accessed April 25, 2021.
6. Jolicoeur L. Homeless Shelter Pine Street Inn sees significant drop in number of positive coronavirus tests. *WBUR*. May 27, 2020. Available at: <https://www.wbur.org/commonhealth/2020/05/27/homeless-shelter-pine-street-inn-sees-significant-drop-in-number-of-positive-coronavirus-tests>. Accessed April 8, 2021.
7. US Census Bureau. Week 11 Household Pulse Survey: July 9–July 14. July 22, 2020. Available at: <https://www.census.gov/data/tables/2020/demo/hhp/hhp11.html>. Accessed April 7, 2021.
8. Walensky RP. *Temporary Halt in Residential Evictions to Prevent the Further Spread of COVID-19*. Atlanta, GA: Dept of Health and Human Services; 2021.
9. Byrne T, Treglia D, Culhane DP, Kuhn J, Kane V. Predictors of homelessness among families and single adults after exit from homelessness prevention and rapid re-housing programs: evidence from the Department of Veterans Affairs Supportive Services for Veteran Families Program. *Hous Policy Debate*. 2016;26(1):252–275. <https://doi.org/10.1080/10511482.2015.1060249>
10. Miller JA, Carver H, Foster R, Parkes T. Provision of peer support at the intersection of homelessness and problem substance use services: a systematic "state of the art" review. *BMC Public Health*. 2020;

20(1):641. <https://doi.org/10.1186/s12889-020-8407-4>

11. Magwood O, Leki VY, Kpade V, et al. Common trust and personal safety issues: a systematic review on the acceptability of health and social interventions for persons with lived experience of homelessness. *PLoS One*. 2019;14(12):e0226306. <https://doi.org/10.1371/journal.pone.0226306>
12. Tinoco M. LA will spend \$30M this year on homeless sweeps. Do they even work? April 10, 2019. Available at: https://laist.com/2019/04/10/homeless_sweeps_los_angeles_public_health.php. Accessed February 21, 2021.
13. Foundations for Social Change. The New Leaf Project. 2020. Available at: <https://forsocialchange.org/new-leaf-project-overview>. Accessed February 21, 2021.
14. Finkes R. *City Sanctioned Homeless Encampments: A Case Study Analysis of Seattle's City-Permitted Villages* [thesis]. Columbus, OH: Ohio State University; 2019.
15. Lupkin S. Defense Production Act speeds up vaccine production. *NPR*. March 13, 2021. Available at: <https://www.npr.org/sections/health-shots/2021/03/13/976531488/defense-production-act-speeds-up-vaccine-production#:~:text=Ethics-,Defense%20Production%20Act%20Hastens%20COVID%2D19%20Vaccine%20Production%20%3A%20Shots%20%2D,the%20country%20against%20the%20coronavirus>. Accessed April 8, 2021.

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Stakeholder Involvement in Systematic Reviews: Lessons From Cochrane's Public Health and Health Systems Network

Bronwen Merner, PhD, Dianne Lowe, PhD, Louisa Walsh, MStratComm, BPhysio (Hons), Anneliese Synnot, MPH, BPhysio (Hons), Jan Stratil, MD, Simon Lewin, PhD, Claire Glenton, DrPhilos, Peter von Philipsborn, MD, MSc, MA, Lina Schonfeld, BPsych (Hons), Rebecca Ryan, PhD, Denise O'Connor, PhD, Jan L. Hoving, PhD, and Sophie Hill, PhD

ABOUT THE AUTHOR

Bronwen Merner, Dianne Lowe, Louisa Walsh, Anneliese Synnot, Lina Schonfeld, Rebecca Ryan, and Sophie Hill are with Cochrane Consumers and Communication, Centre for Health Communication and Participation, School of Psychology and Public Health, La Trobe University, VIC, Australia. Jan Stratil is with the Institute for Medical Informatics, Biometry, and Epidemiology, Ludwig Maximilian University of Munich, Munich, Germany. Simon Lewin and Claire Glenton are with the Norwegian Institute of Public Health, Oslo, Norway. Peter von Philipsborn is with the Pettenkofer School of Public Health, Ludwig Maximilian University of Munich, Munich, Germany. Denise O'Connor is with the School of Public Health and Preventive Medicine, Monash University, VIC, Australia. Jan L. Hoving is with the Department of Public and Occupational Health, Amsterdam University Medical Center, Amsterdam, Netherlands.

Translating evidence, including evidence from systematic reviews, into policy and practice is a major challenge for evidence producers.¹⁻³ Stakeholder involvement in how reviews are prioritized, produced, and disseminated may improve their relevance and translation into policy and practice.^{2,4} Stakeholder involvement is continuing to grow, with a 2018 scoping review identifying nearly 300 examples in the field of systematic reviews.⁵ However, many reported too few details for replication, thus limiting evidence to inform recommendations for future practice.⁵

In Cochrane Reviews, as in other types of health research, stakeholder involvement has taken different forms and involved a range of methods.^{6,7} Levels of

involvement within and across reviews can also vary, as categorized by the ACTIVE (Authors and Consumers Together Impacting on eVidence) framework.⁷ According to ACTIVE, involvement may fall on a continuum (Table 1).

We share the stakeholder involvement experiences of three Cochrane editorial groups (Consumers and Communication, Effective Practice and Organization of Care, and Public Health) that form part of the Cochrane Public Health and Health Systems Network.⁸ The network is responsible for wide-ranging evidence syntheses published in the Cochrane Library.

We present the lessons of our collective experiences from four major

research activities in systematic review prioritization, production, and dissemination. In describing key elements of stakeholder involvement in each project, we have used the ACTIVE framework as a transparent way of categorizing how stakeholders were engaged (Table 1).

The lessons from each case study help to draw out potential facilitators and barriers to stakeholder involvement in future research activities. Given the state of knowledge and evidence in this field, future measurement of the effect of stakeholder involvement on the uptake of systematic reviews into health policy and practice should incorporate an examination of barriers and facilitators to involvement.

We include the following groups as stakeholders: policymakers, health decision-makers, health professionals, consumers (meaning patients, caregivers, their representatives, and the public), guideline developers, and research funders.

Stakeholder involvement is defined as “any role or contribution of stakeholders toward the development of a review protocol, completion of any of the stages of a systematic review, or dissemination of the findings of a review.”^{7(p246)}

CASE STUDY 1

Case study 1 describes stakeholder involvement in setting systematic review priorities.

Description

In this project, the goal of Cochrane Consumers and Communication was to set priorities for future Cochrane Reviews in the areas of health communication and participation.⁹ The aim of involving stakeholders was to ensure that future end users of Cochrane

TABLE 1— Case Study Examples Using the ACTIVE Continuum of Stakeholder Involvement

Level of Involvement	Description	Case Study Examples
Leading	Lead responsibility for conducting and completing the review; initiating the review	Deciding on the scope of the project (case study 1)
		Coauthoring the protocol (case study 2)
Controlling	Making decisions for 1 or more aspects of the review process	Deciding on the study design (case study 2)
		Deciding which interventions would be included (case study 3)
		Deciding whether individual studies are included in a review (case study 2)
Influencing	Providing information or input that directly influences the review process but without direct control over decisions	Participating in a workshop to prioritize review topics (case study 1)
		Providing views about aspects of the PICO question (case study 3)
		Providing feedback on a template for an evidence summary for policymakers (case study 4)
Contributing	Providing views or information that may indirectly influence the review process (e.g., participants in a survey or focus group)	Contributing views to an online survey (case study 1)
Receiving	Receiving the results of a review or other information about a review	Receiving review information in a tailored form (case study 4)

Note. ACTIVE = Authors and Consumers Together Impacting on eVidenceE; PICO is a mnemonic for Population/Patient/Problem, Intervention, Comparison, Outcome.

Source. Pollock et al.⁷

Reviews had the evidence they needed for decision-making. Reflecting this aim, and to ensure best practice in stakeholder involvement, we worked in partnership with stakeholders throughout the project.

This project consisted of four stages. First, we recruited an 11-member steering group to oversee the project via our extensive consumer, health service, and policymaker networks. The steering group provided a leading level of input because they were responsible for making key decisions related to the methods and execution of the review. For example, they determined how broad the range of topics should be that were included in the priority-setting exercise.

In the second stage, we identified the research priorities of consumers and other stakeholders through an international online survey. We invited participation from anyone interested in health care communication and participation.⁹

The survey yielded 151 responses and comprised a combination of consumers' (30%), health professionals' (50%), and others' (20%) views. The stakeholders who participated in the survey provided a contributing level of input because they shared their views or opinions relevant to the topic but were not involved in how their input would shape the final priorities.

In the third stage, we held a face-to-face workshop for stakeholders to further prioritize and convert the topics identified in the survey into systematic review questions.¹⁰ The 28 workshop participants engaged in group discussions, a voting round, and then small group work to explore the top 12 research priorities in depth. They provided an influencing level of input because their participation directly shaped the final research priorities.

Finally, the researchers mapped prioritized questions against existing

Cochrane Consumers and Communication Cochrane Reviews and editorial criteria (i.e., feasibility) to shortlist five priority questions for future reviews of key importance to a wide range of end users.¹⁰

Key Lessons

As this project involved consumers and other stakeholder groups, we learned that skills and techniques to proactively lessen power differences between stakeholder groups were required. In the workshop, for example, we ensured that consumers would constitute at least half of the participants. We also hired an independent workshop facilitator who was skilled in actively seeking consumers' opinions. Previous research supports the use of these strategies to reduce power differences.¹¹

Financial support was also vital to this project. Through the funding body and

small grants, we were able to employ two part-time researchers, pay workshop costs (i.e., food, participant payment, facilitator payment), and produce a professional report in partnership with our stakeholders.

CASE STUDY 2

Case study 2 describes stakeholder involvement in a qualitative evidence synthesis.

Description

Commencing in 2018, the Cochrane Consumers and Communication group has been working with a stakeholder advisory panel to undertake a qualitative evidence synthesis (QES) on one of the priority questions identified in case study 1.¹² The scope of the synthesis is to identify the evidence to support best practices for partnerships between health providers and consumers at the governance level to improve person-centered health services.

Before the commencement of the project, we undertook Cochrane's online training modules about involving stakeholders in reviews.¹³ These modules provided us with ideas about how to involve stakeholders at different stages of the review, including topic selection, protocol development, developing the search, and data collection and analysis.

We recruited an 18-member stakeholder panel to provide guidance throughout the review. We recruited consumer, health provider, and policy-maker stakeholders through the researchers' professional networks and through the mailing list of an Australian national health organization. Panel members reflected key end users of the review. We have used various modes of involvement throughout the project so

far, including teleconferences and face-to-face meetings.

The stakeholder panel has predominantly been involved at a controlling level in this project by making decisions about aspects of the review process. For example, the panel voted on the type of review that should be conducted: an effectiveness review or a QES. The majority voted for a QES, and hence this was commenced.¹²

When the protocol was under development, we sought the stakeholder panel's advice via in-depth discussion during teleconferences to ensure that the protocol draft was addressing the right questions. Stakeholders critiqued the protocol, for example, requesting further justification for the exclusion of certain types of articles. All stakeholder panel members were invited to be coauthors of the protocol. Many accepted and thereby took lead responsibility for the publication.

During the selection of studies for the review, stakeholders were engaged in controlling, rather than leading, roles. This was because of the technical nature of the task and limited time available for both researchers and stakeholders to select studies. During a face-to-face meeting, we grouped the stakeholders into teams with the researchers and asked them to apply the selection criteria to a range of qualitative studies. The stakeholders thus had control over decisions about whether a selection of studies was included in the review, but researchers retained overall responsibility for the data collection phase.

Key Lessons

Consistent with previous research, we found that flexibility was vital when asking stakeholders to make key decisions. When stakeholders chose between a

QES and an effectiveness review, the researchers needed to be willing to change direction and flexible enough to be skilled in both review types. The funders also needed to be flexible in accepting either a QES or an effectiveness review as the final product.¹⁴

Undertaking training on working with stakeholders facilitates stakeholder involvement.¹⁵ For us, it was particularly useful in the initial setup of the project when outlining the different levels of stakeholder involvement and different methods for decision-making (e.g., voting). Once the project started though, we ultimately determined methods of involvement through negotiation with the stakeholder panel, rather than leaving them fixed. Listening to stakeholder needs is key to engagement.¹⁶

We also learned that we needed more time than originally anticipated to involve stakeholders in different tasks. For example, after publication of the protocol we realized that several of the stakeholders were still unsure of the process for conducting a Cochrane Review. Involving stakeholders in study selection also required the development of a specialized training package before our face-to-face meeting. Next time, we would factor in more time and resources to help stakeholders engage in different review tasks.

CASE STUDY 3

Case study 3 describes stakeholder involvement in Cochrane Reviews for a guideline process.

Description

In case study 3, researchers at Cochrane Effective Practice and Organization of Care worked with stakeholders and the World Health Organization (WHO) to

prioritize questions for Cochrane Reviews for a guideline process and to scope those reviews. The guideline aimed to develop recommendations on digital interventions for health systems strengthening.¹⁷

We invited representatives of key stakeholder groups and people with relevant specialist knowledge and programmatic experience of digital health programs in a range of settings to join the guideline development group. This group partnered with the WHO and researchers to scope the guideline and design the research. For example, the WHO and the guideline development group had control of the final decision about the interventions to be included in the guideline. The guideline development group also influenced the design of the Cochrane Reviews that would inform the recommendations. They provided their views about the design of the PICO questions (PICO is a mnemonic for Population/Patient/Problem, Intervention, Comparison, Outcome), which stakeholder groups' views needed to be captured in these syntheses, and which comparison groups and outcome measures were the most relevant.

The WHO also carried out surveys across relevant global and regional networks to further prioritize the questions and outcome measures and received responses from more than 300 people working with digital health and health systems. We incorporated these views into the final protocols. For instance, for the guideline question on telemedicine for communication between health care providers, the stakeholders agreed that the QES should focus on health care providers' and managers' perspectives on acceptability and feasibility. However, for guideline questions, such as targeted messaging to service users via mobile phone, the stakeholders found that

service user acceptability and feasibility were equally important to consider.

Key Lessons

The WHO routinely incorporates stakeholder feedback into their guideline processes and makes stakeholder involvement feasible through a number of practical measures.¹⁸ For instance, expenses related to stakeholder feedback, such as the reimbursement of stakeholders' travel expenses, were incorporated into the guideline budget. In addition, the different stages of stakeholder feedback were incorporated into the guideline's timeline, helping to ensure that the researchers had sufficient time to properly consider this feedback and incorporate it into the development of the reviews. These types of practical measures are key to facilitating stakeholder involvement.^{4,6,14}

CASE STUDY 4

Case study 4 describes supporting stakeholders to use review findings.

Description

The final case study demonstrates an approach to working with stakeholders to broaden the access and use of Cochrane Review evidence in public health policy and practice.

Members of Cochrane Public Health Europe (CPHE) developed a German language summary format for Cochrane Reviews in collaboration with public health decision-makers. The format was based on scientific literature and user tested with public health decision-makers in Austria, Germany, and Switzerland. The decision-makers played an influencing role in this project by providing feedback on the draft format,

which the researchers incorporated into the final summary format. Users welcomed the final summary format as a useful and credible source of information.¹⁹

Additionally, CPHE translated the plain language summaries, abstracts, and press releases of the most relevant, recently published CPH reviews into German. German was chosen because CPHE currently consists of institutions in Germany, Austria, and Switzerland, and summaries in English were less accessible to the targeted stakeholders. CPHE developed a tailored message about the review and compiled stakeholder lists for each country. Subsequently, CPHE members sent personalized e-mails with links to the translated review to stakeholders via an automated mailing platform. As the reviews being disseminated had already been published, stakeholders could not play an active role in shaping the review process, thus they were in receiving roles. However, providing them with tailored dissemination information facilitated their decisions about the applicability and implementation of the results in their own contexts. This project is currently being evaluated through monitoring stakeholders' response rates as well as a stakeholder survey about the usage and relevance of the information provided. Revisions and adaptations to the project will be implemented based on the results of the evaluation.

Key Lessons

Although summarizing, translating, and tailoring dissemination messages for individual reviews is time consuming, CPHE found that these forms of targeted dissemination contribute to reaching new audiences beyond the research community (e.g., federal and national

ministries beyond the health sector, nongovernment organizations, and private companies). This is consistent with previous research demonstrating that stakeholders' access to Cochrane Review findings is facilitated by providing a brief summary of findings, without jargon, translated into their preferred language.¹⁹

IMPACT OF STAKEHOLDER INVOLVEMENT

Although various studies have proposed instrumental impacts of stakeholder involvement at the beginning of and during the research process, few empirical studies have tested these impacts so far.²⁰ The integration of systematic review results into policy and practice is a complex, nonlinear process.^{2,3} Consequently, it may be more beneficial and enhance the relevance of research to focus on understanding the process of stakeholder involvement and impact.²¹ Our case studies suggest that future assessments of stakeholder involvement should include an analysis of the attitudinal and practical factors that facilitate or impede stakeholder involvement in reviews, such as availability of time, researchers' willingness to be flexible, the commitment of the funding body to stakeholder involvement, and researchers' skills and knowledge.

Notably, there is evidence of instrumental impact for involving stakeholders at the final, knowledge dissemination, stage (as shown in case study 4). A Cochrane Review of interventions to improve the use of systematic reviews in decision making found that targeted, tailored messages based on systematic reviews delivered to health care professionals may improve evidence-based practice.²² This suggests that even when

stakeholders are not involved in decision making during the process of the review itself, they can benefit from being involved after its completion.

CONCLUSIONS

Stakeholder involvement in systematic reviews has the potential to enhance relevance and impact on policy and practice. Cochrane case studies across different facets of public health illustrate that different methods, involving varying levels of stakeholder input, can be used to generate and support the use of relevant evidence. Our case studies have shown that factors such as time, researcher flexibility, and researcher skills and training can facilitate or hinder stakeholder involvement. Evidence of the effects of stakeholder involvement are currently limited, and future studies should include an evaluation of the facilitators and barriers to the process of stakeholder involvement. *AJPH*

CORRESPONDENCE

Correspondence should be sent to Bronwen Merner, Cochrane Consumers and Communication, Centre for Health Communication and Participation, School of Psychology and Public Health, La Trobe University, Bundoora, VIC 3086, Australia (e-mail: b.merner@latrobe.edu.au). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Merner B, Lowe D, Walsh L, et al. Stakeholder involvement in systematic reviews: lessons from Cochrane's public health and health systems network. *Am J Public Health*. 2021;111(7):1210–1215.

Acceptance Date: February 19, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306252>

CONTRIBUTORS

B. Merner drafted the background and discussion sections and contributed case study 2. D. Lowe, L. Walsh, and A. Synnot drafted case study 1. J. Stratil and P. von Philipsborn contributed case study 4. S. Lewin and C. Glenton contributed case study 3. L. Schonfeld contributed to writing the background section. R. Ryan, D. O'Connor, J. L. Hoving, and S. Hill

contributed to conceptualizing the article and gave feedback on drafts.

ACKNOWLEDGMENTS

Case study 1 was funded by the Victorian Government Department of Health and Human Services and Safer Care Victoria, the Australian National Health and Medical Research Council, and the La Trobe University Research Focus Area funding scheme. Case study 2 was funded through the La Trobe University Research Platform and Research Focus Areas funding schemes. Case study 3 was funded in part by the World Health Organization. In addition, the Norwegian Satellite of the Effective Practice and Organisation of Care Group receives funding from the Norwegian Agency for Development Co-operation via the Norwegian Institute of Public Health. S. Lewin also receives funding from the South African Medical Research Council. D. O'Connor is supported by a National Health and Medical Research Council Translating Research into Practice fellowship (grant APP1168749). We wish to acknowledge the stakeholders involved in each of the case studies. We also thank Lisa Bero, Professor of Medicine and Public Health, University of Colorado, and senior editor, Cochrane Public Health and Health Systems Network, for her editorial oversight of this publication and commentary series.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

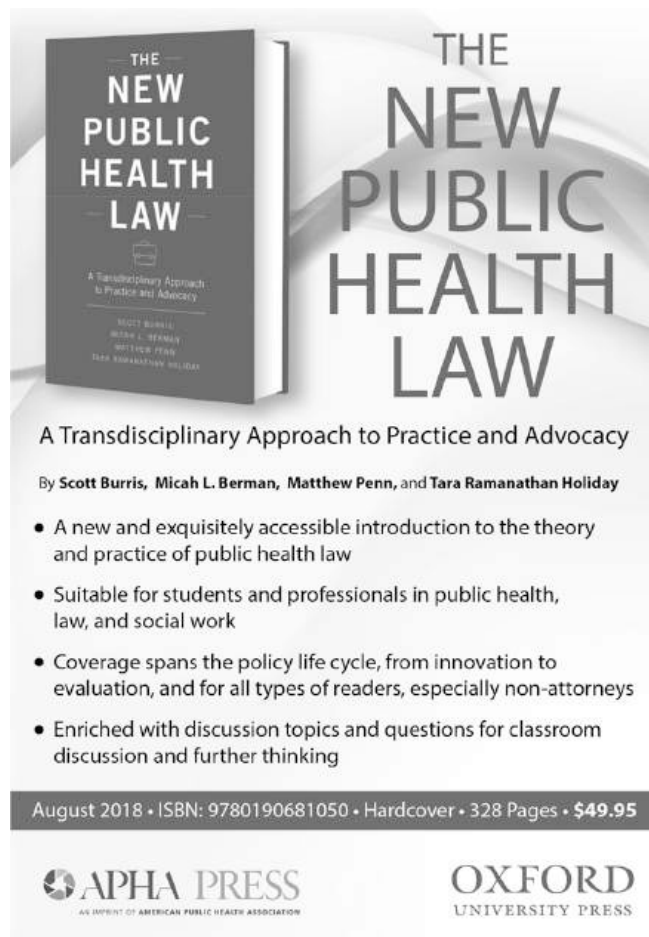
HUMAN PARTICIPANT PROTECTION

We obtained ethics approval for research described in the case studies when required by the home institution where the research occurred.

REFERENCES

1. Fox DM. Evidence and health policy: using and regulating systematic reviews. *Am J Public Health*. 2017;107(1):88–92. <https://doi.org/10.2105/AJPH.2016.303485>
2. Bero L. Systematic review: a method at risk for being corrupted. *Am J Public Health*. 2017;107(1):93–96. <https://doi.org/10.2105/AJPH.2016.303518>
3. Greenhalgh T, Malterud K. Systematic reviews for policymaking: muddling through. *Am J Public Health*. 2017;107(1):97–99. <https://doi.org/10.2105/AJPH.2016.303557>
4. Concannon TW, Grant S, Welch V, et al. Practical guidance for involving stakeholders in health research. *J Gen Intern Med*. 2019;34(3):458–463. <https://doi.org/10.1007/s11606-018-4738-6>
5. Pollock A, Campbell P, Struthers C, et al. Stakeholder involvement in systematic reviews: a scoping review. *Syst Rev*. 2018;7(1):208. <https://doi.org/10.1186/s13643-018-0852-0>
6. Synnot AJ, Hill S. Public involvement in health research. In: Saks M, Allsop J, eds. *Researching Health: Qualitative, Quantitative and Mixed Methods*. 3rd ed. London, England: SAGE; 2019:427–452.

7. Pollock A, Campbell P, Struthers C, et al. Development of the ACTIVE framework to describe stakeholder involvement in systematic reviews. *J Health Serv Res Policy*. 2019;24(4):245–255. <https://doi.org/10.1177/1355819619841647>
8. Bero LA. Improving the quality of systematic reviews in public health: introduction to the series. *Am J Public Health*. 2020;110(11):1601–1602. <https://doi.org/10.2105/AJPH.2020.305914>
9. Synnot A, Bragge P, Lowe D, et al. Research priorities in health communication and participation: international survey of consumers and other stakeholders. *BMJ Open*. 2018;8(5):e019481. <https://doi.org/10.1136/bmjopen-2017-019481>
10. Synnot AJ, Tong A, Bragge P, et al. Selecting, refining and identifying priority Cochrane Reviews in health communication and participation in partnership with consumers and other stakeholders. *Health Res Policy Syst*. 2019;17(1):45. <https://doi.org/10.1186/s12961-019-0444-z>
11. Boivin A, L'Espérance A, Gauvin FP, et al. Patient and public engagement in research and health system decision making: a systematic review of evaluation tools. *Health Expect*. 2018;21(6):1075–1084. <https://doi.org/10.1111/hex.12804>
12. Merner B, Hill S, Colombo C, et al. Consumers and health providers working in partnership for the promotion of person-centred health services: a co-produced qualitative evidence synthesis (protocol). 2019. Available at: <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD013274/full#>. Accessed April 18, 2021.
13. Pollock A, Morley R, Watts C. Involving people: a learning resource for systematic review authors. Available at: <https://training.cochrane.org/involving-people>. Accessed April 18, 2021.
14. Boaz A, Hanney S, Borst R, O'Shea A, Kok M. How to engage stakeholders in research: design principles to support improvement. *Health Res Policy Syst*. 2018;16(1):60. <https://doi.org/10.1186/s12961-018-0337-6>
15. Brunton G, Thomas J, O'Mara-Eves A, Jamal F, Oliver S, Kavanagh J. Narratives of community engagement: a systematic review-derived conceptual framework for public health interventions. *BMC Public Health*. 2017;17(1):944. <https://doi.org/10.1186/s12889-017-4958-4>
16. Walker E, Shaw E, Nunns M, Moore D, Thompson Coon J. No evidence synthesis about me without me: involving young people in the conduct and dissemination of a complex evidence synthesis. *Health Expect*. 2020; Epub ahead of print. <https://doi.org/10.1111/hex.13078>
17. World Health Organization. WHO guideline: recommendations on digital interventions for health system strengthening. 2019. Available at: <https://www.who.int/reproductivehealth/publications/digital-interventions-health-system-strengthening/en>. Accessed April 18, 2021.
18. World Health Organization. *Handbook for Guideline Development*. 2014. Available at: https://www.who.int/publications/guidelines/handbook_2nd_ed.pdf?ua=1. Accessed April 18, 2021.
19. Busert L, Mütsch M, Kien C, et al. Facilitating evidence uptake: development and user testing of a systematic review summary format to inform public health decision-making in German-speaking countries. *Health Res Policy Syst*. 2018;16(1):59. <https://doi.org/10.1186/s12961-018-0307-z>
20. Esmail L, Moore E, Rein A. Evaluating patient and stakeholder engagement in research: moving from theory to practice. *J Comp Eff Res*. 2015;4(2):133–145. <https://doi.org/10.2217/cer.14.79>
21. Synnot A, Tong A, Ryan R, Hill S. Evaluation of the Cochrane Consumers and Communication Group's systematic review priority setting project. *Health Res Policy Syst*. 2020;18(1):98. <https://doi.org/10.1186/s12961-020-00604-x>
22. Murthy L, Shepperd S, Clarke MJ, et al. Interventions to improve the use of systematic reviews in decision-making by health system managers, policy makers and clinicians. *Cochrane Database Syst Rev*. 2012;9:CD009401. <https://doi.org/10.1002/14651858.CD009401.pub2>



Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

How Accountable to the Public Is Funding for Graduate Medical Education? The Case for State Medicaid GME Payments

Thomas M. Henderson, MSPH, MAMC

ABOUT THE AUTHOR

Thomas (Tim) M. Henderson recently retired full time from the Department of Health Administration and Policy, College of Health and Human Services, George Mason University, Fairfax, VA. He continues to work on an adjunct basis and serves as a medical workforce consultant on public policy matters.

Graduate medical education (GME) funding comes from predominantly two public sources: Medicare and Medicaid. In recent years, concerns have been voiced as to whether these GME payments to teaching hospitals and other entities are sufficiently transparent and publicly accountable. Most of these concerns have been directed at the financing and governance of Medicare GME payments. In the past 10 years, two major reports examined this issue.

The main premise of the first report, a 2014 study by the Institute of Medicine (now the National Academy of Medicine), is that Medicare GME payments, and federal funding for GME more broadly, lack a clear purpose. Medicare does not produce enough physicians prepared to practice in the most needed specialties or geographic areas and has insufficient oversight and infrastructure to measure GME program outcomes and reward performance. In terms of accountability, the study found that the stewardship of

the public's investment in GME was critically absent. In particular, any data that teaching hospitals are required to report to the federal government has limited use for program oversight, workforce analysis, or policy development; consequently, the report concluded that most questions about the effectiveness of the Medicare GME program are unanswerable.¹

The second report, a 2018 US General Accounting Office investigation, examined GME spending and related oversight by Medicare and other federal agencies, including what is known about training program costs and what information the federal government collects that documents its investment in GME. The General Accounting Office noted the difficulty the federal government has in identifying GME training costs and how they relate to federal GME funding, including Medicare. The investigation found that because Medicare cost report data are not typically used to

calculate GME payments, federal auditors do not review such data, and there are no federal reporting requirements for how teaching programs use these payments. Ultimately, the General Accounting Office concluded that because the information collected on Medicare GME payments is often incomplete, the federal government lacks sufficient information to comprehensively evaluate their effectiveness.²

Concurrently, the transparency and public accountability of Medicaid GME payments have received little or no scrutiny, in large part because awareness and knowledge of these payments among policymakers and others is limited. I present an overview of Medicaid GME payments and policies, examine some troubling issues regarding the transparency and accountability of these payments, and recommend some federal and state policies to address these issues.

PAYMENTS BY STATE MEDICAID PROGRAMS

Since its inception in the mid-1960s, Medicaid has been an important payor of GME. In the past 20 years alone, state Medicaid programs' GME payments have more than doubled.^{3,4} In 2018, Medicaid GME payments totaled nearly \$5.6 billion—an amount second only to Medicare, the country's largest GME payor. More than half of this amount was paid in the 10 states with the largest number of medical residents, even though Medicaid in two of these states (CA, MA) did not pay for GME (Table 1).⁴

When Medicaid programs are asked why they pay for GME, the most frequent reasons given are to use Medicaid funds to advance state policy goals and to help train the next generation of physicians

who will serve Medicaid beneficiaries.⁴ In particular, 32 states reported in 2015 that they made Medicaid GME payments with the expectation of producing more physicians. Between 1998 and 2009, 10 states consistently stated that they linked Medicaid GME payments to state physician workforce or related policy goals.⁵⁻¹⁰

How Medicaid is administered and financed provides two key incentives to pay for GME. First, the federal Centers for Medicare and Medicaid Services (CMS) give state Medicaid programs significant flexibility in designing and executing their GME payments, including which professions and which settings and organizations are eligible to receive support for health professions education.¹¹ A number of states have used this flexibility to institute innovative payment approaches. In addition to teaching hospitals, medical schools in three states and resident training sites at

nonhospital patient care settings in two states directly receive Medicaid GME payments. Five states make enhanced payments to individual teaching professionals employed by state university hospitals for services associated with the cost of instructing medical residents. Along with physician residencies, programs that educate graduate nurses and other health professions trainees in 13 states are eligible to receive Medicaid GME payments.⁴

Second, states may receive federal matching funds to help pay for GME under Medicaid.^{4,12,13} In 2018, 16 states reported using contributions from local governments to finance the nonfederal share of their Medicaid supplemental GME payments, which allowed them to claim federal matching funds.⁴

Although not required to do so, 43 states in 2018 made GME payments to teaching hospitals and other entities

under their Medicaid program.^{3,4,12} Of these, 41 states paid for GME under their fee-for-service (FFS) program, and 28 states provided some level of support for GME under managed care.⁴ In 2015, the proportion of Medicaid GME payments made under managed care exceeded the proportion of such payments made under FFS for the first time. In 2018, 52% of all Medicaid GME payments were made under managed care (Table 1).

States distribute Medicaid GME funds differently under FFS and managed care. Under FFS, payments are made to teaching hospitals and other eligible providers through a direct add-on adjustment to the institution's base payment rates and as a federally authorized, lump-sum supplemental payment to help offset any GME costs not reimbursed by the add-on adjustment to base rates.^{4,14} Under managed care,

TABLE 1— Graduate Medical Education (GME) Payments by State Medicaid Programs: United States, 1998–2018

	Year ^a						
	2018	2015	2012	2009	2005	2002	1998
No. of states and DC paying for GME	43	43	43	42	48	48	46
Total GME payments, \$ billions ^b	5.58	4.26	3.87	3.78	3.18	2.70	2.41
% of total GME payments made under FFS and MC, FFS/MC ^c	48/52	39/61	59/41	63/37	75/25	DNC	DNC
% of total GME payments in the 10 states and DC with the largest number of medical residents ^d	55	57	62	60	62	69	DNC

Note. DNC = data not collected; FFS = fee for service; MC = managed care.

Source. Henderson.⁴⁻¹⁰

^aAll surveys included DC; the 1998 survey also included Puerto Rico. Surveys conducted in 1998, 2002, 2005, 2012, 2015, and 2018 received a 100% response rate. All but one state (AL) responded to the 2009 survey.

^bThe total amount of Medicaid GME payments by states to teaching programs included funds from federal and state sources and payments made under FFS and managed care. Payments included state-reported and any consultant-estimated amounts. (For 2018, there were no consultant-estimated amounts.) Total payment amounts do not reflect the precise total of individual state amounts because of rounding.

^cFor the survey years shown, the following states reported a total GME payment amount but provided no specific breakdown of amounts paid under FFS or managed care for all or some as noted of their GME payments. GME payment amounts from these states were not included in the calculation of the reported FFS/MC percentages as follows: 2018: GA (some), IL (some), MD, TX (some); 2015: AZ, FL, GA (some), MD, MS (some), OH, TX (some); 2012: AZ, CO, HI, MD, OH; 2009: AZ, CO, HI, IN (some), MD, NJ (some), OH, OR (some); 2005: AZ, CO, FL, IN (some), KS, MD, MA (some), MI, NJ (some), OH, OR (some), RI (some), VA, WA (some).

^dThe 10 states with the largest number of medical residents varies slightly by survey year, and not all of these states paid for GME under Medicaid in each year. States not making Medicaid GME payments for the years noted include the following: CA in 2012, 2015, 2018; IL in 2002, 2005, 2009, 2012; MA in 2009, 2012, 2015, 2018; and TX in 2005, 2009, 2012.

states make GME payments directly to teaching programs or indirectly as part of the capitation rates paid to risk-based managed care organizations.^{4,15} Managed care organizations are not bound to distribute GME payments to teaching hospitals unless required by their state Medicaid program. Six of the 13 states that included GME payments in their managed care organization rates in 2018 required managed care organizations to pass these payments on to teaching hospitals; the remaining states assumed that managed care organizations distributed these payments to hospitals.⁴ Figure A (available as a supplement to the online version of this article at <http://www.ajph.org>) illustrates how Medicaid GME payments are financed and distributed.

CONCERNS AND REMEDIES

Despite the notable growth in Medicaid GME payments and the adoption of innovative GME payment approaches by several states over the past 20 years, the federal government, states, and teaching hospitals now face questions (similar to those directed at Medicare) about the lack of information and accountability, both financial and social, concerning these GME payments.

Incomplete Information

Publicly available information on Medicaid GME payments is often deficient or nonexistent. Medicaid GME payment data collected by CMS is generally acknowledged to be lacking, as (1) not all states provide the requested information, (2) states do not separately report GME payments included in FFS hospital base rates (supplemental GME payments are commonly reported), and (3) state GME

payments made under managed care typically are not reported.^{2,4,11-13}

Moreover, in some states, policymaker and researcher efforts to obtain and evaluate information on GME payments is problematic. For example, the amount of Medicaid GME payments is difficult to quantify precisely in a few states.⁴ Also, most states lack adequate data on the physician workforce implications associated with their Medicaid GME payments (e.g., number and specialty of residents supported, proportion of these residents who go on to serve Medicaid beneficiaries when they enter independent practice).^{2,11,16}

To remedy this data inadequacy, CMS should institute stricter requirements for state Medicaid programs to collect and submit complete and accurate data on GME supplemental payments currently requested as well as GME payments included in FFS hospital base rates and made under managed care. In addition, CMS should require states to collect physician workforce data important to policymakers on their Medicaid GME payments.

Insufficient Financial Accountability

Although Medicaid programs employ a formulaic approach to pay teaching programs for GME,⁴ the means by which hospitals distribute these public funds lacks transparency and is not widely understood by states and affiliated residency programs. In most states, Medicaid GME payments go directly to teaching hospitals and not to the residencies they sponsor.⁴ For many residency programs, this policy obstructs their knowledge of the amount and flow of these payments or whether they even receive such payments.¹⁷ Typically, hospitals distribute GME payments through a general revenue fund with no restriction

that these payments must support only GME. Consequently, this imprecise method of cost accounting makes the benefits to GME of these payments challenging to quantify.^{17,18} Also, there are questions about whether the single amount that most Medicaid programs pay hospitals for resident training accurately reflects the hospital's GME costs when the cost of training is thought to differ by a resident's specialty, year of training, site of training, program size, and other factors.^{2,11,19} In 2018, only one state Medicaid program reported using a payment method that recognizes one or more of these factors.⁴

Teaching programs also have little incentive to keep detailed records of GME revenues and expenses because state and CMS Medicaid payment regulations do not require them to collect and report this information. In 2018, just 14 states required teaching programs to routinely report their allowable direct GME costs; but 21 states noted that they use other sources to obtain this information. In addition, only 14 states said that they routinely audit their GME payments to teaching programs.⁴ Even when these GME costs and audit findings are reported to CMS, the federal government is not required to use the information for oversight or evaluation except in limited cases.²

To improve financial accountability, federal and state regulations should mandate that state Medicaid programs routinely collect detailed records of GME revenues and expenses from teaching hospitals and other entities receiving their GME payments. Moreover, states should be required to regularly audit teaching hospitals to identify or verify the Medicaid GME payments hospitals pass on to residency programs and the number of residents these payments support. In addition, CMS should be compelled to use these audits for

wide-ranging oversight and evaluation. Finally, Medicaid programs should employ a GME payment methodology that recognizes documented cost differences among residencies based on specialty and other variables.

Lack of Social Accountability

Despite Medicaid programs' reported intentions of having GME payments help address their state's health workforce needs, there is no known evidence that such expectations have made any difference. Evidence is lacking because most Medicaid programs do little or nothing to actually track and report the societal value of the public's investment in GME, in part because their state legislatures and CMS do not obligate them to do so. In 2018, just three Medicaid programs stated that they document and report the impact of their GME payments on the state's health care workforce as their state requires.⁴ In addition, CMS does not require states or teaching programs to report any information about the number and characteristics of physician residents that Medicaid GME payments support.²

Nevertheless, most Medicaid programs are unable to document the impact of their GME payments principally because they have not defined clear and explicit goals associated with these payments and the specific, measurable outcomes taxpayers can expect from the payments.⁴ The lack of such goals and performance measures, coupled with a dearth of supporting data, limits efforts by state and federal policymakers to determine whether Medicaid GME payments have made a social difference and what initiatives are needed to enhance the outcomes of these payments.^{2,16}

To make Medicaid GME payments more socially accountable, CMS should require states to define explicit workforce goals and performance measures pertaining to their payments and routinely collect supporting data useful to state and federal policymakers for evaluating the effects of these payments on the state's physician workforce supply and distribution. **AJPH**

CORRESPONDENCE

Correspondence should be sent to Thomas M. Henderson, MSPH, MAMC, Adjunct Faculty, Department of Health Administration and Policy, College of Health and Human Services, George Mason University, 4400 University Dr, Fairfax, VA 22030 (e-mail: thender1@gmu.edu).

PUBLICATION INFORMATION

Full Citation: Henderson TM. How accountable to the public is funding for graduate medical education? The case for state Medicaid GME payments. *Am J Public Health*. 2021;111(7):1216–1219.

Acceptance Date: February 18, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306246>

CONFLICTS OF INTEREST

The author has no potential or actual conflicts of interest from funding or affiliation-related activities.

REFERENCES

- National Academies of Sciences, Engineering, Medicine. Graduate medical education that meets the nation's health needs. 2014. Available at: <https://www.nap.edu/catalog/18754/graduate-medical-education-that-meets-the-nations-health-needs>. Accessed February 14, 2021.
- US Government Accounting Office. Physician workforce: HHS needs better information to comprehensively evaluate graduate medical education funding. 2018. Available at: <https://www.gao.gov/assets/700/690581.pdf>. Accessed February 16, 2021.
- Henderson T. Medicaid's role in financing graduate medical education. *Health Aff (Millwood)*. 2000; 19(1):221–229. <https://doi.org/10.1377/hlthaff.19.1.221>
- Henderson T. Medicaid graduate medical education payments: a 50-state survey. 2019. Available at: https://store.aamc.org/downloadable/download/sample/sample_id/284. Accessed January 12, 2021.
- Henderson T. *Funding of Graduate Medical Education by State Medicaid Programs*. Washington, DC: Association of American Medical Colleges; 1999.
- Henderson T. *Medicaid Direct and Indirect Graduate Medical Education Payments: A 50-State Survey*. Washington, DC: Association of American Medical Colleges; 2003.
- Henderson T. *Direct and Indirect Graduate Medical Education Payments by State Medicaid Programs*. Washington, DC: Association of American Medical Colleges; 2006.
- Henderson T. *Direct and Indirect Graduate Medical Education Payments by State Medicaid Programs*. Washington, DC: Association of American Medical Colleges; 2010.
- Henderson T. *Medicaid Graduate Medical Education Payments: A 50-State Survey*. Washington, DC: Association of American Medical Colleges; 2013.
- Henderson T. *Medicaid Graduate Medical Education Payments: A 50-State Survey*. Washington, DC: Association of American Medical Colleges; 2016.
- Heisler EJ, Mendez BHP, Mitchell A, Viranga Panangala S, Villagrana MA. Federal support for graduate medical education: an overview. 2018. Available at: <https://www.everycrsreport.com/reports/R44376.html>. Accessed December 19, 2020.
- Heffron D. GME payments in Medicaid. Paper presented at: A Workshop of the Institute of Medicine Committee on the Governance and Financing of Graduate Medical Education. Washington, DC; September 4, 2012.
- Medicaid and CHIP Payment and Access Commission. Chapter 3: State approaches to financing Medicaid and update on federal financing of CHIP. 2012. Available at: <https://www.macpac.gov/wp-content/uploads/2012/03/State-Approaches-for-Financing-Medicaid-and-Update-on-Federal-Financing-of-CHIP.pdf>. Accessed February 23, 2021.
- Medicaid and CHIP Payment and Access Commission. Medicaid base and supplemental payments to hospitals. 2020. Available at: <https://www.macpac.gov/publication/medicaid-base-and-supplemental-payments-to-hospitals>. Accessed January 29, 2021.
- Herz EJ, Tilson S. Medicaid and graduate medical education. 2009. Available at: https://www.everycrsreport.com/files/20090217_RS22842_bc17fae81b089239c7fcca8719de29e0ad329c71.pdf. Accessed November 23, 2020.
- Fraher EP, Spero JC, Bacon T. Health workforce policy brief: state-based approaches to reforming Medicaid-funded graduate medical education. 2017. Available at: http://www.shepscenter.unc.edu/wp-content/uploads/2017/01/ExecSumm_FraherGME_y3_final-1.pdf. Accessed February 14, 2021.
- Chaudhry S, Khanijo S, Halvorsen S, McDonald F, Patel K. Accountability and transparency in graduate medical education expenditures. *Am J Med*. 2012;125(5):517–522. <https://doi.org/10.1016/j.amjmed.2012.01.007>
- Massa L, Anderson M. Detangling graduate medical education financing from hospital payment methodologies. *Hamline Law Rev*. 2015;38(2):311–328.
- Wynn BO, Smalley R, Cordasco KM. Does it cost more to train residents or to replace them? A look at the costs and benefits of operating graduate medical education programs. *Rand Health Q*. 2013; 3(3):7.

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

The US Supreme Court and the Future of Sexual and Gender Minority Health

Michael Liu, AB, Jack L. Turban, MD, MHS, and Kenneth H. Mayer, MD

ABOUT THE AUTHOR

Michael Liu is a medical student at Harvard Medical School, Boston, MA. Jack L. Turban is with the Division of Child and Adolescent Psychiatry, Stanford University School of Medicine, Stanford, CA. Kenneth H. Mayer is with Harvard Medical School, and the Fenway Community Health Center, Fenway Institute, Boston, MA.

Over the past decade, the United States has made substantial progress in advancing the rights of sexual and gender minority (SGM) people. In 2015, the Supreme Court of the United States (SCOTUS) decision in *Obergefell v. Hodges* provided same-sex couples the fundamental right to marry across the United States.¹ In 2020, the landmark *Bostock v. Clayton County* decision extended the interpretation of “on the basis of sex” under title VII of the 1964 *Civil Rights Act* to prohibit workplace discrimination on the basis of sexual orientation and gender identity.² This sweeping decision sets the precedent that other sex-based antidiscrimination laws should be interpreted to include SGM people. However, explicit and broad protections based on sexual orientation and gender identity are not common features of federal laws, and existing SGM protections remain tenuous, as they rely on judicial interpretation. With recent shifts in the composition of SCOTUS, there is the increasing possibility that the hard-earned protections for SGM people in the United States will be reversed through recently argued and upcoming cases. Based on

the available empirical evidence, we are concerned about the possible physical and mental health sequelae.

A 2017 Gallup survey found that 4.5% of the US population identify as SGM. Decades of research have revealed that SGM people have higher rates of disability, cardiovascular disease, obesity, substance use, and poor mental health than do their non-SGM counterparts.³ For example, a recent national analysis reported that 40%, 35%, and 25% of sexual minority adolescents were seriously considering, planning, or attempting suicide, respectively.⁴ The corresponding rates among heterosexual adolescents were substantially lower at 15%, 12%, and 6%, respectively. These issues were underscored when the National Institutes of Health designated SGM people as a health disparity population in 2016.³

Health disparities among SGM people are thought to result from stressors related to sexual orientation and gender identity that occur along a continuum from distal to proximal.⁵ Distal stressors involve structural forces and external events, such as family rejection, peer violence, and housing discrimination.

One key distal stressor involves legal decisions that imply marginalization or lack of acceptance of SGM people.³ Proximal stressors involve internal processes, such as expectations of prejudice and internalized stigma, that impair functioning and reduce the capacity of SGM people to participate fully in society.⁵ Collectively, proximal and distal stressors erode the physical and mental health of SGM people, highlighting the urgent need for policies to protect their health.⁶ Such policies include those that directly affect health and those that shape institutions and cultural attitudes that ultimately determine health.

DENIAL OF SERVICES

SCOTUS recently heard oral arguments in *Fulton v. Philadelphia* (docket no. 19-123)—a case deciding whether Philadelphia, Pennsylvania, can enforce non-discrimination policies when contracting with faith-based, public-funded organizations that deny services on account of religious beliefs. The plaintiffs denied adoption screening services to same-sex couples, highlighting the ongoing tensions between SGM civil rights and religious liberties. *Fulton v. Philadelphia* implicates the future of *Employment Division v. Smith*, a case that stated that government actions do not violate the First Amendment if they are neutral and generally applicable.⁷ There is concern that the conservative majority on SCOTUS will vote to narrow the precedent set by *Employment Division v. Smith* and expand religious exemptions, thereby permitting discrimination against vulnerable populations, including SGM people. Discrimination in the form of service denial related to marriage, adoption, and public facility use has been previously shown to be detrimental to SGM health.³ A difference-in-

difference-in-differences analysis found a 46% increase in sexual minority adults experiencing mental distress in states that permitted service denial to same-sex couples.⁸

AFFORDABLE CARE ACT

The 2017 *Tax Cuts and Jobs Act* (Pub L No. 115–97) eliminated the tax penalty associated with the individual mandate of the Affordable Care Act (ACA), which requires individuals to have adequate health insurance. SCOTUS will soon decide in *California v. Texas* (docket 19–840) whether the individual mandate in the absence of a tax penalty is constitutional and, if not, whether the remainder of the ACA can be severed from the individual mandate and survive. Dismantling the full ACA could substantially reduce health care access for SGM people: 34% of SGM people with incomes less than 400% of the federal poverty line were uninsured in 2013.³ This number dropped to 22% in 2017 after coverage expansion through the ACA.

Of particular concern is the potential loss of the nondiscrimination provision (section 1557) of the ACA. SGM people face considerable barriers to accessing health care because of widespread discrimination in health care settings. For gender minority people, this manifests as lack of coverage for gender-affirming care, verbal and physical harassment in health care settings, and denial of care from providers.⁹ A 2015 survey of 27 715 transgender Americans found that 23% of respondents elected not to seek needed health care for fear of being mistreated on the basis of their gender identity.⁹

Section 1557 of the ACA prohibits discrimination on the basis of sex in health care facilities and programs

that receive federal funding.¹⁰ The Obama–Biden presidential administration issued a rule in 2016 clarifying that this includes protections for SGM people. The 2016 rule also prohibits insurers from excluding coverage for transgender-specific care, including gender-affirming surgery, hormone therapy, and mental health counseling. Similar nondiscrimination policies in private insurance plans have been associated with reductions in suicidality among gender minority people.¹¹ In 2020, the Trump–Pence presidential administration issued a new rule narrowing the interpretation of section 1557 and removed virtually all protections for SGM people.¹⁰ Both the 2016 and 2020 rules are currently being litigated. Of note, the recent *Bostock v. Clayton County* decision casts doubt on the viability of the 2020 rule.

In summary, SGM health and health care access would suffer greatly if the full ACA were to be dismantled. Fortunately, the Department of Justice recently changed its position under the Biden–Harris presidential administration, urging SCOTUS to preserve the ACA.

CONVERSION THERAPY

Recently, in *Otto v. City of Boca Raton*, the 11th Circuit Court of Appeals struck down two Florida bans on conversion therapy—practices that attempt to change sexual orientation, gender identity, or gender expression.¹² Challenges to such bans are based on claims that the content and viewpoint of conversion therapy are protected by the First Amendment. All major medical organizations have labeled conversion therapy as ineffective, unethical, and dangerous.³ Given that this decision

created a circuit split (the 3rd and 9th circuits have ruled that conversion therapy bans are constitutional), a case will likely be brought to SCOTUS. A decision to strike down conversion therapy bans would expose SGM people to dangerous practices known to negatively affect health.³ It would also contribute to beliefs that SGM identities can and should be changed, amplifying stigma experienced by SGM people.⁵

MARRIAGE EQUALITY

There are fears among legal experts and SGM advocates that the new strong conservative majority on SCOTUS places marriage equality at risk, given that *Obergefell v. Hodges* was originally decided in a five to four vote by a less conservative court.¹³ The legalization of same-sex marriage confers substantial health benefits on sexual minority people. In a natural experiment, researchers found that sexual minority men experienced significant reductions in medical care visits, mental health care visits, and mental health care costs after same-sex marriage laws were enacted in Massachusetts in 2003.¹⁴ These findings were consistent for both partnered and nonpartnered men, suggesting that health benefits may be attributed in part to the broader cultural impacts of the legislation. This hypothesis was further supported by impacts on adolescent mental health. A difference-in-differences analysis found that marriage equality was associated with a 7% reduction in suicide attempts among high school students in states that had not previously legalized same-sex marriage.¹⁵ These findings are sobering but not surprising. Laws that affirm fundamental civil rights reduce the tremendous burden of day-to-day stigma experienced by sexual

minority youths and provide them with reasons to be hopeful for the future.

Historical evidence also reveals that men and women in same-sex relationships had lower rates of health insurance coverage than did their heterosexual counterparts before marriage equality.³ Marriage equality allows sexual minority people to obtain health insurance coverage through the employer of a spouse, further combating health disparities among this population.

CONCLUSIONS

Permitting service denial, repealing the ACA, legalizing conversion therapy, or overturning marriage equality would have devastating consequences for the health of SGM people. It is our hope that SCOTUS will consider the health consequences of upcoming decisions. Even then, protections for SGM people rely too heavily on the courts and state-level and local-level stopgaps. The Biden–Harris administration and Congress must prioritize legislation, such as the *Equality Act*, that provides explicit protections for SGM people. Homophobia and transphobia are public health problems. How one identifies or who one loves should not determine whether a person is able to maintain good health and access health care. *AJPH*

CORRESPONDENCE

Correspondence should be sent to Kenneth H. Mayer, MD, The Fenway Institute, Fenway Health, Ansin Building, 1340 Boylston St, Boston, MA 02215 (e-mail: kmayer@fenwayhealth.org). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

PUBLICATION INFORMATION

Full Citation: Liu M, Turban JL, Mayer KH. The US Supreme Court and the future of sexual and gender minority health. *Am J Public Health*. 2021;111(7):1220–1222.

Acceptance Date: March 19, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306302>

CONTRIBUTORS

M. Liu created the initial concept for the editorial and led the writing. J. L. Turban and K. H. Mayer contributed to the writing and provided critical revision of the editorial for important intellectual content.

ACKNOWLEDGMENTS

The authors acknowledge the plaintiffs and sexual and gender minority (SGM) leaders who continue to tirelessly advocate and fight for the rights of SGM people across the world.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

REFERENCES

1. *Obergefell v. Hodges*, 576 US 644 (June 26, 2015).
2. *Bostock v. Clayton County*, 590 US ___ (June 15, 2020).
3. National Academies of Sciences, Engineering, and Medicine. *Understanding the Well-Being of LGBTQI+ Populations*. Washington, DC: National Academies Press; 2020. <https://doi.org/10.17226/25877>
4. Caputi TL, Smith D, Ayers JW. Suicide risk behaviors among sexual minority adolescents in the United States, 2015. *JAMA*. 2017;318(23):2349–2351. <https://doi.org/10.1001/jama.2017.16908>
5. Meyer IH. Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues and research evidence. *Psychol Bull*. 2003;129(5):674–697. <https://doi.org/10.1037/0033-2909.129.5.674>
6. Hatzenbuehler ML. How does sexual minority stigma “get under the skin”? A psychological mediation framework. *Psychol Bull*. 2009;135(5):707–730. <https://doi.org/10.1037/a0016441>
7. *Employment Division v. Smith*, 494 US 872 (1990).
8. Raifman J, Moscoe E, Austin SB, Hatzenbuehler ML, Galea S. Association of state laws permitting denial of services to same-sex couples with mental distress in sexual minority adults: a difference-in-difference-in-differences analysis. *JAMA Psychiatry*. 2018;75(7):671–677. <https://doi.org/10.1001/jamapsychiatry.2018.0757>
9. James SE, Herman JL, Rankin S, Keisling M, Mottet L, Anafi M. *The Report of the 2015 US Transgender Survey*. Washington, DC: National Center for Transgender Equality; 2016.
10. Musumeci MB, Kates J, Dawson L, Salganicoff A, Sobel L, Artiga S. The Trump administration’s final rule on section 1557 non-discrimination regulations under the ACA and current status. September 18, 2020. Available at: <https://www.kff.org/racial-equity-and-health-policy/issue-brief/the-trump-administrations-final-rule-on-section-1557-non-discrimination-regulations-under-the-aca-and-current-status>. Accessed April 12, 2021.
11. McDowell A, Raifman J, Progovac AM, Rose S. Association of nondiscrimination policies with mental health among gender minority individuals. *JAMA Psychiatry*. 2020;77(9):952–958. <https://doi.org/10.1001/jamapsychiatry.2020.0770>
12. *Otto v. City of Boca Raton*, 11th Cir, No. 19-10604 (2020).
13. Holbrook T. Same-sex marriage at risk as Supreme Court gets more conservative. CNN. October 6,

2020. Available at: <https://www.cnn.com/2020/10/06/opinions/thomas-alito-obergefell-marriage-equality-at-risk-holbrook/index.html>. Accessed March 15, 2021.

14. Hatzenbuehler ML, O’Cleirigh C, Grasso C, Mayer K, Safren S, Bradford J. Effect of same-sex marriage laws on health care use and expenditures in sexual minority men: a quasi-natural experiment. *Am J Public Health*. 2012;102(2):285–291. <https://doi.org/10.2105/AJPH.2011.300382>
15. Raifman J, Moscoe E, Austin SB, McConnell M. Difference-in-differences analysis of the association between state same-sex marriage policies and adolescent suicide attempts. *JAMA Pediatr*. 2017;171(4):350–356. <https://doi.org/10.1001/jamapediatrics.2016.4529>

Subscribe to the
AJPH Podcast
– in three different
languages!



Listen to *AJPH*’s monthly podcasts highlighting specific public health issues from the *AJPH* Web site, iTunes, Google Play, and on your phone podcast app. They are hosted by *AJPH*’s Editor-in-Chief Alfredo Morabia in English and Spanish, and Associate Editor Stella Yu in Chinese.



Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Vaccination of the Elderly in Assisted Living by the Israeli Emergency Medical Services

Eli Jaffe, PhD, Keren Dopelt, PhD, Nadav Davidovitch, MD, PhD, and Yuval Bitan, PhD

Emergency Medical Services (EMS) in Israel was called on to vaccinate the most vulnerable population—the elderly in assisted living facilities and their caregivers. Two parameters led the operation: (1) maximum use of the scarce COVID-19 vaccine, and (2) minimizing the time it took to reach this entire population. We present the process of vaccinating 126 245 people in two weeks at 756 locations countrywide, focusing on the planning and logistics of this operation. Resilience, flexible logistics, and dedicated personnel provided an efficient public health operation. (*Am J Public Health*. 2021;111:1223–1226. <https://doi.org/10.2105/AJPH.2021.306318>)

The objective of this program was to vaccinate all the elderly people in assisted living facilities for COVID-19 in the shortest amount of time. This operation was part of the Israeli Ministry of Health's effort to vaccinate all of the population of Israel as soon as the COVID-19 vaccine became available.

INTERVENTION

The limited number of vaccine vials and the widespread community transmission of new COVID-19 cases in the country necessitated a quick and efficient operation. The unique characteristic of this operation is that although most of the population is able to travel to health care facilities to receive the vaccine, this most vulnerable population is not mobile; thus, it would be difficult to get them to a health care facility.¹ The operation was complicated by the fact that the vaccine Israel received (Pfizer-BioNTech, New York, NY/Mainz, Germany) is very sensitive and there are strict instructions

for its storage temperature and distribution process.²

Magen-David-Adom, the Israeli national emergency medical services (EMS)³ operated as an ad hoc subcontractor for the Ministry of Health. The goal was to reach out to all assisted living facilities across Israel to vaccinate all residents and their caregivers within three weeks, in time to start providing the second portion of the vaccine. Because the number of vaccine doses that Israel received was limited, one of the goals of this operation was to have minimum waste of the vaccine, despite the complexity of its storage (vaccine vials that were defrosted had to be used within five days, and vials prepared for injection within six hours).

PLACE AND TIME

The operation took place in Israel, starting on December 22, 2020, with a four-day pilot run in eight facilities. The main phase took place between December 27, 2020, and January 6, 2021, when an

additional 748 assisted living facilities were visited, and all residents and staff were vaccinated.

PERSON

A total of 3138 EMS personnel participated in the operation. They had received four hours of training in preparing and administering the vaccine. The first part of the training was a video for an asynchronous study focussed on the process and safety, and the second part was a real-life simulation to practice the procedure.

According to the medical directive, all people who had not experienced anaphylaxis shock in the past and were 16 years old and older were eligible for the vaccine. In total, 126 245 people were vaccinated as part of this operation; 40 240 were residents of the assisted living facilities, and 86 005 were assisted living staff, close family members, and some EMS personnel. Vaccinating the EMS personnel was a planned buffer—the “use it or lose it” characteristic of this

vaccine dictated an effort to vaccinate people who needed to be vaccinated, such as first responders, using the entire amount of the prepared vaccine before it expired.

PURPOSE

Vaccinating the elderly in institutions is of utmost importance.⁴ On December 11, 2020, the US Food and Drug Administration issued the first emergency use authorization for a vaccine for the prevention of COVID-19 in individuals 16 years old and older.⁵ Israel was one of the first countries to receive the Pfizer-BioNTech COVID-19 vaccine, and preparations for a multilayer operation that would allow everyone in the country to be vaccinated started a few weeks before its arrival.

IMPLEMENTATION

In preparation for the operation, the EMS purchased mobile refrigerators and developed a dedicated cloud-based information system that was synchronized with the Ministry of Health database using the national unique ID number. The system was installed on dedicated mobile devices that could be operated by all EMS personnel in the field to identify people before they were given the vaccine, verify their background medical history, record when and where they received the vaccine, and schedule their appointment for the second portion.

A call to validate the expected number of staff and residents that needed to be vaccinated in each assisted living facility was conducted three days ahead of the operation date and led to detailed planning of the number of vials that were needed. As the main objective was to vaccinate everyone in the facility, a

sufficient number of vials had to be transferred in refrigerated trucks from the pharmacy storage, where the vaccine was stored frozen, to the assisted living facility about an hour before beginning the vaccination process. The extra hour was needed to bring the vaccine to the temperature at which it could be prepared and diluted. The EMS instructed each facility on how to prepare the location with a reception area and several workstations to administer the injections.

Vaccination was not mandatory, and only people who wanted to take the vaccine arrived at the location. The EMS team arrived at the facility with refrigerators that kept the vaccine at two degrees centigrade until it was diluted for injection. An EMS paramedic was responsible for diluting the vials according to the pharmaceutical instructions. This procedure was a key part of the process, as it controlled the rate and the number of vaccines that could be used. The paramedic had to coordinate the number of ready vials between the medics who vaccinated the residents. A careful measure of the number of people and vials guaranteed maximum use of the vaccine in the diluted vials. The logistic process is demonstrated in [Figure 1](#).

EVALUATION

Israel is a country of approximately 9 million people who live on about 20 000 square kilometers. A modern network of roads allowed easy transport and supported quick distribution of the vaccine. The high efficacy of the vaccine on the entire population was reported in Dagan et al.⁶ The EMS operation recorded three measurements: duration, vaccine use, and resident satisfaction.

Duration

The vaccine was given at all 756 assisted living facilities in Israel within two weeks, at an average rate of 9000 people every day.

Vaccine Use

The amount of vaccine in the vial was designed for five doses, but by careful measurement, it could be used for six doses. In 90% of the facilities, the teams were able to vaccinate five or six people with each vial. Thus, on average, a vial held enough for 5.42 doses. This improved use saved 1953 vials ([Figure 2](#)). The 10% of the facilities where fewer doses were derived from each vial were smaller, and the number of residents was lower than expected; the team was unable to use the vaccine leftovers. The use of low dead space syringes for the second portion is expected to improve vaccine use in the vials.

Resident Satisfaction

The 258 questionnaires that were collected from the residents a few days after the vaccination reveal that 96% were very thankful and pleased with the process. Although the EMS teams did not sense any vaccine hesitancy, 83% of the residents mentioned the important part the EMS personnel played in providing information about the vaccine and its side effects.

ADVERSE EFFECTS

To perform this operation, the EMS used mainly volunteers and unemployed people who are qualified medics and did not have to rely on its permanent workforce. Therefore, this operation did not

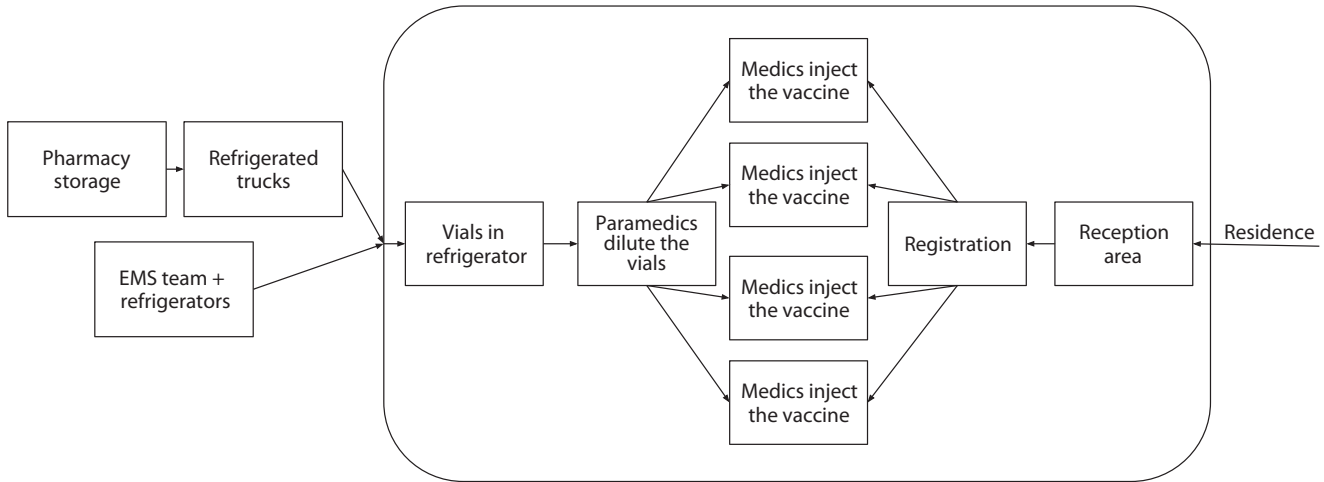


FIGURE 1— The Process of Vaccinating in Assisted Living Facilities: Israel, December 22, 2020–January 6, 2021

Note. EMS = Emergency Medical Services.

affect the response time for emergency calls by the EMS.

The pilot at the beginning of the operation highlighted some complications in flow in the facilities and showed how long it would take to register and administer the vaccine. Based on this information, the EMS added staff to usher and guide people in line before vaccination, observed vaccinated people for 15 minutes after the

vaccination, and separated the process of identifying and registering the people from the injection action.

SUSTAINABILITY

The vaccine is administered in two portions, three weeks apart. The second round is planned to operate in a similar way, demonstrating the success of the

process in both satisfaction and operational aspects.

PUBLIC HEALTH SIGNIFICANCE

This operation is a unique example that demonstrates how an EMS organization can contribute to the national effort in vaccinating at-risk populations, using its resilience and abilities to provide quality care to patients away from health care facilities. The EMS's infrastructure and logistics provide good coverage around the country, its staff is trained to execute health care procedures at varied sites, and it is flexible and easy to respond to changing requirements. All of these features make the EMS a good candidate to perform public health operations that need a fast and professional response on the national level. [AJPH](#)

ABOUT THE AUTHORS

Eli Jaffe is with Magen-David-Adom (Israel National Emergency Medical Services), Tel-Aviv, Israel. Keren Dopelt, Nadav Davidovitch, and Yuval Bitan are with the Department of Health Systems Management, Ben-Gurion University of the Negev, Be'er Sheva, Israel. Keren Dopelt is also with the Department of Public Health, Ashkelon Academic College, Ashkelon, Israel.

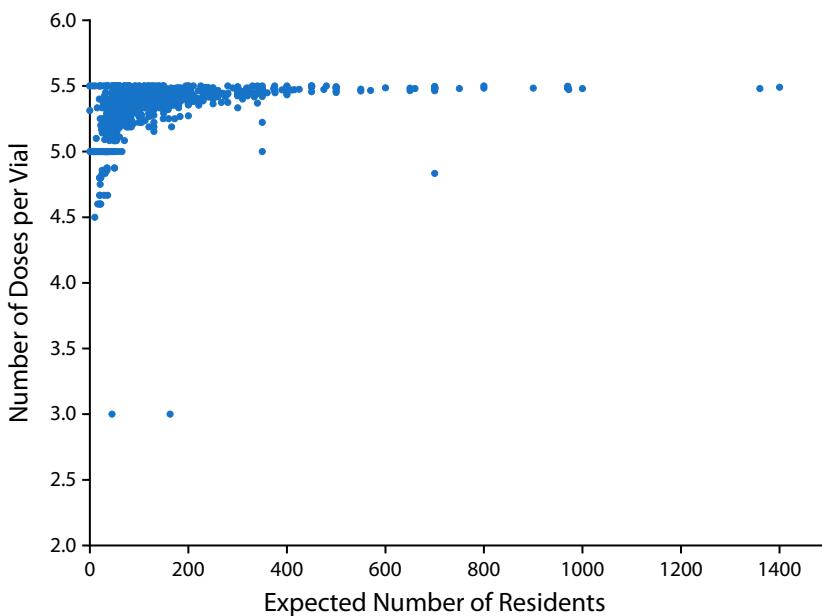


FIGURE 2— The Number of Doses Extracted From Each Vial Relative to the Number of Residents in the Facility: Israel, December 22, 2020–January 6, 2021

AJPH July 2021, Vol 111, No. 7

CORRESPONDENCE

Correspondence should be sent to Yuval Bitan, PhD, Ben-Gurion University of the Negev, 1 Ben-Gurion Blvd, Be'er Sheva 84105, Israel (e-mail: yuval@bitan.net). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Jaffe E, Dopelt K, Davidovitch N, Bitan Y. Vaccination of the elderly in assisted living by the Israeli Emergency Medical Services. *Am J Public Health*. 2021;111(7):1223–1226.

Acceptance Date: April 2, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306318>

CONTRIBUTORS

E. Jaffe conceptualized the article and collected the data. K. Dopelt assisted with the data analyses. N. Davidovitch supervised the study. Y. Bitan led the writing and completed the analyses.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to report.


HUMAN PARTICIPANT PROTECTION

The study was approved by the Magen-David-Adom research committee.

REFERENCES

- Centers for Disease Control and Prevention. Characterization of COVID-19 in assisted living facilities—39 states, October 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(46):1730–1735. <https://doi.org/10.15585/mmwr.mm6946a3>
- Centers for Disease Control and Prevention. Pfizer-BioNTech COVID-19 vaccine. January 12, 2021. Available at: <https://www.cdc.gov/vaccines/covid-19/info-by-product/pfizer/index.html>. Accessed April 27, 2021.
- Ellis DY, Sorene E. Magen David Adom—the EMS in Israel. *Resuscitation*. 2008;76(1):5–10. <https://doi.org/10.1016/j.resuscitation.2007.07.014>
- Persad G, Peek ME, Emanuel EJ. Fairly prioritizing groups for access to COVID-19 vaccines. *JAMA*. 2020;324(16):1601–1602. <https://doi.org/10.1001/jama.2020.18513> [Erratum in Addition of inadvertently omitted financial disclosures. *JAMA*. 2020; 324(15):1572. <https://doi.org/10.1001/jama.2020.20089>]
- US Food and Drug Administration. Pfizer-BioNTech COVID-19 vaccine. January 12, 2021. Available at: <https://www.fda.gov/emergency-preparedness-and-response/coronavirus-disease-2019-covid-19/pfizer-biontech-covid-19-vaccine>. Accessed April 27, 2021.
- Dagan N, Barda N, Kepten E, et al. BNT162b2 mRNA COVID-19 vaccine in a nationwide mass vaccination setting. *N Engl J Med*. 2021;384(15):1412–1423. <https://doi.org/10.1056/NEJMoa2101765>

You Can't Miss a Thing if You've Got the *AJPH* RSS Feed



To stay informed with your personalized *AJPH* content, subscribe to our RSS feed at www.ajph.org. Choose the HTML format to get the subheadings.

American Public Health Association: *AJPH*
Table of Contents for *AJPH*

Terrorism as Disease: Beware of Misleading Metaphors
February 7, 2018 at 4:14 AM

AJPH, Volume 108, Issue 3, Page 293-293, March 2018.


***AJPH* Global News**
February 7, 2018 at 4:15 AM

AJPH, Volume 108, Issue 3, Page 294-294, March 2018.

News From The Nation's Health
February 7, 2018 at 4:14 AM

AJPH, Volume 108, Issue 3, Page 295-295, March 2018.

The Key Role of Work in Population Health Inequities
February 7, 2018 at 4:14 AM



Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Rapid Creation of a Multiagency Alternate Care Site for COVID-19–Positive Individuals Experiencing Homelessness

Chen Y. Wang, MD, Melissa L. Palma, MD, MPH, Christine Haley, MSSA, Jeff Watts, MD, and Keiki Hinami, MD, MS

Cook County Health partnered with the Chicago Departments of Public Health and Family & Support Services and several dozen community-based organizations to rapidly establish a temporary medical respite shelter during the spring 2020 COVID-19 peak for individuals experiencing homelessness in Chicago and Cook County, Illinois. This program provided low-barrier isolation housing to medically complex adults until their safe return to congregate settings. We describe strategies used by the health care agency, which is not a Health Resource and Services Administration Health Care for the Homeless grantee, to provide medical services and care coordination. (*Am J Public Health*. 2021; 111(7):1227–1230. doi: <https://doi.org/10.2105/AJPH.2021.306286>)

Coronavirus disease 2019 (COVID-19) poses unique risks to individuals experiencing homelessness. Through collaboration among city, health care, and community partners, the Temporary Medical Respite Shelter provided a medically monitored isolation setting for people experiencing homelessness to complete COVID-19 isolation in May 2020.

INTERVENTION

The Temporary Medical Respite Shelter (“the program”) was part of a citywide, multiagency public health response to the convergence of two crises: homelessness and COVID-19.¹ Partly because of COVID-19 and its aftermath, the total homeless population of Chicago, Illinois increased in 2020, including the number of homeless individuals with physical disabilities and substance use, while

racial disparities persisted.² Through a rapidly created responsibility-sharing framework, city agencies and Cook County Health, the framework’s lead health care organization, worked with a consortium of community organizations to establish a medically supported alternate care site for COVID-19–confirmed homeless individuals. The program provided isolation housing for homeless clients from shelters and congregate settings that were unable to provide in-house isolation. Program clients received care coordination services, primary care, behavioral health, and addiction medicine services in addition to COVID-19 isolation.

PLACE AND TIME

The program operated out of a community fitness center in a geographically underserved area of Chicago from May

1–30, 2020, during the first local peak of the pandemic.³

PERSON

The clients were homeless adults with confirmed COVID-19. They were referred from emergency shelters undergoing facility-wide screening or from hospitals conducting testing in emergency departments or inpatient settings. Clients with substance use disorder, stable mental health disorder appropriate for outpatient treatment, history of criminal justice involvement, or requiring chronic hemodialysis were not restricted from the program. Our goal was to lower entry barriers into our program relative to existing COVID-19 isolation programs. The exclusion criteria pertaining to medically unstable conditions and mental health crises served to encourage conversation about appropriate levels of care and to prevent premature hospital discharges.

BOX 1— Client Exclusion Criteria of the Temporary Medical Respite Shelter, Chicago, IL, May 2020

1. Younger than 18 years
2. No laboratory-confirmed COVID-19
3. Unable to perform activities of daily living
4. Temperature > 103 degrees Fahrenheit, oxygen saturation < 92% on room air, respiratory rate > 30 breaths per minute, or increased work of breathing
5. Glucose readings > 300 mg/dL
6. Uncontrolled or symptomatic hypertension
7. Disorientation
8. Severe uncontrolled psychosis
 - Clients currently taking antipsychotic medications and clinically stable are not excluded
9. Current suicidal or homicidal ideation
10. Contact precautions for acute diarrheal illness, active extensively drug resistant organism infection, *Candida auris* colonization, or infection
11. Current diagnosis of acute tuberculosis
12. Lack of dialysis facility or routine transportation established for hemodialysis
13. Pregnant beyond 20 weeks gestational age
14. Current scabies or bedbug infestation
 - Clients who completed treatment are not excluded
15. Personality disorders that challenge the person's ability to abide by the rules of the shelter
16. Unwilling or unable to stay at the isolation facility through completion of the isolation period

PURPOSE

Widespread testing of congregate settings was a part of the city's COVID-19 mitigation strategy.³ This program provided medically monitored COVID-19 isolation to reduce transmission in congregate settings such as shelters and encampments. It also served as a discharge destination for hospitals to facilitate patient flow.

IMPLEMENTATION

The program was operated jointly by Cook County Health, a large public safety-net health care organization; departments of the City of Chicago, including Family and Support Services, Public Health, and Emergency Management; and several dozen community-based organizations, including those providing shelters, behavioral health services, and other social services. Within the span of a few weeks in April 2020, partner agencies established an arrangement wherein the city provided the facility, shelter staff, and laundry and

food services. The health care agency provided medical staff, coordinated medical services across organizations, and managed the day-to-day operations. A multiagency staff from health care, shelter service, security, and environmental service were trained in infection control, harm reduction, and trauma-informed care approaches.

Potential clients were referred either by the city's centralized intake, which triaged homeless individuals with COVID-19 based on medical complexity to isolation facilities in the city, or by local hospitals treating COVID-19 patients. The program medical director confirmed eligibility prior to accepting clients (Box 1).

Physicians and nurses, who were employees of the lead health care organization, volunteered to staff the site 24 hours a day, and they assessed clients daily by vital monitoring and physical exams. Clients who became clinically unstable were transferred to local emergency departments by ambulance. Real-time communication with hospitals facilitated transfers of patients back to the program upon discharge.

Telehealth visits were used for primary care, behavioral health, and substance use disorder. These visits also provided a technology-based solution to register patients in the health care organization. This qualified them for the Health Resources and Services Administration (HRSA) 340B Drug Pricing Program for no-cost prescription medications. Because the health care agency is not an HRSA-recognized provider of health care for the homeless, on-site physician services were located outside the usual place of care and so were not billable. However, on-site clinicians served an important role in building therapeutic trust to enable telehealth encounters, a format novel to most clients and providers.

Most clients (45 of 51) were able to establish relationships with care coordinators, who were able to assist with Medicaid application, stable housing applications, or identification of a primary care provider.

EVALUATION

The program received 69 client referrals, about half from hospitals and half from shelters, and 51 clients arrived at the program. In most cases, accepted clients who did not arrive found alternate housing themselves. Most accepted clients were male (82%) and Black (69%), reflecting the demographics of Chicago's homeless population. Median length of stay was seven days (Table 1). Most clients had mental illness (88%), similar to the broader population of homeless patients served by the health care system. All clients completed the full isolation period recommended by the Centers for Disease Control and Prevention.

Telehealth encounters (n = 75) consisted of 36 visits for primary care, 27 for substance use disorder, and 12 for

mental health care. Prescribed medications were delivered for 23 clients. Successes in substance use treatment services included on-site recovery support, initiation of buprenorphine therapy via telehealth, methadone delivery from a community treatment provider, naloxone training, and assistance with entering residential drug treatment. Accomplishments in care coordination included facilitating transportation of clients to and from outpatient hemodialysis.

Client satisfaction was high, with most clients rating their stay as “excellent” (74%); some clients were reluctant to leave the program. Most clients returned to the same congregate settings from which they were referred. A minority went to stay temporarily with friends or family or in a street encampment. On the basis of formal and informal feedback involving a satisfaction questionnaire or interview, our service-orientation and trauma-informed care approach fostered a program that clients and shelter staff reported as unique among shelters in the city.

ADVERSE EFFECTS

To help manage stress levels among clients and staff, we deliberately discouraged characterizing our work as heroic. Instead, we were guided by kindness as the organizing principle and a trauma-informed approach to addressing conflicts. However, several incidents illustrated how on-site security's disciplinary approach to behavioral health contrasted with health care staffs' de-escalation approach. The need to negotiate these differences in organizational culture among participating

TABLE 1— Characteristics of Clients Accepted at the Temporary Medical Respite Shelter: Chicago, IL, May 2020

	No. (%) or Median (IQR)
Total sample	51
Gender	
Male	42 (82.4)
Female	8 (17.6)
Other	1 (2.0)
Age, y	
18–24	2 (3.9)
25–34	3 (5.8)
35–44	11 (21.6)
45–54	10 (19.6)
55–64	22 (43.1)
≥ 65	3 (5.8)
Race	
White	5 (9.8)
Black	35 (68.6)
Latino	11 (21.6)
Other/unknown	0 (0.0)
Insurance status	
Insured	37 (72.5)
Uninsured	12 (23.5)
Unknown	2 (3.9)
Clinical characteristics	
Diabetes	6 (11.7)
Heart condition ^a	6 (11.7)
HIV/AIDS	4 (7.8)
Other immunosuppressing condition	2 (3.9)
Mental illness ^b	45 (88.2)
Duration of homelessness, months	12 (8–33)
Length of stay, days	7 (6–10)
Disposition following isolation at TMRS	
Shelter	31
With friends or family	5
Substance use disorder treatment program	1
Street encampment	1
Hospitalized	1
Transferred to other isolation facility	1
Missing/unknown	7

Note. IQR = interquartile range; TMRS = Temporary Medical Respite Shelter.

^aHeart condition includes heart failure, arrhythmia, and coronary artery disease.

^bMental illness detected by self-reported diagnosis, pharmacologic treatment history, psychiatric hospitalizations, illicit drug use, substance use or behavioral health visit onsite or telehealth, or observed behavioral dysregulation.

agencies posed a challenge to the program's multiagency leadership.

SUSTAINABILITY

The program was supported financially by medical billing, grant support from charitable organizations, and public emergency funds. By the end of May, demand for isolation beds decreased as COVID-19 cases temporarily declined and the program closed after one month. Thereafter, the program served as a template for the health care agency to establish a separate medical respite program that met isolation needs during the winter peak of COVID-19 and various post-acute care needs of a medically complex homeless population. Our adaptive approach to the provision of medical respite care has attracted ongoing funding from county government, Medicaid managed care, and charitable foundations.

PUBLIC HEALTH SIGNIFICANCE

As an example of a collaboration by city government, community organizations, and safety net health care system to serve a high-risk homeless population, this program adds to existing models of alternate care sites.⁴⁻⁶ It was a collaborative, low-barrier public health intervention in which homeless individuals with medical and behavioral health comorbidities completed COVID-19 isolation. Our ability to care for complex clients was possible because of innovative aspects of the program, including our hybrid model of on-site health care and telehealth that allowed uptake of telehealth for primary and specialty care without compromising quality of care, qualification of patients for 340B Drug Pricing for discounted medications, and

care coordination to facilitate housing after respite care. The rapid and successful implementation of this project by a health care agency operating outside of its usual care settings may encourage other health care providers to participate in health care for the homeless. *AJPH*

ABOUT THE AUTHORS

Chen Y. Wang is with Cook County Health and the Northwestern University Feinberg School of Medicine Program in Public Health, Chicago, IL. Melissa L. Palma, Christine Haley, Jeff Watts, and Keiki Hinami are with Cook County Health, Chicago, IL.

CORRESPONDENCE

Correspondence should be sent to Chen Y. Wang, MD, 1950 W Polk St, 6th Floor, Chicago, IL 60612 (e-mail: chenwang@gmail.com). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Wang CY, Palma ML, Haley C, Watts J, Hinami K. Rapid creation of a multiagency alternate care site for COVID-19-positive individuals experiencing homelessness. *Am J Public Health*. 2021;111(7):1227-1230.

Acceptance Date: March 15, 2021

DOI: <https://doi.org/10.2105/AJPH.2021.306286>

CONTRIBUTORS

C. Y. Wang wrote the initial draft of the article. K. Hinami, M. L. Palma, and C. Y. Wang collected and analyzed the data. All authors contributed to the study conceptualization, revised drafts, and approved the final version.

CONFLICTS OF INTEREST

M. L. Palma's spouse is a cofounder of and holds equity in Satellite Biosciences Inc, which is an early-stage life sciences company focused on liver disease. The remaining authors have no conflicts of interest to disclose.

HUMAN PARTICIPANT PROTECTION

This project was approved by the Cook County Health institutional review board.

REFERENCES

1. Cumming C, Wood L, Davies A. People experiencing homelessness urgently need to be recognised as a high risk group for COVID-19. *Health Promot J Austr*. 2021;32(2):359-360. <https://doi.org/10.1002/hpja.355>
2. City of Chicago Department of Family and Support Services. City of Chicago 2020 homeless Point-in-Time count and survey report. 2020. Available at: <https://www.chicago.gov/content/dam/city/depts/>

fss/supp_info/Homeless/2020/2020%20PIT%20Report_vFinal.pdf. Accessed September 29, 2020.

3. Chicago Department of Public Health. Preventing COVID-19 in Chicago's sheltered homeless population. June 16, 2020. Available at: https://www.chicago.gov/content/dam/city/depts/cdph/statistics_and_reports/COVID-19%20Homeless%20Data%20Brief_June_IG_final.pdf. Accessed September 29, 2020.
4. Kaysin A, Carvajal DN, Callahan CW. The role of alternate care sites in health system responsiveness to COVID-19. *Am J Public Health*. 2020;110(9):1362-1364. <https://doi.org/10.2105/AJPH.2020.305838>
5. Baggett TP, Racine MW, Lewis E, et al. Addressing COVID-19 among people experiencing homelessness: description, adaptation, and early findings of a multiagency response in Boston. *Public Health Rep*. 2020;135(4):435-441. <https://doi.org/10.1177/0033354920936227>
6. Alarcón J, Khan TV. Adapting backpack medicine in COVID-19 response for people experiencing homelessness in southern California. *Am J Public Health*. 2021;111(1):58-61. <https://doi.org/10.2105/AJPH.2020.305956>

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Forty Years of HIV: The Intersection of Laws, Stigma, and Sexual Behavior and Identity

David W. Purcell, JD, PhD

ABOUT THE AUTHOR

David W. Purcell is retired from the Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, Atlanta, GA.

🔗 See also Morabia, p. 1175, Landers et al., p. 1180, and the HIV/AIDS and Our World: 1981–2021 section, pp. 1231–1266.

Forty years after the Centers for Disease Control and Prevention's (CDC's) June 1981 *Morbidity and Mortality Weekly Report* about five gay men with a syndrome that came to be called AIDS, both the impact of HIV and the legal landscape in the United States for the most affected population have changed dramatically. Laws, policies, and how they are enforced reflect the values and prejudices of society, and laws can help or hinder public health efforts, regardless of intent. From the outset, HIV aroused widespread fear and new stigmatizing laws and policies, and the crisis revealed injustices in existing laws that compounded stigma and health disparities among the most affected groups. In the 1980s, HIV engulfed already stigmatized communities of gay and bisexual men and other men who have sex with men (MSM) and people who inject drugs. The CDC's HIV surveillance reports show that, throughout the epidemic, MSM have constituted the majority of annual and prevalent cases, and the burden on racial or ethnic minority MSM has increased disproportionately since the

early 1990s.¹ It is timely to reflect on the intertwining of HIV, laws, stigma, and inequity in the United States and their intersection with the lives of gay and bisexual men (both cisgender and transgender).

Since its beginnings, the US legal framework defined homosexual sex or relationships as criminal, inferior, aberrant, and worthy of discrimination.² Throughout most of the 20th century, sexual stigma kept homosexual and bisexual persons hidden and legitimized their abuse, but this stigma began to be challenged in the 1970s, after the Stonewall riots and the removal of homosexuality from the psychiatric manual of mental disorders.^{2,3} When the AIDS crisis rapidly emerged, government action was slow and muted partly because of broad stigma against who was most affected.⁴ Despite growing resistance to and activism against society's stigmatization of sexual minorities, HIV emerged in a bleak legal environment of widespread prejudice and discrimination reflected by individuals and most of society's institutions.^{2,5} In the

1980s, almost 20 states, many in the South, still had sodomy laws on the books that criminalized sex between members of the same sex or all non-procreative sex.⁵ In 1986, in *Bowers v. Hardwick* (478 US 186), the Supreme Court reinforced stigma when it narrowly upheld the right of Georgia to enforce a sodomy law that prohibited homosexual conduct, even when it occurred in a private home.⁵ Although seldom enforced, sodomy laws often were used to justify discrimination in other laws and institutions.⁵ Thus, as HIV took hold in the United States, same-sex behaviors and relationships had no legal protections, gay parents often lost their parental rights during divorce, violence and victimization was too common, and, in almost all circumstances, discrimination was legal in employment (including the military), housing, and social services.^{2,5}

In addition, during HIV's first decade, intense fear and stigma led to new HIV-specific criminal laws. In the name of public health, criminal laws were passed in more than 35 states that punished behaviors that might transmit HIV; states without HIV-specific laws used general criminal laws to accomplish the same end.⁶ These laws were considered unjust because of their harsh penalties (felony), often for acts unlikely to transmit HIV; punishment regardless of intent or actual transmission; and lack of evidence that such laws reduced HIV transmission and might even unintentionally promote less disclosure of HIV status and resistance to HIV testing.⁶

Stigma also was channeled into overt discrimination toward gay and bisexual men and people with HIV, leading to gross injustices by family members, friends, and institutions. People with AIDS were kicked out of homes by family members and landlords, not touched or

avoided by medical professionals, and lost their jobs. Obituaries often excluded AIDS as the cause of death, and surviving partners were often not named as bereaved survivors or able to obtain survivors benefits. Partnered gay men were considered legal strangers in the absence of a legally executed will, with the families of deceased men refusing to acknowledge partners and taking personal effects and property. Partners also were routinely excluded from hospitals, funerals, and their own homes and perceived to be part of a “lifestyle” that everyone from medical professionals to blood relatives did not accept.⁴

From this dark period came activism and increased visibility of gay and bisexual men and people with HIV that moved social attitudes. The rapidly increasing impact of HIV gave rise to community-based organizations to serve and fight for the rights and HIV treatments that were sorely lacking, and these agencies continue to provide crucial advocacy for key populations. Activists pushed for faster Food and Drug Administration approval of HIV treatments,⁴ and scientists developed increasingly better treatments, culminating in the introduction of highly active antiretroviral therapy and antiretroviral therapy in the mid-1990s. Among society at large, almost every survey finds dramatic changes in attitudes toward sexual minorities since the early 1990s, although some groups, such as evangelicals and African Americans, showed less change. For example, the proportion of Americans who said same-sex sexual activity was “not wrong at all” was only 11% in 1970 and 13% in 1990 but had increased to 49% by 2014,⁷ and support for gay marriage completely reversed from 2004 to 2019, from 31% for and 61% against to 61% for and 31% against.⁸

Although progress was uneven, and attitudes were not universally supportive, HIV sparked activism for fairness and against stigma, which contributed to two landmark bills in 1990: the Ryan White Comprehensive AIDS Resources Emergency Act (Pub L No. 101–381, 104 Stat. 576) provides medical care for people with HIV without other options,⁹ and the Americans with Disabilities Act prohibits most HIV-related discrimination. In 1996, the federal Defense of Marriage Act denied benefits to same-sex couples and allowed states to ignore same-sex marriages from other states.^{2,10} Many states quickly passed laws or constitutional amendments to define marriage as between a man and a woman, and some to also ban civil unions and domestic partnerships. In response, a patchwork of laws and regulations was passed by cities, states, corporations, or professional organizations to provide limited protections for same-sex relationships and against discrimination.² The Supreme Court finally provided protection for same-sex sexual behavior in 2003, declaring sodomy laws unconstitutional in *Lawrence v. Texas* (539 US 558) and relationships in 2015 upholding the right for same-sex persons to marry in *Obergefell v. Hodges* (576 US 644).

The landmark 2010 Affordable Care Act and 2014 Medicaid expansion show that health legislation can help HIV prevention and care and thereby support gay and bisexual men. States with Medicaid expansion (approximately 38 in 2019) show large increases in insurance coverage, diagnoses and ongoing treatment of chronic conditions, and HIV testing.¹¹ Similarly, a recent study found that MSM in expansion states were more likely to have insurance (87.9% vs 71.6%), have Medicaid (21.3% vs 3.8%), discuss preexposure prophylaxis with a provider

(58.8% vs 44.3%), and use preexposure prophylaxis (31.1% vs 17.5%).¹²

Over the past decade, public health has increased its focus on addressing stigma and the social determinants of health to improve disparities in HIV care and prevention and among gay and bisexual men. The benefits of passing supportive laws was shown in a study that linked state-level laws and policies that were more favorable to sexual minorities to better HIV outcomes among MSM.¹³ But the increase in favorable laws and policies over time has not stopped the increasing disproportionate impact of HIV among racial and ethnic minority gay and bisexual men. Persistent stigmas related to HIV, sexual orientation, race, and other domains also continue to be expressed in laws, policies, and attitudes of individuals and social institutions. For example, HIV criminalization laws have remained stubbornly resistant to change despite their obvious flaws, although in the past decade a handful of states have updated their laws to be more consistent with the science.⁶ Unfortunately, these laws have been applied disproportionately to African American MSM,^{6,14} highlighting that changing laws is just part of the challenge when addressing stigmas and reducing health inequities.

The past 40 years has seen remarkable progress in HIV prevention and care as well as undeniable legal and policy progress as stigmatized communities fought for basic rights and dignity related to behaviors, identities, and HIV. But this progress has occurred in conjunction with growing HIV disparities for racial and ethnic minority gay and bisexual men.¹ Although potential reasons for these persistent disparities are multifaceted and complex, some of the factors likely to play a role in HIV

disparities among African American and Latino MSM include the following:

- 1 a deeply entrenched and widely unacknowledged caste system that devalues non-White identities¹⁵;
- 2 the disparate application of laws and policies that disadvantage racial and ethnic minorities, including HIV criminalization laws¹⁵;
- 3 the increased medicalization of HIV prevention and care in conjunction with medical systems that are difficult to access and not culturally competent or trusted by key populations;
- 4 the concentration of minority populations in Southern states that have a long history of stigmatizing African American and gay people and rejecting public health policy solutions; and
- 5 challenges in managing intersectional stigma (e.g., racism and homophobia).

Tackling a range of disparities is the cutting edge of where public health and legal and policy work need to unite to increase justice for all gay and bisexual men and end HIV during the coming fifth decade. *AJPH*

CORRESPONDENCE

Correspondence should be sent to David W. Purcell, Centers for Disease Control and Prevention, 1600 Clifton Rd, MS D-21, Atlanta, GA 30333 (e-mail: dwpurcell61@gmail.com). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Purcell DW. Forty years of HIV: the intersection of laws, stigma, and sexual behavior and identity. *Am J Public Health*. 2021;111(7):1231–1233.

Acceptance Date: April 12, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306335>

ACKNOWLEDGMENTS

I would like to express deep gratitude to Robert P. Cabaj, MD, a mentor and friend who we lost unexpectedly in 2020 and who encouraged my interest in the intersection of law and sexuality

back in the 1990s. I would also like to thank Yuko Mizuno, PhD, and Cynthia Lyles, PhD, for their input on this editorial.

Note. The findings and conclusions of this editorial are those of the author and do not necessarily represent the views of the Centers for Disease Control and Prevention.

CONFLICTS OF INTEREST

The author has no conflicts of interest to declare.

REFERENCES

1. Centers for Disease Control and Prevention. HIV surveillance reports. Available at: <https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Accessed February 9, 2021.
2. Herek GM, Chopp R, Strohl D. Sexual stigma: putting sexual minority health issues in context. In: Meyer IH, Northridge ME, eds. *The Health of Sexual Minorities: Public Health Perspectives on Lesbian, Gay, Bisexual and Transgender Populations*. New York, NY: Springer; 2007:171–208. https://doi.org/10.1007/978-0-387-31334-4_8
3. Silverstein C. History of treatment. In: Cabaj RP, Stein TS, eds. *Textbook of Homosexuality and Mental Health*. Washington, DC: American Psychiatric Press; 1996:3–16.
4. Shilts R. *And the Band Played On*. New York, NY: St. Martin's Press; 1987.
5. Purcell DW, Hick DW. Institutional discrimination against lesbians, gay men, and bisexuals: the courts, legislature, and the military. In: Cabaj RP, Stein TS, eds. *Textbook of Homosexuality and Mental Health*. Washington, DC: American Psychiatric Press; 1996:763–782.
6. Mermin J, Valentine SS, McCray E. HIV criminalisation laws and ending the US HIV epidemic. *Lancet HIV*. 2021;8(1):e4–e6. [https://doi.org/10.1016/S2352-3018\(20\)30333-7](https://doi.org/10.1016/S2352-3018(20)30333-7)
7. Twenge JM, Sherman RA, Wells BE. Changes in American adults' reported same-sex sexual experiences and attitudes, 1973–2014. *Arch Sex Behav*. 2016;45(7):1713–1730. <https://doi.org/10.1007/s10508-016-0769-4>
8. Masci D, Brown A, Kiley J. 5 facts about same-sex marriage. June 24, 2019. Available at: <https://www.pewresearch.org/fact-tank/2019/06/24/same-sex-marriage>. Accessed February 9, 2021.
9. Parham D, Conviser R. A brief history of the Ryan White CARE Act in the USA and its implications for other countries. *AIDS Care*. 2002;14(suppl 1):S3–S6. <https://doi.org/10.1080/09540120220149920>
10. Cabaj RP, Purcell DW, eds. *On the Road to Same Sex Marriage: A Supportive Guide to Psychological, Political, and Legal Issues*. San Francisco, CA: Jossey-Bass; 1998.
11. Menon A, Patel PK, Karmakar M, Tipirneni R. The impact of the Affordable Care Act Medicaid expansion on racial/ethnic and sex disparities in HIV testing: national findings from the Behavioral Risk Factor Surveillance System. *J Gen Intern Med*. 2021; Epub ahead of print. <https://doi.org/10.1007/s11606-021-06590-2>
12. Baugher AR, Finlayson T, Lewis R, et al. Health care coverage and preexposure prophylaxis (PrEP) use among men who have sex with men living in 22 US cities with Medicaid expansion, 2017. *Am J Public Health*. 2021;111(4):743–751. <https://doi.org/10.2105/AJPH.2020.306035>

13. Hatzenbuehler ML, Mcketta S, Goldberg N, et al. Trends in state policy support for sexual minorities and HIV-related outcomes among men who have sex with men in the United States, 2008–2014. *J Acquir Immune Defic Syndr*. 2020;85(1):39–45. <https://doi.org/10.1097/QAI.0000000000002395>
14. Cann D, Harrison SE, Qiao S. Historical and current trends in HIV criminalization in South Carolina: implications for the Southern HIV epidemic. *AIDS Behav*. 2019;23(suppl 3):233–241. <https://doi.org/10.1007/s10461-019-02599-1>
15. Wilkerson I. *Caste: The Origins of Our Discontents*. New York, NY: Random House; 2020.

A New Approach to Understanding the U.S. Health Care System

APHA PRESS
A DIVISION OF AMERICAN PUBLIC HEALTH ASSOCIATION

A New Text Designed for Those Pursuing Careers as Community Health Workers or Health Navigators.

Instructor exam copies available at go.jblearning.com/NilesN

JONES & BARTLETT LEARNING
— An Ascend Learning Company

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Beyond the Magic Bullet: What Will It Take to End the AIDS Epidemic?

Wafaa M. El-Sadr, MD, MPH, MPA

ABOUT THE AUTHOR

Wafaa M. El-Sadr is Global Director of ICAP at Columbia University, Mailman School of Public Health, Columbia University, New York, NY.

🔗 See also Morabia, p. 1175, Landers et al., p. 1180, and the HIV/AIDS and Our World: 1981–2021 section, pp. 1231–1266.

I vividly recall that spring day four decades ago when I came upon the June 5, 1981, *Morbidity and Mortality Reports (MMWR)* issue that reported on the first five *Pneumocystis carinii* pneumonia cases, a signature condition for AIDS, among young gay men in Los Angeles, California. I was sitting at my workstation in the laboratory in Cleveland, Ohio, when my mentor walked in and put that *MMWR* issue on my desk. Knowing that I would be returning to New York City soon thereafter to pursue a career in clinical infectious diseases and public health, he said, “You might want to take a look at this.” Little did I realize then how this report would be the harbinger of a global epidemic and a catalyst that would transform my career and my life.

Since then, 32.7 million children and adults have died from HIV/AIDS, and currently more than 38 million persons are living with HIV globally.¹ At the same time, major advances have been achieved in confronting the HIV epidemic. HIV testing is highly accurate and offers rapid results in minutes, and the scale-up of effective and well-tolerated treatment to millions has been a remarkable achievement. Extensive social and

behavioral research has shed light on factors that influence the risk of HIV. HIV prevention, however, has lagged. In 2019, more than 1.7 million new HIV infections were reported, far higher than the target of less than 500 000 annual cases.¹ This shortfall raises several questions. Where and among whom are new infections occurring? Why have we lagged in preventing HIV infections? And, most importantly, what can be done to stem the spread of this virus?

In the early years of the HIV epidemic, HIV prevention was focused on influencing sexual and injecting behaviors and promoting the avoidance of higher-risk behaviors, such as multiple sex partners, unprotected sex, and sharing needles and syringes.² In 1992, a decade after those first five cases were reported, HIV prevention was furthered by the recognition that zidovudine, the first antiretroviral agent, could prevent mother-to-child transmission of HIV.³ This motivated researchers to determine whether antiretroviral drugs could also prevent the sexual transmission of HIV. Two decades later, the landmark HIV Prevention Trials Network (HPTN) 052 study clearly demonstrated that antiretroviral treatment

prevented the sexual transmission of HIV among heterosexual serodiscordant couples. Evidence soon followed of similar efficacy among gay men in serodiscordant partnerships.⁴ The recognition that treatment not only provides individual benefit but also prevents transmission to others further energized efforts to expand global access to antiretroviral therapy.^{1,5}

Prevention research then turned to the next big question, whether antiretroviral drugs would also work for primary prevention (i.e., to prevent HIV acquisition by HIV-negative persons). A pivotal study, the IPrEX study, conducted among men and transgender women who have sex with men, first proved that preexposure prophylaxis was a successful strategy for HIV prevention.⁶ However, efforts to replicate these findings among heterosexual women and in demonstration projects led to inconclusive findings, largely because of limited adherence with daily oral preexposure prophylaxis.⁷

The challenges of uptake, adherence, and persistence inspired efforts to identify long-acting antiretroviral drugs for preexposure prophylaxis. Two studies, HPTN 083 and HPTN 084—of injectable long-acting cabotegravir given every two months to men and transgender persons who have sex with men and to heterosexual women in sub-Saharan Africa—recently demonstrated the superiority of this approach when compared with daily oral preexposure prophylaxis. Another long-acting antiretroviral provided via a monthly vaginal dapivirine ring also offered encouraging findings.⁸ Further innovations continue with exciting efforts in pursuit of long-acting antiretroviral pills, implants, and patches, all in an effort to overcome the challenge of adherence.⁹



FIGURE 1— Integrated Strategies for HIV Prevention

Despite these advances, the successful prevention of HIV transmission requires a fundamental reconceptualization of the overall approach, recognizing that the HIV epidemic is not a monolith but consists of diverse epidemics. The unique characteristics and life experiences of populations at risk need to drive our efforts to protect them from HIV. In the United States, for example, men who have sex with men are disproportionately more severely affected than are other groups, with Black and Latinx men accounting for 25% and 20% of new infections, respectively.¹⁰ Transgender persons around the world have a 13-fold higher risk of HIV, and female sex workers are 30 times more likely to acquire HIV than are people in the general population.¹ Persons who inject drugs have also borne the brunt of HIV and are at additional high risk for other infectious diseases such as hepatitis and tuberculosis.¹¹ All these groups face profound barriers, particularly stigma and discrimination, two issues that drive them to avoid HIV services (e.g., testing, treatment, prevention).¹²

At the same time, for young women in sub-Saharan Africa, who continue to account for 59% of new HIV infections

in this region, misperceptions regarding personal risk, competing life priorities, and difficulties in negotiating safer sex continue to put them in harm's way. This, combined with structural impediments (e.g., economic vulnerabilities, lack of supportive services at health facilities and in the community, and the fact that their male partners are often unaware of their HIV-positive status and consequently have an unsuppressed viral load), results in increasing the women's risk of HIV acquisition.^{2,13} In addition, although the efficacy of antiretroviral drugs for prevention of mother-to-child transmission of HIV first sparked the truly transformative, game-changing research on the use of antiretroviral drugs for primary and secondary prevention, elimination of mother-to-child transmission remains beyond our reach.¹⁴ Tragically, an estimated 150 000 new infections among children were reported in 2019, because of stigma faced by HIV-positive pregnant and breastfeeding women and difficulties in accessing antenatal and HIV services.²

What will it take to get us to the end of the HIV epidemic? Clearly, it will take more than the pursuit of biomedical "magic bullets." We must celebrate and

acknowledge progress in identifying new tools, and we need to harness similar vigor to identify how best to use these tools to maximize their benefits for people at risk. Developing a vibrant, integrated strategy research agenda is critical. This involves combining behavioral and structural interventions with biomedical tools in ways that meet the needs of each population (Figure 1).¹⁵ For young women in sub-Saharan Africa, for example, we must seek effective interventions that enhance their accurate perception of risk, empower their agency in negotiating safer sex, and address their economic vulnerabilities. For disenfranchised groups, we need to study ways to change or mitigate the effects of punitive laws and overcome stigmatization by the health system.

Forty years on in an epidemic that has changed the lives of millions around the world and the face of global health, we have come to a broader understanding of the factors that must be examined and addressed if we are to successfully realize a world without AIDS. Although biomedical solutions are a critical linchpin, we must also learn how to address wider behavioral and systemic obstacles to adoption and persistence with biomedical prevention methods. However, unfortunately, research into integrated strategies for HIV prevention often does not receive the same priority as research with a purely biomedical focus, perhaps because it is not perceived to be as "scientific" or it is thought that incorporating behavioral or structural interventions is not likely to be of added value. These perceptions must change. Ultimately, to achieve the goal of ending the AIDS epidemic, we must learn how to address the realities and the contexts of the people at its heart. **AJPH**

CORRESPONDENCE

Correspondence should be sent to Wafaa El-Sadr, MD, MPH, MPA, ICAP at Columbia University, Mailman School of Public Health, 722 West 168th St, Room 1312, New York, NY 10032 (e-mail: wme1@columbia.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

PUBLICATION INFORMATION

Full Citation: El-Sadr WM. Beyond the magic bullet: what will it take to end the AIDS epidemic? *Am J Public Health*. 2021;111(7):1234–1236.

Acceptance Date: March 14, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306290>

ACKNOWLEDGMENTS

Partial funding for this work was provided by the HIV Prevention Trials Network, National Institutes of Health (grant UM1AI154468).

Inputs from Jessica Justman, Hugh Siegel, Melissa Reyes, and Joseph Stegemerten are deeply appreciated.

CONFLICTS OF INTEREST

The author has no conflicts of interest from funding or affiliation-related activities to declare.

REFERENCES

1. Joint United Nations Programme on HIV/AIDS. Global HIV & AIDS statistics—2020 fact sheet. Available at: <https://www.unaids.org/en/resources/fact-sheet>. Accessed March 1, 2021.
2. CDC AIDS Community Demonstration Projects Research Group. Community-level HIV intervention in 5 cities: final outcome data from the CDC AIDS Community Demonstration Projects. *Am J Public Health*. 1999;89(3):336–345. <https://doi.org/10.2105/AJPH.89.3.336>
3. ACTG 076 and reduction of perinatal transmission. *Update Natl Minor AIDS Councl*. 1997;4–7:9.
4. Rodger AJ, Cambiano V; PARTNER Study Group, et al. Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV-positive partner taking suppressive antiretroviral therapy (PARTNER): final results of a multi-centre, prospective, observational study. *Lancet*. 2019;393(10189):2428–2438. [https://doi.org/10.1016/S0140-6736\(19\)30418-0](https://doi.org/10.1016/S0140-6736(19)30418-0)
5. El-Sadr WM, Holmes CB, Mugenyi P, et al. Scale-up of HIV treatment through PEPFAR: a historic public health achievement. *J Acquir Immune Defic Syndr*. 2012;60(suppl 3):S96–104. <https://doi.org/10.1097/QAI.0b013e31825eb27b>
6. Grant RM, Lama JR; iPrEx Study Team, et al. Pre-exposure chemoprophylaxis for HIV prevention in men who have sex with men. *N Engl J Med*. 2010;363(27):2587–2599. <https://doi.org/10.1056/NEJMoa1011205>
7. National Institute of Allergy and Infectious Diseases. Pre-exposure prophylaxis (PrEP) to reduce HIV risk. Available at: <https://www.niaid.nih.gov/diseases-conditions/pre-exposure-prophylaxis-prep>. Accessed March 1, 2021.
8. Baeten JM, Palanee-Phillips T; HOPE Study Team, et al. Safety, uptake, and use of a dapivirine vaginal ring for HIV-1 prevention in African women (HOPE): an open-label, extension study. *Lancet HIV*. 2021;8(2):e87–e95. [https://doi.org/10.1016/S2352-3018\(20\)30304-0](https://doi.org/10.1016/S2352-3018(20)30304-0)
9. Flexner C, Owen A, Siccardi M, Swindells S. Long-acting drugs and formulations for the treatment and prevention of HIV infection. *Int J Antimicrob Agents*. 2021;57(1):106220. <https://doi.org/10.1016/j.ijantimicag.2020.106220>
10. HIV.gov. U.S. statistics. Available at: <https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics>. Accessed March 1, 2021.
11. Degenhardt L, Peacock A, Colledge S, et al. Global prevalence of injecting drug use and sociodemographic characteristics and prevalence of HIV, HBV, and HCV in people who inject drugs: a multistage systematic review. *Lancet Glob Health*. 2017;5(12):e1192–e1207. [https://doi.org/10.1016/S2214-109X\(17\)30375-3](https://doi.org/10.1016/S2214-109X(17)30375-3)
12. Wouters E, Sommerland N, Masquillier C, et al. Unpacking the dynamics of double stigma: how the HIV-TB co-epidemic alters TB stigma and its management among healthcare workers. *BMC Infect Dis*. 2020;20(1):106. <https://doi.org/10.1186/s12879-020-4816-3>
13. Camlin CS, Ssemmondo E; SEARCH Collaboration, et al. Men “missing” from population-based HIV testing: insights from qualitative research. *AIDS Care*. 2016;28(suppl 3):67–73. <https://doi.org/10.1080/09540121.2016.1164806>
14. Hamilton E, Bossiky B, Ditekemena J, et al. Using the PMTCT cascade to accelerate achievement of the global plan goals. *J Acquir Immune Defic Syndr*. 2017;75(suppl 1):S27–S35. <https://doi.org/10.1097/QAI.0000000000001325>
15. Goodenow MM, Gaist P. Importance of HIV/AIDS-related behavioral and social sciences research at the NIH and beyond. *J Acquir Immune Defic Syndr*. 2019;82(suppl 2):S84–S87. <https://doi.org/10.1097/QAI.0000000000002163>

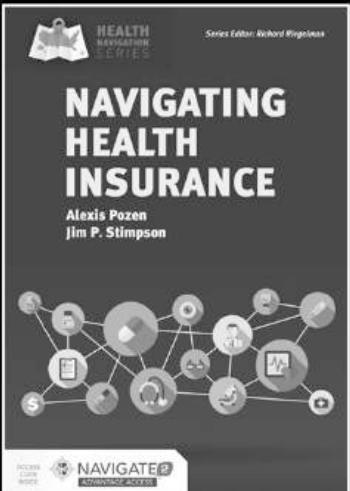
A Practical, Balanced Guide to Understanding Health Insurance

Written from the perspective of the consumer, this new text is a comprehensive yet accessible examination of health insurance in the United States.

Instructor exam copies available at go.jblearning.com/Pozen

APHA PRESS
AN IMPRINT OF AMERICAN PUBLIC HEALTH ASSOCIATION

JONES & BARTLETT LEARNING
An Ascend Learning Company



Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

The Sankofa Paradox: Why Black Women Know the HIV Epidemic Ends With “WE”

Dázon D. Diallo, DHL, MPH

ABOUT THE AUTHOR

Dázon Dixon Diallo is with SisterLove Inc, Atlanta, GA, and Johannesburg, South Africa.

🔗 See also Morabia, p. 1175, Landers et al., p. 1180, and the HIV/AIDS and Our World: 1981–2021 section, pp. 1231–1266.

Sankofa is an aphorism from the Akan people of Ghana. Derived from the words San (return), Ko (go), and Fa (look, seek, and take), the word and its symbol translate as “It is not taboo to fetch what is at risk of being left behind.” The Sankofa symbol is a mythical bird shown with its feet and body facing forward, its head turned backward, and its beak holding an egg in place on its back. The Akan believe that the past serves as a guide for the future, and that it is the wisdom of the past that ensures a strong future. Many interpretations suggest that the egg is protected as it represents those who are not yet born, and it holds the connection between the past and the present. The Akan also believe that there must be movement and new learning as time passes.¹

As the HIV community takes this moment to look back on the 40-year history of the HIV epidemic, like the Akan people, we must remember and bring forward the knowledge of the past four decades of the US and global responses to the HIV epidemic. Indeed, we must look even further beyond these years to

learn from a longer history of how societies respond to pandemics that lay bare the inequities and injustices that precede current public health crises. As we proceed with great efforts to end HIV as an epidemic, we must also incorporate what we have learned from a long history of systemic racism, sexism, colonialism, imperialism, and enslavement. One of the biggest HIV history lessons is that women,² especially women and girls who are Black or of African descent, have been disproportionately affected by and engaged in the HIV epidemic since the very beginning. Yet, up to this very moment, we have been in a constant fight for inclusion and for our places at the tables of design, decision, and distribution of life-saving knowledge and resources.

I call this lesson the Sankofa Paradox of ending the HIV epidemic. Without the full spectrum of inclusion and engagement of the lived experiences of women, girls, femmes, and trans–nonbinary individuals who were assigned female at birth, there will be no end to the HIV epidemic. Nearly every time the needs and contributions

of Black and African women have been left out or left behind, it has slowed progress at reducing overall incidence of new HIV infections, increasing viral suppression, and facilitating the uptake of new technologies and interventions such as treatment as prevention, pre-exposure prophylaxis, postexposure prophylaxis, and the discovery of a vaccine and a cure for HIV. By default, excluding us has reinforced the unacceptable inequalities that exist for priority and key populations, including women and girls, sex workers, LGBTQIA+ (lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual, plus) people, incarcerated individuals, and people who inject drugs.

Since its founding in 1989, SisterLove has been a consistent advocate and voice for the inclusion of women in every aspect and every level of the HIV response. Despite the reality that most women who were diagnosed with AIDS at that time were infected through injection drug use, they received this news when they were pregnant, after having their babies, terminating pregnancies, or seeking permanent contraception through tubal ligations, and AIDS and HIV were not treated or integrated as issues of sexual and reproductive health or rights.³ We have been fighting since the days when we organized, mobilized, and “ACTed UP” for the inclusion of women’s opportunistic infections in the Centers for Disease Control and Prevention’s Clinical Guidelines for AIDS Diagnosis, Treatment and Care—a four-year campaign from 1990 to 1993 that resulted in the recognition of thousands of women who were experiencing unique conditions associated with their bodies and gender in relation to HIV/AIDS.⁴

Considering that women have always been at least half of the global HIV

pandemic, it is still painful to recall how we have had to hold various global entities—which were responsible for defining and monitoring women’s sexual and reproductive health, rights, and justice (SRHRJ)—accountable for failing to significantly embrace HIV/AIDS as core issues. In the 1994 International Conference on Population and Development’s Program of Action, HIV and AIDS were barely mentioned. The 1995 Beijing Platform of Action from the Fourth World Conference on Women addresses the human rights and dignity of women living with AIDS, but it fails to draw the connections and intersections of HIV as an issue for SRHRJ responses. It was not until 2016 that the United Nations explicitly expressed the intersectionality of HIV and SRHRJ in the Declaration of Commitment on HIV/AIDS, which was first enacted in 2001.⁵

When the United States finally produced a National HIV/AIDS Strategy in 2010, women’s coalitions had to fight for the inclusion of SRHRJ and intersectional issues such as gender-based violence and trauma-informed care into the five-year plan to reduce new HIV infections, treat and provide care for everyone living with HIV, and eliminate the social determinants and inequities that drive the epidemic. Also, with each new administration, women and girls around the globe are subject to the unilateral decision by the US president of whether funds for humanitarian and public health services will afford them access to full sexual and reproductive health care. We need legislation that removes the power of the US president to implement executive orders that detrimentally affect the SRHRJ of women and girls at home and abroad.

The fight to ensure that women, girls, femmes, and transgender people who were assigned female at birth are

prioritized and included in every aspect of the US and global HIV response is key to ending the HIV epidemic. In the landmark documentary, “Nothing Without Us: The Women Who Will End AIDS,” when someone asked why they were filming her, reproductive justice activist Gina Marie Brown unapologetically stated, “Because I am one of the women who will end AIDS.” We agree with her, and we know that without women—especially women of African descent—around the world leading the way through the final years of the HIV epidemic, no one gets to the end until we all do.

Over the course of history, Black women have shown that when we organize to change things for ourselves, we change things for everyone. Recent and historical events have shaped this truth as the evidence—civil and voting rights, sexual harassment accountability, gender-based violence, housing and food justice, environmental justice, economic justice, human rights, racial and reproductive justice, science and technology, education equity, civic and political engagement, abolitionism, ending state violence against Black and Brown communities, and fighting concurrent pandemics. We live intersectional lives; therefore, we seek intersectional solutions. Yet it seems that with every change we effect, incremental and monumental, there are efforts to forget us, exclude us, leave us, overlook us, delegitimize us, exploit us, criminalize us, and even erase us, as if we did not matter or did not exist.

Despite this ongoing cycle of relegating us to the bottom of nearly every barrel, Black and African women still rise to the occasion and deliver on our promise because we do not do what we do for ourselves. We do it for “WE”—the people, the planet, and the

progeny. This has remained true throughout the course of the domestic and global fight to end the HIV epidemic and AIDS. It remains as the essence of my core belief that when we end the HIV epidemic for Black and African women and girls in all our diversities, and in our communities, we end it for everyone. If only WE could all remember and learn from the lessons of our past, and the challenges in our present, and transform the movement as we look forward to our future without HIV and AIDS.

I know a young Black woman who was born living with HIV. She is 25 years old, vibrant, smart, sex-positive, in love, undetectable, and pregnant. She champions HIV prevention, treatment, care, and sexual and reproductive justice for herself and all her friends who are queer, gender diverse, and engaged in sexual activities. She will most surely have a baby who will be born free of HIV. This young woman and her community of peers are the egg on the symbolic bird’s back. Their collective future beholds the end of HIV. Together, WE are all the embodiment of Sankofa. We owe them the ability to remember and learn the lessons from the past 40 years of HIV. Looking back with our feet moving forward, we hold them safe on our backs, while WE all follow the women leading us through the end of HIV and AIDS, and to the beginning of a new era of sexual and reproductive well-being and justice for everyone. **AJPH**

CORRESPONDENCE

Correspondence should be sent to Dázon Dixon Diallo, PO Box 10558, Atlanta, GA 30310 (e-mail: ddiallo@sisterlove.org). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

PUBLICATION INFORMATION

Full Citation: Diallo DD. The Sankofa paradox: why Black women know the HIV epidemic ends with “WE.” *Am J Public Health*. 2021;111(7):1237–1239.

Acceptance Date: April 18, 2021

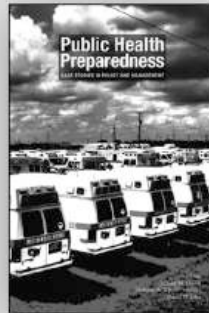
DOI: <https://doi.org/10.2105/AJPH.2021.306358>

CONFLICTS OF INTEREST

The author has no conflicts of interest to report.

REFERENCES

1. Carter G Woodson Center, Berea College. The power of Sankofa: know history. Available at: <https://www.berea.edu/cgwc/the-power-of-sankofa>. Accessed March 20, 2021.
2. Durvasula R. A history of HIV/AIDS in women: shifting narrative and a structural call to arms. *Psychology and AIDS Exchange Newsletter*. American Psychological Association. March 2018. Available at: <https://www.apa.org/pi/aids/resources/exchange/2018/03/history-women>. Accessed March 21, 2021.
3. Institute of Medicine Committee on Prenatal and Newborn Screening for HIV Infection. *HIV Screening of Pregnant Women and Newborns*. Hardy LM, ed. Washington, DC: National Academies Press; 1991.
4. 1993 Revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. *MMWR Recomm Rep*. 1992;41(RR-17):1–19.
5. UN Women. Global norms and standards. Available at: <https://www.unwomen.org/en/what-we-do/hiv-and-aids/global-norms-and-standards#:~:text=The%20Beijing%20Declaration%20and%20Platform,girls%20from%20HIV%20FAIDS%2Drelated>. Accessed March 20, 2021.



Public Health Preparedness: Case Studies in Policy and Management

Edited by Arnold M. Howitt, Herman B. "Dutch" Leonard, and David W. Gilles

2017, Softcover, 9780875532837

Public Health Preparedness: Case Studies in Policy and Management provides detailed accounts of a range of public health emergencies. Topics range from natural disasters, to infectious diseases, to pandemics, and more. With chapters on Superstorm Sandy, H1N1, the Ebola virus, and bioterrorism, these cases cover major areas in public health preparedness. This book is suited for public health professionals, specialists in related fields, students, and concerned citizens. These case studies strongly portray the challenges that public health faces in our times.

Order online at www.aphabookstore.org

APHA PRESS
AN AFFILIATE OF AMERICAN PUBLIC HEALTH ASSOCIATION

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

HIV Is a Story First Written on the Bodies of Gay and Bisexual Men

George Ayala, PsyD, and Andrew Spieldenner, PhD

ABOUT THE AUTHOR

George Ayala is with the Alameda County Public Health Department, San Leandro, CA. Andrew Spieldenner is with California State University, San Marcos, and MPact Global Action for Gay Men's Health and Rights, Oakland, CA.

🔗 See also Morabia, p. 1175, Landers et al., p. 1180, and the HIV/AIDS and Our World: 1981–2021 section, pp. 1231–1266.

Whatever else it may be, AIDS is a story, or multiple stories, and read to a surprising extent from a text that does not exist: the body of the male homosexual.¹

In 1980, Ken Horne, a gay sex worker in San Francisco, California, became the first person to be diagnosed with acquired immune deficiency syndrome (AIDS) in the United States.² A year later, the Centers for Disease Control and Prevention's (CDC's) *Morbidity and Mortality Weekly Report* described five cases of Pneumocystis pneumonia among young "homosexual" men living in Los Angeles, California.³ By 1982, the term "gay-related immune deficiency" gained traction in the media and among health care professionals to describe the assumed inherent link between homosexuality and what would later be known as human immunodeficiency virus (HIV).⁴ The term "gay-related immune deficiency" reflected homophobic ignorance and the dearth of epidemiologic evidence that existed at the time. In 1983, frustrated by their shared experiences of stigma, gay men with AIDS at the Fifth Annual Gay and Lesbian Health

Conference brought forth the Denver Principles, which catalyzed self-empowerment across health movements for decades to come.

As significant as these time markers are, the HIV story in the United States likely dates back two or more decades before the 1980s. Robert Rayford, a Black adolescent who grew up in the Old North neighborhood of St. Louis, Missouri, died of pneumonia in 1969, after enduring a severe chlamydia infection and Kaposi's sarcoma. In 1987, western blot postmortem testing on Rayford's tissue samples confirmed HIV infection. Although we may never know for certain, Rayford may have contracted HIV selling sex or, like too many gay and bisexual youths worldwide, because he was the target of sexual violence.⁵

These early events remind us that HIV is a story first written on the bodies of gay and bisexual men. And the goal of this editorial commemorating the first published cases of AIDS is to underscore the critical importance of human rights for sexual minority men and women and as the basis of the HIV response.

HIV AMONG GAY AND BISEXUAL MEN

Race, class, and sexual orientation continue to shape the HIV epidemic in the United States and around the world, with new infections disproportionately affecting men who have sex with men in Black and Brown communities. Globally, from 2010 to 2019, HIV diagnoses increased by 25% among gay and bisexual men, even as infections in other groups declined.⁶ In the United States, gay and bisexual men make up nearly 70% of all new HIV diagnoses each year; among them 31% are Black and 25% are Latinx.⁷

Reliably collected epidemiologic evidence continue to tell a story that centers the HIV pandemic on gay and bisexual men, yet public health agencies continue to resource HIV responses cast broadly to the "general population."⁸ Adopting HIV responses geared toward the general population (as opposed to carefully targeted strategies that are commensurate with epidemiologic trends) is a discursive public health norm that often presumes groups are heterosexual, cisgender, able bodied, socioeconomically secure, and—in the Global North—White.⁹ As a result, HIV services are rendered difficult to safely access for those in need and most marginalized.

COMMUNITY-LED HIV RESPONSES

Building on the civil rights, women's rights, and gay and lesbian liberation movements in the United States, lesbian, gay, bisexual, transgender, queer (LGBTQ) people, and their allies worked together to establish HIV service organizations even as governments struggled to respond.¹⁰ In 1986, Craig Harris, a

Black gay man living with HIV, stormed the stage of the American Public Health Association (APHA) annual convention. Harris and other activists were frustrated that there were no people of color scheduled to speak at the first APHA plenary on HIV.¹¹ Actions like Harris' gave rise to community-led service and advocacy organizations. These organizations brought community members living with and affected by HIV at the grassroots level into the non-profit industry, often providing job security, decent wages, health care coverage, and dignity. Community members developed and implemented programs that were most culturally appropriate to their needs. These same organizations also played a critical role in safeguarding an increasingly visible LGBTQ community.

HIV activism has been integral to politicizing gay and bisexual men because the homophobia and HIV-related stigma they have experience at individual, community, and institutional levels are interlocked. Founded in 1986 and 1987, respectively, the Global Network of People Living with HIV and AIDS Coalition to Unleash Power were global activist groups with large LGBTQ contingents, central in determining strategy, deliberating scientific updates, and organizing protests. In addition, gay bars and businesses were involved in a range of HIV activism, including safer sex education and fundraising to cover the daily living and funeral costs of gay and bisexual men dying from AIDS. This model of power sharing was pioneered in the early years of the HIV response and subsequently enshrined in 1994 as the Meaningful Involvement of People living with HIV. Sadly, its principles have been eroding, as the HIV response was corporatized and HIV organizations and planning bodies began viewing people

living with HIV as passive recipients or "consumers" of services.

The advent of antiretroviral treatment in 1996 transformed the HIV response. Although universally embraced as a hard-fought achievement, biomedical advances in the prevention and treatment of HIV can inadvertently mask social drivers of the epidemic and keep people living with and affected by HIV in narrowly defined roles (e.g., outreach workers or peer educators). This is because a biomedicalized HIV response situates power with the clinician and trained professional. Community members are often the lowest paid but hardest working—the last hired and first fired. They are also repeatedly the last involved in decision making, thereby entrenching power differentials between those who determine what services and programs are needed and those who use them.¹² HIV funding has incrementally shifted away from community mobilization, social support, and advocacy and toward clinics meant to make access to antiretroviral treatment easier. The HIV sector has become beholden to clinics and their funders. Ironically, access to culturally appropriate health care remains difficult for people living with and disproportionately affected by HIV, including gay and bisexual men, even with the proliferation of clinics.⁶

HIV has also ravaged gay and bisexual men's communities. The high death rate in the early epidemic was concentrated largely among four intersecting groups: transgender people, sex workers, people who use drugs, and gay and bisexual men. This had a devastating impact on activism and community organizations, especially in Black and Brown communities, as people died, burned out, or otherwise left in mourning. Their absence hollowed the HIV

response, as cultural, community, and political programs they led in coalition with one another closed. Gay and bisexual men carry the burden of this community trauma, one that is often unaddressed because of public amnesia, HIV-related stigma, homophobia, gender inequities, racism, and classism.¹¹

A HUMAN RIGHTS LENS

Economic disenfranchisement, racism, gender inequality, and homophobia, codified in laws and policies, have limited the provision and uptake of HIV services.¹³ Same-sex sexual behavior, sex work, and drug use are criminalized in 68, 48, and 85 countries, respectively. Eighty-nine countries have laws that specifically criminalize HIV transmission, exposure, or nondisclosure.¹⁴ Thirty-seven US states still criminalize people living with HIV, and these laws disproportionately affect economically poor people, Black and Brown people, and gay men.¹⁵ Such laws encourage violence, discrimination, and stigma, which worsen health- and HIV-related racial/ethnic disparities among gay and bisexual men.

Human rights violations experienced by young gay and bisexual men are exacerbated by legal and policy barriers embedded in social values. For instance, laws requiring parental consent for health services and policies curtailing comprehensive sex education restrict access to sexual health services that LGBTQ youths need. Similarly, the dearth of legal protections for gender nonbinary or transgender people results in discriminatory gender policies and practices at clinics and service organizations, hindering access and exacerbating health disparities.¹⁴

A common thread that runs through the human rights abuses described here is a lack of respect for and protection of bodily autonomy and integrity. Bodily autonomy and integrity are sacrosanct. This means all people, including gay and bisexual men, have agency and autonomy over their own bodies. It also means that all people have the right to be self-determining; be secure from violence, including sexual assault; and have opportunities for sexual satisfaction, pleasure, and reproductive choice. Public health responses to the HIV and overall health needs of gay and bisexual men are too often designed and enacted solely with a disease containment focus and without serious consideration for these fundamental human rights principles.

CONCLUSIONS

After 40 years, not only do power inequities and HIV disparities remain, but they have also deepened, particularly for gay and bisexual men of color. Community-led action to eliminate racism, classism, gender inequalities, and homophobia are necessary in addressing structural barriers to services, which fuel persistent HIV disparities. Creative approaches to foster power sharing are also needed in the development and delivery of biomedical interventions. Finally, trauma-informed community reparations must be integral to all public health HIV responses. This includes funding for rights-based, evidence-informed, community-led programs that actively affirm the lives and histories of gay and bisexual men. *AJPH*

CORRESPONDENCE

Correspondence should be sent to George Ayala, PsyD, Deputy Director, Alameda County Public Health Department, 1100 San Leandro Blvd, San Leandro, CA 94577 (e-mail: george.ayala@acgov.org). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Ayala G, Spieldenner A. HIV Is a story first written on the bodies of gay and bisexual men. *Am J Public Health*. 2021;111(7):1240–1242.

Acceptance Date: April 15, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306348>

CONTRIBUTORS

G. Ayala developed the first full draft of the editorial. Both authors conceptualized and outlined, drafted assigned sections of, and reviewed and edited the editorial.

ACKNOWLEDGMENTS

The authors would like to acknowledge gay and bisexual men worldwide who courageously put their bodies on the line, every day, to advance social justice and human rights—often at great personal cost. We humbly thank you!

CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

REFERENCES

1. Treichler PA. *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*. Durham, NC: Duke University Press; 1999.
2. KQED. History and culture: lesbian, gay, bisexual, and transgender pride. 1994–2008. Available at: <https://web.archive.org/web/20080318025809/http://www.kqed.org/topics/history/heritage/lgbt/timeline.jsp>. Accessed February 14, 2021.
3. Centers for Disease Control and Prevention. Pneumocystis pneumonia—Los Angeles. *MMWR Morb Mortal Wkly Rep*. 1981;30(21):250–252.
4. Altman LK. New homosexual disorder worries health officials. *New York Times*. May 11, 1982. Available at: <https://www.nytimes.com/1982/05/11/science/new-homosexual-disorder-worries-health-officials.html>. Accessed February 14, 2021.
5. Hendrix S. A mystery illness killed a boy in 1969. Years later, doctors believed they'd learned what it was: AIDS. *Washington Post*. May 15, 2019. Available at: <https://www.washingtonpost.com/history/2019/05/15/mystery-illness-killed-boy-years-later-doctors-learned-what-it-was-aids>. Accessed February 14, 2021.
6. Joint United Nations Programme on HIV/AIDS. Seizing the moment: tackling entrenched inequalities to end epidemics. July 6, 2020. Available at: https://www.unaids.org/sites/default/files/media_asset/2020_global-aids-report_en.pdf. Accessed February 14, 2021.
7. Centers for Disease Control and Prevention. Diagnoses of HIV infection in the United States and dependent areas, 2018. Available at: <https://www.cdc.gov/hiv/library/reports/hiv-surveillance/vol-31/index.html>. Accessed February 14, 2021.
8. World Health Organization. Report on key populations in African HIV/AIDS: national strategic plans, July 2018. Available at: <https://apps.who.int/iris/bitstream/handle/10665/275494/WHO-AF-CDS-HIV-02.2018-eng.pdf?ua=1>. Accessed February 14, 2021.
9. Makofane K, van der Elst EM, Walimbwa J, Nema S, Baral SD. From general to specific: moving

past the general population in the HIV response across sub-Saharan Africa. *J Int AIDS Soc*. 2020;23(suppl 6):e25605. <https://doi.org/10.1002/jia2.25605>.

10. Trapence G, Collins C, Avrett S, et al. From personal survival to public health: community leadership by men who have sex with men in the response to HIV. *Lancet*. 2012;380(9839):400–410. [https://doi.org/10.1016/S0140-6736\(12\)60834-4](https://doi.org/10.1016/S0140-6736(12)60834-4)
11. Bost D. *Evidence of Being: The Black Gay Cultural Renaissance and the Politics of Violence*. Chicago, IL: University of Chicago Press; 2019. <https://doi.org/10.7208/chicago/9780226589961.001.0001>
12. Aggleton P, Parker R. Moving beyond biomedicalization in the HIV response: implications for community involvement and community leadership among men who have sex with men and transgender people. *Am J Public Health*. 2015;105(8):1552–1558. <https://doi.org/10.2105/AJPH.2015.302614>
13. Arreola S, Solares D, Tohme J, Ayala G. Criminalization of consensual sex between men associated with poor access to HIV-services for gay, bisexual, and other men who have sex with men worldwide: findings from GMHR 2019–2020. Paper presented at: *The 23rd International AIDS Conference*. San Francisco, CA; 2020.
14. Joint United Nations Programme on HIV/AIDS; World Health Organization. Laws and policies analytics. Available at: <http://lawsandpolicies.unaids.org>. Accessed February 14, 2021.
15. Sykes BL, Hoppe TA, Maziarka KD. Cruel intentions? HIV prevalence and criminalization during an age of mass incarceration, US 1999 to 2012. *Medicine (Baltimore)*. 2016;95(16):e3352. <https://doi.org/10.1097/MD.0000000000003352>

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Joseph Sonnabend and the AIDS Epidemic: Pioneering and Its Discontents

Ronald Bayer, PhD, and Gerald M. Oppenheimer, PhD, MPH

ABOUT THE AUTHOR

Ronald Bayer and Gerald M. Oppenheimer are with the Center for the History and Ethics of Public Health, Department of Sociomedical Sciences, Mailman School of Public Health, Columbia University, New York, NY.

🔗 See also Morabia, p. 1175, Landers et al., p. 1180, and the HIV/AIDS and Our World: 1981–2021 section, pp. 1231–1266.

Joseph Sonnabend, a pioneering figure in the early effort to confront the multiple dimensions of the AIDS epidemic in the United States, died January 24, 2021, at the age of 88. A lengthy and admiring obituary published in the *New York Times* said of him that he was “one of the most important figures in the fight against AIDS, if also one of the most unheralded.”¹(pD6) In the current moment, when the language of heroism is routinely employed in describing the work of medical workers struggling to control COVID-19, it is sometimes difficult to recall that the life and work of those regarded as AIDS pioneers were all too often tinged by recrimination and bitter controversy. Such was the career of Sonnabend, someone who saw himself and was viewed by others as a devoted clinician and a combative iconoclast.

Sonnabend was born in South Africa, where he studied medicine; he then trained in immunology and microbiology in England with Alick Isaacs, the codiscoverer of interferon. After moving to

New York City in 1969 to continue interferon research at Mount Sinai Medical Center, he became increasingly involved in treating gay men, eventually starting a private practice in Greenwich Village at a time when such work was reviled as “VD medicine.” Like other physicians treating young gay men in the late 1970s, he began to observe new and unusual illnesses for which adequate explanations failed him.

Although accepting that the new syndrome, eventually called AIDS, was microbially caused, Sonnabend was initially both skeptical that a single pathogen could account for the plethora of diseases that infected his patients and supportive of an etiology, anathema to many gay activists, that implicated a sexual lifestyle of multiple partners. In a 1983 article published in *JAMA*, he theorized that multiple, recurrent sexually acquired infections could overwhelm the immune system, leaving it susceptible to opportunistic microbes.² Perhaps underestimating the risk of facing opprobrium from calling the behavior of

those with many sexual partners “promiscuous,” he believed that he had no alternative. “There could be no equivocation,” he said. “A desire to appear nonjudgmental, a desire to remain untinged by moralism, fear of evoking ire, have all fostered a conspiracy of silence. . . . Gay men have been poorly served by their medical attendants during the past years.”³(p25)

Sonnabend again stepped into controversy as the catalyst for one of the early important AIDS tracts, “How to Have Sex in an Epidemic: One Approach,” published in 1983. Written by two of his patients, Michael Callen and Richard Berkowitz, whom he introduced and advised, the pamphlet was among the first to offer a route to safer sex. But its arguments, initially based on Sonnabend’s multiple infection theory, were criticized by those who saw the authors as moralistic and as pathologizing gay sex.

In the epidemic’s first years, Sonnabend also faced opposition from medical colleagues to his stance that Bactrim, an inexpensive sulfa drug, should be used prophylactically to prevent *Pneumocystis carinii* pneumonia (recently renamed *Pneumocystis jirovecii* pneumonia), one of the major causes of AIDS-associated deaths. Sonnabend could reference his own expertise as an immunologist and the established use of Bactrim to prevent *Pneumocystis carinii* pneumonia in childhood leukemia and organ transplant patients; however, more established physicians treating AIDS patients often dismissed him, insisting that there were insufficient data to prescribe the drug.⁴ It was not until 1988 that a clinical trial finally supported Bactrim prophylaxis for HIV-infected patients; years of treatment were lost. To Sonnabend, this was a sure indictment of an irresponsible or indifferent AIDS medical leadership.⁵

In 1987, Sonnabend was again at odds with colleagues over early clinical trial results that appeared to demonstrate that AZT (azidothymidine) would be an effective drug against the viral cause of AIDS. Given the absence of alternative chemotherapies to manage HIV and HIV's high case fatality rate, AZT produced unwarranted hope in AIDS practitioners. Not alone, but among the most outspoken, Sonnabend questioned its safety and efficacy. He later asserted, "I didn't believe the [results of the] original AZT trials. . . . The approval of AZT was I suppose [a concession] to the pharmaceutical industry and to the activists. . . . who were screaming for their AZT."⁴(p32) In time, the enormous initial enthusiasm for AZT would change to a cascade of disappointments.

Critical of the inadequacy of what he saw as the "clinical research establishment," Sonnabend became a strong proponent of independent community-based research. He organized the Community Research Initiative, in which physicians and their patients played a central role in identifying trials of potential therapeutic agents. But with experience, Sonnabend became a skeptic of his own approach. Like other clinicians, he had a perhaps too simplistic view of clinical trial research. In retrospect, he admitted:

I too had the idea that anybody could do a clinical trial, but I've come to respect it a lot more. It has its own vocabulary, its own expertise. Physicians, when they do become [principal investigators], have no idea of what is involved or what should be involved.⁴(pp154–155)

If Sonnabend's skepticism often involved the embrace of an idea, like Bactrim prophylaxis, that would in time gain

evidentiary support, his instincts could just as often be erroneous. Thus, he found he was wrong in his initial opposition to the use of antiretroviral drugs in asymptomatic individuals with HIV.

Against this background of controversy, it is noteworthy that Sonnabend earned strong praise, even from those with whom he had a falling out. The American Foundation for AIDS Research, a pioneering organization that he cofounded with the immunologist and renowned philanthropist Mathilda Krim, but from which he ultimately split after a dispute, honored him in 2000 for his "Olympian contributions to the fight against AIDS during years when this was a lonely and thankless endeavor."¹

Sonnabend was also lauded by many of his patients, those drawn by his compassionate care. According to the documentary filmmaker and author David French:

As a clinician, he was really unmatched. His sense of urgency and responsibility to his patients was superhuman. Everyone says of him that he kept more of his patients alive longer than any other AIDS doctor, and that wasn't because he created magic but because he never let a symptom go unexamined or untreated, including preventively. He responded to the battlefield of the body like he was at war, and he did it at great personal cost to his own personal life.⁶

Looking back in 2020 on the early AIDS years, Sonnabend's memories were both sad and bitter. He never felt part of the professional community of AIDS physicians in New York City. "On the contrary they were hostile to me," and although he could call on memories of the "tremendous" support he received

from his patients, he remained "bewildered" by the criticism levied by the organized gay community (J. Sonnabend, personal communication, April 24, 2020).

In a letter about the challenges posed by COVID-19, Sonnabend wrote, "Whatever goes into the establishment of medical leadership in times of crisis, in the case of HIV/AIDS it failed miserably. Can we trust that it will not fail us today?" (J. Sonnabend, personal communication, April 24, 2020). [AJPH](#)

CORRESPONDENCE

Correspondence should be sent to Gerald M. Oppenheimer, PhD, MPH, Department of Sociomedical Sciences Rm 931, Mailman School of Public Health, Columbia University, 722 West 168th St, New York, NY 10032 (e-mail: go10@cumc.columbia.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Bayer R, Oppenheimer GM. Joseph Sonnabend and the AIDS epidemic: pioneering and its discontents. *Am J Public Health*. 2021;111(7):1243–1245.

Acceptance Date: March 13, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306291>

CONTRIBUTORS

The authors performed research for the editorial equally. R. Bayer wrote the first draft, and G. Oppenheimer the second and final drafts.

ACKNOWLEDGMENTS

The authors thank Daniel M. Fox, PhD, for his scrupulous and critical reading of the first drafts of this editorial.

CONFLICTS OF INTEREST

The authors have no potential or actual conflicts of interest from funding or affiliation-related activities to report.

REFERENCES

1. Seelye KQ. Joseph Sonnabend, early force in the fight against AIDS, is dead. *New York Times*. February 1, 2021:D6.

2. Sonnabend J, Witkin SS, Purtilo DT. Acquired immunodeficiency syndrome, opportunistic infections, and malignancies in male homosexuals. A hypothesis of etiological factors in pathogenesis. *JAMA*. 1983;249(17):2370–2374. <https://doi.org/10.1001/jama.1983.03330410056028>
3. Bayer R. *Private Acts, Social Consequences: AIDS and the Politics of Public Health*. New York, NY: Free Press; 1989.
4. Bayer R, Oppenheimer GM. *AIDS Doctors: Voices From the Epidemic*. New York, NY: Oxford University Press; 2000.
5. New York Lesbian & Gay Experimental Film Festival. ACTUP Oral History Project. 2016. Available at: <http://actuporalhistory.org/interviews/images/sonnabend.pdf>. Accessed March 5, 2021.
6. Murphy T. Joseph Sonnabend, brilliant early AIDS doctor, would treat patients for free. February 3, 2021. Available at: <https://www.thebody.com/article/remembering-dr-joseph-sonnabend>. Accessed March 5, 2021.

Our Communities Our Sexual Health

Awareness and Prevention for African Americans

Edited By: Madeline Sutton, MD, MPH;
Jo A. Valentine, MSW; and
William C. Jenkins, PhD, MS, MPH

This groundbreaking book provides a comprehensive historical perspective of the disproportionate burden of HIV and other sexually transmitted infections (STIs) among African Americans. Chapters that follow explore the context of HIV and STIs in African American communities and include discussions of sexuality and the roles of faith and spirituality in HIV and STI prevention efforts. Additional chapters provide insight into strategies, e.g., HIV testing, condom distribution and marketing campaigns, parent-child communication, effective clinical care and support, and partnerships, for addressing HIV and other STI-related health disparities within these communities. The book is a valuable resource for practitioners, scholars, clinicians, educators, providers, policy makers and students.



2016, 283 pp., soft cover
ISBN: 978-0-87553-275-2
Order Online at
www.aphabookstore.org

APHA PRESS
AN IMPRINT OF AMERICAN PUBLIC HEALTH ASSOCIATION

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Then and Now: Historical Landscape of HIV Prevention and Treatment Inequities Among Latinas

Hortensia Amaro, PhD, and Guillermo Prado, PhD

ABOUT THE AUTHORS

Hortensia Amaro is with the Robert Stempel College of Public Health and Social Work and the Herbert Wertheim College of Medicine, Florida International University, Miami. Guillermo Prado is with the School of Nursing and Public Health Studies, University of Miami, Miami, FL.

See also Morabia, p. 1175, Landers et al., p. 1180, and the HIV/AIDS and Our World: 1981–2021 section, pp. 1231–1266.

Scientific advances in HIV/AIDS prevention and treatment have transformed AIDS from a death sentence to a preventable and manageable chronic disease. Yet, progress has not equitably benefited Latinas. Even at the beginning of the epidemic, inequities in HIV/AIDS incidence, survival, and death among Latinas were evident.¹ Among Latinas, from 1988 to 1991, the AIDS case rate was 7.5 times higher than that of their non-Latina White counterparts (<https://bit.ly/3gSSeXT>). Early research and prevention largely ignored women except for their roles as vectors or vessels of disease transmission.² This heightened stigmatization of women living with HIV led to vigorous calls for a gender-focused understanding of HIV risk, including the effects of social determinants of health and HIV vulnerability.^{3,4} Simultaneously, the lack of attention to HIV/AIDS among Latinas by government agencies, funders, and the research community left Latino

community organizations working on HIV prevention without sufficient support or funding.^{1,5}

Not until the 1999 calls to action by the Latino and Black congressional caucuses was there the first major federal effort to develop an integrated community-based HIV and substance abuse prevention program to address these dual crises in Latino and Black communities: the Minority AIDS Initiative (<https://bit.ly/3aUpkmw>). And it was not until 2014 that the Centers for Disease Control and Prevention reported that Latinas were disproportionately affected by HIV, with rates three times those of non-Hispanic Whites, and called for efforts to improve HIV-related care (<https://bit.ly/3nE2iFy>).

FORTY YEARS OF UNHEEDED EVIDENCE

Inequities in timely HIV testing and access to competent HIV/AIDS

prevention, care, and treatment of Latinas persist today.^{6–8} In 2018, HIV diagnosis among Latino adults was 16.4 per 100 000 compared to 4.8 per 100 000 for non-Latina Whites. Latina adolescents and adults continue to be disproportionately affected. For example, the HIV incidence rate for Latinas is 4.9 per 100 000 compared with 1.6 per 100 000 for non-Latina White females (<https://bit.ly/3eOHk2D>). These inequities coupled with Latino invisibility in the larger HIV/AIDS scientific literature and public discourse are astounding given that Latinas are the largest minority group in the United States—from 6.4% in 1980 to 18.5% in 2019 and 29% projected by 2050 (<https://pewrsr.ch/3vzj8YU>). Despite the diversity of the US-based Latino population, throughout US history and contemporary times, Latinas have been subjected to anti-immigrant and anti-Latina policies (<https://bit.ly/3ufzghN>) and racism (<https://pewrsr.ch/3nKuBIQ>), including in health care (<https://bit.ly/3xGMUg2>). Yet, inadequate public health attention to Latino HIV inequities and related social determinants of health and HIV vulnerability, including racism, xenophobia, and discrimination, continue to render Latinas invisible. Contributing to this invisibility in public health, including HIV prevention, is the prevailing focus on Black–White inequities, history of injustice, and civil rights struggles, referred to as the Black–White binary paradigm of race in the United States.^{9,10} It leads to an incomplete understanding (<https://bit.ly/3eeDzEN>) of the role of inequities and racism in health and HIV vulnerability and care among other racialized groups (i.e., Latinas, Native Americans/Alaska Natives, Asian Americans) and renders invisible their histories and how racism affects groups and their

health because it does not fit in the prevailing paradigm.

GESTALT AND CONSEQUENCES OF INVISIBILITY

The context of longstanding Latino health inequities and the history of discrimination has shaped access to and receipt of HIV prevention. For example, delivery of preexposure prophylaxis (PrEP) to Latinos lags significantly behind delivery to non-Latino Whites, and there are no systematic behavioral interventions scaled to prevent HIV among Latinos. Specifically, of the 1.1 million adults who were PrEP eligible in 2015, approximately 26% were Latinos and 28% were non-Latino Whites. Yet, PrEP use was 13% among Latinos and 69% among non-Latino Whites (<https://bit.ly/3vzjoak>).

This is a significant gap and is partially explained by structural factors such as lack of health insurance (<https://bit.ly/3eJFyjk>)—which is highest among Latinos (29.7% vs 7.5% among non-Latino Whites)—and barriers to HIV care across patient, clinic, provider, health system, and community levels (<https://bit.ly/3eMI4Fu>). These structural barriers must be addressed by improving health insurance access and implementing strategic and evidence-based, culturally efficacious behavioral and community-level interventions to increase access to and uptake of PrEP (<https://bit.ly/33ahjFK>).

This is especially needed for at-risk Latinas, for whom stigma, acculturation challenges, discrimination, social rejection, and substance use may be barriers to PrEP uptake (<https://bit.ly/3vFoj9w>). Other prevention approaches, including behavioral, family, and social network (peer) interventions, have demonstrated efficacy in HIV prevention by increasing condom use and decreasing sexual activity while

under the influence of drugs or alcohol, but they have not been taken to scale. Interventions that engage parents as agents of change, such as Familias Unidas,¹¹ have been found to reduce HIV risk behaviors for both female and male youths.

Similarly, interventions such as *Cúdate!* (<https://bit.ly/3t7oyZu>), *keepin' it R.E.A.L.* (<https://bit.ly/2SbrS95>), and *Families Talking Together* (<https://bit.ly/3ta5N7H>) have also proven efficacious in preventing and reducing sexual risk behaviors and substance use in Latinos. The number and quality of evidence-based interventions for adult Latinas are more limited owing to lack of or limited inclusion of Latinas in samples and analyses establishing efficacy in Latinas and a glaring absence of studies on HIV prevention focused on Latina drug users.^{12–15}

A 2015 review of randomized clinical trials on HIV prevention interventions that focused on women who use alcohol and other drugs showed that, from the 1990s to 2015, only one of 23 focused on US Latinas (<https://bit.ly/33c8j9r>). Yet, some studies designed to be culturally tailored have demonstrated efficacy in sexual risk behavior change among sexually active adult Latinas (e.g., *Amigas* [<https://bit.ly/3uhsfx5>], *SEPA* [<https://bit.ly/3nLjokL>], *VOICES* [<https://bit.ly/3gVumCU>]). Despite the availability of efficacious interventions for Latina adolescents and adults, the lack of dissemination at the population level or scaled-up implementation in community or clinical contexts has stymied efforts to reduce HIV disparities in Latinas.

Furthermore, there is a need to develop and scale-up scientifically proven HIV prevention interventions for specific subgroups of Latinos, such as sexual minorities and Latina transgender females (<https://bit.ly/2PIQwgt>) and US Latinas who use drugs (<https://bit.ly/3xJK4qy>), as there are no evidence-

based behavioral HIV preventive interventions specifically shown to be efficacious in these groups. More interventions at all levels, but particularly at the community, macro, and structural levels (e.g., to address gender-based power differentials, systemic discrimination, and racism), must be developed and evaluated. Understanding downstream and upstream factors impeding the adoption of evidence-based preventive interventions is critical to their dissemination. Easily scalable eHealth (<https://bit.ly/3ecjREF>) interventions have proven to be efficacious in Latinos and may reduce some barriers (e.g., level of resources needed) to widespread dissemination. Funding these interventions via reimbursement through insurance and public health program funding is essential to sustaining them and their impact on eliminating HIV/AIDS inequities among Latinos.

Finally, another critical tool in HIV prevention is access to and engagement in efficacious treatment of substance use disorders (SUDs). Again, data indicate that Latinas are among the most underserved and severely uninsured (<https://bit.ly/3xAvfqm>) in need of SUD treatment in the United States. Latinas have lower access to SUD treatment, including opioid treatment (<https://bit.ly/3eNjPqT>); receive lower quality of care; and drop out of treatment at higher rates than do non-Latinas.

Key features of SUD treatment programs (<https://bit.ly/3niXLlm>); e.g., cultural competence, counselor's Spanish-language proficiency [<https://bit.ly/2RgudiE>], availability of Spanish-language treatment-related material) are associated with reduced wait time to SUD treatment entry and greater treatment engagement among Latinas. Access to and utilization of treatment is hampered by a host of multilevel factors, including

limited health insurance coverage, sufficient availability of providers and programs (<https://bit.ly/3nN1A8O>), underrepresentation of Latinos in the workforce (<https://bit.ly/3eS5F7G>), social stigma, individual and community-level lack of understanding of SUD treatment, and services that do not meet the needs of Latinas. Additionally, significant inequities in access to care and HIV treatment outcomes persist (<https://bit.ly/3gXmuAI>).

Specifically, compared with non-Latino Whites living with HIV, Latinos have lower rates of care initiation (61%), retention in care (49%), and viral suppression (53%). Rates among non-Latino Whites living with HIV are 70%, 52%, and 63%, respectively. Much more progress has to be made to provide access to HIV care and improve viral suppression among Latinos (<https://bit.ly/3z5ICzu>).

CORRECTING THE COURSE

Despite significant scientific advances in HIV prevention and treatment, little progress has been made in reducing HIV inequities in Latinos (<https://bit.ly/3ecPSBu>). These disparities continue to disproportionately lead to the death of Latinos from what is now a preventable and manageable chronic disease. This is unacceptable and requires a call to action for policy, science, and public health programming dedicated to eliminating HIV inequities among Latinos.

At the policy level, we need initiatives to reduce stigma and racism against Latino populations, including immigrants; adequate reimbursement for comprehensive and quality SUD treatment; and insurance coverage that provides equitable access to HIV prevention and treatment, including SUD treatment.

At the scientific level, we must invest more aggressively in funding to evaluate

and disseminate behavioral interventions at all levels—from individual to community. We must champion for greater inclusivity of Latinos in federally funded studies and call on journal editors and reviewers to evaluate whether sample sizes of Latinos included in studies are sufficient to draw conclusions for this population separately and, if so, require that such analyses be conducted and reported.

At a population level, we must change the anti-Latino sentiment of public discourse and collectively push for an equitable agenda and life for Latinos free of HIV. The public health community must examine how it has contributed to the invisibility of Latino HIV inequities and courageously take action to correct course. **AJPH**

CORRESPONDENCE

Correspondence should be sent to Hortensia Amaro, Herbert Wertheim College of Medicine and Robert Stempel College of Public Health and Social Work, 11200 SW 8th St, AHC4 Room 419, Miami, FL 33199 (e-mail: hamaro@fiu.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

PUBLICATION INFORMATION

Full Citation: Amaro H, Prado G. Then and now: Historical landscape of HIV prevention and treatment inequities among Latinas. *Am J Public Health*. 2021;111(7):1246–1248.

Acceptance Date: April 12, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306336>

CONTRIBUTORS

Both authors conceptualized and wrote the editorial.

ACKNOWLEDGMENTS

We would like to thank Erick Guerrero, PhD, for his suggestions on an early draft.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

REFERENCES

1. Singer M, Flores C, Davison L, et al. SIDA: the economic, social, and cultural context of AIDS among Latinos. *Med Anthropol Q*. 1990;4(1):72–114. <https://doi.org/10.1525/maq.1990.4.1.02a00060>

2. Faden R, Kass N, McGraw D. Women as vessels and vectors: lessons from the HIV epidemic. In: Wolf SM, ed. *Feminism and Bioethics: Beyond Reproduction*. New York, NY: Oxford University Press; 1996:252–281.
3. Amaro H. Love, sex, and power: considering women's realities in HIV prevention. *Am Psychol*. 1995;50(6):437–447. <https://doi.org/10.1037/0003-066x.50.6.437>
4. Zierler S, Krieger N. Reframing women's risk: social inequalities and HIV infection. *Annu Rev Public Health*. 1997;18:401–436. <https://doi.org/10.1146/annurev.pubhealth.18.1.401>
5. Amaro H, McGuire J, Hardy-Fanta C, Weissman G. Participation of Latino community-based organizations in the RWCA process: a study of two metropolitan areas. *Free Inq Creat Sociol*. 1999;27(2):29–44.
6. Benbow ND, Aaby DA, Rosenberg ES, Brown CH. County-level factors affecting Latino HIV disparities in the United States. *PLoS One*. 2020;15(8):e0237269. <https://doi.org/10.1371/journal.pone.0237269>
7. Nosyk B, Krebs E, Zang X, et al. “Ending the Epidemic” will not happen without addressing racial/ethnic disparities in the United States human immunodeficiency virus epidemic. *Clin Infect Dis*. 2020;71(11):2968–2971. <https://doi.org/10.1093/cid/ciaa566>
8. Guilamo-Ramos V, Thimm-Kaiser M, Benzekri A, et al. The invisible US Hispanic/Latino HIV crisis: addressing gaps in the national response. *Am J Public Health*. 2020;110(1):27–31. <https://doi.org/10.2105/AJPH.2019.305309>
9. Alcoff LM. Latino/as, Asian Americans, and the Black-White binary. *J Ethics*. 2003;7:5–27. <https://doi.org/10.1023/A:1022870628484>
10. Gonzalez-Sobrinho B, Goss DR. Exploring the mechanisms of racialization beyond the Black-White binary. *Ethn Racial Stud*. 2019;42(4):505–510. <https://doi.org/10.1080/01419870.2018.1444781>
11. Prado G, Pantin H, Huang S, et al. Effects of a family intervention in reducing HIV risk behaviors among high-risk Hispanic adolescents: a randomized controlled trial. *Arch Pediatr Adolesc Med*. 2012;166(2):127–133. <https://doi.org/10.1001/archpediatrics.2011.189>
12. Althoff MD, Grayson CT, Witt L, Holden J, Reid D, Kissinger P. A meta-analysis of the efficacy of behavioral interventions to reduce risky sexual behavior and decrease sexually transmitted infections in Latinas living in the United States. *Health Educ Behav*. 2015;42(6):709–718. <https://doi.org/10.1177/1090198114540461>
13. Daniel-Ulloa J, Ulibarri M, Baquero B, Sleeth C, Harig H, Rhodes SD. Behavioral HIV prevention interventions among Latinas in the US: a systematic review of the evidence. *J Immigr Minor Health*. 2016;18(6):1498–1521. <https://doi.org/10.1007/s10903-015-0283-0>
14. Herbst JH, Kay LS, Passin WF, Lyles CM, Crepaz N, Marín BV. A systematic review and meta-analysis of behavioral interventions to reduce HIV risk behaviors of Hispanics in the United States and Puerto Rico. *AIDS Behav*. 2007;11(1):25–47. <https://doi.org/10.1007/s10461-006-9151-1>
15. Ruiz-Perez I, Murphy M, Pastor-Moreno G, Rojas-García A, Rodríguez-Barranco M. The effectiveness of HIV prevention interventions in socioeconomically disadvantaged ethnic minority women: a systematic review and meta-analysis. *Am J Public Health*. 2017;107(12):e13–e21. <https://doi.org/10.2105/AJPH.2017.304067>

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Forty Years of Fighting for Equitable Partnering in HIV Research: We Are Not There Yet

Marcia V. Ellis, MA

ABOUT THE AUTHOR

The author is with the District of Columbia Center for AIDS Research, Milken Institute School of Public Health, George Washington University, Washington, DC.

See also Morabia, p. 1175, Landers et al., p. 1180, and the HIV/AIDS and Our World: 1981–2021 section, pp. 1231–1266.

I call them my Rosa Parks moments. Parks made the following comment in a KPFA radio interview recorded in April 1956, referring to the day in 1955 when she refused to give up her seat on the bus:

The time had just come when I had been pushed as far as I could stand to be pushed, I suppose. I had decided that I would have to know, once and for all, what rights I had as a human being and a citizen.¹

I am reminded by her example that advocacy often begins with a simple act that can lead to monumental change and be of historical significance. I have seen how, in the past 40 years of the HIV epidemic, advocacy and action have motivated necessary changes that have forged more meaningful and equitable partnerships between community members and HIV researchers. I also see more clearly what remains to be done to ensure that equitable partnering is not only maintained but strengthened moving forward.

I am a Black woman approaching my 70th year, 35 of which include HIV. Here I want to reflect on how advocacy has

shown up throughout that time. I am grateful to lend my story to others in this 40-year retrospective, humbled by the fact that I have witnessed firsthand most of this very special history.

As a person with HIV, I am wholly committed to, if not obsessed with, ensuring that the rights of people with HIV are embedded from the start to the finish of the entire HIV research process. We, people with HIV, are the ones most affected and therefore our lives and lived experiences should be the focus and the lens through which researchers look. Two parts of the Denver Principles of 1983² stand out for me:

For people living with HIV: Be involved at every level of decision-making.

Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.

In addition to the Denver Principles, two other sets of frameworks were developed to guide community engagement in research as well as meaningful and effective researcher–community partnerships.

Those frameworks are the GIPA/MIPA Principles of 1994 (Greater and Meaningful Involvement of People with AIDS) and AVAC's Good Participatory Practices.

THE INTEGRAL ROLE OF COMMUNITY

After living in extreme fear and secrecy during the first 10 years after my diagnosis, I joined a community of people with HIV and learned that the clinical trials and research in which we were involved should respect our right to always be a full partner. The principal investigator for the Georgetown AIDS Clinical Trials Groups (ACTG) approached me to ask if I would help revive ACTG's Community Advisory Board. I did not claim to know or understand the science, but I did know what it felt like to be respected, to exercise my rights to be an active partner in my care, and to maintain control over an illness whose grip seemed so strong while choices and options for healing seemed elusive.

Finding ways to give to something bigger than yourself can help to make you feel whole and hope filled. The Community Advisory Board allowed me to join a global community of amazing and inspiring people whose own lives of activism, advocacy, and action inspired and informed me. I continued what I began to learn years before HIV: to advocate for myself with my physicians and other caregivers. I was buoyed by and honored the lessons from the early HIV/AIDS activists and those who used their own personal stories to create organizations for the care and support of others.

As part of the ACTG Global Community Advisory Board, I have witnessed and been a participant in community leadership and advocacy throughout the

structure of this large and critically important National Institutes of Health research network. Thanks to the early activists, community advisory boards are now required at ACTG research sites. Global community leaders involved in treatment research have assumed critical roles in ACTG with respect to determining research priorities, developing and reviewing protocols, ensuring ethics in research, and ensuring representation of communities underrepresented in research. Community advisory board members now share the stage with world-class researchers demonstrating their own equally groundbreaking knowledge fortified by their own experiences. As a result of ongoing advocacy, the number of women in HIV research has grown but still begs more attention.

WHERE THERE'S ADVOCACY (AND A WILL), THERE'S A WAY

I attribute my own growth in advocacy largely to those individual and organizational advocates and activists who continue to be leading voices promoting change to support families and communities still disproportionately affected by HIV, economic and health disparities, and racial injustice. Those voices must be heard and incorporated throughout the research process to build buy-in and trust and increase the likelihood of consequential results. I began working with the District of Columbia Center for AIDS Research (CFAR) 12 years ago, the first 10 as a volunteer chair of the Community Advisory Board (now the Community Partnership Council). Now a part-time CFAR employee, I facilitate and provide a community perspective throughout the organization. Having a community person on the staff demonstrates the value of community

input. I am now able to interact and collaborate with researchers regularly.

I take seriously my responsibility to be a voice and conscience for the different communities represented on the Community Partnership Council and other community partners. The tireless work of community stakeholders on the ground helps to inform research. They fight for the resources required to increase and enhance HIV prevention and treatment services. In response to community concerns, CFAR recently launched an academic–community partnership award program in which pilot research is led equally by a joint team of academic and community principal investigators. Community members co-lead scientific interest and working groups in areas of high priority to them and participate fully in planning and strategizing meetings with Executive Committee members, many of whom are also leading researchers.

Furthermore, the Community Partnership Council is involved in the development of the next generation of researchers through our role in reviewing pilot award applications. We now have a compensation plan that partially recognizes the professional contributions that members make. The CFAR environment is collegial and respectful and honors distinct identities. I am proud to be one of the leaders not only initiating necessary changes but also working to make sure that there are structures and processes in place to sustain them.

MORE HARD WORK REMAINS TO ACHIEVE A FULL PARTNERSHIP

Much progress has been made that benefits us all. Nonetheless, despite a long history of demanding and ensuring community involvement in HIV research, further action is needed. People with

HIV, long-term survivors, women, LGBTQ (lesbian, gay, bisexual, transgender, and queer or questioning) individuals, people of trans experience, Latinx individuals, the faith community, Black heterosexual men, younger people, and others have many more important questions to be answered through research. Moreover, they are closest to some of the best solutions. As Paul Kawata, executive director of NMAC, notes: “It’s time to build real solutions that aren’t window dressing and come from the communities we need to reach.”³

Some of what remains to be done is difficult because it requires structural change and cultural shifts. Actions needed include, but are not limited to, the following:

- Continue to build community trust, something compromised by decades of unethical practices and unfair and intersectionally discriminatory practices and treatment
- Use lay language to translate and disseminate research findings and avoid stigmatizing, devaluing, and diminishing language
- Build research capacity within communities (e.g., programs to increase research and data literacy)
- Facilitate the ability of academic researchers to partner with communities without professional risk (e.g., tenure and promotion concerns)
- Be intentionally inclusive: ask who is not in the room and then take steps to involve such individuals
- Hire people from the communities hardest hit by HIV to assist with all aspects of the research process
- Recognize and change the power dynamic by ensuring equal access to information, resources, compensation, and recognition

- Find innovative ways to routinely disseminate research processes and findings
- Recognize that old paradigms, narratives, and organizational cultures and practices are barriers to true academic–community partnerships and require constant vigilance and change

I am grateful to have lived many more years than I expected. Alas, aging with HIV has ushered in substantial challenges for long-term survivors and requires continued and forceful advocacy. My concerns, and those of my aging cohort, have now turned to the comorbidities that emerge sooner than in those who are HIV negative. These comorbidities in turn increase vulnerability to COVID-19, which I have experienced firsthand. I am even more committed to wellness and dignified aging for people with HIV, and I am also committed to increasing attention to this important topic. May the example of Rosa Parks continue to inspire us to achieve equity in partnering in HIV research. *AJPH*

CORRESPONDENCE

Correspondence should be sent to Marcia V. Ellis, MA, Milken Institute School of Public Health, George Washington University, 950 New Hampshire Ave NW, 6th Floor, Washington, DC 20052 (e-mail: marciavellis@gwu.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

PUBLICATION INFORMATION

Full Citation: Ellis MV. Forty years of fighting for equitable partnering in HIV research: we are not there yet. *Am J Public Health*. 2021;111(7):1249–1251.

Acceptance Date: April 16, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306357>

ACKNOWLEDGMENTS

This work was facilitated in part by the infrastructure and services provided by the District of Columbia Center for AIDS Research (grant P30AI117970).

I acknowledge the ancestors and trailblazers to whom we owe much and the communities of advocates and activists. Lisa Bowleg, Meredith Loui, and Lorena Segarra provided invaluable support and guidance in the completion of this editorial.

CONFLICTS OF INTEREST

The author declares no conflicts of interest.

REFERENCES

1. Roger S. Commentary of a black southern bus rider: Rosa Parks. <https://www.pacificradioarchives.org/recording/bb0566>. Accessed May 5, 2021.
2. The Denver Principles. *Women Alive*. Winter 2000:12.
3. Kawata P. Language has consequences. Available at: <https://www.poz.com/blog/language-consequences>. Accessed May 5, 2021.

Conducting Health Research with Native American Communities

Edited by Teshia G. Arambula Solomon, PhD and Leslie L. Randall, RN, MPH, BSN



The current research and evaluation of the American Indian and Alaska Native (AIAN) people demonstrates the increased demand for efficiency, accompanied by solid accountability in a time of extremely limited resources. This environment requires proficiency in working with these vulnerable populations in diverse cross-cultural settings. This timely publication is the first of its kind to provide this information to help researchers meet their demands.

This book provides an overview of complex themes as well as a synopsis of essential concepts or techniques in working with Native American tribes and Alaska Native communities. *Conducting Health Research with Native American Communities* will benefit Native people and organizations as well as researchers, students and practitioners.

APHA PRESS
AN IMPRINT OF AMERICAN PUBLIC HEALTH ASSOCIATION

2014, 340 pp., softcover, ISBN 978-0-87553-2028
Available as an eBook and softcover
ORDER ONLINE at www.aphabookstore.org

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Intersections of Treatment, Surveillance, and Criminal Law Responses to HIV and COVID-19

Colin Hastings, PhD, Alexander McClelland, PhD, Adrian Guta, PhD, MSW, Maureen Owino, MES, Eli Manning, PhD, MSW, Michael Orsini, PhD, Richard Elliott, LLM, Marilou Gagnon, PhD, RN, and Stephen Mollidrem, PhD

ABOUT THE AUTHORS

Colin Hastings is with the Department of Sociology and Anthropology, Concordia University, Montreal, QC. Alexander McClelland is with the Institute of Criminology and Criminal Justice, Carleton University, Ottawa, ON. Adrian Guta is with the School of Social Work, University of Windsor, Windsor, ON. Maureen Owino is with the Faculty of Environmental Studies, York University, Toronto, ON. Eli Manning is with the School of Social Work, Dalhousie University, Halifax, NS. Michael Orsini is with the Institute of Feminist and Gender Studies, University of Ottawa, Ottawa, ON. Richard Elliott is with the HIV Legal Network, Toronto, ON. Marilou Gagnon is with the School of Nursing, University of Victoria, Victoria, BC. Stephen Mollidrem is with the Department of Anthropology, University of California, Irvine.

See also Morabia, p. 1175, Landers et al., p. 1180, and the HIV/AIDS and Our World: 1981–2021 section, pp. 1231–1266.

Public health institutions are playing an increasingly central role in everyday life as part of the response to the COVID-19 pandemic (e.g., through stay-at-home orders, contact tracing, and the enforcement of disease control measures by law enforcement). In light of this, we consider how COVID-19 disparities and disease control practices intersect with the response to the more longstanding epidemic of HIV infection in Canada and the United States.

In a series of developments that predate COVID-19, the HIV response has been shaped by advances in antiretroviral treatment that made HIV infection a manageable condition for people with continuous access to high-quality health care. However, the HIV response has also involved the

emergence of novel forms of public health surveillance, sometimes punitive disease control measures, and criminalization measures that have been criticized by people living with HIV and critical public health scholars.¹ Developments in this area include the increased use of novel forms of phylogenetic analysis and molecular surveillance without individual consent or community consultation. In 2020, multiple epidemiological research groups published articles noting that they have begun to use phylogenetic analysis of HIV genetic sequence data (also called “molecular” HIV data) to infer the direction of HIV transmission between two individuals (i.e., to discern if “person A” transmitted HIV to “person B”) with greater precision than was previously

possible.² This has raised concerns about how analyses of these data may propel prosecution of alleged HIV transmission or nondisclosure.³

In the context of COVID-19, we have also witnessed enhanced collaboration between police and public health as well as an expansion of policing in response to the pandemic. Critical public health scholarship⁴ can help make sense of how criminal law, the logics of criminalization, and public health work may be converging in new ways. As critical public health scholars, we argue that critical public health research agendas in this area can have the most impact when they (1) center race and racism, (2) investigate how public health surveillance technologies operate across key HIV disparity groups and across health systems (i.e., on the body, in laboratories, in health departments, and in care settings), and (3) enhance understandings of carceral public health practices.

RACE AND RACISM

To meaningfully address the convergence of HIV-prevention technologies, public health surveillance, HIV criminalization, and coercive public health measures, it is imperative to foreground how these practices can come to bear in particularly harsh ways on communities of Black and Indigenous people and people of color. Seemingly neutral public health activities, such as outreach informed by molecular surveillance data, may extend the disproportionate and ever-present forms of surveillance and regulation that communities of Black and Indigenous people and people of color already face.⁵ In the context of COVID-19, data released by police in multiple jurisdictions show that Black people and people of color are more likely to be targeted by COVID-19

emergency laws than are White people.⁶ New forms of racial profiling and targeting linked to COVID-19 disease control reflect entrenched racism in institutions of policing and show how law enforcement can intersect with public health in harmful ways.

Critical public health researchers can support efforts to combat racism by collecting data about racism. Sociologist of science and technology Ruha Benjamin shows how studying systemic racism means shifting the research lens toward powerful institutions that are involved in the production of vulnerability and risk.⁷ This approach has been modeled by activists and researchers who call attention to how the science of HIV infection treatment and prevention tools relate to HIV criminal laws. Activists express concerns about how inserting the language of viral “undetectability” into a law can exclude or further disadvantage those who experience structural harms.⁸ Studies should call greater attention to how having undetectable HIV serostatus is a privileged position only achievable to those with access to care and basic necessities and should also center the impact of racism in housing instability, food insecurity, lack of transportation, lack of medication and health care access, and inadequate social supports. Critical public health research and advocacy should aim to support efforts to equalize these social determinants of health, which are crucial to helping people living with HIV reach and sustain an undetectable viral load.

HIV SURVEILLANCE TECHNOLOGY

There is little social science research on how public health surveillance technologies actually operate in practice and the impact such technologies have on

individuals and communities of people living with HIV.⁹ One way to address this gap is through critical studies of how public health agencies collect, store, and circulate personal information about one’s HIV status in particular jurisdictions. By studying how surveillance mechanisms produce and circulate knowledge about segments of the population, critical research can hold up for public analysis and scrutiny the technologies that are used to monitor, control, and regulate behaviors, with a focus on groups made marginalized by structural conditions.¹⁰ Findings can also contribute to broader demands for public health practices to be proportionate, informed by scientific evidence, and in-line with human rights principles and the specific needs of different key populations.¹¹

In addition to uncovering how public health surveillance infrastructures collect and distribute public health data, critical public health research can advance political movements that aim to mobilize alternative uses of data. For example, Data for Black Lives is consolidating state-level data to examine the disproportionate impact of COVID-19 on Black people in the United States. The group centers an effort to “avoid weaponizing COVID-19 data” by specifying that data “should not be used to surveil, criminalize, cage, and/or deny critical benefits” and should instead inform a reparative stimulus plan and long-term structural change.¹²

In Canada, Indigenous leaders and researchers have emphasized that Indigenous public health responses to COVID-19 must be self-determined and connected to the work of decolonizing health care. Such public health approaches ought to be, per Canadian public health scholars Lisa Richardson and Allison Crawford, “informed by ongoing monitoring of data as governed by appropriate data sovereignty agreements”¹³(pE1100) and a

commitment to redressing colonial health disparities. Yeshimabeit Milner argues that the goal is to “make data a tool for profound social change instead of a weapon of political oppression.”¹⁴ This sentiment is highly relevant to both HIV and COVID-19, although the respective pathogens causing these diseases and how they are managed are fundamentally different from one another.

CARCERAL PUBLIC HEALTH

We understand “carceral public health practices” as coercive public health interventions that use tools, technologies, and forms of reasoning from the realm of criminal law to respond to public health issues. We discuss this in previous examples related to HIV and COVID-19; however, carceral public health practices are also found in responses to sex work, the opioid crisis, and other areas. Studies examining the convergence of public health and criminal law should be grounded in the experiences and perspectives of people who have been targets of coercive public health interventions.

Such research should also address the specific policy mechanisms and infrastructures that facilitate the expansion of carceral public health apparatuses. Critical studies of carceral public health practices can help to inform community-based responses by advocating the maintenance of transparent, consistent, and clear boundaries between public health and criminal law. This is a pressing issue in the midst of the COVID-19 pandemic, considering that at the outset of the pandemic, health departments in various US and Canadian jurisdictions were sharing identifiable COVID-19 diagnosis information with police forces

under rules newly established under emergency measures.⁶ Studies should identify best practices for public health agencies to limit the spread of personal health data to criminal justice system actors and illuminate the harms that emerge when distinctions between public health and criminal law enforcement are blurred.⁶

Researchers can adopt what critical public health scholars have referred to as a “critical social science with public health perspective.”¹⁵ Such an approach seeks opportunities for research that engages with public health to transform public health practice; it seeks to lessen the harmful effects, while contributing to critical social science. This work may begin by identifying public health ally practitioners who understand how public health and criminal law convergences come to bear on the social determinants of health of individuals who are subject to enhanced public health interventions. These ally practitioners may then become research participants or be better positioned to translate critical public health research in their workplaces.

CONCLUSIONS

We are concerned about how the punitive enforcement of public health measures in some jurisdictions may challenge human rights standards and propel carceral responses similar to those that have emerged in response to HIV.¹¹ Particularly in light of the expansion of public health during the COVID-19 pandemic, we endorse a research and practice agenda that focuses on the social determinants of health, centers on the human rights of people living with and affected by HIV and other communicable and infectious diseases (particularly those who already experience structural harm), and broadens

knowledge about public health surveillance. Critical HIV public health researchers who are interested in following the changing conditions in the HIV treatment, prevention, and criminalization landscapes can use these lessons to benefit other health issues and communities. We hope that the parameters laid out in this editorial are useful for carrying this work forward.

AJPH

CORRESPONDENCE

Correspondence should be sent to Colin Hastings, Concordia University Department of Sociology & Anthropology, 1455 De Maisonneuve Blvd W, Montreal, QC H3G 1M8, Canada (e-mail: colin.hastings@mail.concordia.ca). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

PUBLICATION INFORMATION

Full Citation: Hastings C, McClelland A, Guta A, et al. Intersections of treatment, surveillance, and criminal law responses to HIV and COVID-19. *Am J Public Health*. 2021;111(7):1252–1254.

Acceptance Date: February 13, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306236>

CONTRIBUTORS

The authors contributed equally to this editorial.

ACKNOWLEDGMENTS

This work was supported by the Canadian Institute of Health Research (grant 422342; principal applicants A. G. and A. M.). A. Guta is further supported by a University of Windsor Humanities Research Group fellowship.

The authors wish to thank the anonymous reviewers and editors at *AJPH* for their valuable reviews and support throughout the publication process of this editorial.

CONFLICTS OF INTEREST

There are no potential or actual conflicts of interest to declare.

REFERENCES

- McClelland A, Guta A, Gagnon M. The rise of molecular HIV surveillance: implications on consent and criminalization. *Crit Public Health*. 2020; 30(4):487–493. <https://doi.org/10.1080/09581596.2019.1582755>
- Taylor BS, Sapién H. Determining the direction of human immunodeficiency virus transmission: benefits and potential harms of taking phylogenetic analysis one step further. *Clin Infect Dis*. 2021; 72(1):38–40. <https://doi.org/10.1093/cid/ciz1248>
- Galletly CL, Benbow N, Killela A, Lazzarini Z, Edwards R. Considerations for modernized criminal HIV laws and assessment of legal protections against release of identified HIV surveillance data for law enforcement. *Am J Public Health*. 2020;109(11):1576–1579. <https://doi.org/10.2105/AJPH.2019.305284>
- Eakin J, Robertson A, Poland B, Coburn D, Edwards R. Towards a critical social science perspective on health promotion research. *Health Promot Int*. 1996;11(2):157–165. <https://doi.org/10.1093/heapro/11.2.157>
- Dunbar A, Jones N. Race, police, and the pandemic: considering the role of race in public health policing. *Ethn Racial Stud*. 2021;44(5):773–782. <https://doi.org/10.1080/01419870.2020.1851381>
- Moldrem S, Hussain MI, McClelland A. Alternatives to sharing COVID-19 data with law enforcement: recommendations for stakeholders. *Health Policy*. 2021;125(2):135–140. <https://doi.org/10.1016/j.healthpol.2020.10.015>
- Abdillahi I, Benjamin R, Cole D, James L. Race-based data, AI, COVID-19 & Black well-being: why data literacy matters during the pandemic and beyond. Presented at: COVID Conversations Symposium. YouTube; May 29–30, June 4–6, 2020.
- Center for HIV Law & Policy. Consensus statement on HIV “treatment as prevention” in criminal law reform. 2017. Available at: <https://www.hivlawandpolicy.org/resources/consensus-statement-hiv-treatment-as-prevention-criminal-law-reform-2017>. Accessed April 13, 2021.
- Moldrem S, Smith AK. Reassessing the ethics of molecular HIV surveillance in the era of cluster detection and response: toward HIV data justice. *Am J Bioeth*. 2020;20(10):10–23. <https://doi.org/10.1080/15265161.2020.1806373>
- French M, Smith G. “Health” surveillance: new modes of monitoring bodies, populations, and politics. *Crit Public Health*. 2013;23(4):383–392. <https://doi.org/10.1080/09581596.2013.838210>
- Mykhalovskiy E, Kazatchkine C, Foreman-Mackey A, et al. Human rights, public health, and COVID-19 in Canada. *Can J Public Health*. 2020;111(6):975–979. <https://doi.org/10.17269/s41997-020-00408-0>
- Data for Black Lives. The impact of COVID-19 on Black communities. 2020. Available at: <https://d4bl.org/covid19-data>. Accessed April 13, 2021.
- Richardson L, Crawford A. COVID-19 and the decolonization of Indigenous public health. *CMaj*. 2020;192(38):E1098–E1100. <https://doi.org/10.1503/cmaj.200852>
- Milner Y. Abolish Big Data. March 4, 2020. Available at: <https://datasociety.net/library/abolish-big-data>. Accessed April 13, 2021.
- Mykhalovskiy E, Frohlich KL, Poland B, Di Ruggiero E, Rock MJ, Comer L. Critical social science with public health: agonism, critique and engagement. *Crit Public Health*. 2019;29(5):522–533. <https://doi.org/10.1080/09581596.2018.1474174>

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Ending HIV in the United States Is Possible With the Proper Leadership and Sufficient and Targeted Resources

Carl Schmid, MBA, BA

ABOUT THE AUTHOR

Carl Schmid is with the HIV and Hepatitis Policy Institute, Washington, DC.

🔗 See also Morabia, p. 1175, Landers et al., p. 1180, and the HIV/AIDS and Our World: 1981–2021 section, pp. 1231–1266.

After 40 years of living and, sadly, dying with HIV, the United States has become rather complacent. Perhaps this is partially attributable to our own success in treating, preventing, and responding to HIV. But imagine if we allowed another deadly infectious disease, such as COVID-19, to continue to spread for 40 years without investing the attention and resources needed to wipe it out. We must end this dangerous cycle, and we can with the right tools and leadership. But will we?

It is indisputable that combatting HIV/AIDS has been one of the modern miracles of medicine and that the scientific advances made have propelled what was once a likely deadly disease into a manageable chronic condition if people have access to health care and medications. The innovative treatment advances have brought the number of yearly infections from a high of 130 000 in the mid-1980s¹ to about 37 000 in 2018.² Although this demonstrates progress, the number of annual infections has been relatively stagnant since 2014.³

It is now estimated that there are 1.2 million people in the United States living with HIV/AIDS,⁴ an incurable infectious disease that left untreated can kill and infect others. Sadly, there are still nearly 16 000 people with HIV/AIDS who die each year.⁵ We now have the testing and treatment technologies that allow people to live with HIV, but that entails a lifetime of medications and a disruption of people's lives and their families. We can and must do better.

FEDERAL INITIATIVES

The recent federal Ending the HIV Epidemic initiative,⁶ which focuses on high-priority jurisdictions and the most affected communities, provides a roadmap for potential success. It ramps up testing and prevention, including preexposure prophylaxis (PrEP) and syringe service programs, and treatment that leads to viral suppression. It builds on the existing programs that people living with HIV and their advocates have successfully created through decades of

AIDS activism. This includes the Ryan White HIV/AIDS Program (<https://bit.ly/2Sfk4hQ>), which provides care, treatment, and support services for low-income people living with HIV, and HIV prevention programs at the Centers for Disease Control and Prevention,⁷ which fund testing, surveillance, education, condom distribution programs, and now PrEP outreach and syringe services. For people living with HIV who need housing, there is the Housing Opportunities for People With AIDS program,⁸ and for ongoing innovative breakthroughs, the National Institutes of Health has an extensive AIDS research program.

Altogether, the US government spends \$35 billion annually for HIV.⁹ Although most of it is through Medicaid and Medicare, few single diseases have such a high level of dedicated resources. Even with all these resources, it is not enough to end HIV. So, what is needed to end HIV and how can we do better with the current dedicated resources?

WHAT IS NEEDED TO END HIV

The Obama administration issued the nation's first comprehensive national HIV/AIDS strategy,¹⁰ which included the necessary elements to make positive change that was propelled with supportive policies, including the Affordable Care Act.¹¹ There was a focus on the communities most affected, including Black and Hispanic/Latino gay men and Black women, and a better allocation of prevention funding to meet the needs of the Southern region of the United States. But because few additional dollars were allocated, progress fell short.

Despite all of its failures—including attacks on health care, transgender rights, and immigrants—the Trump administration launched the Ending the

HIV Epidemic initiative, which provided leadership and financial resources to jurisdictions and resulted in Congress appropriating more than \$400 million in new funding.¹² Despite well-deserved community distrust, state and local governments, along with community-based organizations, began talking seriously about ending HIV. This was particularly important in conservative Southern states, where stigma against HIV remains high. However, the COVID-19 pandemic hit HIV efforts hard and slowed the momentum. In the final days of the administration, the HIV National Strategic Plan¹³ was released, providing a more detailed roadmap to end HIV nationwide. Now it will be up to the Biden administration to implement it.

THE BIDEN ADMINISTRATION

President Biden's priorities include the COVID-19 crisis, strengthening our health care system, and addressing racial, ethnic, and other inequities, such as those experienced by the lesbian, gay, bisexual, transgender, and questioning (LGBTQ) community. These priorities are conducive to continued progress in ending HIV. However, we cannot miss this opportunity to advance significant change; if we continue to do the same thing we have been doing, we will never achieve better outcomes.

In a stroke of bipartisanship, something President Biden has repeatedly said he strongly believes in, he should adopt the Ending the HIV Epidemic initiative, invest the increased resources needed to achieve its goals, and take the necessary steps to build community support and partnerships. In his first preliminary budget request (<https://bit.ly/3gYwART>), President Biden highlighted a number of priorities and, to the

relief of AIDS advocates, included continuing the Ending the HIV Epidemic initiative. Although his proposed funding levels fell short of what the Trump administration proposed, Biden is asking Congress to increase funding for the initiative by \$267 million. The budget proposal demonstrates an initial commitment to ending HIV. In the coming months, we will learn how much attention and energy the administration puts behind the initiative.

PROPOSED CHANGES FOR THE FUTURE

Moving forward, the initiative, including its resources, should focus on gay men of color and in the South, as most new infections are among this group and in this region. President Biden has issued the executive order Advancing Racial Equity and Support for Underserved Communities,¹⁴ which asks for a review of government programs and proposed changes for improvements. Existing domestic HIV programs focus primarily on racial and ethnic communities, the poor, and LGBTQ folks. But we must do better to end HIV.

The Ryan White HIV/AIDS Program is a model program that—working with existing health coverage programs such as private insurance, Medicaid, and Medicare—provides care, medications, and support services that address the social determinants of health, and helps improve drug adherence and health outcomes. Sixty-one percent of their clients have a poverty level of 100% or below, nearly 74% of their clients represent communities of color, and the viral suppression rate for Black and Hispanic/Latino clients is 84.1% and 89.1%, respectively, just slightly lower than the viral suppression rate for White clients of

91%.¹⁵ The Ryan White Program's success is key to ending HIV.

Almost all Ryan White Program funding by law is distributed based on the number of people living with HIV in a particular jurisdiction, which means that underserved areas, such as those in the South, where many people of color reside, receive the same amount of funding as high-resourced areas. These communities are already dealing with limited Medicaid programs, and unfortunately state leaders have chosen not to expand Medicaid. Although I hope that will change, they are still underserved and deserve more resources from the Ryan White Program as well as HIV prevention and community health center funding, particularly because that is where the funding for PrEP resides.

The Ending the HIV Epidemic initiative got it right by first dedicating new resources to where more than 50% of HIV diagnoses occur (<https://bit.ly/3ect4Sa>). To lay the groundwork, funding was distributed based on case counts. However, because the initiative is not tied to funding formulas, the Biden administration should evaluate how future funding is distributed to better address the needs of underserved communities. Because all these jurisdictions already receive funding from the various historic domestic HIV programs, in the future the Ending the HIV Epidemic program should consider those resources as they carry out their programs. At the same time, we need to examine existing programs to determine how their funding is being used and distributed. No matter the program, all need to be held accountable for their spending and results. If certain areas need more funding and technical assistance, they should receive it. The funding must follow the data.

New medications, such as long-acting treatment and PrEP, will help achieve the

goal of ending HIV easier. Hopefully, the new technologies developed to deliver vaccines for COVID-19 can be used to develop an HIV vaccine. Companies and research institutions are also working on cure research.

COVID-19 has shed a light on the weak public health infrastructure of the United States and demonstrated the value of having a robust health care system. Hopefully, the federal government will invest the resources needed to build it up. This will benefit our response to not only HIV but other infectious diseases, such as hepatitis and diseases that we do not even know about today. Our government and communities cannot tackle these epidemics in silos but must approach them comprehensively as a syndemic. Funding streams make that difficult, but accommodations must be made.

We can end HIV, but it will take the right leadership, and sufficient resources, prioritized for those who need them most. *AJPH*

CORRESPONDENCE

Correspondence should be sent to Carl Schmid, Executive Director, HIV+Hepatitis Policy Institute, 1602B Belmont St NW, Washington, DC 20009 (e-mail: cschmid@hivhep.org). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Schmid C. Ending HIV in the United States is possible with the proper leadership and sufficient and targeted resources. *Am J Public Health*. 2021;111(7):1255–1257.

Acceptance Date: April 15, 2021

DOI: <https://doi.org/10.2105/AJPH.2021.306349>

CONFLICTS OF INTEREST

The author has no conflicts of interest to declare.

REFERENCES

- Hall HI, Song R, Rhodes P, et al. Estimation of HIV incidence in the United States. *JAMA*. 2008;300(5):520–529. <https://doi.org/10.1001/jama.300.5.520>
- Centers for Disease Control and Prevention. Diagnoses of HIV infection in the United States and dependent areas, 2018: diagnoses. May 2020. Available at: <https://www.cdc.gov/hiv/library/reports/hiv-surveillance/vol-31/content/diagnoses.html>. Accessed February 10, 2021.
- Centers for Disease Control and Prevention. Estimated HIV incidence and prevalence in the United States, 2014–2018. HIV Surveillance Supplemental Report. 2020;25(1). Available at: <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Accessed February 10, 2021.
- HIV.gov. U.S. statistics. June 30, 2020. Available at: <https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics>. Accessed February 10, 2021.
- Centers for Disease Control and Prevention. HIV basics. January 27, 2021. Available at: <https://www.cdc.gov/hiv/basics/statistics.html>. Accessed February 10, 2021.
- HIV.gov. What is ending the HIV epidemic in the U.S.? Ending the HIV epidemic: a plan for America: overview. Available at: <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview>. Accessed February 10, 2021.
- Centers for Disease Control and Prevention. HIV prevention in the United States: mobilizing to end the epidemic. February 2, 2021. Available at: <https://www.cdc.gov/hiv/pdf/policies/cdc-hiv-prevention-bluebook.pdf>. Accessed May 2, 2021.
- US Department of Housing and Urban Development. Housing opportunities for people with AIDS (HOPWA). Available at: <https://www.hud.gov/hudprograms/hopwa>. Accessed February 10, 2021.
- Kaiser Family Foundation. The HIV/AIDS epidemic in the United States: the basics. March 25, 2019. Available at: <https://www.kff.org/hivaids/fact-sheet/the-hivaids-epidemic-in-the-united-states-the-basics>. Accessed February 10, 2021.
- White House, President Barack Obama. National HIV/AIDS strategy for the United States. July 2010. Available at: <https://obamawhitehouse.archives.gov/sites/default/files/uploads/NHAS.pdf>. Accessed February 10, 2021.
- US Department of Health and Human Services. About the Affordable Care Act. March 23, 2021. Available at: <https://www.hhs.gov/healthcare/about-the-aca/index.html>. Accessed May 2, 2021.
- HIV.gov. Ending the HIV epidemic funding. January 12, 2021. Available at: <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/funding>. Accessed May 2, 2021.
- HIV.gov. HIV national strategic plan (2021–2025). January 15, 2021. Available at: <https://www.hiv.gov/federal-response/hiv-national-strategic-plan/hiv-plan-2021-2025>. Accessed February 10, 2021.
- White House. Executive order on advancing racial equity and support for underserved communities through the federal government. January 20, 2021. Available at: <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/20/executive-order-advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government>. Accessed February 10, 2021.
- Health Resources and Services Administration. Ryan White HIV/AIDS Program: Annual Client-Level Data Report. 2018. December 2019. Available at: <https://hab.hrsa.gov/sites/default/files/hab/data/data-reports/RWHAP-annual-client-level-data-report-2018.pdf>. Accessed February 11, 2021.

Gun Violence Prevention: A Public Health Approach

Edited By: Linda C. Degutis, DrPH, MSN, and Howard R. Spivak, MD



Gun Violence Prevention: A Public Health Approach acknowledges that guns are a part of the environment and culture. This book focuses on how to make society safer, not how to eliminate guns. Using the conceptual model for injury prevention, the book explores

the factors contributing to gun violence and considers risk and protective factors in developing strategies to prevent gun violence and decrease its toll. It guides you with science and policy that make communities safer.

2021, SOFTCOVER, 230 PAGES, 9780875531117



Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

HIV's Trajectory: Biomedical Triumph, Structural Failure

Leo Beletsky, JD, MPH, Meaghan Thumath, MScPH, BSN, RN, Danielle F. Haley, PhD, MPH, Gregg Gonsalves, PhD, and Ayana Jordan, MD, PhD

ABOUT THE AUTHORS

Leo Beletsky is with the School of Law, Bouvé College of Health Sciences, and Health in Justice Action Lab, Northeastern University, Boston, MA, and the Division of Infectious Disease and Global Public Health, University of California San Diego School of Medicine, La Jolla, CA. Meaghan Thumath is with the School of Nursing, Faculty of Applied Science, University of British Columbia, Vancouver, BC, and the Centre for Evidence Based Intervention, Department of Social Policy and Intervention, University of Oxford, Oxford, UK. Danielle F. Haley is with School of Public Health, Boston University, Boston, MA. Gregg Gonsalves is with Yale School of Public Health, New Haven, CT. Ayana Jordan is with the Yale University School of Medicine, New Haven, CT.

See also Morabia, p. 1175, Landers et al., p. 1180, and the HIV/AIDS and Our World: 1981–2021 section, pp. 1231–1266.

The evolution of HIV care since the reporting of the first cases of what was called “Gay-Related Immune Deficiency” 40 years ago has been truly remarkable. In the early years of the AIDS crisis, fervent advocacy from social movements rapidly transformed biomedical research. Accelerated drug development, regulatory change, and improved ability to parse toxic experimental treatments from medications that are safe and effective all improved the HIV response. In time, focus shifted to treatment as prevention. Improvements in the “HIV care continuum” helped save many lives, reframing HIV from a death sentence to a manageable chronic condition.

But the trajectory of HIV is as much a story of biomedical triumph as it is a story of abject structural failure. Despite remarkable scientific advances, this epidemic has persisted and morphed, placing an increasing burden on our society's most vulnerable. Early gains

have stalled in the United States and around the world. New hotspots are emerging, with a disproportionate impact on minoritized and stigmatized populations, especially people who use drugs (PWUD).¹ As PWUD and other key populations have not benefited equally from biomedical advances, infection control targets remain out of reach.

TODAY'S HIV EPIDEMIC

From the early days, substance use has remained one of HIV's principal risk factors. As of 2018, people who inject drugs are 22 times more likely to acquire HIV than is the general population.² This is further exacerbated among minoritized racial and ethnic groups, who continue to face a disproportionate burden of new infections and HIV-related disease.³ Although the proportion of new cases attributed to injection drug use was decreasing, there is now an increase in cases

among people who inject drugs in parallel with the overdose crisis. As injection-related drug consumption has expanded to new settings, both urban and rural areas have seen new outbreaks.⁴

Substance use also increases HIV risk among those who do not inject drugs. A number of mechanisms explain why substance use affects HIV risk. These include biological vulnerability to seroconversion during drug consumption and sexual activities. For instance, among women who use substances, HIV seroincidence was five times that of the general population.⁵ Substance use also shapes HIV risk through situational contexts and social networks. However, a major source of the HIV risk environment for PWUD emanates from policies related to substance use and other kinds of addiction.

DRUG POLICY'S TOXIC ROLE

Often billed as population-level “remedies,” laws and other policies play a central role as responses to societal ills. These include public health challenges, whereby policies across institutions and governments shape disease prevention, control, and treatment. Despite the “remedy” moniker, however, claims rationalizing drug policies rarely receive sufficient scrutiny. Partly as a result of the AIDS crisis, reasonably robust systems of biomedical research and regulatory approval are now in place to ensure that medical remedies for individuals are safe and effective before they hit the market. By contrast, little protection currently exists to shield communities from ineffective, even toxic, policies.

Of course, the “policy remedy” metaphor is limited by the marked differences in how policy measures are generated, adopted, and analyzed. Their remedial public health function is complicated by the reality that policies are developed with a diverse—and often conflicting—set of motivations, rationales, biases, and technical expertise. Empirical research continues to play a limited role in policy formation; certainly nothing akin to a regulatory gatekeeper is available to evaluate potential benefits and harms of proposed policy solutions. As a result, poorly designed policies and gaps in their implementation often limit street-level benefits. Policies’ collateral harms are seldom systematically documented; when known, they are too often ignored.⁶

Drug laws in the United States aptly exemplify a policy arena where many interventions are neither safe nor effective.⁷ Spurred by racism and xenophobia, the United States has charted a hyperpunitive path in regulating certain forms of substance use for nearly a century.⁸ This approach has failed to exert meaningful “control” over supplies or problematic use. Instead, it cascades to iatrogenic detriment, including fueling crisis levels of HIV, hepatitis, and overdose.⁷ It has caused broader structural damage, with a disproportionate impact on Black, Indigenous, and Latinx people, including the extensive harms of mass incarceration, environmental degradation, and the crowding out of resources for health and supportive programming. The United States has exported its toxic approach globally by transplanting its drug policies to and imposing them on other countries—sometimes using direct force.

There are numerous examples of drug policies hampering HIV response. Laws criminalizing possession and distribution of injection equipment have

directly fueled transmission among people who inject drugs. Incarceration for drug-related and other substance use-related charges have detrimentally affected the continuum of care, including adherence to treatment and access to prevention (e.g., preexposure prophylaxis) for people living with HIV. Disruptions in substance use disorder treatment not only adversely affect adherence to HIV pharmacotherapy and prevention, but also sharply amplify the risk of overdose on reentry.

By codifying stigma, these policies have also resulted in a separate and unequal system of care for addiction. The byzantine regulation of opioid agonist therapy has reduced access and increased racial disparities.⁹ Relatedly, the reliance on criminalizing women who use drugs has also fueled family separation and traumatic foster care removals for Black and Indigenous communities, disproportionately increasing intergenerational trauma, overdose, and HIV risk.¹⁰

The criminalization of substance use also affects broader access to health care. This limits the availability of psychotherapies and other modalities to treat cocaine, alcohol, and various substance use disorders, including the use of psychedelics. Various administrative gaps, stigma, and other factors limit the integration of HIV and hepatitis screening and pharmacotherapy with substance use treatment. Discriminatory zoning and other enforcement policies further marginalize PWUD from essential health and social services. Punitive policies also affect structural supports for PWUD and others in their communities and social networks. This includes availability of housing, employment, and social assistance, such as supplementary income and food programs.

Despite ample scientific knowledge about what works, legal barriers have suppressed the number and scope of syringe services and other harm-reduction programs. Well-researched interventions that reduce the risk of HIV and other drug-related harms, such as syringe services, have remained limited by policy constraints. Supervised consumption facilities, provision of injectable opioid agonist therapy, and other safe supply options available elsewhere globally have yet to be authorized in the United States. This has resulted in significant excess morbidity and mortality, including recent HIV outbreaks in Indiana, West Virginia, and Massachusetts.⁴ Gains in expanding services for PWUD have often been reversed on ideological grounds; for harm reduction in the United States, progress has often been one step forward, two steps back.⁸ The only thing more tragic than shuttering vital harm reduction program that could prevent HIV outbreaks is aborting services that had successfully brought such outbreaks under control; and yet, Scott County, Indiana, recently did just that (<https://bit.ly/3xmiTKO>).

Despite successful linking, retaining, and managing patients with HIV on antiretroviral therapy, substance use disorder treatment access remains low. By failing to diagnose and to engage and sustain significant proportions of people in evidence-based treatment, we are failing patients at every step. This results in surging levels of overdose, HIV, and other outcomes with a disproportionate impact on racialized groups.³

The toxic consequences of policy go beyond formal law. Law enforcement functions as an important mediator of the impact of policies on health risk. Research has shown that policing practices can and do block access to syringe

distribution, condoms, and other harm-reduction and treatment services for PWUD.^{6,11} Based on persistent racial gradients in drug law enforcement, police encounters translate into racial disparities in HIV risk and seroconversion.⁷

In democratic societies, policies are amenable to feedback through participatory processes.¹² But pernicious legal and logistical barriers have blocked such possibilities by systematically excluding PWUD, especially minoritized populations, from civic participation. Disenfranchisement has created the inability to select representatives who craft drug and broader policies to advance, rather than hamper, public health gains.¹³

SHIFTING THE POLICY ENVIRONMENT

Currently, a failed drug policy framework blocks our ability to achieve key HIV-control targets. Our 2030 goals will require not only eradicating toxic laws but also addressing the downstream effects of these policies.¹⁴

Progress in HIV prevention and treatment among PWUD demands major policy reforms. Because the very purpose of criminal law is to stigmatize, there can be little progress on stigma reduction without reforming criminal law. Statewide drug decriminalization in Oregon along with local efforts indicate growing momentum for positive change.⁸ Policies outside criminal law must also relinquish punitive, stigmatizing, and intrusive approaches to substance use now dominant in family, housing, education, immigration, voting, and numerous other legal arenas.^{14,15}

Although formal policy reform is vital, it alone is not sufficient. Advances in HIV response must also engage the intersectional movements to reform

policing that are now unfolding globally.⁸ Reclaiming resources from carceral, racist systems creates opportunities to address the root causes of drug use, namely early childhood trauma, poverty, homelessness, and violence.¹⁴

As with biomedical advances, there is a positive feedback loop between scientific progress, social movements, and government action. Given the extensive evidence of iatrogenesis in current approaches, what is needed now more than ever is a major social movement to relegate these toxic policies to the dustbin of history; ending HIV depends on it. *AJPH*

CORRESPONDENCE

Correspondence should be sent to Leo Beletsky, Professor of Law and Health Sciences, Northeastern University School of Law, 400 Huntington Ave, Boston, MA 02115 (e-mail: beletsky@northeastern.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Beletsky L, Thumath M, Haley DF, Gonsalves G, Jordan A. HIV's trajectory: biomedical triumph, structural failure. *Am J Public Health*. 2021;111(7):1258–1260.

Acceptance Date: April 15, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306354>

CONTRIBUTORS

L. Beletsky conceptualized and drafted the editorial, with input from M. Thumath, D. F. Haley, G. Gonsalves, and A. Jordan. All authors contributed to writing and editing the editorial.

ACKNOWLEDGMENTS

M. Thumath is supported by a doctoral grant from the Pierre Elliot Trudeau Foundation.

The authors gratefully acknowledge Justine Law for able research assistance.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

REFERENCES

- Des Jarlais DC, Bramson HA, Wong C, et al. Racial/ethnic disparities in HIV infection among people who inject drugs: an international systematic review and meta-analysis. *Addiction*. 2012;107(12):2087–2095. <https://doi.org/10.1111/j.1360-0443.2012.04027.x>
- Joint United Nations Programme on HIV/AIDS. Miles to go: closing gaps, breaking barriers, righting injustices. August 13, 2018. Available at:

<https://www.unaids.org/en/resources/documents/2018/global-aids-update>. Accessed May 13, 2021.

- Cooper HLF, Linton S, Kelley ME, et al. Racialized risk environments in a large sample of people who inject drugs in the United States. *Int J Drug Policy*. 2016;27:43–55. <https://doi.org/10.1016/j.drugpo.2015.07.015>
- Centers for Disease Control and Prevention. Notes from the field: outbreak of human immunodeficiency virus infection among persons who inject drugs—Cabell County, West Virginia, 2018–2019. *MMWR Morb Mortal Wkly Rep*. 2020;69(16):499–500. <https://doi.org/10.15585/mmwr.mm6916a2>
- Frew PM, Parker K, Vo L, et al. Socioecological factors influencing women's HIV risk in the United States: qualitative findings from the women's HIV Seroincidence study (HPTN 064). *BMC Public Health*. 2016;16(1):803. <https://doi.org/10.1186/s12889-016-3364-7>
- DeBeck K, Cheng T, Montaner JS, et al. HIV and the criminalisation of drug use among people who inject drugs: a systematic review. *Lancet HIV*. 2017;4(8):e357–e374. [https://doi.org/10.1016/S2352-3018\(17\)30073-5](https://doi.org/10.1016/S2352-3018(17)30073-5)
- Strathdee SA, Beletsky L, Kerr T. HIV, drugs and the legal environment. *Int J Drug Policy*. 2015;26(suppl 1):S27–S32. <https://doi.org/10.1016/j.drugpo.2014.09.001>
- del Pozo B, Beletsky L. No "back to normal" after COVID-19 for our failed drug policies. *Int J Drug Policy*. 2020;83:102901. <https://doi.org/10.1016/j.drugpo.2020.102901>
- James K, Jordan A. The opioid crisis in Black communities. *J Law Med Ethics*. 2018;46(2):404–421. <https://doi.org/10.1177/1073110518782949>
- Thumath M, Humphreys D, Barlow J, et al. Overdose among mothers: the association between child removal and unintentional drug overdose in a longitudinal cohort of marginalised women in Canada. *Int J Drug Policy*. 2020; Epub ahead of print. <https://doi.org/10.1016/j.drugpo.2020.102977>
- Shannon K, Strathdee SA, Shoveller J, Rusch M, Kerr T, Tyndall MW. Structural and environmental barriers to condom use negotiation with clients among female sex workers: implications for HIV-prevention strategies and policy. *Am J Public Health*. 2009;99(4):659–665. <https://doi.org/10.2105/AJPH.2007.129858>
- Béland D. Reconsidering policy feedback: how policies affect politics. *Adm Soc*. 2010;42(5):568–590. <https://doi.org/10.1177/0095399710377444>
- Haley DF, Edmonds A, Schoenbach VJ, et al. Associations between county-level voter turnout, county-level felony voter disenfranchisement, and sexually transmitted infections among women in the Southern United States. *Ann Epidemiol*. 2019;29:67–73.e1. <https://doi.org/10.1016/j.annepidem.2018.10.006>
- Park JN, Rouhani S, Beletsky L, Vincent L, Saloner B, Sherman SG. Situating the continuum of overdose risk in the social determinants of health: a new conceptual framework. *Milbank Q*. 2020;98(3):700–746. <https://doi.org/10.1111/1468-0009.12470>
- Wakeman SE, Jordan A, Beletsky L. When reimagining systems of safety, take a closer look at the child welfare system. *Health Affairs Blog*. Available at: <https://www.healthaffairs.org/doi/10.1377/hblog20201002.72121/full>. Accessed May 13, 2020.

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

The Importance of Social Movements: A Student Perspective on HIV/AIDS

Christopher N. Garcia-Wilde

ABOUT THE AUTHOR

The author is with the Miller School of Medicine, University of Miami, Miami, FL.

See also Morabia, p. 1175, Landers et al., p. 1180, and the HIV/AIDS and Our World: 1981–2021 section, pp. 1231–1266.

As a community organizer and medical student, I study social movements and their effects on public health. My understanding of social movements helps me build trust with patients and anticipate structural barriers they navigate. The histories of HIV/AIDS activism that I have come across are brimming with lessons that inform my understanding of the pandemic and should shape our approaches to ending it. One historical moment that is relatively forgotten but especially relevant today is the case of the world's first HIV prison camp.

THE FIRST HIV PRISON CAMP

Following the military coup of Haitian president Jean Bertrand Aristide in 1991, thousands of Haitian refugees fled on boats headed for the United States. Among these refugees was a Haitian woman named Yolande Jean who had been organizing adult literacy programs before she was arrested and beaten by Haitian military officials.¹ Yolande Jean experienced a miscarriage from her injuries and sought asylum in the United States.² Unfortunately, she and the other refugees who fled to-

gether were captured by the United States Coast Guard after just two days at sea.¹ They were taken to Guantanamo Bay and tested for HIV upon arrival. Yolande Jean and about 250 Haitian refugees who tested positive were separated and held in the world's first prison camp for HIV-positive refugees, known as Camp Bulkeley.

While held at the HIV prison camp, Yolande Jean and her fellow Haitian refugees were starved and physically abused. They were housed in shabby tents that offered scant protection from the elements, and their belongings were burned by the US Immigration and Naturalization Service.¹ Women held in the camp were forcibly injected with Depo-Provera, a long-acting contraceptive, and all of the refugees dealt with early morning military sweeps by soldiers dressed in riot gear.¹ Even as many refugees experienced complications from HIV/AIDS in addition to deplorable living conditions, US government officials resisted initial efforts to relocate the refugees to the mainland.³

As a result of the military's abuse and the US government's inaction, Yolande Jean gathered other refugees within the prison camp and launched a

hunger strike in January 1993.¹ After 15 days, she was beaten, arrested, and placed in solitary confinement.¹ Notice of the strike spread quickly in the United States, and the protest was picked up by students at Yale Law School.³ The law students coordinated a rolling hunger strike that was "passed" from one university to another across the country.³ Awareness of the HIV prison camp grew, and members of the US government faced pressure from religious leaders, immigration groups, and HIV/AIDS activists.³ Even two Hollywood actors went off script and spoke out at the 65th Academy Awards to draw attention to the camp.⁴ After a year and a half, the camp was finally ordered closed in March 1993, and all surviving refugees, including Yolande Jean, were transported to the United States.³

SOCIOPOLITICAL CONTEXT OF HIV/AIDS

As a medical and public health student, I am cognizant of the ways in which population health is influenced by social, political, and economic forces. My conversations with patients often focus on the insurance, housing, and immigration policies that influence their health. The lived experiences of patients in clinical settings and the literature in my public health courses make it clear that prevention and treatment of HIV/AIDS are inextricably tied to patients' sociopolitical contexts.

For Yolande Jean and her fellow refugees at Camp Bulkeley, internment in a military prison because they were HIV-positive political refugees completely negated their ability to receive proper medical care. Although not as horrific as the experiences of Yolande Jean, the social, economic, and political conditions

that continue to drive the HIV/AIDS pandemic are frequently overlooked, assumed to be inevitable, and fiscally neglected. As a result, many public health resources to reduce viral transmission and improve HIV/AIDS-related outcomes are directed to the dissemination and development of antiretroviral therapies and prevention technologies.

Yolande Jean and fellow refugees at Camp Bulkeley experienced unsafe, unsanitary, and deplorable living conditions that were oppressive and diametrically opposed to their health. Similarly, many people living with HIV are affected by government policies, corporate patents, health care systems, and discriminatory social conditions that are in opposition to their health. This reality holds true around the world, with millions of HIV-positive people facing daily food insecurity, poverty, language barriers, racism, sexism, homophobia, and criminalization. Therefore, our efforts to end the HIV/AIDS epidemic cannot rely solely on vaccine developments, sexual education, biomedical prevention, or novel antiretroviral medications. We must also seek universal housing, universal health care, and access to healthy foods and clean water. We know from history that social movements are capable of shifting these material conditions, so how do we organize this process today?

SOCIAL MOVEMENTS AND THE FUTURE

The coalition that forced the closure of the world's first HIV prison camp had a broad base. Leaders in different sectors were aligned with the refugees who were directly affected, and together they worked toward the goal of closing the camp. In community organizing, this is known as coalition building, and it is a

crucial first step in launching effective social movements grounded in greater legitimacy, visibility, and power. Coalition building has been a large part of HIV/AIDS activism for decades. Most recently, HIV/AIDS activists and organizations of sex workers have collaborated against the criminalization of sex work and HIV nondisclosure.⁵ Grassroots relationships among different stakeholders are crucial to ending the HIV/AIDS pandemic, but they are not enough on their own.

The coalition that advocated for the closure of the HIV prison camp identified and pressured specific government officials who were capable of closing the camp. In community organizing, the intentional study of decision makers, their institutions, and their influence over an issue is referred to as a power analysis. This essential step in establishing a successful social movement allows a critical evaluation of key individuals and organizations that may be worth engaging. Historically, HIV/AIDS activists have been very strategic with respect to their language and direct-action protests. This was most visible in 1989, when members of the AIDS Coalition to Unleash Power disrupted the New York Stock Exchange by chaining themselves to a balcony, displaying a banner, and blaring foghorns.⁶ The activists symbolically confronted the pharmaceutical corporation producing and selling AZT (azidothymidine), the most expensive medication in history at the time and the only one that was approved to treat AIDS. The corporation responsible reduced the cost by 20% soon after.⁶

Today's efforts to end HIV require us to study and confront sources of power deliberately and strategically, as activists have done in the past. As it becomes increasingly clear that ending HIV is a project of social transformation, we should turn to the history of HIV/AIDS activism.

Scientific discoveries rightfully give us hope, but we also need to reinvent institutions and policies to guarantee that human rights and needs are met around the globe. History tells us that this is possible through social movements with broad coalitions, common goals, creative strategies, sharp power analyses, and courage of the caliber that Yolande Jean and countless unnamed HIV activists have demonstrated in the last 40 years. **AJPH**

CORRESPONDENCE

Correspondence should be sent to Christopher N. Garcia-Wilde, Miller School of Medicine, University of Miami, 1600 NW 10th Ave #1149, Miami, FL 33136 (e-mail: cgarciaw@umiami.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Garcia-Wilde CN. The importance of social movements: a student perspective on HIV/AIDS. *Am J Public Health*. 2021;111(7):1261–1262.

Acceptance date: April 15, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306347>

ACKNOWLEDGMENTS

I am thankful for all of the community organizers, known and unknown, who have fought for freedoms and public health around the world.

CONFLICTS OF INTEREST

The author does not have conflicts of interest to disclose.

REFERENCES

1. Farmer P. *Partner to the Poor: A Paul Farmer Reader*. Oakland, CA: University of California Press; 2010.
2. Quindlen A. Public and private: a death watch. Available at: <https://www.nytimes.com/1993/05/30/opinion/public-private-a-death-watch.html>. Accessed January 14, 2021.
3. Michael R. How we closed the Guantanamo HIV camp: the intersection of politics and litigation. *Harv Hum Rights J*. 1998;11:187–220.
4. *Unforgiven* wins film editing: 1993 Oscars [video]. Available at: <https://www.youtube.com/watch?v=PpTd065vi60>. Published February 4, 2016. Accessed January 14, 2021.
5. The Advocate. After three decades, our work to end HIV isn't over. Available at: <https://www.advocate.com/commentary/2019/12/01/after-three-decades-our-work-end-hiv-isnt-over>. Accessed January 14, 2021.
6. Handelman D. Act up in anger. Available at: <https://www.rollingstone.com/culture/culture-news/aids-activism-larry-kramer-act-up-fauci-241225>. Accessed January 14, 2021.

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Reimagining Inclusivity in Health Care for Sexual Minorities to End the HIV Epidemic: A Student Perspective

Brady D. Hanshaw

ABOUT THE AUTHOR

Brady D. Hanshaw is with the Institute for Global Health and Infectious Diseases, University of North Carolina, Chapel Hill.

See also Morabia, p. 1175, Landers et al., p. 1180, and the HIV/AIDS and Our World: 1981–2021 section, pp. 1231–1266.

Over the last 40 years, the HIV epidemic has disproportionately burdened men who have sex with men (MSM), and especially MSM of color, in the United States.¹ This subpopulation alone accounted for 69% of the nation's transmissions in 2018, with one in six MSM expected to acquire HIV in their lifetime without intervention.¹ The high incidence among MSM is multifactorial, incorporating factors beyond individual behavior.² Social and structural risk factors (classism, racism, heterosexism) place this marginalized community at increased risk for HIV.^{2,3} Systems of oppression operate at the provider level through provider-based heterosexism and cultural incompetence among providers serving queer individuals.^{4,5} These provider-based factors contribute to the HIV disparity among MSM at the societal level by reducing access to inclusive health care and reducing progression across the preexposure prophylaxis (PrEP) continuum.^{4–6} Effectively reducing HIV incidence among MSM

necessitates access to inclusive and queer-competent health care. We must view diversity and inclusion efforts—and all interventions against heterosexism, classism, and racism in medicine—as a part of the national HIV response and the efforts to end the HIV epidemic.⁷ Until we achieve these goals, HIV prevention and treatment efforts will continue to be impeded by provider-based heterosexism and heteronormative standards, perpetuating the stereotype of MSM as victims of the epidemic. However, to foster greater inclusivity in our health care system as an intervention for MSM, we must first ask ourselves how to define an inclusive, queer-competent provider.

Our current beliefs about inclusivity in queer health care often focus on a patient's experience in the clinical setting. The mission to offer inclusive care is centered on how a clinic or provider can present a welcoming atmosphere. Providers may worry about asking for pronouns and using the right language in

order not to offend queer patients. Providers add rainbows to their badges. The concept of an inclusive provider or health care setting has been defined as an interaction that does not further traumatize the patient and as a physical environment that signals acceptance. To be clear, a queer-friendly clinical environment and appropriate language should be a goal. However, such a definition alone neglects recognition of the prior trauma and experiences of oppression of the queer patient. We must understand that, no matter how welcoming a health care setting or provider, queer patients have experienced and are still experiencing societal and structural heterosexism outside the clinic walls. Heteronormative standards traumatize queer patients and directly undermine their ability to achieve optimal health and well-being.^{4,5,8,9}

To bring us closer to ending the HIV epidemic among MSM, inclusivity in health care ought to be conceptualized as an approach in which providers recognize the collective traumas and barriers, driven by marginalization, that MSM experience and contextualize treatment accordingly. Inclusivity requires both trauma-informed and oppression-informed care for queer communities.¹⁰ Providers must go beyond the aim of not inadvertently retraumatizing the queer patient by the collective traumas of microaggressions and understand the pervasive nature of oppression, the forms of trauma prevalent among the queer communities, and how standards of care informed by oppression and trauma can promote environments of healing and recovery.^{10–12} This recenters the focus of inclusivity on how medicine can combat societal oppression faced by marginalized populations. These efforts will

promote more equitable health outcomes for MSM by furthering access to HIV prevention and care services, improving treatment outcomes, and fostering more effective provider–patient relationships.¹²

An example of how we are able to operationalize a trauma- and oppression-informed standard of care includes how we can remove the queer patient from the assumption of heterosexuality without the burden of disclosure. Knowledge of queer health can be integrated as routine health information, disseminated to all patients regardless of patient-reported or unreported sexuality. These conversations should not be the limit of inclusivity, nor replace practices like taking an inclusive sexual health history, but should rather serve as standard, baseline conversations that guarantee a degree of inclusivity for each patient. In the context of HIV prevention, this could take form as a routine conversation in which PrEP is discussed with each patient, regardless of reported sexual behavior or risk.¹³

Another example includes HIV counseling with each patient that encompasses all types of sexual activity, sexual orientations, and gender identities. Neutral and inclusive counseling recognizes how marginalization outside of the clinic disincentivizes disclosure and therefore removes it as a requirement for access to care.¹⁴ Furthermore, these examples illustrate how, moving forward, providers who embrace and apply these inclusive approaches can serve as an intervention to mitigate the marginalization of queer patients and, in return, work to improve HIV outcomes among queer patients. A provider may not be able to directly modify a patient's systems of oppression, but they can apply informed care to combat them. In the end, employing this more extensive

model of clinical inclusion will better serve the MSM population and help us finally eliminate their long-standing burden in the HIV epidemic. *AJPH*

CORRESPONDENCE

Correspondence should be sent to Brady D. Hanshaw, 130 Mason Farm Rd, CB# 7030, Chapel Hill, NC 27599 (e-mail: brady191@live.unc.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Hanshaw BD. Reimagining inclusivity in health care for sexual minorities to end the HIV epidemic: a student perspective. *Am J Public Health*. 2021;111(7):1263–1264.

Acceptance Date: April 15, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306346>

ACKNOWLEDGMENTS

I acknowledge the mentorship of Lina Rosengren, MD, MPH, MS, Kathryn E. Muessig, PhD, and Lisa Hightow-Weidman, MD, MPH.

CONFLICTS OF INTEREST

The author reports no real or perceived vested interests related to this article (including relationships with pharmaceutical companies, biomedical device manufacturers, grantors, or other entities whose products or services are related to the topics covered in this manuscript) that could be construed as a conflict of interest.

REFERENCES

1. Jeffries WL IV, Dailey AF, Jin C, Carter JW Jr, Scales L. Trends in diagnosis of HIV infection, linkage to medical care, and viral suppression among men who have sex with men, by race/ethnicity and age—33 jurisdictions, United States, 2014–2018. *MMWR Morb Mortal Wkly Rep*. 2020;69(38):1337–1342. <https://doi.org/10.15585/mmwr.mm6938a1>
2. Magnus M, Kuo I, Phillips G II, et al. Elevated HIV prevalence despite lower rates of sexual risk behaviors among black men in the District of Columbia who have sex with men. *AIDS Patient Care STDS*. 2010;24(10):615–622. <https://doi.org/10.1089/apc.2010.0111>
3. Arnold EA, Rebchook GM, Kegeles SM. "Triply cursed": racism, homophobia and HIV-related stigma are barriers to regular HIV testing, treatment adherence and disclosure among young black gay men. *Cult Health Sex*. 2014;16(6):710–722. <https://doi.org/10.1080/13691058.2014.905706>
4. Calabrese SK, Earnshaw VA, Krakower DS, et al. A closer look at racism and heterosexism in medical students' clinical decision-making related to HIV pre-exposure prophylaxis (PrEP): implications for PrEP education. *AIDS Behav*. 2018;22(4):1122–1138. <https://doi.org/10.1007/s10461-017-1979-z>
5. Maloney KM, Krakower DS, Ziobro D, Rosenberger JG, Novak D, Mayer KH. Culturally competent sexual healthcare as a prerequisite for obtaining preexposure prophylaxis: findings from a qualitative study. *LGBT Health*. 2017;4(4):310–314. <https://doi.org/10.1089/lgbt.2016.0068>
6. Nunn AS, Brinkley-Rubinstein L, Oldenburg CE, et al. Defining the HIV pre-exposure prophylaxis care continuum. *AIDS*. 2017;31(5):731–734. <https://doi.org/10.1097/QAD.0000000000001385>
7. Fauci AS, Redfield RR, Sigounas G, Weahkee MD, Giroir BP. Ending the HIV epidemic: a plan for the United States. *JAMA*. 2019;321(9):844–845. <https://doi.org/10.1001/jama.2019.1343>
8. Layland EK, Exten C, Mallory AB, Williams ND, Fish JN. Suicide attempt rates and associations with discrimination are greatest in early adulthood for sexual minority adults across diverse racial and ethnic groups. *LGBT Health*. 2020;7(8):439–447. <https://doi.org/10.1089/lgbt.2020.0142>
9. Earnshaw VA, Bogart LM, Poteat VP, Reisner SL, Schuster MA. Bullying among lesbian, gay, bisexual, and transgender youth. *Pediatr Clin North Am*. 2016;63(6):999–1010. <https://doi.org/10.1016/j.pcl.2016.07.004>
10. SAMHSA's *Concept of Trauma and Guidance for a Trauma-Informed Approach*. Rockville, MD: Substance Abuse and Mental Health Services Administration; 2014. Publication No. (SMA) 14-4884.
11. Institute on Trauma and Trauma-Informed Care, University of Buffalo. The road to trauma-informed care. 2020. Available at: <http://socialwork.buffalo.edu/social-research/institutes-centers/institute-on-trauma-and-trauma-informed-care/what-is-trauma-informed-care.html>. Accessed January 10, 2021.
12. Sales JM, Swartzendruber A, Phillips AL. Trauma-informed HIV prevention and treatment. *Curr HIV/AIDS Rep*. 2016;13(6):374–382. <https://doi.org/10.1007/s11904-016-0337-5>
13. Calabrese SK, Krakower DS, Mayer KH. Integrating HIV preexposure prophylaxis (PrEP) into routine preventive health care to avoid exacerbating disparities. *Am J Public Health*. 2017;107(12):1883–1889. <https://doi.org/10.2105/AJPH.2017.304061>
14. Qiao S, Zhou G, Li X. Disclosure of same-sex behaviors to health-care providers and uptake of HIV testing for men who have sex with men: a systematic review. *Am J Mens Health*. 2018;12(5):1197–1214. <https://doi.org/10.1177/1557988318784149>

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Missed Opportunities for HIV Prevention in Puerto Rico: An Argument for Inclusivity and Community Coalitions

Javier Lopez-Rios, MPH

ABOUT THE AUTHOR

The author is with the HIV Center for Clinical and Behavioral Studies, New York State Psychiatric Institute, and Columbia University, New York, and is a doctoral candidate at the Graduate School of Public Health and Health Policy, City University of New York.

🔗 See also Morabia, p. 1175, Landers et al., p. 1180, and the HIV/AIDS and Our World: 1981–2021 section, pp. 1231–1266.

Growing up as a gay cisgender man on the rural west coast of Puerto Rico, I was no stranger to the dearth of resources to manage my sexual health and navigate a patriarchal society that often ignored the needs of my community. Puerto Rico, a commonwealth territory, ranks as the third most densely populated area in the United States and has among the highest rates of HIV prevalence and incidence in the country. The HIV epidemic in Puerto Rico is largely concentrated among sexual minority men.¹

GAPS IN HIV SERVICES AND SEXUAL HEALTH EDUCATION

HIV testing and support services tailored to the needs of youths identifying as LGBTQ (lesbian, gay, bisexual, transgender, and queer or questioning) were more readily available in the capital of San Juan, a two-hour drive away, than in

the western and southern parts of the archipelago. Those of us on the west coast persistently faced difficulty in accessing current and up-to-date HIV prevention services (e.g., testing and counseling). The nearest no-cost HIV testing center was a 45-minute drive away and hidden in a lot behind the biggest hospital in the region, thus making HIV testing, the most basic tenet of our national HIV/AIDS strategy for ending the epidemic, out of reach for those with limited resources.

Moreover, sexual health education, pivotal to understanding one's risk for HIV and how to manage it, is limited in both outreach and scope because it is based on a heteronormative assumption of sexuality. In 2017, the government of Puerto Rico expressed its opposition to gender-based curricula wherein schools would ensure provision of sexual health education on the basis of gender and sexuality. The Centers for Disease Control and Prevention

recognizes sexual health education as an evidence-based intervention for HIV prevention. As such, failure to adopt such curricula represents a missed opportunity to educate young people at risk for HIV and other sexually transmitted infections. Furthermore, the few available community spaces for LGBTQ-identified individuals are overburdened and lack adequate funding to address the needs of a growing and increasingly visible community.

STRUCTURAL AND SOCIAL DETERMINANTS OF HIV VULNERABILITY

The series of natural disasters and ensuing sociopolitical turmoil over the past three years, increasing local poverty, and now the global COVID-19 pandemic have highlighted the poor infrastructure for supporting HIV prevention efforts, a situation caused by an overburdened health workforce and poor distribution of federal funds.² These are just some of the myriad examples of years of US government colonization and inequity; recently, a fiscal oversight board instituted by the federal government imposed severe austerity measures that have crumbled an already weakened public health infrastructure. Rodríguez-Díaz calls for structural changes to address social determinants of health for residents of Puerto Rico.^{3,4} I argue that a cultural shift is needed as well, one that addresses the stigma and discrimination fueling the HIV epidemic among Puerto Rican men who have sex with men, fosters inclusivity and community capacity building, and capitalizes on people's resilience.

Particularly, people's HIV risk should be contextualized in terms of the specific social and structural factors that hinder their access to services, such as stigma

and discrimination in health care settings, low health literacy, and lack of community spaces. It is by understanding the unique barriers to prevention that we can start to develop tailored interventions to reduce HIV infection rates. Furthermore, the HIV prevention landscape in Puerto Rico urgently needs to evolve from a sexual risk avoidance paradigm to one that fosters reproductive justice, including increased access to testing and biomedical tools such as preexposure prophylaxis. There is a lack of current scientific research on the availability and uptake of HIV prevention tools on the island, pointing to a significant gap in our understanding of the local epidemic among this population.

There is power in harnessing civic and community resilience as a means of addressing this epidemic. Those leading future interventions or government programs will benefit by working collaboratively with local organizations to influence the local HIV response. Public health research has taught us that community coalitions provide a vehicle for bringing about sustainable structural and political changes.^{5,6} Grassroots organizations in the United States such as ACT Up and the Treatment Action Group exemplify the power of the synergy between community and research in enacting meaningful change in the HIV drug approval process. I believe a similar approach can be taken in Puerto Rico.

Although considerable progress has been made in the prevention and management of HIV/AIDS since the first reported cases 40 years ago, there is room for improvement in reaching rural sexual minorities in Puerto Rico. Local organizations such as COAI Inc., Puerto Rico CoNCRA, and Migrant Health have been diligently filling the gaps in access to HIV prevention for years by creating community spaces and fostering

altruism, compassion, and resilience through workshops and educational activities for LGBTQ individuals. In addition, they have extended services to localities outside the San Juan metropolitan area and provided resources in areas where HIV is being spread but is often overlooked. Indeed, public health responses to HIV cannot be successfully implemented or achieved without bolstering community resources. Doing so will certainly have a significant impact in reducing HIV disparities in Puerto Rico.

AJPH

CORRESPONDENCE

Correspondence should be sent to Javier Lopez-Rios, MPH, CUNY Graduate School of Public Health & Health Policy, 55 W 125th St, New York, NY 10027 (e-mail: javier.lopez-rios87@sphmail.cuny.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Lopez-Rios J. Missed opportunities for HIV prevention in Puerto Rico: an argument for inclusivity and community coalitions. *Am J Public Health*. 2021;111(7):1265–1266.

Acceptance Date: April 12, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306342>

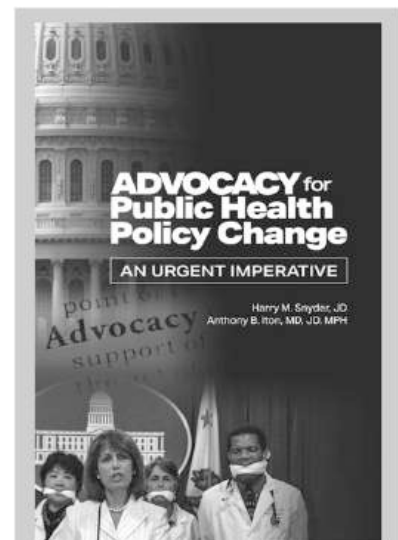
CONFLICTS OF INTEREST

The author has no conflicts of interest to disclose.

REFERENCES

- Centers for Disease Control and Prevention. HIV surveillance report, 2018 updated edition. Available at: <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Accessed January 3, 2021.
- Joseph SR, Voyles C, Williams KD, Smith E, Chilton M. Colonial neglect and the right to health in Puerto Rico after Hurricane Maria. *Am J Public Health*. 2020;110(10):1512–1518. <https://doi.org/10.2105/AJPH.2020.305814>
- Rodríguez-Díaz CE. Maria in Puerto Rico: natural disaster in a colonial archipelago. *Am J Public Health*. 2018;108(1):30–32. <https://doi.org/10.2105/AJPH.2017.304198>
- Rodríguez-Díaz CE. Community resistance as public health activism in Puerto Rico. *Am J Public Health*. 2020;110(10):1454–1455. <https://doi.org/10.2105/AJPH.2020.305884>
- Chutuaque KS, Willard N, Sanchez K, et al. Mobilizing communities around HIV prevention for youth: how three coalitions applied key strategies to bring about structural changes. *AIDS Educ Prev*. 2010;22(1):15–27. <https://doi.org/10.1521/aeap.2010.22.1.15>

- Valdiserri RO, Holtgrave DR. Ending HIV in America: not without the power of community. *AIDS Behav*. 2019;23(11):2899–2903. <https://doi.org/10.1007/s10461-019-02496-7>



Advocacy for Public Health Policy Change: An Urgent Imperative

Harry M. Snyder, MD
Anthony B. Iton, MD, JD, MPH

Improving laws and policies start with advocacy and now more than ever this new book, *Advocacy for Public Health Policy Change: An Urgent Imperative* will be instrumental in training public health practitioners and students to turn their expertise into sound policies and laws. It will help these readers in these five key areas:

- Address the growing need to turn knowledge into better health policy.
- Offer a step-by-step planning and implementation framework for public health advocacy campaigns from start to finish.
- Expand professional development and satisfactions opportunities for the field.
- Improve service delivery.
- Improve health outcomes.

Place orders at
aphabookstore.org.

Email
bookstoreservices@apha.org
to request an exam copy for classroom use.

ISBN 978-0-87553-313-1 2020,
SOFTCOVER, 250 PAGES

 **APHA PRESS**
AN IMPRINT OF THE AMERICAN PUBLIC HEALTH ASSOCIATION

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

A Centenary Tale of Two Pandemics: The 1918 Influenza Pandemic and COVID-19, Part II

David M. Morens, MD, Jeffery K. Taubenberger, MD, PhD, and Anthony S. Fauci, MD

Both the 1918 influenza pandemic and the 2019–2021 COVID-19 pandemic are among the most disastrous infectious disease emergences of modern times. In addition to similarities in their clinical, pathological, and epidemiological features, the two pandemics, separated by more than a century, were each met with essentially the same, or very similar, public health responses, and elicited research efforts to control them with vaccines, therapeutics, and other medical approaches. Both pandemics had lasting, if at times invisible, psychosocial effects related to loss and hardship. In considering these two deadly pandemics, we ask: what lessons have we learned over the span of a century, and how are we applying those lessons to the challenges of COVID-19? (*Am J Public Health*. 2021;111(7):1267–1272. <https://doi.org/10.2105/AJPH.2021.306326>)

There are many similarities, and some differences, between the influenza pandemic of 1918–1919 and the COVID-19 pandemic of 2019–2021. Epidemiological and clinical similarities, including viral origin, transmission, and disease morbidity and mortality, were discussed in Part I of this article.¹

PUBLIC HEALTH RESPONSES

In 1918, fundamental knowledge of sanitation, hygiene, and principles of disease transmission were almost as well understood as they are today.² Mechanisms of respiratory spread and means of preventing respiratory transmission were particularly well understood (Figure 1). The dangerous effects of crowding in public places and closed airflow in buildings and the need to socially distance were likewise fully appreciated. This knowledge had been accumulating since the beginning of the sanitary movement

in the 1840s, was greatly advanced by acceptance of a “germ theory” in the 1870s, and had been publicly visible since the 1880s in international public health efforts to control the spread of tuberculosis, then a major killer.

Masks, coughing etiquette, use of clean handkerchiefs, proscription of spitting, placement of spittoons in saloons, isolation of the ill, avoidance of congregation, and closing of sports events, theaters, schools, and churches were all employed in 1918 (Figure 1). In the pandemics of both 1918 and 2019–2021, public health officials recommended wearing face masks. As neither N95 nor modern surgical masks were available in 1918, newspapers printed illustrated instructions on making homemade masks using cloth handkerchiefs and string. Both pandemics prompted fanciful improvisations, including morbid art that seemed to mock death; others made masks for domestic pets (Figure 1). In 1918, some

professional, collegiate, and other sports events were closed,³ but in other cases athletes went on playing with or without masks (Figure 1). Public refusal to wear masks was nearly as common as it is today, even though in 1918 scofflaws often faced stiff fines.

Church gatherings and even court proceedings in 1918 were held outdoors, even in the streets. Forced and self-isolation were common. Just as Boccaccio and friends had done more than five centuries earlier, during the 1348 pandemic of bubonic and pneumonic plague, in 1918 citizens took their own public health actions, such as isolating themselves away from crowds, work, and school. After he was rejected for US military service, future novelist William Faulkner fled to Canada for air force training; the Royal Canadian Air Force locked down (i.e., isolated) Faulkner and the other trainees for a period of time during the pandemic, preventing them from being infected. In the



FIGURE 1— Wearing of Face Masks, 1918 and 2020

Note. In the pandemics of both 1918 (influenza) and 2019–2021 (COVID-19), public health officials recommended wearing face masks for both casual outings and at sports events, and at other large gatherings. Parts a and b: Masked pet owners and pets, circa 1918 (a) and 2020 (b). Parts c and d: Fanciful masks seem to mock the pandemic’s “grim reaper” circa 1918 (c) and 2020 (d). Parts e and f: In 1918, some sports events were canceled but others went on, often with masked players or spectators, or both (e). In 2019–2021, many live sports events have been canceled or played without live spectators (f; Photo by Mike Kireev/NurPhoto via Getty images; published with permission).

COVID-19 pandemic, many more people are able to self-isolate at home because of teleworking and better-organized food-delivery services.

Public health programs in the United States in 1918 were largely state- and city-based. The key pandemic decision-makers were governors, mayors, local health departments, businessmen, and community leaders, and sometimes nurses and volunteers. Because the pandemic spread so rapidly across the United States,⁴ there was little time for planning or coordination. In smaller towns, the pandemic abruptly emerged, peaked, and was often receding or gone within three or four weeks. Different public health response plans were improvised on the spot. Some were more effective than others; mortality varied greatly from one place to

the next. Many citizens defied public health recommendations.

Associations between strictness of public health measures and low mortality were immediately noted and much discussed in 1918, especially in cities such as Pittsburgh and Philadelphia, Pennsylvania, where overcrowding, lockdown resistance, and tolerance of social gatherings were associated with increased mortality. Modern analyses are consistent with the beneficial effects of stricter measures.² Inactivated bacterial vaccines, intended to prevent death from influenza-associated secondary bacterial pneumonia, which caused the vast majority of pandemic deaths, were often used in 1918, and seem to have been moderately effective in preventing death.^{5,6}

Similarities between the public health responses in 1918–1919 and 2019–2021 are many. National and international public health approaches to both pandemics varied widely, with predictable and unpredictable successes and failures. COVID-19 public health responses rely on the basic strategies of 1918: public “lock down,” social distancing, hygiene, and self-isolation. During the COVID-19 pandemic, we have also had polymerase chain reaction and serologic testing to identify the virus and its immune fingerprints, as well as contact tracing, well understood in 1918 but not widely used, probably in part because pandemic explosivity led quickly to an overwhelming number of unmanaged cases. In 2019–2021, we have had bacterial vaccines for two of the bacteria (*Streptococcus pneumoniae* and *Haemophilus*

influenzae type b) associated with fatal secondary pneumonias in 1918.⁷ Deployment of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) vaccines (ongoing as of May 1, 2021) is expected to offer the most realistic hope of ending or at least slowing down the pandemic in the immediate future, although many months of scale-up and vaccine distribution and uptake, prioritizing who gets vaccinated, overcoming vaccine hesitancy, and conceivably dealing with vaccine complications, remain as challenges, especially in countries such as India.

An ominous turn of events now unfolding (as of May 2021) is the emergence of multiple SARS-CoV-2 genetic variants apparently associated with increased transmissibility and possible immune escape, potentially affecting vaccine efficacy and diagnostic test sensitivity.⁸ Though some of these variants have been suspected of causing more severe disease, this has not been scientifically established at the time of this writing. In 1918–1919, high influenza mortality was associated with viral genetic stability, but over the decade of the 1920s, as population immunity rose, mortality and case–fatality declined. Because viruses have not been recovered from the period of 1920–1932, it is unclear whether and when viral attenuation occurred and what were its genetic determinants. In contrast to early suspicions about SARS-CoV-2, there are no data to support that the 1918 influenza virus became more transmissible or more deadly after its emergence.

DIAGNOSIS AND TREATMENT

As the viral cause of the 1918 pandemic was unknown, diagnosis was clinical and

treatment largely supportive. This was the first major disease emergence in which the new technique of diagnostic radiology was used, particularly in the US military.⁹ Although most physicians did not have access to diagnostic x-rays, they were often remarkably skilled at using auscultation, percussion, elicitation of tactile fremitus, and observation of respiration, among other diagnostic skills. Oxygen was often available and used. Appearance of so-called “heliotrope cyanosis” of the prominent facial parts,^{4,10} although not unique to the 1918 pandemic, was recognized as a terminal event associated with profound hypoxia attributable to loss of gas exchange together with metabolic acidosis.

Those who survived bacterial pneumonias often developed life-threatening empyemas, requiring difficult clinical and surgical management.¹¹ In an era when therapeutic successes for various other diseases had been achieved with immune plasmas obtained from hyperimmunized horses, goats, or other animals, some influenza patients were treated, with apparent success, by using human convalescent plasmas,¹² as is now the case with COVID-19.¹³ Then, as now, the pandemics brought out wishfully repurposed drugs that had little chance of success (e.g., quinine in 1918, hydroxychloroquine in 2020). Then, as now, irrational and often harmful remedies enticed the hopeful (enemas and laxatives in 1918; bleach, disinfectants, and colloidal silver in 2020), in addition to known therapeutics such as immune plasmas and monoclonal antibodies, dexamethasone, and the antiviral remdesivir (used in the United States under Food and Drug Administration emergency use authorization), but the efficacy and appropriate therapeutic indications of the latter remain uncertain. Early data, for example, suggest

that in certain patients remdesivir may be of some benefit in shortening illness, although reduction in overall mortality has yet to be fully established.¹⁴

Lacking antivirals and antibiotics in 1918, supportive care was the mainstay of treatment, with an emphasis on attentive nursing care, and was considered the most effective way to save lives. Nurses from the Red Cross and other agencies, as well as volunteer nurses, mostly women with little or no previous nursing training, went into homes, especially in poorer neighborhoods, to tend to the sick; they were widely regarded as pandemic heroes, as are frontline health care workers in 2019–2021. It is of note that deployment of physicians in the war opened leadership positions for women physicians and scientists on the home front at a time when the women’s suffrage movement was at its peak.

The COVID-19 pandemic arrives at a time when remarkable medical advances create a diagnostic and therapeutic world unimagined in 1918: rapid viral diagnostics, x-rays and magnetic resonance imaging, blood gasses and chemistries, antibiotics, antivirals, intensive care units with ventilators and monitors, and extracorporeal membrane oxygenation. However, even with the very best care, many patients who survive the period of SARS-CoV-2 replication and cellular damage still do not survive, or survive with serious long-term complications. Lack of complete understanding of the natural history and pathogenesis of COVID-19 stands in counterpoint to the high level of understanding of the mechanisms of secondary bacterial pneumonia in 1918, even though, ironically, treatment options were far fewer in that era. COVID-19 causes pneumonia; however, unlike influenza, it also damages a wide



FIGURE 2— The 1918 Pandemic Inspired Many Artists

Source. Part b used with permission of the artist, Pete Ryan (<https://www.peterthomasryan.com>).

Note. Part a: Dying in his Vienna, Austria, apartment of influenza pneumonia (1918), painter Egon Schiele produced his last artistic work, a drawing of his wife, Edith Harms, 6 months pregnant and suffering from the same disease. She died hours after the drawing. Part b: A 2020 illustration captures the anxieties of COVID-19 spread; design by Pete Ryan for Vox, printed with permission.

range of organ systems, causing vascular¹⁵ and neurologic symptoms,¹⁶ and may be associated with aberrant immune responses¹⁷ that may differ from those of influenza, often complicated by microthrombi in lungs and other organs associated with thromboembolic phenomena.¹⁸ Our understanding of the natural history and pathogenesis of COVID-19 is just beginning.

RESEARCH

The 1918 pandemic occurred at the dawn of the era of virology. Viruses as we know them today had been characterized only as “filter-passing agents,” submicroscopic entities of some sort

that were able to cause diseases after passage through porcelain filters that trapped bacteria.¹⁹ Although a descendant of the 1918 human influenza virus was not officially isolated until 15 years after the pandemic, it seems likely that in 1918 two research groups, one in Tunisia and the other in Japan, actually did isolate the virus, but had no way to maintain the agent via continuous passage in humans or animals, or via freezing.^{20,21} Human challenge studies were conducted with human secretions; however, results were problematic. The 1918 pandemic came and went so quickly that comprehensive research programs could not be set up in time, and isolates of virus-containing

infectious material could not be easily propagated or maintained.

In contrast, complete genome sequences of SARS-CoV-2 were made public in early January 2020, and, as of May 2021, many tens of thousands of genome sequences have already been published in online databases. In vitro culture and initiation of in vivo experimental animal modeling have occurred rapidly, followed by extensive basic and clinical testing of diagnostic assays, therapeutics, and vaccines leading to studies on natural history and pathogenesis. The rapidity with which important scientific knowledge about COVID-19 has accrued in just a few months would have astonished scientists in 1918.

RESPONSES TO PSYCHOLOGICAL AND PSYCHOSOCIAL EFFECTS

Then, as now, contemporary photographs show images of horror: stacked bodies, rows of grave markers, and open pits into which bodies are thrown (see [Figure 1](#) in Part I¹). People were dying alone, in their own homes, with no one to comfort them in their final hours. Mercifully, the horrors of the 1918 pandemic were brief, as the pandemic passed through most towns and cities like lightning and was suddenly gone. In 2019–2021, many months of ever-climbing COVID-19 deaths, lockdown, dread, and uncertainty, have added to the tragedy and led to outbreaks of depression, suicide, anger, hopelessness, and even anomie.

It has often been said that the 1918 pandemic was quickly forgotten, reflecting a global exercise in intentional amnesia; however, a closer look at the legacy of 1918 suggests otherwise. For example, the pandemic inspired many artists. In a Vienna, Austria, apartment, a brilliant painter who always aimed to shock and infuriate, Egon Schiele (1890–1918), lay dying of influenza pneumonia in late October 1918. Schiele's last work was a drawing of his wife, Edith Harms (1893–1918), six months pregnant and dying beside him, also of influenza pneumonia ([Figure 2](#)). She died hours after the drawing; Schiele survived another two days. Before dying, he arranged with friend Marta Fein-Spraidler (1894–c. 1941) to take a photograph at the moment of his death.²² There are also the self-portraits of painter Edvard Munch suffering from influenza in his own bedroom; Thomas Wolfe's wrenching account of the death of his beloved brother Benjamin, written down in

exacting autobiographical detail (*Look Homeward, Angel* and *O Lost: A Story of the Buried Life*); Katherine Anne Porter's haunting tale of her own survival (*Pale Horse, Pale Rider*), unfolding dream-like to its tragic ending; the surge in the Dada art movement in response to the horrors of the war and the pandemic; the hedonistic escapism of the Roaring Twenties; and the exhaustingly comprehensive files of millions of photos, letters, diaries, and recollections that still survive today, and that still speak to us. The 1918 pandemic was never really forgotten. We just forgot that we had never forgotten it.

It will probably be a long time until we can fairly look back to compare and contrast all of the effects of these centenary pandemics. Both came at times of upheaval, periods in which dramatic changes seemed inevitable, but in what direction could not be predicted. In 1918, the world had been stunned by the carnage of the Great War (around 40 million deaths), including the senseless deaths of a whole generation of young men, leaving widows, orphans, and broken, grieving families. Shock, disbelief, anhedonia, and dark cynicism prevailed. Then, just at the war's end, the pandemic came, lightning-like, killing tens of millions more.

The year 1918 marked the last year of the deadliest war, and the first year of the deadliest pandemic in human history, up to that time. Looking back across the last century, we can see that the "War to End All Wars" did not, in fact, end wars, and that the deadliest pandemic did not end deadly pandemics. A century later, tragic wars and tragic pandemics are still occurring, and we are still struggling to deal with them. We retain a hope that we can one day end wars, pandemic diseases, and many other human ills, but, in May

2021, as the COVID-19 pandemic still spreads, it is hard for many to be optimistic.

Like global wars, pandemics are clearly existential threats. Even in the midst of fear and loss, such deadly challenges can bring out the best in us. If 2021 seems the worst of times, we can still look back, as did centenarian Marilee Shapiro Asher,¹ down a path that is dark and long, but still seeded with hope. Asher, the artist who survived both the 1918 and the 2020 pandemics, died at home on September 11, 2020. Through two pandemics, four major wars, a Great Depression, and a Great Recession, Asher saw more than a century of progress and struggle and was able to find a life-long joy and fulfillment. Near the end, she confronted humankind's latest existential challenge, COVID-19, and survived it. If we can remember the best in Asher and in humankind, so will most of the rest of us. [AJPH](#)

ABOUT THE AUTHORS

David M. Morens and Anthony S. Fauci are with the Office of the Director, National Institute of Allergy and Infectious Diseases, National Institutes of Health, Bethesda, MD. Jeffery K. Taubenberger is with the Viral Pathogenesis and Evolution Section, Laboratory of Infectious Diseases, National Institute of Allergy and Infectious Diseases.

CORRESPONDENCE

Correspondence should be sent to David M. Morens, MD, Senior Advisor to the Director, National Institutes of Health, National Institute of Allergy and Infectious Diseases, Bldg 31, Room 7A-03, 31 Center Drive, Bethesda, MD 20892-2550 (e-mail: dm270q@nih.gov). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Morens DM, Taubenberger JK, Fauci AS. A centenary tale of two pandemics: the 1918 influenza pandemic and COVID-19, part II. *Am J Public Health*. 2021;111(7):1267–1272.

Acceptance Date: April 6, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306326>

CONTRIBUTORS

All three authors contributed to the writing and editing of the article.

ACKNOWLEDGMENTS

This work was supported by the Office of the Director and by the Intramural Research Program of the National Institute of Allergy and Infectious Diseases, National Institutes of Health.

We thank John and Aaron Weddle for graphics design support.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

REFERENCES

- Morens DM, Taubenberger JK, Fauci AS. A century tale of two pandemics: the 1918 influenza pandemic and COVID-19, part I. *Am J Public Health*. 2021;111(6):1086–1094. <https://doi.org/10.2105/AJPH.2021.306310>
- Markel H, Lipman HB, Navarro JA, et al. Nonpharmaceutical interventions implemented by US cities during the 1918–1919 influenza pandemic. *JAMA*. 2007;298(6):644–654. <https://doi.org/10.1001/jama.298.6.644>
- Weinreb M. When the Stanley Cup Final was canceled because of a pandemic. 2020. Available at: <https://www.smithsonianmag.com/history/when-stanley-cup-finals-was-cancelled-because-pandemic-180974439>. Accessed December 16, 2020.
- Jordan EO. *Epidemic Influenza: A Survey*. Chicago, IL: American Medical Association; 1927.
- Chien YW, Klugman KP, Morens DM. Efficacy of whole-cell killed bacterial vaccines in preventing pneumonia and death during the 1918 influenza pandemic. *J Infect Dis*. 2010;202(11):1639–1648. <https://doi.org/10.1086/657144>
- Chien YW, Klugman KP, Morens DM. Bacterial pathogens and death during the 1918 influenza pandemic. *N Engl J Med*. 2009;361(26):2582–2583. <https://doi.org/10.1056/NEJMc0908216>
- Morens DM, Taubenberger JK, Fauci AS. Predominant role of bacterial pneumonia as a cause of death in pandemic influenza: implications for pandemic influenza preparedness. *J Infect Dis*. 2008;198(7):962–970. <https://doi.org/10.1086/591708>
- Centers for Disease Control and Prevention. Emerging SARS-CoV-2 variants. 2021. Available at: <https://www.cdc.gov/coronavirus/2019-ncov/more/science-and-research/scientific-brief-emerging-variants.html>. Accessed February 3, 2021.
- Mollura DJ, Morens DM, Taubenberger JK, Bray M. The role of radiology in influenza: novel H1N1 and lessons learned from the 1918 pandemic. *J Am Coll Radiol*. 2010;7(9):690–697. <https://doi.org/10.1016/j.jacr.2010.01.007>
- Taubenberger JK, Kash JC, Morens DM. The 1918 influenza pandemic: 100 years of questions answered and unanswered. *Sci Transl Med*. 2019;11(502):eaau5485. <https://doi.org/10.1126/scitranslmed.aau5485>
- Morens DM, Taubenberger JK. A forgotten epidemic that changed medicine: measles in the US Army, 1917–18. *Lancet Infect Dis*. 2015;15(7):852–861. [https://doi.org/10.1016/S1473-3099\(15\)00109-7](https://doi.org/10.1016/S1473-3099(15)00109-7)
- Luke TC, Kilbane EM, Jackson JL, Hoffman SL. Meta-analysis: convalescent blood products for Spanish influenza pneumonia: a future H5N1 treatment? *Ann Intern Med*. 2006;145(8):599–609. <https://doi.org/10.7326/0003-4819-145-8-200610170-00139>
- Thijssen M, Devos T, Ejtahed HS, Amini-Bavil-Olyaei S, Pourfathollah AA, Pourkarim MR. Convalescent plasma against COVID-19: a broad-spectrum therapeutic approach for emerging infectious diseases. *Microorganisms*. 2020;8(11):1733. <https://doi.org/10.3390/microorganisms8111733>
- Nili A, Farbod A, Neishabouri A, Mozafarhashjin M, Tavakolpour S, Mahmoudi H. Remdesivir: a beacon of hope from Ebola virus disease to COVID-19. *Rev Med Virol*. 2020;30(6):1–13. <https://doi.org/10.1002/rmv.2133>
- Roberts KA, Colley L, Agbaedeng TA, Ellison-Hughes GM, Ross MD. Vascular manifestations of COVID-19—thromboembolism and microvascular dysfunction. *Front Cardiovasc Med*. 2020;7:598400. <https://doi.org/10.3389/fcvm.2020.598400>
- Rodriguez M, Soler Y, Perry M, Reynolds JL, El-Hage N. Impact of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) in the nervous system: implications of COVID-19 in neurodegeneration. *Front Neurol*. 2020;11:583459. <https://doi.org/10.3389/fneur.2020.583459>
- Lariccia V, Magi S, Serfilippi T, Toujani M, Gratteri S, Amoroso S. Challenges and opportunities from targeting inflammatory responses to SARS-CoV-2 infection: a narrative review. *J Clin Med*. 2020;9(12):4021. <https://doi.org/10.3390/jcm9124021>
- Rapkiewicz AV, Mai X, Carsons SE, et al. Megakaryocytes and platelet-fibrin thrombi characterize multi-organ thrombosis at autopsy in COVID-19: a case series. *EClinicalMedicine*. 2020;24:100434. <https://doi.org/10.1016/j.eclinm.2020.100434>
- Taubenberger JK, Hultin JV, Morens DM. Discovery and characterization of the 1918 pandemic influenza virus in historical context. *Antivir Ther*. 2007;12(4 pt B):581–591.
- Nicolle C, Lebaillly C. Quelques notions expérimentales sur le virus de la grippe. *Comptes rendus de l'Académie des Sciences*. 1918;167:607–610.
- Yamanouchi T, Sakakami K, Iwashima S. The infecting agent in influenza. An experimental research. *Lancet*. 1919;193(4997):971. [https://doi.org/10.1016/S0140-6736\(01\)30275-1](https://doi.org/10.1016/S0140-6736(01)30275-1)
- Morens DM, Taubenberger JK. Influenza catadysm, 1918. *N Engl J Med*. 2018;379(24):2285–2287. <https://doi.org/10.1056/NEJMp1814447>

Public Health CareerMart



job site for Public Health Professionals

- Career Coaching:** Work with one of our experienced and certified coaches to better manage, plan, and develop your career goals.
- Résumé Writing:** Take advantage of professional résumé writing for all professional levels.
- Résumé Critiques:** Our expert résumé writer provides helpful feedback.
- Career Tips:** Search by career stages or services you need using keywords or phrases.
- Salary and Benefits:** Negotiation techniques and salary analysis. Learn how to negotiate effectively and confidently for a job offer or raise!
- Reference Checking/Employment Verification:** Identify questionable references before they talk to prospective employers.
- Social Networking/Profile Development:** Make the right connections and open up job opportunities you never knew existed.
- You can find it all here:** careers.apha.org/jobseekers/resources/



Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

State Gun-Control, Gun-Rights, and Preemptive Firearm-Related Laws Across 50 US States for 2009–2018

Jennifer L. Pomeranz, JD, MPH, Diana Silver, PhD, MPH, and Sarah A. Lief, MPH

 See also Blocher, p. 1192.

Objectives. To assess state policy environments and the relationship between state gun-control, gun-rights, and preemptive firearm-related laws in the United States.

Methods. In 2019 through 2020, we evaluated substantive firearm laws and preemptive firearm laws across 50 US states for 2009 through 2018. For each state, we compared substantive measures with preemptive measures on the same policy topic for 2018.

Results. The presence of state firearm-related laws varied across states, but with the exception of “punitive preemption” the number of gun-control, gun-rights, and preemptive measures remained unchanged in most states from 2009 through 2018. As of 2018, a majority of states had preemptive measures on almost all gun-control policy topics without enacting substantive gun-control measures. Several states had a combination of gun-control and preemptive measures. Only a small number of states had gun-control measures with few to no preemptive measures.

Conclusions. Even where state legislators were unable to pass statewide gun-rights measures, they succeeded in passing preemption, preserving state authority over a wide range of gun-control and gun-rights policy topics. The majority of states used preemption as a tool to support policy frameworks favoring gun rights. (*Am J Public Health.* 2021;111(7):1273–1280. <https://doi.org/10.2105/AJPH.2021.306287>)

Firearm violence is an increasing public health problem in the United States. In 2018, there were 39 740 firearm-related deaths (109/day) resulting from firearms used in suicides, homicides, and accidental shootings.¹ Yet, the Second Amendment of the US Constitution has been interpreted to protect most gun ownership, and, based on prevailing judicial interpretation, provides robust protection for gun rights. The federal government has enacted few gun-control measures, leaving the policy debate about reducing gun violence to state and local action. States have created different regulatory

environments with respect to firearms, with the policy objective of either decreasing firearm-related death and disability (i.e., gun control) or protecting gun rights.^{2,3} One legal tool that can be used for either purpose is preemption. Preemption occurs when a higher level of government (here the state) removes or limits the authority of a lower level (local governments) to act on a specific issue.⁴

Previous research indicates that states preempt local control over firearms more than any other public health topic,⁴ and yet firearm-related preemptive bills still outnumber

preemptive bills on any other public health topic.⁵ However, the question of whether states are preempting local control over firearm safety while simultaneously enacting state-level protections has not been empirically studied. States that do not enact protective measures but simultaneously preempt the ability of localities to do so create a regulatory void on topics that the federal government does not regulate⁶; such preemption also eliminates communities’ ability to protect their members and hinders grassroots movements that may form around the policy topic.⁷ This is particularly

concerning for localities that have high rates of firearm violence but an inability to enact laws to address it because they are preempted.⁸

Comparing states' substantive firearm law measures and preemptive firearm law measures on the same policy topic is thus necessary to determine whether states that preempt local laws are simultaneously enacting statewide protections or simply retaining state control. We evaluated substantive and preemptive firearm law measures across all 50 US states over a 10-year period to understand the context in which preemption is occurring. In this context, we assessed the relationship between preemptive and substantive measures on the same policy topics that protected gun control or gun rights by examining and comparing each state's firearm laws in 2018.

METHODS

In 2019, we sourced firearm-related state preemption laws from Giffords Law Center to Prevent Gun Violence⁹ and Grassroots Change/Preemption Watch¹⁰ (both of which display their respective analysis of preemptive laws to date). We retrieved sourced statutes and all other statutes in the same topical chapter, title, or section, as arranged by the state's legislature, from LexisNexis for the years 2009 through 2018. To identify substantive firearm laws, we used the RAND State Firearm Law Database, which provides historical state statute data.¹¹ We evaluated each entry, and when we found discrepancies in the database, we retrieved and evaluated the statute from LexisNexis and fixed the data. J. L. P. directed and oversaw this process, with assistance from a law school student and a research assistant.

Based on our review of the state statutes and literature,^{2,3,9} we categorized provisions of substantive laws as "gun-control" or "gun-rights" measures. State statutes may have thus included gun-rights, gun-control, or preemptive measures over the same policy topics. For example, states could have laws with a substantive gun-control measure of banning assault weapons and a preemptive measure on the same policy topic of banning assault weapons.

Per the standard in the field for coding legal statutes,¹² our codebook records the presence of gun measures in each state and year 2009 through 2018, as well as other features, such as exceptions or limitations. For statutes enacted before 2009, we established that they were still in effect and coded them accordingly. For statutes that became effective or were repealed during our 10-year time frame, we recorded these dates and coded accordingly. In those cases, we recorded the month the statute went into effect or was repealed to capture the portion of the year that a measure was effective in the state.

For laws that had more than 1 relevant policy topic in the statute, we treated each individual measure separately, yielding 39 possible gun-control measures, 12 possible gun-rights measures, and 47 possible preemptive measures. The gun-rights measures had overlapping goals, so states would typically choose among policy options in the same policy area (e.g., expanded castle doctrine or stand your ground). Conversely, a state could have laws for all 39 gun-control measures and all 47 preemptive measures.

We coded preemptive laws for the presence of the preemptive measure and to capture the type of preemption, ceiling or floor, and the presence of a savings clause. Ceiling preemption

occurs when a state removes or limits local governments' ability to enact laws on a specific topic. Floor preemption refers to minimum standards whereby a state provides baseline requirements and allows localities to build on those standards. States may also or instead enact a savings clause that expressly allows local governments to enact laws on a specific topic, whether or not the state passed the policy itself.¹³ Finally, we also coded "punitive preemption" laws¹⁴ (also referred to as "super preemption"¹⁵) that authorize the state attorney general or grant individuals or membership organizations standing to sue local governments or local officials for engaging in preempted actions. These statutes may also include specific punitive measures, such as fines, legal liability, and removal from office.¹⁴

To understand the firearm policy context for each state, we created indices for the number of gun-control, gun-rights, and preemptive measures in each state for each year 2009 through 2018. We divided states into quartiles for each year based on the number of measures present for each category for each year. We used Stata version 14 (StataCorp, College Station, TX) to generate the indices and divide states into quartiles for each index.

We then investigated the relationship between substantive and preemptive measures in 2018 by matching the substantive measure with the preemptive measure on the same policy topic for each state, allowing us to determine whether states had both the substantive and the preemptive measure for the same policy topic. We counted each pairing for each state, then divided the states into quartiles, for ease of presentation. Unlike the substantive measures that either promote gun control or protect firearm ownership, by definition all

preemptive measures removed local jurisdictions' authority to enact stronger gun-control measures. Thus, we interpreted the presence of a preemption measure as pro-gun rights.

RESULTS

Figure 1 presents the indices of the number of state gun-control, gun-rights, and preemptive measures in effect for each state in quartiles for 2009 through 2018. Appendix A, Tables A1–A3 (available as a supplement to the online version of this article at <http://www.ajph.org>) list the number of states with each policy topic in 2018,

the most recent year of data, and Appendix B, Tables B1–B3 (available as a supplement to the online version of this article at <http://www.ajph.org>) present quartiles of states for each category of measures in 2018. In Figure 1a–c, the first quartile includes states with the fewest measures, and the fourth quartile includes states with the most measures.

As presented in Figure 1a, the number of gun-control measures in effect remained constant in most states between 2009 and 2018. Twenty-nine states maintained the same number of gun-control measures (1–22) over the 10-year period, whereas 10 states

enacted 1 or 2 new gun-control measures during the 10-year period, and 5 states enacted more: California (5), Maryland (4), Delaware (3), Vermont (3), and Wyoming (2.5). (Decimals indicate that the measure was effective for a part of the year.) Nonetheless, 6 states repealed gun-control measures over this time: South Carolina and Wisconsin repealed 2 gun-control measures each, and Georgia, Illinois, Virginia, and South Dakota repealed 1 gun-control measure each. As can be seen in Appendix B, Table B1, by 2018, California had the most gun-control measures (25) in 2018, followed closely by Hawaii (22) and Massachusetts (21), whereas 13 states had 3 or fewer

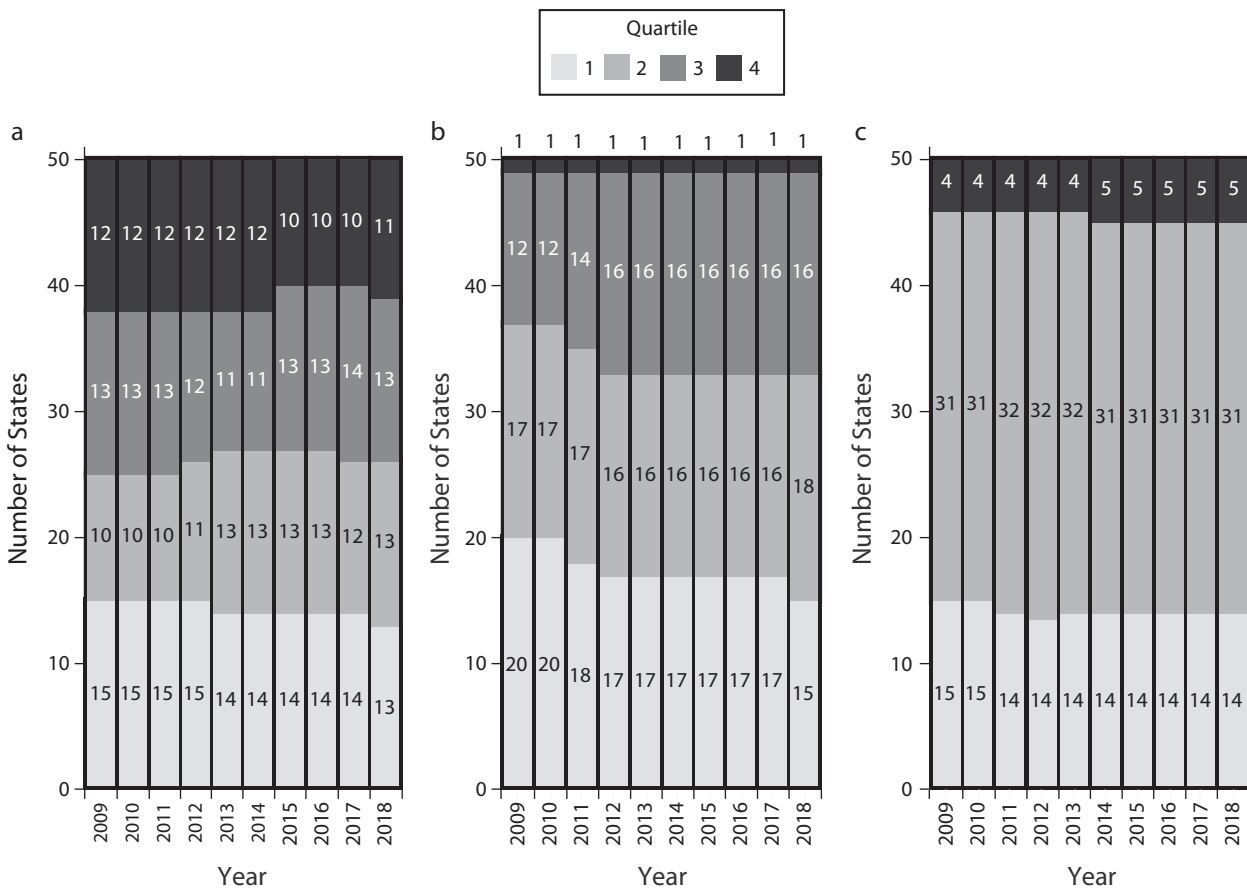


FIGURE 1— Indices of Number of (a) State Gun-Control Measures, (b) Gun-Rights Measures, and (c) Preemption Measures, by Year, in Quartiles: United States, 2009–2018

Note. States in part c were not able to be divided into 4 quartiles because so many states enacted the same number of preemptive laws. The second quartile represents, in effect, the second and third quartiles.

TABLE 1— Comparison of State Preemption and Substantive Gun-Control Measures on the Same Policy Topic, by Quartiles: United States, 2018

	No. of State Gun-Control Measures With Corresponding Preemption on the Same Policy Topic, by Quartile			
	1st Quartile (Range = 0–2 Laws)	2nd Quartile (Range = 3–4 Laws)	3rd Quartile (Range = 5–7 Laws)	4th Quartile (Range = 8–16 Laws)
No. of state preemption measures without corresponding gun-control measures on the same policy topic, by quartile				
1st quartile (0–28 laws)	AK (1, 0)		CA (6, 6)	FL (25, 8.75 ^a)
	CT (0, 0)		NE (21, 5)	MD (24, 16)
	HI (0, 0)			PA (28, 12)
	IL (10, 2)			RI (25, 15)
	MA (0, 0)			
	NJ (0, 0)			
	NY (0, 0)			
2nd quartile (30–34 laws)			AZ (33, 7)	DE (30, 10)
			NV (34, 6)	IA (30, 10)
			NC (33, 7)	MI (31, 9)
			TN (33, 7)	MN (32, 8)
			WI (34, 6)	OR (32, 8)
				UT (31, 9)
				WA (30, 10)
3rd quartile (35–36 laws)		AR (36, 3)	CO (35, 5)	
		GA (36, 4)	IN (35, 5)	
		ID (36, 4)	OK (35, 5)	
		KY (36, 4)	VA (35, 5)	
		MS (36, 4)		
		NH (36, 4)		
		TX (36, 4)		
		VT (36, 4)		
	WV (36, 4)			
4th quartile (37–40 laws)	KS (38, 2)	AL (37, 3)		
	ME (38, 2)	LA (37, 3)		
	MO (38, 2)	WY (37, 3)		
	MT (39, 1)			
	NM (39, 1)			
	ND (38, 2)			
	OH (38, 2)			
	SC (40, 0)			
	SD (39, 1)			

Note. The values in parentheses are the number of laws (row, column).

^aDecimals indicate that the measure was effective for a part of the year.

gun-control measures, including Montana, New Mexico, and South Dakota, with 1 each, and South Carolina had zero, the fewest in the country.

As shown in [Figure 1b](#), the number of gun-rights measures also remained constant for most states over the 10-year period. Forty states maintained

the same number of gun-rights measures (0–4) for the period 2009 through 2018; but during our study period, 9 states passed 1 new gun-rights

measure (IA, ID, IL, KY, MO, NV, NH, NC, WY), and 1 state, Wisconsin, passed 2 new gun-rights measures between 2009 through 2018. As seen in Appendix B, Table B2, by 2018, Pennsylvania had the most gun-rights measures (4), and 15 states had the fewest gun-rights measures, with 0 or 1.

Similar to the pattern we observed for gun-control and gun-rights measures, from 2009 to 2018 the number of states with ceiling preemption (Figure 1c) remained relatively constant over the 10-year period, increasing only slightly, with the majority of states (31) having 44 preemptive measures in effect over the period. As can be seen in Appendix B, Table B3, by 2018, 2 states, Arizona and Alabama, had ceiling preemption over all 47 policy topics evaluated. Only 9 states had fewer than 39 preemptive measures (NE [27], CA [15], IL [14], AK [2], and CT, HI, MA, NJ, NY [0]). In addition, only Illinois regularly had minimum standards (floor preemption) or a savings clause to expressly allow localities to regulate firearms and did so for 32 of the policy topics evaluated (data not shown).

By contrast to the pattern for ceiling preemption over the period 2009 through 2018, there was a dramatic increase in states enacting punitive preemption. In 2009, only 2 states had punitive preemption. By 2018, 15 states had punitive preemption measures (AL, AZ, FL, GA, ID, IN, IA, KY, ME, MS, NV, NC, OK, TN, TX; Figure 2). All of the punitive preemption measures allowed the state attorney general to sue or gave standing to individuals or membership organizations (e.g., the National Rifle Association) to petition the state attorney general or to directly sue local governments or local officials if they believed they were adversely affected by local actions they deemed

preempted. As shown in Appendix B, Table B3, these 15 states are also among those that, by 2018, had the most preemptive measures. Several punitive preemption measures additionally fined or imposed civil penalties on local governments or legislators (4 states) or authorized the removal of local officials from office for violating the state's firearm preemption statute (2 states; data not shown).

Despite the relative consistency nationally across the 10 years for gun-control, gun-rights, and preemption measures, by 2018, state policy environments varied substantively across states. Table 1 presents the state quartiles of 2 comparisons for 2018: first, the pairings of states having gun-control measures with state preemption of gun-control measures on the same policy topic; and second, pairings of states that had preemption but no gun-control measure for the same policy topic. There were 40 possible pairings for both. The number of pairings of gun-control measures with corresponding preemption varied from 0 to 16, with 16 states having between 0 and 2 of these pairs and 11 states having 8 to 16 pairs (column quartiles 1 and 4).

Conversely, the highest number of state preemption measures without corresponding gun-control measures was 40, with most states having at least 30 (row quartiles 2–4). The difference in these 2 quartile ranges illustrates states' wide use of preemption without substantive gun-control measures. Six states (AK, CT, HI, MA, NJ, NY) had the fewest preemptive measures, whether paired with gun-control measures or not. Four states (FL, MD, PA, RI) had the most gun-control measures that were paired with preemption (8.75–16) but among the fewest state preemption

measures without gun-control measures (24–28).

By contrast, 9 states had the fewest gun-control measures with corresponding preemption but the most preemptive measures without corresponding gun-control measures (KS, ME, MO, MT, NM, ND, OH, SC, SD). Thus, in these states, there were few to no statewide gun-control measures, but localities were also preempted from engaging in policymaking over these gun-control policy topics—creating state policy environments that almost exclusively favored gun rights. Moreover, as the quartile ranges indicate, the differences in the contexts between these 9 states and the 12 states in the closest quartiles to these (AR, GA, ID, KY, MS, NH, TX, VT, WV, AL, LA, WY) are fairly minimal.

In data not shown, in 2018, 42 states had 1 to 3 gun-rights measures with corresponding preemption, whereas 45 states preempted local governments from enacting laws related to gun rights without having a substantive state measure on 4 to 10 gun-rights policy topics (with the majority preempting 9). These pairings demonstrate that states used preemption to preserve state authority over a wide range of gun-rights topics. Of note, only 2 of the states without any such preemption had zero gun-rights substantive measures: New York and Massachusetts.

DISCUSSION

To our knowledge, this is the first evaluation of the relationship between state laws with substantive firearm measures and preemptive measures on the same firearm policy topic. The public health significance and variation across states is clearest when examining the pairing

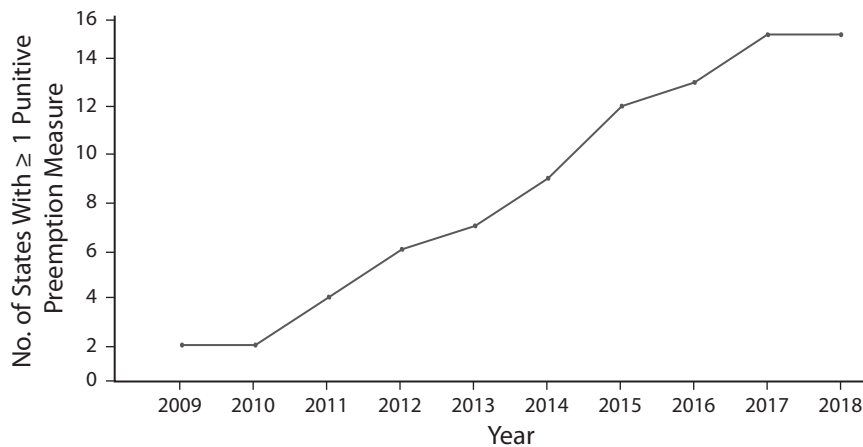


FIGURE 2— Number of States With Gun-Related Punitive Preemption Measures: United States, 2009–2018

Note. A gun-related punitive preemption measure is a state law that authorizes the state attorney general or individuals or membership organizations to sue local governments or local officials for engaging in preempted actions. These statutes may also include the threat of fines, legal liability, and removal from office.

of substantive measures with corresponding preemptive measures for the same gun-control policy topic. States generally fell into 3 types of policy frameworks. A handful of states had the most gun-control measures with few to no preemptive measures (i.e., CT, HI, MA, NJ, NY). Another handful of states had nuanced policy environments with a mix of substantive gun-control measures and a moderate number of preemptive measures (e.g., FL, MD, PA, RI). Nonetheless, the majority of states fell into the third category of having preemptive measures over almost all gun-control policy topics without enacting substantive gun-control measures. In this way, preemption functioned as a form of “deregulation”⁶ by protecting gun rights and eliminating the ability of localities to enact gun-control protections.

In the minority of states that had laws with gun-control measures and simultaneously preempted localities from doing so, legislators’ goals may have been to create uniform gun-control

protections across the state. In this context, preemption reduced further local policy action and innovation but with presumably less impact on the population compared with a state that did not otherwise enact substantive measures. Nonetheless, even if these states were seeking to ensure uniformity with respect to gun-control protections, the legislatures still preempted local control over a range of other gun-control topics. For example, Maryland and Rhode Island had the most substantive gun-control measures and preemptive measures on the same policy topic—16 and 15, respectively—but they still had preemption over 24 and 25 additional gun-control policy topics, respectively, without enacting substantive measures. As a result, the overall policy environment in these states is more nuanced and may reflect policy frameworks championed by diverse legislators over various periods.

In the case of gun rights, states preempted a wider range of gun-rights policy topics than the number of

substantive gun-rights measures they had. Thus, even in states where legislators did not have the political capacity or will to pass statewide gun-rights laws, they succeeded in routinely passing statewide preemption to preserve state authority over a range of gun-rights policy topics. Previous research highlighted that preemption concentrates power in state legislatures and provides a “powerful indirect method of control” over local governments.¹⁶ We have provided direct evidence that the vast majority of states used preemption to support gun rights and remove communities’ authority to enact gun-control protections.

Our research also highlights that little changed in the national landscape of gun laws between 2009 and 2018, despite numerous mass shootings, public demonstrations, and public outcry, with the important exception of punitive preemption. The firearm industry was among the first to use preemption as a tool to block public health policymaking in localities where enacting such measures would have been the most politically feasible¹⁶; it has now succeeded in supporting a national framework that almost universally preempts local gun-control measures. Although a handful of states enacted additional gun-control laws (most notably CA, MD, DE, and VT), others repealed them, and some states enacted additional gun-rights laws. Ultimately, most measures in these states were in place for the entire study period. Although one might expect that localities, especially in areas affected by shootings, would have enacted more gun-control measures, the preemptive landscape may have made that impossible. This barrier to local policymaking also hindered states’ ability to learn from, and thus potentially adopt, local

ordinances that may have proven successful at addressing firearm violence.

States' enactment of punitive preemption measures against local governments and officials is a concerning trend. Punitive preemption is an extreme method to ensure that local governments and officials do not engage in policy activity disfavored by the state legislature. In addition to providing standing to sue local governments and officials, including the availability of monetary damages, some punitive preemption laws explicitly punish local officials for simply engaging in the democratic process to address the needs of their communities.¹⁷

The extensive use of preemption, coupled with a rise in punitive preemption, reinforces the national gun-rights policy framework. Once preemption passes, it is difficult to repeal. Therefore, in states where, and for policy topics for which, preemption is not yet widespread, such as punitive preemption, prevention is key.¹⁸ Gun-control advocates can elevate antipreemption advocacy alongside their propolicy work to defeat preemption before it passes. Stakeholders in Nebraska, for example, have repeatedly defeated punitive preemption using this strategy. As seen in our results, Nebraska had a high number of both gun-control and gun-rights measures but also preserved local control by passing fewer preemptive measures than did other similarly situated states. One reason may be that Nebraska is unique in having a unicameral legislature, where state senators work more closely together and thus appreciate the range of issues across communities in the state.

The National Academy of Medicine (formerly known as the Institute of Medicine) and other experts have argued that states should enact minimum public health standards (floor

preemption) to provide statewide protection and allow localities to engage in additional policymaking to meet the needs of their communities.^{6,19} Only 1 state, Illinois, regularly had minimum standards or a savings clause in the context of firearms. One possible explanation may be that Chicago has a high rate of firearm violence because of firearms trafficking into the city from surrounding states with strong gun-rights and weak gun-control laws.^{20,21} Given the lack of federal antitrafficking laws, Illinois, and thus Chicago, is left to fend for itself.²¹

Limitations

Like all studies, this study has limitations. First, despite diligent efforts to identify all possible gun laws, we may have missed some because we partially relied on other databases to construct our own. However, given the overall trend and lack of change during the period, such omissions are unlikely to challenge these results. Still, our indices are likely a crude measure of the strength of state policy environments, because we did not quantitatively assess the relative effectiveness of different measures in reducing mortality from firearms.

Second, we did not code state laws that would preempt the ability of local governments from passing gun-rights measures. Nonetheless, a review of the state statutes and other databases we used indicated that few to none of these laws exist. Yet, this issue warrants further investigation as a potential gun-control policy option.

Third, we did not examine local gun laws to assess whether localities in states without preemption do in fact enact firearm-related laws. Although anecdotal evidence suggests they do,²²

a deeper investigation would add to our understanding of how preemptive laws affect public health policy environments.

Fourth, we did not include policy topics related to prohibited possessors because the original RAND State Firearm Law Database did not collect these data. We also did not collect or assess federal law or compare federal requirements with state laws.

Last, we did not look at bills that were introduced but not passed or laws that became effective after 2018, so we cannot give a full picture of state policymaking on firearms. As a result, although little changed in the national landscape of gun laws across the states, we should not conclude that there have not been efforts during or laws passed after our study period to make broader changes. Further research is needed to address these issues.

Public Health Implications

Firearm violence is a substantial public health problem. Rather than enact strong gun-control measures, the majority of US states did not engage in substantive policymaking but preempted the ability of local governments to do so. Even states that had substantive gun-control measures preempted local control over other policy topics. Our study shows that the majority of states refrained from providing statewide public health protections and simultaneously used preemption to support gun rights by removing local communities' authority to enact gun-control measures. **AJPH**

ABOUT THE AUTHORS

All authors are with the School of Global Public Health, New York University, New York.

CORRESPONDENCE

Correspondence should be sent to Jennifer L. Pomeranz, Department of Public Health Policy and Management, School of Global Public Health, New York University, 708 Broadway, New York, NY 10003 (e-mail: jlp284@nyu.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Pomeranz JL, Silver D, Lief SA. State gun-control, gun-rights, and preemptive firearm-related laws across 50 US states for 2009–2018. *Am J Public Health*. 2021;111(7):1273–1280.

Acceptance Date: March 13, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306287>

CONTRIBUTORS

J. L. Pomeranz oversaw and conducted the legal analysis, including law retrieval and coding, and interpreted the legal significance of the results. J. L. Pomeranz and D. Silver developed the study and led the article writing. D. Silver developed the codebook with input from the other authors and oversaw and managed the quantitative analysis. D. Silver and S. A. Lief evaluated and interpreted the quantitative results. S. A. Lief conducted the quantitative analysis. All authors contributed to writing and revising the article.

ACKNOWLEDGMENTS

This research was supported by the Robert Wood Johnson Foundation and the Urban Institute (Policies for Action grant 76098).

The authors wish to thank Shrivats Sanganaria, JD, and Mallory Yung, MPH, for their research assistance.

Note. The views expressed here do not necessarily reflect the views of the Robert Wood Johnson Foundation or the Urban Institute.

CONFLICTS OF INTEREST

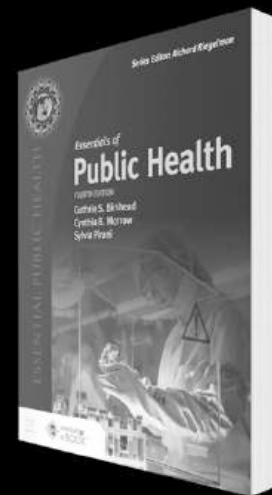
The authors have no conflicts of interest to declare.

REFERENCES

- Centers for Disease Control and Prevention. Firearm violence prevention. Available at: <https://www.cdc.gov/violenceprevention/firearms/fastfact.html>. Accessed October 24, 2020.
- Siegel M, Pahn M, Xuan Z, et al. Firearm-related laws in all 50 US states, 1991–2016. *Am J Public Health*. 2017;107(7):1122–1129. <https://doi.org/10.2105/AJPH.2017.303701>
- Kalesan B, Mobily ME, Keiser O, Fagan JA, Galea S. Firearm legislation and firearm mortality in the USA: a cross-sectional, state-level study. *Lancet*. 2016;387(10030):1847–1855. [https://doi.org/10.1016/S0140-6736\(15\)01026-0](https://doi.org/10.1016/S0140-6736(15)01026-0)
- Pomeranz JL, Pertschuk M. State preemption: a significant and quiet threat to public health in the United States. *Am J Public Health*. 2017;107(6):900–902.
- Wetter S, Rutkow L. State-level preemption legislation, 2017–2018: implications for public health policy and practice. *J Public Health Manag Pract*. 2021;27(2):105–108. <https://doi.org/10.1097/PHH.0000000000001047>
- Pomeranz JL, Zellers L, Bare M, Sullivan PA, Pertschuk M. State preemption: threat to democracy, essential regulation, and public health. *Am J Public Health*. 2019;109(2):251–252. <https://doi.org/10.2105/AJPH.2018.304861>
- Pertschuk M, Hobart R, Paloma M, Larkin MA, Balbach ED. Grassroots movement building and preemption in the campaign for residential fire sprinklers. *Am J Public Health*. 2013;103(10):1780–1787. <https://doi.org/10.2105/AJPH.2013.301317>
- Branas CC, Nance ML, Elliott MR, Richmond TS, Schwab CW. Urban–rural shifts in intentional firearm death: different causes, same results. *Am J Public Health*. 2004;94(10):1750–1755. <https://doi.org/10.2105/AJPH.94.10.1750>
- Giffords Law Center to Prevent Gun Violence. Preemption of local laws. Available at: <https://giffords.org/lawcenter/gun-laws/browse-state-gun-laws/?filter0=,297>. Accessed December 10, 2020.
- Grassroots Change. Preemption map firearms. Available at: <https://grassrootschange.net/preemption-watch/#/category/guns>. Accessed December 10, 2020.
- RAND State Firearm Law Database, Version 2.0 [database]. Santa Monica, CA: RAND Corporation; October 10, 2019.
- Burris S. A technical guide for policy surveillance. October 10, 2014. Available at: http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2469895. Accessed December 10, 2020. <https://doi.org/10.2139/ssrn.2469895>
- Grassroots Change. Savings clause: express protection against preemption. Available at: <https://grassrootschange.net/wp-content/uploads/2018/08/Countering-Preemption-Savings-Clause-FINAL.pdf>. Accessed December 10, 2020.
- Briffault R. The challenge of the new preemption. *Stanford Law Rev*. 2018;70:1995–2027.
- Pough B. Understanding the rise of super preemption in state legislatures. *J Law Polit*. 2018;34:67–116.
- Gorovitz E, Mosher J, Pertschuk M. Preemption or prevention?: Lessons from efforts to control firearms, alcohol, and tobacco. *J Public Health Policy*. 1998;19(1):36–50. <https://doi.org/10.2307/3343088>
- Pomeranz JL, Silver D. State legislative strategies to pass, enhance, and obscure preemption of local public health policy-making. *Am J Prev Med*. 2020;59(3):333–342. <https://doi.org/10.1016/j.amepre.2020.03.023>
- Bare M, Zellers L, Sullivan PA, Pomeranz JL, Pertschuk M. Combatting and preventing preemption: a strategic action model. *J Public Health Manag Pract*. 2019;25(2):101–103. <https://doi.org/10.1097/PHH.0000000000000956>
- Institute of Medicine. *For the Public's Health: Revitalizing Law and Policy to Meet New Challenges*. Washington, DC: National Academies Press; 2011.
- Aisch G, Keller J. How gun traffickers get around state gun laws. Available at: <https://www.nytimes.com/interactive/2015/11/12/us/gun-traffickers-smuggling-state-gun-laws.html>. Accessed February 13, 2021.
- Giffords Law Center to Prevent Gun Violence. Trafficking & straw purchasing. Available at: <https://giffords.org/lawcenter/gun-laws/policy-areas/crime-guns/trafficking-straw-purchasing>. Accessed February 13, 2021.
- Kaste M. Does New York City need gun control? 2019. Available at: <https://www.npr.org/2019/12/19/788440932/does-new-york-city-need-gun-control>. Accessed October 24, 2020.

Introduce and Inspire Your Students in the Field of Public Health

This thorough introduction to public health and the U.S. public health system also explores the wide range of career opportunities available in the field.



Instructor exam copies available at:
go.jblearning.com/Birkhead4

APHA PRESS
AN IMPRINT OF AMERICAN PUBLIC HEALTH ASSOCIATION

JONES & BARTLETT LEARNING
An Ascend Learning Company

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Factors Associated With Calling 911 for an Overdose: An Ethnographic Decision Tree Modeling Approach

Karla D. Wagner, PhD, Brandon Koch, PhD, Jeanette M. Bowles, DrPH, MSW, Silvia R. Verdugo, MD, MPH, Robert W. Harding, and Peter J. Davidson, PhD

Objectives. To identify factors that influence when people who use drugs (PWUDs) call 911 for an overdose.

Methods. We conducted 45 qualitative interviews and 180 surveys with PWUDs who had recently witnessed overdoses in Southern California from 2017 to 2019. We used conditional inference tree and random forest models to generate and validate a model to predict whether 911 would be called.

Results. Our model had good in- (83%) and out-of-sample (84%) predictive accuracy. Three aspects of the social and policy environment influenced calling 911 for an overdose: the effectiveness of response strategies employed, the behavior of other bystanders, and whether the responder believes it is their responsibility to call.

Conclusions. Even in the presence of policies that provide some protections, PWUDs are faced with difficult decisions about calling 911 and must weigh their own safety against that of an overdose victim. Potential interventions include strengthening training and safety planning for PWUDs, bolstering protections for PWUDs when they call 911, and separating law enforcement response from emergency medical response to overdoses. (*Am J Public Health.* 2021;111(7):1281–1283. <https://doi.org/10.2105/AJPH.2021.306261>)

Opioid overdose is a leading cause of death among people who use drugs (PWUDs).¹ Best practices for layperson opioid overdose response includes calling 911, giving rescue breathing, and administering naloxone.^{2,3} However, PWUDs often fear calling 911, particularly if law enforcement officers routinely attend overdoses.^{4,5} In the United States, “911 Good Samaritan Laws,” which provide nominal protections to 911 callers for minor drug-related offenses, have failed to overcome this barrier.^{4,6} As part of a larger study, we used ethnographic decision tree modeling⁷ to identify factors that predict when PWUDs call 911 for an overdose, with the goal of identifying intervention targets.

METHODS

Between February 2017 and May 2018, we conducted qualitative interviews with 45 PWUDs who had seen an overdose, recruited from San Diego County, California, using outreach, referrals, and flyers. Respondents were compensated \$40. Interviews were conducted in locations chosen by the respondents and used a semistructured guide to ask about the context of the most recently witnessed overdose. Interview transcripts were reviewed by 4 analysts, who created “decision trees” illustrating the events described in each interview using a series of branching if-then decision points. The trees were used to

develop a quantitative survey with 74 “yes or no” questions that captured each of the decision points, demographics, and circumstances related to overdoses. From February to December 2019, the survey was administered to 180 PWUDs who had recently been present at an overdose.

We applied a conditional inference tree (CTree⁸) model to accurately classify whether 911 would be called in 177 cases with complete survey data (R version 3.6.3 “ctree” function from “partykit” package [version 1.2-9; R Foundation for Statistical Computing, Vienna, Austria]). The top of the tree is based on the variable with the most significant bivariate association with calling 911; if the *P* value

is small, then CTree creates 2 lower nodes based on the answer. CTree next calculates bivariate P values among respondents within each bottom node and uses the same criterion ($P < .05$) to determine if a bottom node should be split again. CTree repeats this until no additional splits can be made. Finally, the tree breaks the sample into distinct subgroups, and 911 calls are predicted based on the proportion in the sample who called 911 within each subgroup. Almost everyone (94%) tried at least 1 method of waking up the victim, by giving naloxone, doing cardiopulmonary resuscitation or rescue breathing, injecting them with a stimulant or milk or water, or giving Suboxone (buprenorphine and naloxone). At least 1 of these things worked in 67% of cases. So, we combined the questions asking if respondents did any of these things and the questions asking whether it worked into a single independent variable representing whether “something was tried and worked” to wake the person. Missing data were ignored when building the tree and imputed when making predictions.

Because single trees often give predictions with large variability and can be inaccurate when used to predict outside the sample, we used an ensemble of classification trees (i.e., random forests⁹), which decreases variability and increases the accuracy of out-of-sample predictions compared with a single tree. We used a random forest algorithm (“randomForest” function in the R package “randomForest” version 4.6-14) to estimate the out-of-bag (OOB) accuracy, which provides an unbiased estimate of the expected predictive accuracy outside the sample. We present the results from this model along with 2 subanalyses that split the decision tree into additional subgroups based on larger P value cutoffs.

These subgroup analyses do not affect the in-sample predictive accuracy of the overall model, but they do identify additional variables that increase the random forest OOB accuracy and help explain cases in which 911 was not called.

RESULTS

In 43 of 177 (24.3%) cases, 911 was called (see Table A for descriptive statistics; available as a supplement to the online version of this article at <http://www.ajph.org>). Respondents were 68.6% male, 85.6% White, and 72.9% non-Hispanic/Latinx. Our CTree model correctly predicts 911 calling 83% of the time, using 4 variables: whether something was tried and worked to reverse the overdose, how many overdoses the respondent had seen, whether someone other than the respondent called 911, and whether there was a hospital nearby (Figure A, Part a, available as a supplement to the online version of this article at <http://www.ajph.org>). OOB accuracy was 82%.

When no response technique was attempted or worked, nobody else called 911, and there was not a hospital nearby, 911 was called 13 out of 16 times (81%). When there was a hospital nearby and none of the response techniques worked or was attempted, and nobody else called 911, 911 was called 3 out of 10 times (30%). When 1 of the response techniques was attempted and worked and the respondent had previously witnessed 13 or fewer overdoses in the past year, 911 was called 15% of the time. When 1 of the response techniques worked and the respondent had witnessed greater than 13 overdoses in the past year, 911 was called 5 out of 7 times (71%). When no response technique was attempted or worked but someone else called 911, the respondent called 911 in 5 out of 32 cases (16%).

The first subanalysis included additional subgroups based on a larger P value (Figure A, Part b, available as a supplement to the online version of this article at <http://www.ajph.org>). The in-sample predictive accuracy of this model remained 83%; OOB accuracy increased to 84%. This subanalysis revealed that when 1 of the response techniques was tried and worked and the respondent had witnessed 13 or fewer overdoses in the past year, respondents who did not believe it was their responsibility to call 911 did not do so (0/24), while respondents who believed it was their responsibility called 911 in 17 of 88 cases (19%). Feeling “responsible” often had to do with whether one was “in charge” of the location or scene where the overdose occurred.

The second subanalysis shows differences among those who believed it was their responsibility to call 911, determined by (1) whether someone else called 911, (2) whether there was a large amount of drugs at the scene, (3) if the respondent had a warrant, and (4) if the respondent had access to a phone (Figure A, Part c, available as a supplement to the online version of this article at <http://www.ajph.org>). Nearly 30% of those who had warrants but did not have a large amount of drugs at the scene called 911. The in-sample and OOB accuracy were equivalent (83% and 84%, respectively) to the previous models.

DISCUSSION

Three aspects of the social and policy environment predicted whether PWUDs call 911 for an overdose: the effectiveness of response strategies employed, the behavior of other bystanders, and whether the responder believed calling is their responsibility (and contextual issues

related to this (e.g., presence of drugs or warrants). These findings suggest that PWUDs engage in collective action to respond to overdoses. Recommendations include expanded naloxone distribution to ensure PWUD networks are sufficiently naloxone-saturated and that PWUDs have the skills to reverse overdoses. Advance safety planning, in which networks of PWUDs are encouraged to determine preferences and responsibilities for calling 911 in advance, might expedite decisions and improve network safety in the event that an overdose does occur. This work also highlights the need for stronger legal protections that ensure that PWUDs feel safe calling 911, bolsters support for efforts to separate law enforcement from medical responses for overdoses, and demonstrates the need to include PWUDs in intervention development.^{10,11} Limitations include an inability to generalize beyond the area where data were collected; these models should be tested in other samples to increase confidence in our conclusions. **AJPH**

ABOUT THE AUTHORS

Karla D. Wagner, Brandon Koch, and Robert W. Harding are with the School of Community Health Sciences, University of Nevada, Reno. Jeanette M. Bowles is with Centre on Drug Policy Evaluation, Li Ka Shing Knowledge Institute, Toronto, ON, Canada. Silvia R. Verdugo is with FirstWatch Solutions Inc, Carlsbad, CA. Peter J. Davidson is with Division of Infectious Diseases and Global Public Health, University of California San Diego.

CORRESPONDENCE

Correspondence should be sent to Karla D. Wagner, PhD, 1664 N Virginia St, MC 0274, Reno, NV 89509 (e-mail: karlawagner@unr.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Wagner KD, Koch B, Bowles JM, Verdugo SR, Harding RW, Davidson PJ. Factors associated with calling 911 for an overdose: an ethnographic decision tree modeling approach. *Am J Public Health*. 2021;111(7):1281–1283.

Acceptance Date: February 27, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306261>

CONTRIBUTORS

K. D. Wagner conceptualized the analysis and wrote the original draft. K. D. Wagner, B. Koch, and R. Harding performed formal analysis. J. M. Bowles, S. R. Verdugo, R. Harding, and P. J. Davidson participated in conceptualization. K. D. Wagner and R. Harding contributed to project administration. K. D. Wagner, S. R. Verdugo, P. J. Davidson developed the study methodology. K. D. Wagner and P. J. Davidson acquired funding. J. M. Bowles and S. R. Verdugo collected the data. B. Koch, J. M. Bowles, S. R. Verdugo, R. Harding, and P. J. Davidson contributed to validation of analyses. R. Harding curated the data. All authors participated in writing, reviewing, and editing.

ACKNOWLEDGMENTS

Research reported in this publication was supported by the National Institute on Drug Abuse (NIDA) of the National Institutes of Health (NIH) under award R01DA040648.

We would like to thank the participants who provided data for this report and to acknowledge the following team members: Greer Hennessy, Elizabeth Copulsky, Maria Luisa Mittal, and Leah Baker.

Note. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

CONFLICTS OF INTEREST

S. R. Verdugo is currently the medical director for FirstWatch Solutions Inc. FirstWatch is a company that creates technological solutions to manage and use real-time 911 data to inform emergency medical response. Before working at FirstWatch, S. R. Verdugo was a project coordinator on the NIH/NIDA-funded study related to this report. S. R. Verdugo conducted data collection and analysis related the larger study while she was employed as project coordinator for the NIH/NIDA-funded study. Her contributions toward the preparation of the current article occurred while she was employed by FirstWatch Inc. FirstWatch was compensated as a vendor to query 911 data for the larger NIH-funded studies related to this report, but has not contributed in any way to the development of the current article other than with salary support paid to S. R. Verdugo. K. D. Wagner and P. J. Davidson. These authors also have testified as unpaid invited experts (Davidson) and public comment (Wagner) on the topic of opioid overdose and naloxone availability for the US Food and Drug Administration, NIH, and other state and local governmental bodies.

HUMAN PARTICIPANT PROTECTION

The University of California, San Diego, Institutional Review Board approved all study activities. Respondents provided verbal informed consent using a script that described the study and the risks and benefits of participation. Because a signature would have been the only identifying information provided by participants, the study was granted a waiver of documentation of consent by the institutional review board.

REFERENCES

1. Sporer KA. Acute heroin overdose. *Ann Intern Med*. 1999;130(7):584–590. <https://doi.org/10.7326/0003-4819-130-7-199904060-00019>
2. SAMHSA Opioid Overdose Toolkit. Rockville, MD: Substance Abuse and Mental Health Services Administration; 2014.
3. Wheeler E, Burk K, McQuie H, Stancliff S. Guide to Developing and Managing Overdose Prevention and Take-Home Naloxone Projects. New York, NY: Harm Reduction Coalition; 2012.
4. Bowles JM, Smith LR, Verdugo SR, Wagner KD, Davidson PJ. "Generally, you get 86'ed because you're a liability": an application of Integrated Threat Theory to frequently witnessed overdoses and social distancing responses. *Soc Sci Med*. 2020;260:113190. <https://doi.org/10.1016/j.socscimed.2020.113190>
5. Wagner KD, Harding RW, Kelley R, et al. Post-overdose interventions triggered by calling 911: centering the perspectives of people who use drugs (PWUDs). *PLoS One*. 2019;14(10):e0223823. <https://doi.org/10.1371/journal.pone.0223823>
6. Koester S, Mueller SR, Raville L, Langegger S, Binswanger IA. Why are some people who have received overdose education and naloxone reticent to call emergency medical services in the event of overdose? *Int J Drug Policy*. 2017;48:115–124. <https://doi.org/10.1016/j.drugpo.2017.06.008>
7. Gladwin CH. Ethnographic Decision Tree Modeling. Vol 19. Thousand Oaks, CA: Sage; 1989.
8. Hothorn T, Hornik K, Zeileis A. Unbiased recursive partitioning: a conditional inference framework. *J Comput Graph Stat*. 2006;15(3):651–674. <https://doi.org/10.1198/106186006X133933>
9. Breiman L. Random forests. *Mach Learn*. 2001;45(1):5–32. <https://doi.org/10.1023/A:1010933404324>
10. Selfridge M, Greer A, Card KG, Macdonald S, Pauly B. "It's like super structural"—overdose experiences of youth who use drugs and police in three non-metropolitan cities across British Columbia. *Int J Drug Policy*. 2020;76:102623. <https://doi.org/10.1016/j.drugpo.2019.102623>
11. van der Meulen E, Chu SKH, Butler-McPhee J. "That's why people don't call 911": ending routine police attendance at drug overdoses. *Int J Drug Policy*. 2021;88:103039. <https://doi.org/10.1016/j.drugpo.2020.103039>

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

COVID-19 and the Drug Overdose Crisis: Uncovering the Deadliest Months in the United States, January–July 2020

Joseph Friedman, MPH, and Samir Akre, BS

 See also Fliss et al., p. 1194.

Objectives. To determine the magnitude of increases in monthly drug-related overdose mortality during the COVID-19 pandemic in the United States.

Methods. We leveraged provisional records from the Centers for Disease Control and Prevention provided as rolling 12-month sums, which are helpful for smoothing, yet may mask pandemic-related spikes in overdose mortality. We cross-referenced these rolling aggregates with previous monthly data to estimate monthly drug-related overdose mortality for January through July 2020. We quantified historical errors stemming from reporting delays and estimated empirically derived 95% prediction intervals (PIs).

Results. We found that 9192 (95% PI = 8988, 9397) people died from drug overdose in May 2020—making it the deadliest month on record—representing a 57.7% (95% PI = 54.2%, 61.2%) increase over May 2019. Most states saw large-magnitude increases, with the highest in West Virginia, Kentucky, and Tennessee. We observed low concordance between rolling 12-month aggregates and monthly pandemic-related shocks.

Conclusions. Unprecedented increases in overdose mortality occurred during the pandemic, highlighting the value of presenting monthly values alongside smoothed aggregates for detecting shocks.

Public Health Implications. Drastic exacerbations of the US overdose crisis warrant renewed investments in overdose surveillance and prevention during the pandemic response and postpandemic recovery efforts. (*Am J Public Health.* 2021;111(7):1284–1291. <https://doi.org/10.2105/AJPH.2021.306256>)

Unofficial data sources, proxies, and provisional records indicate that overdose deaths in the United States are spiking during the COVID-19 pandemic.^{1–4} National Emergency Medical Services (EMS) data—disaggregated by week—show very-large-magnitude increases in overdose during the pandemic period, reaching more than double baseline values by May 2020.²

Syndromic surveillance data from emergency departments show similar increases in visits for overdose, as well as mental health conditions and intimate partner violence.⁵ Several states have also published provisional mortality records for the same period, demonstrating large-magnitude spikes in overdose deaths.^{6,7} A similar pattern is likely to be present at the national level.

However, given limitations of provisional overdose mortality reporting, the magnitude of the increase cannot yet be determined from official mortality statistics.

In December 2020, the Centers for Disease Control and Prevention (CDC) released an emergency advisory showing that from June 2019 to May 2020, 81 320 people died of a drug overdose in the United States—representing an

increase of 18.0% over the previous 12 months.⁸ However, this 12-month period covered only the first 3 months of pandemic-related disruptions—March through May 2020. As provisional trends are disaggregated by month, any large spikes occurring during the pandemic would be combined with—and potentially masked by—9 months of lower prepandemic values.

In a typical year, the practice of providing rolling aggregate trends is useful for stabilizing rates—especially in states with small populations—given numerous challenges in overdose surveillance. Mortality records are contributed by all 50 US states and the District of Columbia to the National Center for Health Statistics, where they are analyzed centrally.⁹ The lag time between a death's occurrence and the date upon which it is reported to the central repository is generally longer for overdose than other causes of death¹⁰ and can vary by state.⁹ Therefore, provisional estimates of overdose mortality are typically released on at least a 6-month lag. Even then, modeling is undertaken to correct estimates for additional underreporting.¹¹ Provisional records consequently include both “reported” deaths for a given period as well as “predicted” deaths, which are estimated by observing previous reporting delays and assuming they will affect current death levels in a similar fashion.¹¹ In this context, reporting rolling 12-month sums can help to insulate estimates against stochasticity or shocks, which could stem from shifts in reporting lags, and also adjust for seasonality, as all 12 months of each calendar year are always included in each estimated rate.^{9,11}

Nevertheless, during an unprecedented event such as the COVID-19 pandemic—in which the potential

exists for drastic month-to-month shifts—we argue that there is value in assessing the existing data for the presence of shocks alongside smoothed trends. We estimated the original monthly mortality values underlying aggregated provisional trends to determine how many individuals died of overdose in March through July of 2020, as the pandemic dramatically changed life in the United States.

METHODS

We estimated the original monthly mortality values underlying provisional aggregate trends. To accomplish this, we leveraged the fact that (1) precise monthly values are known through the end of 2019¹² and (2) provisional rolling sums are released for 12-month periods with end dates spanning January to July 2020.⁹ By cross-referencing these 2 time series, we can estimate monthly values for 2020, drawing on a straightforward algorithm.

For example, let us consider the case of overdose mortality for January 2020. We have a 12-month cumulative value (for a particular state) pertaining to February 2019 through January 2020. We subtracted off monthly values for February 2019 through December 2019, leaving only the monthly value for January 2020. We subsequently extracted the value for February 2020 using the 12-month data from March 2019 through February 2020 and subtracting off precise monthly values from March 2019 through January 2020. We repeated this exercise for March, April, May, June, and July 2020. In this way, we used each recovered value to help extract data from the next month, in a set of chained calculations. We did this for each US state, and aggregated

them up to the level of census divisions and the national total.

We also quantified how precisely this algorithm can recover monthly values by assessing its performance on previously released provisional aggregates, for which we now have exact monthly values. This method can perfectly recover monthly values when the final and provisional statistics provided by the CDC are internally consistent. In practice, though, these 2 data sources do have small differences, largely because the provisional numbers use modeling to attempt to compensate for reporting lags of greater than 6 months, but these methods are imperfect. Furthermore, there are some small definitional differences between the 2 data sources that could introduce errors. For example, provisional records include all deaths occurring in a given state, whereas final numbers reflect the deceased's state of residence. In addition, counts of fewer than 10 deaths per state-month are suppressed in final death data, requiring assumptions about the distribution of deaths for the small number of state-months with low values.

We quantified the errors stemming from these differences by comparing the data sources for the period for which both are complete, 2015 through 2019. We calculated the average degree to which our algorithmically derived values deviated from subsequently released final trends and used these errors to produce empirically derived 95% prediction intervals (PIs). The full set of recovered values can be seen in Table A (available as a supplement to the online version of this article at <http://www.ajph.org>), and the algorithm and all code used in this analysis is available in a public repository (https://github.com/akre96/cdc_overdose).

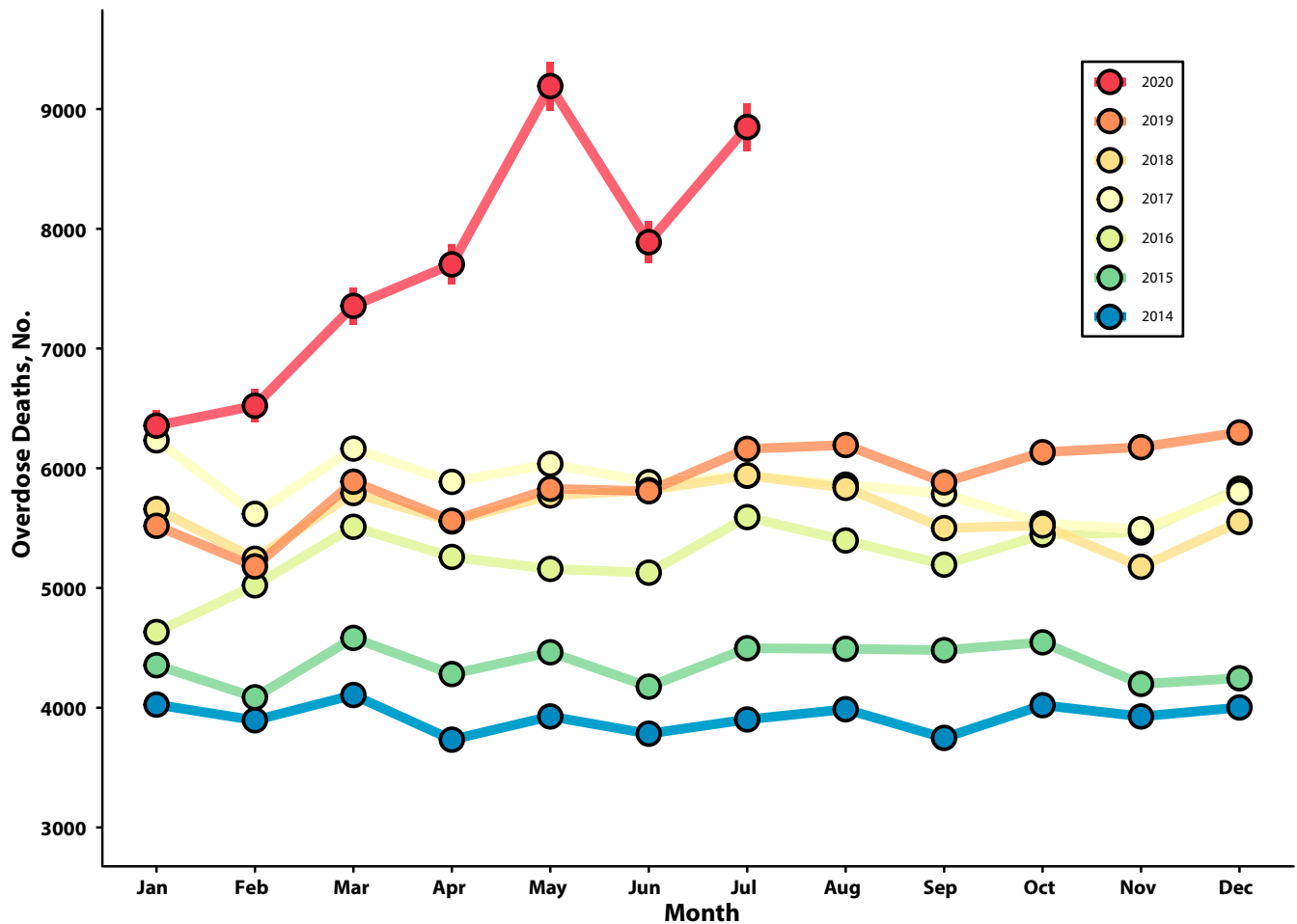


FIGURE 1— Monthly Overdose Deaths From January 2014 to July 2020: United States

Note. Overdose deaths in the United States are shown by month, from January 2014 to July 2020. For values in 2020, 95% prediction intervals are shown, recovered using the algorithm described in this analysis. This figure reveals that May 2020 was the deadliest month for overdose death in the United States in recent history, elevated above May 2019 by about 60%.

RESULTS

We found that 9192 (95% PI = 8988, 9397) people died of overdose in May 2020—making it the deadliest month on record—representing a 57.7% (95% PI = 54.2%, 61.2%) increase over May 2019 (Figure 1). Values remained elevated in June 2020, at 35.8% (95% PI = 32.8%, 38.8%) above June 2019. Mortality rates increased again in July 2020, reaching 43.6% (95% PI = 40.4%, 46.9%) above July 2019. Overall, values in the first 7 months of 2020 were elevated by 34.8% (95% PI = 31.9%,

37.8%) relative to the equivalent months of 2019.

At the census division level, the largest relative increases in overdose deaths in May 2020 compared with May 2019 were seen in the East South Central, South Atlantic, and Pacific divisions, with increases of 99.2% (95% PI = 87.8%, 110.7%), 72.7% (95% PI = 66.6%, 78.8%), and 62.0% (95% PI = 56.4%, 67.7%), respectively (Table 1 and Figure C, available as a supplement to the online version of this article at <http://www.ajph.org>). New England had the smallest relative increase of 25.1% (95% PI = 17.8%, 32.3%).

At the state level, a large-magnitude increase in May 2020 could be seen for nearly every state with a large-enough population to assess monthly trends (Figure 2). West Virginia, Kentucky, and Tennessee had the highest per capita monthly death rates in May 2020 of 93.2 (95% PI = 81.6, 104.8), 56.0 (95% PI = 52.1, 59.8), and 51.0 (95% PI = 48.3, 53.7) per million inhabitants, respectively, representing 178.3% (95% PI = 143.6%, 213.1%), 140.4% (95% PI = 123.8%, 157.0%), and 97.7% (95% PI = 87.2%, 108.2%) increases over May 2019, respectively. Precise values for all

TABLE 1— Overdose Deaths in May 2020 by Census Division: United States

Location	Deaths in May 2020, No. (95% PI)	% Change 2020 vs 2019, (95% PI)	Deaths per Million, No. (95% PI)
National	9192 (8988, 9397)	57.7 (54.2, 61.2)	28.0 (27.4, 28.6)
East South Central	779 (735, 824)	99.2 (87.8, 110.7)	40.6 (38.3, 43.0)
East North Central	1706 (1665, 1748)	55.4 (51.6, 59.2)	36.4 (35.5, 37.3)
New England	489 (461, 518)	25.1 (17.8, 32.3)	32.9 (31.0, 34.8)
South Atlantic	2150 (2074, 2227)	72.7 (66.6, 78.8)	32.7 (31.5, 33.8)
Middle Atlantic	1209 (1158, 1261)	36.3 (30.5, 42.1)	29.4 (28.1, 30.6)
Mountain	637 (597, 678)	53.5 (43.7, 63.3)	25.6 (24.0, 27.3)
Pacific	1097 (1059, 1136)	62.0 (56.4, 67.7)	20.5 (19.8, 21.2)
West North Central	421 (405, 438)	60.7 (54.4, 67.0)	19.6 (18.9, 20.4)
West South Central	704 (671, 738)	52.1 (44.8, 59.3)	17.3 (16.5, 18.2)

Note. PI = prediction interval. Overdose deaths occurring in May 2020 are shown as counts, and rates per million people, nationally and by 9 US census divisions. The percent change between overdose deaths in May 2019 and May 2020 is also shown and used to sort the row order. Counts of deaths are rounded up to the nearest whole person. Maps showing these values graphically, as well as indicating the geographic location of each census division, are available in Figure C (available as a supplement to the online version of this article at <http://www.ajph.org>).

states, census regions, and census divisions can be seen in Table A (available as a supplement to the online version of this article at <http://www.ajph.org>).

The states with the greatest pandemic-related increases were, in many instances, not the same states with the largest 12-month increases in the latest CDC-produced aggregates ending in 2020. This is illustrated in Figure D (available as a supplement to the online version of this article at <http://www.ajph.org>). For example, West Virginia and Connecticut had similar percent increases in rolling aggregates ending in May 2020, of 22% and 24%, respectively. However, in monthly data from May 2020, West Virginia had an increase of 178% compared with only 14% in Connecticut. Nevada had a negative percent change of -4% in rolling 12-month trends ending in May 2020; nevertheless, monthly data from May 2020 showed a 63% increase. The overall *R*² between the percent increase in monthly data from May 2020 and 12-month rolling sums ending in May

2020 was 0.272, reflecting a relatively low level of correlation.

On average, the algorithmic approach outlined here was able to estimate monthly values from provisional aggregates with a high level of precision, compared with subsequently released finalized monthly values, for the 2015–2019 period in which both could be compared. Errors are summarized in Table B (available as a supplement to the online version of this article at <http://www.ajph.org>). At the national level, for example, estimating from 1 to 7 months out from the most recent final monthly trends (the task necessary to recover values from January to July 2020), the median absolute percent error (MAPE) was 0.47%. In other words, the method predicted subsequently reported monthly values on average within half a percent. The standard deviation of the percent error was 1.1%. Therefore, a 95% PI for a national-level estimate would reflect that we expect the final monthly value to fall within a margin of approximately plus or minus 2% of the prediction

made using our algorithm. MAPEs for division-level statistics also tended to be quite small, ranging from 0.7% in East North Central division to 2.8% in New England. State-level errors varied to a much larger degree. For example, Ohio and California had very low MAPEs of 1.1% and 1.3%, respectively. A handful of states with smaller populations—for which results are not highlighted in the main text of this analysis—had substantially larger MAPE values. For 44 states, the MAPE was found to be below 10%, indicating relatively reliable predictive performance.

DISCUSSION

By disaggregating monthly trends, we found that unprecedented increases in overdose mortality occurred during the early months of pandemic in the United States. At the peak, overdose deaths in May 2020 were elevated by nearly 60% compared with the previous year, and the first 7 months of 2020 were overall elevated by 35% compared with the same period for 2019. To put this in

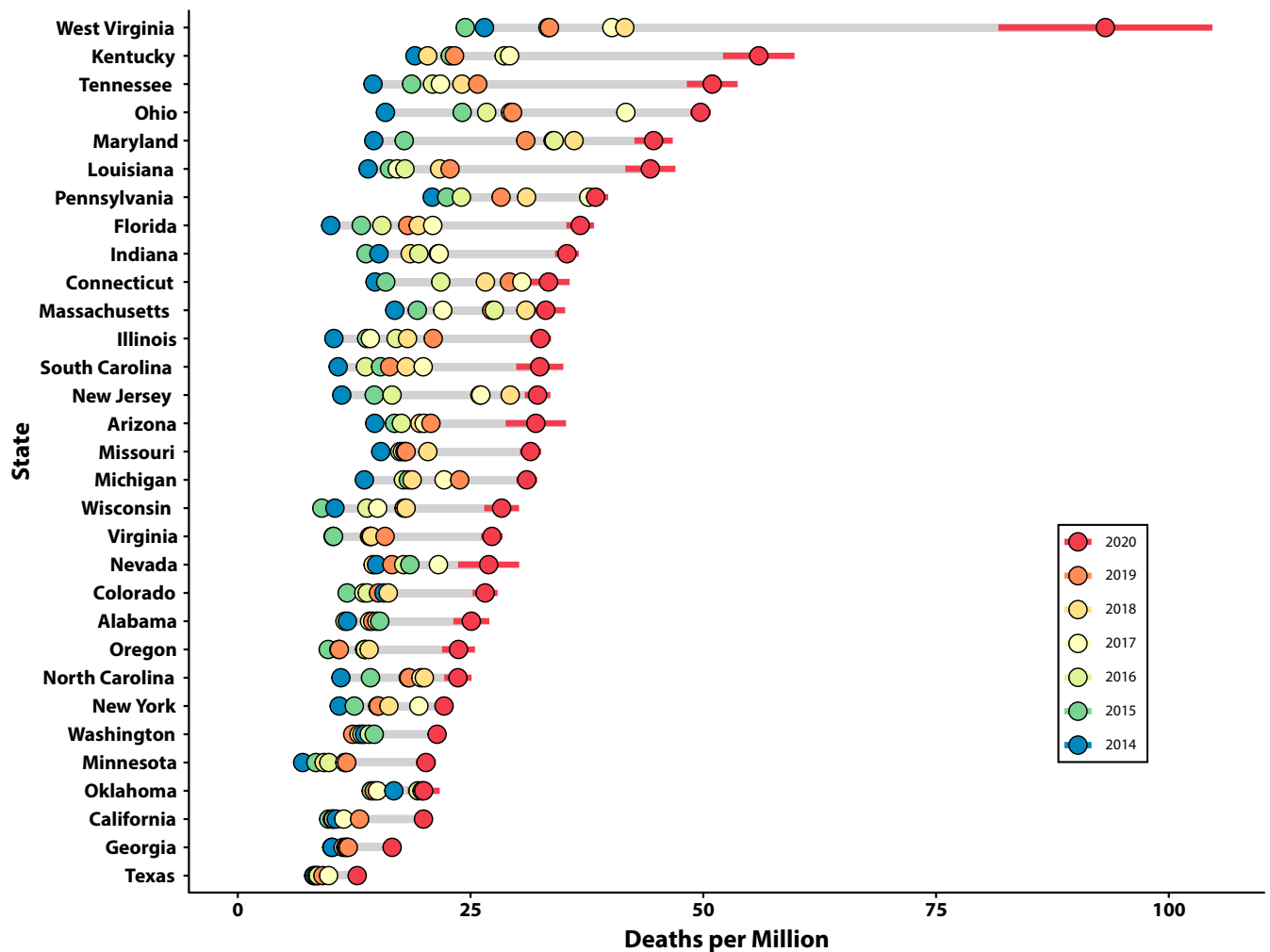


FIGURE 2— Monthly Overdose Deaths in May 2014 Through 2020: Selected US States

Note. Deaths per million people in the month of May are shown for 2014 through 2020, for a subset of states with the highest total number of overdose deaths in 2020 (to avoid states with small numbers, where trends are less stable). For values in 2020, 95% prediction intervals are shown, recovered using the algorithm described in this analysis. This figure highlights large-magnitude increases in overdose deaths in May 2020 compared with previous years, for nearly all states assessed. Particularly large increases were seen in West Virginia, Kentucky, and Tennessee.

perspective, if the final values through December 2020 were to be elevated by a similar margin, we would expect a total of 93 000 to 98 000 deaths to eventually be recorded for the year. Values for the remaining 5 months of 2020 have yet to be seen; however, it is very likely that 2020 will represent the largest year-to-year increase in overdose mortality in recent history for the United States.

The very sharp increases observed in this analysis highlight the value of more

granular data for detecting shocks related to major disruptive events. In many cases, smoothed rolling aggregates tell a very different story from monthly values that highlight pandemic-related shocks. In future epidemiological surveillance efforts of overdose mortality, the presentation of monthly or weekly values alongside smoothed trends may be helpful for more fully characterizing the available data. While this may be difficult for states with small populations, we found

that the majority of US states, all census divisions, and certainly national-level statistics have relatively small prediction errors when data are displayed in a monthly format.

More generally, the COVID-19 pandemic has highlighted issues related to the timely reporting of publicly available data for key public health issues. In the case of direct COVID-19 mortality, the pandemic proved that daily, public reporting of mortality is feasible, given sufficient governmental coordination

and political will. Yet, for the nation's overdose crisis—which has increased constantly over the past several decades and claimed nearly 600 000 American lives in the decade before the pandemic¹²—mortality statistics lag by considerable margins for many jurisdictions.

Furthermore, provisional national records do not include any details about the race, ethnicity, or other social characteristics of the people dying of overdose. Just as with direct COVID-19 mortality, overdose death data disaggregated by race/ethnicity are often available only at a significant lag compared with total numbers. This is especially concerning because recent trends suggest a rapidly shifting social profile of the US overdose crisis, with racial/ethnic minorities most affected.¹³⁻¹⁵ Communities of color are likely facing a dual burden of disproportionate COVID-19 mortality and rapidly rising overdose deaths during the pandemic, yet the depth of this issue cannot yet be described in the available data.

The rapid reporting of overdose mortality is complicated by numerous challenges. The detection and registration of overdose deaths can be delayed by backlogs in medical examiners' or coroners' offices, lengthy toxicological analyses, or other bottlenecks in data processing.¹⁰ Many important efforts have been undertaken by a number of states to improve the timeliness of overdose death reporting,¹⁶ but results remain heterogeneous among locations, and overdose mortality reporting still lags behind that of other causes nationally.¹⁰ Further investments in data infrastructure for vital records systems are therefore warranted to improve the speed of reporting on this critical public health issue.

The results presented here provide public information characterizing

national and regional trends in monthly overdose mortality more rapidly than they would otherwise be available. In addition, for states that do not already provide expedited public data releases—which include many of the states that we find had the largest increases during March through July 2020—the trends presented here may also represent the first publicly available monthly values. These data may be most helpful when considered together with other forms of rapid surveillance, such as syndromic surveillance tools drawing on EMS and emergency department data. These forms of data are available in many states with short lags. Similar information is provided by the CDC National Syndromic Surveillance Program⁵ and the National EMS Information System,² which are national samples of emergency departments and EMS agencies, respectively. Although they represent proxies of overdose mortality, they are available much more rapidly than final mortality numbers and can therefore provide a very useful early warning system for rapid increases.⁴

Importantly, these early data resources, as well as other forms of real-time overdose surveillance, are often available to decision-makers much more rapidly than they are made publicly available. Although the sensitive nature of these data and reporting lags can understandably delay public reporting, we argue that in the context of a large magnitude and growing public health crisis such as overdose in the United States, public data transparency is paramount. Many groups working on issues related to overdose such as harm reduction and other community organizations may not have access to early epidemiological information

unless they are made publicly available. In addition, public statistics often garner significant media attention and can galvanize political conversations, public support, and additional resources to address public health challenges.

Limitations

Our results are limited in several important ways. Perhaps most notably, provisional overdose statistics leverage models that assume that historical levels of reporting lags will continue. If underreporting was exacerbated by pandemic-related strain on public health data systems, then provisional CDC records and, subsequently, our results could underestimate the true level of monthly mortality. Our results should perhaps therefore be regarded as a conservative estimate of the true burden of overdose during the COVID-19 pandemic. Reported decreases following peaks in May 2020, perhaps in particular, should be interpreted with caution, as underreporting may have worsened during this period, artificially deflating overdose mortality estimates. A key area of future research will entail assessing how reporting lags differed during the pandemic, once final numbers are available. For a limited set of states with small numbers of overdose fatalities, our methods rely on assumptions to distribute deaths when state-month counts are below 10. Our empirically derived prediction intervals reflect the degree of uncertainty introduced by these limitations, yet they should be considered for the potential to affect emergent trends. Also, given the observational nature of the results, we cannot ensure that our findings were directly caused by the COVID-19 pandemic. Although timing

and ubiquity of increases during the initial stages of COVID-19–related lockdowns are highly suggestive of the pandemic playing a key role, we cannot rule out other contemporaneous factors that may have also contributed to the increases during this period.

Public Health Implications

Assessing the driving forces behind large increases in overdose mortality during the pandemic will be a complicated task, and it remains an important area for further study. Social isolation is likely playing a role,² with a greater proportion of individuals using substances alone, where they are less likely to receive life-saving help quickly in the event of an overdose. Treatment of substance use disorder, and other medical care, has also been disrupted during the pandemic.¹⁷ With treatment limited—and in a context of increased levels of social and economic stress—many individuals may turn to illicit markets to purchase substances, which are increasingly contaminated with unpredictable quantities of powerful synthetic opioids such as fentanyl.¹⁸ Pandemic-related disruptions to the illicit drug supply may have also accelerated this trend.^{19,20} Furthermore, many upstream structural drivers of addiction and overdose mortality—such as precarious access to housing, employment, quality education, and health care—have been sharply exacerbated during the pandemic.^{21,22} In the wake of COVID-19, the social and economic fallout may continue to drive increasing rates of overdose mortality and other “deaths of despair.”^{5,23}

The drastic exacerbations of the US overdose crisis described here warrant renewed investments in overdose

surveillance and prevention during the pandemic response and postpandemic recovery efforts. Lowering logistical and financial barriers to accessing substance use treatment is paramount. Proposed strategies include facilitating pharmacy-based methadone prescription,¹⁹ eliminating special requirements for the prescription of buprenorphine,²⁴ and providing financial support for patients to pay for these often costly medications and related medical visits.²⁵ In the context of widespread and increasing fentanyl prevalence in the illicit drug supply, making substance use safer is also a key objective.^{26,27} This can be accomplished through harm-reduction strategies such as increasing the availability of naloxone to reverse overdoses,^{28,29} providing “drug checking” services to test substances for the presence of illicit fentanyl,^{8,30} providing individuals with a safe supply of opioid medications known to be free of contaminants,³¹ and creating overdose-prevention sites where individuals can use in the presence of medical professionals prepared to reverse overdoses.³² Investments in upstream social determinants will also represent a key aspect of postpandemic recovery for the prevention of overdose and a host of other related, socially bound public health concerns.^{22,23} Finally, to ensure that such efforts are guided by the best possible information, continued investments in public, transparent, and actionable overdose surveillance remain of paramount importance to equip a broad range of decision-makers, frontline organizations, and community members to work on this growing public health challenge. *AJPH*

ABOUT THE AUTHORS

Joseph Friedman and Samir Akre are with the University of California, Los Angeles (UCLA) Medical Informatics PhD Program, Los Angeles, CA.

J. Friedman is also with the Center for Social Medicine and Humanities, and the Medical Scientist Training Program at UCLA.

CORRESPONDENCE

Correspondence should be sent to Joseph Friedman, Center for Social Medicine and Humanities, B7-435, UCLA Semel Institute, Box 951759, 760 Westwood Plaza, Los Angeles, CA 90024 (e-mail: joseph.robert.friedman@gmail.com). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

PUBLICATION INFORMATION

Full Citation: Friedman J, Akre S. COVID-19 and the drug overdose crisis: uncovering the deadliest months in the United States, January–July 2020. *Am J Public Health*. 2021;111(7):1284–1291.

Acceptance Date: February 25, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306256>

CONTRIBUTORS

J. Friedman conceptualized the study. J. Friedman and S. Akre wrote the analytical code, conducted the analysis, and wrote and revised the article.

ACKNOWLEDGMENTS

J. Friedman received support from the UCLA Medical Scientist Training Program (National Institute of General Medical Sciences training grant GM008042).

The authors are grateful to David Schriger, MD, MPH, and Alex Bui, PhD, for helpful conversations related to this work.

CONFLICTS OF INTEREST

The authors report that they have no conflicts of interest.

HUMAN PARTICIPANT PROTECTION

This study was a secondary analysis of aggregated, publicly available statistics, and was therefore deemed exempt from institutional ethics review at UCLA.

REFERENCES

1. Katz J, Goodnough A, Sanger-Katz M. In shadow of pandemic, US drug overdose deaths resurge to record. *New York Times*. July 15, 2020. <https://www.nytimes.com/interactive/2020/07/15/upshot/drug-overdose-deaths.html>. Accessed September 6, 2020.
2. Friedman J, Beletsky L, Schriger DL. Overdose-related cardiac arrests observed by emergency medical services during the US COVID-19 epidemic. *JAMA Psychiatry*. 2020; Epub ahead of print. <https://doi.org/10.1001/jamapsychiatry.2020.4218>
3. American Medical Association. Issue brief: Reports of increases in opioid- and other drug-related overdose and other concerns during COVID pandemic. Available at: <https://www.ama-assn.org/system/files/2020-12/issue-brief->

- increases-in-opioid-related-overdose.pdf. Accessed November 15, 2020.
4. Slavova S, Rock P, Bush HM, Quesinberry D, Walsh SL. Signal of increased opioid overdose during COVID-19 from emergency medical services data. *Drug Alcohol Depend.* 2020;214:108176. <https://doi.org/10.1016/j.drugalcdep.2020.108176>
 5. Holland KM, Jones C, Vivolo-Kantor AM, et al. Trends in US emergency department visits for mental health, overdose, and violence outcomes before and during the COVID-19 pandemic. *JAMA Psychiatry.* 2021; Epub ahead of print. <https://doi.org/10.1001/jamapsychiatry.2020.4402>
 6. North Carolina Department of Health and Human Services, Division of Public Health. IVP Branch: poisoning data. Available at: <https://www.injuryfreenc.ncdhhs.gov/DataSurveillance/Poisoning.htm>. Accessed February 13, 2021.
 7. California Department of Public Health. California Opioid Overdose Surveillance Dashboard. Available at: <https://skylab.cdph.ca.gov/ODdash>. Accessed March 30, 2021.
 8. Centers for Disease Control and Prevention. Increase in fatal drug overdoses across the United States driven by synthetic opioids before and during the COVID-19 pandemic. Health Alert Network. HAN-00438. December 17, 2020. Available at: <https://emergency.cdc.gov/han/2020/han00438.asp>. Accessed December 25, 2020.
 9. National Center for Health Statistics. Provisional drug overdose death counts. *Vital Statistics Rapid Release.* December 8, 2020. Available at: <https://www.cdc.gov/nchs/nvss/vsrr/drug-overdose-data.htm>. Accessed December 25, 2020.
 10. Spencer MR, Ahmad F. Timeliness of death certificate data for mortality surveillance and provisional estimates. *Vital Statistics Rapid Release.* Report No. 1. December 2016. Available at: <https://www.cdc.gov/nchs/data/vsrr/report001.pdf>. Accessed March 30, 2021.
 11. Rossen LM, Ahmad F, Spencer MR, Warner M, Sutton P. Methods to adjust provisional counts of drug overdose deaths for underreporting. *Vital Statistics Rapid Release.* Report No. 6. August 2018. Available at: <https://www.cdc.gov/nchs/data/vsrr/report006.pdf>. Accessed March 30, 2021.
 12. Centers for Disease Control and Prevention. CDC WONDER. Available at: <https://wonder.cdc.gov>. Accessed December 30, 2020.
 13. Spencer M, Warner M, Bastian BA, Trinidad JP, Hedegaard H. Drug overdose deaths involving fentanyl, 2011–2016. March 21, 2019. National Center for Health Statistics. Available at: <https://stacks.cdc.gov/view/cdc/77832>. Accessed November 15, 2020.
 14. James K, Jordan A. The opioid crisis in Black communities. *J Law Med Ethics.* 2018;46(2):404–421. <https://doi.org/10.1177/1073110518782949>
 15. Hansen H, Netherland J. Is the prescription opioid epidemic a White problem? *Am J Public Health.* 2016;106(12):2127–2129. <https://doi.org/10.2105/AJPH.2016.303483>
 16. Centers for Disease Control and Prevention. Enhanced state opioid overdose surveillance. October 15, 2020. Available at: <https://www.cdc.gov/drugoverdose/foa/state-opioid-mm.html>. Accessed February 13, 2021.
 17. Herring AA, Kalmin M, Speener M, et al. Sharp decline in hospital and emergency department initiated buprenorphine for opioid use disorder during COVID-19 state of emergency in California. *J Subst Abuse Treat.* 2021;123:108260. <https://doi.org/10.1016/j.jsat.2020.108260>
 18. Ciccarone D. Fentanyl in the US heroin supply: a rapidly changing risk environment. *Int J Drug Policy.* 2017;46:107–111. <https://doi.org/10.1016/j.drugpo.2017.06.010>
 19. Wakeman SE, Green TC, Rich J. An overdose surge will compound the COVID-19 pandemic if urgent action is not taken. *Nat Med.* 2020;26(6):819–820. <https://doi.org/10.1038/s41591-020-0898-0>
 20. Beletsky L, Davis CS. Today's fentanyl crisis: Prohibition's Iron Law, revisited. *Int J Drug Policy.* 2017;46:156–159. <https://doi.org/10.1016/j.drugpo.2017.05.050>
 21. Bamba C, Riordan R, Ford J, Matthews F. The COVID-19 pandemic and health inequalities. *J Epidemiol Community Health.* 2020;74(11):964–968. <https://doi.org/10.1136/jech-2020-214401>
 22. Dasgupta N, Beletsky L, Ciccarone D. Opioid crisis: no easy fix to its social and economic determinants. *Am J Public Health.* 2018;108(2):182–186. <https://doi.org/10.2105/AJPH.2017.304187>
 23. Arena PJ, Malta M, Rimoin AW, Strathdee SA. Race, COVID-19 and deaths of despair. *Eclinical-Medicine.* 2020;25:100485. <https://doi.org/10.1016/j.eclinm.2020.100485>
 24. Stancliff S, Greene D, Zucker HA. Why 24 state and territorial health officials support buprenorphine deregulation. *Am J Public Health.* 2019;109(12):1678–1679. <https://doi.org/10.2105/AJPH.2019.305370>
 25. Kaplan-Dobbs M, Kattan JA, Tuazon E, Jimenez C, Saleh S, Kunins HV. Increasing access to buprenorphine in safety-net primary care clinics: the New York City Buprenorphine Nurse Care Manager Initiative. *Am J Public Health.* 2021;111(2):215–218. <https://doi.org/10.2105/AJPH.2020.306000>
 26. Shover CL, Falasinnu TO, Dwyer CL, et al. Steep increases in fentanyl-related mortality west of the Mississippi River: recent evidence from county and state surveillance. *Drug Alcohol Depend.* 2020;216:108314. <https://doi.org/10.1016/j.drugalcdep.2020.108314>
 27. Burris S. Research on the effects of legal health interventions to prevent overdose: too often too little and too late. *Am J Public Health.* 2020;110(6):768–770. <https://doi.org/10.2105/AJPH.2020.305678>
 28. Doe-Simkins M, Walley AY, Epstein A, Moyer P. Saved by the nose: bystander-administered intranasal naloxone hydrochloride for opioid overdose. *Am J Public Health.* 2009;99(5):788–791. <https://doi.org/10.2105/AJPH.2008.146647>
 29. Green TC, Davis C, Xuan Z, Walley AY, Bratberg J. Laws mandating coprescription of naloxone and their impact on naloxone prescription in five US States, 2014–2018. *Am J Public Health.* 2020;110(6):881–887. <https://doi.org/10.2105/AJPH.2020.305620>
 30. Reed MK, Roth AM, Tabb LP, Groves AK, Lankeau SE. "I probably got a minute": Perceptions of fentanyl test strip use among people who use stimulants. *Int J Drug Policy.* 2021; Epub ahead of print. <https://doi.org/10.1016/j.drugpo.2021.103147>
 31. Ivins A, Boyd J, Beletsky L, McNeil R. Tackling the overdose crisis: the role of safe supply. *Int J Drug Policy.* 2020;80:102769. <https://doi.org/10.1016/j.drugpo.2020.102769>
 32. Beletsky L, Baker P, Arredondo J, et al. The global health and equity imperative for safe consumption facilities. *Lancet.* 2018;392(10147):553–554. [https://doi.org/10.1016/S0140-6736\(18\)31469-7](https://doi.org/10.1016/S0140-6736(18)31469-7)



Racism: Science & Tools for the Public Health Professional

Edited by
Chandra L. Ford, PhD
Derek M. Griffith, PhD
Marino A. Bruce, PhD
and Keon L. Gilbert, DrPH

ISBN: 978-0-87553-303-2
2019, Softcover
List Price: \$69
APHA Member Price: \$48.30

This important publication builds on the racial health equity work that public health advocates and others have been doing for decades. They have documented the existence of health inequities and have combatted health inequities stemming from racism. This book, which targets racism directly and includes the word squarely in its title, marks an important shift in the field's antiracism struggle for racial health equity. It is intended for use in a wide range of settings including health departments, schools, and in the private, public, and nonprofit sectors where public health professionals work.

ORDER TODAY AT
aphabookstore.org

FOR REVIEW COPIES CONTACT
david.hartogs@apha.org

 **APHA PRESS**
AN IMPRINT OF AMERICAN PUBLIC HEALTH ASSOCIATION

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Homicide Epidemic in Cali, Colombia: A Surveillance System Data Analysis, 1993–2018

Rodrigo Guerrero-Velasco, MD, PhD, MSc, Víctor Hugo Muñoz, MSc, Alberto Concha-Eastman, MD, MSc, Álvaro J. Pretel-Meneses, MSc(Econ), María I. Gutiérrez-Martínez, MD, PhD, MSc, and Julian Santaella-Tenorio, DVM, DrPH, MSc

Objectives. To examine homicide rates in Cali, Colombia, during the 1993–2018 period, using information derived from an interagency surveillance system.

Methods. We used homicide data from Cali's Epidemiological Surveillance System to examine homicide trends by victim's age and sex, time, and type of method used. We estimated trend changes and the annual percentage changes using joinpoint regression analyses.

Results. Homicide rates per 100 000 inhabitants dropped from 102 in 1993 to 47.8 in 2018. We observed reductions in homicide rates across age and sex groups. Most homicide victims were men aged 20 to 39 years from poor, marginalized areas. Firearms were used in 84.9% of all cases. The average annual percentage change for the entire period was -3.6 (95% confidence interval = $-6.7, -0.4$).

Conclusions. Fluctuations in homicide rates in Cali show a clear epidemic pattern, occurring concurrently with the "crack epidemic" in different countries. Reliable and timely information provided by an Epidemiological Surveillance System allowed opportune formulation of public policies to reduce the impact of violence in Cali. (*Am J Public Health.* 2021;111(7):1292–1299. <https://doi.org/10.2105/AJPH.2021.306254>)

Cali, the third largest Colombian city by number of inhabitants, has experienced significant fluctuations in homicide rates in the past 3 decades. According to analysis of death certificates issued by the Colombian Institute of Legal Medicine and Forensic Sciences (IMLCF; Spanish acronym) carried out by the Municipal Secretariat of Health of Cali, the homicide rate per 100 000 people quadrupled from 23 in 1983 to 93 in 1992; during this period, homicides became the first cause of general mortality, surpassing ischemic cardiovascular diseases and contagious diseases.¹

In 1993, Cali adopted the public health method for violence prevention.^{1,2} The public health method

required reliable and opportune information about violent events, which were provided by an Epidemiological Surveillance System (ESS), an interinstitutional committee (*Comité Interinstitucional de Muertes por Causa Externa*) created to resolve the notorious discrepancies among the homicide databases from the police, the attorney general's office, and the IMLCF.³ Since 1993, representatives of these 3 institutions meet once a week to discuss all violent deaths occurring in Cali in the previous week. This process validates and consolidates the data from these sources while it collects information about victims, and when, how, and where events occurred. The ESS

approach collects similar information to that collected by the US National Violent Death Reporting System on violent deaths.⁴ The ESS model, with the name of Observatories of Crime/Violence, has spread to other countries in the Americas.⁵

Using information from the ESS, Concha-Eastman et al.,⁶ analyzed socio-demographic characteristics and homicide trends in Cali from 1993 to 1998 and found a reduction in homicide rates per 100 000 inhabitants from 124 in 1994 to 86.1 in 1997; the authors found that low-income men aged 20 to 34 years were the most affected and that homicides were more frequently occurring on weekend nights and were

associated with alcohol consumption and use of firearms.⁶ Also using data from the ESS, Fandiño-Losada et al. found that Cali experienced a substantial reduction in homicide rates from 2012 to 2015, mainly attributable to reductions in organized crime-related homicides.⁷ However, despite this evidence, little is known about the trend in homicide rates in Cali over time and the potential factors influencing these rates.

With this study, we aimed to descriptively specify the homicide rate in Cali, overall and by subgroups, to examine trend changes over time, and to describe policies and contextual factors that could be linked to changes in homicide rates, using data from the Cali ESS from 1993 to 2018.

METHODS

We included all homicides that occurred in Cali between January 1, 1993, and December 31, 2018, within the urban and rural perimeter of Cali, regardless of whether the victims were residents of the city. For those who died after being injured, we recorded the date of initial injury. We did not include homicides in which the initial injury occurred outside of Cali.

Initially, homicides were recorded by the working group of the Development, Security, and Peace Program,¹ which was part of the mayor's office. Since 1993, homicides are recorded weekly by the Cali ESS with information provided by the institutions that are primary sources of data: the attorney general's office, the national police, and the IMLCF. Weekly meetings are also joined by a member of the Municipal Secretariat of Public Health and a member of the Cisalva Institute (Violence Prevention Research Institute from Universidad del Valle). Figure A (available as a

supplement to the online version of this article at <http://www.ajph.org>) describes the institutions and the type of data shared during the ESS weekly meetings. We obtained data from Colombia for 1993 to 2018 from the national official publication from the National Department of Statistics,⁸ which regularly collects information from death certificates from all municipalities classified in accordance with the *International Classification of Diseases, 10th Revision*.⁹

We standardized rates by using the direct method and the average world population between 2000 and 2025 as reference.¹⁰ We calculated adjusted rates with the Tiwari et al. 2006 method.¹¹ We used the Joinpoint Regression Program (version 4.8.0.1; Statistical Research and Applications Branch, National Cancer Institute, Rockville, MD) to describe trends over time. The software estimates a series of permutations with differing inflection points and determines the model with the best fit based on permutations tests or the lowest Bayesian information criterion score.¹² We calculated the annual percentage change (APC) for trends between joinpoints, and we calculated the average APC for the overall trend for the entire study period. We conducted a spatial analysis by using ArcGis (release 10; Environmental Systems Research Institute, Redlands, CA) to describe the neighborhoods with highest number of homicides in specific years.

RESULTS

Between 1993 and 2018, there were 45 819 homicides in Cali, with an average of 1762 per year and 4.8 per day. There was an overall decreasing trend of homicide rates over the study period (53.2% reduction). However, there were 2 periods in which homicide rates increased:

from 1998 to 2003 (APC = 3.35) and from 2006 to 2012 (APC = 3.63; Figure 1). The APC in homicide rates for the periods between trend-change points is presented in Table 1. The average APC for the entire period was -3.6 (95% confidence interval [CI] = $-6.7, -0.4$).

Colombia's homicide rate showed similar fluctuations to those in Cali, with a decreasing trend for most of the period (69.1% reduction) and a period when the trend changed from 1997 to 2002 (with a 28.6% increase in homicides). Throughout the study period, the rates in Cali were higher than those in Colombia (Figure B, available as a supplement to the online version of this article at <http://www.ajph.org>).

Homicides by Age and Sex Groups

We observed significant reductions in homicide rates of 47%, 57%, and 68% for the groups aged 20 to 29, 30 to 39, and 40 to 49 years, respectively; in the group aged 10 to 19 years, rates were more stable, staying above 85 per 100 000 inhabitants for most of the years (Figure 2). The group aged 20 to 29 years had the highest homicide rate throughout the study period; on average, this group had 2.5, 2.1, and 1.5 times the rate of the groups aged 30 to 39, 10 to 19, and 40 to 49 years, respectively. After 2013, all age groups experienced reductions in their homicide rates. In the groups aged 50 to 59 and 60 to 69 years, we also observed reductions of 71% (from 69.4 to 19.6 per 100 000) and 45% (from 25.4 to 14.0 per 100 000; not shown in Figure 2).

Regarding the sex of the victim, 93.5% (42 848) of the deceased were men. The male-to-female ratio was 14.5 to 1 (Table A, available as a supplement to the online version of this article at <https://>

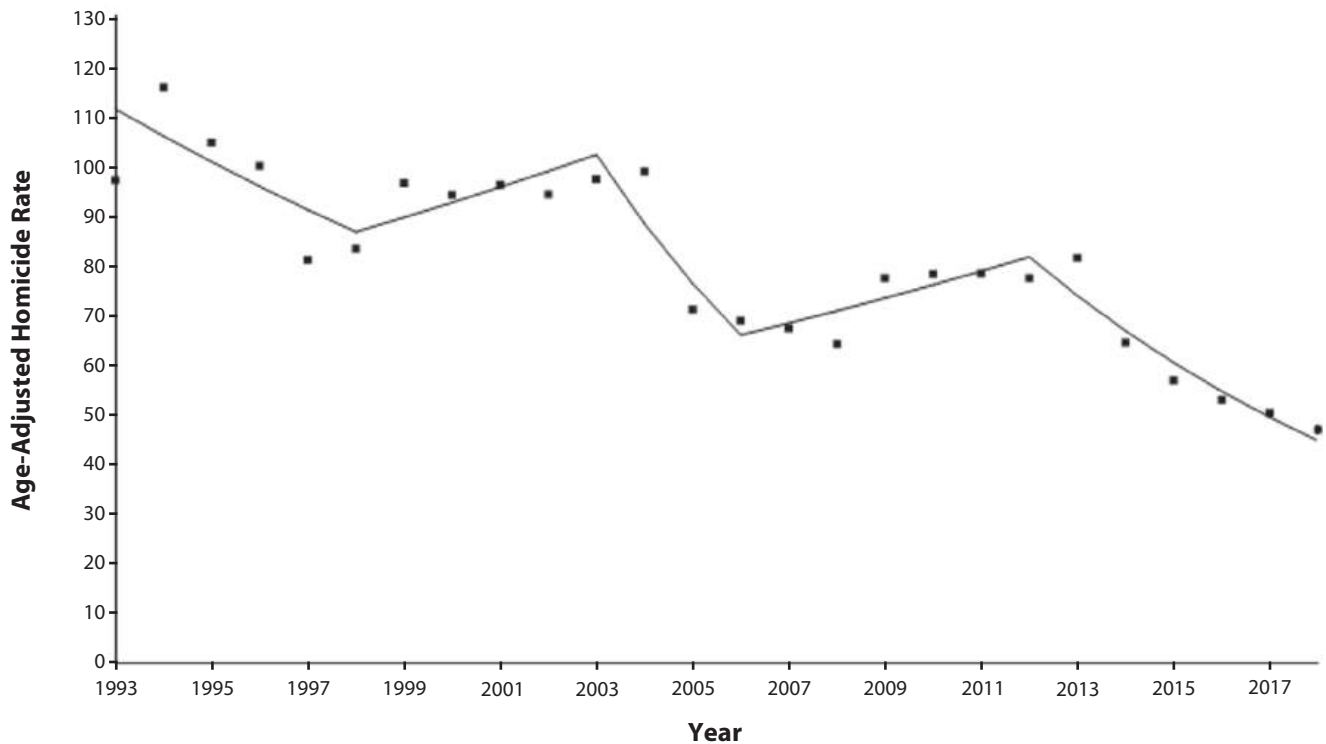


FIGURE 1— Age-Adjusted Homicide Rates: Cali, Colombia, 1993–2018

Note. 1993–1998 annual percentage change (APC) = -4.9 ($P < .05$); 1998–2003 APC = 3.35 ; 2003–2006 APC = -13.6 ; 2006–2012 APC = 3.63 ; 2012–2018 APC = -9.58 ($P < .05$). Lines represent modeled trends via joinpoint regression.

www.ajph.org, shows the number of homicides per year by sex). Reductions were of similar magnitude in males (58%) and females (53%). Figure 3 shows the trends for males and females.

Homicides According to Month, Day, and Time

The daily average of homicides for the entire period was 4.8. A decreasing trend was observed in the daily average of homicides, from 5.0 in 1993 to 3.2 in 2018. December and February had the highest and lowest numbers of homicides per day on average (5.7 and 4.5 homicides per day, respectively).

Sunday and Saturday (7.6 and 5.5 homicides, respectively) had, on average, the highest number of homicides, and Tuesday and Wednesday had the lowest number of homicides (3.9 and 4.0 homicides,

respectively). There were 259 Mondays that were holidays during the study period; the average number of homicides on Mondays that were holidays was higher than on nonholiday Mondays (4.9 homicides and 4.1 homicides, respectively). For both males and females, the highest proportion of homicides occurred on Sundays; the odds of dying on a Tuesday (odds ratio [OR] = 1.52; 95% CI = 1.33, 1.73) or Thursday (OR = 1.46; 95% CI = 1.28, 1.67), compared with Sunday, were higher among females than among males.

A total of 41% of homicides occurred between 18:00 and 23:59, and 23% occurred between 00:01 and 06:00. For most days of the week, the hour with the highest number of homicides was between 20:00 and 20:59 (9.8%). The lowest number of homicides was observed between 07:00 and 07:59

(2.1%). This tendency was observed throughout the study period.

Multiple Homicides

A multiple homicide was defined as 3 or more people killed in a single event. In Cali, multiple homicides are often the product of retaliations between

TABLE 1— Trends in Homicides in Cali, Colombia: 1993–2018

Period	Change Year	APC (95% CI)
1993–1998	1998	-4.9^* ($-9.1, -0.5$)
1998–2003	2003	3.35 ($-2.9, 10.0$)
2003–2006	2006	-13.6 ($-32.9, 11.2$)
2006–2012	2012	3.63 ($-1.0, 8.5$)
2012–2018		-9.58^* ($-12.8, -6.2$)

Note. APC = annual percentage change; CI = confidence interval.

* $P < .05$.

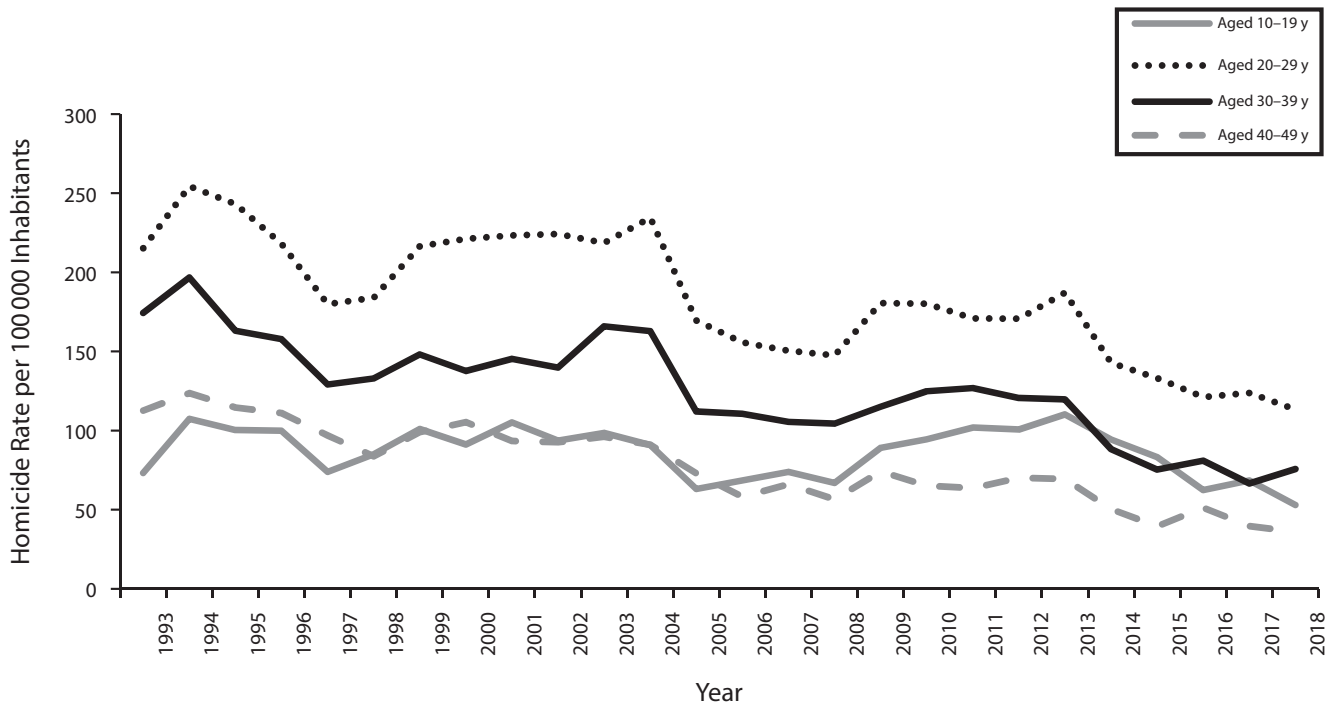


FIGURE 2— Homicide Rate per 100 000 People in Cali, Colombia, by Age Groups: 1993–2018

Source. Cali Epidemiological Surveillance System (1993–2018).

organized crime gangs (as evidenced from the information provided by data primary sources in ESS meetings). According to information (available only as of 2007) the distribution of multiple homicides was as follows: 2 events with 8 homicides, 1 with 7 homicides, 1 with 5 homicides, 60 with 4 homicides, and 168 with 3 homicides. The year with the highest frequency of multiple homicides was 2012 (11 events with 3 homicides and 3 events with 4 homicides, for a total of 45 homicides). From 2015 to 2018 there were 2, 5, 1, and 3 multiple homicides per year. December was the month and Sunday the day with the highest number of multiple homicides.

Homicides by Weapon Used

Of all homicides, 84.9% were perpetrated with a firearm, and 12.3% with knives or similar bladed instruments. Figure C

(available as a supplement to the online version of this article at <http://www.ajph.org>) shows that both firearm homicide (left margin) and knife homicide rates (right margin) decreased approximately by half during the study period. Starting in 2013, the knife homicide rate increased slightly while the firearm homicide rate continuously decreased until 2018. The odds that a homicide was committed with a knife (i.e., knife vs firearm) were higher in females than males (OR = 1.41; 95% CI = 1.27, 1.56).

The proportion of homicides committed with knives was higher on Sundays (17.2%) and lower on Wednesdays (12%); it was also higher in the early morning (00:00–05:59; 19.1%), and lower at night (18:00–23:59; 10%).

Homicide Rates by Commune

Figure D (available as a supplement to the online version of this article at [http://](http://www.ajph.org)

www.ajph.org) shows the distribution of homicides in Cali in 2004, 2011, and 2018. Homicides tended to accumulate in areas of marginalization and more recent development in the east and southeast of Cali. For example, 35.5% of all homicides were concentrated in the Aguablanca District (communes 13, 14, 15, and 21) and adjacent commune 16, 8.7% in downtown communes 3 and 9, 10.2% in communes 18 and 20 (in the western part of the city), and 5.8% in commune 6 (located in the north), all areas at economic disadvantage.

DISCUSSION

Cali specifically and Colombia generally experienced a drastic increase, considered an epidemic, in homicide rates from the early 1980s until the early 1990s, associated with the increase in drug trafficking and cocaine

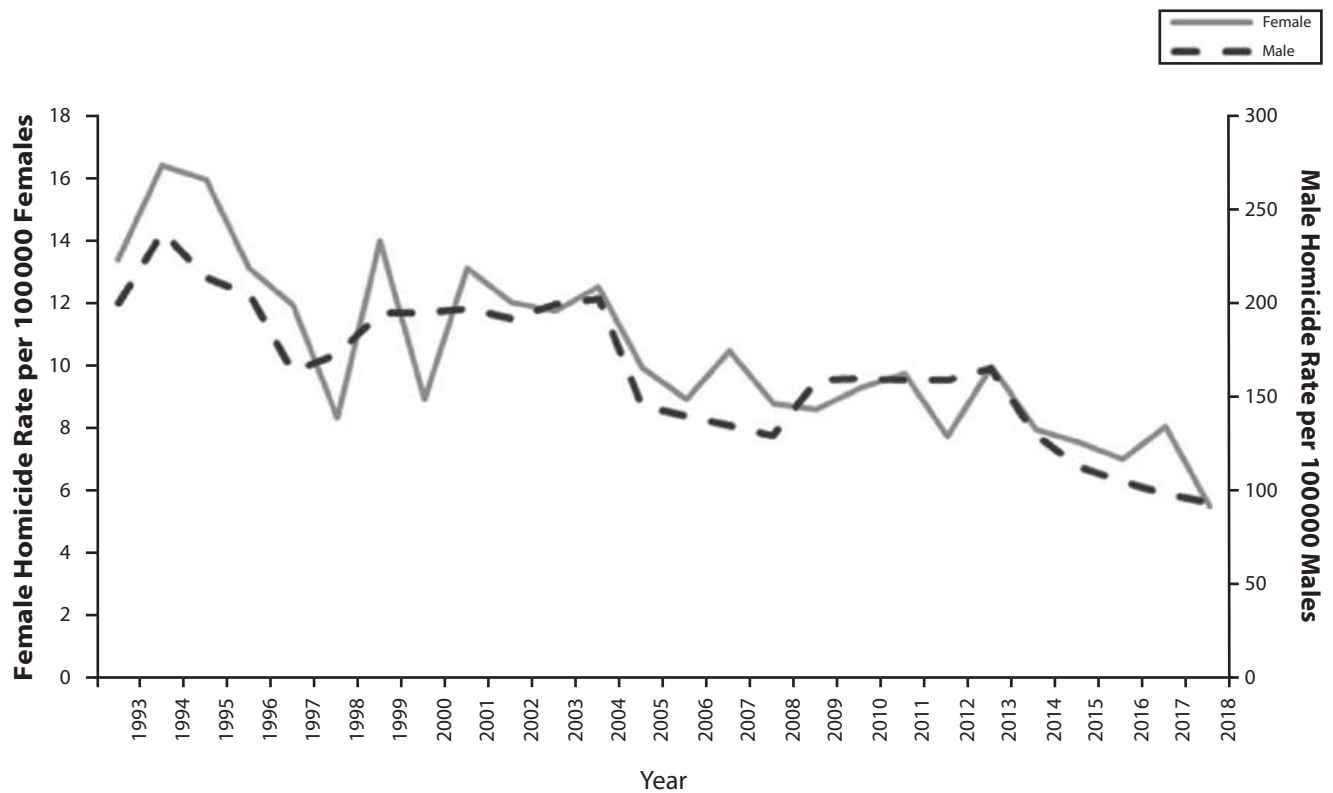


FIGURE 3— Homicide Rate per 100 000 People in Cali, Colombia, by Sex: 1993–2018

Source: Cali Epidemiological Surveillance System (1993–2018).

production,¹³ the presence of drug cartels and guerrilla groups,¹⁴ and the emergence of paramilitary groups.^{15–18}

Cali and Medellín were the Colombian cities most affected by the 2 largest drug trafficking cartels and the confrontation between them: the Medellín cartel, led by Pablo Escobar, and the Cali cartel, led by the Rodríguez Orejuela brothers. Homicide rates per 100 000 increased to 390 in Medellín and 124 in Cali in 1992. By contrast, Bogotá, which did not have such a strong presence of drug cartels, had a homicide rate of 80 per 100 000 in 1992.⁸ The increases in homicide rates in Colombian cities are similar to those observed during the 1980s in some large cities in the United States and in other cities in Latin America, such as São Paulo, Brazil.¹⁹ These increases in homicide rates were also found to be

associated with the trafficking and use of crack cocaine across communities at economic disadvantage.²⁰ In Cali, homicide victims were mostly young adult males from disadvantaged areas, who, compared with females and older adults, usually participated more in street gangs or in organized crime and drug trafficking. This is similar to what has been observed in other countries.^{19,21,22}

The reduction of homicide rates observed in Cali and in Colombia since 1994 is likely explained, at least in part, by the reforms undertaken by the central government at the beginning of the 1990s, such as the ones in the national police and the judicial system, and also the strengthening of the armed forces, which led to the dismantling of the Cali and Medellín cartels, and resulted in reaching a peace agreement with the

guerrilla group M-19 in 1994.²³ Also, data from the Cali ESS provided timely information on the disproportionately high numbers of firearm homicides during weekend nights in Cali. This information was used by the city mayor's office, in coordination with the metropolitan police, to implement legislation forbidding citizens to carry firearms on selected weekends that were associated with high alcohol consumption and violence (e.g., weekends after semimonthly paydays, holidays, and Mother's Days). The city also implemented a policy restricting alcohol sales in public places after 2 AM and on Sundays, periods associated with higher frequency of homicides associated with quarrels and interpersonal problems linked to alcohol consumption.²⁴ The legislation suspending

carrying permits, implemented from November 1993 and throughout 1994, was associated with a 14% reduction in homicides in Cali.²⁴ Female homicides also decreased in Cali since 1994, likely in response to these interventions, given their influence on alcohol consumption and use of firearms among violent partners. A few months later, similar legislation implemented in Bogotá showed similar reductions in homicides.²⁴

Cali experienced an increase in homicide rates from 1998 to 2003 that was also accompanied by increases in kidnappings.¹⁸ This increase has been attributed to the strengthening and reorganization of guerrilla and paramilitary groups that operated mostly in rural areas but also in many urban areas.¹⁸ From 2003 to 2006, homicide rates declined in Cali and in the rest of Colombia. This reduction in homicides has been attributed, at least in part, to the increased number of military operations against FARC (*Fuerzas Armadas Revolucionarias de Colombia*) and paramilitary groups, and the Demobilization, Disarmament, and Reintegration program offered to paramilitary organizations in 2004.²⁵ Some of these actions were supported by United States, mainly through the Plan Colombia,²⁵ a plan with the goal of reducing illicit coca crops, improving economic and social justice, and reducing violence in Colombia.

From 2006 to 2012, homicide rates in Cali once again increased, and the data from the ESS indicated that more than 50% of homicides were mainly related to newly organized criminal groups⁷ (data not shown). Cali received support from the national police and from specialized groups from the National Colombian Intelligence Agency and the National Prosecuting Agency to develop intelligence-based actions to identify

criminal organizations, their operations, and members, and to prosecute and dismantle these organizations. As a result, from 2012 to 2015, a total of 322 criminal organizations were dismantled with an estimate of 60% of their members being sent to prison.⁷ Homicide rates in Cali declined during this period mainly because of reductions in organized crime-related homicides.⁷ There was also a reduction in multiple homicides, which, as mentioned before, are usually the result of unsettled issues and revenge attacks between organized criminal groups.⁷ There was a simultaneous slight increase in knife homicides in this period, which can be interpreted as a partial substitution in the type of method.

Additional reductions in homicide rates since 2015 can be partly attributed to the firearm carrying ban in the national territory (since December 2015 onward), the ceasefire and peace agreement with FARC in 2016, and also the improvement in socioeconomic conditions in recent years.²⁶

Spatial analysis of homicides indicates a higher concentration of homicides in low-income neighborhoods, where there is usually greater presence of criminal bands and street gangs. Reductions in homicides in Cali since 2013 could also be linked to social interventions implemented in the city. In 2012, Cali designed and implemented the TIO (Territories of Inclusion and Opportunities) project to direct resources in the poorest neighborhoods to improve social and economic conditions in these areas.²⁷ The project has improved neighborhood conditions through the development of school facilities and early childhood development centers, improving illumination in parks and alleys to increase safety, increasing access to potable water, and improving road conditions. Also, since

2016, Cali implemented a street gang transformation program that favors inclusion and citizen participation and offers job and educational opportunities and skill development to youths involved in street gangs. The ESS data showed significant reductions (around 80%) in the number of gang-related homicides in targeted communities.²⁸ This is an important outcome given the previously reported 100% increase in gang-related homicides from 2012 to 2015 in Cali.⁷

Limitations

This study has some limitations. First, the ESS does not regularly characterize homicides according to variables such as the blood alcohol concentration levels of the victim or the aggressor. Missing data on the aggressor, which could be as high as 40% during specific periods (e.g., 2000–2011),⁷ also prevent us from examining homicide trends based on categories of homicide types. Currently, the ESS has implemented actions to improve the quality of the data on alcohol and causes of homicides, and it is expected that this information may be incorporated into other studies in the future. Second, the aggregated nature of our analysis limits us from making clear causal statements about the link between legislation and homicide trends.

Public Health Implications

The public health method applied in Cali has been a key tool to improve the quality of homicide data from primary sources and to generate and evaluate policies for the prevention of homicides in Cali. The increase in homicides in Cali since the early 1980s, in addition to being clearly in excess of previous

numbers, occurred in a short period, suggestive of a true epidemic.²⁹ Furthermore, the speed with which they occurred allows us to postulate that those changes are attributable to external causes rather than to a genetic component in this population, whose changes are noticeable in the long term.³⁰ The similar, almost parallel, oscillations in Cali and Colombia suggest the presence of common factors. The multiple actions to fight crime and prevent homicide rates in Cali and Colombia seem to have worked to certain extent, as the 2018 homicide rate in Cali was 47.8 per 100 000, the lowest in the past 25 years. However, Cali is still ranked 28th among the cities with the highest homicide rate in the world.³¹ Future local administrations must continue working in violence prevention strategies using the ESS data and also developing new methods that can improve the quality of homicide data to better understand the dynamics of homicides in the city. **AJPH**

ABOUT THE AUTHORS

Rodrigo Guerrero-Velasco, Maria I. Gutiérrez-Martínez, and Julian Santaella-Tenorio are with Cisalva Institute, Universidad del Valle, Cali, Colombia. Victor Hugo Muñoz is with Cali Secretariat of Security and Justice, Cali. Alberto Concha-Eastman is an independent researcher. Álvaro J. Pretel-Meneses is with the Department of Economics, Universidad del Valle.

CORRESPONDENCE

Correspondence should be sent to Julian Santaella-Tenorio, Calle 4B No. 36-00 Edificio 135, Cisalva Institute, Universidad del Valle, Cali, Colombia (e-mail: js4222@columbia.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Guerrero-Velasco R, Muñoz V, Concha-Eastman A, Pretel-Meneses Á, Gutiérrez-Martínez MI, Santaella-Tenorio J. Homicide epidemic in Cali, Colombia: a surveillance system data analysis, 1993–2018. *Am J Public Health*. 2021;111(7):1292–1299.

Acceptance Date: February 25, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306254>

CONTRIBUTORS

R. Guerrero-Velasco and J. Santaella-Tenorio developed the design and conceptualization of the study, interpreted the results, and wrote the original draft of the article. V. H. Muñoz and J. Santaella-Tenorio collected and analyzed the data. A. Concha Eastman, A. J. Pretel-Meneses, and M. I. Gutiérrez-Martínez contributed to the interpretation of results and helped draft the article.

ACKNOWLEDGMENTS

The authors would like to thank the institutions participating in the in the homicide Epidemiological Surveillance System.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

HUMAN PARTICIPANT PROTECTION

Ethics approval was not needed for this work because it used secondary, de-identified data.

REFERENCES

- Concha-Eastman A, Guerrero R, Álvarez A, Cobo G, de Roux G, Alzate A. Development, Security and Peace Program (DESEP AZ): strategies of the mayor's office of Cali to face insecurity and violence [in Spanish]. In: Concha-Eastman A, Carrión F, Cobo G, eds. *City and violence in Latin America* [in Spanish]. Quito, Ecuador: Alcaldía de Cali y Programa de Gestión Urbana de las Naciones Unidas; 1994:122.
- Guerrero R, Concha-Eastman A. The public health approach in action: DESEPAZ in Colombia. In: Krug EG, Dahlberg LL, Mercy JA, eds. *World Report on Violence and Health*. Geneva, Switzerland: World Health Organization; 2002:4. Available at: https://apps.who.int/iris/bitstream/handle/10665/42495/9241545615_eng.pdf;jsessionid=20020002001000003. Accessed November 2, 2020.
- Guerrero R. Information systems in violence prevention programs [in Spanish]. In: Erik A, Beliz G, eds. *What Is the Way Out? The Unfinished Agenda for Citizen Security* [in Spanish]. Washington, DC: Banco Interamericano de Desarrollo; 2007:119–148.
- Centers for Disease Control and Prevention. National Violent Death Reporting System. Available at: <https://www.cdc.gov/violenceprevention/datasources/nvdrs/index.html>. Accessed January 9, 2020.
- Jabar A, Fong F, Chavira M, et al. Is the introduction of violence and injury observatories associated with a reduction in violence-related injury in adult populations? A systematic review and meta-analysis. *BMJ Open*. 2019;9(7):e027977. <https://doi.org/10.1136/bmjopen-2018-027977>
- Concha-Eastman A, Espitia V, Espinosa R, Guerrero R. The epidemiology of homicides in Cali, 1993–1998: six years of a population model [in Spanish]. *Pan Am J Public Health*. 2002;12(4):230–239. <https://doi.org/10.1590/S1020-49892002001000003>
- Fandiño-Losada A, Guerrero-Velasco R, Mena-Muñoz J, Gutiérrez-Martínez M. *Effect of the*

control of organized crime on homicidal violence in Cali (Colombia) [in Spanish]. Barcelona, Spain: CIDOB D'Afers Internacionals; 2017:159–178.

- Departamento Administrativo Nacional de Estadísticas. Deaths [in Spanish]. Available at: <https://www.dane.gov.co/index.php/estadisticas-por-tema/salud/nacimientos-y-defunciones/defunciones>. Accessed January 11, 2021.
- International Classification of Diseases, 10th Revision*. Geneva, Switzerland: World Health Organization; 1992.
- Ahmad O, Boschi-Pinto C, Lopez A, Murray C, Lozano R, Inoue M. Age standardization of rates: a new WHO standard (technical report). GPE Discussion Paper Series: No.31. Geneva, Switzerland: World Health Organization; 2001.
- Tiwari RC, Clegg L, Zou Z. Efficient interval estimation for age-adjusted cancer rates. *Stat Methods Med Res*. 2006;15(6):547–569. <https://doi.org/10.1177/0962280206070621>
- Kim HJ, Fay MP, Feuer EJ, Midthune DN. Permutation tests for joinpoint regression with applications to cancer rates. *Stat Med*. 2000;19(3):335–351. [https://doi.org/10.1002/\(SICI\)1097-0258\(20000215\)19:3<335::AID-SIM336>3.0.CO;2-Z](https://doi.org/10.1002/(SICI)1097-0258(20000215)19:3<335::AID-SIM336>3.0.CO;2-Z)
- Montenegro A. Violence, crime, and justice: another view from the economy [in Spanish]. *Coyunt Econ*. 2000;(2):85–132.
- Pizarro León Gómez E. *The FARC (1949–2011) From Peasant Guerrilla to War Machine* [in Spanish]. Bogotá, Colombia: Editorial Norma; 2011:194–201.
- Melo JO. Fifty years of homicides: trends and prospects [in Spanish]. *Razón Pública*. August 11, 2008. Available at: <https://razonpublica.com/cincuenta-a-de-homicidios-tendencias-y-perspectivas>. Accessed October 21, 2020.
- Abello C. *Security Provision and Governing Processes in Fragile Cities of the Global South: The Case of Medellín 2002–2012*. Doctoral thesis. Bradford, England: University of Bradford; 2015.
- García HI, Giraldo C, Lopez M, Pastor M, Cardona M, Tapias C. Thirty years of homicides in Medellín, Colombia, 1979–2008. *Cad Saude Publica*. 2012;28(9):1699–1712. <https://doi.org/10.1590/S0102-311X2012000900009>
- Sánchez-Torres F, Diaz A, Fornisano M. Conflict, violence and criminal activity in Colombia: a spatial analysis [in Spanish]. *Arch Econ*. No. 002185. Bogotá, Colombia: Departamento Nacional de Planeación; 2003.
- Murray J, De Castro-Cerqueira DR, Khan T. Crime and violence in Brazil: systematic review of time trends, prevalence rates and risk factors. *Aggress Violent Behav*. 2013;18(5):471–483. <https://doi.org/10.1016/j.avb.2013.07.003>
- Messner S, Deane G, Anselin L, Pearson-Nelson B. Locating the vanguard in rising and falling homicide rates across US cities. *Criminology*. 2005;43(3):661–696. <https://doi.org/10.1111/j.0011-1348.2005.00020.x>
- Cooper A, Smith E. Homicide trends in the United States, 1980–2008. Annual rates for 2009 and 2010. US Department of Justice, Office of Justice Programs, Bureau of Justice Statistics. NCJ 236018. November 2011. Available at: <https://www.bjs.gov/content/pub/pdf/htus8008.pdf>. Accessed October 20, 2020.
- Fowler KA, Dahlberg L, Haileyesus T, Annett J. Firearm injuries in the United States. *Prev Med*.

- 2015;79:5–14. <https://doi.org/10.1016/j.jpmed.2015.06.002>
23. Melo J. *Minimum History of Colombia* [in Spanish]. Madrid, Spain: Turner Publicaciones; 2017:265–281. <https://doi.org/10.2307/j.ctv1nhm21.17>
 24. Villaveces A, Cummings P, Espitia V, Koepsell T, McKnight B, Kellermann A. Effect of a ban on carrying firearms on homicide rates in 2 Colombian cities. *JAMA*. 2000;283(9):1205–1209. <https://doi.org/10.1001/jama.283.9.1205>
 25. DeShazo P, Primiani T, McLean P. *Back From the Brink: Evaluating Progress in Colombia, 1999 to 2007*. Washington, DC: Center for Strategic and International Studies; 2007.
 26. Organization for Economic Cooperation and Development. *OECD Economic Studies: Colombia 2019* [in Spanish]. Paris, France: OECD Publishing; 2019. <https://doi.org/10.1787/805f2a79-es>
 27. Rojas-Rentería O, Cock-Misas JC. The juggling of poverty, testimonies of beneficiaries of the Territories of Inclusion and Opportunities strategy [in Spanish]. unIstartCali, Colombia: Alcaldía de Santiago de Cali. 2017.
 28. Gutiérrez M, Valencia R, Santaella-Tenorio J. The holistic transformative street-street gang intervention impact and its association with homicide rates in Cali, Colombia. *Rev Crim*. 2020;62(3):39–48.
 29. MacMahon B, Trichopoulos D. *Epidemiology: Principles and Methods*. 2nd ed. Boston, MA: Little, Brown and Company; 1996.
 30. Guerrero R, Fandiño-Losada A. Is Colombia a violent country [erratum in *Colomb Med (Cali)*. 2017;48(2):101]? *Colomb Med (Cali)*. 2017;48(1):9–11.
 31. Seguridad, Justicia y Paz, Consejo Ciudadano para la Seguridad Pública y la Justicia Penal. List of the 50 most violent cities in the world in 2017 [in Spanish]. Available at: <http://www.seguridadjusticiaypaz.org.mx/ranking-de-ciudades-2017>. Accessed January 12, 2020.



Moving Life Course Theory Into Action: Making Change Happen

Edited by Sarah Verbiest
DrPH, MSW, MPH

Over the past decade, practitioners in the field of maternal and child health have gained a general understanding of Life Course Theory and its potential application to practice. This book focuses on moving Life Course Theory into practice, thereby filling a need for practitioners across a variety of fields and providing them with valuable strategies on how to apply this approach.

Moving Life Course Theory Into Action is designed to fit into the busy lives of practitioners. With new ideas and strategies delivered in a compact handbook style format, each chapter includes key points that offer a quick summary of the main lessons advanced by the authors.

ISBN: 978-087553-2950, 496 pages, Softbound, 2018

APHABOOKSTORE.ORG



Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Youth–Police Contact: Burdens and Inequities in an Adverse Childhood Experience, 2014–2017

Amanda Geller, PhD

See also Jackson, p. 1189, and Galea and Vaughan, p. 1202.

Objectives. To assess police contact as a potential adverse childhood experience by measuring its prevalence, nature, and distribution among urban adolescents.

Methods. Detailed US population-based data on youth–police contact were collected in the Fragile Families and Child Wellbeing Study (n = 2478) from 2014 to 2017. Using regression modeling, I assessed adolescents' police exposure and the magnitude and robustness of racial disparities in police contact. Sensitivity analyses examined disparities by behavior and socioeconomic context.

Results. Urban youths are heavily policed, beginning in preadolescence. Exposure to policing is unevenly distributed, with non-White adolescents—particularly Black boys—reporting more, and more aggressive, contact than their White counterparts. Hispanic–White differences and disparities in girls' experiences were less pronounced but present, particularly in how intrusive stops were. Intrusion disparities were robust to most behavioral controls, but not observed among youths with higher socioeconomic status.

Conclusions. Given extant literature documenting adverse health consequences of police encounters, findings implicate policing as a driver of health disparities in adolescence and throughout the life course. Public health infrastructure dedicated to the prevention and treatment of adverse childhood experiences is well suited for mitigating these harms and inequities. (*Am J Public Health*. 2021;111(7):1300–1308. <https://doi.org/10.2105/AJPH.2021.306259>)

Adverse childhood experiences (ACEs) are potentially traumatic events that occur in childhood or environmental circumstances that can undermine a child's sense of safety, stability, and bonding.^{1,2} ACEs may contribute to toxic stress that can harm development through changes to the nervous, endocrine, and immune systems.² These, in turn, influence adult health and health risk behaviors and may be transmitted intergenerationally.² The Centers for Disease Control

and Prevention have made the identification of ACEs, and mitigation of their harms, priorities for public health.²

Recent incidents of police violence against Black people have brought widespread attention to policing as a threat to health and driver of health disparities.^{3–9} Ethnographic research finds that in urban communities and communities of color, traumatic experiences with police begin early in life,^{10–12} suggesting that they warrant consideration as an ACE. However, little is known

about whether these news stories and qualitative accounts fit a broader population pattern¹³ or if they highlight the most aggressive contexts of police surveillance and racial inequity, providing a misleading portrait of youth experiences. I used national data from the Fragile Families and Child Wellbeing Study (FFCWS) to measure police contact experienced by urban adolescents, and racial disparities in these experiences, providing a population perspective on youth–police contact.

POLICE CONTACT, PUBLIC HEALTH, AND HEALTH DISPARITIES

Police encounters carry a significant threat to physical and psychological health. A long history documents police violence in American life, particularly in Black communities.^{14,15} For decades, police brutality and law enforcement homicides were not systematically documented¹⁶; however, the recent proliferation of violent incidents recorded on video and widely publicized has brought police violence to the forefront of national and public health discourse.^{16,17} Recent data indicate that police officers have killed approximately 1000 people annually since 2015.¹⁸ Individuals experiencing frisks, searches, and other police intrusion report elevated symptoms of anxiety and post-traumatic stress disorder,⁴ stresses that may manifest physically.^{3,5,6,9} Entrenched racial inequality in criminal justice^{15,19,20} suggests that police encounters may also trigger stresses associated with exposure to racism.^{21,22} Police contact can also harm the health of individuals not personally stopped by police,⁵ particularly if “vicarious contact,” such as witnessing an encounter or knowing someone stopped,^{23,24} signals one’s personal vulnerability to police violence. These effects are racially patterned, reflecting the historical and ongoing traumas of systemic racism.^{2,8,22}

Recent evidence suggests that adolescents—particularly non-White adolescents—face considerable police exposure. A survey of Chicago, Illinois, students found that approximately half had been stopped by a police officer, questioned, and “told off or told to move on” by ninth or tenth grade.¹² A study of

Black and Latino boys in “a large city in the Southern United States” found substantial police contact and adverse developmental consequences.²⁵ Ethnographic and journalistic work also documents substantial police contact among girls of color, who experience police contact in qualitatively different ways than their male counterparts—including elements of sexual harassment or assault.^{11,26} The early ages at which many Black and Hispanic youths encounter the police,^{10–12,25} coupled with the developmental importance of ACEs^{1,2} and adolescence,²⁷ suggest that police contact could drive health inequality throughout the life course, necessitating public health intervention. However, to date, we know little about the burdens or distribution of youth–police contact on a population level.

MEASUREMENT CHALLENGES

The vast majority of police–public encounters,²⁸ including physically intrusive encounters such as “stop and frisk” activity,²⁹ do not lead to arrests and are less systematically measured.¹³ What we know about involuntary contacts between minors and the police has been inferred from older populations,^{4,28} based on group-level analyses³⁰ or individual-level data limited in scope or generalizability.

Single-city surveys and qualitative studies^{10–12,23,25,26} may not generalize nationally. The National Longitudinal Study of Adolescent to Adult Health (AddHealth) asked basic questions on police contact of a national sample³¹; however, the AddHealth cohort came of age in the 1990s, before the rise in “stop and frisk” and other “proactive” policing.²⁹ AddHealth also captured limited

information about the quantity, timing, and intrusion of reported encounters, information critical for understanding their health consequences.^{4,32} Analyses of administrative data are further limited; administrative data tend to be incident-level rather than person-level, deidentified, and unsuitable for measuring repeated police contact or its potential consequences.

CURRENT CONTRIBUTIONS

As the first population survey of youth–police contact in the proactive policing era, the FFCWS measures adolescents’ experiences of personal and vicarious police contact, alongside detailed longitudinal information about their behavior, family background, and broader well-being. These data place policing in context and further understanding of its role as a social determinant of health.

This study provides detailed measures of police contact among boys and girls, across race and ethnicity, and estimates the extent to which observed disparities exceed what might be predicted by behaviors that generate police attention. Aggressive policing is increasingly recognized as a contributor to premature morbidity and mortality. Measuring the prevalence and distribution of youth–police contact in a national sample furthers our understanding of how policing and its individual consequences shape population health inequality.

METHODS

The FFCWS is a population-based cohort survey that follows 4898 children born in 20 large cities between 1998 and 2000, along with their families. Sixteen of these

cities were selected using a multistage random sampling process,³³ providing a sample that, when weighted, represents urban births nationwide (national sample baseline $n = 3442$).

Families were recruited at the hospital following the child's birth, using a systematic oversample of nonmarital births. The resulting sample was socioeconomically disadvantaged, with high proportions of Black and Hispanic families and high rates of criminal justice involvement. Parents were contacted for follow-up interviews 5 times, most recently between 2014 and 2017. In the 2 most recent waves (year [Y] 9 and Y15, when the children were aged approximately 9 and 15 years), the children were also interviewed. Sampling weights adjusted for family selection into the baseline sample and the child's retention and participation at Y15.^{33,34}

Key Measures

Police contact. The FFCWS adolescent survey measured several aspects of adolescents' experiences with the police, including whether they had personally been stopped by police and whether they had vicarious police contact—witnessing a stop or hearing about a stop of somebody they knew. (Less than 1% of the Y15 national sample “didn't know” or “refused” to answer the question on police contact or was missing for unknown reasons.) Adolescents personally stopped provided details of their experiences, including the number of stops they experienced, their age when first stopped, and officer behavior in the incident that most stood out in their mind (which I refer to as their “critical stop”). Analyses focused on 2 measures: a binary indicator of personal police contact and an additive scale

summarizing critical stop intrusion: whether the officer frisked them, searched their bags or pockets, used harsh language, handcuffed them, used racial slurs, threatened physical force, or used physical force ($\alpha = 0.85$). Items were coded to zero for adolescents not personally stopped and for those who answered “don't know” or who “refused” to answer a question. (Only 1% of adolescents stopped by the police responded “don't know” or “refused” to answer any of the intrusion questions.) This provided a conservative estimate of disparities with alternative model choices explored in sensitivity analyses.

Demographic background. Adolescents' self-reported racial/ethnic backgrounds were coded into 5 categories (White, Black, Hispanic, other race, and multiple races). Adolescents' sex was recorded at birth, and their age was measured on their interview date.

Adolescent behavior and social environment. Adolescents' experiences with police were interpreted in the context of their participation in and exposure to behavior that might attract police attention. Behavior at Y15 was measured using self-reported past-year participation in a series of delinquent activities. The adolescents also reported illegal behaviors their peers engaged in, which comprised a second additive measure, and their own behaviors at Y9, which comprised a third. These indicators, detailed in Appendix A (available as a supplement to the online version of this article at <http://www.ajph.org>) were used as covariates, for sample stratification, and as predictors of adolescents' propensity for police contact. In sensitivity analyses, I examined socioeconomic moderation of racial disparities, measuring socioeconomic status (SES) by using mothers' baseline educational attainment.

Analytical Approach

Analyses examined the extent to which police contact among the FFCWS adolescents might contribute to racial disparities in health. I began with a detailed description of urban adolescents and their exposure to the police, nationally and by race and sex.

Assessing racial disparities. I assessed racial disparities in adolescents' police contact and critical stop intrusion by using weighted logistic, negative binomial, and ordinary least squares regression models, separately for boys and girls. Models adjusted for adolescent age and self-reported and peer delinquency.

Sensitivity analyses. I examined the sensitivity of findings to several analytic choices and explored variation across the socioeconomic spectrum. As an alternative to regression adjustment for adolescent behavior, I ran models using a sample stratification approach, defining 3 subsamples based on Y15 self-reported delinquency: adolescents reporting none, 1 delinquent behavior, and 2 or more listed behaviors. (Intrusion was modeled by using complete case and ordinary least squares models in the sample stratification analysis, because negative binomial models did not converge in the imputed data set. Details are provided in Appendix B, available as a supplement to the online version of this article at <http://www.ajph.org>.) To understand the robustness of intrusion disparities to modeling choices, I estimated 2 additional sets of models: limiting the analysis sample to adolescents personally stopped by the police and combining the sampling weights with inverse probability of treatment weighting to control for selection into police contact.³⁵

Analysis sample and sample description. Adolescents were included in the analysis sample ($n = 2478$) if they were part of

the national sample, interviewed at Y15, and reported on personal and vicarious contact with police. Missing predictors were imputed using multiple imputation. (Less than 1% of the analysis sample was missing data on adolescent age, Y15 delinquency, or maternal education. Five percent of the sample was missing peer delinquency data, and 12% was missing Y9 delinquency data.)

Analyses were weighted to represent adolescents born in large cities between 1998 and 2000. A description of the analysis sample is provided in Table 1.

The analysis sample and population it represents are predominantly non-White: more than half the weighted sample was Black or Hispanic; just over one third was White, and approximately 5% were “other” or multiple races. Because of the small sample size, disparities involving “other race” and multi-racial adolescents are not reported.

RESULTS

Approximately 19% of adolescents reported having been stopped by the police, and 69% reported vicarious contact. As detailed in Table 1, adolescents reported diverse experiences, beginning at young ages. The population average of 0.44 stops per adolescent included several adolescents stopped 10 or more times. Although frisks, searches, and other police intrusion were rare overall, their prevalence in adolescents’ critical stops (e.g., 23% involved frisks, 30% involved searches, 19% involved handcuffing) suggest that many adolescents’ experiences were far from benign. Notably, 30% of adolescents reporting personal contact were first stopped as pre-adolescents (ages 8–12 years).

Race differences in adolescents’ experiences with the police are

TABLE 1— Description of Analysis Sample: Based on National Sample From the Fragile Families and Child Wellbeing Study, United States

Variables	% or Mean (SD)
Demographic description	
Adolescent race	
White	36
Black	24
Hispanic	30
Other	6
Multiple races/ethnicities	5
Adolescent sex	
Male	56
Female	44
Adolescent age	
15.2 (0.48)	
Mom’s baseline education	
< High school	25
High school only	30
Some college	20
College graduate	25
Adolescent behavior	
Y9 delinquency (range = 0–17)	1.03 (1.82)
Y15 delinquency (range = 0–16)	1.09 (1.85)
Y15 peer delinquency (range = 0–11)	1.20 (2.07)
Police contact	
Ever stopped (personally)	
19	
Vicarious contact	
69	
Summary of stop experience	
First stopped age 10 y or younger	3
First stopped age 11–12 y	3
First stopped age 13–15 y	13
First stopped after age 15 y	< 1
Age first stopped not reported	< 1
Not personally stopped	81
Average number of stops reported	0.44 (1.73)
Ever arrested?	
3	
Critical stop experience: any critical stop intrusion?	
9	
Did the officer . . .	
Frisk you?	5
Search your pockets or bags?	6
Use harsh language?	3
Use racial slurs?	< 1
Threaten physical force?	2
Use physical force?	1
Handcuff you?	4
Intrusion index (0–7)	0.22 (0.83)

Continued

TABLE 1— Continued

Variables	% or Mean (SD)
Any intrusion among adolescents stopped	48
Intrusion index among adolescents stopped	1.17 (1.60)

Note. Y = year. Statistics are weighted to represent urban births between 1998 and 2000 nationwide. The total sample size was n = 2478. Means and standard deviations are based on observed, rather than imputed, data (n = 2187 for Y9 delinquency, n = 2456 for Y15 delinquency, n = 2343 for Y15 peer delinquency, n = 2478 for the number of stops experienced and critical stop intrusion, and n = 677 for critical stop intrusion among adolescents stopped). Percentages may not total 100 because of rounding.

Source. The Fragile Families and Child Wellbeing Study is a longitudinal study in which participants were born over a 3-year time period (1998–2000) and families were reinterviewed 5 times over approximately a 15-year period.

presented in Table 2. Police exposure was common across race, with most Black, White, and Hispanic adolescents reporting vicarious contact. In personal

experiences, however, disparities were pronounced. Black boys and girls were each more likely than their White counterparts to report being stopped: 39% of

Black boys and 14% of Black girls reported police contact, while only 23% of White boys and 10% of White girls did ($P < .001$ among boys). Hispanic–White differences were statistically insignificant.

Table 2 indicates racial disparities in critical stop intrusion, most pronounced among boys: more than two thirds of Black and Hispanic boys stopped reported intrusion in their critical stops, while fewer than one quarter of White boys did. Approximately 12% of Black boys reported frisks, 14% reported searches, 10% reported harsh language, and 12% reported being handcuffed, experiences extremely rare among White

TABLE 2— Unadjusted Racial Disparities in Police Exposure and Contact by Sex: Analysis Sample Based on Fragile Families and Child Wellbeing Study National Sample, 2014–2017

	Boys, No., %, or Mean (SD)				Girls, No., %, or Mean (SD)			
	Total	White	Black	Hispanic	Total	White	Black	Hispanic
No.	1283	264	560	348	1195	259	509	322
Police exposure								
Vicarious contact	73	76	77	72	66	58	69	70
Ever stopped (personally)	26	22	40*	21	10	10	14	6
Number of stops reported	0.66 (2.21)	0.60 (2.69)	0.84 (1.97)	0.57 (1.58)	0.17 (0.66)	0.13 (0.47)	0.24 (0.78)	0.13 (0.67)
Any critical stop intrusion?	14	5	26***	15**	3	2	6	3
Ever arrested?	4	< 1	9	3	1	< 1	2	1
In your critical stop (if any), did the officer . . .								
Frisk you?	7	2	13***	9**	1	0	3**	1
Search your pockets or bags?	9	3	14**	12**	2	2	4	2
Use harsh language?	5	< 1	10*	6*	< 1	0	2***	< 1
Use racial slurs?	2	< 1	3*	2	< 1	0	< 1*	< 1
Threaten physical force?	4	< 1	6**	4	< 1	0	1**	< 1
Use physical force?	2	< 1	2*	4*	< 1	0	1**	< 1
Handcuff you?	6	1	13*	5*	2	< 1	3*	2
Intrusion index (0–7)	0.34 (1.02)	0.08 (0.40)	0.60*** (1.27)	0.41*** (1.14)	0.07 (0.45)	0.03 (0.19)	0.15** (0.75)	0.06 (0.41)
Among those stopped	473	76	240	116	204	34	107	39
Age first stopped, y	12.84 (1.64)	12.55 (1.76)	12.93* (1.54)	13.23*** (0.15)	12.99 (1.94)	13.02 (2.24)	12.82 (2.00)	13.39 (1.35)
Any critical stop intrusion?	53	21	67***	68***	31	20	42	44
Intrusion index (0–7)	1.33 (1.66)	0.35 (0.80)	1.53*** (1.65)	1.91*** (1.78)	0.66 (1.27)	0.26 (0.56)	1.05** (1.72)	1.00 (1.31)

Note. Statistics are weighted to represent urban births between 1998 and 2000 nationwide. N = 1277 for number of stops reported by boys, n = 1189 for girls. N = 463 for age boys first stopped, n = 197 for girls, with missing observations distributed across racial groups.

* $P < .05$; ** $P < .01$; *** $P < .001$ based on comparisons of Black to White, and Hispanic to White adolescents (within sex) using ordinary least squares and linear probability models.

TABLE 3— Relative Odds of Reporting Personal Police Contact: Analysis Sample Based on Fragile Families and Child Wellbeing Study National Sample, 2014–2017

Variables	Boys, OR (95% CI)		Girls, OR (95% CI)	
	Unadjusted Model (n = 1283)	Adjusted Model (n = 1283)	Unadjusted Model (n = 1195)	Adjusted Model (n = 1193)
Adolescent race (Ref = White)				
Black	2.29 (1.12, 4.71)	2.04 (0.96, 4.31)	1.55 (0.72, 3.36)	1.23 (0.53, 2.84)
Hispanic	0.96 (0.48, 1.89)	0.81 (0.39, 1.68)	0.64 (0.25, 1.65)	0.48 (0.15, 1.50)
Other	0.37 (0.09, 1.50)	0.46 (0.11, 1.93)	0.01 (0.00, 0.08)	0.01 (0.00, 0.10)
Multiracial	1.65 (0.45, 5.98)	1.31 (0.42, 4.07)	3.06 (0.99, 9.41)	2.49 (0.70, 8.80)
Y9 delinquency		0.96 (0.84, 1.08)		1.20 (0.87, 1.65)
Y15 delinquency		1.49 (1.26, 1.77)		1.56 (1.26, 1.94)
Y15 peer delinquency		1.05 (0.88, 1.26)		0.95 (0.80, 1.13)
Age		1.14 (0.72, 1.82)		0.86 (0.41, 1.81)
Constant	0.29 (0.16, 0.50)	0.02 (0.00, 30.85)	0.11 (0.06, 0.21)	0.65 (0.00, 57986.76)

Note. CI = confidence interval; OR = odds ratio; Y = year. Analyses are weighted to represent urban births between 1998 and 2000 nationwide.

boys. Hispanic–White differences were less pronounced but also significant. Police intrusion was less common among girls; however, intrusion was predominantly reported by Black girls and virtually nonexistent for White girls. Black–White differences in the additive index of stop intrusion were substantial and statistically significant for boys and girls, as were Hispanic–White differences among boys.

Table 3 presents racial disparities in police contact for boys and girls, unadjusted and regression-adjusted for adolescent behavior.

Black boys had odds of reporting police contact that were more than twice those of White boys. This difference narrowed slightly when adjusting for age and behavior, but this finding was not significant ($P = .063$). Differences among girls were smaller in magnitude and statistically nonsignificant.

Table 4 presents unadjusted and adjusted racial differences in reported critical stop intrusion. The rate ratios indicate significant, substantial, and robust Black–White differences among

both boys and girls. Differences slightly widened when adjusting for adolescent behavior. Hispanic–White differences were smaller in magnitude and also widened slightly when adjusting for adolescent behavior, but were only statistically significant for boys. Adjusting for behavior did not significantly change either Black–White or Hispanic–White racial gaps; confidence intervals around the rate ratio estimates overlapped substantially between the unadjusted and adjusted models.

Sensitivity analyses are provided in Appendix B. When stratified by self-reported delinquency, racial disparities in stop experience were most pronounced among boys reporting more delinquent behaviors. Black boys in this group had more than 3 times greater odds of reporting police contact than their White counterparts. Black–White differences among boys reporting fewer delinquent activities were smaller in magnitude and statistically nonsignificant. Black–White disparities in critical stop intrusion, on the

other hand, were robust and statistically significant among boys reporting no, 1, or multiple delinquent behaviors. Hispanic–White differences were significant among boys reporting 1 or more delinquent behaviors. Among girls, Black–White and Hispanic–White disparities were concentrated in those reporting multiple delinquent behaviors.

When the critical stop intrusion analysis was limited to adolescents stopped and inverse probability of treatment weights were applied, Black–White and Hispanic–White differences remained large and statistically significant. However, sensitivity analyses examining socioeconomic context suggested considerable SES moderation: Black–White disparities were largely robust across adolescents of less-educated mothers, but not observed among children of college graduates. Hispanic–White differences in stop intrusion were significant among children of mothers with a high-school education or less, but not children of more educated mothers.

TABLE 4— Incidence Rate Ratios From Negative Binomial Models Predicting Critical Stop Intrusion: Analysis Sample Based on Fragile Families and Child Wellbeing Study National Sample, 2014–2017

Variables	Boys, IRR (95% CI)		Girls, IRR (95% CI)	
	Unadjusted Model (n = 1283)	Adjusted Model (n = 1283)	Unadjusted Model (n = 1195)	Adjusted Model (n = 1193)
Adolescent race (Ref = White)				
Black	7.83 (3.71, 16.53)	10.19 (4.92, 21.11)	5.980 (1.45, 24.68)	6.22 (1.72, 22.44)
Hispanic	5.31 (2.36, 11.95)	6.35 (2.90, 13.91)	2.57 (0.52, 12.67)	2.87 (0.63, 12.98)
Other	1.89 (0.46, 7.83)	4.17 (0.87, 19.93)	0.23 (0.02, 2.71)	0.63 (0.07, 6.15)
Multiracial	11.41 (3.51, 37.10)	6.30 (2.08, 19.08)	2.68 (0.37, 19.56)	0.74 (0.13, 4.10)
Y9 delinquency		0.99 (0.89, 1.10)		1.45 (0.86, 2.47)
Y15 delinquency		1.34 (1.14, 1.59)		1.70 (1.28, 2.26)
Y15 peer delinquency		1.15 (0.96, 1.39)		1.03 (0.78, 1.36)
Age		1.23 (0.84, 1.79)		0.80 (0.29, 2.22)
α	7.26 (4.46, 11.82)	4.21 (2.49, 7.14)	30.52 (17.28, 53.89)	10.79 (4.23, 27.51)
Constant	0.08 (0.04, 0.15)	0.00 (0.00, 0.41)	0.03 (0.01, 0.10)	0.14 (0.00, 919.593.42)

Note. CI = confidence interval; IRR = incident rate ratio; Y = year. Analyses are weighted to represent urban births between 1998 and 2000 nationwide.

DISCUSSION

Findings suggest that urban adolescents face broad, potentially toxic exposure to police, beginning as early as childhood. Most adolescents in the FFCWS reported vicarious police contact, and nearly one fifth reported personal police contact. Many reported frisks and physical force, and verbal indignities including harsh language and, for some, racial slurs. This exposure to aggressive policing has the potential for lasting harm to the health of a new generation.

Although vicarious police contact was common across race, personal experiences were racially disparate and patterned by class. These findings—particularly the robust disparities in critical stop intrusion—suggest that police encounters with non-White adolescents are qualitatively different, substantially more aggressive than those with White adolescents, and potentially traumatic. Notably, disparities were concentrated among children of less educated mothers, and not observed among the

children of college graduate mothers. These findings stand in contrast to previous literature that has found high-SES minority youth to experience particularly disparate policing³⁶ and underscore the salience of policing in the lives of already-vulnerable young people.

Limitations and Directions for Future Research

Although the FFCWS advances our understanding of interactions between urban adolescents and the police, these analyses have limitations. Like all longitudinal surveys, the FFCWS suffers from attrition, raising generalizability concerns. However, attrition was greatest among more disadvantaged families; the findings therefore likely understate the prevalence and severity of youth–police interactions.

The sample was also too small for detailed examinations of within-group differences such as those between Black and White Latinos, or of adolescents of “other” or multiple races. Descriptive statistics indicated that multiracial adolescents

reported more intrusive police encounters than other adolescents. More research is needed to understand these experiences, which likely vary by both adolescents’ physical presentation and social contexts.

Analyses adjusted for adolescents’ self-reported behavior, and conclusions largely depended on the validity of these self-reports. However, the vast majority of results suggest that the intrusive police experiences of Black and Hispanic adolescents extend beyond a reflection of behavioral differences. One likely contributor to these disparities is the disparate social contexts in which adolescents function. Structural racism in the United States³⁷ has contributed to residential and school segregation, with predominantly Black neighborhoods particularly heavily policed.^{29,30} The lack of observed racial disparities among children of college graduate mothers suggests that educational attainment may provide Black families a pathway out of segregated, heavily policed neighborhoods. Linking health surveys to external data on neighborhood conditions

can advance our understanding of these dynamics.

Although beyond the scope of this analysis, research is also needed to examine disparities in policing across other dimensions of social identity, including skin tone, religion, sexual orientation, gender presentation, disability status, and intersections of each of these with race and sex. Future studies would also benefit from the measurement of sexual misconduct in police encounters, which is likely to occur disproportionately along several of these dimensions as well.

Finally, the extensive exposure to aggressive policing faced by young people, through their own contact, that of their peers, and media exposure to high-profile events, has the potential to have an impact on their immediate and long-term well-being beyond the effects currently documented. Public health researchers should follow today's youths prospectively with an eye toward these experiences, to understand and treat their effects now and in adulthood.

Public Health Implications

Adverse health outcomes associated with police contact, both early in life⁵ and in adulthood,^{4,9} implicate aggressive policing as an ACE that requires institutional attention toward prevention efforts, in the immediate aftermath of contact, and throughout the life course.

Prevention efforts may come from multiple sources. Police departments have several avenues for reform: a reduced reliance on aggressive tactics, equitable treatment of community members, and both individual and institutional accountability for unjust and harmful practices. Public health approaches can be integrated into policing to improve community safety without the harms of more aggressive

practices.³⁸ Legislation and public education campaigns can provide material and political support for this integration.² Public health also has the potential to address the vulnerabilities that bring young people to police attention, including substance misuse, mental illness, and behavioral challenges that might be addressed with educational or therapeutic services. Other institutions, such as schools, afterschool programs, and mentorship programs, can also support healthy youth development without the harms of aggressive policing.²

When police contact cannot be preempted among their patients, health professionals should be prepared to treat the resulting harms: to ask about police experiences alongside other ACEs and to help patients process any associated stress and trauma. An initial pediatric screening question, asked of the child or a caregiver, could simply be, "Have you/Has your child ever been stopped by the police?" Follow-up questions related to whether the encounter was physical (e.g., involving a frisk or physical force) or verbally aggressive (e.g., involving racial or homophobic invective, sexual harassment, the threat of force, or other harsh language) could help to guide subsequent care. Particularly for Black adolescents, whose police experiences are significantly more intrusive than those of White adolescents, treatment should deal explicitly with the potential for racialized trauma.^{22,39} School personnel should be similarly attentive to the possibility that their students have experienced police contact. Providing an environment in which students feel comfortable disclosing such experiences can help to connect affected youths to support.

Because the health consequences of childhood trauma may persist into adulthood, physicians treating adults should

also inquire about experiences with police. If an adult patient reports a history of police contact, their age at first contact, as well as their specific experiences, should determine their treatment needs.

As with other ACEs, screening for police contact and treatment of its effects must be done with care and without stigma. Trauma-informed care must be appropriately nuanced for the unique reactions that individuals have to their experiences. Physicians, educators, and others must also treat the topic with the sensitivity it deserves, to avoid inflicting additional trauma in the retelling of an incident.³²

Police contact has been referred to as a "fact of urban life" that young people must tolerate to stay safe.⁴⁰ This, however, ignores the context in which policing takes place—the potential for police aggression and adverse health consequences and the documented racial inequity in police practices. Designating early police contact as an ACE would provide institutional recognition of the potential for harm in police encounters and draw on an established literature and policy and practice framework for the prevention, identification, and treatment of these harms. In heavily policed communities, such care is critical to public health. *AJPH*

ABOUT THE AUTHOR

Amanda Geller is with the Department of Criminology, Law, and Society, University of California, Irvine. At the time of the study (until 2020), A. Geller was with the Department of Sociology, New York University, New York, NY.

CORRESPONDENCE

Correspondence should be sent to Amanda Geller, PhD, Department of Criminology, Law, and Society, 2315 Social Ecology 2, Irvine, CA 92697 (e-mail: amanda.geller@uci.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Geller A. Youth-Police Contact: Burdens and inequities in an adverse childhood experience, 2014–2017. *Am J Public Health*. 2021; 111(7):1300–1308.

Acceptance Date: February 27, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306259>

ACKNOWLEDGMENTS

Research reported in this article was supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development of the National Institutes of Health under award numbers R01HD36916, R01HD39135, and R01HD40421, as well as a consortium of private foundations (see <https://fragilefamilies.princeton.edu/about/funders>).

Sara McLanahan, Irwin Garfinkel, Jeffrey Fagan, Sarah K. Cowan, Jeff Manza, Vesla Weaver, John MacDonald, and Kristin Turney provided valuable feedback on earlier versions of this article, as did participants in the New York University Department of Sociology Inequality Workshop, the New York University Blueprints for Juvenile Justice Working Group, and the Fragile Families Working Group. Nicholas Mark provided outstanding research assistance.

Note. The content is solely the responsibility of the author and does not necessarily represent the official views of the National Institutes of Health. All errors are my own.

CONFLICTS OF INTEREST

The author declares no conflicts of interest.

HUMAN PARTICIPANT PROTECTION

This study was not human participant research.

REFERENCES

- Felitti VJ, Anda RF, Nordenberg D, et al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study. *Am J Prev Med.* 1998;14(4):245–258. [https://doi.org/10.1016/S0749-3797\(98\)00017-8](https://doi.org/10.1016/S0749-3797(98)00017-8)
- Centers for Disease Control and Prevention. *Preventing Adverse Childhood Experiences (ACEs): Leveraging the Best Available Evidence.* Atlanta, GA: Division of Violence Prevention, National Center for Injury Prevention and Control; 2019.
- DeVylder JE, Frey JJ, Cogburn CD, et al. Elevated prevalence of suicide attempts among victims of police violence in the USA. *J Urban Health.* 2017;94(5):629–636. <https://doi.org/10.1007/s11524-017-0160-3>
- Geller A, Fagan J, Tyler T, Link BG. Aggressive policing and the mental health of young urban men. *Am J Public Health.* 2014;104(12):2321–2327. <https://doi.org/10.2105/AJPH.2014.302046>
- McFarland MJ, Geller A, McFarland C. Police contact and health among urban adolescents: the role of perceived injustice. *Soc Sci Med.* 2019;238:112487. <https://doi.org/10.1016/j.socscimed.2019.112487>
- Sewell AA, Jefferson KA. Collateral damage: the health effects of invasive police encounters in New York City. *J Urban Health.* 2016;93(suppl 1):42–67. <https://doi.org/10.1007/s11524-015-0016-7>
- American Public Health Association. Addressing law enforcement violence as a public health issue. APH Policy Statement 201811. Available at: <https://www.apha.org/Policies-and-Advocacy/Public-Health-Policy-Statements/Policy-Database/2021/01/14/Advancing-Public-Health-Interventions-to-Address-the-Harms-of-the-Carceral-System>. Accessed May 10, 2021.
- Bor J, Venkataramani AS, Williams DR, Tsai AC. Police killings and their spillover effects on the mental health of Black Americans: a population-based, quasi-experimental study. *Lancet.* 2018;392(10144):302–310. [https://doi.org/10.1016/S0140-6736\(18\)31130-9](https://doi.org/10.1016/S0140-6736(18)31130-9)
- McFarland MJ, Taylor J, McFarland CAS. Weighed down by discriminatory policing: perceived unfair treatment and Black–White disparities in waist circumference [erratum in *SSM Popul Health.* 2020;12:100716]. *SSM Popul Health.* 2018;5:210–217. <https://doi.org/10.1016/j.ssmph.2018.07.002>
- Rios VM. *Punished: Policing the Lives of Black and Latino Boys.* New York, NY: NYU Press; 2011.
- Morris M. *Pushout: The Criminalization of Black Girls in Schools.* New York, NY: New Press; 2016.
- Shedd C. *Unequal City: Race, Schools, and Perceptions of Injustice.* New York, NY: Russell Sage Foundation; 2015.
- Alang S, McAlpine D, McCreedy E, Hardeman R. Police brutality and Black health: setting the agenda for public health scholars. *Am J Public Health.* 2017;107(5):662–665. <https://doi.org/10.2105/AJPH.2017.303691>
- The Challenge of Crime in a Free Society.* Washington, DC: President's Commission on Law Enforcement and Administration of Justice; 1967.
- The Kerner report: the 1968 report of the National Advisory Commission on Civil Disorders. New York, NY: National Advisory Commission on Civil Disorders; 1968.
- Krieger N, Chen JT, Waterman PD, Kiang MV, Feldman J. Police killings and police deaths are public health data and can be counted. *PLoS Med.* 2015;12(12):e1001915. <https://doi.org/10.1371/journal.pmed.1001915>
- Serwer A. The new reconstruction. *The Atlantic.* October 2020. Available at: <https://www.theatlantic.com/magazine/archive/2020/10/the-next-reconstruction/615475>. Accessed February 12, 2021.
- Tate J, Jenkins J, Rich S. Fatal force database. *Washington Post.* Available at: <https://www.washingtonpost.com/graphics/investigations/police-shootings-database>. Accessed April 27, 2021.
- McLeod MN, Heller D, Manze MD, Echeverria SE. Police interactions and the mental health of Black Americans: a systematic review. *J Racial Ethn Health Disparities.* 2020;7(1):10–27. <https://doi.org/10.1007/s40615-019-00629-1>
- Weitzer R. Racial discrimination in the criminal justice system: findings and problems in the literature. *J Crim Justice.* 1996;24(4):309–322. [https://doi.org/10.1016/0047-2352\(96\)00015-3](https://doi.org/10.1016/0047-2352(96)00015-3)
- Phelan JC, Link BG. Is racism a fundamental cause of inequalities in health? *Annu Rev Sociol.* 2015;41(1):311–330. <https://doi.org/10.1146/annurev-soc-073014-112305>
- Bryant-Davis T, Adams T, Alejandre A, Gray AA. The trauma lens of police violence against racial and ethnic minorities. *J Soc Issues.* 2017;73(4):852–871. <https://doi.org/10.1111/josi.12251>
- Brunson RK, Weitzer R. Police relations with Black and White youths in different urban neighborhoods. *Urban Aff Rev.* 2009;44(6):858–885. <https://doi.org/10.1177/1078087408326973>
- Rosenbaum DP, Schuck AM, Costello SK, Hawkins DF, Ring, MK. Attitudes toward the police: the effects of direct and vicarious experience. *Police Q.* 2005;8(3):343–365. <https://doi.org/10.1177/1098611104271085>
- Del Toro J, Lloyd T, Buchanan KS, et al. The criminogenic and psychological effects of police stops on adolescent Black and Latino boys. *Proc Natl Acad Sci USA.* 2019;116(17):8261–8268. <https://doi.org/10.1073/pnas.1808976116>
- Ruderman W. For women in street stops, deeper humiliation. *New York Times.* August 7, 2012. Available at: <https://www.nytimes.com/2012/08/07/nyregion/for-women-in-street-stops-deeper-humiliation.html>. Accessed April 27, 2021.
- Steinberg L. *Age of Opportunity: Lessons From the New Science of Adolescence.* Boston, MA: Houghton Mifflin Harcourt; 2014.
- Davis E, Whyde A, Langton L. Contacts between police and the public, 2015. Bureau of Justice Statistics Special Report. Washington, DC: US Department of Justice; 2018.
- Fagan J, Geller A, Davies G, West V. Street stops and broken windows revisited: the demography and logic of proactive policing in a safe and changing city. In: Rice SK, White MD, eds. *Race, Ethnicity, and Policing: New and Essential Readings.* New York, NY: NYU Press; 2010. <https://doi.org/10.18574/nyu/9780814776155.003.0013>
- Legewie J, Fagan J. Aggressive policing and the educational performance of minority youth. *Am Sociol Rev.* 2019;84(2):220–247. <https://doi.org/10.1177/0003122419826020>
- Carolina Population Center. *Add Health Codebook Explorer (ACE).* 2016. Available at: <http://www.cpc.unc.edu/projects/addhealth/documentation/ace/tool/codebooksearch?field=questionresponse&match=contains&text=police>. Accessed July 18, 2016.
- De Sa K, Nittle N. Painful questions. *The Imprint.* August 18, 2020. Available at: <https://imprintnews.org/child-welfare-2/painful-questions-critics-question-california-universal-aces-screening/46670>. Accessed November 25, 2020.
- Reichman N, Teitler JO, Garfinkel I, McLanahan SS. Fragile Families: sample and design. *Child Youth Serv Rev.* 2001;23(4-5):303–326. [https://doi.org/10.1016/S0190-7409\(01\)00141-4](https://doi.org/10.1016/S0190-7409(01)00141-4)
- Kennedy LA, Gelman A. *Year 15 Fragile Families survey weight adjustment.* Princeton, NJ: Center for Research on Child Wellbeing; 2020.
- Hirano K, Imbens GW, Ridder G. Efficient estimation of average treatment effects using the estimated propensity score. *Econometrica.* 2003;71(4):1161–1189. <https://doi.org/10.1111/1468-0262.00442>
- Tapia M. Untangling race and class effects on juvenile arrests. *J Crim Justice.* 2010;38(3):255–265. <https://doi.org/10.1016/j.jcrimjus.2010.03.002>
- Myrdal G. *An American Dilemma: The Negro Problem and Modern Democracy.* New York, NY: Harper & Bros, Transaction Publishers; 1944.
- National Academies of Sciences, Engineering, and Medicine. Community violence as a population health issue: proceedings of a workshop. Washington, DC: The National Academies Press; 2017.
- Bryant-Davis T, Ocampo C. A therapeutic approach to the treatment of racist-incident-based trauma. *J Emotional Abuse.* 2006;6(4):1–22. https://doi.org/10.1300/J135v06n04_01
- Fagbenle T, Williams V, Fromer E, Frazier AJ, Person B, Cruz V. The effect of stop and frisk in the Bronx. *Radio Rookies.* August 31, 2012. Available at: <http://www.wnyc.org/story/232447-radio-rookies-kelly>. Accessed February 13, 2014.

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Stigma, Structural Vulnerability, and “What Matters Most” Among Women Living With HIV in Botswana, 2017

Lawrence H. Yang, PhD, Ohemaa B. Poku, MPH, Supriya Misra, ScD, Haitisha T. Mehta, MA, Shathani Rampa, MSc, Marlene M. Eisenberg, PhD, Lyla S. Yang, MS, Thi Xuan Dai Cao, MSc, Lilo I. Blank, BA, Timothy D. Becker, MD, Bruce G. Link, PhD, Patlo Entaile, BSW, Philip R. Opondo, MBChB, MMed (Psych), Tonya Arscott-Mills, MD, MPH, Ari R. Ho-Foster, MSc, and Michael B. Blank, PhD

 See also Galea and Vaughan, p. 1202.

Objectives. To explore whether beneficial health care policies, when implemented in the context of gender inequality, yield unintended structural consequences that stigmatize and ostracize women with HIV from “what matters most” in local culture.

Methods. We conducted 46 in-depth interviews and 5 focus groups (38 individuals) with men and women living with and without HIV in Gaborone, Botswana, in 2017.

Results. Cultural imperatives to bear children bring pregnant women into contact with free antenatal services including routine HIV testing, where their HIV status is discovered before their male partners'. National HIV policies have therefore unintentionally reinforced disadvantage among women with HIV, whereby men delay or avoid testing by using their partner's status as a proxy for their own, thus facilitating blame toward women diagnosed with HIV. Gossip then defines these women as “promiscuous” and as violating the essence of womanhood. We identified cultural and structural ways to resist stigma for these women.

Conclusions. Necessary HIV testing during antenatal care has inadvertently perpetuated a structural vulnerability that propagates stigma toward women. Individual- and structural-level interventions can address stigma unintentionally reinforced by health care policies. (*Am J Public Health.* 2021;111(7); 1309–1317. <https://doi.org/10.2105/AJPH.2021.306274>)

In Botswana, which has among the highest HIV prevalences worldwide (~20%),¹ national health care policies to reduce barriers to HIV services are necessary and beneficial strategies to address population burden of HIV. Such policies could also mitigate HIV stigma by making testing and treatment more socially normative.^{2,3} Yet universal policies unintentionally risk benefitting socially privileged groups more than less privileged ones.⁴ In Botswana and many regions of sub-Saharan Africa (SSA), gender inequality means women

experience higher risk for and prevalence of HIV.⁵ Because being associated with HIV results in stigma—which powerfully impedes antiretroviral therapy (ART) adherence⁶—unintended consequences for disenfranchised groups including women could be created.⁷ These dynamics can be investigated using theoretical perspectives that consider how unintentional disadvantage results from structural factors like health care policies (i.e., structural vulnerability framework) and interacts with culturally based stigma that excludes individuals

from activities that “matter most” in everyday life (i.e., “what matters most” [WMM] stigma framework).

Botswana has implemented policies to address the HIV epidemic, notably a 2001 nationwide program to prevent mother-to-child transmission of HIV, followed in 2002 by routine HIV testing and universal access to ART (Figure 1), including in antenatal settings. These policies represent landmark public health achievements to address HIV in SSA; however, as a result of the epidemic's urgency, stakeholder

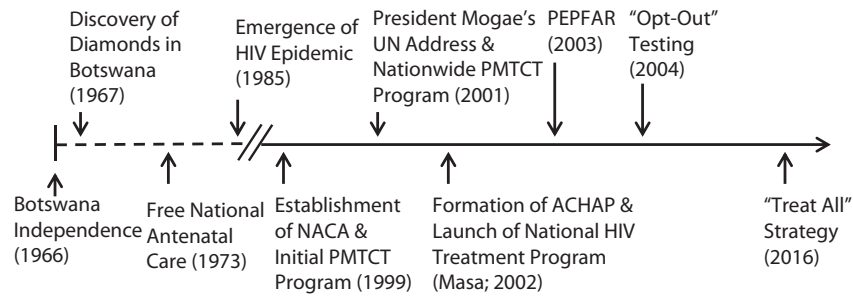


FIGURE 1— Timeline for Implementation of Policies to Address the HIV Epidemic in Botswana

Notes. ACHAP = African Comprehensive HIV/AIDS Partnership; NACA = National AIDS Coordinating Agency; PEPFAR = President's Emergency Plan for AIDS Relief; PMTCT = prevention of mother-to-child transmission.

perspectives were not assessed before implementation.⁸ Thus, whether these vital policies could unintentionally reinforce disadvantaged positions for certain groups has not been examined. Botswana's confluence of HIV policies and free antenatal care (since 1973) could inadvertently make women susceptible to structurally perpetuated HIV stigma.

Gender inequality exacerbates HIV stigma for women in high-, middle-, and low-income contexts.⁷ In Botswana and SSA, HIV is linked with culturally based conceptions of promiscuity and immorality among women that elicit fears⁹ of abandonment by partners¹⁰ and impair ART adherence.^{9,11–13} Women with HIV are blamed for contracting it,^{11,14} as women are held accountable for any family wrongdoing.^{14,15} Detecting HIV during pregnancy may powerfully elicit these stigma dynamics, challenging ART adherence during pregnancy, postpartum,¹¹ and throughout adulthood.^{12,13} However, to our knowledge, no studies have examined how positive policies could unintentionally intensify HIV stigma; studies of structural stigma instead focus on policies that perpetuate stigma (e.g., separate HIV clinics).

The structural vulnerability framework can help elucidate how beneficial HIV

policies could reinforce preexisting vulnerabilities for women with HIV in Botswana. Drawing upon structural violence,¹⁶ structural vulnerability encompasses the political and institutional forces that constitute structural disadvantage¹⁷ produced via positions within relationships of power. Because of attributed promiscuity and immorality for women with HIV, health care policies could intensify disadvantage to locate these women in severely marginalized positions.¹⁸ Structurally vulnerable groups can internalize their devalued status (e.g., via self-concept),¹⁹ illuminating how structural circumstances could interact with local cultural processes of stigma.

Stigma has broad consequences for individuals, groups, and societies.²⁰ Elucidating how cultural dynamics intersect to elicit structural vulnerability and stigma can be advanced via a theory that articulates how culture shapes stigma.²¹ According to the WMM framework, stigma is felt most acutely when people are unable to participate in the activities that “matter most” and determine “personhood” in their culture. Building upon research in Botswana and West Africa²² identifying that “a woman becomes a woman when she becomes able to bear children,”²² we proposed that achieving full status for women in

Botswana is expressed by being a mother, which involves bearing and caring for children. We thus conceptualized that HIV stigma is most powerfully felt by threatening these cultural capabilities that determine “full womanhood.” The WMM perspective also identifies how cultural capabilities protect against HIV stigma; a woman with HIV who fulfills the capabilities of being a “good mother” (e.g., raising children in culturally endorsed ways) could effectively resist stigma.

Important intersections between culturally based dynamics and health care policies require clarification: do health care policies differentially elicit HIV identification among certain groups, thus reinforcing culturally based stigma? Moreover, does culturally based stigma increase the likelihood that certain groups will be disadvantaged by health care policies from the outset? Concurrently, we considered whether and how cultural dynamics associated with “being a good mother” could enable resistance to HIV stigma. We employed the structural vulnerability and WMM frameworks via deductive qualitative analysis, hypothesizing that gendered structural vulnerability and stigma interact with HIV policies for women living with HIV in Botswana. Our study represents a necessary evolution from evaluating policies for reducing the population burden of HIV to considering their sociocultural impacts upon disadvantaged groups.

METHODS

We used purposive sampling to recruit respondents (n = 84) for (1) 5 focus groups (FGs; n = 38), and (2) 46 in-depth, semistructured interviews (IDIs; Table 1). Because the interpersonal engagements that “matter most” are shared by the stigmatized (i.e., persons living with HIV/AIDS [PLWHA]) and stigmatizers (i.e.,

those not necessarily identified with HIV), both FGs and IDIs included PLWHA and community respondents with unknown HIV status. Men and women were sampled equally; while women's perspectives were prioritized, we assessed men to determine whether they agreed. In 2017, we recruited PLWHA from a large, publicly funded HIV clinic and community respondents from the Main Mall in Gaborone, Botswana. Written informed consent was obtained. Participants were compensated approximately US \$5.

Data Collection

FGs and IDIs were used sequentially. First, separate male and female FGs (4–10 participants each) were held with

PLWHA and community respondents (90–120 minutes each) to elicit core themes. Sessions were conducted in private rooms in the HIV clinic (for known PLWHA; hereafter, "known HIV status") and a community center (for community respondents). FGs were facilitated by the principal investigator (L. H. Y.) alongside a Setswana-speaking research assistant. FGs were used to iteratively modify the IDI guide by adding probes to questions; IDIs were then used to capture in-depth responses to core themes. Three senior interviewers (L. H. Y., M. B. B., and M. M. E.) trained 4 bilingual research assistants to conduct IDIs in Setswana or English, per interviewee preference (60–90 minutes each). Sessions were audio-recorded, transcribed, and, if needed, translated into English.

Drawing from studies that elicited WMM and structural vulnerability,^{21,23} FG and IDI guides were adapted from the Devaluation–Discrimination Scale²⁴ using 6 original, plus 3 culturally tailored, items (Appendix A, available as a supplement to the online version of this article at <http://www.ajph.org>). These guides assessed perceptions of community stereotypes (e.g., blameworthiness) and how stigma affected participation in work, dating, and interactions with friends and family. One item assessed how health care policies could shape HIV identification and stigma (i.e., when a woman or man typically finds out they are HIV positive). One question elicited narratives describing personhood (i.e., being a proper woman in Botswana); in

TABLE 1— Sociodemographic Characteristics of Participants at Baseline: Botswana, Africa, 2017

Baseline Characteristic	Full Sample (n = 84), No. (%) or Mean ±SD	Female (n = 43), No. (%) or Mean ±SD	Male (n = 41), No. (%) or Mean ±SD
Interview method			
Individual interviews	46 (54.8)	23 (53.4)	23 (56.1)
Focus group participant	38 (45.2)	20 (46.6)	18 (43.9)
HIV status			
Living with HIV	45 (53.6)	24 (55.8)	21 (51.2)
HIV status unknown	39 (46.4)	19 (44.2)	20 (48.8)
Age, y	41.8 ±13.1	42.2 ±12.5	41.4 ±14.1
Education			
< 7 y (< Form 1)	17 (20.2)	7 (16.3)	10 (24.4)
≥ 7 y (≥ Form 1)	54 (64.3)	29 (67.4)	25 (61.0)
Unknown	13 (15.5)	7 (16.3)	6 (14.6)
Employment			
Unemployed	29 (34.5)	20 (46.5)	9 (22.0)
Employed or self-employed	43 (51.2)	14 (32.6)	29 (70.7)
Retired	1 (1.2)	0 (-)	1 (2.4)
Unknown	11 (13.1)	9 (20.9)	2 (4.9)
Relationship status			
Married or cohabitating	21 (25.0)	8 (18.6)	13 (31.7)
Single	43 (51.2)	24 (55.8)	19 (46.4)
Single with partner	12 (14.3)	6 (14.0)	6 (14.6)
Unknown	8 (9.5)	5 (11.6)	3 (7.3)
Children, no.	2.2 ±1.0	2.2 ±1.1	2.2 ±1.0

addition, respondents could spontaneously articulate examples illustrating WMM for each item.

Analysis

We used a primarily deductive qualitative analysis via a 2-step direct content analysis approach,^{25,26} which is suitable because it seeks to conceptually extend existing theoretical frameworks and utilizes theory to focus the research questions and guide initial codes. This primarily deductive approach (step 1) was followed by selected inductive analyses (step 2):

Step 1. Operationally defining coding categories. First, we identified initial codes from previously formulated theoretical analyses illustrating how stigma was worsened (or mitigated) in relation to WMM and how disparities could be perpetuated via structural vulnerability.²⁷ We thereby identified when participants described key concepts of WMM and structural vulnerability as initial coding categories. Coders independently and deductively assigned predetermined categories to passages describing (1) cultural capabilities that “matter most” to womanhood (WMM), (2) how WMM shapes stigma, (3) how achieving WMM protects against stigma, and (4) structural vulnerabilities (i.e., attributable to health care policies; Figure 2, Step 1). Two coding pairs independently discussed 2 FG transcripts over 6 meetings and formulated theoretically based, operational definitions for each deductive category (Box 1). These definitions were used by 2 additional coding pairs (4 pairs total) to independently code remaining transcripts (3 FGs; 46 IDIs); pairs resolved discrepancies through consensus. Incorporated within our deductive approach, we also searched for disconfirming evidence within each category. Codes were presented to the multidisciplinary team

(including a researcher and policy contributor [A. R. H.], a Botswana-based physician [T. A.-M.] and a counselor and native Botswana expert [S. R.]) during 70 calls (~70 hours) over 18 months.

Step 2. Formulating relationships between categories and establishing sub-themes. Second, we inductively identified relationships between categories²⁸ to elucidate how structural conditions intersected with WMM to perpetuate positions of disadvantage²⁷; we also explored whether culturally based stigma shaped structural vulnerability to health care policies. A subteam (L. H. Y., O. B. P., and S. R.) met 13 times (~26 hours) to establish relationships between categories. This led to a conceptual reordering of categories, such that achieving WMM was identified as initiating earlier HIV testing and diagnosis for women (via structural vulnerability from health care policies); identification as having HIV then reinforced culturally based stigma (Figure 2, Step 2). This subteam then inductively formulated subthemes within each category, which were only retained when agreement was unanimous (Figure 2). Finally, subthemes were presented to the multidisciplinary team for refinement.

RESULTS

The conceptually reordered categories, and illustrative subthemes (Figure 2, step 2), are detailed here.

“What Matters Most” Among Botswana Women

Bearing and caring for children was essential to the concept of womanhood. Because this represented a fundamental capability signifying what was “most at stake” for women, to be childless initiated gossip about one’s “wholeness”:

With women, if you don’t have children, you are not really a woman. (Woman, known HIV status, IDI)

If you don’t have kids and are single, they [community members] don’t respect you. . . . They will gossip, “you are a barren woman, you don’t bear children, you are like a bull in a kraal [your purpose is to bear children], but you are a woman [you are denying your purpose].” (Woman, known HIV status, IDI)

Men agreed that women’s perceived competence in caretaking for children determined social standing:

A proper woman is judged in the community; [her standing] is reflected by the way she takes care of her children, especially bathing them, making sure they have food and go to school. . . . (Man, known HIV status, FG)

In upholding womanhood, women were viewed as the foundation of the household:

Someone said “The woman is the foundation,” because as a woman you are the one who has to care for the home, husband, and kids . . . that’s why most of the blame is placed on the woman [if she is promiscuous]. (Woman, known HIV status, FG)

When we examined disconfirming evidence, the centrality of marriage (although not motherhood) appeared to be weakening among a minority of women and warrants further investigation.

Structural Vulnerability Via Health Policies

Women’s core duties to bear and care for children intersected with structural vulnerability via health care policies offering

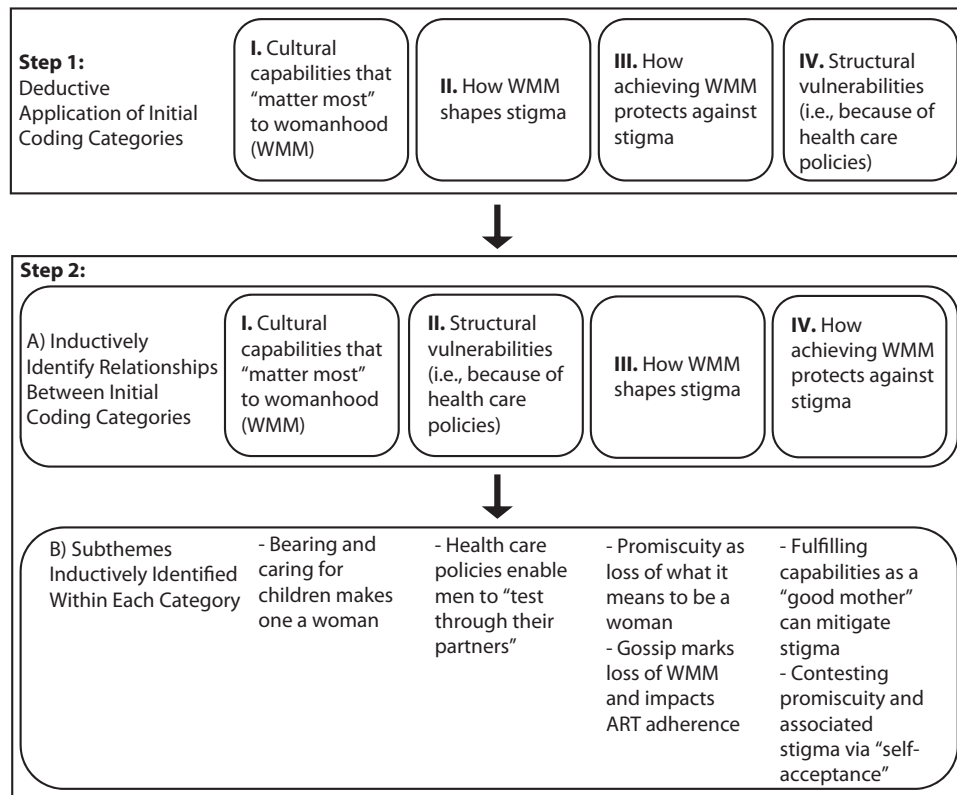


FIGURE 2— Qualitative Analytic Approach Examining Key Concepts of “What Matters Most” and Structural Vulnerability

Note. ART = antiretroviral therapy; WMM = “what matters most.”

free antenatal care accompanied by routine HIV testing; accordingly, HIV identification first occurred when women underwent HIV testing during pregnancy:

Most women found it [their HIV status] due to pregnancy and tests were done, and most men came into the hospital when they were weak; that is when they got diagnosed with HIV. (Man, known HIV status, IDI)

Following structurally initiated identification of HIV status, both genders noted that men used women’s testing as a proxy for their own status, enabling men to intentionally delay or completely avoid testing:

Men are reluctant to test, but women are required to do a routine HIV test during prenatal care. It’s not like men aren’t sick; it’s only that they don’t go for testing

since they rely on the women’s status and assume it’s the same as theirs. (Woman, unknown HIV status, FG)

People are reluctant to test; women would mostly know [their HIV status] when they are pregnant. It’s compulsory that when you’re pregnant, you should go for tests. . . . Men are also reluctant to test, they would mostly go if their pregnant partner has also tested [and had HIV]; they basically rely on their partner’s results. (Man, known HIV status, IDI)

These structural conditions reinforce blame toward the individual officially diagnosed with HIV (i.e., female partner).

Stigma Shapes “What Matters Most”

Health care policies, by eliciting earlier HIV identification and blame for women,

reinforced stigma that jeopardized the capabilities that “mattered most.”

Promiscuity as loss of what it means to be a woman. Stigma did not ensue solely with HIV status; instead, promiscuity was routinely attributed to women with HIV that molded their experience of stigma:

They [other people] think that someone living with HIV was very sexually active and promiscuous even though they may be wrong, they don’t think of other ways of HIV transmission. Botswana mostly think that if you have HIV, then it means you had unprotected sex with multiple partners. (Woman, known HIV status, FG)

Via perceived promiscuity and neglect of duties, gender-based stigma was exacerbated following HIV identification. Because of perceived disregard of

BOX 1— Operational Definition of Coding Categories for “What Matters Most” and Structural Vulnerability

Category	Operational Definition
Cultural capabilities that “matter most” to womanhood (“what matters most”)	Participating in the activities or capabilities that determine “personhood” (or “womanhood”) in Botswana by achieving full status as a woman including (but not limited to) being a mother, which involves bearing, raising, and caring for children; caring for and respecting her husband; and ensuring the well-being of the household.
How “what matters most” shapes HIV stigma	The ways in which the stigma of being identified as having HIV, via attributions of promiscuity and immorality, exerts its effects by threatening the capabilities that determine “full womanhood” in Botswana, including (but not limited to) being a mother, caring for her husband, and ensuring the well-being of the household. Includes core mechanisms that enabled culturally based stigma to persist, and ways in which these mechanisms impaired antiretroviral therapy adherence.
How achieving “what matters most” protects against HIV stigma	The ways in which achieving cultural capabilities can protect against HIV stigma; in other words, how HIV stigma can be potentially mitigated if a woman with HIV in Botswana fulfills the capabilities of being a “good mother” (including, but not limited to, bearing and raising children in culturally endorsed ways). Includes other ways in which stigma and attributions of promiscuity were contested outside of motherhood.
Structural vulnerability (health care policies reinforcing vulnerabilities)	The ways in which health care policies can inadvertently reinforce and intensify the marginalization associated with HIV identification to locate women differentially within disadvantaged hierarchical positions, either in the health care system or society at large. This includes the internalization of attributed devalued status via behaviors and self-concept.

WMM, women were judged as blame-worthy for violating the essence of womanhood:

We take it that a woman belongs to the home, so we wonder if she has HIV, there is no woman in her. She is a *lebelele* [whore]; there is no woman. (Man, known HIV status, IDI)

The responsibility would be on the woman that she's the one who's at fault. . . . Even if I stay at home and he [male partner] is [going] around with many women, his family will say that I'm the one who gave him HIV. (Woman, known HIV status, IDI)

Gossip marks loss of “what matters most” and affects antiretroviral therapy adherence. Gossip emerged as the key cultural mechanism that marked loss of “womanhood.” Gossip's effects were enduring and made community reintegration extremely challenging:

As a victim you will not forget [being called HIV positive] . . . there is a

Setswana saying that, the perpetrator could forget, but the victim doesn't forget (i.e., “a word that goes out of mouth never returns empty”) . . . you will never forget. (Women, known HIV status, IDI)

Gossip, and fear of its consequences, could threaten women's capabilities to form romantic partnerships, jeopardizing the process by which “womanhood” is achieved:

They [neighbors] will gossip [about my HIV status]. . . . They will come to that person [my boyfriend] and say, “Hey why do you want that girl, she's dangerous, she will infect you. . . .” He [boyfriend] never came [back]. (Woman, known HIV status, IDI)

Women's attempts to avoid gossip, such as avoiding being seen at an HIV clinic, could compromise ART adherence:

Women, they seem to get hurt more when being gossiped about. . . . A

woman can stop going to take medications, either completely or somewhere along the way. . . . My elder sister was going to take ARVs [antiretrovirals] at the clinic and she started seeing people she knew at the village . . . people were saying that they see that she takes medication. So she stopped going; she only started going back when her health became so bad that she had to go. (Woman, unknown HIV status, FG)

Achieving “What Matters Most” Reduces Stigma

Both genders reported that possessing the capabilities to fulfill “motherhood” could enable resistance to stigma:

I think the lady who is HIV positive, who's got kids is much better [off than a childless, HIV-negative woman]. (Woman, known HIV status, IDI)

The woman who has HIV will be treated better, having children [than

a childless, HIV-negative woman]. . . . Because that person has dignity. (Man, unknown HIV status, FG)

Fulfilling cultural capabilities central to “womanhood” could, in the absence of explicit promiscuity, preserve standing as a “whole woman”:

As long as the woman keeps [cares for] all the children like before [bathing, feeding, and ensuring they attend school], and nobody actually witnessed her sleeping around, and it happens that she’s HIV positive, and she stays that way [as a caretaker], people won’t change how they view her as a woman. (Man, known HIV status, IDI)

Contesting promiscuity and associated stigma via self-acceptance. Although not directly rooted in WMM via motherhood, an alternate means to resist gossip’s effects, achieved by some women, was to adopt self-acceptance (or “to be free”) by coming to terms with one’s status:

Gossip doesn’t affect me; personally I’m proud living with this disease [HIV] because I feel I have never been promiscuous in any way. . . . These people [like me] have accepted themselves, that they’re living with HIV. (Woman, known HIV status, IDI)

Yet this strategy was most effective when persons with a professional status were involved in promoting “self-acceptance”:

He/she will need social workers; they’re the ones who can manage because it’s their professional duty. . . that person [PLWHA] will “be free” [accept themselves] by talking to that person [social worker]; it’s not the same as when just a regular person does it [helps someone to

accept themselves]. (Man, known HIV status, IDI)

DISCUSSION

Our theoretically informed qualitative approach revealed how beneficial health care policies can unintentionally reinforce stigma among groups who face structural vulnerability. Previous studies have suggested that universal provision of HIV care could ameliorate stigma by making HIV testing and treatment more routine.^{2,3} Yet we found that Botswana’s convergence of universal HIV testing and treatment with free nationwide antenatal care inadvertently generated structural vulnerability by eliciting earlier HIV identification for women, allowing male partners to forgo identification and avoid stigma. HIV diagnosis thus perpetuates blame toward women, leading them to bear the brunt of stigma. Our results yielded novel bidirectional findings, wherein the cultural dynamics of WMM influenced susceptibility to structural vulnerability posed by health care policies—attempting to achieve WMM (i.e., have children) increased the likelihood of structural vulnerability (i.e., antenatal HIV testing leading to diagnosis); this then perpetuated further vulnerability by activating perceptions of promiscuity and blame that jeopardized women’s capabilities to achieve WMM.

The WMM lens also extends findings²⁷ regarding how culture shapes stigma. Per other studies,²⁹ gossip comprised the main cultural mechanism marking women as promiscuous, blameworthy, and no longer meriting status as “whole women.” Nonetheless, identifying women’s urgency to preserve “womanhood” clarified why gossip’s effects (including abandonment by male partners) were so feared that some women risked ART

nonadherence. Furthermore, the WMM framework provided a new way of conceptualizing how the capabilities that were most at stake (i.e., bearing and raising children) could protect women against HIV stigma; this conceptualization has received recent psychometric support.³⁰ Our findings extend studies in SSA whereby resistance to HIV stigma was engendered by participating in valued social roles³¹ by identifying these cultural roles in the Botswana context.

Identifying how health care policies can inadvertently perpetuate stigma offers insights to rectify resulting inequities. We propose 2 strategies: the first to immediately mitigate this structurally reinforced stigma, and the second to evolve HIV policy from its initial emergency response toward sustained, antistigma-based care to promote social integration. First, individual-level interventions for pregnant women with HIV can be implemented to reduce stigma and improve ART adherence. For example, our team’s intervention integrates empirically based antistigma strategies with promoting the capabilities of WMM (e.g., being a good mother, promoting self-acceptance)³² to resist stigma.

Second, we propose acting at the site where structural vulnerability is reinforced by revising HIV policy to further integrate antistigma interventions into free nationwide antenatal services. In addition to the previously mentioned individual- and structural-level strategies for women, gender transformative interventions with men are needed to address inequitable gender norms³³ that are further reified by enabling men to avoid testing; this could be further augmented by disseminating gender transformative messages via traditional (e.g., TV dramas) and social media that model equitable behaviors. As men do not visit health care facilities, structural

change can also be achieved by integrating regular HIV testing and treatment into community spaces where men frequent (e.g., workplace, farms, bars, and shebeens).³⁴ This structural change can facilitate gender parity for men in HIV testing, potentially shifting blame from female partners at the outset. Incorporating gender-informed HIV stigma reduction programs during schools' existing sexual and reproductive curricula could further help reach adolescents of both genders before antenatal testing. We propose engaging stakeholders at multiple levels, including women with HIV and men in the community, in dialogue with policymakers and health care providers to reverse this unintended structural vulnerability from existing HIV policies while underscoring potential structural harms that could otherwise be perpetuated, including stigma.

Study limitations included sampling restricted to urban participants, which may underrepresent traditional views regarding the capabilities that “matter most” for women. While using deductive analysis may increase likelihood of finding supportive evidence, we mitigated this by searching for disconfirming evidence and having a binational, multidisciplinary team evaluate the findings. We included theoretically justified samples of men and women with known and unknown HIV status, which provided diverse perspectives to corroborate the aforementioned structural vulnerability for women; despite this, much of the confirmatory evidence was derived from people with known HIV status via IDIs, reflecting stigma's salience in their lives. While we looked for differences by gender, we detected no major discrepancies in themes. Although we could have included other stakeholders, we focused on those most severely experiencing

structurally perpetuated stigma and its consequences.

Our study is among the first to our knowledge to indicate how structural vulnerability to culturally based forms of stigma could be unintentionally reinforced by otherwise effective health care policies. In addition, the intersectional identities³⁵ of being a woman and living with HIV, experienced within this context of structural vulnerability, produced a distinct lived experience of stigma within Setswana culture that should be considered in its entirety. As a leader in increasing access to lifesaving HIV services, Botswana can now take the lead in evolving biomedical HIV policies toward considering their sociocultural impacts. Insights gained from the WMM framework, including intersections with structural vulnerability, promise to facilitate beneficial structural changes in Botswana and across SSA to address these unintended inequities. *AJPH*

ABOUT THE AUTHORS

Lawrence H. Yang is with the Department of Social and Behavioral Sciences, School of Global Public Health, New York University, New York, NY. Ohe-maa B. Poku is with the Department of Mental Health, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, MD. Supriya Misra is with San Francisco State University, San Francisco, CA. Haitisha T. Mehta is with the Department of Counseling and Clinical Psychology, Teachers College, Columbia University, New York, NY. Shathani Rampa is with the Department of Psychology, University of Botswana, Gaborone, Botswana. Marlene M. Eisenberg and Michael B. Blank are with the Department of Psychiatry, Perelman School of Medicine, University of Pennsylvania, Philadelphia. Lyla S. Yang is with the Columbia School of Social Work, Columbia University. Thi Xuan Dai Cao is with the Department of Epidemiology, Biostatistics, and Occupational Health, McGill University, Montreal, QC, Canada. Lilo I. Blank is with the College of Arts and Sciences, University of Rochester, Rochester, NY. Timothy D. Becker is with the Department of Psychiatry, Icahn School of Medicine at Mount Sinai, New York, NY. Bruce G. Link is with the Department of Sociology, University of California Riverside. Patlo Entaile is with the Botswana-UPenn Partnership, Gaborone. Philip R. Opondo is with the Department of Psychiatry, University of Botswana. Tonya Arcscott-Mills is with the Perelman School of Medicine, University

of Pennsylvania. Ari R. Ho-Foster is with the Faculty of Medicine, University of Botswana.

CORRESPONDENCE

Correspondence should be sent to Lawrence H. Yang, PhD, 715 Broadway, Department of Social and Behavioral Sciences, School of Global Public Health, New York University, New York, NY 10012 (e-mail: lawrence.yang@nyu.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

PUBLICATION INFORMATION

Full Citation: Yang LH, Poku OB, Misra S, et al. Stigma, structural vulnerability, and “what matters most” among women living with HIV in Botswana, 2017. *Am J Public Health*. 2021;111(7):1309–1317.

Acceptance Date: March 11, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306274>

CONTRIBUTORS

L. H. Yang, A. R. Ho-Foster, and M. B. Blank conceptualized and planned the study. A. R. Ho-Foster, O. B. Poku, P. R. Opondo, and P. Entaile coordinated the study and data collection. A. R. Ho-Foster, S. Rampa, M. M. Eisenberg, L. I. Blank, O. B. Poku, L. S. Yang, H. T. Mehta, and D. T. X. Cao analyzed the data. L. H. Yang, A. R. Ho-Foster, M. B. Blank, O. B. Poku, H. T. Mehta, S. Rampa, P. Entaile, and T. Arcscott-Mills interpreted the data. S. Misra, T. D. Becker, and B. G. Link reviewed the write up of data analyses. O. B. Poku, S. Misra, H. T. Mehta, and A. R. Ho-Foster conducted the literature search. L. H. Yang, O. B. Poku, and H. T. Mehta wrote the first draft. L. H. Yang, O. B. Poku, S. Misra, and B. G. Link revised the article for intellectual content. L. H. Yang, O. B. Poku, S. Misra, H. T. Mehta, and A. R. Ho-Foster revised the article in response to reviewers' comments. All authors reviewed the article for important intellectual content and approved the article for publication.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

ACKNOWLEDGMENTS

This research was supported by a grant and core support services from the Penn Mental Health AIDS Research Center, a National Institutes of Health (NIH)-funded program (P30MH097488); a Fogarty International Center and National Institutes of Mental Health R21 grant (TW011084-01; PI: L. H. Yang); and the Focus for Health Foundation. O. B. Poku is supported by the T32 Global Mental Health Training Program at the Bloomberg School of Public Health, Department of Mental Health (5T32MH1032). The study also benefited from core support services provided by the Penn Center for AIDS Research, an NIH-funded program (P30AI045008).

We wish to thank the staff of the Princess Marina Hospital Infectious Disease Care Clinic, Vincent Ikageng Dipatane, MBBS, Letumile Rodgers Moeng, MD, Calvin Gonte, and Tuhto Salepito for

supporting recruitment and data collection. We thank Evan Eschliman for his help with formatting.

HUMAN PARTICIPANT PROTECTION

Institutional review boards of the Botswana Ministry of Health, University of Botswana, Princess Marina Hospital, University of Pennsylvania, and New York University granted study approval.

REFERENCES

- UNAIDS. Botswana. 2019. Available at: <https://www.unaids.org/en/regionscountries/countries/botswana>. Accessed November 6, 2020.
- Chan BT, Tsai AC, Siedner MJ. HIV treatment scale-up and HIV-related stigma in sub-Saharan Africa: a longitudinal cross-country analysis. *Am J Public Health*. 2015;105(8):1581–1587. <https://doi.org/10.2105/AJPH.2015.302716>
- Wolfe WR, Weiser SD, Leiter K, et al. The impact of universal access to antiretroviral therapy on HIV stigma in Botswana. *Am J Public Health*. 2008;98(10):1865–1871. <https://doi.org/10.2105/AJPH.2007.122044>
- White M, Adams J, Heywood P. How and why do interventions that increase health overall widen inequalities within populations? In: Babones SJ, ed. *Social Inequality and Public Health*. Bristol, England: Bristol University Press; 2009:65–82. <https://doi.org/10.2307/j.ctt9qgz3s.10>
- Phaladze N, Tlou S. Gender and HIV/AIDS in Botswana: a focus on inequalities and discrimination. *Gend Dev*. 2006;14(1):23–35. doi:10.1080/13552070500518095
- Rueda S, Mitra S, Chen S, et al. Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. *BMJ Open*. 2016;6(7):e011453. <https://doi.org/10.1136/bmjopen-2016-011453>
- Monteiro SS, Villela WV, Soares PS. The interaction between axes of inequality in studies on discrimination, stigma and HIV/AIDS: contributions to the recent international literature. *Glob Public Health*. 2013;8(5):519–533. <https://doi.org/10.1080/17441692.2013.779738>
- Ramogola-Masire D, Poku O, Mazhani L, et al. Botswana's HIV response: policies, context, and future directions. *J Community Psychol*. 2020;48(3):1066–1070. <https://doi.org/10.1002/jcop.22316>
- Turan JM, Nyblade L. HIV-related stigma as a barrier to achievement of global PMTCT and maternal health goals: a review of the evidence. *AIDS Behav*. 2013;17(7):2528–2539. <https://doi.org/10.1007/s10461-013-0446-8>
- Oyugi JH, Byakika-Tusiime J, Ragland K, et al. Treatment interruptions predict resistance in HIV-positive individuals purchasing fixed-dose combination antiretroviral therapy in Kampala, Uganda. *AIDS*. 2007;21(8):965–971. <https://doi.org/10.1097/QAD.0b013e32802e6bfa>
- Currier JS, Britto P, Hoffman RM, et al. Randomized trial of stopping or continuing ART among postpartum women with pre-ART CD4 \geq 400 cells/mm 3 . *PLoS One*. 2017;12(5):e0176009. <https://doi.org/10.1371/journal.pone.0176009>
- Clouse K, Pettifor A, Shearer K, et al. Loss to follow-up before and after delivery among women testing HIV positive during pregnancy in Johannesburg, South Africa. *Trop Med Int Health*. 2013;18(4):451–460. <https://doi.org/10.1111/tmi.12072>
- Ngarina M, Popenoe R, Kilewo C, Biberfeld G, Ekstrom AM. Reasons for poor adherence to antiretroviral therapy postnatally in HIV-1 infected women treated for their own health: experiences from the Mitra Plus study in Tanzania. *BMC Public Health*. 2013;13(1):450. <https://doi.org/10.1186/1471-2458-13-450>
- Schuklenk U, Kleinsmidt A. Rethinking mandatory HIV testing during pregnancy in areas with high HIV prevalence rates: ethical and policy issues. *Am J Public Health*. 2007;97(7):1179–1183. <https://doi.org/10.2105/AJPH.2006.093526>
- Denison JA, McCauley AP, Dunnett-Dagg WA, Lungu N, Sweat MD. The HIV testing experiences of adolescents in Ndola, Zambia: do families and friends matter? *AIDS Care*. 2008;20(1):101–105. <https://doi.org/10.1080/09540120701427498>
- Galtung J. Violence, peace, and peace research. *J Peace Res*. 1969;6(3):167–191. <https://doi.org/10.1177/002234336900600301>
- Quesada J, Hart LK, Bourgois P. Structural vulnerability and health: Latino migrant laborers in the United States. *Med Anthropol*. 2011;30(4):339–362. <https://doi.org/10.1080/01459740.2011.576725>
- Bourgois P, Holmes SM, Sue K, Quesada J. Structural vulnerability: operationalizing the concept to address health disparities in clinical care. *Acad Med*. 2017;92(3):299–307. <https://doi.org/10.1097/ACM.0000000000001294>
- Holmes SM. Structural vulnerability and hierarchies of ethnicity and citizenship on the farm. *Med Anthropol*. 2011;30(4):425–449. <https://doi.org/10.1080/01459740.2011.576728>
- Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. *Am J Public Health*. 2013;103(5):813–821. <https://doi.org/10.2105/AJPH.2012.301069>
- Yang LH, Kleinman A, Link BG, Phelan JC, Lee S, Good B. Culture and stigma: adding moral experience to stigma theory. *Soc Sci Med*. 2007;64(7):1524–1535. <https://doi.org/10.1016/j.socscimed.2006.11.013>
- Musheke M, Ntalasha H, Gari S, et al. A systematic review of qualitative findings on factors enabling and deterring uptake of HIV testing in sub-Saharan Africa. *BMC Public Health*. 2013;13(1):220. <https://doi.org/10.1186/1471-2458-13-220>
- Yang LH, Thornicroft G, Alvarado R, Vega E, Link BG. Recent advances in cross-cultural measurement in psychiatric epidemiology: utilizing “what matters most” to identify culture-specific aspects of stigma. *Int J Epidemiol*. 2014;43(2):494–510. <https://doi.org/10.1093/ije/dyu039>
- Link BG, Cullen FT, Struening E, Shrout PE, Dohrenwend BP. A modified labeling theory approach to mental disorders: an empirical assessment. *Am Sociol Rev*. 1989;54(3):400–423. <https://doi.org/10.2307/2095613>
- Mayring P. Qualitative content analysis. *FQS*. 2000;1(2). <https://doi.org/10.17169/fqs-1.2.1089>
- Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277–1288. <https://doi.org/10.1177/1049732305276687>
- Yang LH, Chen F, Sia KJ, et al. “What matters most”: a cultural mechanism moderating structural vulnerability and moral experience of mental illness stigma. *Soc Sci Med*. 2014;103:84–93. <https://doi.org/10.1016/j.socscimed.2013.09.009>
- Potter WJ, Levine-Donnerstein D. Rethinking validity and reliability in content analysis. *J Appl Commun Res*. 1999;27(3):258–284. <https://doi.org/10.1080/00909889909365539>
- Kim MH, Zhou A, Mazenga A, et al. Why did I stop? Barriers and facilitators to uptake and adherence to ART in Option B+ HIV care in Lilongwe, Malawi. *PLoS One*. 2016;11(2):e0149527. <https://doi.org/10.1371/journal.pone.0149527>
- Yang LH, Ho-Foster AR, Becker TD, et al. Psychometric validation of a scale to assess culturally-salient aspects of HIV stigma among women living with HIV in Botswana: engaging “what matters most” to resist stigma. *AIDS Behav*. 2021;25(2):459–474. <https://doi.org/10.1007/s10461-020-03012-y>
- Goudge J, Ngoma B, Manderson L, Schneider H. Stigma, identity and resistance among people living with HIV in South Africa. *SAHARA J*. 2009;6(3):94–104. <https://doi.org/10.1080/17290376.2009.9724937>
- Poku OB, Ho-Foster AR, Entaile P, et al. “Mothers moving towards empowerment” intervention to reduce stigma and improve treatment adherence in pregnant women living with HIV in Botswana: study protocol for a pragmatic clinical trial. *Trials*. 2020;21(1):832. <https://doi.org/10.1186/s13063-020-04676-6>
- Fleming PJ, Colvin C, Peacock D, Dworkin SL. What role can gender-transformative programming for men play in increasing men's HIV testing and engagement in HIV care and treatment in South Africa? *Cult Health Sex*. 2016;18(11):1251–1264. <https://doi.org/10.1080/13691058.2016.1183045>
- Misra S, Mehta HT, Eschliman EL, et al. Identifying “what matters most” to men in Botswana to promote resistance to HIV-related stigma. *Qual Health Res*. 2021; epub ahead of print March 25, 2021. <https://doi.org/10.1177/10497323211001361>
- Bowleg L. The problem with the phrase women and minorities: intersectionality—an important theoretical framework for public health. *Am J Public Health*. 2012;102(7):1267–1273. <https://doi.org/10.2105/AJPH.2012.300750>

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

ActionHealthNYC: Effectiveness of a Health Care Access Program for the Uninsured, 2016–2017

Rishi K. Sood, MPH, Jin Yung Bae, JD, MPH, Adrienne Sabety, PhD, Pui Ying Chan, MPH, and Caroline Heindrichs, MA

 See also Haley, p. 1186.

Objectives. To evaluate the effectiveness of a novel health care access program (ActionHealthNYC) for uninsured immigrants.

Methods. The evaluation was conducted as a randomized controlled trial in New York City from May 2016 through June 2017. Using baseline and follow-up survey data, we assessed health care access, patient experience, and health status.

Results. At baseline, 25% of participants had a regular source of care; two thirds had visited a doctor in the past year and reported 2.5 visits in the past 12 months, on average. Nine to 12 months later, intervention participants were 1.2 times more likely to report having a primary care provider (58% vs 46%), were 1.2 times more likely to have seen a doctor in the past 9 months (91% vs 77%), and had 1.5 times more health care visits (4.1 vs 2.9) compared with control participants.

Conclusions. ActionHealthNYC increased health care access among program participants.

Public Health Implications. State and local policymakers should build on the progress that has been made over the last decade to expand and improve access to health care for uninsured immigrants. (*Am J Public Health.* 2021;111(7):1318–1327. <https://doi.org/10.2105/AJPH.2021.306271>)

The Patient Protection and Affordable Care Act (ACA) expanded health insurance coverage to 17 million persons in the United States, driving uninsurance rates to record lows. The ACA extended insurance eligibility to lawfully present immigrants, including legal permanent residents, refugees, and asylees. However, more than 28 million people remain uninsured.^{1,2} Several factors contribute to this, including that costs for insurance can be prohibitively high.³ Furthermore, there are few alternatives for undocumented immigrants who are legally prohibited from applying for

public health insurance programs or purchasing insurance on the ACA exchanges.

Without insurance, individuals are less likely to receive necessary medical care.⁴ Uninsurance can have severe consequences for patients with chronic conditions who require regular contact with health care providers to manage their conditions.^{5,6} In addition to health and equity concerns, lack of access translates into increased downstream costs for public health systems as well as federal, state, and local governments.^{7,8} These costs and consequences are likely particularly high in New York City (NYC), the

metropolitan area with the largest number of immigrants nationwide.⁹

ActionHealthNYC was a 1-year “direct-access” demonstration program that provided comprehensive, patient-centered, and coordinated care through a primary care home (PCH) model without involvement of a health insurance plan.¹⁰ Existing literature on patient-centered medical homes (PCMHs) has yielded mixed results, with some patient-centered medical homes not being associated with reduced cost, improved quality, or increased access to primary care.¹¹ The direct-access model leverages components of

patient-centered medical homes likely to improve access and provides comprehensive health services through a limited network within a confined geographical area. Although these programs do not offer insurance, they include transparent pricing, care coordination, and linkages to PCHs.¹² Our goal was to leverage the direct-access model to increase access to care for uninsured NYC residents who did not qualify for insurance such as Medicaid or qualified health plans through the state's health insurance marketplace. According to the ACA and New York law, those ineligible for insurance consist of undocumented immigrants, Deferred Action for Childhood Arrivals recipients who do not qualify for state-sponsored Medicaid, and certain temporary nonimmigrant residents.

We evaluated the effectiveness of the demonstration program through a randomized controlled trial design, in which participants were randomly enrolled as either intervention or control. To our knowledge, this study is the first randomized controlled trial of a direct-access program and the first to make pre- and postprogram survey data comparisons. The dimensions of access we considered were affordability, availability, accessibility, accommodation, and acceptability.¹³ Results will contribute to increasing evidence about policy interventions that can improve access to primary care among uninsured populations.

METHODS

ActionHealthNYC operated from May 2016 through June 2017 at 9 sites, including 7 federally qualified health centers and 2 NYC Health + Hospitals facilities. Uninsured NYC residents aged 19 years or older with household

incomes less than or equal to 200% of the federal poverty level, according to the Department of Health and Human Services, were eligible if they were ineligible for insurance. Although all NYC residents could apply, recruitment was focused on neighborhoods with high concentrations of potentially eligible individuals and neighborhoods with high use of the participating public hospitals, determined by American Community Survey statistics and utilization data analyzed by participating health facilities. Recruitment was conducted through community-based organizations, media coverage, mailings, and materials distributed at the PCH sites.

All prospective participants were required to have the NYC municipal identification card (IDNYC; available to all New Yorkers aged 14 years and older), which served as the program's membership card. NYC has a robust set of policies and laws to protect the privacy and confidentiality of IDNYC card holders and does not ask applicants to share immigration status. In addition, IDNYC provides wide-ranging benefits, including discounts at grocery stores and museums. As a result, more than 1 million cards have been issued since the program launched. Prospective participants were screened for health insurance eligibility. Those who qualified for insurance were encouraged to enroll in insurance and deemed ineligible for this study.

Eligible individuals consented to enroll in the study and completed an in-person survey in their preferred language. Participants were randomized to the intervention (ActionHealthNYC Program) or control group (no formal program) and provided an \$11 NYC MetroCard. Couples or members of the same household were randomized together to minimize contamination. To boost recruitment,

randomization was modified during the final 10 days (August 4–13, 2016). Participants during this period were twice as likely to be randomized into the program. Regardless of intervention assignment, all participants received information about no- or low-cost health care options in NYC, including information about the facilities participating in the program, as these sites are part of NYC's safety net. All participants were enrolled into Emergency Medicaid, a limited form of insurance coverage, and received information about social services available to New Yorkers regardless of immigration status.

Intervention Design

At the time of enrollment, individuals in the intervention group selected 1 site as their designated PCH. PCHs offered comprehensive primary care and referrals to specialty care when needed. Primary care appointments were scheduled for intervention participants. A standardized fee scale was applied across all facilities for the intervention group (\$15 or \$20 copay for outpatient visits, based on income), and US Preventive Services Task Force A and B screening services were available without additional cost. A written care plan, appointment reminders, and outreach for missed appointments were provided. Intervention participants with certain conditions, unstable housing, or recent incarceration were eligible for enhanced care coordination, which included at least 6 care coordination encounters, previsit planning, and referrals to social services. Intervention participants were provided a member handbook, which described how to get care, associated costs, and how to access customer service. Customer service included access to a phone line

where participants could ask questions, file complaints, and change their PCH. All intervention resources and materials were available in 12 languages (Arabic, Bengali, Simplified Chinese, English, Haitian Creole, Hindi, Korean, Nepali, Punjabi, Russian, Spanish, and Urdu), and encounters were conducted in the participant's preferred language.

Data Sources

Baseline and follow-up surveys were the primary data sources. The baseline survey was conducted in person during enrollment (May 1–August 13, 2016) and consisted of 75 questions about sociodemographics, health care access, utilization, cost, health behaviors, and health status. A follow-up survey was conducted via telephone (May 8, 2017–June 3, 2017) and consisted of 23 questions about health care access, utilization, cost, and health status. Surveys were administered in the participant's preferred language and participants were compensated \$30.

Outcomes

The primary outcomes assessed were self-reported health care access, patient experience, and health status. Addressing the access dimensions,¹³ the following were used as a proxy for intent to access care: (1) having a primary care provider (PCP), (2) having visited a doctor's office, (3) number of visits to a doctor's office, (4) having attempted to make an appointment, and (5) how often individuals were able to get an appointment as soon as needed. Except for the question about a PCP, all questions were asked using a lookback period of 12 months on the baseline survey and 9 months at follow-up. Patient experience was measured

by participants' rating of health care received in the past 6 months on a scale of 0 to 10 and those who received enhanced care coordination were asked if they had been assisted by a care coordinator in the past 9 months (not asked in the baseline survey), related to accessibility.¹³ For health status, we evaluated participants' physical and mental health using Patient-Reported Outcomes Measurement Information System (PROMIS), a 4-item instrument for which 50 indicates the average score of the US population, and a higher score indicates better health.¹⁴

Analysis

We used the χ^2 test to examine whether the intervention and control groups differed by sociodemographic characteristics. We considered a *P* value less than .05 statistically significant. We also performed a joint test to determine if the entire set of characteristics was different between the 2 groups. We performed these tests separately within the baseline sample (all participants) and the follow-up sample (participants who responded to both surveys) to assess potential demographic imbalance introduced by nonresponse at follow-up.

Participants who completed both surveys were included in the evaluation. We used an intent-to-treat framework to quantify differences in our outcomes of interest between the intervention and control groups at follow-up. We conducted regression for each outcome separately and obtained the coefficient for intervention status by using generalized estimating equations with robust standard error calculation to account for correlated data attributable to couple or household clustering. We ran log-binomial models (or robust

Poisson model when a log-binomial model failed to converge) for binary outcome variables and estimated relative risks (RRs). We ran negative binomial models, which fit overdispersed count data, for the number of doctor visits in the past 9 months and estimated the incidence rate ratio (IRR). For continuous outcomes, we ran ordinary least squares models. Both the PROMIS physical and mental health variables were normally distributed. The health care rating variable was skewed to the left. However, estimates from generalized estimating equations are robust to model misspecification. We also included a sensitivity analysis on this outcome using a transformed variable (squared term) in the supplementary materials. Our independent variables included intervention status and the baseline outcome variable. In addition, characteristics that showed a χ^2 *P* value of less than .10 at baseline or follow-up were included into the models because they could be confounders (i.e., the intervention assignment might be dependent on these characteristics and they could also affect the outcomes theoretically). See "Description of Participants" for the characteristic variables.

We conducted 2 subgroup analyses. First, we expected the program would have greater impact among individuals who had no visits to doctors at baseline; thus, we repeated the analysis on the number of doctor's office visits within participants who did not visit a doctor in the past 12 months at baseline. Second, we quantified participants' rating of their health care before and after the program's duration among individuals who reported having visited a doctor at baseline.

To assess the impact of attrition, we compared demographics between

participants who did and did not respond to the follow-up survey by using the χ^2 test and conducted 2 sensitivity analyses. First, we imputed missing outcomes with responses reported at baseline and reran the analysis. This sensitivity analysis assumed that the outcomes remained unchanged among those who dropped out. While this was an unlikely assumption, the purpose of this analysis was to examine how robust our findings were under a conservative scenario. Second, we reran the analysis with inverse probability weighting (IPW). IPW can address potential bias attributable to attrition when the observed variables can sufficiently explain drop out. We used logistic modeling to estimate the probability of drop out, and considered characteristics that were different between the participants who remained in the study and those who did not ($P < .05$ based on the χ^2 test) and their possible 2-way interactions as potential predictors. The final set of predictors were age, sex, primary language, employment, years living in NYC, and 6 interaction terms (age*primary language, age*employment, age*years living in NYC, sex*primary language, sex*employment, and sex*years living in NYC). Details about the IPW analysis can be found in Table B (available as a supplement to the online version of this article at <http://www.ajph.org>).

Written consent was obtained from all participants. We conducted all analyses by using R version 3.5.1 (R Foundation for Statistical Computing, Vienna, Austria) and SAS version 9.4 (SAS Institute Inc, Cary, NC).

RESULTS

Among the 6101 individuals who applied, 8% ($n = 500$) did not meet the

eligibility criteria, 6% ($n = 358$) declined to provide consent, and 46% ($n = 2815$) did not complete the application (Figure 1). In total, 2428 applicants were randomized into the study, with 1286 assigned to the intervention and 1142 being controls. All participants answered the baseline survey, but 77 were not usable because of Internet issues, resulting in a final baseline sample of 2351 participants (1264 intervention and 1087 control participants). Of these, 45% ($n = 1067$) completed the follow-up survey, including 47% of intervention participants ($n = 591$) and 44% of control participants ($n = 476$). There was no differential nonresponse by assignment, but participants lost to follow-up were more likely to be male, unemployed, aged 45 years or older, to have attended some college or beyond, to speak English as their primary language, and to have lived in the United States or NYC for less than 5 years, and less likely to be Asian (Table A, available as a supplement to the online version of this article at <http://www.ajph.org>).

Description of Participants

Table 1 presents participants' characteristics. The modal age range was 35 to 54 years. Seventy-seven countries of origin and 32 primary languages were reported, with Spanish (48.7%) and Chinese (21.1%) being the most common. Most participants did not speak English well or at all (69.9%), identified themselves as either Asian (44.4%) or Latino (50.3%), and resided in the United States (64.0%) or NYC (61.0%) for 10 years or longer. A majority had an annual household income of less than \$20 000 (80%). Demographic characteristics did not differ between intervention and control participants within the baseline sample overall (joint test

$P = .23$). However, fewer intervention participants reported living in the United States (19.1% vs 23.7%; $P = .008$) or NYC (21.1% vs 25.5%; $P = .01$) for less than 5 years than the control group. Among those who also completed the follow-up survey, demographics characteristics did not differ by intervention status overall (joint test $P = .07$), but fewer intervention participants lived in NYC for less than 5 years (17.5% vs 22.9%; $P = .048$). We adjusted for years living in NYC but not years living in the United States because their constructs overlapped. In addition, we adjusted for age ($P = .06$ at baseline) and English proficiency ($P = .06$ at follow-up).

Health Care Access

Before the program, a quarter of intervention (25.7%) and control (25.3%) participants reported having a PCP, and about two thirds of both groups (59.6% and 61.0%, respectively) had seen a doctor in the past 12 months (Table 2). At follow-up, intervention participants were 1.2 times more likely to have a PCP than the control group (intervention: 57.9%, control: 46.0%; RR = 1.22; 95% confidence interval [CI] = 1.09, 1.37). Intervention participants were also 1.2 times more likely to have seen a doctor in the past 9 months (intervention: 91.2%, control: 76.8%; RR = 1.16; 95% CI = 1.11, 1.24). Among those who had not seen a doctor in the past 12 months at baseline, intervention participants were 1.3 times more likely to have seen a doctor at follow-up (intervention: 88.2%; control: 64.6%; RR = 1.36; 95% CI = 1.15, 1.48). While the average number of visits was similar among groups at baseline (2.5 and 2.6, respectively), the intervention group had 1.5 times more visits after

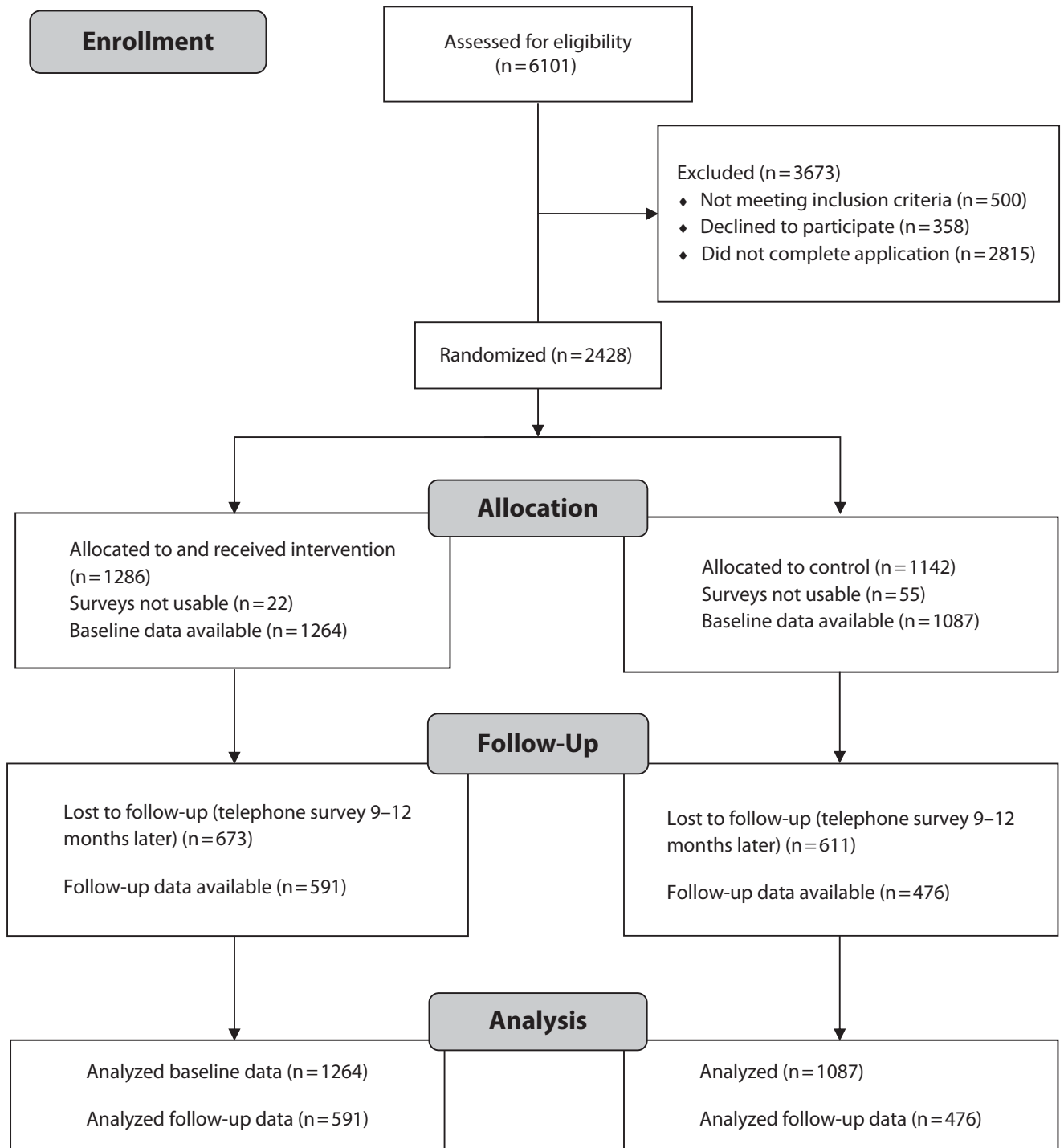


FIGURE 1— Inclusion and Exclusion Criteria for ActionHealthNYC Study Population: New York City, May 2016–June 2017

the launch of the program (intervention: 4.1; control: 2.9; IRR = 1.46; 95% CI = 1.26, 1.69). Two thirds of participants (intervention: 65.7%; control: 63.0%) attempted to make an

appointment in the past 12 months at baseline, and one third of both groups (intervention: 34.3%; control: 33.6%) could get an appointment as soon as needed. After the program started,

intervention participants were 1.2 times more likely to have attempted to make an appointment (intervention: 88.8%; control: 71.9%; RR = 1.20; 95% CI = 1.13, 1.27), and were 1.3 times

TABLE 1— Distribution of Demographic Characteristics and Socioeconomic Status Among Participants in the ActionHealthNYC Evaluation Study: New York City, May 2016–June 2017

	Randomized (n = 2351)			Follow-Up Survey Respondents (n = 1067)	
	All, %	Intervention (n = 1264), %	Control (n = 1087), %	Intervention (n = 591), %	Control (n = 476), %
Age, y					
18–24	3.9	3.4	4.5	3.4	3.8
25–34	18.3	16.9	20.1	19.1	23.4
35–44	30.8	31.7	29.7	32.8	31.5
45–54	27.2	29.1	25.0	28.2	22.6
55–64	12.4	12.2	12.7	11.4	12.1
≥ 65	7.3	6.7	8.1	5.1	6.6
Sex					
Female	50.8	50.8	50.7	55.3	51.7
Male	49.3	49.2	49.3	44.7	48.3
Race/ethnicity					
Non-Latino White	1.4	1.4	1.3	0.9	0.6
Non-Latino Black	2.9	3.1	2.5	1.2	1.9
Latino	50.3	49.9	50.7	51.4	48.6
Non-Latino Asian	44.4	44.4	44.2	45.4	47.4
Non-Latino other	1.1	1.0	1.2	1.2	1.5
Primary language					
Spanish	48.7	48.0	49.4	49.7	48.1
Chinese	21.1	21.2	20.9	32.1	32.4
English	9.7	9.5	10.0	5.2	8.6
Other	20.5	21.3	19.6	12.9	10.9
English proficiency					
Well or very well	30.1	29.8	30.5	27.1	32.3
Not well or not at all	69.9	70.2	69.5	72.9	67.7
Years living in the United States*					
< 5	21.2	19.1	23.7	16.9	20.4
5–9	14.8	16.2	13.1	15.7	13.1
≥ 10	64.0	64.8	63.2	67.4	66.5
Years living in NYC^{*,†}					
< 5	23.1	21.1	25.5	17.5	22.9
5–9	15.8	17.2	14.2	17.9	14.2
≥ 10	61.0	61.7	60.3	64.6	62.9
Education completed					
Primary school or less	26.6	26.7	26.6	26.7	24.4
Secondary school	22.1	22.1	22.1	23.9	26.1
High school	28.8	28.6	28.9	28.9	27.9
Some college or beyond	22.5	22.6	22.4	20.5	21.6
Employment					
Full-time	20.6	21.7	19.3	19.0	18.6
Part-time	38.4	39.2	37.4	43.5	39.7
Others (e.g., student, homemaker)	15.6	15.6	15.6	17.5	16.5
Unemployed	25.4	23.5	27.6	20.0	25.3

Continued

TABLE 1— Continued

	Randomized (n = 2351)			Follow-Up Survey Respondents (n = 1067)	
	All, %	Intervention (n = 1264), %	Control (n = 1087), %	Intervention (n = 591), %	Control (n = 476), %
Marital status					
Married	46.8	47.3	46.2	45.4	48.9
Living together but not married	14.2	13.6	14.8	16.3	13.7
Divorced, widowed, or separated	18.3	19.2	17.4	19.7	16.5
Never married or single	20.7	19.9	21.6	18.6	20.9
Household income in 2015, \$^a					
0–10 000	43.2	43.2	43.2	42.9	41.9
10 001–20 000	36.8	35.9	38.0	36.4	39.3
> 20 000	20.0	20.9	18.8	20.7	18.8

Note. We used χ^2 to test significance. For the race/ethnicity variable among the follow-up survey respondents, we used the Fisher exact test because of small cell counts.

^aThe number of missing variables (nonresponse) for the value was equal to or higher than 10% of n.

* $P < .05$ in the baseline survey.

[†] $P < .05$ in the follow-up survey.

more likely to obtain an appointment as soon as needed (intervention: 58.0%; control: 42.4%; RR = 1.33; 95% CI = 1.17, 1.51).

Patient Experience and Self-Reported Health Status

Intervention and control participants reported similar ratings of health care (6.5) at baseline, and ratings were not different at follow-up (8.2 vs 8.0, respectively; Table 3). The ratings also did not differ among those who had seen a doctor at baseline (8.1 vs 7.9). Based on PROMIS T-scores, intervention and control groups had similar physical health (46.7 and 47.2, respectively) and mental health (47.5 for both groups) before the program, and their scores remained similar at follow-up.

Sensitivity Analyses

Results of the sensitivity analyses for addressing attrition were consistent

with our main findings. See Table C (available as a supplement to the online version of this article at <http://www.ajph.org>) for details.

DISCUSSION

Our results show that intervention participants were 1.2 times more likely than control participants to report having utilized primary care, having a PCP, and having seen a doctor in the past 9 months. Previous studies have shown that having a PCP or usual source of care is associated with increased continuity and access to primary care, including prevention and screening services.¹⁵ Participants also reported being more able to get an appointment when needed. Key informant interviews provided information that implied the increase in demand was likely to have been need based. Participants' self-reported experience with the health system and health status did not significantly change. PROMIS T-scores

remaining similar was not surprising because of the program's short duration. ActionHealthNYC obtained some of the first descriptive information on NYC undocumented immigrants' health status and utilization, highlighting significant unmet need for primary care. About 25% of study participants reported having a PCP at baseline, substantially lower than the 90.8% of NYC Medicaid enrollees who reported having a PCP in 2017.¹⁶

Increases in health care access were likely driven by 4 main factors. First, the PCHs chosen for the program were facilities with longstanding relationships with local communities, enabling participants to feel at ease with the providers, improving accessibility. Second, because cost is a known barrier, we standardized the fee scale, lowering the cost to all patients in the intervention group, improving affordability. Third, to increase availability, program enrollers made appointments for intervention participants, and care

TABLE 2— Self-Reported Health Care Access Among Participants of ActionHealthNYC Evaluation Study at Baseline and Follow-Up by Intervention Status: New York City, May 2016–June 2017

	Baseline (n = 2351)		Follow-Up (n = 1067)			
	Intervention (n = 1264), % or Mean (SD)	Control (n = 1087), % or Mean (SD)	Intervention (n = 591), % or Mean (SD)	Control (n = 476), % or Mean (SD)	Difference, RR (95% CI)	Difference, IRR (95% CI)
Has a primary care provider or other usual source of care					1.22 (1.09, 1.37)	NA
Yes	25.7	25.3	57.9	46.0		
No	74.3	74.7	42.1	54.0		
Saw a doctor in the past 12 mo (baseline) or 9 mo (follow-up)					1.16 (1.11, 1.24)	NA
Yes	59.6	61.0	91.2	76.8		
No	40.4	39.0	8.8	23.2		
Saw a doctor in the past 9 mo at follow-up among participants who reported no doctor visit 12 mo before baseline	NA	NA	88.2	64.6	1.31 (1.15, 1.48)	NA
No. of doctor visits in the past 12 mo (baseline) or 9 mo (follow-up)	2.5 (4.2)	2.6 (4.3)	4.1 (4.1)	2.9 (3.7)	NA	1.46 (1.26, 1.69)
Attempted to make a medical appointment in the past 12 mo (baseline) or 9 mo (follow-up)					1.20 (1.13, 1.27)	NA
Yes	65.7	63.0	88.8	71.9		
No	34.3	37.0	11.2	28.1		
Got an appointment as soon as needed in the past 12 mo (baseline) or 9 mo (follow-up) ^a					1.33 (1.17, 1.51)	NA
Yes	34.3	33.6	58.0	42.4		
No	65.7	66.4	42.0	57.6		

Note. CI = confidence interval; IRR = incidence rate ratio; NA = not applicable; RR = relative risk. Baseline n refers to the number of participants who completed the baseline survey, and follow-up n refers to the number of participants who completed both baseline and follow-up surveys. Values are presented as percentages unless otherwise indicated. RR is reported for binary outcomes and IRR is reported for count outcomes. An RR or IRR greater than 1 indicates greater likelihood of having an outcome or greater rate among the intervention participants. Models were adjusted for baseline outcome (except for subgroup analysis), age, English proficiency, and years living in NYC.

^a“Yes” was defined by a response of “usually” or “always” to the survey question; “no” was defined by a response of “sometimes,” “never,” or “did not try to make an appointment.”

coordination was integrated into the program. Fourth, staff worked closely with PCHs to address linguistic and cultural barriers that intervention participants were likely to experience in using health services, increasing acceptability. All communication materials were translated to accommodate common language needs. These additional measures that addressed barriers

encountered by low-income immigrants likely enabled them to utilize services more easily at the PCHs.

Highlighting the need for primary care among uninsured and undocumented immigrants, primary care use significantly increased in both intervention and control groups relative to their baseline rate of 25%. At follow-up, 58% of intervention participants and 46% of

control participants reported having a PCP. This may be because all participants were given a list of hospitals and health centers that provide low- to no-cost care to the uninsured, including the program PCHs. NYC government maintains that no one should go without needed health care, and the local safety net is designed to ensure access to care regardless of ability to

TABLE 3— Self-Reported Health Care Rating and Health Status Among Participants of ActionHealthNYC Evaluation Study at Baseline and Follow-Up by Intervention Status: New York City, May 2016–June 2017

	Baseline (n = 2351)		Follow-Up (n = 1067)			
	Intervention (n = 1264), % or Mean (SD)	Control (n = 1087), % or Mean (SD)	Intervention (n = 591), % or Mean (SD)	Control (n = 476), % or Mean (SD)	Difference, b (95% CI)	Difference, RR (95% CI)
Was helped by a care coordinator in the past 9 mo (follow-up)	NA	NA	17.1	8.9	NA	1.90 (1.34, 2.69)
Rating of health care received in the past 6 mo (scale = 0–10)	6.5 (3.0)	6.5 (3.0)	8.2 (1.9)	8.0 (1.9)	0.18 (–0.10, 0.46)	NA
Rating of health care received in the last 6 mo (scale = 0–10) among those who reported seeing a doctor at baseline	7.1 (2.4)	7.1 (2.4)	8.1 (2.0)	7.9 (1.8)	0.26 (–0.06, 0.58)	NA
Global Physical Health PROMIS T-score (range = 16.2–67.7)	46.7 (8.8)	47.2 (8.6)	48.0 (8.4)	47.7 (8.4)	0.68 (–0.20, 1.56)	NA
Global Mental Health PROMIS T-score (range = 21.2–67.6)	47.5 (7.7)	47.5 (7.1)	47.8 (7.9)	47.4 (7.4)	0.49 (–0.35, 1.33)	NA

Note. CI = confidence interval; NA = not applicable; RR = relative risk. Baseline n refers to the number of participants who completed the baseline survey, and follow-up n refers to the number of participants who completed both baseline and follow-up surveys. The Global Physical and Mental Health T-score reflects 4-item calculation for enrollees that answered all relevant questions. PROMIS T-scores are normalized with a mean of 50 as the average score of the US general population. T-score difference of 10 from 50 (i.e., score 40 or 60) represents 1 standard deviation from the population mean, with a higher score indicating a better rating of health than the US average. RR is reported for binary outcomes and b is reported for continuous outcomes. An RR greater than 1 indicates greater likelihood of having an outcome among the intervention participants. A b greater than 0 indicates a higher mean among the intervention participants. Models were adjusted for baseline outcome (except for the care coordination outcome), age, English proficiency, and years living in NYC.

pay or immigration status. Progressive local policy combined with a robust safety net network was likely a significant factor in increased primary care utilization in both groups. This indicates that each jurisdiction will require adjustments to program design and outreach approach when implementing a direct-access program.

ActionHealthNYC reached many low-income immigrants, a population that faces especially large barriers to accessing health care,¹⁷ and helped reduce disparities in access to care. Though recruitment targeted hard-to-reach communities, it attracted more than 6000 applicants for a study seeking approximately 2500 participants. This was likely driven by a multipronged approach that targeted the eligible population, including outreach through community-based organizations,

advertisements in local non-English-language newspapers, and mailings to participants of other programs. Recruitment and retention of most of the participants throughout the program show that local government can engage immigrant communities through strategic outreach even when the social context leaves them politically vulnerable. The program's success, particularly within the access dimensions of availability, accessibility, and acceptability, is noteworthy given the political climate and federal policies that were hostile to immigrants throughout the program period. Still, the significant loss to follow-up highlights the difficulties of engaging this population. It is likely that the follow-up response was low because of undocumented immigrants working long hours and being more likely to move compared with other

groups. Our experience highlights the need to dedicate resources to engage marginalized populations in ways that facilitate access to care.

Limitations

Our study had 4 main limitations. First, external validity was limited because of sample size, participant demographics (skewed toward certain groups of immigrants), and nonresponse at follow-up. Results cannot be generalized to all uninsured or undocumented populations in NYC, and generalizing our follow-up survey responses to overall program participants requires caution. Second, the analysis primarily relied on self-reported information. Third, all participants were given a list of hospitals and health centers that they could visit for low- to

no-cost care. Thus, there could have been contamination between intervention and control. Finally, because of concerns about survey length, we did not collect information about chronic conditions on the follow-up survey.

Public Health Implications

States and local authorities can build on the progress that has been made over the past decade to expand and improve access to health care for uninsured populations. Although each jurisdiction has unique aspects of its health system, policymakers seeking to improve access to care can learn from experiences of others. The results of our program indicate that, similar to the success of Healthy San Francisco, myHealthLA, and other established health access programs, even in areas with strong safety net systems, a coordinated health care access program can increase access to care for the uninsured. ActionHealthNYC's experience suggests that such a program should include a formal membership component, a designated PCH network, a set fee scale, and customer service. As the COVID-19 pandemic continues to exacerbate inequities in health systems and disparities in health care access, direct-access programs can play a key role in facilitating access to care. Local officials should consider creating formal health access programs for the uninsured to improve health care access and, ultimately, population health. [AJPH](#)

ABOUT THE AUTHORS

Rishi K. Sood is with the Bureau of Equitable Health Systems, New York City Department of Health and Mental Hygiene, Queens, NY. Jin Yung Bae and Caroline Heindrichs were with the Bureau of Primary Care Access and Planning, New York City Department of Health and Mental

Hygiene. Adrienne Sabety was with the Interfaculty Initiative in Health Policy at Harvard University, Cambridge, MA. Pui Ying Chan is with the Bureau of Epidemiology Services, New York City Department of Health and Mental Hygiene.

CORRESPONDENCE

Correspondence should be sent to Rishi K. Sood, MPH, New York City Department of Health and Mental Hygiene, 42-09 28th St, Queens, NY 11101 (e-mail: rsood@health.nyc.gov). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Sood RK, Bae JY, Sabety A, Chan PY, Heindrichs C. ActionHealthNYC: effectiveness of a health care access program for the uninsured, 2016–2017. *Am J Public Health*. 2021;111(7):1318–1327.

Acceptance Date: March 4, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306271>

CONTRIBUTORS

R. K. Sood conceptualized the project and led the writing of the article. A. H. Sabety and P. Y. Chan conducted data analyses. J. Y. Bae and C. Heindrichs led the design and implementation of the surveys. All the authors interpreted results and contributed to writing and editing the article.

ACKNOWLEDGMENTS

This work was funded by the Altman, Rockefeller, and Robin Hood Foundations. A. H. Sabety received funding from the National Science Foundation Graduate Research Fellowship Program under grant DGE1144152.

We thank Sungwoo Lim, Sam Solomon, Chris Keeley, Sonia Angell, and the entire ActionHealthNYC outreach and enrollment team for their contributions.

Note. The funding organizations played no role in the conduct of the research or preparation of the article.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

HUMAN PARTICIPANT PROTECTION

This study was approved by the institutional review board at the New York City Department of Health and Mental Hygiene. A Certificate of Confidentiality was issued by the National Institutes of Health.

REFERENCES

- American Community Survey 1-year estimates. Washington, DC: US Census Bureau; 2017.
- Tolbert J, Orgera K, Damico A. Key facts about the uninsured population. Kaiser Family Foundation. 2020. Available at: <https://www.kff.org/uninsured/fact-sheet/key-facts-about-the-uninsured-population>. Accessed November 9, 2020.
- Kaiser Family Foundation. 2019 Employer Health Benefit Survey. 2019. Available at: <https://www.kff.org/report-section/ehtbs-2019-section-1-cost-of-health-insurance>. Accessed February 18, 2020.
- Ortega AN, Fang H, Perez VH, et al. Health care access, use of services, and experiences among undocumented Mexicans and other Latinos. *Arch Intern Med*. 2007;167(21):2354–2360. <https://doi.org/10.1001/archinte.167.21.2354>
- Institute of Medicine Committee on the Consequences of Uninsurance. *Care Without Coverage: Too Little, Too Late. Effects of Health Insurance on Health*. Washington, DC: National Academies Press; 2002.
- Hatch B, Marino M, Killerby M, et al. Medicaid's impact on chronic disease biomarkers: a cohort study of community health center patients. *J Gen Intern Med*. 2017;32(8):940–947. <https://doi.org/10.1007/s11606-017-4051-9>
- Rosano A, Loha CA, Falvo R, et al. The relationship between avoidable hospitalization and accessibility to primary care: a systematic review. *Eur J Public Health*. 2013;23(3):356–360. <https://doi.org/10.1093/eurpub/cks053>
- Parchman ML, Culler S. Primary care physicians and avoidable hospitalizations. *J Fam Pract*. 1994;39(2):123–128.
- Passel JS, Cohn D. 20 metro areas are home to six-in-ten unauthorized immigrants in US. 2019. Available at: <https://www.pewresearch.org/fact-tank/2019/03/11/us-metro-areas-unauthorized-immigrants>. Accessed August 20, 2019.
- Patient-Centered Primary Care Collaborative. Joint principles of the patient-centered medical home. 2007. Available at: <http://www.pcpcc.net/content/joint-principles-patient-centered-medical-home>. Accessed August 20, 2019.
- Sinaiko AD, Landrum MB, Meyers DJ, et al. Synthesis of research on patient-centered medical homes brings systematic differences into relief. *Health Aff (Millwood)*. 2017;36(3):500–508. <https://doi.org/10.1377/hlthaff.2016.1235>
- Barrios-Paoli LN. Improving immigrant access to health care in New York City: a report from the Mayor's Task Force on Immigrant Health Care Access. 2015. Available at: https://www1.nyc.gov/assets/cidi/downloads/pdfs/immigrant_health_task_force_report.pdf. Accessed September 28, 2019.
- Penchansky R, Thomas JW. The concept of access: definition and relationship to consumer satisfaction. *Med Care*. 1981;19(2):127–140. <https://doi.org/10.1097/00005650-198102000-00001>
- HealthMeasures (Person-Centered Assessment Resource). PROMIS Profile Instruments: a brief guide to the PROMIS Profile Instruments for adult respondents. 2019. Available at: http://www.healthmeasures.net/images/PROMIS/manuals/PROMIS_Adult_Profile_Scoring_Manual.pdf. Accessed August 20, 2019.
- Blewett LA, Johnson PJ, Lee B, Scal PB. When a usual source of care and usual provider matter: adult prevention and screening services. *J Gen Intern Med*. 2008;23(9):1354–1360. <https://doi.org/10.1007/s11606-008-0659-0>
- NYC Community Health Survey. Queens, NY: NYC Department of Health and Mental Hygiene; 2017.
- Deroser KP, Escarce JJ, Lurie N. Immigrants and health care: sources of vulnerability. *Health Aff (Millwood)*. 2007;26(5):1258–1268. <https://doi.org/10.1377/hlthaff.26.5.1258>

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Community Health Worker Asthma Interventions for Children: Results From a Clinically Integrated Randomized Comparative Effectiveness Trial (2016–2019)

Molly A. Martin, MD, MAPP, Oksana Pugach, PhD, Giselle Mosnaim, MD, Sally Weinstein, PhD, Genesis Rosales, MSW, Angkana Roy, MD, Andrea A. Pappalardo, MD, and Surrey Walton, PhD

 See also Homaira and Jaffe, p. 1183.

Objectives. To compare asthma control for children receiving either community health worker (CHW) or certified asthma educator (AE-C) services.

Methods. The Asthma Action at Erie Trial is a comparative effectiveness trial that ran from 2016 to 2019 in Cook County, Illinois. Participants (aged 5–16 years with uncontrolled asthma) were randomized to 10 home visits from clinically integrated asthma CHWs or 2 in-clinic sessions from an AE-C.

Results. Participants (n = 223) were mainly Hispanic (85%) and low-income. Both intervention groups showed significant improvement in asthma control scores over time. Asthma control was maintained after interventions ended. The CHW group experienced a greater improvement in asthma control scores. One year after intervention cessation, the CHW group had a 42% reduction in days of activity limitation relative to the AE-C group (b = 0.58; 95% confidence interval = 0.35, 0.96).

Conclusions. Both interventions were associated with meaningful improvements in asthma control. Improvements continued for 1 year after intervention cessation and were stronger with the CHW intervention.

Public Health Implications. Clinically integrated asthma CHW and AE-C services that do not provide home environmental remediation equipment may improve and sustain asthma control. (*Am J Public Health*. 2021;111(7):1328–1337. <https://doi.org/10.2105/AJPH.2021.306272>)

For decades, poor asthma control in low-income urban minority children has been linked to increased hospitalizations, emergency department (ED) visits, and urgent care (UC) visits, and missed school and caregiver work days.^{1–3} With proper medication usage and reduced exposure to triggers, asthma can be controlled.⁴ Despite

comprehensive asthma management guidelines,² asthma disparities persist.^{1,5–7} Effective interventions that support and connect high-risk families and health systems are needed.⁸

Certified asthma educators (AE-Cs) providing reimbursable asthma education are a potential intervention for improving community asthma care.⁹

However, research demonstrating the ability of AE-Cs to improve asthma outcomes is limited. Another promising approach is community health workers (CHWs). CHWs connect patients and communities to health and social services.¹⁰ In randomized controlled trials, CHWs working with families of low-income children with asthma reduced

home triggers, asthma symptoms, and UC use.¹¹⁻¹⁴

CHW and AE-C services provide a pathway to deliver guidelines-based asthma self-management support² for high-risk families, but application of these interventions to real-world practice is limited. CHW training, hiring, and supervisory needs in the clinical environment are not standardized. The number of visits needed to achieve optimal outcomes is unknown. Home remediation equipment, such as vacuums, cleaning kits, and allergy mattress covers, were provided free to families in many CHW asthma studies but are not covered by insurance.¹¹⁻¹⁵ Finally, the lack of data on asthma efficacy for AE-C services may further influence their uptake.

The Asthma Action at Erie Trial was designed to address these gaps. Aim 1 was to assess the efficacy of CHW home intervention, relative to clinic-based AE-C education, over 12 months on asthma control. Aim 2 was to assess maintenance of intervention efficacy on asthma control at 24 months. The results of this trial provide guidance for community health systems regarding the implementation of CHW and AE-C programs for asthma support services for children.

METHODS

The Asthma Action at Erie Trial (NCT 02481986) used a 2-group comparative effectiveness design to assess asthma control changes in low-income urban minority children with uncontrolled asthma.¹⁶ Participants were randomized to in-clinic AE-C services or home CHW visits to determine if asthma control differed between groups. To align with normal services covered by insurance, participants did not receive home

environmental remediation equipment or monetary incentives for intervention completion. We hypothesized that children in the CHW group would show greater, sustainable improvements in asthma control than those in the AE-C group. To evaluate sustainability, we assessed asthma control at 24 months.

Participants

In partnership with Erie Family Health Center (Erie), a federally qualified health system providing clinical services for low-income families in the Chicago area, we recruited 223 children and their caregivers. Recruitment occurred sequentially at 6 clinics in Chicago and Evanston, Illinois, over a period of 18 months. Eligibility required being a patient at Erie aged 5 to 16 years, living with the caregiver at least 5 days out of the week, and having uncontrolled asthma. To capture asthma impairment and risk,² we used the Asthma Control Test (ACT) or childhood Asthma Control Test (cACT; score < 20), the Asthma Control Questionnaire (ACQ; score ≥ 1.25), and self-report of at least 1 oral corticosteroid burst in the past year.¹⁶⁻²⁰ Only 1 child and caregiver per household could be enrolled. Exclusion criteria included lack of fluency in English or Spanish, transient living conditions, or the child having significant developmental delays or comorbidities limiting their ability to participate.

Procedures

Details of the methods have been reported elsewhere.¹⁶ Briefly, Erie mailed introductory letters to potentially eligible families identified through their electronic medical record (EMR). Families were then screened for eligibility by telephone. Child age, asthma

control, language, living conditions, and health exclusions were assessed. If eligible and interested, a home data collection visit was scheduled. Research assistants (RAs) collected standard demographic data, the child's asthma symptoms and history, medications used, inhaler technique, and triggers. If an inhaled corticosteroid was present, adherence was monitored over 2 weeks using an electronic adherence device (DoserCT: MEDITRACK Products, Easton, MA) or the medication counter. A saliva sample for cotinine analysis was obtained from the child.

After completing the baseline assessment, participants were randomized to the AE-C or CHW group in a 1-to-1 ratio using stratified block randomization with randomly mixed permuted blocks of size 4 and 6. The stratum was defined based on a combination of Erie clinic sites, race/ethnicity, and age.

Interventions

Details of the interventionist hiring, training, protocols, and supervision are described elsewhere.^{16,21} Briefly, 1 AE-C and 2 CHWs were hired by Erie. All were fluent in English and Spanish. The AE-C had previous asthma educator experience; the CHWs did not. The AE-C passed the National Asthma Educator Certification Board Exam. No formal certifications exist for CHWs in Illinois, but the CHW hiring and training process was designed to ensure that the CHWs had the recommended skills and qualities defined by the national CHW Core Consensus Project (<https://www.c3project.org>). The CHWs and AE-C completed a 16-hour initial asthma training, followed by additional training on asthma medications and trigger remediation, home visitation, emergency mental health, and the

study protocol. Intervention was then delivered from May 2016 through August 2018. Although the AE-C and CHWs met regularly with investigators for protocol and fidelity monitoring, they operated as full Erie employees and communicated directly with clinical staff. Study participant encounters were documented in the Erie EMR and study database.

Families randomized to the AE-C were offered a 1-hour session at an Erie clinic within a month of randomization and again at 6 months. Sessions were followed with a telephone call from the AE-C 2 weeks later to answer any questions. Sessions covered asthma symptoms, control, triggers, action plans, medication technique, adherence, and caregiver or child concerns. The AE-C visit frequency and topics were chosen to align with national guidelines for asthma self-management education.² The AE-C rotated among the 6 Erie clinic sites on a set schedule, also providing general asthma support and supervising the CHWs.

Families randomized to CHW intervention were offered 10 visits over 12 months; the number of visits and intervention duration were informed by previous research in the same community.^{16,21,22} Visits were intended for the home, although CHWs had the flexibility to meet at other locations. CHWs covered the same asthma topics as the AE-C. However, their protocol was flexible, allowing for prioritization of specific family needs. CHW visits ended with families completing a written behavioral change plan detailing short-term goals.

Outcomes Assessment

To preserve data integrity, the data collection team was completely separate from the intervention team; they did

not communicate regarding participants, and interventionists did not have access to baseline or follow-up data. RAs collected outcomes data in person in homes at 6, 12, and 24 months. Telephone data were collected at 18 months. Families were reimbursed by RAs \$50 for the main assessments and \$25 for the 18-month call. RAs also called monthly to collect caregiver reports of any new asthma-related hospital, ED, or UC visits, or corticosteroid bursts. These were then verified using EMR reviews.

The primary outcome, asthma control, was captured in 2 ways: ACT (≥ 12 years) or cACT (5–11 years)^{18,20,23} and self-reported asthma-related activity limitation over the past 14 days.²⁴ Additional measures included the ACQ, health care utilization for asthma (verified by EMR at 12 and 24 months), oral corticosteroid bursts, asthma medication (type, technique, and adherence), and home triggers. Covariates included child and caregiver depression and posttraumatic stress disorder, as well as family social support and functioning. Outcomes assessment procedures and covariate details have been previously published.¹⁶

Statistical Analysis

To capture the minimally important increase (3 points,²³ a 0.4 SD) in cACT or ACT scores with 80% power (2-sided $P < .05$) at 15% attrition, 110 participants per group was sufficient.¹⁶ According to previous data on baseline rates and assumed effect size,^{15,16} this sample size was also adequate to capture 30% fewer days of activity limitation between groups at 12 months.

We calculated descriptive statistics for the total sample and by groups. As recommended by the CONSORT

Statement for clinical trials (www.consort-statement.org), we did not conduct significance testing on baseline covariates. The primary statistical analysis used the marginal models framework.²⁵ Specifically, linear covariance pattern modeling was used for the continuous cACT or ACT outcome. We used generalized estimating equation with negative binomial distribution and log-link function for activity limitation. We measured both outcomes repeatedly over time. To correctly evaluate the model estimates' covariance matrix, we used heterogeneous Toeplitz and unstructured variance-covariance parametrization,²⁵ with empirical-based estimators for continuous and count outcomes.

Analyses used an intention-to-treat approach. Imputation was not needed because of minimal missing outcomes. Under assumptions of covariate-dependent missing completely at random, both methods give unbiased estimates and use all available observations. Eighteen-month data were not included in the models as the data collection mode was different. Final models included categorical time, group, group-by-time interaction, stratification variables used for restricted randomization (site, ethnicity, age group), and season. Season was not an initial stratification variable but was included in the models because the follow-up data collection windows sometimes crossed seasons.

We compared asthma-related health care utilization and corticosteroid bursts by using binomial and logit-link generalized estimating equation models, each with an unstructured variance-covariance matrix. The regression models controlled for the same covariates as the primary analysis.

We performed sensitivity analyses to evaluate the influence of the amount

of CHW visits on the results. Four participants had more than the protocol-defined 10 CHW visits. When these outliers were omitted, the results remained consistent. The progression of outcomes over time as a function of visit completeness was evaluated by summarizing observed outcomes by groups using procedures that account for repeated observations in standard error calculations.²⁶ To examine the RA influence on outcomes, number of RA contacts was added to final primary analysis models as a control variable.

RESULTS

We randomized 223 children and their caregivers out of 1688 children that were identified from 6 Erie clinic locations (Figure 1): 108 to the CHW group and 115 to the AE-C group. Primary outcomes data were complete for 96.0% (cACT or ACT) and 96.4% (activity limitation) of the sample at 12 months, and 93.7% for both at 24 months. Two participants withdrew. In the AE-C group, 49% received no intervention, 29% received 1 session, and 22% received 2. In the CHW group, 6% received no intervention, with a median of 7 visits (interquartile range = 4) received (Table 1).

Demographics reflected the service populations of Erie and did not differ by treatment group (Table 1). While the mean child age was 9 years, 176 (78.9%) were aged 5 to 11 years, and 47 (21.1%) were aged 12 to 16 years at baseline. Eighteen percent of children were of Black race and 85.2% of Hispanic ethnicity. Of those that identified as Hispanic, 83.7% claimed Mexican heritage, and 44.4% of their caregivers were born in Mexico. Depressive symptoms in caregivers (14.8%) and children (18.0%) were evident. Posttraumatic

stress disorder symptoms were high in children, with 51.3% reporting in the clinically symptomatic range.^{27,28}

Both groups showed significant improvement in cACT or ACT scores over time, with the greatest improvement at 6 months from baseline. Maintenance of asthma control continued through 24 months (Table 2; Figure 2). While cACT or ACT scores were not significantly different between groups at any time point, the CHW group experienced a greater change in cACT or ACT from baseline to 12 months, with an average increase of almost 5 points compared with 3 points for the AE-C group ($P = .01$). Activity limitation also improved in both groups over time. At 12 months, the CHW group had a 37% reduction in days of activity limitation relative to the AE-C group ($b = 0.63$; 95% confidence interval [CI] = 0.40, 1.00). At 24 months, the CHW group reduction was more pronounced at 42% ($b = 0.58$; 95% CI = 0.35, 0.96).

We compared asthma-related health care utilization and oral corticosteroid bursts by intervention group as well. Any ED visits or hospitalizations for asthma declined from baseline at 12 months (CHW group: OR = 0.18; 95% CI = 0.09, 0.34; AE-C group: OR = 0.24; 96% CI = 0.14, 0.40) and 24 months (CHW group: OR = 0.08; 95% CI = 0.04, 0.18; AE-C group: OR = 0.17; 95% CI = 0.09, 0.31). The odds of any ED visits or hospitalizations for asthma were lower in the CHW group compared with the AE-C group at 12 months (OR = 0.52; 95% CI = 0.24, 1.10) and reached significance at 24 months (OR = 0.35; 95% CI = 0.14, 0.88). Similarly, the odds of UC visits were lower in the CHW group than the AE-C group at 24 months (OR = 0.52; 95% CI = 0.27, 1.01). The CHW group also had lower odds of any oral

corticosteroid bursts at 24 months compared with the AE-C group (OR = 0.35; 95% CI = 0.15, 0.81).

To better understand the changes over time, we compared participants by intervention dose (Figure A, available as a supplement to the online version of this article at <http://www.ajph.org>). By 24 months, participants receiving no AE-C intervention had improved a mean of 3.9 cACT or ACT points. Participants who received the full AE-C intervention started at a higher cACT or ACT score and had the least average improvement (2.6 points) at 24 months. The CHW group was more heterogeneous in response patterns, given the larger range of potential intervention visits. Participants who refused all CHW visits showed some improvement between baseline and 12 months (mean = 2.1 points) and finished with a mean improvement of 7.2 points at 24 months. Those receiving 1 to 3 CHW visits started with lower cACT or ACT scores and improved a mean of 6.3 points at 12 months, followed by a slight decline (1.6 points) at 24 months. Those receiving 4 to 6 and 7 to 9 visits followed parallel paths of steady improvement (5.0 points at 12 months) and maintenance. Participants with 10 or more visits started with the worst cACT or ACT scores but improved a mean of 5.4 points at 12 months and continued to improve. We saw similar patterns with activity limitation.

Because of the improved asthma control noted in participants who received no intervention, we investigated if RA contact was associated with asthma control and if it influenced intervention effects. Controlling for RA contacts did not change the overall intervention effects. Meanwhile, additional RA contacts were independently associated with an incremental

increase of 0.21 in cACT or ACT score ($b = 0.21$; $SE = 0.10$; $P = .04$) and a 6.8% reduction in days with activity limitation more than 24 months ($b = -0.07$; $SE = 0.02$; $P < .01$).

DISCUSSION

This study aimed to inform community health systems regarding the

implementation of asthma CHW and AE-C programs. First, we tested if clinically integrated asthma CHWs and the AE-C could improve asthma control without providing home environmental remediation equipment. Asthma control often improves over time in children before puberty, but the increases seen in our study exceeded the cACT or ACT minimally important difference and were larger than would be

expected by just time. Activity limitation was also reduced in both groups. Effects were stronger in the CHW group.

Because our study did not compare the interventions to a pure usual care, our results can be compared with others to understand their relevance. In a landmark asthma CHW study, which included environmental remediation equipment, Krieger et al. reported

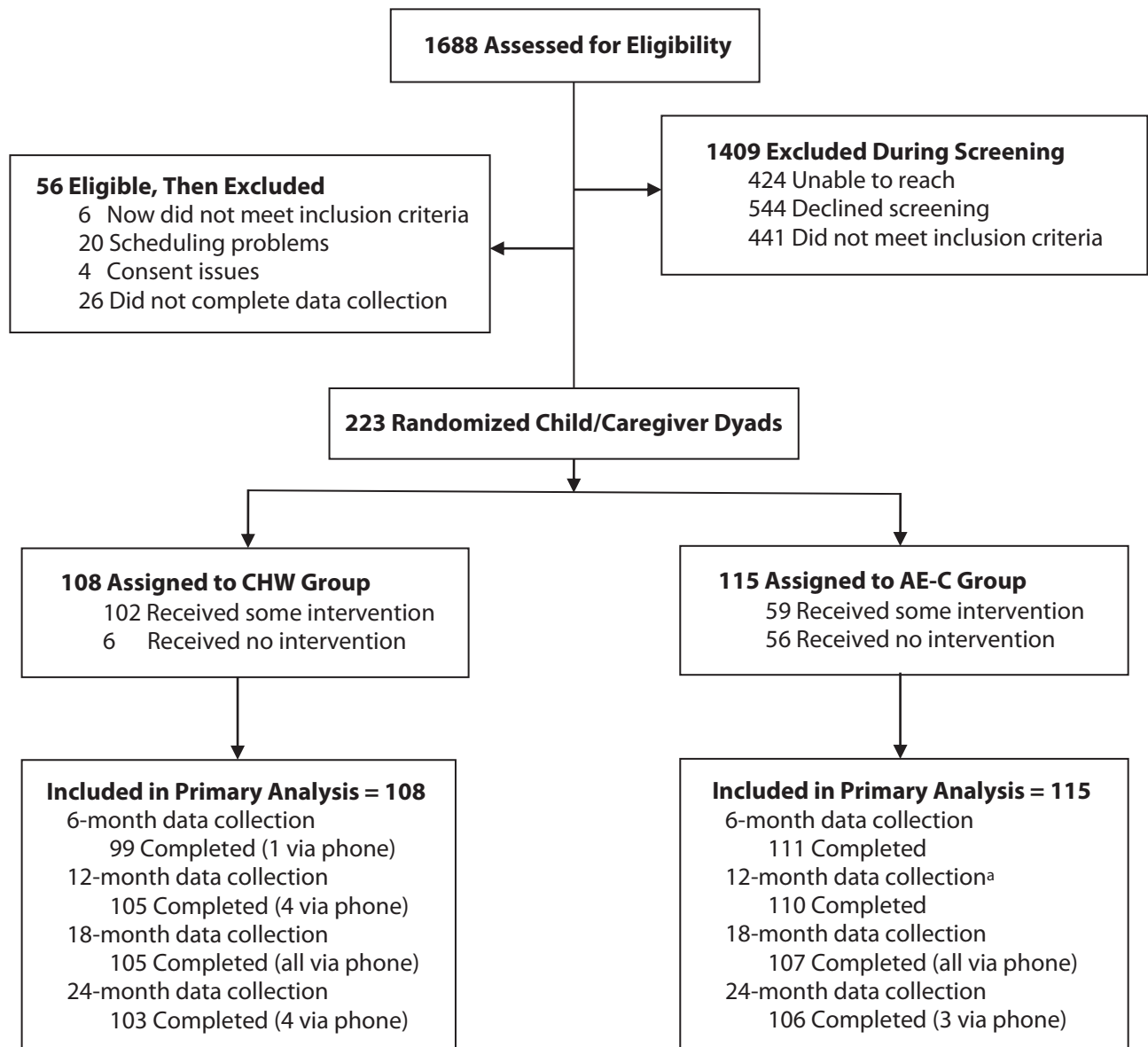


FIGURE 1— Asthma Action at Erie CONSORT Diagram

Note. AE-C = certified asthma educator; CHW = community health worker; CONSORT = Consolidated Standards of Reporting Trials.

^aTwo formal withdrawals: 1 at 12 months and 1 at 24 months.

TABLE 1— Participant Demographics, Baseline, Asthma Control, and Intervention Delivery: Cook County, IL, 2016–2019

	AE-C Group (n = 115), Mean ± SD or No. (%)	CHW Group (n = 108), Mean ± SD or No. (%)	Total (n = 223) Mean ± SD or No. (%)
Child demographics			
Age, y	9.5 ± 3.2	9.3 ± 2.9	9.4 ± 3.0
Female	52 (45.2)	46 (42.6)	98 (44.0)
Race ^a			
Black	21 (18.4)	18 (16.7)	39 (17.6)
White	30 (26.3)	33 (30.6)	63 (28.4)
Hispanic	98 (85.2)	92 (85.2)	190 (85.2)
Mexican ^b	83 (84.7)	76 (82.6)	159 (83.7)
Puerto Rican ^b	10 (10.2)	10 (10.9)	20 (10.5)
Other Hispanic ^b	5 (5.1)	6 (6.5)	11 (5.8)
Child baseline asthma control			
Uncontrolled asthma by ACT or cACT ^c	59 (51.3)	64 (60.4)	123 (55.7)
Days of activity limitation in the past 2 weeks	3.4 ± 4.0	3.7 ± 3.9	3.6 ± 3.9
Emergency department visits for asthma in past 12 mo ^a	2.2 ± 1.5	1.9 ± 1.4	2.1 ± 1.5
Hospitalized for asthma in past 12 mo ^a	1.2 ± 0.5	2.1 ± 1.8	1.5 ± 1.1
Oral corticosteroid bursts for asthma in past 12 mo ^a	2.1 ± 1.4	2.1 ± 1.8	2.1 ± 1.6
Caregiver demographics			
Age, y	36.5 ± 7.6	36.0 ± 6.6	36.3 ± 7.1
Married or live with partner ^c	75 (65.8)	69 (64.5)	144 (65.2)
Highest degree earned			
< high school	33 (28.7)	31 (28.7)	64 (28.7)
High school or GED	42 (36.5)	42 (38.9)	84 (37.7)
Some college	28 (24.4)	26 (24.1)	54 (24.2)
College graduate or more	12 (10.4)	9 (8.3)	21 (9.4)
Language of interview			
English	57 (49.6)	52 (48.2)	109 (48.9)
Spanish	36 (31.3)	34 (31.5)	70 (31.4)
Mixed English and Spanish	22 (19.1)	22 (20.4)	44 (19.7)
Born outside of the mainland United States	62 (53.9)	59 (54.6)	121 (54.3)
Intervention receipt			
AE-C intervention			
No sessions	56 (48.7)		
Initial clinic session	52 (45.2)		
Initial follow-up phone call	23 (20.0)		
6-mo clinic session	32 (27.8)		
6-mo follow-up phone call	15 (13.0)		
CHW intervention			
No visits		6 (5.6)	
1–3		10 (9.3)	
4–6		23 (21.3)	
7–9		59 (54.6)	
≥ 10		10 (9.3)	

Note. ACT = Asthma Control Test; AE-C = certified asthma educator; cACT = childhood Asthma Control Test; CHW = community health worker; GED = general educational development.

^aThe sample size was n = 222; the majority reported “other” race.

^bThe denominator was the number endorsing Hispanic.

^cThe sample size was n = 221.

a reduction of 4.1 days of activity limitation over 2 weeks in the CHW arm¹⁴—larger than the reduction seen in our CHW group of 2.54 days at 12 months. The Inner City Asthma Study reported a smaller effect, a reduction of 2.34 days.¹⁵ Most recently, Campbell et al. reported a reduction of 2.93 days of activity limitation in their CHW group. At 12 months, their results showed 1.80 days of activity limitation in their usual care arm compared with 1.23 days in the CHW arm.¹¹ Our AE-C group had 1.95 days of activity limitation at 12 months compared with 1.17 in the CHW group, which is very similar to the Campbell et al. results obtained with a usual care control. This comparison also suggests comparable asthma control can be obtained with CHW intervention that does not include environmental remediation equipment.

Our results show a robust change in asthma control for those in the AE-C intervention group. However, almost half of this group got no intervention, which makes it difficult to understand the actual intervention impact. Despite strong recommendations for AE-C services and a well-defined certification program,^{2,9,29} the existing evidence for AE-C effectiveness is small. Wang et al. recently reported reduced corticosteroid bursts and clinic visits associated with a nurse AE-C intervention.³⁰ Other studies reported reduced ED visits and fewer asthma symptoms with combined AE-C and CHW, and AE-C and pharmacist interventions.^{31,32} Most AE-Cs are nurses and respiratory therapists, but ours was neither. Our results suggest that additional research is needed to determine the ability of an AE-C intervention to improve asthma control in a community setting. The recently improved availability and acceptance

TABLE 2— Adjusted Models of Asthma Outcomes Immediately After Intervention (12 Months) and 1 Year Later (24 Months): Cook County, IL, 2016 to 2019

	Unadjusted			Adjusted			
	Baseline	12 Mo	24 Mo	Change Over 12 Mo From Baseline	Intervention Difference at 12 Mo	Change Over 24 Mo From Baseline	Intervention Difference at 24 Mo
cACT or ACT, mean (95% CI)					0.65 (-0.45, 1.75)		0.33 (-0.69, 1.34)
CHW	17.56 (16.58, 18.54)	22.52 (21.70, 23.33)	22.99 (22.23, 23.75)	4.89 (3.96, 5.83)**		5.42 (4.44, 6.39)**	
AE-C	18.53 (17.69, 19.36)	21.70 (20.84, 22.55)	22.57 (21.84, 23.29)	3.17 (2.16, 4.18)**		4.02 (2.99, 5.04)**	
Days of activity limitation, mean ^a (95% CI)					0.63 (0.40, 1.00)		0.58 (0.35, 0.96)*
CHW	3.71 (2.97, 4.45)	1.17 (0.80, 1.55)	1.10 (0.60, 1.59)	0.33 (0.22, 0.48)**		0.29 (0.19, 0.43)**	
AE-C	3.43 (2.70, 4.17)	1.95 (1.32, 2.59)	1.82 (1.27, 2.37)	0.56 (0.38, 0.83)**		0.54 (0.39, 0.76)**	
ED or hospitalizations, OR (95% CI) ^b					0.52 (0.24, 1.10)		0.35 (0.14, 0.88)
CHW	0.42 (0.33, 0.52)	0.13 (0.07, 0.20)	0.07 (0.02, 0.12)	0.18 (0.09, 0.34)		0.08 (0.04, 0.18)	
AE-C	0.50 (0.41, 0.60)	0.21 (0.13, 0.29)	0.16 (0.09, 0.23)	0.24 (0.14, 0.40)		0.17 (0.09, 0.31)	
Urgent care use, OR (95% CI) ^b					0.81 (0.46, 1.45)		0.52 (0.27, 1.01)
CHW	0.62 (0.53, 0.72)	0.37 (0.28, 0.47)	0.17 (0.10, 0.25)	0.34 (0.19, 0.60)		0.12 (0.06, 0.22)	
AE-C	0.61 (0.52, 0.70)	0.41 (0.32, 0.50)	0.28, 0.20, 0.37)	0.42 (0.25, 0.69)		0.23 (0.13, 0.40)	
Oral corticosteroid bursts, OR (95% CI) ^b					0.67 (0.36, 1.26)		0.35 (0.15, 0.81)
CHW	0.56 (0.46, 0.65)	0.26 (0.17, 0.34)	0.10 (0.04, 0.16)	0.23 (0.12, 0.43)		0.07 (0.03, 0.15)	
AE-C	0.69 (0.60, 0.78)	0.32 (0.23, 0.41)	0.22 (0.14, 0.30)	0.18 (0.11, 0.31)		0.10 (0.06, 0.19)	

Note. ACT = Asthma Control Test; AE-C = certified asthma educator; cACT = childhood Asthma Control Test; CHW = community health worker; CI = confidence interval; ED = emergency department; OR = odds ratio. Models control for site, race/ethnicity, age, and seasonality.

^aPercent change over time and intervention difference estimated using negative-binomial modeling. Effect sizes are ratios of days.

^bPredicted probability of outcome estimated by marginal standardization, which allows inference to the overall sample. Effect sizes are ORs.

For ORs, significance indicated by 95% CIs; for means, * $P < .05$; ** $P < .01$.

of telehealth also offers new opportunities for AE-Cs to reach families.

Because behavior change can be a slow process and potentially requires ongoing support, we assessed outcomes following intervention cessation. Asthma control was maintained for 12 months without intervention in both groups. The interventions were designed to strengthen families' skills in using existing clinic and community resources, and our results suggest that this was achieved, especially by CHWs.

This study was designed as a comparative effectiveness trial of 2 interventions, but ultimately ended up testing 3. While the CHW intervention resulted in slightly better asthma control than the AE-C intervention, a meaningful change also appeared to be associated with the data collection process. Although the RAs did not provide direct intervention,

caregivers frequently asked them asthma care questions; RAs would encourage families to speak with their interventionist or physician instead. The RAs asked detailed questions about asthma and caregiver and child mental health, likely raising the families' awareness of these issues. Monthly RA calls were brief, but we suspect the data collection process created strong connections between the RAs and families. A follow-up survey conducted by Erie supported this theory. These data show how the research process itself often influences study outcomes.³³ In-person in-home ongoing asthma and mental health assessments by bicultural, compassionate RAs in the context of access to health care from Erie proved to be a driver of our intervention effects.

These results should also be viewed with an implementation science lens.

By partnering with a community health center, we identified many children with uncontrolled asthma, but most lacked the clinical severity that would typically be encountered in a specialty clinic or ED. This sample is, therefore, more generalizable to urban minority community populations. The uptake of the interventions by providers, staff, and patients was high. When not performing study activities, the AE-C and CHWs quickly became highly valued members of the care teams.

The AE-C in-clinic sessions proved difficult to schedule. Because of clinic rotation, the AE-C was in certain neighborhoods only on specific days, and families found aligning their schedules and physically getting to the clinics challenging. In-home visits by CHWs did not have the same scheduling issues; families accommodated the CHWs and

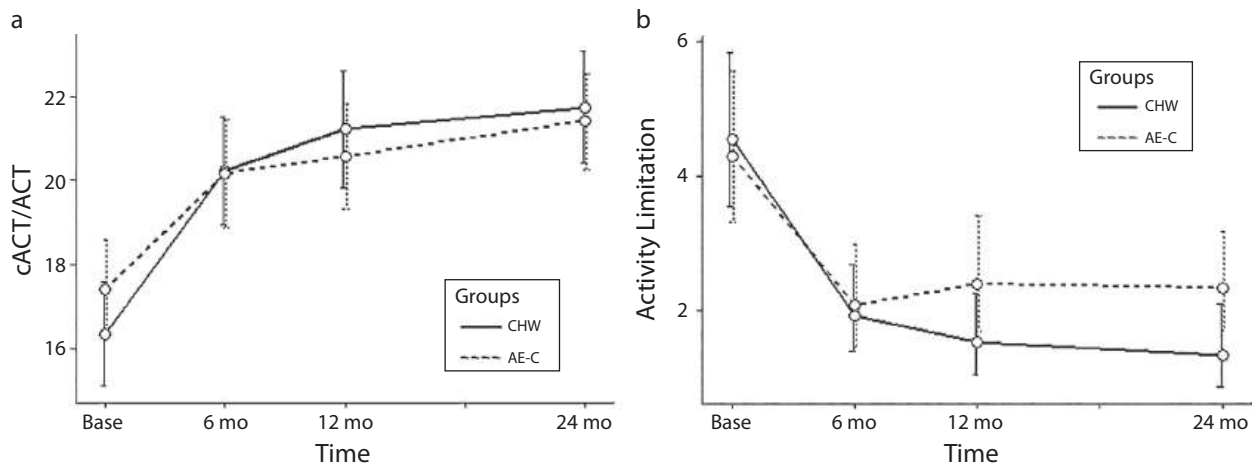


FIGURE 2— Adjusted Models of Asthma Control at Various Timepoints for (a) Asthma Control Test (ACT) or Childhood Asthma Control Test (c-ACT) and (b) Activity Limitation Over Past 14 Days: Cook County, IL, 2016–2018

Note. AE-C = Childhood Asthma Control Test.

appreciated the home visits. To deliver 84 AE-C sessions cost \$11 373 (\$135 per session), and to deliver 722 CHW visits cost \$53 390 (\$74 per visit). These costs are lower than asthma CHW costs published by others.¹¹ When the study ended, Erie internally funded 1 of the asthma interventionists, demonstrating intervention sustainability.

Our results also demonstrated that some families did not need any asthma CHW services to achieve improvements in asthma control, while others needed varying amounts. The amount of CHW visits delivered was often related to social issues limiting family participation. The optimal number of visits to achieve asthma goals, as defined by the family and CHW, was 7 to 10.²¹ Our results suggest a flexible approach to determining the “dose” of CHW intervention, based on family need and individual asthma control.

Limitations

Several additional factors should be considered when one is interpreting these results. Determining asthma

control in research is challenging.¹⁷ Our study used the cACT or ACT because of its clinical utility, although the clinical cut point and minimally important difference we applied were conservative. Other studies with non-White, low-income populations suggest that the cACT or ACT cut point should be higher in these populations and that a minimally important difference of 2 is acceptable.^{34,35} When we repeated analyses with the ACQ, results were similar. Although our health care utilization outcomes were adjudicated (not self-report), overall events were low, and the study was not sufficiently powered for these as outcomes. This was by design, but it does limit comparisons to other studies. The comparative effectiveness design did not include a pure comparison arm, although sufficient research has been conducted with similar populations to suggest the expected trend without intervention.

Public Health Implications

We showed that clinically integrated asthma CHW and AE-C interventions

were associated with meaningful improvements in asthma control even when no environmental remediation equipment was provided. Improvements continued after intervention cessation and were stronger with the CHW intervention. The mechanisms for these changes are unclear, as some children had improvements even without receiving intervention. It is possible that just sharing health information with culturally sensitive compassionate individuals in the home setting may have its own impact on asthma control. Health systems deciding between CHW and AE-C interventions now face a complicated cost comparison. CHWs typically cost less to employ than AE-Cs and have been shown to have significant returns on investments.¹¹ Our AE-C intervention cost less to deliver than the CHW intervention, but that was because of low participation in the AE-C group. We also saw an effect of the data collection protocol itself.

Future research and policy efforts should use implementation science methods to support health systems to determine how and when to apply

these interventions. In populations experiencing health disparities, perhaps one-on-one basic asthma and behavioral health screening from a general CHW followed by social support is a sufficient starting point. CHW intervention could then be appropriately scaled; individuals with more difficult social or clinical challenges could receive additional visits with asthma interventionists (CHW or AE-C) or be transferred to the appropriate teams (medical, behavioral health, or social work). Overall, CHWs and AE-Cs offer the potential to improve asthma care, and more work is needed to fully optimize the use of these strategies. *AJPH*

ABOUT THE AUTHORS

Molly A. Martin is with the Department of Pediatrics and the Institute for Health and Research Policy at the University of Illinois at Chicago. Oksana Pugach and Genesis Rosales are with the Institute for Health and Research Policy at the University of Illinois at Chicago. Giselle Mosnaim is with Northshore University Health System, Evanston, IL. Sally Weinstein is with the Department of Psychiatry at the University of Illinois at Chicago. Angkana Roy is with Erie Family Health Center, Chicago. Andrea A. Pappalardo is with the Department of Pediatrics at the University of Illinois at Chicago. Surrey Walton is with the College of Pharmacy at the University of Illinois at Chicago.

CORRESPONDENCE

Correspondence should be sent to Molly A. Martin, MD, MAPP, University of Illinois at Chicago, Department of Pediatrics, 840 South Wood St, M/C 856, Chicago, IL 60612 (e-mail: mollyma@uic.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Martin MA, Pugach O, Mosnaim G, et al. Community health worker asthma interventions for children: results from a clinically integrated randomized comparative effectiveness trial (2016–2019). *Am J Public Health*. 2021;111(7):1328–1337.

Acceptance Date: March 6, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306272>

CONTRIBUTORS

M. A. Martin led the study design and implementation and wrote the primary article draft. O. Pugach, G. Mosnaim, S. Weinstein, A. Roy, and S. Walton participated in study design, implementation, and article preparation. G. Rosales led data

collection and supported the article preparation. A. A. Pappalardo participated in analyses and article preparation. All authors contributed to the article and approved the final version.

ACKNOWLEDGMENTS

This study was funded by the National Institutes of Health, National Heart, Lung, and Blood Institute (R01HL123797).

We want to recognize the Asthma Action at Erie investigators and staff that are not authors: Gizelle Alvarez, Michael Berbaum, Hannah Chi, Daisy Cintron, Andrea Fragoso, Denise Guerrero, Melissa Hernandez-Contreras, Jazmin Morales, Steven Rothschild, Anna Sandoval, and Nattant Songthangtham. The Chicago Asthma Consortium Asthma Community Advisory Board provides oversight for the study. We would like to thank everyone at Erie Family Health Center. This includes medical directors, providers, and staff at the West Town Health Center, Evanston/Skokie Health Center, Erie Helping Hands Health Center, Erie Humboldt Park Health Center, Erie Westside Health Center at Laura S. Ward Elementary School, and Erie Johnson School-Based Health Center. Finally, we would like to thank all the families who made this research possible.

CONFLICTS OF INTEREST

G. Mosnaim has received research grant support from AstraZeneca, GlaxoSmithKline, and Propeller Health; has owned stock in Electrocore; and has served as a consultant or member of a scientific advisory board for GlaxoSmithKline, Sanofi-Regeneron, Teva, Novartis, Astra Zeneca, Boehringer Ingelheim, and Propeller Health. A. A. Pappalardo is a consultant for Optum Rx/United Health Group and had a relationship ending in 2017 as a speaker for Boehringer Ingelheim. M. A. Martin and A. A. Pappalardo are on the board of directors of the Chicago Asthma Consortium.

HUMAN PARTICIPANT PROTECTION

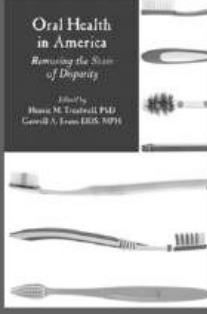
Institutional review boards at the University of Illinois at Chicago, Rush University Medical Center, and Northshore University HealthSystem approved the study protocol. Children older than 7 years and caregivers provided written signed assent and consent, respectively.

REFERENCES

1. Moorman JE, Akinbami LJ, Bailey CM, et al. National surveillance of asthma: United States, 2001–2010. *Vital Health Stat* 3. 2012;(35):1–58.
2. National Asthma Education and Prevention Program, Third Expert Panel on the Diagnosis and Management of Asthma. Expert Panel Report 3: Guidelines for the diagnosis and management of asthma. Bethesda, MD: National Heart, Lung, and Blood Institute; 2007.
3. American Lung Association. Asthma and children fact sheet. 2017. Available at: <https://www.lung.org/lung-health-diseases/lung-disease-lookup/asthma/learn-about-asthma/asthma-children-facts-sheet>. Accessed August 5, 2020.

4. Cloutier MM, Hall CB, Wakefield DB, Balit H. Use of asthma guidelines by primary care providers to reduce hospitalizations and emergency department visits in poor, minority, urban children. *J Pediatr*. 2005;146(5):591–597. <https://doi.org/10.1016/j.jpeds.2004.12.017>
5. Weiss KB, Shannon JJ, Sadowski LS, et al. The burden of asthma in the Chicago community fifteen years after the availability of national asthma guidelines: the design and initial results from the CHIRAH study. *Contemp Clin Trials*. 2009;30(3):246–255. <https://doi.org/10.1016/j.cct.2009.01.006>
6. Akinbami LJ, Moorman JE, Bailey C, et al. Trends in asthma prevalence, health care use, and mortality in the United States, 2001–2010. *NCHS Data Brief*. 2012;(94):1–8.
7. Gupta RS, Rivkina V, DeSantiago-Cardenas L, Smith B, Harvey-Gintoft B, Whyte SA. Asthma and food allergy management in Chicago public schools. *Pediatrics*. 2014;134(4):729–736. <https://doi.org/10.1542/peds.2014.0402>
8. Martin MA, Kapheim MG, Erwin K, et al. Childhood asthma disparities in Chicago: developing approaches to health inequities. *Fam Community Health*. 2018;41(3):135–145. <https://doi.org/10.1097/FCH.000000000000187>
9. Cataletto C, Abramson S, Meyerson K, et al; on behalf of the Board of Directors of the National Asthma Educator Certification Board. The certified asthma educator: the United States experience. *Pediatr Allergy Immunol Pulmonol*. 2011;24(3):159–163. <https://doi.org/10.1089/ped.2011.0083>
10. American Public Health Association Community Health Worker Section. Community health workers. Available at: <https://www.apha.org/apha-communities/member-sections/community-health-workers>. Accessed August 5, 2020.
11. Campbell JD, Brooks M, Hosokawa P, Robinson J, Song L, Krieger J. Community health worker home visits for Medicaid-enrolled children with asthma: effects on asthma outcomes and costs. *Am J Public Health*. 2015;105(11):2366–2372. <https://doi.org/10.2105/AJPH.2015.302685>
12. Postma J, Karr C, Kieckhefer G. Community health workers and environmental interventions for children with asthma: a systematic review. *J Asthma*. 2009;46(6):564–576. <https://doi.org/10.1080/02770900902912638>
13. Crocker DD, Kinyota S, Dumitru GG, et al. Effectiveness of home-based, multi-trigger, multicomponent interventions with an environmental focus for reducing asthma morbidity: a community guide systematic review. *Am J Prev Med*. 2011;41(2, suppl 1):S5–S32. <https://doi.org/10.1016/j.amepre.2011.05.012>
14. Krieger JW, Takaro TK, Song L, Weaver M. The Seattle-King County Healthy Homes Project: a randomized, controlled trial of a community health worker intervention to decrease exposure to indoor asthma triggers. *Am J Public Health*. 2005;95(4):652–659. <https://doi.org/10.2105/AJPH.2004.042994>
15. Morgan WJ, Crain EF, Gruchalla RS, et al. Results of a home-based environmental intervention among urban children with asthma. *N Engl J Med*. 2004;351(11):1068–1080. <https://doi.org/10.1056/NEJMoa032097>
16. Mosnaim GS, Weinstein SM, Pugach O, et al. Design and baseline characteristics of a low-income urban cohort of children with asthma:

- the Asthma Action at Erie Trial. *Contemp Clin Trials*. 2019;79:55–65. <https://doi.org/10.1016/j.cct.2019.02.006>
17. Cloutier MM, Schatz M, Castro M, et al. Asthma outcomes: composite scores of asthma control. *J Allergy Clin Immunol*. 2012;129(3, suppl):S24–S33. <https://doi.org/10.1016/j.jaci.2011.12.980>
 18. Liu AH, Zeiger R, Sorkness C, et al. Development and cross-sectional validation of the Childhood Asthma Control Test. *J Allergy Clin Immunol*. 2007;119(4):817–825. <https://doi.org/10.1016/j.jaci.2006.12.662>
 19. Nguyen JM, Holbrook J, Wei CY, Gerald LB, Teague WG, Wise RA, on behalf of the American Lung Association Asthma Clinical Research Centers. Validation and psychometric properties of the Asthma Control Questionnaire among children. *J Allergy Clin Immunol*. 2014;133(1):91–97.e1–6. <https://doi.org/10.1016/j.jaci.2013.06.029>
 20. Schatz M, Sorkness CA, Li JT, et al. Asthma Control Test: reliability, validity, and responsiveness in patients not previously followed by asthma specialists. *J Allergy Clin Immunol*. 2006;117(3):549–556. <https://doi.org/10.1016/j.jaci.2006.01.011>
 21. Martin MA, Bisarini R, Roy A, et al. Implementation lessons from a randomized trial integrating community asthma education for children. *J Ambul Care Manage*. 2020;43(2):125–135. <https://doi.org/10.1097/JAC.0000000000000326>
 22. Martin MA, Floyd EC, Nixon SK, Villalpando S, Shalowitz M, Lynch E. Asthma in children with comorbid obesity: intervention development in a high-risk urban community. *Health Promot Pract*. 2016;17(6):880–890. <https://doi.org/10.1177/1524839916652845>
 23. Schatz M, Kosinski M, Yarlas AS, Hanlon J, Watson ME, Jhingran P. The minimally important difference of the Asthma Control Test. *J Allergy Clin Immunol*. 2009;124(4):719–723.e1. <https://doi.org/10.1016/j.jaci.2009.06.053>
 24. Zeiger RS, Yegin A, Simons FE, et al. Evaluation of the National Heart, Lung, and Blood Institute guidelines impairment domain for classifying asthma control and predicting asthma exacerbations. *Ann Allergy Asthma Immunol*. 2012;108(2):81–87. <https://doi.org/10.1016/j.anai.2011.12.001>
 25. Fitzmaurice G, Davidian M, Verbeke G, Molenberghs G. *Longitudinal Data Analysis*. Boca Raton, FL: Chapman & Hall/CRC; 2009.
 26. Morey RD. Confidence intervals from normalized data: a correction to Cousineau (2005). *Reason*. 2008;4(2):61–64. <https://doi.org/10.20982/tqmp.04.2.p061>
 27. Weinstein SM, Pugh O, Rosales G, Mosnaim GS, Walton SM, Martin MA. Family chaos and asthma control. *Pediatrics*. 2019;144(2):e20182758. <https://doi.org/10.1542/peds.2018-2758>
 28. Greenwald R, Rubin A. Assessment of posttraumatic symptoms in children: development and preliminary validation of parent and child scales. *Res Soc Work Pract*. 1999;9(1):61–75. <https://doi.org/10.1177/104973159900900105>
 29. Gardner A, Kaplan B, Brown W, et al. National standards for asthma self-management education. *Ann Allergy Asthma Immunol*. 2015;114(3):178–186.e1. <https://doi.org/10.1016/j.anai.2014.12.014>
 30. Wang L, Timmer S, Rosenman K. Assessment of a university-based outpatient asthma education program for children. *J Pediatr Health Care*. 2020;34(2):128–135. <https://doi.org/10.1016/j.pedhc.2019.09.004>
 31. Rapp KI, Jack L, Wilson C, et al. Improving asthma-related outcomes among children participating in the Head-off Environmental Asthma in Louisiana (HEAL), phase II study. *Health Promot Pract*. 2018;19(2):233–239. <https://doi.org/10.1177/1524839917740126>
 32. Abraham TG, Huggins C, Diaz-Fuentes G, Roglieri J. Combining pharmacy expertise with asthma educator certification: assessing the impact on inner-city asthma patients. *J Asthma*. 2019;56(8):891–896. <https://doi.org/10.1080/02770903.2018.1501697>
 33. Luc F, Prieur E, Whitmore GA, Gibson PG, Vandemheen KL, Aaron SD. Placebo effects in clinical trials evaluating patients with uncontrolled persistent asthma. *Ann Am Thorac Soc*. 2019;16(9):1124–1130. <https://doi.org/10.1513/AnnalsATS.201901-071OC>
 34. Bime C, Gerald JK, Wei CY, et al. Measurement characteristics of the childhood Asthma-Control Test and a shortened, child-only version. *NPJ Prim Care Respir Med*. 2016;26(1):16075. <https://doi.org/10.1038/npjpcrm.2016.75>
 35. Shi Y, Tatavoosian AV, Aledia AS, George SC, Galant SP. Cut points for Asthma Control Tests in Mexican children in Orange County, California. *Ann Allergy Asthma Immunol*. 2012;109(2):108–113. <https://doi.org/10.1016/j.anai.2012.06.002>



Oral Health in America: Removing the Stain of Disparity

Edited by: *Henrie M. Treadwell, PhD*
and *Caswell A. Evans, DDS, MPH*

Oral Health in America details inequities to an oral health care system that disproportionately affects the poor, those without insurance, underrepresented and underserved communities, the disabled, and senior citizens. This book addresses issues in workforce development including the use of dental therapists, the rationale for the development of racially/ethnically diverse providers, and the lack of public support through Medicaid, which would guarantee access and also provide a rationale for building a system, one that takes into account the impact of a lack of visionary and inclusive leadership on the nation's ability to insure health justice for all.

Place orders at aphabookstore.org. Email bookstoreservices@apha.org to request exam copy for classroom use.

ISBN: 978-087553-3056 2019, Softcover List Price: \$30 APHA Member Price: \$21

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Monitoring Self-Perceived Occupational Health Inequities in Central America, 2011 and 2018

Michael Silva-Peñaherrera, PhD, David Gimeno Ruiz de Porras, PhD, George L. Delclos, PhD, Marianela Rojas Garbanzo, PhD, Pamela Merino-Salazar, PhD, Maria Lopez-Ruiz, PhD, and Fernando G. Benavides, PhD

 See also Siqueira, p. 1197.

Objectives. To analyze changes in occupational health inequity between 2011 and 2018 among workers in Central America.

Methods. Data were collected by face-to-face interviews at the workers' homes for the 2 Central America Working Conditions Surveys (n = 12 024 in 2011 and n = 9030 in 2018). We estimated health inequity gaps by means of absolute and relative population attributable risks and the weighted Keppel index. We stratified all analyses by gender.

Results. Between 2011 and 2018, the proportion of workers reporting poor self-perceived health decreased both in women (from 32% to 29%) and men (from 33% to 30%). However, the health inequity gaps remained wide in the 4 stratifiers. Measured by the Keppel index, health inequity gaps between countries increased from 22% to 39% in women and from 20% to 29% in men.

Conclusions. While health improved between 2011 and 2018, health inequity gaps remained wide. Wider health inequity gaps were observed between countries than by gender, age, occupation, or education.

Public Health Implications. This first benchmark of occupational health inequities in Central America could be useful when developing and evaluating the impact of public policies on work. (*Am J Public Health*. 2021;111(7):1338–1347. <https://doi.org/10.2105/AJPH.2021.306276>)

Health equity, a key goal of the United Nations' 2030 Agenda for Sustainable Development Goals, is a basic condition of social justice that allows other human rights to be achieved.¹ Health inequities are systematic differences in health status that are also deemed unjust or unfair because of socially determined circumstances.² Wealth distribution varies for each world's region, with Central America being the most inequitable and one of the world's fastest-growing workforces together with the rest of Latin America.³ Most people in Central America face

many challenges to overcome the social and economic vulnerability they experience. Common challenges are the lack of economies of scale in production, proneness to external financial shocks, limited transport and communications infrastructure, and high levels of emigration of skilled individuals to North America or Europe.⁴ Furthermore, the population's health in the Central American region is negatively affected by weak social protection systems, inadequate access to health care, and migration patterns that disrupt family and social network caregiving structures.⁵

Paid work is the primary source of income for the majority of the adult population and, in most countries, work provides access to social protections such as unemployment or health insurance covering work-related ill health, injury, or disability.^{6,7} As such, paid work is an important determinant of population health as well as health inequity.⁸ Employment conditions such as the contract type (e.g., permanent, temporary, or without contract), the salary level, or worker participation tend to determine a worker's income level and her or his place in the social

hierarchy. Working conditions related to the work environment, specific job tasks, or psychosocial conditions also affect workers' health. Both employment and working conditions shape the socioeconomic gradient in health. The social gradient in health refers to health inequities affecting all socioeconomic strata (whether countries or people), with the bottom of the strata having the worst health indicators, and the higher in the socioeconomic hierarchy having better health than those below. This pervasive gradient, which is associated with the circumstances in which people grow, live, work, and age, highlights the role of work and employment as a leading social determinant of health and health inequities.⁹ Therefore, improving employment and working conditions could be one of the most efficient ways to reduce health inequity.

Gender also plays an important role in health inequities, particularly those related to work. While women are joining the worldwide paid labor force at a rapidly growing rate, their participation is driven by more precarious jobs, lower wages, and higher job insecurity than the men.¹⁰

Previous evidence indicates that employment and working conditions and workers' health vary widely across Latin America, particularly in Central America.¹¹ Periodic gathering of reliable, comparable, and high-quality data are basic features of effective surveillance of workers' health.¹² However, a critical obstacle for effective occupational health surveillance and the study of health inequities in Central America is the traditional lack of reliable centralized administrative national data to fully assess the impact of work on health.¹³ This limitation is especially relevant given the predominance of workers in Central America who work under poor employment and hazardous working

conditions, and the high proportion of workers who have informal or precarious employment and lack proper social protections.¹⁴ Informality refers to "informal work"—that is, employment arrangements that do not provide social protection benefits. While informality is a key element when defining precariousness, it is not the defining component based on the conceptualization by the International Labor Organization.¹⁵ In this definition, precarious work also includes type of contract (i.e., temporary arrangements), salary (i.e., lower earnings), and employee empowerment (i.e., lack or low degree of autonomy and control over the work).

To overcome the scarcity of publicly available data, national surveys of employment, working conditions, and health are a crucial source of data. Key examples of such surveys are the ones conducted every 5 years in Europe, which have contributed to policy development on quality of work and employment issues.¹⁶ In Central America, the 2011 and 2018 Central American Working Conditions and Health Surveys (ECCTS, by its Spanish acronym) represent a similar effort among the 6 Spanish-speaking countries of Central America (i.e., all but Belize).¹⁷

Finally, when studying health inequity, one must consider the use of appropriate statistical techniques and specific health indicators. At a minimum, for a health equity metric to be useful for policymaking and research, it should allow comparisons across space (e.g., countries) and time (e.g., years), it must be calculated using publicly available health data (that is, to be transparent and reproducible), and it must include all socially marginalized groups.¹⁸ Transparent and reproducible indicators would provide needed information for policymakers and stakeholders

when prioritizing interventions for the improvement of health conditions and the reduction of social and health inequities.¹⁸ The aim of this study was to analyze 8-year changes in occupational health inequities among workers in Central America according to gender, age, educational level, occupational category, and country of residence.

METHODS

Data for this study were drawn from the 2011 (n = 12 024) and 2018 (n = 9032) ECCTS. The ECCTS is a cross-sectional survey of a nationally representative sample of workers aged 18 years and older, in formal and informal employment from all economic sectors, in the 6 Spanish-speaking Central American countries: Costa Rica, El Salvador, Guatemala, Honduras, Nicaragua, and Panama. Four equity stratifiers were selected: age (asking participants how old they were in years), educational level (asking participants the last year or grade level or level of education that they passed or completed), occupational rank (asking participants what job tasks or duties they usually performed in their job), and country of residence (each of the 6 Spanish-speaking countries in Central America). The questionnaire was administered face to face in interviews at the worker's home. More methodological details are available elsewhere.¹⁹

Health Indicator

The health indicator selected for the examination of health inequity gaps was self-perceived general health (SPGH). SPGH is a well-established measure of health status meeting the previously mentioned attributes of a good health indicator because SPGH was demonstrated to be a reliable,

valid, simple, and cost-effective health measure.²⁰ In both ECCTS, SPGH was measured by asking the participants the question: “In general, how do you consider your health status to be?” To answer the question, participants could select 1 of the 5 following options: very good, good, fair, poor, or very poor. Responses were dichotomized into “good” (options very good and good) and “poor” (fair, poor, and very poor).

Equity Stratifiers

Age was grouped into 18 to 24 years, 25 to 44 years, 45 to 64 years, and 65 years and older. Educational level was grouped into “low” (elementary school or less), “middle” (high school), and “high” (more than high school). Data on occupation were first coded into the 9 major occupational categories of the International Standard Classification of Occupations²¹ and then collapsed into “skilled nonmanual” (managers, professionals, technicians, and associate professionals), “nonskilled nonmanual” (clerical support workers, service workers, and sales workers), “skilled manual” (skilled agricultural, forestry, and fishery workers; craft and related trades workers; plant and machine operators; and assemblers), and “nonskilled manual” (elementary occupations).

Inequity Measures and Data Analysis

First, we calculated the prevalence of poor SPGH and the corresponding 95% confidence intervals (CIs) for each category of the 4 equity stratifiers and, as appropriate, by country. Survey-specific (2011 or 2018) sample weights by gender, age, and industrial sector were applied to region (all countries combined) and country-specific data. We assessed differences in the prevalence of

poor SPGH between 2011 and 2018 with the χ^2 statistic. We conducted all analyses separately for women and men.

Next, we calculated both the absolute (population-attributable risk [PAR]) and relative (PAR%) differences between the prevalence of poor SPGH in the healthiest group and the country's mean, respectively. The absolute PAR indicates the percentage of workers that would not have reported poor SPGH if the entire working population had the prevalence of poor SPGH of the most privileged group. We calculated the relative PAR% by dividing the country's PAR by the country's mean and multiplying the result by 100. Absolute and relative inequity measures are complementary measures, so both metrics should be reported to make comparisons between indicators easy.²² A higher PAR or PAR% indicates more inequity.

In addition, we estimated the Keppel index,²³ which indicates the relative inequity among groups within each equity stratifier (e.g., age groups). When taking into account the size of the group, the result is the weighted Keppel index. In our study, the Keppel index indicated the spread of the prevalence of poor SPGH of each equity stratifier in relation to the country's average. To obtain this index, we multiplied the relative population weight of each group in the category of interest by the absolute difference between the prevalence of poor SPGH of each group and the country's mean. We then divided the sum of these weighted differences by the country's prevalence of poor SPGH and multiplied by 100.²⁴ A low Keppel index indicates that, on average, the health of the groups is close to the country's mean. A high index indicates more inequity—that is, the prevalence of poor SPGH is more spread out among the groups. For each of the

monitoring variables examined (i.e., age, education, and occupation), we selected the group with the lowest prevalence as the reference groups against which we can compare the other groups to ensure that the metrics would fall in the conventional positive range.²² To assess health inequity between countries, the reference was the combined prevalence of SPGH in Central America.

RESULTS

Between 2011 and 2018, the prevalence of poor SPGH in the Central America region decreased from 34% (95% CI = 32.7%, 35.3%) to 29% (95% CI = 27.5%, 30.5%) in women, and from 33% (95% CI = 31.9%, 34.1%) to 30% (95% CI = 28.7%, 31.1%) in men (Table 1). The prevalence of poor SPGH was lower in younger workers and in the highest occupational rank and educational group and increased with older age, lower occupational rank, and lower educational level. There were also large differences between countries; Figure 1 shows country differences stratified by occupation. Between 2011 and 2018, workers' health status improved in Guatemala for both genders and in El Salvador for men but worsened in Panama for both genders. In Costa Rica and Honduras, the SPGH in men overall worsened between 2011 and 2018. However, in Costa Rica, the differences were only for manual skilled workers. In Honduras, there was a worsening of SPGH prevalence in the group aged 25 to 64 years, in low educational level, and in manual nonskilled workers.

In both years, the overall prevalence of poor SPGH was higher in women than in men in all countries except Guatemala and Honduras. The prevalence of poor SPGH in 2011 ranged from 14.3% in men in Panama to 51.1%

TABLE 1— Prevalence of Poor Self-Perceived General Health (%) by Gender, Age, Educational Level, and Occupational Categories: Central American Countries, 2011 and 2018

	Costa Rica		El Salvador		Guatemala		Honduras		Nicaragua		Panama		Central America	
	2011	2018	2011	2018	2011	2018	2011	2018	2011	2018	2011	2018	2011	2018
Women														
Overall	23.5	27.8	30.1	31.4	32.6	19.6**	36.9	43.2	51.1	48.0	14.3	30.1**	34.0	29.0**
Age groups, y														
18–24	16.9	11.1	17.9	11.4	22.9	15.5	12.6	35.4**	27.3	35.5	8.1	13.8	20.0	19.1
25–44	18.2	21.3	25.7	26.1	29.4	15.4**	32.8	38.6	47.2	45.1	8.1	27.9**	29.9	26.6
45–64	35.4	41.0	45.7	35.6	50.0	33.6	53.5	56.2	70.9	60.3	32.5	38.6	51.1	41.8**
≥ 65	41.2	46.7	100.0	51.6	73.3	36.7	63.0	79.2	76.5	75.0	62.5	71.4	66.4	48.9*
Educational level														
High	20.3	20.5	13.1	24.0	23.3	11.9	20.0	20.3	34.4	33.0	9.4	25.6**	23.3	20.8**
Middle	17.2	25.6	24.4	24.9	22.7	17.1	26.8	30.9	52.0	44.0	12.5	25.0**	27.3	24.7**
Low	32.7	34.5	38.8	39.1	41.2	22.5**	45.9	55.3**	64.3	58.8	37.3	54.9	44.0	34.9**
Occupational categories														
Nonmanual skilled	21.4	13.6	19.0	36.4	25.0	13.3	16.3	37.2	44.8	37.9	16.4	24.7	29.5	23.6
Nonmanual nonskilled	23.4	28.6	29.2	26.8	31.5	16.1**	39.4	42.9	52.7	44.9	12.0	23.7**	34.0	24.5**
Manual skilled	28.4	32.2	34.4	33.3	36.8	27.2	41.1	43.9	53.1	59.9	18.4	43.4**	37.8	35.7
Manual nonskilled	20.7	27.5	31.6	40.4	20.6	12.7	22.2	44.4*	51.8	40.0	20.0	35.5	28.8	30.3
Men														
Overall	19.8	25.5*	31.8	26.8*	35.9	24.3**	35.1	43.8**	47.0	43.4	14.3	22.9**	33.0	29.9**
Age groups, y														
18–24	8.9	16.3	13.6	11.5	25.1	18.5	20.6	18.8	38.5	27.6	6.8	11.8	22.8	19.1
25–44	14.6	16.6	26.0	21.2	28.8	17.5**	29.2	38.8*	41.5	41.7	7.2	16.4**	26.4	25.4
45–64	29.4	35.8	43.5	26.2**	51.1	32.5**	48.7	61.4*	59.0	59.0	26.8	32.0	45.1	38.0**
≥ 65	37.1	35.1	25.0	45.8	71.0	50.0	62.2	75.0	72.6	70.8	65.6	57.1	63.9	51.6**
Educational level														
High	7.3	9.7	17.9	10.0	18.2	7.2	19.3	26.8	35.7	31.7	9.9	16.3	18.5	16.4
Middle	17.3	18.6	24.7	23.2	28.0	16.0**	24.0	24.2	36.6	37.1	10.8	16.1*	24.0	21.8
Low	25.9	32.1	40.9	32.6*	41.0	31.2**	40.6	53.7**	57.9	51.5	34.9	38.5	41.5	37.5**
Occupational categories														
Nonmanual skilled	8.7	13.6	21.5	11.1	25.5	6.0*	10.0	23.6	37.5	30.0	8.1	16.7	18.9	14.7
Nonmanual nonskilled	18.4	17.4	25.1	32.4	26.0	13.0**	30.7	33.7	38.7	36.4	12.7	25.2**	25.7	21.0*
Manual skilled	22.4	33.7**	38.3	25.6**	39.3	30.0**	40.0	47.1	51.3	45.3	17.7	24.1*	38.2	32.9**
Manual nonskilled	22.7	19.0	17.4	32.3	41.7	23.6	28.2	45.6*	38.5	46.1	12.4	20.2	28.2	33.3

* $\chi^2 P < .01$; ** $\chi^2 P < .001$.

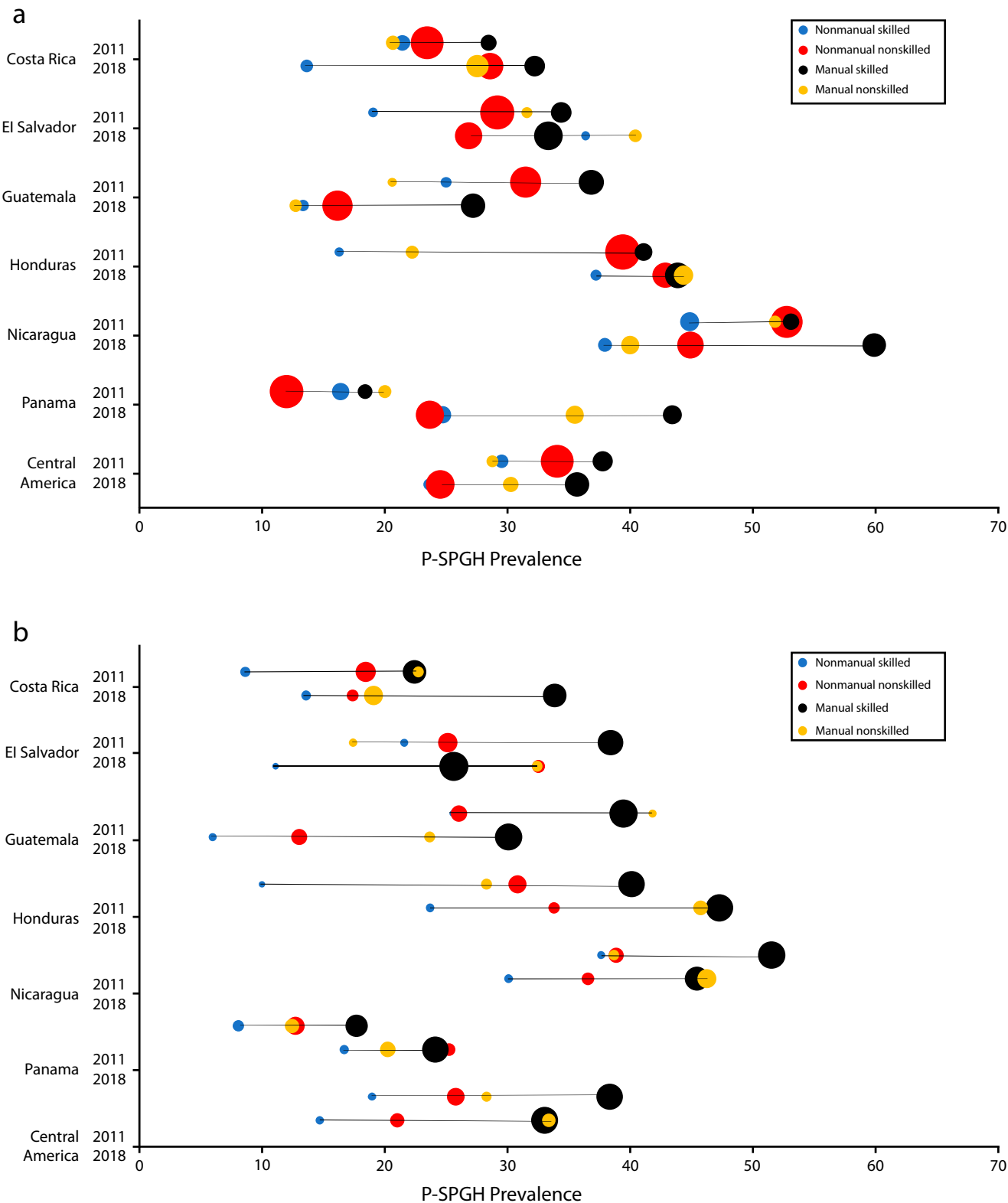


FIGURE 1— Prevalence of Poor Self-Perceived General Health (P-SPGH) by Occupational Categories and Country of Residence for (a) Women and (b) Men: Central American Countries, 2011 and 2018

TABLE 2— Inequities in Self-Perceived General Health (SPGH; %) by Gender, Age, Educational Level, and Occupational Categories: Central American Countries, 2011 and 2018

	Population Attributable Risk (Absolute)		Population Attributable Risk (Relative %)		Keppel Index	
	2011	2018	2011	2018	2011	2018
Women						
Age groups						
Costa Rica	6.6	16.7	28.1	60.0	32.9	37.2
El Salvador	12.2	20.1	40.4	63.8	27.7	25.6
Guatemala	9.6	4.1	29.6	20.9	25.1	32.9
Honduras	24.3	7.8	65.9	18.1	31.3	19.9
Nicaragua	23.8	12.5	46.5	26.0	22.0	15.5
Panama	6.2	16.3	43.4	54.3	66.8	24.5
Central America	13.9	9.9	41.0	34.2	28.3	27.2
Educational level						
Costa Rica	3.2	7.3	13.8	26.3	29.0	16.7
El Salvador	17.0	7.4	56.5	23.6	27.5	22.7
Guatemala	9.3	7.6	28.6	38.9	28.2	16.4
Honduras	16.9	22.8	45.8	52.9	26.8	30.5
Nicaragua	16.8	15.0	32.8	31.2	17.2	18.5
Panama	4.9	4.5	34.4	14.8	33.1	26.9
Central America	10.7	8.2	31.4	28.4	25.5	19.2
Occupational categories						
Costa Rica	2.1	14.1	8.8	50.9	3.9	9.7
El Salvador	11.0	-4.9	36.7	-15.7	7.5	12.1
Guatemala	7.6	6.2	23.2	31.8	9.6	27.1
Honduras	20.6	6.0	55.9	13.8	13.1	2.4
Nicaragua	6.3	10.0	12.3	20.9	4.9	15.5
Panama	-2.1	5.4	-14.8	17.9	19.5	24.6
Central America	4.5	5.3	13.2	18.4	5.1	16.8
Inequality among countries					22.0	39.2
Men						
Costa Rica	11.0	9.3	55.4	36.3	41.5	37.2
El Salvador	18.3	15.3	57.4	57.0	30.6	29.4
Guatemala	10.8	5.7	30.2	23.6	32.2	33.9
Honduras	14.5	25.0	41.3	57.1	30.8	35.8
Nicaragua	8.4	15.8	17.9	36.5	18.9	19.1
Panama	7.5	11.2	52.3	48.7	68.7	42.3
Central America	10.2	10.8	30.8	36.0	30.3	28.0
Educational level						
Costa Rica	12.5	15.9	63.1	62.1	26.7	29.6
El Salvador	13.9	16.8	43.7	62.6	27.3	21.5
Guatemala	17.7	17.0	49.4	70.2	18.1	33.6
Honduras	15.8	17.0	45.0	38.7	21.5	29.8
Nicaragua	11.3	11.7	24.1	26.9	22.8	18.4

Continued

in women in Nicaragua. In 2018, it ranged from 19.6% in women in Guatemala to 48% in Nicaragua in women.

Considering the absolute (PAR) and relative (PAR%) differences between the healthier category and the country's mean, in general, the PAR in the region was quite similar in both surveys in men and for the 4 stratifiers. The PAR% was higher in 2018 in Guatemala and El Salvador by both occupational rank and educational level. In women, for Central America as a whole, both the PAR and the PAR% increased from 2011 to 2018 by occupational rank and decreased by educational level. Both the PAR and the PAR% inequity gap by occupational rank and educational level were always higher in men than in women (Table 2).

In general, as indicated by the within-country Keppel index (Table 2), the 2011 health gaps in the 4 equity stratifiers remained high in 2018. In both years, the widest gap was found among age groups, followed by educational levels and occupational categories. Between 2011 and 2018, the health inequity gaps became wider (from 5.1% to 16.8%) among women by occupational rank in all the countries, but in Honduras, the gap by educational level decreased from 25.5% to 19.2%. In men, the gaps for the whole region decreased slightly by occupational rank from 18.8% to 16.6%. Yet, in Costa Rica and Guatemala, the gaps increased. Finally, the Keppel index between countries (Table 2) indicates an increase from the 2011 to the 2018 survey from 22% to 39% in women, and from 20% to 29% in men.

DISCUSSION

The overwhelming finding, with few exceptions, is that health inequity gaps by occupation and education seem to

TABLE 2— Continued

	Population Attributable Risk (Absolute)		Population Attributable Risk (Relative %)		Keppel Index	
	2011	2018	2011	2018	2011	2018
Panama	4.4	6.6	30.7	28.9	43.4	41.2
Central America	14.4	13.4	43.7	45.0	27.9	27.8
Occupational categories						
Costa Rica	11.2	12.0	56.4	46.8	14.8	31.2
El Salvador	10.3	15.7	32.4	58.5	22.7	10.5
Guatemala	10.4	18.3	29.0	75.3	14.7	29.3
Honduras	25.1	20.2	71.5	46.0	16.1	11.0
Nicaragua	9.5	13.4	20.1	30.8	12.3	8.1
Panama	6.2	6.3	43.4	27.3	20.3	8.6
Central America	14.0	15.2	42.6	50.9	18.8	16.0
Inequality among countries					20.1	29.4

Note. Weight Keppel index of disparity = $\left(\sum |r_{(1-n)} - R| * w\right) / R * 100$ where r = group poor SPGH prevalence; R = country poor SPGH prevalence; and w = weight of the group with respect to the country's population.

have worsened between 2011 and 2018, or at least remained at the same levels. Age tends to display a similar pattern, but it is less clear in women. Importantly, this widening of health inequity gaps has occurred despite a general pattern of improvement in perceived health status among workers in Central America between 2011 and 2018. Overall, the inequity gaps remain high in Central America, and there was no indication of progress in closing the health gaps within countries between 2011 and 2018. In fact, the health gaps among countries grew significantly in both women and men between 2011 and 2018. Only for men in El Salvador and for both men and women in Guatemala we observed statistically significant reductions in the prevalence of poor SPGH.

The apparent divergence between region and country-specific (e.g., Guatemala) health patterns could be explained because Guatemala represents almost 40% of the total

population in the region (17.2 million out of 48.8 million),²⁵ contributing significantly to the regional improvement. Guatemala, with the lowest prevalence of poor SPGH in the region in 2018, showed a significant reduction in the prevalence of poor SPGH, which is further supported by the fastest reduction in the adult mortality rate since 2000 in the region, with an annual average decrease of 4.5%.²⁶ In addition, this reduction in poor SPGH could be attributable to improvements, especially in the health of the indigenous population, which represents approximately 60% of the Guatemalan population. Many strategies have been proposed to reduce inequity in health among indigenous populations as the creation of the health care unit for the indigenous and interculturality in 2009, and the inclusion of the popular, alternative, and traditional medicine program.²⁷ Guatemala implemented a quality management health system in 2010 designed to improve health services.²⁸

However, the health and social gap is still marked among social groups.²⁹ Further research is needed to assess this improvement in population's health in Guatemala.

When we analyzed absolute (PAR) and relative (Keppel index and PAR%) differences in the prevalence of poor SPGH, we found that in the countries where poor SPGH decreased (e.g., Guatemala) the relative inequity gap grew, whereas in countries where poor SPGH increased (e.g., Panama) the inequity relative gap decreased; in both cases the absolute gap remained almost the same. The prevalence of poor SPGH in Panama in 2011 was the lowest in Central America. And, while in 2018 the prevalence of SPGH almost doubled in both genders, the absolute inequity (PAR) was similar in both years and for groups. These results could be explained because the absolute gap between the best health group and the country's mean remained stable over time, with no progress in reducing this gap among different groups, whereas the relative gap is affected by an increase or decrease of the country's mean. This result reaffirms the importance of measuring both absolute and relative inequity.²² The PAR% shows that, in 2018, around 51% and 18% of reports of poor SPGH in men and women, respectively, could be avoided if their working and employment conditions were similar to those of nonmanual skilled workers, and around 45% of men and 28% of women if all workers achieved a high level of education.

The health gaps among countries grew significantly in both women and men between 2011 and 2018. This increase in the Keppel index suggests that the prevalence of poor SPGH in the 6 countries is more spread out in 2018 than in 2011, with respect to the Central

American mean. This could be a consequence of the improvement of worker health in some countries, such as Guatemala and El Salvador, versus the deterioration of health in the others.

The variation in magnitude of the Keppel index among countries is even larger than those associated with gender, education level, or occupational rank within countries. A similar result was also found in a recent analytical cross-sectional study done by our group that included 15 Latin American and Caribbean countries, where country borders seem to be the most important source of difference when examining health inequities.³⁰ A possible explanation could be related to international differences in regulations that expose workers to poorer working and employment conditions, with a high proportion of jobs in the informal economy, with high levels of employment precarity.

In addition, some differences among countries could be attributable to cultural factors reflecting values, beliefs, and expectations regarding poor health.³¹ However, these cultural differences should not have affected the increase in gaps among countries, as these same factors were likely present and similar in both surveys. In summary, our results suggest that the country where people work is more important, as a determinant of workers' general health, than age, education, or occupation.

Our results regarding occupation inequities are to be interpreted taking into account some methodological and conceptual considerations. Within each occupation category, there may be far more heterogeneity than within age and education. Heterogeneity within occupation may relate not only to differences in the type of work (e.g., manual vs nonmanual) but also to its

precariousness levels. Furthermore, specific occupational hazards (e.g., ergonomic or psychosocial factors) may also vary by occupation while contributing to occupational health inequities. Because our interest was to describe inequities by occupational categories, we did not control by potential explanatory factors. Future studies may want to explore how much of the inequities in occupation relate to specific working conditions and their effect on health inequity indices.

Within countries, there was no progress in closing the health gaps among different groups. The magnitude of the weighted Keppel index remains high in most countries, across the 4 equity stratifiers. Actually, this index was significantly higher in 2018 than in 2011 among women by occupational categories in all countries except Honduras. This increase in the gap could be explained in part by the increasing participation of women in the labor market over the past decade, mainly via informal employment. In 45% of cases, this informal employment is involuntarily forced by family constraints.³² Another explanation could be related to changes in the distribution of women across occupational rank. The percentage of women having a manual skilled job in Central America increased from 22% in 2011 to 34% in 2018, whereas nonmanual unskilled jobs decreased from 60% in 2011 to 45% in 2018 (Table A, available as a supplement to the online version of this article at <http://www.ajph.org>). The manual skilled jobs show worse health than nonmanual unskilled jobs; thus, poor health is more spread out among these groups.

In contrast with what was previously reported, we found that, in the whole region, men reported poor SPGH

similar to women's, 33% and 34%, respectively, in 2011, and 30% and 29%, respectively, in 2018.³³ However, this higher prevalence in men was only observed in Guatemala; thus, again, the proportion of the overall study sample reflected by Guatemalans could be influencing the region's average. Men in Guatemala are more likely to have a manual skilled job (around 60% in both 2011 and 2018), and this is the category showing the highest prevalence of poor SPGH. This coincides with a study in Latin American countries that found small differences in SPGH between women and men.³⁴ In addition, although women tended to report worse SPGH than men, the difference disappears when socioeconomic and health covariates are included in the analysis. The same study found no significant differences in tolerance of health problems between women and men, concluding that it is appropriate to compare perceived health by gender.³⁵

Limitations and Strengths

The limitations of this study are mainly related to study design. First, participation was voluntary, and response rates differed by country, which could have introduced selection bias. However, the sampling design, randomization, and use of sampling weights minimize this potential selection bias and increase cross-country comparability. In fact, when we compared our sample with available census data according to gender, age, and sector of economic activity, we found no relevant differences.

Second, the ECCTS includes only workers aged 18 years and older, leaving children and adolescents who may work out of the sample. We used this criterion because 18 years is the legal

age for adulthood in most countries and because, except under specific circumstances and regulations, the employment of children aged younger than 18 years is not legal. In addition, to apply a survey in children aged younger than 18 years, additional permission from their parents or guardians is necessary.

Third, as health status was based on the respondent's self-perception, information bias may be present as it is known that SPGH may be affected by cultural factors and health values,³¹ which could vary from one country to another and within countries, among different social groups. However, SPGH has been repeatedly shown to be a reliable measure of health.²⁰

Our study has several strengths as well. First, the ECCTS provides reliable, updated information, obtained from representative samples of workers in Central America. As such, our findings may be generalized to the adult working population (aged 18 years and older) of the region. In this region, occupational health data are poor and seriously underreported; hence, our survey represents the best available data. Second, this study sheds light on the true magnitude of, and changes in, the inequity gaps in Central American countries in 2 periods of time among different groups. To our knowledge, this is the first study that tracks the changes in inequity in health gaps in a representative sample of workers of Central America. In fact, it provides benchmark surveillance information, underscoring the importance of periodically gathering information to monitor conditions at work, track the progress of programs to reduce inequities, measure the impact of public policies, and identify disadvantaged and vulnerable groups. Finally, and while cross-country

comparisons should always be made with caution, our study provides an opportunity to track differences in Central America using the same questionnaire and data collection strategy in all 6 countries over almost a decade.

Conclusions

Despite all the efforts of the international community to reduce health inequities,³⁶ we found no evidence of progress in closing health inequity gaps in Central America between 2011 and 2018. Instead, inequity among countries grew in the context of improvement in self-reported health. Improving health in the less-favored social groups is essential, especially in those countries with a large percentage of workers with poor SPGH. The COVID-19 pandemic has made obvious the importance of having enough high-quality data to make sound data-driven decisions. The same approach applies to the field of occupational health, which is in need of benchmark surveillance data. Unfortunately, while occupational health monitoring is common in most high-income regions (e.g., the European Union), the situation in Central America would benefit from efforts to create a reliable occupational health monitoring system, an essential tool for making better public policy decisions. Therefore, we suggest that epidemiologists and public health professionals should engage with decisionmakers to seek their support to provide the necessary infrastructure, resources, and a normative body of how to strengthen and broaden occupational surveillance data collection, their correct use, and their proper interpretation. We expect this study will serve as an initial stimulus to foster strong, reliable, and

available national and regional worker health monitoring systems. **AJPH**

ABOUT THE AUTHORS

Michael Silva-Peñaherrera, David Gimeno Ruiz de Porras, George L. Delclos, Maria Lopez-Ruiz, and Fernando G. Benavides are with the Center for Research in Occupational Health, Universitat Pompeu Fabra, Hospital del Mar Medical Research Institute, Network of Biomedical Research Center in Epidemiology and Public Health, Barcelona, Spain. D. Gimeno Ruiz de Porras and G. L. Delclos are also with the Southwest Center for Occupational and Environmental Health, The University of Texas Health Science Center at Houston, School of Public Health, Houston. Marianela Rojas Garbanzo is with the Health, Work and Environment Program in Central America within the Regional Institute for Studies of Toxic Substances, Universidad Nacional, Heredia, Costa Rica. Pamela Merino-Salazar is with the Universidad Internacional SEK, Quito, Ecuador.

CORRESPONDENCE

Correspondence should be sent to Michael Silva-Peñaherrera, Center for Research in Occupational Health, Edificio PRBB, Doctor Aiguader, 88, Barcelona 08003, Spain (e-mail: michael.silvap@gmail.com). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Silva-Peñaherrera M, Gimeno Ruiz de Porras D, Delclos GL, et al. Monitoring self-perceived occupational health inequities in Central America, 2011 and 2018. *Am J Public Health*. 2021;111(7):1338-1347.

Acceptance Date: March 11, 2021

DOI: [10.2105/AJPH.2021.306276](https://doi.org/10.2105/AJPH.2021.306276)

CONTRIBUTORS

M. Silva-Peñaherrera and F. G. Benavides contributed to the conceptualization and design of the study, data analyses, interpretation of data, and drafting of the article. D. Gimeno Ruiz de Porras and G. L. Delclos contributed to the interpretation of results and drafting of the article. M. Rojas Garbanzo, P. Merino-Salazar, and M. Lopez-Ruiz made substantial contributions to the interpretation of results and review of the article. All authors critically revised the article for important intellectual content and final approval of the published version.

ACKNOWLEDGMENTS

This study was partially supported by the Center for Research in Occupational Health, Universitat Pompeu Fabra, Barcelona. D. Gimeno Ruiz de Porras and G. L. Delclos were partly supported by the Southwest Center for Occupational and Environmental Health (SWCOEH), the Centers for Disease Control and Prevention National Institute for Occupational Safety and Health Education and Research Center (grant T42OH008421) at The

University of Texas Health Science Center at Houston (UTHealth) School of Public Health. The second Central American Working Conditions and Health Survey (ECCTS) was partially funded by a Cooperative Agreement (IL-29677-16-75-K-48) between the US Department of Labor Bureau of International Labor Affairs and the SWCOEH at UTHealth School of Public Health (PI: D. Gimeno). The first ECCTS was partially funded by a contract between the Organización Iberoamericana de Seguridad Social and the Universidad Nacional de Costa Rica (Heredia), and also by Fogarty International Center, US National Institutes of Health grant (D4TW00064) to the SWCOEH at UTHealth School of Public Health.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

HUMAN PARTICIPANT PROTECTION

Respondents were informed and gave consent to participate in the survey. Participation was voluntary and anonymous. Both the UTHealth Committee for Protection of Human Subjects (<https://www.uth.edu/cphs>) and the Ethics Committee of the Universidad Nacional in Costa Rica gave their approval for the study protocol.

REFERENCES

- United Nations Development Programme. Sustainable development goals. 2018. Available at: <https://www.undp.org/sustainable-development-goals>. Accessed May 6, 2021.
- Braveman P, Gruskin S. Defining equity in health. *J Epidemiol Community Health*. 2003;57(4):254–258. <https://doi.org/10.1136/jech.57.4.254>
- Ravallion M. Income inequality in the developing world. *Science*. 2014;344(6186):851–855. <https://doi.org/10.1126/science.1251875>
- The Caribbean outlook, 2018. Vol LC (Ses 37). Santiago, Chile: Economic Commission for Latin America and the Caribbean; 2018.
- Latin American economic outlook 2019: development in transition. Paris, France: Organisation for Economic Co-operation and Development; 2019. <https://doi.org/10.1787/g2g9ff18-en>
- Bambra C. *Work, Worklessness, and the Political Economy of Health*. New York, NY: Oxford University Press; 2011. <https://doi.org/10.1093/acprof:oso/9780199588299.001.0001>
- de Andrade LOM, Pellegrini Filho A, Solar O, et al. Social determinants of health, universal health coverage, and sustainable development: case studies from Latin American countries. *Lancet*. 2015;385(9975):1343–1351. [https://doi.org/10.1016/S0140-6736\(14\)61494-X](https://doi.org/10.1016/S0140-6736(14)61494-X)
- Bambra C. Work, worklessness and the political economy of health inequalities. *J Epidemiol Community Health*. 2011;65(9):746–750. <https://doi.org/10.1136/jech.2009.102103>
- Kröger H, Pakpahan E, Hoffmann R. What causes health inequality? A systematic review on the relative importance of social causation and health selection. *Eur J Public Health*. 2015;25(6):951–960. <https://doi.org/10.1093/eurpub/ckv111>
- Women and Men in the Informal Economy: A Statistical Picture*. 3rd ed. Geneva, Switzerland: International Labour Organization; 2018.
- Merino-Salazar P, Artazcoz L, Cornelio C, et al. Work and health in Latin America: results from the working conditions surveys of Colombia, Argentina, Chile, Central America and Uruguay. *Occup Environ Med*. 2017;74(6):432–439. <https://doi.org/10.1136/oemed-2016-103899>
- European Foundation for the Improvement of Living and Working Conditions. *Working Conditions in Central America*. Luxembourg: Publications Office of the European Union; 2015.
- Merino-Salazar P, Artazcoz L, Campos-Serna J, Gimeno D, Benavides FG. National working conditions surveys in Latin America: comparison of methodological characteristics. *Int J Occup Environ Health*. 2015;21(3):266–274. <https://doi.org/10.1179/2049396715Y.0000000004>
- Benavides FG, Wesseling C, Delclos GL, Felknor S, Pinilla J, Rodrigo F; Research Team of the first Central American Survey of Working Conditions and Health. Working conditions and health in Central America: a survey of 12,024 workers in six countries. *Occup Environ Med*. 2014;71(7):459–465. <https://doi.org/10.1136/oemed-2013-101908>
- International Labour Organization. *Measuring Informality: A Statistical Manual on the Informal Sector and Informal Employment*. 2013. Available at: https://www.ilo.org/wcmsp5/groups/public/-dgreports/-dcomm/-publ/documents/publication/wcms_222979.pdf. Accessed June 6, 2020.
- Eurofound. European Working Conditions Surveys. 2020. Available at: <https://www.eurofound.europa.eu/surveys/european-working-conditions-surveys-ewcs>. Accessed July 21, 2020.
- Gimeno Ruiz de Porrassa D, La II. The II Central American Survey of Working Conditions and Health [in Spanish]. *Arch Prev Riesgos Labor*. 2019;22(3):118–120. <https://doi.org/10.12961/apr.2019.22.03.1>
- Zimmerman FJ. A robust health equity metric. *Public Health*. 2019;175:68–78. <https://doi.org/10.1016/j.puhe.2019.06.008>
- Organización Iberoamericana de Seguridad. Executive report: I Central American Survey of Working Conditions and Health [in Spanish]; 2012. Available at: http://www.saltra.una.ac.cr/images/SALTRA/Documentacion/Informes/Informe_I_ECCTS_cuantitativo.pdf. Accessed July 21, 2020.
- Benyamini Y, Blumstein T, Murad H, Lerner-Geva L. Changes over time from baseline poor self-rated health: for whom does poor self-rated health not predict mortality? *Psychol Health*. 2011;26(11):1446–1462. <https://doi.org/10.1080/08870446.2011.559231>
- International Standard Classification of Occupations ISCO-08*. Vol I. Geneva, Switzerland: International Labour Organization; 2012.
- Handbook on Health Inequality Monitoring: With a Special Focus on Low- and Middle-Income Countries*. Geneva, Switzerland: World Health Organization; 2013. <https://doi.org/10.1093/ije/dyu124>
- Pearcy JN, Keppel KG. A summary measure of health disparity. *Public Health Rep*. 2002;117(3):273–280. [https://doi.org/10.1016/S0033-3549\(04\)50161-9](https://doi.org/10.1016/S0033-3549(04)50161-9)
- Keppel K, Pamuk E, Lynch J, et al. Methodological issues in measuring health disparities. *Vital Health Stat*. 2005;2(141):1–16.
- United Nations. World population prospect 2019. Department of Economic and Social Affairs Population Dynamics. 2019. Available at: <https://population.un.org/wpp/Download/Standard/Population>. Accessed October 1, 2020.
- World Health Organization. Mortality database. 2015. Available at: <https://www.who.int/topics/mortality/en>. Accessed October 15, 2019.
- Organización Panamericana de la Salud. Health profile of the Indigenous Peoples of Guatemala [in Spanish]. 2015. Available at: http://www.paho.org/gut/index.php?option=com_docman&view=download&category_slug=publicaciones&alias=792-perfil-de-salud-de-los-pueblos-indigenas-de-guatemala&Itemid=518. Accessed July 21, 2020.
- Becerril-Montekio V, López-Dávila L. The health system of Guatemala [in Spanish]. *Salud Publica Mex*. 2011;53(suppl 2):s197–s208.
- Organización Panamericana de la Salud/Organización Mundial de la Salud. Health inequalities in Guatemala [in Spanish]. Gobierno de Guatemala. Ministerio de Salud Pública y Asistencia Social. 2016. Available at: http://www.paho.org/gut/index.php?option=com_docman&view=download&category_slug=publicaciones&alias=793-desigualdades-en-salud-en-guatemala&Itemid=255. Accessed August 5, 2020.
- Silva-Peñaherrera M, Lopez-Ruiz M, Merino-Salazar P, Gómez-García AR, Benavides FG. Health inequity in workers of Latin America and the Caribbean. *Int J Equity Health*. 2020;19(1):109. <https://doi.org/10.1186/s12939-020-01228-x>
- Lora E. Health perceptions in Latin America. *Health Policy Plan*. 2012;27(7):555–569. <https://doi.org/10.1093/heapol/czr078>
- Günther I, Launov A. Informal employment in developing countries: opportunity or last resort? *J Dev Econ*. 2012;97(1):88–98. <https://doi.org/10.1016/j.jdeveco.2011.01.001>
- Sixth European Working Conditions Survey. Luxembourg: Eurofound; 2017. <https://doi.org/10.2806/422172>
- Dachs JNW, Ferrer M, Florez CE, Barros AJD, Narváez R, Valdívila M. Inequalities in health in Latin America and the Caribbean: descriptive and exploratory results for self-reported health problems and health care in twelve countries. *Rev Panam Salud Publica*. 2002;11(5-6):335–355. <https://doi.org/10.1590/S1020-49892002000500009>
- Zajacova A, Huzurbazar S, Todd M. Gender and the structure of self-rated health across the adult life span. *Soc Sci Med*. 2017;187:58–66. <https://doi.org/10.1016/j.socscimed.2017.06.019>
- Commission on Social Determinants of Health. Closing the gap in a generation: health equity through action on the social determinants of health, final report of the Commission on Social Determinants of Health. Geneva, Switzerland: World Health Organization; 2008.

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Digital Health Engagement in the US Population: Insights From the 2018 Health Information National Trends Survey

Chelsea L. Ratcliff, PhD, Melinda Krakow, PhD, MPH, Alexandra Greenberg-Worisek, PhD, MPH, and Bradford W. Hesse, PhD

Objectives. To examine prevalence and predictors of digital health engagement among the US population.

Methods. We analyzed nationally representative cross-sectional data on 7 digital health engagement behaviors, as well as demographic and socioeconomic predictors, from the Health Information National Trends Survey (HINTS 5, cycle 2, collected in 2018; n = 2698–3504). We fitted multivariable logistic regression models using weighted survey responses to generate population estimates.

Results. Digitally seeking health information (70.14%) was relatively common, whereas using health apps (39.53%) and using a digital device to track health metrics (35.37%) or health goal progress (38.99%) were less common. Digitally communicating with one's health care providers (35.58%) was moderate, whereas sharing health data with providers (17.20%) and sharing health information on social media (14.02%) were uncommon. Being female, younger than 65 years, a college graduate, and a smart device owner positively predicted several digital health engagement behaviors (odds ratio range = 0.09–4.21; P value range < .001–.03).

Conclusions. Many public health goals depend on a digitally engaged populace. These data highlight potential barriers to 7 key digital engagement behaviors that could be targeted for intervention. (*Am J Public Health.* 2021;111(7):1348–1351. <https://doi.org/10.2105/AJPH.2021.306282>)

Digital technologies have become vital tools for empowering individuals to engage with their health. Through the use of health information technology and digital communication platforms, people can now access health care or health resources, exchange health knowledge with social networks, and keep track of their personal health data conveniently and inexpensively.^{1,2}

The nation's vision for precision health—that is, tailoring disease prevention and treatment strategies to patients' genomic, physiologic, environmental, and behavioral profiles³—will

also require digital undergirding. For example, the All of Us research initiative (the forefront of data collection in precision medicine) uses patient-generated health data as the basis for both discovery and clinical implementation.^{3,4} Furthermore, precision public health goals include using publicly shared information to track outbreaks and identify the need for community- and population-level health interventions.^{5,6}

Accordingly, a key national objective is to achieve widespread digital health engagement among patients and the broader public.⁷ Yet, despite

increased uptake, data from the past decade point to persistent inequalities in both access and usage, with racial/ethnic minority and lower socioeconomic status individuals more likely to be among the digitally disadvantaged.^{8–10} Thus, understanding the prevalence of digital health engagement behaviors and potential social gaps is a priority.¹⁰ We used 2018 data from the National Cancer Institute's Health Information National Trends Survey (HINTS) to provide baseline estimates and sociodemographic predictors of 7 digital

engagement behaviors central to national public health goals.

METHODS

HINTS is administered annually to a stratified probability sample of noninstitutionalized US adults. Weights are applied to the data to generate estimates representative of the US population in terms of sex, age, and race and ethnicity distribution.¹¹ We used items from HINTS 5, cycle 2 (collected January–April 2018) to estimate population levels of digital health engagement ($n = 3504$) and predictors of engagement ($n = 2698$). Sample characteristics, including levels of technology access, are presented in Table A (available as a supplement to the online version of this article at <http://www.ajph.org>). Detailed information about HINTS sampling, data collection, and weighting methods are available at <https://hints.cancer.gov/data>.

We conducted all analyses using SAS version 9.4 (SAS Institute, Cary, NC). We used descriptive statistics to estimate population digital health engagement. We used multivariable logistic regression models to estimate relationships between engagement behaviors and predictors, controlling for all other sociodemographic characteristics in each model. The analytic sample for estimating engagement predictors consisted of the 2698 respondents with complete data for all survey items used in those analyses. We used jackknife weighting methods to generate conservative estimates of variance.

HINTS measures are developed through a process of extensive cognitive testing.¹¹ We classified the behaviors we selected for this study into categories of digital health engagement—accessing, communicating, and generating health information—

TABLE 1— Level of Digital Health Engagement by Type: Health Information National Trends Survey 5, Cycle 2, United States, 2018

Behavior	Weighted Prevalence Estimates, % (95% CI)
Accessing	
In the past 12 mo, have you used a computer, smartphone, or other electronic means to look for health or medical information for yourself?	70.14 (67.26, 73.02)
On your tablet or smartphone, do you have any “apps” related to health and wellness? ^a	49.24 (45.79, 52.69) ^b
Communicating	
In the past 12 mo, have you used e-mail or the Internet to communicate with a doctor or a doctor’s office?	35.58 (33.14, 38.02)
Have you shared health information from either an electronic monitoring device or a smartphone with a health professional within the past 12 mo?	17.20 (15.20, 19.20)
In the past 12 mo, have you used the Internet to share health information on social networking sites, such as Facebook or Twitter?	14.02 (11.87, 16.17)
Generating	
Has your tablet or smartphone helped you track progress on a health-related goal such as quitting smoking, losing weight, or increasing physical activity?	38.99 (36.56, 41.43)
Other than a tablet or smartphone, have you used an electronic device to monitor or track your health within the past 12 mo? Examples include Fitbit, blood glucose meters, and blood pressure monitors.	35.37 (32.74, 38.00)

Note. CI = confidence interval. Survey population size was $n = 3504$. The full questionnaire and data set can be found at <https://hints.cancer.gov/data>. Less than 3% of data were missing for each of these variables.

^aAssessed only among respondents who reported having a smart device ($n = 2770$).

^bOf smart device owners.

for ease of reporting and interpretation. Items are described in Table 1.

We also examined sociodemographic characteristics as predictors of digital health engagement as well as 3 access-related predictors: (1) having access to the Internet, (2) having a smart device, and (3) receiving access to one’s electronic health record (EHR).

RESULTS

Prevalence estimates and confidence intervals are reported in Table 1.

We report complete results of multivariable logistic regression models, including referent category information,

in Tables B–D (available as supplements to the online version of this article at <http://www.ajph.org>) and highlight statistically significant predictors here. For interested readers, we also report bivariate relationships in Tables E–G (available as supplements to the online version of this article at <http://www.ajph.org>).

Individuals were more likely to seek health information digitally if they had access to the Internet (odds ratio [OR] = 4.21; $P < .01$), a smart device (OR = 2.82; $P = .03$), or their EHR (OR = 1.86; $P < .01$) but less likely if they were 65 years old or older (65–74 years: OR = 0.42; $P = .03$; ≥ 75 years: OR = 0.27; $P < .01$). They were more

likely to have health and wellness apps if they had EHR access (OR = 2.20; $P < .01$) but less likely if they were 65 years old or older (65–74 years: OR = 0.33; $P < .01$; ≥ 75 years: OR = 0.26; $P < .01$).

Individuals were more likely to digitally communicate with their health care provider if they owned a smart device (OR = 2.45; $P < .01$), had EHR access (OR = 3.10; $P < .01$), or had a college degree (OR = 2.83; $P < .01$). They were more likely to share health information from a digital device with a health professional if they had EHR access (OR = 2.08; $P < .01$) or were Black/African American (OR = 2.04; $P = .01$). Respondents were more likely to share health information on social media if they had a smart device (OR = 3.67; $P = .02$) or were female (OR = 2.49; $P < .01$) but less likely if they were 65 years old or older (65–74 years: OR = 0.32; $P < .01$; ≥ 75 years: OR = 0.22; $P = .02$) or residing in a rural area (OR = 0.55; $P = .03$).

Individuals were more likely to use a smart device to track a health goal if they had EHR access (OR = 1.84; $P < .01$), were female (OR = 1.63; $P < .01$), or had attended college (some college: OR = 2.70; $P < .01$; college degree: OR = 2.93; $P < .01$) but less likely if they were 35 years old or older (OR range = 0.09–0.57; P value range = .03 to $< .01$). They were more likely to monitor health with non-smart digital devices if they had EHR access (OR = 1.83; $P < .01$), a smart device (OR = 2.03; $P < .01$), or a college degree (OR = 2.17; $P = .02$).

DISCUSSION

Results from nationally representative HINTS data suggest that in 2018, less than half of Americans had engaged in any digital health behavior in the past year except digitally seeking health information. This

highlights potential digital divides, with greater barriers to engagement for older individuals, males, those with lower levels of education, and (for social media) rural residents. Unsurprisingly, access to Internet and digital devices predicted digital health engagement. Race and ethnicity were not major predictors, although Black individuals were more likely to digitally share data with providers.

These prevalence rates and sociodemographic predictors are similar to reports from earlier HINTS data, suggesting limited progress between 2013 and 2018.^{8,9} For instance, in 2013, one third of Internet users digitally communicated with their health care provider or tracked personal health information, and one fourth of Internet users shared health information on social media.⁸ Age, gender, and education have remained consistent predictors across many types of digital health activity,^{8,9} and a recent analysis also identified access barriers among patients with chronic health conditions.¹²

A digitally engaged populace is expected to enable superior public health surveillance⁵ and patient surveillance that facilitates better care.³ Yet low or unequal rates of digital health engagement behaviors—especially sharing health information on social media and sharing digitally generated health data with providers—pose a threat to these goals. It will be particularly vital to assess whether these gaps have narrowed or widened during the COVID-19 pandemic, and the data from this study could serve as a useful baseline.

HINTS data are cross-sectional, so causal claims require careful interpretation. Additionally, we did not evaluate health outcomes of engagement behaviors. Past work has shown that low socioeconomic status and medically underserved individuals may not

benefit equally from health information technology access,¹⁰ making outcomes important to assess in future research.

PUBLIC HEALTH IMPLICATIONS

To lessen rather than exacerbate health inequities will require widespread digital health engagement among patients and healthy people across all population groups.¹⁰ HINTS data suggest that although a majority of Americans use digital devices to seek health information, fewer use these to communicate with health care providers or track their health. Participation in digital health interventions and digitally based research is likely limited among certain population groups, pointing to areas for digital access or digital literacy interventions. **AJPH**

ABOUT THE AUTHORS

Chelsea L. Ratcliff is with the Department of Communication Studies, University of Georgia, Athens. Melinda Krakow is with the University of Mississippi Medical Center, Jackson, and during the study was also with the Health Communication and Informatics Research Branch, National Cancer Institute, Bethesda, MD. Alexandra Greenberg-Worisek was with Mayo Clinic College of Medicine, Rochester, MN, during the study. Bradford W. Hesse served as branch chief for the Health Communication and Informatics Research Branch, National Cancer Institute, Bethesda, when this work began; he has since retired.

CORRESPONDENCE

Correspondence should be sent to Chelsea L. Ratcliff, PhD, Department of Communication Studies, University of Georgia, 617 Caldwell Hall, 302 Herty Dr, Athens, GA 30602 (e-mail: Chelsea.Ratcliff@uga.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

PUBLICATION INFORMATION

Full Citation: Ratcliff CL, Krakow M, Greenberg-Worisek A, Hesse BW. Digital health engagement in the US population: insights from the 2018 Health Information National Trends Survey. *Am J Public Health*. 2021;111(7):1348–1351.

Acceptance Date: March 12, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306282>

CONTRIBUTORS

C. L. Ratcliff wrote the brief. M. Krakow performed the analysis. M. Krakow, A. Greenberg-Worisek, and B. W. Hesse provided substantive feedback on the brief. All authors designed the study.

ACKNOWLEDGMENTS

The Health Information National Trends Survey is a publicly available data set funded by the National Cancer Institute.

Data from this study were presented at the HINTS Data Users Conference; May 22, 2019; Bethesda, MD.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to report.

HUMAN PARTICIPANT PROTECTION

No protocol approval was necessary because the work reported was a secondary data analysis.

REFERENCES

1. Topol E. *The Creative Destruction of Medicine: How the Digital Revolution Will Create Better Health Care*. New York, NY: Basic Books; 2013.
2. Swan M. Health 2050: the realization of personalized medicine through crowdsourcing, the quantified self, and the participatory biocitizen. *J Pers Med*. 2012;2(3):93–118. <https://doi.org/10.3390/jpm2030093>
3. Collins FS, Varmus H. A new initiative on precision medicine. *N Engl J Med*. 2015;372(9):793–795. <https://doi.org/10.1056/NEJMp1500523>
4. Weber GM, Mandl KD, Kohane IS. Finding the missing link for big biomedical data. *JAMA*. 2014;311(24):2479–2480. <https://doi.org/10.1001/jama.2014.4228>
5. Khoury MJ, Iademarco MF, Riley WT. Precision public health for the era of precision medicine. *Am J Prev Med*. 2016;50(3):398–401. <https://doi.org/10.1016/j.amepre.2015.08.031>
6. Sarker A, Ginn R, Nikfarjam A, et al. Utilizing social media data for pharmacovigilance: a review. *J Biomed Inform*. 2015;54:202–212. <https://doi.org/10.1016/j.jbi.2015.02.004>
7. US Department of Health and Human Services. Health communication and health information technology. Available at: <https://www.healthypeople.gov/2020/topics-objectives/topic/health-communication-and-health-information-technology/objectives>. Accessed April 18, 2021.
8. Jackson DN, Chou W-YS, Coa KI, Oh A, Hesse B. Implications of social media use on health information technology engagement: data from HINTS 4 cycle 3. *Transl Behav Med*. 2016;6(4):566–576. <https://doi.org/10.1007/s13142-016-0437-1>
9. Prestin A, Vieux SN, Chou WS. Is online health activity alive and well or flatlining? Findings from 10 years of the Health Information National Trends Survey. *J Health Commun*. 2015;20(7):790–798. <https://doi.org/10.1080/10810730.2015.1018590>
10. Robinson L, Cotten SR, Ono H, et al. Digital inequalities and why they matter. *Inf Commun Soc*. 2015;18(5):569–582. <https://doi.org/10.1080/1369118X.2015.1012532>
11. Finney Rutten LJ, Blake KD, Skolnick VG, Davis T, Moser RP, Hesse BW. Data resource profile: the National Cancer Institute's Health Information National Trends Survey (HINTS). *Int J Epidemiol*. 2020;49(1):17–17j. <https://doi.org/10.1093/ije/dyz083>
12. Griffin AC, Chung AE. Health tracking and information sharing in the patient-centered era: a Health Information National Trends Survey (HINTS). *AMIA Annu Symp Proc*. 2019;1041–1050.

Read
AJPH
A PUBLICATION OF THE
AMERICAN PUBLIC HEALTH ASSOCIATION

Earn Continuing Education credits while you learn

Thanks to APHA's program with the *American Journal of Public Health*, earning continuing education credits is easy.

By reading select articles from *AJPH*, you can get credits for **CHES®**, **CME**, **CNE**, and **CPH**.

SIGN UP TODAY!

Introductory rate:
 APHA members: \$10 per credit
 Non-members: \$20 per credit

APHA.org/continuing-education

APHA
AMERICAN PUBLIC HEALTH ASSOCIATION
For a Healthier, More Active, and Healthier World

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Excess Mortality During the COVID-19 Pandemic in Philadelphia

Megan Todd, PhD, Meagan Pharis, MS, Sam P. Gulino, MD, Jessica M. Robbins, PhD, and Cheryl Bettigole, MD

 See also Ku, p. 1199.

Objectives. To estimate excess all-cause mortality in Philadelphia, Pennsylvania, during the COVID-19 pandemic and understand the distribution of excess mortality in the population.

Methods. With a Poisson model trained on recent historical data from the Pennsylvania vital registration system, we estimated expected weekly mortality in 2020. We compared these estimates with observed mortality to estimate excess mortality. We further examined the distribution of excess mortality by age, sex, and race/ethnicity.

Results. There were an estimated 3550 excess deaths between March 22, 2020, and January 2, 2021, a 32% increase above expectations. Only 77% of excess deaths ($n = 2725$) were attributed to COVID-19 on the death certificate. Excess mortality was disproportionately high among older adults and people of color. Sex differences varied by race/ethnicity.

Conclusions. Excess deaths during the pandemic were not fully explained by COVID-19 mortality; official counts significantly undercount the true death toll. Far from being a great equalizer, the COVID-19 pandemic has exacerbated preexisting disparities in mortality by race/ethnicity.

Public Health Implications. Mortality data must be disaggregated by age, sex, and race/ethnicity to accurately understand disparities among groups. (*Am J Public Health.* 2021;111(7):1352–1357. <https://doi.org/10.2105/AJPH.2021.306285>)

Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) emerged in December 2019 in China and quickly became a worldwide pandemic. By February 2021, more than 500 000 people in the United States were known to have died of COVID-19, the disease caused by SARS-CoV-2.¹ However, the true death toll from COVID-19 is likely much higher.^{2,3} Estimating mortality from COVID-19 is challenging. Incomplete scientific understanding of this novel virus and limited viral testing have likely led to an undercount of deaths directly caused by SARS-CoV-2 infection. Furthermore, it is difficult to assess mortality indirectly

caused by the COVID-19 pandemic, such as deaths resulting from the interruption of health care or other socioeconomic disruptions caused by the pandemic.

Researchers have argued that excess all-cause mortality—that is, comparing the number of deaths that occurred in 2020 to what would have been expected based on mortality trends from recent years—is the best way to understand the full mortality toll from COVID-19.^{3,4} This approach estimates the number of deaths caused both directly and indirectly by the pandemic, and has already been used to estimate preliminary mortality from COVID-19 in England and

Wales⁵; New York, NY⁶; Portugal⁷; Europe⁸; and the United States.⁹

In this study, we used data from Pennsylvania's vital registration system to estimate excess all-cause mortality in Philadelphia, Pennsylvania, from March 22, 2020, to January 2, 2021. We then assessed what fraction of these excess deaths were attributed to COVID-19 on death certificates. Finally, we examined the distribution of excess mortality by demographic characteristics—sex, race/ethnicity, and age.

METHODS

Data were from Pennsylvania's vital registration system and included

information on deaths of Philadelphia residents that occurred anywhere in Pennsylvania. We examined deaths that occurred on or after January 1, 2015.

Mortality is reported with a delay; many deaths are recorded in the vital registration system within a week of the date of death, but some deaths are not reported until weeks or months later. In this study, we examined mortality through the last week in December 2020 (December 27, 2020–January 2, 2021). Based on the pattern of death reporting from 2019 to 2020, we estimated that death counts from December 2020 were the least complete at 96%, November 2020 counts were about 99% complete, and counts for previous months were greater than 99% complete (details in the Appendix, section 1, available as a supplement to the online version of this article at <http://www.ajph.org>).

For each decedent, we examined the following demographic characteristics: 2 categories of sex (male and female), 4 categories of race/ethnicity (non-Hispanic Black, non-Hispanic White, Hispanic, and non-Hispanic other race),

and 5 categories of age at death (< 25 years, 25–39 years, 40–54 years, 55–69 years, and ≥ 70 years). Between January 1, 2015, and January 2, 2021, there were 89 735 deaths of Philadelphia residents. Of these, 292 records were dropped because of missing information on age, sex, or race/ethnicity. There were 15 deaths with missing race/ethnicity information between March 22, 2020, and January 2, 2021; none were missing age or sex.

We searched the text of each death certificate for “COVID” and “coronavirus” and classified a death as a COVID-19 death if it contained 1 of these keywords.

We fit a Poisson regression model to weekly death counts between January 1, 2015, and February 1, 2020, allowing for variation by season and by calendar year (details in Appendix, section 2). We projected these Poisson models forward for the weeks beginning February 2 to December 27, 2020, to obtain expected mortality, then calculated excess mortality as the difference between observed and expected weekly death counts. We stratified the mortality data by sex, race/

ethnicity, and age group, and repeated this model for each subpopulation group.

To assess whether more deaths occurred during the COVID-19 pandemic than were expected in each population subgroup, we fit Poisson models to all deaths between January 1, 2015, and January 2, 2021, then tested the statistical significance of a COVID-19 pandemic indicator variable equal to 1 for each week beginning March 22, 2020, or later, and zero for earlier weeks (details in Appendix, section 2). To assess whether one population subgroup experienced a higher burden of mortality than another, we examined P values from asymptotic χ^2 tests of nested Poisson models that did and did not include the demographic covariate of interest. All analysis was conducted in R version 4.0.3 with base R statistical packages (R Foundation for Statistical Computing, Vienna, Austria).

RESULTS

Figure 1 shows expected and observed weekly death counts from all causes of Philadelphia residents in 2020. Based

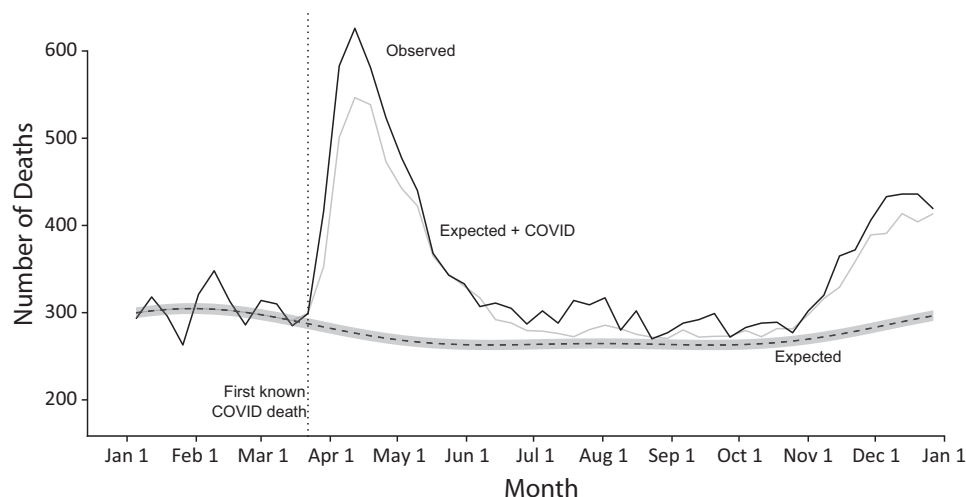


FIGURE 1— Expected and Observed Weekly Death Counts From All Causes: Philadelphia, PA, 2020

Note. Hypothesis test that $\text{sum}(\text{observed}) = \text{sum}(\text{expected})$ for Mar 23, 2020–Jan 2, 2021: $z = 21.8$; $P < .001$.

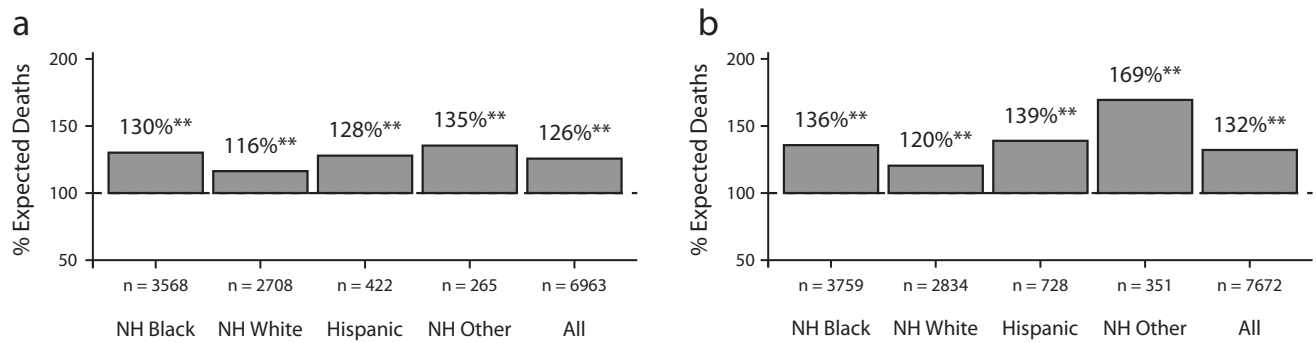


FIGURE 2— Observed Deaths as a Percentage of Expected Deaths From All Causes by Race/Ethnicity Among (a) Females and (b) Males: Philadelphia, PA, March 22, 2020–January 2, 2021

Note. NH = non-Hispanic. Counts fewer than 10 are suppressed. For a full breakdown, see Appendix Figure C, available as a supplement to the online version of this article at <http://www.ajph.org>.

* $P < .05$; ** $P < .01$.

on the pattern from the previous 5 years, approximately 300 deaths per week were expected. In the first 3 months of 2020, the number of observed deaths closely matched the number of expected deaths. The first known COVID-19 death of a Philadelphia resident occurred near the end of March; shortly thereafter, the number of weekly deaths spiked dramatically. In each of the first 3 weeks of April, the number of observed deaths was more than 200% of expected deaths (see Appendix, section 3, for weekly counts). The number of weekly observed deaths declined through May and June, then remained slightly elevated (102%–120%) relative to expectations through summer and early fall. A second spike began in late October, with observed weekly death counts that reached 133% to 151% of expectations through November and December. The gray line in Figure 1 shows the number of expected deaths plus the number of deaths attributed to COVID-19 on death certificates. COVID-19 accounted for many of the excess deaths, but in nearly every week, there were additional excess deaths above and beyond those directly attributed to COVID-19.

We aggregated the expected and observed deaths of Philadelphia residents between March 22, 2020, and January 2, 2021. Based on recent historical data, our model predicted 11 085 deaths of Philadelphia residents from all causes between March 22, 2020, and January 2, 2021. Instead, 14 635 deaths occurred—an increase of 32% above expectations across this entire period. There were an estimated 3550 excess deaths of Philadelphia residents in just over 9 months. “COVID” or “coronavirus” appeared on the death certificates of 2725 Philadelphians between March 22, 2020, and January 2, 2021, accounting for only 77% of the excess deaths in this period.

Figure 2 shows the ratio of observed deaths to expected deaths, stratified by sex and race/ethnicity. (For further breakdown by age group, see Appendix Figure C.) A value less than 100% indicates that fewer deaths occurred between March 22, 2020, and January 2, 2021, than were expected for a given sex–race/ethnicity (in Figure 2) or sex–age–race/ethnicity (Appendix Figure C) subpopulation group; a value greater than 100% indicates that there were excess deaths in this time period compared with expectations. For each subpopulation group, asterisks indicate

the P value from a hypothesis test that the sum of observed deaths equaled the sum of expected deaths over this time period.

Figure 2 indicates that excess mortality was not equally distributed throughout the population. With all age and race/ethnicity groups combined, men experienced greater excess mortality than women: observed deaths were 32% higher than expected among men compared with 26% higher than expected among women ($P < .01$ from an asymptotic χ^2 test of nested Poisson models; not shown). However, the sex pattern in excess mortality differed by race/ethnicity. Among non-Hispanic White Philadelphians, the increase in observed deaths relative to expected mortality was not significantly different by sex (16% for women compared with 20% for men; $P = .48$). But for Philadelphians of color, men did face more excess mortality compared with women ($P < .01$): observed mortality compared with expected mortality was 30% (women) and 36% (men) higher than expectations for non-Hispanic Black Philadelphians ($P < .01$); 28% (women) and 39% (men) higher than expectations for Hispanic Philadelphians ($P < .01$); and 35% (women) and 69% (men) higher for

non-Hispanic Philadelphians of another race ($P < .01$).

Race/ethnicity was also associated with excess deaths ($P < .01$; test not shown). As listed previously, with all age groups combined, non-Hispanic White Philadelphians experienced smaller increases in mortality compared with expectations than did Philadelphians of color. Unsurprisingly, excess deaths also increased with age ($P < .01$; test not shown).

The relationship between age and excess mortality differed by sex (Appendix Figure C). Among women (all race/ethnicity groups combined), excess mortality was monotonically associated with age: for women aged younger than 40 years, the numbers of observed deaths between March 22, 2020, and January 2, 2021, were not significantly different from expectations, while deaths among women aged 40 years or older were 21% to 27% higher than expected ($P < .01$). Women of each race/ethnicity group saw a similar pattern of increasing excess mortality with age; excess deaths were statistically significant only above age 55 years for the largest groups, and only above age 70 years for the smaller groups.

Excess mortality among men, however, was substantial even in younger age groups. As well as being significantly elevated for men aged 40 years and older (all race/ethnicity groups combined, estimated excess mortality of 21% to 36%), observed deaths were 27% higher than expectations in the youngest age group (< 25 years; $P < .01$). This increase in male mortality at young ages can clearly be attributed to significant excess mortality among young, non-Hispanic Black men; those aged younger than 25 years experienced 35% more deaths than expected ($P < .05$), and those aged 25 to 39 years experienced 29% more deaths than expected ($P < .01$). Non-Hispanic Black men experienced significant

excess mortality in every age category. No other sex–race/ethnicity group saw significant excess mortality in those aged younger than 40 years. At age 40 years and older, non-Hispanic Black men, Hispanic men, and non-Hispanic men of another race experienced disturbingly high levels of excess mortality: increases of 29% to 39% above expectations for non-Hispanic Black men ($P < .01$), increases of 36% to 60% for Hispanic men ($P < .01$), and increases of 69% to 75% for non-Hispanic men of another race aged 55 years or older ($P < .01$).

DISCUSSION

Our study calculated a preliminary estimate of excess mortality during the COVID-19 pandemic between March 22, 2020, and January 2, 2021, in Philadelphia. We identified 3550 excess deaths during this period, of which 2725—77%—were attributed to COVID-19 on the death certificates. An alternative source of data on the number of COVID-19 deaths in Philadelphia comes from the Philadelphia Department of Public Health's surveillance system, which tracks confirmed and suspected cases of COVID-19 identified by hospitals and health care providers; this figure represents the city's official tally of COVID-19 deaths. The City of Philadelphia has publicly shared the number of deaths and other information related to COVID-19 via OpenDataPhilly,¹⁰ a repository for numerous public data sets about Philadelphia. As of March 1, 2021, Philadelphia's surveillance system had identified 2639 deaths attributable to COVID-19 that had occurred by January 2, 2021—74% of the excess deaths we identified. It is not surprising that the surveillance system identified fewer COVID-19 deaths than our death certificate scan because,

early in the pandemic, the city reported only confirmed COVID-19 cases, not suspected cases; we know testing was limited at that time. Another reason that the official tally might report fewer COVID-19 deaths than our death certificate scan is that local surveillance may have been less likely to have captured deaths of Philadelphia residents that occurred outside Philadelphia.

Our finding that the official COVID-19 death tally accounted for 74% of excess deaths while the death certificate scan accounted for 77% of excess deaths is in line with other studies from the United States. An early estimate of COVID-19 mortality from the New York City Department of Health and Mental Hygiene found that confirmed and probable COVID-19 cases accounted for 78% of the excess deaths between March 11 and May 2, 2020, using a method similar to our death certificate scan.⁶ Weinberger et al.⁹ compiled COVID-19 deaths in the United States from the National Center for Health Statistics and a database from *The Atlantic* and found that official COVID-19 death counts accounted for 78% of the excess deaths between March 1 and May 30, 2020. Studies from other countries suggest that official COVID-19 death tallies were substantially lower than the estimated number of excess deaths at the start of the pandemic; an early official tally in Portugal represented somewhere between 20% and 35% of excess deaths,⁷ and the early official tally in England and Wales accounted for 30% to 50% of excess deaths.⁵

In our study, as in many others,^{8,11} older age was associated with increased mortality. We found that the increase in mortality occurred at younger ages among men of color compared with non-Hispanic White men, a pattern

also found in the United Kingdom and South Africa.¹²

We found that the sex pattern in excess mortality differed by race/ethnicity: non-Hispanic White men and women experienced similar increases in mortality relative to expectations, while men of color saw significantly larger increases than women of the same race/ethnicity. Much has been written about the differences in COVID-19 mortality rates by sex—COVID-19 has even been called a “mankiller”¹³—but as Krieger et al.¹⁴ pointed out, many sex-specific analyses fail to take into account the higher baseline mortality rates experienced by men. Krieger et al. found no sex difference in COVID-19 mortality in Massachusetts once prepandemic mortality rates were accounted for. By estimating excess mortality, our study likewise incorporates prepandemic mortality rates; thus, it is not surprising that our findings for non-Hispanic White Philadelphians are consistent with Krieger et al.’s findings from Massachusetts, a population that is more than 70% non-Hispanic White.¹⁵ Among Philadelphians of color, however, we found that men experienced more excess mortality than women. To our knowledge, no other studies of excess mortality have examined sex patterns by race/ethnicity in age strata.

Excess mortality associated with the COVID-19 pandemic was disproportionately felt by people of color in Philadelphia, affirming a pattern identified in numerous other studies.¹⁶⁻²² Researchers have hypothesized that this race/ethnicity pattern may result from disproportionate employment in essential jobs, residential segregation, crowded living conditions, comorbidities, and the compounded effects of living with systemic racism. Less well-understood is the effect of non-COVID-19 mortality. In

future work, as cause-of-death information is added to the vital registration system, we plan to examine the causes of death that are responsible for excess mortality not attributable to COVID-19. Certainly, undetected infection with SARS-CoV-2 is responsible for a portion of these deaths. There has also been speculation that some of these excess deaths may be attributable to untreated chronic conditions; drug overdoses, which, once final counts are in for 2020, are expected to exceed the city’s previous record high set in 2017^{23,24}; and homicide, which has spiked in Philadelphia (as in other cities) during the pandemic.²⁵ Homicide is a leading cause of death among young non-Hispanic Black men,²⁶ making it plausible that the increase in homicide is playing a large role in the excess mortality felt by this group during the COVID-19 pandemic. While we do not yet have detailed cause-of-death data for each death that occurred in 2020, we do know that COVID-19 appeared on the death certificate for only 4% of excess deaths among non-Hispanic Black men aged younger than 25 years, and for only 11% of excess deaths among non-Hispanic Black men aged 25 to 39 years. For the population as a whole, COVID-19 appeared on the death certificate for 77% of excess deaths.

In addition to the importance of adjusting for baseline mortality, our study highlights the importance of considering age distributions when calculating excess mortality attributable to COVID-19, as other demographers have argued.²⁷ In Philadelphia, age structure varies substantially by race/ethnicity. As shown in Appendix Figure D, the non-Hispanic White population is the oldest of the racial/ethnic groups while the Hispanic population is the youngest; among men, 31% of the non-Hispanic White population is aged 55 years or older compared

with just 14% of the Hispanic population. An analysis that simply calculated the crude mortality rate in each race/ethnicity group without adjusting for age might conclude that COVID-19 mortality was lower for Hispanic men than non-Hispanic White men, but it would miss the dramatic differences in mortality rates within age strata.

Limitations

A limitation of our approach is that we relied on a simple text search of the death certificate to determine whether COVID-19 was the cause of death rather than waiting for the Centers for Disease Control and Prevention to assign final underlying and multiple causes of death based on a multicriteria assessment of the text of a death certificate. However, early in the pandemic, the Pennsylvania Department of Health sent detailed and specific instructions to clinicians, medical examiners, and coroners on how death certificates should be worded for suspected and confirmed COVID-19 cases; this proactive standardization for COVID-19 deaths may have served to minimize the difference in death counts based on our death certificate text scan and assigned *International Classification of Diseases, Tenth Revision* codes.

A further limitation is the delay in the reporting of deaths: some deaths that occurred in 2020 have not yet been captured in the vital registration system, especially those that happened near the end of 2020. We examined the completeness of the death data from each calendar month (see description in the Appendix, section 1). We estimated that about 119 deaths that occurred between March 22, 2020, and January 2, 2021, have not yet been reported, implying that the 2020 death

count is 99.2% complete. Sensitivity analyses (not shown) that dropped the most recent (and, thus, least complete) monthly data did not alter our findings.

Public Health Implications

In this study, we provided an early estimate of excess mortality in Philadelphia during the COVID-19 pandemic: 3550 excess deaths between March 22, 2020, and January 2, 2021, an increase of 32% compared with expectations. Of these, COVID-19 was the cause of death for only an estimated 77%. Excess mortality was disproportionately felt by older adults, people of color, and men of color.

Our study is a contribution to the literature on disparities in mortality in the COVID-19 pandemic by sex, age, and race/ethnicity, and our findings clearly highlight the need to disaggregate mortality data by these demographic characteristics. We encourage more researchers to do the same. *AJPH*

ABOUT THE AUTHORS

All authors are with the Philadelphia Department of Public Health, Philadelphia, PA.

CORRESPONDENCE

Correspondence should be sent to Megan Todd, 1101 Market St, 9th Floor, Philadelphia, PA 19107 (e-mail: megan.todd@phila.gov). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Todd M, Pharis M, Gulino SP, Robbins JM, Bettigole C. Excess mortality during the COVID-19 pandemic in Philadelphia. *Am J Public Health*. 2021;111(7):1352–1357.

Acceptance Date: March 13, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306285>

CONTRIBUTORS

M. Todd originated and led the study. M. Todd and M. Pharis conducted analysis. All authors contributed to writing.

ACKNOWLEDGMENTS

The authors thank Annaka Scheeres for exceptional research assistance.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

HUMAN PARTICIPANT PROTECTION

This study was determined to be exempt by the Philadelphia Department of Public Health's institutional review board.

REFERENCES

- Tompkins L, Smith M, Bosman J, Pietsch B. Entering uncharted territory, the U.S. counts 500,000 Covid-related deaths. *New York Times*. February 23, 2021. Available at: <https://www.nytimes.com/2021/02/22/us-us-covid-deaths-half-a-million.html>. Accessed February 27, 2021.
- Woolf SH, Chapman DA, Sabo RT, Weinberger DM, Hill L. Excess deaths from COVID-19 and other causes, March–April 2020. *JAMA*. 2020;324(5):510–513. <https://doi.org/10.1001/jama.2020.11787>
- Kiang MV, Irizarry RA, Buckee CO, Balsari S. Every body counts: measuring mortality from the COVID-19 pandemic. *Ann Intern Med*. 2020;173(12):1004–1007. <https://doi.org/10.7326/M20-3100>
- Leon DA, Shkolnikov VM, Smeeth L, Magnus P, Pechholdová M, Jarvis CI. COVID-19: a need for real-time monitoring of weekly excess deaths. *Lancet*. 2020;395(10234):e81. [https://doi.org/10.1016/S0140-6736\(20\)30933-8](https://doi.org/10.1016/S0140-6736(20)30933-8)
- Vandoros S. Excess mortality during the Covid-19 pandemic: early evidence from England and Wales. *Soc Sci Med*. 2020;258:113101. <https://doi.org/10.1016/j.socscimed.2020.113101>
- New York City Department of Health and Mental Hygiene COVID-19 Response Team. Preliminary estimate of excess mortality during the COVID-19 outbreak—New York City, March 11–May 2, 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(19):603–605. <https://doi.org/10.15585/mmwr.mm6919e5>
- Nogueira PJ, Nobre MDA, Nicola PJ, Furtado C, Vaz Carneiro A. Excess mortality estimation during the COVID-19 pandemic: preliminary data from Portugal. *Acta Med Port*. 2020;33(6):376–383. <https://doi.org/10.20344/amp.13928>
- Vestergaard LS, Nielsen J, Richter L, et al. Excess all-cause mortality during the COVID-19 pandemic in Europe—preliminary pooled estimates from the EuroMOMO network, March to April 2020. *Euro Surveill*. 2020;25(26):2001214. <https://doi.org/10.2807/1560-7917.ES.2020.25.26.2001214>
- Weinberger DM, Chen J, Cohen T, et al. Estimation of excess deaths associated with the COVID-19 pandemic in the United States, March to May 2020. *JAMA Intern Med*. 2020;180(10):1336–1344. <https://doi.org/10.1001/jamainternmed.2020.3391>
- City of Philadelphia. COVID deaths - OpenData-Philly. Available at: <https://www.opendataphilly.org/dataset/covid-deaths>. Accessed August 25, 2020.
- Bonanad C, García-Blas S, Tarazona-Santabalbina F, et al. The effect of age on mortality in patients with COVID-19: a meta-analysis with 611,583 subjects. *J Am Med Dir Assoc*. 2020;21(7):915–918. <https://doi.org/10.1016/j.jamda.2020.05.045>
- Klugman KP, Zewdu S, Mahon BE, et al. Younger ages at risk of Covid-19 mortality in communities of color. *Gates Open Res*. 2020;4:69. <https://doi.org/10.12688/gatesopenres.13151.1>
- Reeves RV, Ford TN. COVID-19 much more fatal for men, especially taking age into account. Brookings. May 15, 2020. Available at: <https://www.brookings.edu/blog/up-front/2020/05/15/covid-19-much-more-fatal-for-men-especially-taking-age-into-account>. Accessed August 25, 2020.
- Krieger N, Chen JT, Waterman PD. Excess mortality in men and women in Massachusetts during the COVID-19 pandemic. *Lancet*. 2020;395(10240):1829. [https://doi.org/10.1016/S0140-6736\(20\)31234-4](https://doi.org/10.1016/S0140-6736(20)31234-4)
- US Census Bureau. QuickFacts. Massachusetts. Available at: <https://www.census.gov/quickfacts/MA>. Accessed August 26, 2020.
- Mahajan UV, Larkins-Pettigrew M. Racial demographics and COVID-19 confirmed cases and deaths: a correlational analysis of 2886 US counties. *J Public Health (Oxf)*. 2020;42(3):445–447. <https://doi.org/10.1093/pubmed/fdaa070>
- Karaca-Mandic P, Georgiou A, Sen S. Assessment of COVID-19 hospitalizations by race/ethnicity in 12 states. *JAMA Intern Med*. 2021;181(1):131–134. <https://doi.org/10.1001/jamainternmed.2020.3857>
- Moore JT, Ricaldi JN, Rose CE, et al. Disparities in incidence of COVID-19 among underrepresented racial/ethnic groups in counties identified as hot-spots during June 5–18, 2020—22 states, February–June 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(33):1122–1126. <https://doi.org/10.15585/mmwr.mm6933e1>
- Yancy CW. COVID-19 and African Americans. *JAMA*. 2020;323(19):1891–1892. <https://doi.org/10.1001/jama.2020.6548>
- Drexel University Urban Health Collaborative. COVID-19 in context: racism, segregation, and racial inequities in Philadelphia. June 24, 2020. Available at: https://drexel.edu/uhc/resources/briefs/Covid-19_in_Context. Accessed August 25, 2020.
- Chowkwanyun M, Reed AL. Racial health disparities and Covid-19—caution and context. *N Engl J Med*. 2020;383(3):201–203. <https://doi.org/10.1056/NEJMp2012910>
- Ravi K. Ethnic disparities in COVID-19 mortality: are comorbidities to blame? *Lancet*. 2020;396(10243):22. [https://doi.org/10.1016/S0140-6736\(20\)31423-9](https://doi.org/10.1016/S0140-6736(20)31423-9)
- Philadelphia Department of Public Health. The impact of COVID-19 on unintentional drug overdoses in Philadelphia. *Chart*. 2020;5(6). Available at: <https://www.phila.gov/departments/departments-of-public-health/data/chart>. Accessed May 4, 2021.
- Whelan A. Philadelphia may be on the way to a record for fatal drug overdoses in 2020, another COVID-19 consequence. *Philadelphia Inquirer*. December 6, 2020. Available at: <https://www.inquirer.com/health/opioid-addiction/overdoses-philadelphia-covid-opioid-fentanyl-20201206.html>. Accessed February 28, 2021.
- Farr S. Philly's homicide toll reached 300 this weekend, the highest it's been at the end of August in at least 13 years. *Philadelphia Inquirer*. August 30, 2020. Available at: <https://www.inquirer.com/crime/philadelphia-shootings-homicides-300-ongoing-gun-violence-20200830.html>. Accessed September 15, 2020.
- Philadelphia Department of Public Health. Health of the City. 2020. Available at: <https://www.phila.gov/media/20201230141933/HealthOfTheCity-2020.pdf>. Accessed May 4, 2021.
- Dowd JB, Andriano L, Brazel DM, et al. Demographic science aids in understanding the spread and fatality rates of COVID-19. *Proc Natl Acad Sci USA*. 2020;117(18):9696–9698. <https://doi.org/10.1073/pnas.2004911117>

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

The Importance of Reporting Lag in Assessing Excess Deaths During the COVID-19 Pandemic

Jason L. Salemi, PhD, MPH

ABOUT THE AUTHOR

Jason L. Salemi is with the College of Public Health and the Morsani College of Medicine, University of South Florida, Tampa.

The American Journal of Public Health published an article by Tatar et al. in the April 2021 issue that sought to quantify the excess deaths occurring in Florida during a seven-month period at the beginning of the COVID-19

pandemic (March to September 2020).¹ Although the Farrington surveillance algorithm implemented by the Centers for Disease Control and Prevention (CDC) to generate jurisdiction-specific expected all-cause deaths for each week beginning February 1, 2020 is well suited to detect excess deaths,² I commend the authors' efforts to implement and validate a more sophisticated approach to estimating expected deaths. The primary aim of this letter is to express several concerns I have regarding the authors' analysis and conclusions and to underscore the importance of reporting lag in interpreting such data.

All-cause excess deaths are extremely useful in providing a comprehensive assessment of deaths both directly and indirectly attributable to COVID-19.³ Moreover, focusing on all-cause deaths overcomes concerns regarding the accuracy of COVID-19-specific deaths, which is dependent on the availability and utilization of diagnostic testing and appropriate documentation of underlying and

contributing causes of death. For a particular time frame and locale, excess deaths are calculated as the number of people who have died from any cause above and beyond what would have been expected. Here, the authors implement seasonal autoregressive integrated moving average (SARIMA) regression modeling to generate monthly expected death estimates. Despite differing from the CDC's estimation approach, excess death estimates from May to September 2020 are very similar to the CDC's reported range.

However, despite the existence of a publicly available electronic file from the Florida Department of Health,⁴ updated daily, that captures resident deaths by date of death, the authors use deaths by date reported. On the basis of reported deaths, the authors then state that in July 2020 there were "6315 excess deaths, of which 3338 (52.9%) were attributed to COVID-19." They continue to argue that this "implies an undercount of 2977 for publicly reported COVID-19-related deaths in July."^{1(p705)}

First, the number of Florida-resident COVID-19 deaths that actually occurred in July 2020 was 5223, meaning that the authors underestimated the number of COVID-19 deaths by 36%. In fact, during the analytic time frame, the authors underestimated deaths by 12.7% (16 409 actual vs 14 317 reported in the study). This is because, as illustrated in Figure 1,⁵ the death reporting lag can mean that a significant proportion of deaths occurring during the authors' time frame are actually reported well after September 30, 2020. Second, I believe it is incorrect to attribute the difference in all-cause excess deaths and COVID-19-specific deaths reported by the

Letters to the editor referring to a recent *AJPH* article are encouraged up to 3 months after the article's appearance. By submitting a letter to the editor, the author gives permission for its publication in *AJPH*. Letters should not duplicate material being published or submitted elsewhere. The editors reserve the right to edit and abridge letters and to publish responses. Text is limited to 400 words and 7 references. Submit online at www.editorialmanager.com/ajph. Queries should be addressed to the Editor-in-Chief, Alfredo Morabia, MD, PhD, at editorajph@qc.cuny.edu.

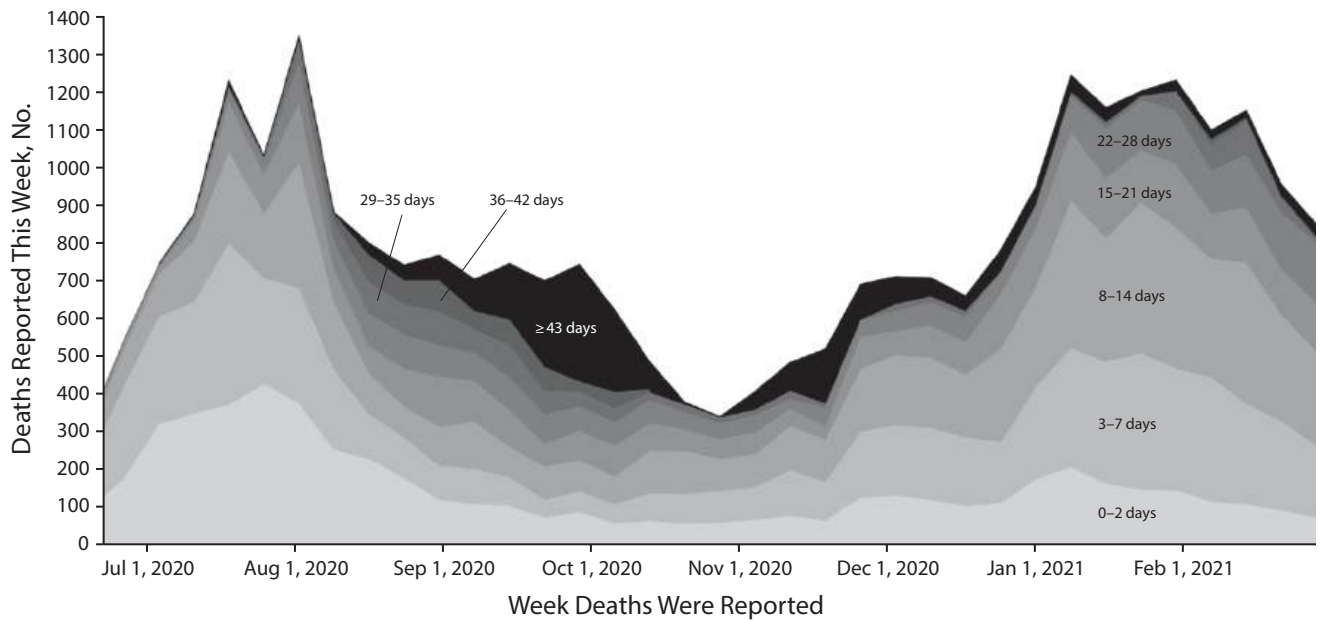


FIGURE 1— Weekly Trends in Reporting Lag for Deaths Reported in Florida Between July 1, 2020 and February 28, 2021

Note. “Reporting lag” is defined as the number of days between the date on which a COVID-19 death occurs and the date on which the death is reported. For example, it was common in September and October 2020 for four in 10 deaths that were reported during a given week to have actually occurred more than 30 days prior.

state as “an undercount.” The goal of the state-reported numbers is to capture deaths in which COVID-19 was likely an underlying or contributing cause of death, whereas all-cause excess deaths are intended to capture deaths both directly and indirectly associated with the pandemic.

As the authors point out, in Florida, there has been “increasing controversy regarding the accuracy of the officially reported number of COVID-19 deaths” despite no evidence that inaccuracies are more severe in Florida than in other states.^{1(p706)} My concern is that these two details—(1) undercounting actual COVID-19 deaths in Florida (by using deaths based on date reported instead

of date occurred) and (2) suggesting that an undercount has occurred on the basis of a comparison of numbers with different purposes—will unintentionally perpetuate a narrative not supported by these data. *AJPH*

CORRESPONDENCE

Correspondence should be sent to Jason L. Salemi, PhD, MPH, 13201 Bruce B. Downs Blvd, MDC 56, Tampa, FL 33612 (e-mail: jsalemi@usf.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

PUBLICATION INFORMATION

Full Citation: Salemi JL. The importance of reporting lag in assessing excess deaths during the COVID-19 pandemic. *Am J Public Health*. 2021;111(7):e1–e2.

Acceptance Date: April 12, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306341>

CONFLICTS OF INTEREST

The author has no conflicts of interest to declare regarding the publication of this letter.

REFERENCES

1. Tatar M, Habibdoust A, Wilson FA. Analysis of excess deaths during the COVID-19 pandemic in the state of Florida. *Am J Public Health*. 2021;111(4):704–707. <https://doi.org/10.2105/AJPH.2020.306130>
2. National Center for Health Statistics. Excess deaths associated with COVID-19. 2021. Available at: https://www.cdc.gov/nchs/nvss/vsrr/covid19/excess_deaths.htm. Accessed March 23, 2021.
3. Rossen LM, Branum AM, Ahmad FB, Sutton P, Anderson RN. Excess deaths associated with COVID-19, by age and race and ethnicity—United States, January 26–October 3, 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(42):1522–1527. <https://doi.org/10.15585/mmwr.mm6942e2>
4. Florida Dept of Health. Florida COVID-19 deaths by day. 2021. Available at: <https://fdoh.maps.arcgis.com/home/item.html?id=230270972343459a812a1ae8c28574a6>. Accessed March 23, 2021.
5. Salemi JL. Florida COVID-19 dashboard: deaths. 2021. Available at: <https://covid19florida.mystrikingly.com/deaths>. Accessed March 23, 2021.

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Excess Deaths Reveal the Substantial Impact of COVID-19 Pandemic on Mortality in the State of Florida

Moosa Tatar, PhD, Amir Habibdoust, PhD, and Fernando A. Wilson, PhD

ABOUT THE AUTHORS

Moosa Tatar and Fernando A. Wilson are with the Matheson Center for Health Care Studies and the Department of Population Health Sciences, University of Utah, Salt Lake City. Amir Habibdoust is with the Department of Economics and Accounting, University of Guilan, Rasht, Iran.

Our study published in the April 2021 issue of *AJPH* found that Florida experienced 19 241 excess deaths from March to September 2020.¹ Official numbers link 14 317 of these deaths to COVID-19, suggesting that 4924 excess deaths are unexplained. In 2020, Florida experienced a significant increase in all-cause mortality (Table 1), and prior research indicated substantial excess deaths during the pandemic.²⁻⁴ Little is known about the change in deaths from non-COVID-19 causes during the pandemic; however, suicidal

ideation and substance use increased nationally, for example, which may have led to increased deaths from these causes.⁵ On the other hand, studies suggest that avoidance of health care services, lack or restricted access to care, limited availability of COVID-19 diagnostic tests, and severe lack of contact tracing may have resulted in several deaths that were not counted in official COVID-19 death records, especially in the beginning of the pandemic.^{3,4,6}

Our estimates using seasonal autoregressive integrated moving average

(SARIMA) regression modeling with historical mortality trends from 2010 to 2019 are conservative and are within the Centers for Disease Control and Prevention range of excess death estimates. Also, we do not believe reporting lags substantively affected our analyses. However, we have updated our analyses using data for the entire year of 2020 (Table 1). Using the SARIMA model predictions, Table 1 indicates that, in Florida, there were 27 238 excess deaths in 2020 compared with 2019. Excluding the 21 673 officially reported COVID-19 deaths, this results in a difference of 5565 all-cause deaths that are unexplained.

Thus, our findings suggest that all-cause deaths in 2020 are substantially higher than historical deaths in Florida based on mortality data since 2010, even when we exclude officially reported COVID-19 deaths.¹ Hence, the mortality burden associated with the COVID-19 pandemic is significantly higher than what would be predicted on the basis of prepandemic historical trends. These excess deaths may have been directly or indirectly associated with COVID-19. We need further research to determine specific reasons for this. *AJPH*

TABLE 1— Total Deaths and COVID-19–Related Deaths in Florida From 2017 to 2020

Deaths	2017	2018	2019	2020
Total all-cause recorded deaths	206 187	208 126	209 746	243 089
SARIMA-predicted deaths based on pre-COVID-19 data				215 851
Excess deaths				27 238
Official reported COVID-19 deaths				21 673
Estimated change in all-cause, excluding COVID-19, deaths				5 565

Note. SARIMA = seasonal autoregressive integrated moving average.

CORRESPONDENCE

Correspondence should be sent to Moosa Tatar, PhD, Visiting Scholar, Department of Population Health Sciences, School of Medicine, University of Utah, 295 Chipeta Way, Salt Lake City, UT 84108 (e-mail: moosa.tatar@utah.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

PUBLICATION INFORMATION

Full Citation: Tatar M, Habibdoust A, Wilson FA. Excess deaths reveal the substantial impact of COVID-19 pandemic on mortality in the state of Florida. *Am J Public Health*. 2021;111(7):e3–e4.

Acceptance Date: April 12, 2021.

DOI: <https://doi.org/10.2105/AJPH.2021.306340>

CONTRIBUTORS

M. Tatar and A. Habibdoust had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis; they were responsible for acquisition, analysis, or interpretation of data and for statistical analysis. M. Tatar and F. A. Wilson were responsible for administrative, technical, or material support. All authors contributed to concept and design, drafting the letter, and critical revision of the letter for important intellectual content.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare or any financial disclosures to report.

REFERENCES

1. Tatar M, Habibdoust A, Wilson FA. Analysis of excess deaths during the COVID-19 pandemic in the state of Florida. *Am J Public Health*. 2021;111(4):704–707. <https://doi.org/10.2105/AJPH.2020.306130>
2. Olson DR, Huynh M, Fine A, et al. Preliminary estimate of excess mortality during the COVID-19 outbreak—New York City, March 11–May 2, 2020. 2020. Available at: <https://stacks.cdc.gov/view/cdc/87858>. Accessed April 7, 2021.
3. Weinberger DM, Chen J, Cohen T, et al. Estimation of excess deaths associated with the COVID-19 pandemic in the United States, March to May 2020. *JAMA Intern Med*. 2020;180(10):1336–1344. <https://doi.org/10.1001/jamainternmed.2020.3391>
4. Woolf SH, Chapman DA, Sabo RT, Weinberger DM, Hill L. Excess deaths from COVID-19 and other causes, March–April 2020. *JAMA*. 2020;324(5):510–513. <https://doi.org/10.1001/jama.2020.11787>
5. Czeisler MÉ, Lane RI, Petrosky E, et al. Mental health, substance use, and suicidal ideation during the COVID-19 pandemic—United States, June 24–30, 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(32):1049–1057. <https://doi.org/10.15585/mmwr.mm6932a1>
6. Rao A. “People are dying at home”: virus fears deter seriously ill from hospitals. *The Guardian*. May 6, 2020. Available at: <https://www.theguardian.com/world/2020/may/06/dying-at-home-non-covid-19-hospitals-coronavirus>. Accessed August 25, 2020.

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Erratum In: Violent Victimization Among Lesbian, Gay, and Bisexual Populations in the United States: Findings From the National Crime Victimization Survey

In: Bender AK, Lauritsen JL. Violent victimization among lesbian, gay, and bisexual populations in the United States: findings from the national crime victimization survey, 2017–2018. *Am J Public Health*. 2021;111(2):318–326. <https://doi.org/10.2105/AJPH.2020.306017>

On page 318, placeholder text was not updated before publication. The cross-reference entry should read:

 See also Blosnich, p. 190.

On page 321 two row labels were interchanged in Table 1 of the manuscript. Table 1 should appear as follows:

TABLE 1— Descriptive Statistics for Sociodemographic Characteristics by Sexual Orientation: Weighted National Crime Victimization Survey Data: United States, 2017–2018

	Gay or Lesbian (n = 5380), ^a % (95% CI)	Bisexual (n = 2585), ^a % (95% CI)	Heterosexual (n = 418 003), ^a % (95% CI)
Age, y			
16–24	17.1 (15.3, 19.1)	49.1 (46.3, 51.9)	15.7 (15.4, 16.1)
25–39	32.1 (29.8, 34.5)	30.6 (28.0, 33.4)	23.8 (23.5, 24.2)
40–54	26.7 (24.5, 29.1)	12.6 (10.9, 14.5)	24.1 (23.8, 24.4)
≥ 55	24.1 (22.1, 26.1)	7.7 (6.4, 9.1)	36.3 (35.8, 36.8)
Sex			
Female	42.9 (40.7, 45.2)	75.0 (72.0, 77.8)	51.8 (51.6, 52.1)
Male	57.1 (54.8, 59.3)	25.0 (22.2, 28.0)	48.2 (47.9, 48.4)
Race/ethnicity			
Non-Hispanic White	68.8 (66.4, 71.1)	64.9 (61.3, 68.4)	63.4 (62.5, 64.3)
Non-Hispanic Black	9.9 (8.6, 11.5)	10.4 (8.6, 12.50)	12.0 (11.3, 12.6)
Hispanic	15.0 (13.3, 17.0)	15.5 (13.1, 18.2)	16.4 (15.8, 17.0)
Non-Hispanic other race	6.1 (5.0, 7.5)	9.1 (7.3, 11.3)	8.1 (7.8, 8.5)
Household income, \$			
< 25 000	15.1 (13.4, 17.0)	26.5 (23.9, 29.2)	13.7 (13.2, 14.2)
25 000–49 999	17.3 (15.5, 19.2)	22.3 (19.9, 25.0)	19.2 (18.7, 19.7)
50 000–74 999	15.3 (13.5, 17.2)	13.3 (11.3, 15.6)	13.9 (13.6, 14.2)
≥ 75 000	36.3 (34.0, 38.7)	25.3 (22.7, 28.1)	28.3 (27.8, 28.9)
Unknown	16.1 (14.3, 18.0)	12.6 (10.7, 14.8)	25.0 (24.1, 25.9)
Residential area type			
Metropolitan central city	48.7 (45.7, 51.8)	45.1 (41.4, 48.9)	33.1 (31.7, 34.5)
Surrounding area	43.1 (40.1, 46.2)	45.0 (41.5, 48.6)	52.5 (50.8, 54.1)
Nonmetropolitan area	8.2 (6.3, 10.6)	9.9 (6.9, 13.8)	14.4 (12.1, 17.1)
Population percentage ^a	1.37 (1.30, 1.46)	0.69 (0.64, 0.75)	97.93 (97.83, 98.03)

Note. CI = confidence interval.

^aPopulation percentage and sample size based on persons aged 16 years and older and coded nonmissing on sexual orientation.

This correction does not affect the paper's conclusions.

<https://doi.org/10.2105/AJPH.2020.306017e>

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Erratum In: A Redesigned AJPH for the Times That Are “A-Changin’”

In: Morabia A. A redesigned *AJPH* for the times that are “A-Changin’.” *Am J Public Health*. 2021;111(1):6. <https://doi.org/10.2105/AJPH.2020.306052>

The degree listing was missing from the author affiliation. It should read:

Alfredo Morabia, MD, PhD
AJPH Editor-in-Chief
@AlfredoMorabia

<https://doi.org/10.2105/AJPH.2020.306052e>

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.

Erratum In: People-Centered Innovations in Data Collection: The Oregon Experience

In: Fiala S, Landers S. People-centered innovations in data collection: the Oregon experience. *Am J Public Health*. 2019;109(S2):S121-S122. <https://doi.org/10.2105/AJPH.2019.305009>

Two authors were omitted from the paper. On p. S121 the About the Authors section should read:

ABOUT THE AUTHORS

Steven Fiala is the *AJPH* Student Editor and is with the Oregon Public Health Division. Stewart Landers is an *AJPH* Associate Editor and is with John Snow, Inc., Boston, MA. Margaret Braun is a Research Scientist at Program Design and Evaluation Services (PDES) within Multnomah County Health Department and Oregon Health Authority. Julie Maher is Director of PDES.

On page S122 a phrase was omitted from a sentence in column 1, paragraph 2. It should read:

Given this cultural norm, Chuukese respondents may actually be in excellent (or even poorer) health, but their survey responses were moderated by cultural expectations relative to humility.

The author byline should read:

Steven Fiala, MPH
Stewart Landers, JD, MCP
Margaret Braun, PhD
Julie Maher, PhD

The Contributors section should read:

CONTRIBUTORS

Each author contributed by discussing what would be written about and drafting portions of the text. S. Fiala took the lead on the Oregon data experience with significant contributions from M. Braun and J. Maher, and S. Landers linked the articles in the Lerner supplement and shaped the editorial overall.

The Acknowledgments section was omitted. It should read:

ACKNOWLEDGMENTS

This Oregon Health Authority work was funded by the Office of Equity and Inclusion and Oregon Public Health Division. We thank our Chuukese community leaders Melba Heldart, Lahaina Phillips, Jes Phillips, and Joe Enlet for their collective wisdom, cultural guidance, and interviewing support. We also thank Barbara Pizacani, Jamie Matson, and Virginia Luka for research design, consultation, and logistics. Finally, we thank our community organization partners, Asian Pacific American Network of Oregon and Micronesian Islander Community.

<https://doi.org/10.2105/AJPH.2019.305009e>

Reproduced with permission of copyright owner. Further reproduction prohibited without permission.